

Double Helix, Double Standards: Private Matters and Public People

Teneille R. Brown

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DOUBLE HELIX, DOUBLE STANDARDS: PRIVATE MATTERS AND PUBLIC PEOPLE

TENEILLE R. BROWN*

ABSTRACT

In this article, I hope to challenge our thinking on perhaps the most private type of health information by applying its disclosure to someone incredibly public. I will review the relevant constitutional, tort law, and statutory frameworks for disclosure of a presidential candidate's health information by applying these concepts to the specific disclosure of a candidate's genetic testing results. In some cases, the analysis will shift into a discussion of accessing health information of the winning candidate. After surveying the different types of genetic tests and possible methods for disclosure, I then will compare legal and ethical concerns to discuss the degree to which the public interest may be served by accessing our potential presidents' genetic information. I will end by questioning whether a double standard is developing in privacy rights doctrine as it relates to the testing of public figures.

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I. INTRODUCTION: PRIVATE MATTERS, PUBLIC PEOPLE

Is it true that Barack Obama enjoyed carving pumpkins as a child in Hawaii,¹ and Hillary Clinton ate lots of bologna sandwiches in suburban Chicago?² Newspapers publish silly details about presidential candidates because *we want to know*, and we often digest these tidbits without thoughtful consideration of their public utility. That is, we rarely pause to ask whether this information helps us analyze the candidates' leadership styles or governance. Voting is inherently discriminatory, and it is therefore not unreasonable to inquire into the private lives of candidates as we may gather private details that can be used to predict public beliefs or political actions. For example, it makes sense to ask about the source of Mitt Romney's estimated worth of \$250 million.³ This may help determine whether he actively participates in the management of the funds, which could lead to conflicts over tax policy or government contracts.⁴ It may be less socially valuable, however, for the public to know specific details about how he settles his religious tithing on that \$250 million.

Predicting a candidate's actions and expressions has become quite newsworthy in recent political campaigns.⁵ Perhaps our emphasis on prediction has grown because in the last fifty years, the President's power, nuclear and otherwise, has increased astronomically.⁶ We may also want stronger politicians where policies have failed, as personal diplomacy may trump long-term strategies and goals.⁷ Whatever the reason, the focus on predicting presidential behavior has

1. Jennifer Steinhauer, *Charisma and a Search for Self in Obama's Hawaii Childhood*, N.Y. TIMES, Mar. 17, 2007, at A1.

2. Nancy Benac, *Hillary Clinton's Life Pivots Once More*, WASH. POST, Jan. 22, 2007, available at <http://www.washingtonpost.com/wp-dyn/content/article/2007/01/22/AR2007012200323.html>.

3. Lisa Wangsness & Ross Kerber, *Romneys are Worth up to \$250m: Personal Finance Data are Detailed*, BOSTON GLOBE, Aug. 14, 2007, at A1.

4. Casey Ross, *Mitt to Fine-Tune Portfolio; Cashing out of Stocks in Stem Cells*, BOSTON HERALD, Aug. 16, 2007, at 4; *Romney Blind Trust to Reduce Investing Conflicts, He Says*, ST. LOUIS POST-DISPATCH, Aug. 16, 2007, at A3.

5. James David Barber, a political scientist at Duke University, affirms the importance of personal prediction in presidential politics, stating: "[T]he crucial differences [in the presidency] can be anticipated by an understanding of a potential President's character, his world view, and his style." JAMES DAVID BARBER, *THE PRESIDENTIAL CHARACTER: PREDICTING PERFORMANCE IN THE WHITE HOUSE 3* (4th ed. 1992).

6. See STANLEY A. RENSHON, *THE PSYCHOLOGICAL ASSESSMENT OF PRESIDENTIAL CANDIDATES 29-32, 43* (1996) (explaining that concerns with "psychological suitability of presidential candidates" developed partly out of fear over nuclear weapons in addition to the central role a president plays in economic development).

7. Author Stanley Renshon posits that historically we could better predict a candidate's stance by his party affiliation. *Id.* at 38-39. We have currently grown accustomed to interpreting a candidate's particular blend of social programs and budget priorities, rather than relying steadfast on what the party line would suggest. See *id.* at 39 ("Voters can no longer rely on party labels to inform them of policy approaches of a party's candidates. . . . [T]hey must make their own way through the haze of blurred political personas of the candidates."). Renshon argues however, that more than ever, we need to assess

reached an all-time high. In an age where analyzing someone's personal history is limited only by one's internet access, there is a great supply of tabloid-type news to fill the public's appetite.⁸

Having said that, Americans do deserve to legitimately scrutinize our candidates to see if they are up for the enormous challenges and responsibilities.⁹ The press would not be performing its civic duty in this regard if it let certain facts slide by without comment, or if critical details about the candidates were treated as gossip, published by way of reckless speculation instead of rich investigative reporting. Presidential candidates invite others to see them as they see themselves, and reporters have an obligation to critically examine the nexus between the candidate's true self and her constructed persona.¹⁰

Careful consideration must be given as to what sort of information may be reliably and properly disclosed in this pursuit. In some cases, the public interest necessitates more disclosure, and in others, the privacy rights of the individual candidate should prevail. If we want to know trivial data such as presidential candidates' pumpkin-paring proclivities, it seems curious to limit access to information that is *not* entirely trivial. One such example is information about the candidate's health. As with any employee, the mental and physical health of the candidate can affect many aspects of performance such as ability to handle stress, resilience to sleep deprivation, and the strength of the immune system's response to common colds. Poor neurological health may also lead to poor executive decisions, and it is for this reason that air traffic controllers are required by the Federal Aviation Administration (FAA) to undergo intense psychological and neurological testing before they are hired.¹¹ The military and the Central Intelligence Agency

the likelihood that a president will keep his word. *Id.* Lyndon B. Johnson, for example, campaigned heavily on not sending American troops to Vietnam; but once he was elected to office, he nonetheless did so. *Id.* at 33. Johnson's abrupt change in policy may have contributed to public suspicion that a disconnect exists between campaign promises and presidential delivery. *Id.*

8. Carl M. Cannon, *Here We Go Again: The Public's Right to Know – or Prurient Interest?*, NAT'L J., May 25, 2007, at 20, 20–22 (“The gaggle of 2008 candidates will be acting out their various pathologies in a technological environment more suited for entertainment than for serious policy discussion. YouTube, the blogs, and an unfettered cable culture did not exist in 1988 and 1992, the years that the privacy barriers came tumbling down. They do now.”); see also Gina Angie Lee, *Privacy Year in Review: The Intersection of the Rights to Privacy and of a Free Press: Can They Co-Exist?*, 1 J.L. & POL'Y INFO. SOC'Y 441, 472 (2005) (“With a multitude of outlets and venues for disseminating private yet newsworthy information about public figures and officials, the press necessarily infringes on their right to solitude.”).

9. Robert Streiffer et al., *Medical Privacy and the Public's Right to Vote: What Presidential Candidates Should Disclose*, 31 J. MED. & PHIL. 417, 422 (2006) (“We propose that candidates are morally required to disclose information about any medical conditions that are likely to seriously undermine the candidates ability to fulfill what we will call the core functions of the office.”).

10. RENSHON, *supra* note 6, at 53.

11. Fed. Aviation Admin., Air Traffic Controllers, http://www.faa.gov/about/office_org/headquarters_offices/ahr/jobs_careers/occupations/atc/ (last visited

(CIA) also require members to undergo a rigorous pre-employment health screen.¹² If the FAA, the military and the CIA can require their members to undergo health screens, it seems irrational not to require the same for the *head* of these important governmental departments. We currently judge a candidate's health on whether he jogs or eats hamburgers as represented in newspaper photo-ops.¹³ A logical question is, "Why stop there?" What is the logical reason to require less of the leader than we do of his staff? If Americans truly want to gain valuable information that will help guide their vote, we should think about being more precise in our health assessment of the candidates for this very important job.

In this article, I will present the legal framework for a completely new type of disclosure: the results of a presidential candidate's personal genetic tests.¹⁴ This inquiry narrows the more general question of access to a candidate's health information by analyzing the topic through the lens of a specific type of private information. The question that I seek to address is whether it is ethical, legal, or constructive to conduct genetic testing of candidates, and to what degree this information should be shared with the public. There are many ways to frame this issue, and political scientists have been researching access to the health information of politicians more generally for at least 35 years.¹⁵ The lawyers and policy-makers must catch-up. I am interested in the unique ways that a public figure's genetic tests may be useful or harmful to public interest, and how this information is different from other types of private health information. This inquiry may be useful as it falls right at the delicate intersection of our twin goals of protecting individual privacy and disclosing information that is in the public interest.¹⁶

Apr. 17, 2007); *see also* RENSHON, *supra* note 6, at 111 (noting that borderline personality disorder is generally associated with substantial difficulties in psychological functioning).

12. Cent. Intelligence Agency, Careers at CIA: Core Collector, <https://www.cia.gov/careers/jobs/view-all-jobs/core-collector.html> (last visited Apr. 17, 2008).

13. Editorial, *Clinton Puts Heart into Obesity Fight*, CHI. SUN TIMES, May 9, 2005, at 51 ("Gone are the days when Bill Clinton would pose happily mouthing a dripping Big Mac. Or take a fast-food detour in the middle of a jog."); *see also* Richard L. Berke, *Politicians Find Jogging with Clinton Is No Stroll in the Park*, N.Y. TIMES, July 26, 1993, at A1 (noting that Clinton, who others considered a "big lug" was a surprisingly fast jogger).

14. A genetic test has been defined as "the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or karyotypes for clinical purposes." Wylie Burke, *Genomic Medicine: Genetic Testing*, 347 NEW ENG. J. MED. 1867, 1867 (2002) (quoting U.S. TASK FORCE ON GENETIC TESTING, PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES (Neil A. Holtzman & Michael S. Watson eds., 1998)). Genetic tests can be both diagnostic and predictive. *Id.* Diagnostic testing can be used for prenatal diagnosis as well as for pre-implantation diagnosis following in vitro fertilization, or newborn and carrier screening. *Id.* at 1867-71. Predictive testing can identify future health risks, predict drug responses, and assess risks to our unborn children. *Id.* at 1867.

15. *See generally* HUGH L'ETANG, THE PATHOLOGY OF LEADERSHIP 11-12 (1970) (discussing the need for public disclosure of public officials' health information).

16. Legal scholar George Annas aptly pointed out the importance of the legal principle that disclosure of the medical information is contingent upon patient authorization and that "[p]residential

In the first section, I will provide the basic legal framework underpinning the arguments for and against public disclosure of a presidential candidate's health information. Specifically, I will look at some of the existing constraints on disclosure (i.e., the physician-patient privilege, the Health Insurance Portability and Accountability Act (HIPAA), tort law, the Fourth Amendment, and federal non-discrimination statutes) and ask how these apply to genetic information. I suspect there will be other theoretical constraints, but I have focused on those with relevant doctrinal precedent. In the second section, I will ask whether the genetic test could be mandatory as a condition of running for office, or if it must consist entirely of voluntary disclosure. I will also analyze what form this disclosure could take depending on the type of genetic information that is involved, and whether it should consist of a full disclosure of all health records, a succinct report, or something in between the two. In conclusion, I will then apply the policy arguments from the second section to the legal framework of the first, and will distill this down into some basic recommendations. My hope is not to exhaust the universe of possibilities, but merely to begin a dialogue on the utility of accessing presidential candidates' health information, by offering how genetic information may or may not contribute to this discussion. In some cases, it will not matter whether I'm speaking of the presidential candidate or the President herself, as information that is obtained during the campaign phase will become relevant once the candidate is elected.

II. THE LEGAL AND HISTORICAL FRAMEWORK

Historically, Americans have wanted a leader who is "all-wise, all-powerful, [and] the repository of his followers' hopes and dreams, without human imperfection and frailties."¹⁷ We did not want someone we could relate to; we wanted someone mighty to revere. Less deferential media scrutiny of the office over the last thirty years has probably humanized it some, as we have seen presidents impeached, censured, and caught in various scandals and lies.¹⁸ We may now be willing to take the President down a notch from her pedestal, and are more

campaigns . . . are based not so much on descriptions of the present as on predictions about the future. And this is what makes them especially problematic in terms of health information." George J. Annas, *The Health of the President and Presidential Candidates—The Public's Right to Know*, 333 NEW ENG. J. MED. 945, 945 (1995).

17. Robert S. Robins & Jerrold M. Post, *Choosing a Healthy President*, 16 POL. PSYCHOL. 841, 842 (1995).

18. Cannon, *supra* note 8, at 22. ("Watergate and the Vietnam War changed everything," said veteran Republican activist Roger Stone, who was an aide to President Nixon. "Prior to these events, reporters and the public believed in their government and their political leaders, and gave them the benefit of the doubt. Now we assume all politicians are lying and hiding something."); see also Alison Mitchell, *The President's Acquittal: The Overview; Clinton Acquitted Decisively: No Majority for Either Charge*, N.Y. TIMES, Feb. 13, 1999, at A1.

comfortable scouring her personal life.¹⁹ In some areas, perhaps, we are still asking too much—requiring the candidate to hide many natural blemishes that might make him human. This has led several candidates to hide any perceived health imperfections from the public view, worried that they may appear weak or not fit for the job.²⁰ Secrecy over health imperfections only strengthens the signal of stigmatization, by silencing the important message that presidents need not be, and historically have not been, perfectly healthy individuals. Some of the most effective leaders in our country and the world have been physically disabled or otherwise stricken with disease.²¹ And yet, there are some types of diseases that may affect the quality of the President's decision-making in such a way that the public would find troubling.

In a 2004 CNN/Gallup Poll, ninety-six percent of those polled said that the general health of the President is "important" or "very important" to his ability to be a good president. Eighty-four percent believed that the President should have an annual physical examination and seventy-nine percent stated that the President should undergo an annual mental exam to test for conditions such as depression or Alzheimer's.²² While this suggests that Americans still desire a mentally and physically "healthy" candidate, they are also conflicted about how this should be ensured. Sixty-one percent said the President has the same rights as other citizens to keep medical records private, and only thirty-eight percent were in favor of releasing all information that might affect the President's ability to serve.²³ There is definitely friction between the public interest in accessing private information about the candidates and the countervailing privacy interests of the individual; this

19. RENSHON, *supra* note 6, at 320 (discussing the "lies and misfortune" of presidents from the 1960s to 1970s, and how this led to a general distrust of the President and the desire to know the private behavior of leaders); Thomas Fitzgerald, *Likeability May be Kerry's Greatest Hurdle*, PHILA. INQUIRER, Sept. 7, 2004, at A2 ("A recent Zogby/Williams Identity Poll found that 57.3 percent of undecided or persuadable voters would rather have a beer with Bush than Kerry . . .").

20. Annas, *supra* note 16, at 945 (discussing how various presidents took efforts to hide their medical infirmities from the public).

21. KENNETH R. CRISPELL & CARLOS F. GOMEZ, HIDDEN ILLNESS IN THE WHITE HOUSE 2-3 (1988) (revealing that foreign leaders, such as Marshal Tito and Mao Tse-tung kept their health problems secret and eventually died while still in power); Aaron Seth Kesselheim, *Privacy Versus the Public's Right to Know: Presidential Health and the White House Physician*, 23 J. LEGAL MED. 523, 524 (2002) ("[A]t least 14 of the 19 United States Presidents in the twentieth century suffered from significant illnesses while in the White House, ranging from Woodrow Wilson's debilitating stroke to Franklin Delano Roosevelt's congestive heart failure to Ronald Reagan's colon cancer, with varying impacts on their ability to govern."); Robins & Post, *supra* note 17, at 842 ("That Franklin Delano Roosevelt had a physical disability secondary to poliomyelitis did not impair his leadership and decision-making. . . . Consider the major heart attack (myocardial infarction) which Lyndon Johnson suffered while a senator, the multiple illnesses which punctuated Eisenhower's presidency: heart attack, stroke and ileitis.")

22. CNN.com, *American Morning: Looking at the Health of the Presidential Candidates* (Sept. 29, 2004), <http://transcripts.cnn.com/TRANSCRIPTS/0409/29/ltm.05.html> (last visited Apr. 18, 2008).

23. *Id.*

recurring thread and the natural tension that it creates is precisely what I'd like to explore. Just how far are we willing to undermine the candidate's privacy interests so that we can increase the odds of electing a "healthy" candidate?

To help frame the issues for discussion, imagine this hypothetical:

It's a rainy January morning when presidential candidate Eddie enters a diner in New Hampshire and orders some apple pie. He is quickly surrounded by locals, who greet him with handshakes and smiles. During the commotion, Eddie is lightly pricked in his lower right arm (his sleeves are rolled up, of course) by the tip of an umbrella, which serves as a giant syringe and extracts some of the candidate's blood. Eddie doesn't even notice. Steve, the sleazy, rabid journalist, is the owner of the umbrella. Steve submits Eddie's blood to a DNA lab advertised online, but uses his name instead of Eddie's in the contact information. The lab results are eventually returned through the mail, and the devious Steve leaks Eddie's personal genetic information to an anonymous blogger. No interpretive data was provided in the report, which eventually makes its way into the mainstream media. Eddie will not confirm the legitimacy of the findings. He maintains that this implicates confidential information that he hopes the public will respect as private.

Eddie's ostensible genetic profile revealed that he has some of the markers associated with a few potentially serious disorders. He has one copy of the ApoE e4 allele, which has been clinically associated with increased risk for developing Alzheimer's disease.²⁴ His test also reveals mutations on the MLH1 and MSH2 genes, which point to an elevated risk for developing nonpolyposis colorectal cancer.²⁵ Lastly, the results show that Eddie's racial composition does not square with the ethnic genealogy he has sketched in books and in interviews. Eddie is 70 years old, and his much younger opponents have successfully made his age an issue in the primaries. The underlying perception of his infirmity due to age, coupled with the newly exposed genetic data and questions about his ethnic history, presents a blow to his campaign that he cannot overcome. Eddie is forced to remove himself from the election and subsequently lives another twenty years outside of politics in relative good health and peace.

Unlike other explorations into genetics and ethics, this hypothetical is not that remote or futuristic.²⁶ In fact, eventually an abandoned coffee cup or a piece of

24. Nilüfer Ertekin-Taner, *Genetics of Alzheimer's Disease: A Centennial Review*, 25 *NEUROLOGIC CLINICS* 611, 611, 627 (2007). There are people that develop Alzheimer's disease, who do not possess the APOE e4 allele, and there are individuals with two copies of this variation who will never exhibit signs of Alzheimer's. *Id.* at 627. This tells us that the disease has more than one cause, and that the APOE e4 genetic variation is not a necessary component to developing Alzheimer's disease.

25. JOHNS HOPKINS CANCER RISK ASSESSMENT PROGRAM, *HEREDITARY NONPOLYPOSIS COLORECTAL CANCER (HNPCC) AND THE MSH6 GENE* (n.d.), available at <http://www.macgn.org/factsheets/HNPCC%20and%20MSH6.pdf>.

26. See Tom Infield & Derrick Nunnally, "It Wasn't Right," *Diner Boss Says of an Attempt to Sell it on Ebay: Obama's Unfinished Waffle Falls from Glory*, *PHILA. INQUIRER*, Apr. 27, 2008, at A12

chewing gum may provide enough genetic material to conduct reliable commercial genetic testing.²⁷ Commentators are right to point to the mitigating factors on genetic testing's utility and intrusiveness (e.g., the available genetic data is not very useful in predicting many diseases and behaviors). However, it is *not* true that piecing together the composite genetic picture of a human will only arrive after a "considerable number of years."²⁸ Clinical genetic tests exist for over 1,000 diseases, and hundreds more are currently being developed.²⁹ Most of the mail-in genetic testing services focus on paternity testing; however, there are labs that will test for multiple polymorphisms and mitochondrial DNA, and there is potential for widespread growth in this field.³⁰ Already, it is possible to submit blood specimens to a company in Wisconsin, and in exchange for \$590 they will test all of your genetic, hereditary information encoded by DNA (i.e., the "genome") for certain mutations and provide the results to your doctor within thirty days.³¹ A group of ten individuals are currently having their entire genome sequenced,³² and two have

(discussing the sale of Barack Obama's used dinner plate on Ebay, including the seller's statement that the silverware contained Obama's DNA). For simplicity in the hypothetical we will assume enough blood was extracted to conduct the test. Genetic analysis based on hair specimen is less reliable, and while it may be used more in the future, blood samples and buccal swabs remain the gold standard. See Suzanne M. Leanza et al., *Whole Genome Amplification of DNA Extracted From Hair Samples: Potential for Use in Molecular Epidemiologic Studies*, 31 *CANCER DETECTION & PREVENTION* 480, 480 (2007) (finding that blood and buccal DNA are preferred in epidemiological studies because they are excellent sources of gDNA).

27. See Peter Slevin, *For DNA Detectives, the Workload Is Exploding*, WASH. POST, Nov. 14, 2000, at A3 (demonstrating that genetic profiles from saliva left on a drinking cup provided sufficient genetic evidence to indict a suspect for four rapes and three murders).

28. *Contra* Amitai Etzioni, *A Communitarian Approach: A Viewpoint on the Study of the Legal, Ethical and Policy Considerations Raised by DNA Tests and Databases*, 34 *J.L. MED. & ETHICS* 214, 217 (2006) ("There are a number of factors that will work to mitigate the intrusiveness of DNA usages, at least in the near future. It is true that we can divine very specific information from DNA—for example the color of one's hair, or whether one is susceptible to certain diseases—but it will take a considerable number of years before authorities will be able to look at the genetic code and piece together a composite picture of a human being.").

29. Kathy L. Hudson et al., *Oversight of US Genetic Testing Laboratories*, 24 *NATURE BIOTECHNOLOGY* 1083, 1083 (2006).

30. E.g., HomeDNA, *The New Standard in DNA Testing*, https://www.homedna.com/ancestry_tests.html (last visited Apr. 18, 2008); ARGUS BioSciences, *FAQs*, <http://www.argusbio.com/faqs.html> (last visited Apr. 18, 2008).

31. Prevention Genetics, *Genome Polymorphism Scan*, <http://www.preventiongenetics.com/ClinicalTesting/testdescriptions/gps.pdf> (last visited Apr. 18, 2008). Prevention Genetics provides the genome polymorphism scan by reviewing 400 short-tandem repeat polymorphisms (STRPs) in all 24 chromosomes of the individual. *Id.* Higher marker density scans are available for \$59/year. Prevention Genetics, *GenMax Test*, <http://www.preventiongenetics.com/clinicaltesting/TestDescriptions/genmax.pdf> (last visited Apr. 18, 2008). While not a legal requirement, this online service commendably will not release information to individuals themselves, but requires a physician to interpret the data. *Id.*

32. Peter Dizikes, *DNA Unraveled—Gene Information Opens New Frontier in Privacy Debate*, BOSTON GLOBE, Sept. 24, 2007, at C1 ("Pretty soon, all of us will have access to our personal genetic data," said George Church, a Harvard scientist whose study, the Personal Genome Project, will release

already been completed.³³ Online personal genomic testing will be much more common in the next few years due to companies like 23andMe and Navigenics that have received enormous investor interest and funding.³⁴ There are few regulatory safeguards in place to stop an unsavory media outlet from getting its hands on a political candidate's blood, discarded toe nail, or chewing gum, and then irresponsibly publishing the genetic test results without any clinical context or approval by the candidate.³⁵

A. *The Current State of Play for Disclosure of a Candidate's Health Information*

There is no law that requires candidates for the presidency, or the presidents themselves, to disclose anything *at all* about their health. If they choose to disclose their health information, they can decide exactly what is disclosed, who discloses it, and when and how it is disclosed. Some candidates have preferred to condense their overall health report into summaries that their physicians then release to the press.³⁶ Many have outright lied about their health status.³⁷ Others have fought the

genetic records of 10 people this fall, including Church's. Church would like to find 100,000 more volunteers to build a scientific trove of genetic data and estimates he can already sequence the portion of human DNA containing genes for \$1,000.”)

33. Erika Check, *Celebrity Genomes Alarm Researchers*, 447 NATURE 358, 358 (2007); see also Nicholas Wade, *Discoverer Lends His Genome to DNA Study*, INT'L HERALD TRIB., June 2, 2007, at 3 (“The full genome of James Watson, who jointly discovered the structure of DNA in 1953, has been deciphered . . .”).

34. David P. Hamilton, *Google, Genentech Fund Personal-Genetics Startup 23andMe*, VENTUREBEAT, May 22, 2007, <http://venturebeat.com/2007/05/22/google-genentech-fund-personal-genetics-startup-23andme/>. Private companies like 23andMe, Inc. are hoping to deliver high density information about someone's genome, “to connect you to the 23 paired volumes of your own genetic blueprint (plus your mitochondrial DNA), bringing you personal insight into ancestry, genealogy, and inherited traits. . . . [W]ith educational and scientific resources with which to interpret and understand it, your genome will soon become personal in a whole new way.” *Id.* Navigenics, Inc. offers genetic counseling services to its members through the company, and conducts genetic tests through CLIA-certified labs. Navigenics, *About: What Do We Do?*, <http://www.navigenics.com/corp/About/> (last visited Apr. 18, 2008). CLIA certification will be discussed in detail later.

35. See Amy L. McGuire et al., *The Future of Personal Genomics*, 317 SCIENCE 1687, 1687 (2007), available at <http://www.sciencemag.org/cgi/reprint/317/5845/1687.pdf> (“[S]uccessful integration of personal genomics into routine clinical care will require clear standards, multidisciplinary collaboration, and careful consideration of the ethical, social, and clinical implications.”).

36. Editorial, *What's Really Up, Doc?*, CLEVELAND PLAIN DEALER, July 26, 1996, at 10B (“Bill Clinton . . . provided only letters from physicians attesting generally to his good health—‘the least amount of health information,’ the New York Times noted at the time, ‘of any presidential nominee in 20 years.’”).

37. In 1960, during Kennedy's campaign for the Democratic primary, his attack on Eisenhower's and Johnson's health backfired. JOAN & CLAY BLAIR, JR., *THE SEARCH FOR JFK* 162, 575 (1976). His opponents discovered that he had Addison's disease and threw his health into question. *Id.* Kennedy issued a statement that denied the Addison's disease diagnosis. *Id.* at 575–76. In fact, Kennedy's Addison's disease was a matter of public record as of November 1955, when Philip Wilson published his case in the Archives of Surgery. James A. Nicholas et al., *Management of Adrenocortical Insufficiency During Surgery*, 71 AMA ARCHIVES OF SURGERY 737, 739 (1955). Luckily for Kennedy

press in its demands for medical information³⁸ and have provided little or no information about their medical history or current health data.³⁹ Many candidates have decided to voluntarily release information on the status of their physical health. This can be in response to public suspicion,⁴⁰ or opponents egging them on,⁴¹ or just pure convention.

It is telling that the one of the first presidential candidates to publicize his health report was Franklin Delano Roosevelt in 1931.⁴² In releasing his medical information, Roosevelt acted as if he were responding to a challenge set forth by Republican journalist Earle Looker.⁴³ In reality, Roosevelt had arranged the challenge himself.⁴⁴ The report stated that Roosevelt's "powers of endurance are such as to allow him to meet all demands of private or public life."⁴⁵ That may well have been true. However, despite his doctors' knowledge that Roosevelt would

no one publicly made the connection during the presidential election, since his name was omitted from the article. See *id.*; ROBERT E. GILBERT, *THE MORTAL PRESIDENCY: ILLNESS AND ANGUISH IN THE WHITE HOUSE* 156 (1992) ("An article that appeared in a 1955 issue of *AMA Archives of Surgery*, and examined the case of a thirty-seven-year-old male Addisonian who underwent spinal surgery at the New York Hospital for Special Surgery on 21 October 1954, is widely believed to have John Kennedy as its subject."). Presidential candidate Paul Tsongas "said his doctors had declared him cancer free," referring to his cancer relapse as "suspicious cells" and the radiation therapy as precautionary. Herbert L. Abrams, *Presidential Health and the Public Interest: The Campaign of 1992*, 16 *POL. PSYCHOL.* 795, 802 (1995) (internal citation omitted). In fact, in 1987 Tsongas had a recurrence of cancer, which he and his physicians successfully covered up. *Id.*

38. E.g., Lawrence K. Altman, *The 1992 Campaign: Candidate's Health*, *N.Y. TIMES*, Nov. 1, 1992, available at <http://query.nytimes.com/gst/fullpage.html?res=9E0CE6DC143FF932A35752C1A964958260> ("[U]nlike the two other Presidential candidates, the 62 year-old Mr. Perot has refused to disclose any information about this health."); Marlene Cemons, *Quayle Case Renews Debate on Public's Right to Know*, *L.A. TIMES*, Jan. 23, 1995, at A5 (noting that when President Clinton was 48 and seeking reelection, he consistently refused to release his medical records to the public).

39. In 1992, presidential candidate Ross Perot refused to provide even a doctor's letter discussing his health status. Abrams, *supra* note 37, at 806 ("Perot's attitude was that questions to his health were not 'relevant.'"); accord Robert Steinbrook, *Full Disclosure of Candidates Medical Histories Urged*, *L.A. TIMES*, Oct. 8, 1992, at A18.

40. If Dole had been elected, he would have been the oldest person to enter the office. Dole preempted questions about his age and health by calling for an independent panel to review the President's health. Lawrence K. Altman, *Politics: The Candidate's Health*, *N.Y. TIMES*, July 22, 1996, at A12.

41. When Johnson's health was suspect in 1960, Kennedy seized on this perceived weakness by stating that the President needed "the strength and health and vigor of . . . young men." CRISPELL & GOMEZ, *supra* note 21, at 162. For example, Vice President Gore released his medical records "less than a week after Gore's rival for the Democratic nomination, Bill Bradley, canceled a speech because of a briefly erratic heartbeat stemming from a common disorder initially diagnosed in Bradley in 1996." Edwin Chen, *Gore's Health 'Outstanding,' Doctors Say*, *L.A. TIMES*, Dec. 16, 1999, at A16.

42. BETTY HOUCHIN WINFIELD, *FDR AND THE NEWS MEDIA* 20 (1990); Robins & Post, *supra* note 17, at 847.

43. *Id.*

44. See *id.* (demonstrating that the release of FDR's medical information was a plan devised by both him and Earle Looker).

45. ROSS T. MCINTIRE & GEORGIA CREEL, *WHITE HOUSE PHYSICIAN* 54 (1946).

likely never walk again, they stated that Roosevelt could “walk all necessary distances” and had “progressive recovery of power in the legs” and that the restoration continued.⁴⁶ This probably was not true. It is possible that this convention has been perpetuated ever since, where candidates choose what to reveal, and in so doing they create the myth of candid disclosure, which insulates them from accusations of concealment. Since at least 1992, the White House medical office has released only summaries of the presidents’ and vice presidents’ periodic medical exams according to Air Force physician Richard Tubb.⁴⁷

1. *The Physician-Patient Privilege as a Constraint on Disclosure*

Physicians have a professional obligation to protect their patient’s confidential communications, which include any statements made to the physician in the exercise of medical care. This fiduciary duty has been codified into a testimonial physician-patient privilege. The privilege did not exist at common law, and it was not recognized in the United States until New York passed a testimonial privilege statute in 1828, which eventually led to each state providing for some variation of the privilege.⁴⁸ The rationale for these statutes was to encourage people to seek medical assistance for certain diseases that were socially stigmatized, without fear of the information being discovered in court.⁴⁹ Cultural norms of protecting privacy, as well as professional honor, were invoked as justifications for the privilege.⁵⁰ Even in states that recognize the privilege, there are certain situations in which a physician may properly disclose her patient’s confidential information. This includes, *inter alia*, when it is in the public interest, or when

46. *Id.*

47. David Brown, *Vice President’s Overall Health is ‘Outstanding,’ Medical Records Show*, WASH. POST, Dec. 16, 1999, at A8.

48. Robert Wade, Note, *The Ohio Physician-Patient Privilege: Modified, Revised, and Defined*, 49 OHIO ST. L.J. 1147, 1148 (1989); see also *Jaffee v. Redmond*, 518 U.S. 1, 12 (1995) (“[A]ll 50 States and the District of Columbia have enacted into law some form of psychotherapist privilege.”). Some states, however, limit the privilege in criminal cases, and each state defines the scope of physicians differently. Compare COLO. REV. STAT. §§ 13-90-107(1)(d)(I), 13-90-107(3) (West 2007) (waiving the physician-client privilege in cases where a patient has sued his or her physician, surgeon, or registered nurse and explicitly allowing exceptions for physicians to testify about the mental states of a criminal defendant in certain situations.), with MICH. COMP. LAWS ANN. § 600.2157 (West 2007) (waiving the physician-client privilege in cases where a patient brings a personal injury or malpractice action against a defendant and produces a physician who has treated the patient for the injury or for any disease for which the malpractice is alleged).

49. *Developments in the Law—Privileged Communications*, 98 HARV. L. REV. 1450, 1530, 1532 (1985).

50. 8 JOHN HENRY WIGMORE, EVIDENCE IN TRIALS AT COMMON LAW § 2830a (John T. rev. vol. ed. 1961).

there is a duty to warn a third party who the patient plans to imminently harm.⁵¹ The privilege is decidedly not absolute.

History demonstrates that presidential candidates are already less likely to be forthright with their doctors, out of fear that the records may one day be leaked.⁵² They may forego treatment that they think could be discovered, or may not heed the advice of their physicians out of fear that the regimen will negatively affect their public work.⁵³ The justifications for the physician-patient privilege may operate equally on public figures. Even so, we know that even if the privilege is maintained, the status quo is for presidents to be guarded about what they share with their physicians.

a. Permissible Disclosures under the Physician-Patient Privilege

Most states allow for the communication of private health information if it is necessary for public health reporting, i.e., to track disease epidemics, child abuse, or criminal activity.⁵⁴ If a physician alerts the public health authorities to a shooting, or an outbreak of tuberculosis, under most state statutes she is not impermissibly violating her patient's privilege.⁵⁵ The second exception is rooted in

51. *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 347 (Cal. 1976) (holding that mental health professionals may breach a patient's confidentiality, and are required to do so to protect third parties threatened with imminent bodily harm by a patient). The original 1974 decision required warning the third-party that was in danger. *Tarasoff v. Regents of the Univ. of Cal.*, 529 P.2d 553, 559 (Cal. 1974) (en banc), *vacated*, 551 P.2d 334 (Cal. 1976). In a rehearing two years later, the Supreme Court of California recognized a therapist's "obligation to use reasonable care to protect the intended victim against such danger." *Tarasoff*, 551 P.2d at 340. Consequently, a mental health professional may discharge the duty in several ways, including notifying the police, warning the intended victim, or taking other reasonable measures to protect the threatened individual. *Id.*

52. Governor William Casey of Pennsylvania deliberately avoided his regular cardiac evaluation in November of 1990, out of fear that adverse findings regarding the condition of his heart would be leaked, and negatively affect his campaign. Robins & Post, *supra* note 17, at 857. In May of 1984, physicians removed a fibrous polyp from Reagan's descending colon. *Id.* at 847. It should have immediately been followed by a complete examination of the ascending colon, but it was not, due to political concerns that the public would find out. *Id.* Cancer was found in the suspected area a year later; its size and nature indicated it had existed in May of 1984. *Id.*

53. Howard G. Bruenn, *Clinical Notes on the Illness and Death of President Franklin D. Roosevelt*, 72 ANNALS INTERNAL MED. 579, 580 (1970). While President Roosevelt did not object to the many lab tests he underwent at the hands of his doctor, Howard Bruenn, he ignored his doctor's advice to take codeine for a severe cough, to take two weeks off to rest with nursing care, and to undergo sedation to ensure rest. *Id.* Dr. Bruenn's "memorandum was rejected because of the exigencies and demands on the President." *Id.* Again in March 1944, Dr. Bruenn suggested that a mersalyl injection would be beneficial, but "it was decided by the group that in view of the complexity of the situation as little medication as possible be used at this time." *Id.* at 581-82.

54. 45 C.F.R. § 164.512(b) (2007); *see also* N.Y. City Health & Hosp. Corp. v. Morgenthau, 779 N.E.2d 173, 177 (N.Y. 2002); Edelstein v. Dep't of Pub. Health & Addiction Servs., 692 A.2d 803, 806 (Conn. 1996), *abrogated on other grounds by In re Michael S.*, 784 A.2d 317 (Conn. 2001) (citing CONN. GEN. STAT. ANN. § 52-146o (West 2007)).

55. *See, e.g.*, IOWA CODE ANN. § 139A.3 (West 2005); NEB. REV. STAT. § 71-503.01 (Supp. 2006).

a California Supreme Court case, *Tarasoff v. Regents of the University of California*, where the court held that a therapist must warn a third party of possible imminent harm, thereby breaching the physician-patient privilege, when a patient has made threats to harm the third party to the therapist.⁵⁶ In the majority opinion, Justice Mathew O. Tobriner famously stated: "We conclude that the public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins."⁵⁷ Justice Tobriner further noted that "[a] physician may not reveal the confidence entrusted to him in the course of medical attendance . . . unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community."⁵⁸

Lawrence Mohr, M.D., the White House physician from 1987 to 1993, believes that "we must expect and require that the sanctity of the doctor-patient relationship remain inviolate except in the extreme situation of a medically disabled president."⁵⁹ If a physician felt that his patient, the President, were neurologically or physically unstable, he would have an obligation to disclose that to the Vice President to trigger an inquiry into whether the Twenty-Fifth Amendment should be invoked.⁶⁰ The physician may also have an obligation to inform the Vice President and the team of White House physicians if illness presents itself in less than debilitating ways, so that warning signs can be properly assessed. Just what would rise to the level of "disability" as contemplated by the Twenty-Fifth Amendment, or "public peril" as discussed in *Tarasoff*, is currently a fact-specific inquiry, and one that would require a balancing of interests and the reasonable judgment of the physician.⁶¹

Assuming *arguendo* that the physician-patient privilege should operate on presidential candidates in the same way it does on private citizens, a physician would similarly need to advance either a "public health" or a "duty to warn third parties" kind of argument in order to respect the confidentiality of the patient's

56. 551 P.2d at 340.

57. *Id.* at 347.

58. *Id.* at 347 (quoting PRINCIPLES OF MED. ETHICS OF THE AM. MED. ASS'N § 9 (1957)).

59. Lawrence C. Mohr, *The White House Physician: Role, Responsibilities and Issues*, 16 POL. PSYCHOL. 777, 789 (1995).

60. U.S. CONST. amend. XXV, § 1. (outlining the procedures of succession to the presidency and vice-presidency in the event of the removal from office or death of the President). The Twenty-Fifth Amendment will be discussed in detail later on, but suffice it to say for now that it is the constitutional mechanism that provides for presidential succession in the event the President becomes disabled. As we will see, there is much concern over whether the current Amendment is adequate on its own.

61. See CRISPELL & GOMEZ, *supra* note 21, at 226 (stating that the Twenty-Fifth Amendment places the President's physician in a position of power with the ultimate decision to either reveal the President's condition, which may lead to the procedure for medical removal, or participate in a cover-up to keep the President in office).

communications.⁶² Whether the public health exception could successfully be broadened to include the impact of the President's poor health, or the reasoning behind the *Tarasoff* decision extended to a physician's "duty to warn" of diffuse, public peril, is an open issue. The relevant safe havens for disclosure under this privilege would need to be applied in new, but not inconsistent ways for a physician to disclose a presidential candidate's health information without his consent.

Lastly, some of the initial justifications for the physician-patient privilege do not apply in a scenario where the screening would be mandatory. That is, one chief reason for privileged communications between a patient and her physician is to encourage individuals to seek medical care even in situations where the disease or its treatment is stigmatized.⁶³ If an individual were required to undergo genetic testing, there would be no concern of avoiding medical care. In fact, the testing may provide an opportunity to discover more about the candidate's health than would otherwise be known.

2. *HIPAA as a Constraint on Disclosure*

Physicians have an ethical, and now statutory, obligation not to divulge a patient's protected health information.⁶⁴ A physician who discloses the protected health information of his patient without the patient's consent would be subject to HIPAA's enforcement actions. These actions include civil penalties of up to \$100 per occurrence, and criminal penalties ranging from \$50,000 and up to one year in prison for improperly and knowingly obtaining or disclosing individual health information, or \$250,000 and up to ten years in prison for profiting from the improper disclosure of a patient's protected health information.⁶⁵ This is in addition to any professional sanctions that might be imposed by the relevant licensing

62. See 42 C.F.R. § 164.512(b) (2007); *Tarasoff*, 551 P.2d at 347.

63. Cheryl M. Plambeck, *Divided Loyalties: Legal and Bioethical Considerations of Physician-Pregnant Patient Confidentiality and the Prenatal Drug Abuse*, 23 J. LEGAL MED. 1, 22 (2002).

64. Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, §§ 262, 264, 110 Stat. 1936 (codified at 42 U.S.C. § 1320d). The Privacy Rule as called for by this Act, includes the proscription of covered entities' disclosure of protected health information, and was implemented as the "Standards for Privacy of Individually Identifiable Health Information." DEP'T OF HEALTH & HUMAN SERVS., STANDARDS FOR PRIVACY OF INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION: REGULATION TEXT (2003), available at <http://www.dhhs.gov/oct/combinedregtext.pdf>; 45 C.F.R. §§ 160, 164. Protected health information is defined to include "any information, whether oral or recorded in any form or medium, that: [i]s created or received by a health care provider, health plan, public health authority, employer, life insurer, school or university, or health care clearinghouse; and [r]elates to the past, present, or future physical or mental health or condition of an individual . . ." 45 C.F.R. § 160.103 (2007).

65. 42 U.S.C. §§ 1320d-5, 1320d-6 (2000).

boards. HIPAA only applies to “covered entities,” which includes health plans, health care providers, and business associates of health care providers.⁶⁶

a. Permissible Disclosures Under HIPAA

HIPAA provides for disclosure without the patient’s authorization for “public health activities,” which is defined to include such things as “preventing or controlling disease,” for “public health investigations” and to “evaluate whether the individual has a work-related illness or injury.”⁶⁷ HIPAA also allows for disclosure, without the patient’s authorization, to the extent that “such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.”⁶⁸ Under HIPAA, as the public health disclosures are spelled out in detail, it is less likely that “public health” could be defined to encompass the President’s health and its impact on the public interest. There is no language in HIPAA to compel disclosure if a patient has communicated her intention to imminently harm someone, perhaps because the regulations cover health plans and hospitals that have no direct contact with the patient, and therefore no privileged relationship. In order for a covered entity to disclose protected health information under HIPAA, there would generally have to be authorization from the patient or a legal mandate.⁶⁹

We must be careful not to eviscerate the meaning of HIPAA and the physician-patient privilege with laws allowing disclosure. Even so, HIPAA’s exceptions do provide room for a narrow carve-out for physicians to disclose the health of the President in cases where: (1) a law is passed that provides for such disclosure,⁷⁰ (2) there is some palatable public health or a “duty to warn” type of argument,⁷¹ (3) or the President authorized the disclosure.⁷² In an attempt to paint a full picture of the constraints on disclosure of health information, I have included the above discussion of the physician-patient privilege and HIPAA regulations. However, it is important to reiterate that the above constraints on disclosure only apply if it is a provider or covered entity that is asked to disclose the health information. There exists no privilege between a patient and his mother, or the

66. HIPAA defines a “covered entity” as a health plan, a health care clearinghouse, or a health care provider who transmits any health information in electronic form in connection with a HIPAA transaction. 45 C.F.R. § 160.103.

67. *Id.* §§ 164.512(b)(i), (v)(A)(2).

68. *Id.* § 164.512(a).

69. *Id.* § 164.502(a).

70. *Id.* § 164.512(a).

71. *See id.* § 164.512(b), (j) (permitting the disclosure of health information (1) to prevent the spread of communicable diseases, (2) in cases where the covered entity, in good faith, believes that the disclosure is necessary to prevent a serious and imminent threat to an individual or the public, or (3) if the information is needed by law enforcement authorities to identify or apprehend a criminal suspect).

72. *Id.* § 164.512(a).

press for that matter. HIPAA does not apply to a neighbor, colleague, or stranger who improperly discloses someone's protected health information. These people would only be subject to the existing civil privacy tort laws of each state.

3. *Privacy Torts as a Constraint on Disclosure*

Using the hypothetical above, Eddie could sue Steve and the blogger for invasion of privacy under a few tort theories.⁷³ As I am interested in the publication of private information, we will apply the analysis of the tort of "public disclosure of embarrassing private facts." To be held liable under this cause of action, an individual must publicly disclose private information that would be offensive and objectionable to a reasonable person of ordinary sensibilities.⁷⁴ Due to the sweeping constitutional protection of freedom of the press, even a tortious invasion of one's privacy is exempt from civil liability if the publication of private facts is truthful and newsworthy.⁷⁵ "Newsworthy" has been defined as that which is "a legitimate concern to the public."⁷⁶

Let us analyze each element of the claim in turn as it relates to the hypothetical scenario above. First of all, we face the threshold question of public disclosure of private facts, as Eddie's genetic information was previously private (in fact not even known to him) and it was disclosed online in a public forum. We must then proceed to ask whether under these circumstances, disclosure of genetic information is considered offensive or objectionable. Steve is not a health professional, and while he does not have a privilege under HIPAA or an obligation to Eddie, he is also not acting for public health reasons or under the blessing of law. He published this information purely for sensationalism.

The more private and guarded we are about the information that is disclosed, the more it will be considered offensive and objectionable. Courts have recognized the elevated privacy status of an individual's genetic data, stating that "[o]ne can

73. The universe of potentially relevant invasion of privacy actions include a (1) intrusion into an individual's private affairs, (2) public disclosure of embarrassing private facts, (3) appropriation of a private individual's name and likeness, or (4) publicity which places an individual in a false light. William L. Prosser, *Privacy*, 48 CAL. L. REV. 383, 389 (1960). The mere gathering of a person's blood sample in the manner that Steve did would very likely be an intrusion into an individual's private affairs, absent any publication of the data. *See id.* at 389-92 ("The privacy action for [the tort of intrusion] . . . will evidently overlap, to a considerable extent at least, with the action for trespass to land or chattels."). However, I am more interested in the publication of that private data, and therefore the ensuing analysis will investigate the second claim as it is most appropriate to the hypothetical.

74. RESTATEMENT (SECOND) OF TORTS § 652D (1977).

75. *See id.* at cmt. d.

76. *See Cox Broad. Corp. v. Cohn*, 420 U.S. 469, 492 (1975) (finding that the commission of a crime is a legitimate public concern and within the responsibility of the press to report); *Time, Inc. v. Hill*, 385 U.S. 374, 387-88, 400-01 (1967) (holding that a magazine article regarding a play that depicted an actual crime was not a violation of a New York privacy statute because the article reported a "newsworthy event" that was a "a matter of public interest").

think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up."⁷⁷ In addition, recent legislation and executive orders indicate the special status of genetic information and the need to safeguard it from disclosure and abuse.⁷⁸

There is a vast literature surrounding the ethics of genetic testing.⁷⁹ The literature discusses when genetic tests are appropriate, what information should be relayed before and after the genetic test, how it should be communicated, and whether there is an obligation to share the results of the genetic tests with family members.⁸⁰ As genetic testing laboratories surfaced and started offering direct-to-consumer genetic tests, ethicists and scientists also asked who should be permitted to perform these tests, and what sort of privacy safeguards should be imposed. Clearly genetic information has been treated differently from other types of health information; so why is it unique?

The unique treatment of genetic information has historically been known as "genetic exceptionalism." This concept holds that genetic information is not like any other sensitive information in a patient's medical record.⁸¹ But we need not

77. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998) (citing *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994)).

78. On April 25, 2007, the Genetic Nondiscrimination Act of 2007 ("GINA") was passed in the U.S. House of Representatives, by a vote of 420-3. H.R. 493, 110th Cong. (2007) (as passed by House); *Coalition for 21st Century Medicine Urges Senate Passage of Genetic Information Nondiscrimination Act Before Independence Day*, SCIENCE LETTER, Jul. 10, 2007, at 759. It has yet to be passed by the Senate. Erin E. Dooley, *GINA Passes in House*, ENVTL. HEALTH PERSPECTIVES, Aug. 1, 2007, at A401. The act will protect individuals against discrimination based on their genetic information when it comes to health insurance and employment. H.R. 493, §§ 101(a), 202(a). Executive Order 13145 was issued by President Bill Clinton on Feb. 8, 2000 prohibiting genetic discrimination by federal civil employers. Exec. Order No. 13145, 3 C.F.R. 235 (2000), available at <http://www.eeoc.gov/abouteeoc/35th/thelaw/13145.html>. Each suggests that genetic information is to be considered particularly confidential, and additional privacy safeguards are required due to the unique potential for discrimination.

79. While originally emphasizing informed consent, and what that means in the context of genetic testing (i.e., prediction, rate of false positives, treatment options, familial obligations to disclose), the conversation has evolved to include consideration of the social, legal, and psychological risks of genetic testing, and how various institutions such as the family, insurance industry, and health care providers may impact whether these risks materialize. Michael M. Burgess, *Beyond Consent: Ethical and Social Issues in Genetic Testing*, 2 NATURE REV. GENETICS 147, 147-49 (2001).

80. E.g., COMM. ON ASSESSING GENETIC RISKS, INST. OF MED., ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 2-15 (Lori B. Andrews et al. eds., 1994); Francis S. Collins, *BRCA1—Lots of Mutations, Lots of Dilemmas*, 334 N. ENG. J. MED. 186, 187-88 (1996); Michael J. Green & Jeffrey R. Botkin, "Genetic Exceptionalism" in Medicine: Clarifying the Differences Between Genetic and Nongenetic Tests, 138 ANNALS INTERNAL MED. 571, 572-73 (2003); *Statement of the American Society for Human Genetics on Genetic Testing for Breast and Ovarian Cancer Predisposition*, 55 AM. J. HUM. GENETICS at i, i-iii (1994).

81. Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60, 61 (Mark A. Rothstein ed., 1997); Patricia A. Roche & George J. Annas, Opinion, *Protecting Genetic Privacy*, 2 NATURE REV. GENETICS 392, 393 (2001)

think that genetics is wholly unique to recognize that it is at least *different*, and different in meaningful ways that impact identity and privacy. A DNA molecule is a source of medical information with predictive powers to estimate an individual's risk of suffering from a wide variety of conditions in the future.⁸² Genetic information can be stored just like a patient's written medical record, and can potentially be used and accessed downstream by people who have no relationship with the patient.⁸³ Additionally, it can inform people about where they came from, and provide information about their ancestors and their genetic connection to their children.⁸⁴ The potential for extrapolation (and abuse of extrapolation from overstating genetic impact) is huge. Unlike cholesterol or protein levels, genetic sequencing of DNA in the nucleus of blood cells should not fluctuate based on the time of the test.⁸⁵

For these reasons, some have called DNA-sequence information, a coded "future diary."⁸⁶ However, the diary metaphor may connote a stronger genetic basis for some conditions than is appropriate. While the presence of a single genetic anomaly can guarantee disease development in a few cases, the vast majority of genetic mutations can only predict some amorphous genetic contribution or association that may or may not result in disease.⁸⁷ The reason for the imprecision

(categorizing DNA information as "unique" because it contains information beyond that placed in a medical record, such as future health risks). Many have argued that predictive genetic tests are not all that different from other types of diagnostic tests in terms of presentation of clinical options; however, even those who think the data is not clinically exceptional will acknowledge the potential for greater discrimination and stigma. Murray, *supra*, at 64–65; Green & Botkin, *supra* note 80, at 573–74 (refusing to view genetic testing as "exceptional," but acknowledging privacy protection is needed in the event of discovering a stigmatizing disease).

82. Lisa Schriener Lewis, Note, *The Role Genetic Information Plays in the Criminal Justice System*, 47 ARIZ. L. R. 519, 522 (2005) ("Through DNA testing, scientist can use a sample of blood, saliva, skin, tissue, urine, semen, or other tissue to develop a genetic profile."). While urine may contain trace amounts of soluble DNA, it is typically not a reliable source of DNA in healthy individuals. Even so, urine has some value in predicting health outcomes in so far as kidney function or white blood cell count can be assessed through urine output. See Ying-Hsiu Su et al., *Human Urine Contains Small, 150 to 250 Nucleotide-Sized, Soluble DNA Derived from the Circulation and May Be Useful in the Detection of Colorectal Cancer*, 6 J. MOLECULAR DIAGNOSTICS 101, 101, 106–07 (2004).

83. Roche & Annas, *supra* note 81, at 393, 395.

84. Carl Elliot & Paul Brodwin, *Identity and Genetic Ancestry Tracing*, 325 BRIT. MED. J. 1469, 1469 (2002).

85. Douglas L. Riegert-Johnson et al., *The Incidence of Duplicate Genetic Testing*, 10 GENETICS MED. 114, 114 (2008).

86. George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded 'Future Diaries'*, 270 JAMA 2346, 2347–48 (1993). This metaphor has been criticized as perpetuating genetic determinism, i.e., the mistaken belief that genetics leave no room for environmental factors to affect expression of the genes. See Murray, *supra* note 81, at 66–67 ("In complex disorders with many contributing factors . . . genetic information may indicate only a rough range of probabilities, something that falls short of a 'probabilistic future.'").

87. See, e.g., James P. Evans et al., *The Complexities of Predictive Genetic Testing*, 322 BRIT. MED. J. 1052, 1053 (2001) ("The identified risk is sometimes high—for example, in a positive test for Huntington's disease—but always contains a substantial component of uncertainty . . .").

in prediction is that the risk of development is often compounded by synergistic genetic mutations, as well as by environmental factors such as diet, exposure to hormones and pathogens, and lifestyle.⁸⁸ Non-genetic factors are not trivial. They may explain why genome-wide association studies that reported an association between coronary heart disease and a common variant on chromosome 9 only appeared to increase risk of disease from 1% to 1.6% in people with two copies of the gene.⁸⁹ Genetic information has culturally achieved icon-status, and its mystique and significance has far exceeded other types of medical information.⁹⁰ There are those who advance that genetic testing is not conceptually all that different from blood pressure tests, but whether “[r]ight or wrong, genetic information is *believed* to reveal who we ‘really’ are, so information from genetic testing is often seen as more consequential than that from other sources.”⁹¹

While each court would embark upon a fact-intensive inquiry, it is quite likely that given the unique privacy status that genetic information holds, disclosure of someone’s genetic information by the press would be considered offensive or objectionable to a reasonable person. This is because the invasion penetrates many layers of privacy: informational privacy, decision-making privacy, and privacy over our person.⁹² The disclosure of one’s genetic information implicates real concerns of discrimination by colleagues and strangers, self-stigmatization and social stigmatization, and disclosure to the patient and his family of unwanted sensitive information.⁹³

a. *Permissible Disclosures Under Privacy Tort Doctrine*

After passing the first two *prima facie* hurdles of (1) public disclosure and (2) embarrassing facts, we then must ask whether the disclosure is constitutionally protected by the First Amendment. Even if the disclosure is objectionable, the claim of invasion of privacy will fail if the shared information is newsworthy, i.e.,

88. LYNN B. JORDE ET AL., *MEDICAL GENETICS* 275 (3d ed. 2006); Amy L. McGuire et al., *The Future of Personal Genomics*, 317 *SCIENCE* 1687, 1687 (2007).

89. McGuire et al., *supra* note 88, at 1687.

90. See DOROTHY NELKIN, & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* 2 (1995) (“[P]opular images convey a striking picture of the gene as powerful, deterministic, and central to an understanding of both everyday behavior and the ‘secret of life.’ . . . The biological gene—a nuclear structure shaped like a twisted ladder—has a cultural meaning independent of its precise biological properties.”).

91. Green & Botkin, *supra* note 80, at 572 (emphasis added).

92. Roche & Annas, *supra* note 81, at 392–93.

93. Gail Geller et al., *Genetic Testing for Susceptibility to Adult-Onset Cancer: The Process and Content of Informed Consent*, 277 *JAMA* 1467, 1471–72 (1997); Dorothy C. Wertz, *Society and the Not-So-New Genetics: What Are We Afraid of? Some Future Predictions from a Social Scientist*, 13 *J. CONTEMP. HEALTH L. & POL’Y* 299, 308–14 (1997).

“of a legitimate concern to the public.”⁹⁴ This inquiry hinges on our definition of the “public interest,” which traditionally has not been a high hurdle to overcome even when speaking of lower-level public officials, such as city clerks and police officers.⁹⁵ In fact, the U.S. Court of Appeals for the District of Columbia found that there was no invasion of privacy when the media published a police officer’s drug test results, finding that the “fitness for office of a public official and possible improprieties in police drug-testing” were legitimate matters of public concern.⁹⁶ The Supreme Court has emphasized elevated First Amendment protection for political speech, as this reflects our “profound national commitment to the principle that debate on public issues should be uninhibited, robust, and wide-open. . . .”⁹⁷ As the people are sovereign, it is critical that the people be able to make informed choices between candidates for office, “for the identities of those who are elected will inevitably shape the course that we follow as a nation.”⁹⁸ As the Court observed in *Monitor Patriot Co. v. Roy*, “it can hardly be doubted that the constitutional guarantee has its fullest and most urgent application precisely to the conduct of campaigns for political office.”⁹⁹ We see, therefore, that most information relating to public officials, and particularly information related to those running for political office, will pass the newsworthiness test.

Most commentators agree that the status of the President’s health is not only newsworthy, but in fact quite important to the public. In a recent discussion of privacy rights, one scholar wrote on the need to distinguish public *officials* from public *politicians*:

the propriety of disclosures depends upon their purpose, not merely on the type of information disclosed . . . not all public officials are the same. . . . there is a big difference between the nation’s president and a local police officer or a teacher. The president’s health, for example, is considered by many to be of public concern. This is hardly true for a bureaucrat, teacher, local prosecutor, or other minor public official.¹⁰⁰

94. See cases cited *supra* note 76. As will be developed in greater detail later on, whether the presidential candidate’s genetic information is of a legitimate concern to the public is the fulcrum in this analysis. In many ways to resolve this question is to resolve the entire debate.

95. The bar for “newsworthiness” does not appear to be that high under some states’ interpretation of the invasion of privacy tort. In New Jersey, a municipal employee’s medical report was published in connection with a retaliatory employment claim. *Ferraro v. City of Long Branch*, 714 A.2d 945, 948–50 (N.J. Super. Ct. App. Div. 1998). This was not considered an invasion of privacy because the employee was a “public official” and several news articles had been published on the subject of the underlying employment claim. *Id.* at 956–57; accord RESTATEMENT (SECOND) OF TORTS § 652D cmt. e (1977).

96. *White v. Fraternal Order of Police*, 909 F.2d 512, 514 (D.C. Cir. 1990).

97. *N.Y. Times Co. v. Sullivan*, 376 U.S. 254, 270 (1964).

98. *Buckley v. Valeo*, 424 U.S. 1, 14–15 (1976).

99. 401 U.S. 265, 272 (1971).

100. Daniel J. Solove, *The Virtues of Knowing Less: Justifying Privacy Protections Against Disclosure*, 53 DUKE L.J. 967, 967, 1010 (2003).

Perhaps “hardly true” is not consistent with some of the case law, but this commentator may have been making a normative rather than descriptive statement.

Even so, the level of publicity that someone receives has influenced invasion of privacy doctrines. Borrowing from principles developed in defamation law, the “public versus private figure” distinction helps determine if the disclosure of private facts is actionable. In the landmark case, *New York Times Co. v. Sullivan*, the Court held that a public figure may hold a speaker liable for damage to his reputation caused by publication of a defamatory falsehood, but only if the statement was made “with ‘actual malice’—that is, with knowledge that it was false or with reckless disregard of whether it was false or not.”¹⁰¹ Generally, if a newspaper publishes defamatory statements about a non-public individual, the First Amendment protection from liability does not exist as the information is not a legitimate matter of public concern.¹⁰² This demonstrates the now well-established doctrine that public figures have reduced expectations of privacy, as they must establish by clear and convincing evidence that the published information was made with deliberate or reckless falsification.¹⁰³ This is a much higher standard than that for an everyday, private plaintiff.

Speaking of private plaintiffs, it is worth noting that Eddie’s genetic information was obtained illegally through what might amount to a separately actionable battery.¹⁰⁴ The Supreme Court has stated that “[a]lthough stealing documents or private wiretapping could provide newsworthy information, neither reporter nor source is immune from conviction for such conduct, whatever the

101. 376 U.S. at 279–80. Further, in *Monitor Patriot Co.*, the Court stated that, “a candidate who vaults his spotless record and sterling integrity cannot convincingly cry ‘Foul!’ when an opponent or an invidious reporter attempts to demonstrate the contrary.” 401 U.S. at 274.

102. *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 346 (1974) (“On the one hand, a private individual whose reputation is injured by defamatory falsehood that does concern an issue of public or general interest has no recourse unless he can meet the rigorous requirements of *New York Times*. . . . On the other hand, a publisher or broadcaster of a defamatory error which a court deems unrelated to an issue of public general interest may be held liable in damages . . .”).

103. *E.g., id.* at 342 (holding that public figures “may recover for injury to reputation only on clear and convincing proof that the defamatory falsehood was made with knowledge of its falsity or with reckless disregard for the truth.”); *Masson v. New Yorker Magazine, Inc.*, 501 U.S. 496, 499 (1991) (“The First Amendment protects authors and journalists who write about public figures by requiring a plaintiff to prove that the defamatory statements were made with . . . deliberate or reckless falsification.”); *Milkovich v. Lorain Journal Co.*, 497 U.S. 1, 19–20 (1990) (“[W]here a statement of ‘opinion’ on a matter of public concern reasonably implies false and defamatory facts regarding public figures or officials, those individuals must show that such statements were made with knowledge of their false implications or reckless disregard of their truth.”).

104. A battery is an intentional tort where the private individual physically harms the plaintiff. *E.g., Caudle v. Betts*, 512 So.2d 389, 391 (La. 1987). Even though the hypothetical involved a battery by Steve’s pricking Eddie’s forearm, it is not difficult to imagine clever ways for outsiders to obtain genetic information of an individual without committing a battery (filching used coffee cups, discarded toenails, etc.).

impact on the flow of news.”¹⁰⁵ There is some protection, therefore, even for public officials, from the public disclosure of private facts that were obtained illegally.¹⁰⁶ However, the Supreme Court has also allowed illegally obtained information to be disclosed if the “privacy concerns give way when balanced against the interest in publishing matters of public importance.”¹⁰⁷ Quoting the classic law review on privacy by Justices Warren and Brandeis, the Supreme Court reiterated that “[t]he right to privacy does not prohibit any publication of matter which is of public or general interest.”¹⁰⁸ The health of the President is of public interest. So long as the applicable court buys this argument, it is unlikely that, under current precedent, Eddie could succeed in an invasion of privacy claim against Steve. Eddie is even less likely to prevail against the mainstream media who received the illegally obtained information without having contributed to the illegal procurement.¹⁰⁹

4. *The Fourth Amendment as a Constraint on Mandatory Disclosure*

The Fourth Amendment states that people have a right to “be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures,” and that this right “shall not be violated,” and no warrants will be issued absent probable cause.¹¹⁰ This only applies to searches or seizures conducted by the government or an agent of the government, and does not apply in the hypothetical above, unless Steve was acting in some way on behalf of the government.¹¹¹ However, the Fourth Amendment would apply if a state or federal government mandated that a presidential candidate disclose her health information through a

105. *Branzburg v. Hayes*, 408 U.S. 665, 691 (1972).

106. In *The Florida Star v. B.J.F.*, the Court stated that it need not “accept appellant’s invitation to hold broadly that truthful publication may never be punished consistent with the First Amendment. Our cases have carefully eschewed reaching this ultimate question, mindful that the future may bring scenarios which prudence counsels our not resolving anticipatorily.” 491 U.S. 524, 532 (1989). “Although public persons may have forgone the right to live their lives screened from public scrutiny in some areas, it does not and should not follow that they also have abandoned their right to have a private conversation without fear of it being intentionally intercepted and knowingly disclosed.” *Bartnicki v. Vopper*, 532 U.S. 514, 555 (2001) (Rehnquist, C. J. dissenting).

107. *Bartnicki*, 532 U.S. at 534 (2001). In *Bartnicki*, petitioners alleged that the publication of their private phone conversations by respondents was illegal under federal and state wire-tapping laws. *Id.* at 519. The Supreme Court upheld the Court of Appeals’ ruling, finding that the application of statutory provisions violated petitioners’ free speech rights because the statutes imposed sanctions on the publication of truthful information that was a matter of public concern. *Id.* at 533–35.

108. *Id.* at 534 (quoting Samuel Warren & Louis Brandeis, *Right to Privacy*, 4 HARV. L. REV. 193, 214 (1890)).

109. “[I]t by no means follows that punishing disclosures of lawfully obtained information of public interest by one not involved in the initial illegality is an acceptable means of those ends.” *Id.* at 529. Here, the Supreme Court was referring to the removal of incentives for parties to intercept private conversations and minimizing the harm to persons whose conversations have been illegally obtained. *Id.*

110. U.S. CONST. amend. IV.

111. *United States v. Jacobsen*, 466 U.S. 109, 113 (1984).

government-mandated blood test.¹¹² There is a threshold issue as to whether the genetic testing of presidential candidates would constitute a search or a seizure, and this will be discussed below.

The language of the Fourth Amendment includes a built-in test to allow only those searches that are reasonable. The reasonableness of the search and seizure will depend “upon all of the circumstances surrounding the search or seizure and the nature of the search or seizure itself.”¹¹³ The Fourth Amendment governs not only the seizure of tangible items, but also extends to the recording of oral statements, overheard without any “technical trespass under. . . local property law.”¹¹⁴ Similarly, courts have reasoned that one’s voice and handwriting are not protected because the:

Fourth Amendment provides no protection for what a person knowingly exposes to the public. . . . Like a man’s facial characteristics, or handwriting, his voice is repeatedly produced for others to hear. No person can have a reasonable expectation that others will not know the sound of his voice, any more than he can reasonably expect that his face will be a mystery to the world.¹¹⁵

The thinking is that we hold our faces, voices, and handwriting out to the public, and these identifying features require no expert search for interpretation.

The reliance on some form of trespass law aims to protect individuals from the government illegally obtaining information, while allowing the government to obtain identifying information that is in the public realm.¹¹⁶ While trespass law may be an appropriate legal boundary in the context of wiretaps and physical intrusion into the individual’s house, it does not operate quite so neatly when we’re dealing with genetic information. We carry potential genetic samples with us and present

112. *Cf. Skinner v. Ry. Labor Executives’ Ass’n*, 489 U.S. 602, 606, 616 (1989) (holding that the Fourth Amendment applied to mandatory drug testing for railroad employees because the collection and testing of urine intruded upon the employees’ reasonable expectations of privacy as recognized by society).

113. *United States v. De Hernandez*, 473 U.S. 531, 537 (1985) (citing *New Jersey v. T.L.O.*, 469 U.S. 325, 337–42 (1985)).

114. *Katz v. United States*, 389 U.S. 347, 353 (1967) (quoting *Silverman v. United States*, 365 U.S. 505, 511 (1961)).

115. *United States v. Dionisio*, 410 U.S. 1, 14 (1973) (citation omitted). Along the same lines, in *California v. Greenwood*, the Court held that because “respondents placed their refuse at the curb for the express purpose of conveying it to a third party . . . in an area particularly suited for public inspection and, in a manner of speaking, public consumption . . . respondents could have had no reasonable expectation of privacy in the incupatory items that they discarded.” 486 U.S. 35, 40–41 (1988) (citation omitted).

116. An action for trespass to property requires “possession of the property by the plaintiff when the alleged trespass was committed, and an unauthorized entry or interference with the property by the defendant.” 87 C.J.S. *Trespass* § 5 (2002 & Supp. 2007). “Some damage may also be a necessary element, although, because a legal right is involved, the law recognizes that actual harm occurs in every trespass, except where the intrusion is so trifling that the law should not recognize it as trespass.” *Id.*

them publicly everywhere we go, but that does not make our genetic information part of the public realm. We may occasionally drop it on public streets or discard it unwittingly on park benches. While the specimens may not yield as reliable or useful information as blood¹¹⁷—hair, toe-nails, saliva, or skin cells all contain genetic information that the government could argue is in the public domain and therefore not subject to the Fourth Amendment's protection.¹¹⁸

The Supreme Court has repeatedly held that a urinalysis or blood specimen test qualifies as a "search" under the Fourth Amendment.¹¹⁹ However, we should consider framing the laboratory genetic test as the search instead of focusing on the non-trespass search that results in a seizure of genetic material. This may not be the current way of looking at DNA testing, but it makes intuitive sense. Toenails may be publicly observable and obtained without trespass, but the actual sequencing or decoding of the genetic data would involve a search: revealing information that is not public and while detached from the person, still remains part of her property. In the case of *United States v. Amerson*, the Second Circuit categorized the collection of DNA samples from convicted felons as a *search*, as the government sanctioned a "physical intrusion to obtain the tissue sample" and "chemical analysis to obtain private physiological information about a person."¹²⁰ The second prong of this justification (chemical analysis) is critical for safeguarding privacy rights.¹²¹ Some state governments have relied only on the first prong to determine that discarded genetic material is not private. In a recent case, Washington state police surreptitiously obtained and tested genetic information from saliva on a sealed

117. If the hair does not contain the root follicle, the quality and availability of genetic testing is severely limited. Leanza et al., *supra* note 26, at 481. The reliability of DNA testing using hair samples depends on the quality as well as the number of samples used. Benoit Goossens et al., *Plucked Hair Samples as a Source of DNA: Reliability of Dinucleotide Microsatellite Genotyping*, 7 MOLECULAR ECOLOGY 1237, 1238–39 (1998). In some cases, up to ten hairs should be tested from the same specimen. *Id.* at 1238–39.

118. A group of researchers in the Netherlands recently found that toenail material collected twenty years ago could be used as a stable source of DNA for analyses of multiple genetic polymorphisms. Simone G. van Breda et al., Letter to the Editor, *Toenails: An Easily Accessible and Long-Term Stable Source of DNA for Genetic Analyses in Large-Scale Epidemiological Studies*, 53 CLINICAL CHEMISTRY 1168, 1169 (2007).

119. *Skinner v. Ry. Labor Executives' Ass'n*, 489 U.S. 602, 616–17 (1989) (holding that mandatory urinalysis for drug testing purposes is a violation of the Fourth Amendment); *Schmerber v. California*, 384 U.S. 757, 767 (1966) ("[A] compulsory administration of a blood test . . . plainly involves the broadly conceived reach of a search and seizure under the Fourth Amendment."); *Nicholas v. Goord*, 430 F.3d 652, 658 (2d Cir. 2005) ("[T]he extraction and analysis of plaintiffs' blood for DNA-indexing purposes constituted a search implicating the Fourth Amendment.").

120. 483 F.3d 73, 77 (2d Cir. 2007).

121. *Nicholas*, 430 F.3d at 656 n.5 ("In any event, even less intrusive measures of obtaining physiological data, such as cheek swabs, can constitute a search, since the ensuing chemical analysis of the sample may also effect an invasion of the [individual's] privacy interests." (internal citation omitted)).

envelope.¹²² The Washington court did not consider this a search under the Fourth Amendment, finding that the saliva was “discarded genetic material.”¹²³ The laboratory analysis of the genetic information is what could and should constitute the “search” under the Fourth Amendment.

The Fourth Amendment typically requires that a search or seizure result from a warrant issued upon individualized probable cause.¹²⁴ However, in a limited number of circumstances, outside the realm of criminal investigations, the Supreme Court has approved warrantless, suspicionless searches if a “special need” is being fulfilled that obtaining a warrant would thwart.¹²⁵ The Court did *not* find that such a “special need” existed in *Chandler v. Miller*.¹²⁶ In this case, the majority of justices held that a Georgia state law that conditioned candidacy for high public office on successfully passing a drug test was unconstitutional.¹²⁷ Justice Ginsburg delivered the opinion of the Court, which held that the mandatory urinalysis did not fit within the closely guarded category of permissible suspicionless searches.¹²⁸ The lower court disagreed:

122. *Washington v. Athan*, 158 P.3d 27, 37, 43 (Wash. 2007) (en banc).

123. *Id.* (noting that there is no recognized privacy interest in “voluntarily discarded saliva” when police collect it for the legitimate government purpose of DNA identification analysis); *see also* Laura A. Matejik, *DNA Sampling: Privacy and Police Investigation in a Suspect Society*, 61 ARK. L. REV. 53, 55 (2008) (“[C]overt involuntary DNA sampling involves targeting a specific individual to obtain items that he or she discards, such as cigarette butts or coffee cups.”).

124. U.S. CONST. amend. IV; *accord* *Vernonia Sch. Dist. v. Acton*, 515 U.S. 646, 652–53 (1995); *Terry v. Ohio*, 392 U.S. 1, 20–21 (1968).

125. *Int’l Union v. Winters*, 385 F.3d 1003, 1007–08 (6th Cir. 2004). Examples of when these “special needs” cases were found to be reasonable include: (1) the drug testing of customs officials, if their job dealt with combating drug-trafficking or the handling of firearms, since their job duties would be compromised if they were themselves using the illegal drugs or prone to bribery, *Nat’l Treasury Employees v. Von Raab*, 816 F.2d 170 (5th Cir. 1987), *aff’d*, 489 U.S. 656, 666, 679 (1989); (2) the testing of public high school athletes for drugs, since the school’s involvement in recreational sports provides them with a burden to make sure they do not encourage the use of steroids and other drugs, *Vernonia Sch. Dist.*, 515 U.S. at 650, 656–57, 663–65; (3) the drug testing of railroad workers who were working on a train during a serious accident, *Skinner v. Ry. Labor Executives’ Ass’n*, 489 U.S. 602, 603, 606, 624 (1989); and (4) the searching of New York subway passengers to prevent a bombing of the subways by terrorists, *MacWade v. Kelly*, 460 F.3d 260, 263 (2d Cir. 2006). The Supreme Court has held that where the primary purpose of the warrantless search is in fact law enforcement, then the “special needs” exception cannot stand. For instance, a South Carolina medical school began testing urine samples of pregnant women who they suspected of drug use, in order to persuade these women to undergo substance abuse treatment. *Ferguson v. Charleston*, 532 U.S. 67, 70–73 (2001). This was found to be primarily for law enforcement purposes, and thus a warrant was required. *Id.* at 82–86.

126. 520 U.S. 305, 309 (1997).

127. *Id.* It is possible that a candidate may challenge mandatory testing under the Fourteenth Amendment as well, arguing that the test is a violation of his fundamental substantive due process rights to keep his medical information private. *See id.* at 312–313. There has been no fundamental right recognized as such, although there very well could be in the future. Still, this is not the end of the inquiry, as the government may still regulate this right if it has a compelling state interest.

128. *Id.* at 307.

The people of Georgia place in the trust of their elected officials. . . their liberty, their safety, their economic well being, [and] ultimate responsibility for law enforcement. . . . The nature of high public office in itself demands the highest levels of honesty, clear sightedness, and clear thinking. . . . [And] candidates for high office must expect the voters to demand some disclosures about their physical, emotional, and mental fitness for the position.¹²⁹

In reversing this Eleventh Circuit opinion, the Court decided that the competing private and public interests advanced by the parties weighed in favor of the candidates' privacy, prohibiting the warrantless searches.¹³⁰

The Court reasoned that there was no evidence of a drug problem among candidates in Georgia, and since candidates are subject to intense media scrutiny, the media would alert the public to any concerns of drug abuse, should they develop.¹³¹ The Court also reasoned that as their private physicians could perform the tests, candidates could cheat the system by abstaining from drugs for a certain window of time.¹³² In another breath the majority praised the urine collection mechanism for this same reason, saying that it was less intrusive because it could be scheduled any time within a thirty-day window, and at the candidate's physician's offices.¹³³ The *Chandler* opinion did not adequately represent Georgia's articulated interest in ensuring a sober, clear-headed governor. Instead, the Court constructed a symbolic state interest that it precipitously shot down, of Georgia caring only about its image.¹³⁴

Justice Rehnquist authored a dissent, which pointed out another irony in the majority's opinion: they used the very public nature of the figure to argue in favor of more privacy, something that runs afoul of the recognized privacy rights doctrine discussed above.¹³⁵ While Justice Rehnquist concurred that there must be a balancing of individual privacy interests against the utility of the search, he stated that as long as there was a "proper governmental purpose" other than law

129. *Chandler v. Miller*, 73 F.3d 1543, 1546–47 (11th Cir. 1996), *rev'd*, 520 U.S. 305 (1997). Should the candidate test positive, he or she could forfeit the opportunity to run for office, and in that event, nothing would be divulged to law enforcement officials. *Id.* at 1547.

130. *Chandler*, 520 U.S. at 305, 318.

131. *Id.* at 321–22.

132. *Id.* at 319–20.

133. *Id.* at 310, 318.

134. *Id.* at 321 ("What is left, after close review of Georgia's scheme, is the image the State seeks to project. By requiring candidates for public office to submit to drug testing, Georgia displays its commitment to the struggle against drug abuse.").

135. *Id.* at 325 (Rehnquist, C.J., dissenting) ("Under normal Fourth Amendment analysis, the individual's expectation of privacy is an important factor in the equation. But here, the Court perversely relies on the fact that a candidate for office *gives up* so much privacy . . . as a reason for *sustaining* a Fourth Amendment claim.").

enforcement, there was also a “special need.”¹³⁶ The majority required that the special need be “closely guarded” and “substantial,” but Rehnquist countered that the articulated need must only be *reasonable*.¹³⁷ The Chief Justice rightly questioned the logic inherent in the majority’s opinion and found it impractical to require Georgia to first elect a drug addict before a “special need” exists.¹³⁸ In *Skinner v. Skinner Railway Labor Executives Ass’n*, there was evidence that railroad workers were drinking on the job;¹³⁹ however, such specific evidence is not required under the “special needs” doctrine. In *National Treasury Employees Union v. Von Raab*, the Court permitted random drug testing of customs agents absent “any perceived drug problem among Customs employees,” given that “drug abuse is one of the most serious problems confronting our society today.”¹⁴⁰

a. Permissible Disclosures under the Fourth Amendment

The *Chandler v. Miller* case is unusual. It does not necessarily flow from the precedent for other warrantless, suspicionless searches. The Fourth Amendment cases leading up to and following *Chandler* held that the balancing of the privacy and public interest rights allowed mandatory drug testing of many classes of people who are much less public than a state Governor. For example, public school student athletes,¹⁴¹ railroad workers,¹⁴² and customs officials¹⁴³ were all found to have diminished expectations of privacy that permitted warrantless drug testing. This was done to reduce drug use by student athletes,¹⁴⁴ minimize train accidents due to worker insobriety,¹⁴⁵ and prevent customs officials involved in drug interdiction from being bribed by drug-cartels,¹⁴⁶ respectively. In a later case that had nothing to do with drug testing, the Second Circuit held that even if there were no

136. *Id.*

137. *Id.* at 318, 325 (Rehnquist, C.J., dissenting).

138. *See id.* at 326 (arguing that there is a legitimate state interest in preventing the use of illegal drugs which is not undermined by the notice Georgia’s law gives to candidates as to when drug testing will occur).

139. 489 U.S. 602, 607 (1989).

140. 489 U.S. 656, 673–74, 677 (1989).

141. *Vernonia Sch. Dist. v. Acton*, 515 U.S. 646, 648, 664–65 (1995).

142. *Skinner*, 489 U.S. at 634.

143. *Von Raab*, 489 U.S. at 665–66. The distinction between *Von Raab* and *Skinner* explains in part why *Skinner* was a 7-2 decision while *Von Raab* was only a 5-4 decision. Justices Scalia and Stevens abandoned the *Skinner* majority to author a dissent in *Von Raab*, arguing that only demonstrated public necessity could justify such an intrusion without a warrant and probable cause, and that “symbolic opposition to drug use” was an insufficient measure of public necessity. *Id.* at 681. (Scalia, J., dissenting); *see also* *Int’l Union v. Winters*, 385 F.3d 1003, 1009 (6th Cir. 2004) (noting that a context-specific inquiry examining the state’s interest is needed to accept a state’s invocation of special needs).

144. *Acton*, 515 U.S. at 650.

145. *Skinner*, 489 U.S. at 607–08.

146. *Von Raab*, 489 U.S. at 661.

diminished privacy interests, individuals could still be searched by the government, without a warrant, prior to entering the New York subway.¹⁴⁷

After reviewing the opinions in many of these “special needs” cases, one logical way to distinguish *Chandler* from the other relevant Fourth Amendment cases is to say that a double standard exists that favor people in power.¹⁴⁸ The privacy arguments advanced do not comport with previous standards for public figures, as the governor should be thought to have a weaker privacy interest than that of a public school athlete. Even if the privacy status of the individual is not the critical factor, the potential for broad public impact is much greater with the highest executive of a state than with a private individual playing public sports.¹⁴⁹ Further, in *Chandler* the Court reasoned that “respondents have offered no reason why ordinary law enforcement methods would not suffice to apprehend such addicted individuals. . . .”¹⁵⁰ The same could be said for heavily regulated customs officials or closely watched student athletes. Much like preventing a drunk railroad worker from operating trains is in the public interest, is it not possible that the negative consequences flowing from a drunk or drugged Governor could also be sharply against the public interest?

147. *MacWade v. Kelly*, 460 F.3d 260, 263 (2d Cir. 2006). The Court of Appeals held that (1) “the special needs doctrine may apply where . . . the subject of a search possesses a full privacy expectation,” (2) “preventing a terrorist attack on the subway is a ‘special’ need,” and (3) the program is “a reasonably effective deterrent” and thus constitutional. *Id.* at 263, 275. Note that the Court has not upheld all warrantless searches of private citizens under the “special needs” doctrine. The outer bounds were maintained by *Ferguson v. City of Charleston*, where the Court held that (1) urine tests of pregnant women who had tested positive for cocaine use were “searches” within meaning of Fourth Amendment, 532 U.S. 67, 76 (2001), and (2) tests, and reporting of positive test results to police, were unreasonable searches absent patients’ consent, given that the primary purpose of the test appeared to be for law enforcement purposes. *Id.* at 81, 84–85.

148. There are a number of state cases that may permit warrantless, suspicionless drug testing of individuals who apply for public positions. State constitutions may be more protective of the implicated privacy rights, in which case the court undergoes state constitutional review. A Washington state court found that because the government is obligated to protect the safety of its citizens, “suspicionless preemployment drug testing [of city employees] is . . . justified . . . where the duties of a particular position genuinely implicate public safety, such that there is potential jeopardy to members of the public if such duties are performed by a person who abuses drugs.” *Robinson v. Seattle*, 10 P.3d 452, 467 (Wash. Ct. App. 2000); *see also Loder v. Glendale*, 927 P.2d 1200, 1203 (Cal. 1997) (“[A]cross-the-board drug testing . . . is invalid as applied to current employees who have been conditionally approved for promotion, but is valid as applied to job applicants.”); *Willner v. Thornburgh*, 289 U.S. App. D.C. 93, 102 (1991) (“[U]rine tests of applicants for positions as attorneys at the Justice Department do not constitute ‘unreasonable searches’ under the Fourth Amendment.”).

149. After all, the President is the “Commander in Chief of the Army and Navy of the United States.” U.S. CONST. art. II, § 2; *accord Dep’t of the Navy v. Egan*, 484 U.S. 518, 527 (1987) (“His authority to classify and control access to information bearing on national security and to determine whether an individual is sufficiently trustworthy to occupy a position in the Executive Branch that will give that person access to such information flows primarily from this constitutional investment of power in the President and exists quite apart from any explicit congressional grant.”).

150. *Chandler v. Miller*, 520 U.S. 305, 320 (1997).

State cases that upheld drug testing of public officials did so for many reasons that would apply equally, if not more, to a presidential candidate. For example, a Washington state case stated that suspicionless preemployment drug testing of job applicants is justified “where the duties of a particular position *genuinely implicate public safety*, such that there is potential jeopardy to members of the public. . . .”¹⁵¹ It is not altogether obvious why this would not be extended to high-level political figures. After all, while politicians may not be the proximate cause of train collisions, they can certainly jeopardize many aspects of our daily lives. While under the influence, a politician could frustrate diplomacy and lose critical investments in the state, irresponsibly limit funding of critical social welfare programs, neglect the public safety by failing to address critical threats, or have her decision-making powers hijacked by opportunists. Having one’s urine studied seems like a very limited intrusion into privacy when this is what is at stake.

It is not uncommon for courts to concentrate on the *method* of procurement rather than the intrusiveness of the *type of information* being collected. The Court in *Skinner* focused more on the degree of intrusiveness in the test procedure itself, and less on the intrusion flowing from the use of the data collected.¹⁵² A genetic test would be less intrusive than urinalysis in this regard, as the blood draw or buccal swab could be done without infringing on the privacy expectation individuals have when they use the restroom. But if we focus on the way the test could be *used*, genetic tests are much more intrusive into the privacy rights of the individual, for all of the reasons discussed above. A genetic test offers more nuanced, and potentially more reaching information. The specimen could be stored and later mined for newly discovered sequences or behavioral genetics data.¹⁵³ One

151. *Robinson*, 10 P.3d at 467, 469. The Washington court further noted that “[p]reemployment drug testing of applicants who will carry firearms or whose duties may otherwise jeopardize public safety is justified.” *Id.* at 469. The court’s classification likely includes police officers and similar public employees. *See id.*; *Turner v. Fraternal Order of Police*, 500 A.2d 1005, 1008 (D.C. Cir. 1985) (upholding drug analysis testing of the police force for public safety purposes); *Jones v. Jenkins*, 878 F.2d 1476–77 (D.C. Cir. 1987) (per curiam) (upholding a drug testing program for employees involved in the transportation of handicapped children); *Duarte v. Healy*, 537 N.E. 2d 1230, 1233–34 (Mass. 1989) (discussing the split among courts regarding the constitutionality of urinalyses). One wonders whether it is possible for an individual municipal police officer to affect public safety more than the President of the United States.

152. *See Skinner v. Ry. Labor Executives’ Ass’n*, 489 U.S. 602, 626 (1989) (“We recognize, however, that the procedures for collecting the necessary samples, which require employees to perform an excretory function traditionally shielded by great privacy, raise concerns not implicated by blood or breath tests.”).

153. In *Davis v. Mississippi*, 394 U.S. 721, 727 (1969), the Court commented upon the limited intrusion that was caused by fingerprinting in comparison to other types of searches and detentions. The Court noted that fingerprinting did not involve probing into an individual’s life or harassing that person since law enforcement needs only one set of fingerprints. *Id.* Genetic specimens could likewise be obtained with limited intrusion. However, unlike fingerprints, the information that could be gathered from genetic information is much more vast. *See infra* Part II.C–D. Information pertinent to the risk of developing devastating diseases such as Alzheimer’s or Huntington’s could be ascertained. *Id.* In

distinction that renders the genetic test less powerful and intrusive is the fact that unlike a positive result on a drug urinalysis, genetic tests currently have mostly probabilistic power. They can tell you whether someone does or does not possess a specific mutation, but they typically cannot tell you whether that will result in disease.¹⁵⁴ Commercially developed tests, such as BRCA1, cannot predict with certainty whether a woman will develop breast cancer, as BRCA1 alone is not the only cause.¹⁵⁵ There are only a handful of diseases that can be nearly perfectly predicted by the presence of a genetic anomaly.¹⁵⁶

If genetic information could better predict many diseases, it might be considered just another aspect of a candidate's general health. Justice Rehnquist pointed to an important distinction the *Chandler* majority made that could inform this sort of thinking: "Lest readers expect the holding of this case to be extended to any other case, the Court notes that the drug test here is not part of a medical examination designed to provide certification of a candidate's general health."¹⁵⁷ Rehnquist posits that a case involving a general medical exam could not be decided differently unless the state has a "far greater interest in the candidate's 'general health' than it does with respect to his propensity to use illegal drugs. But this is. . . [a] policy judgment that surely must be left to the legislatures. . . ."¹⁵⁸

It is possible that Rehnquist is using this rhetorical tool of challenging the extension of *Chandler* to suggest that we might want to treat the general health of executives differently. Courts or legislatures could argue that the state has a much stronger interest in the candidate's general health than it does in the candidate's drug use. The proponents of the drug testing in *Chandler* argued that public officials needed to make decisions rationally and without compromised mental faculties.¹⁵⁹ This presupposes an interest in the public figure's baseline mental health. Unlike occasional drug-use that a urinalysis would pick up, the genetic test might one day be able to quantify reliable risk probabilities for developing long-term disorders such as Huntington's or Alzheimer's disease. While the genetic test

addition, one day genetic tests could be used to assess the increased risk of developing complex behavioral traits such as alcoholism, depression, or anxiety disorders. *Id.* Therefore, focus on the *intrusion in procuring the specimen* is less important than the nature of the private information that could be gathered *from* that specimen.

154. See Margaret P. Battin, *Genetic Information and Knowing When You Will Die*, in *GENETIC INFORMATION* 219, 221 (Alison K. Thompson & Ruth F. Chadwick eds., 1999) ("Women with mutations in the BRCA1 gene associated with breast cancer have a 50/50 chance of developing the disease by age 50 . . . though some women never contract the disease at all.")

155. See *id.* at 123–24 (stating that environmental factors also trigger disease).

156. See Evans et al., *supra* note 87.

157. *Chandler v. Miller*, 520 U.S. 305, 327 (1997) (Rehnquist, C.J., dissenting).

158. *Id.* at 327–28.

159. *Chandler v. Miller*, 73 F.3d 1543, 1546 (11th Cir. 1996), *rev'd*, 520 U.S. 305 (1997) ("The nature of high public office in itself demands the highest levels of honesty, clear-sightedness, and clear-thinking.")

in no way predicts the onset of most diseases, it might one day foreshadow the likelihood of a president remaining healthy based upon the presence of genotypes¹⁶⁰ that may develop into the phenotypes of dementia or Alzheimer's disease. A president's general health affects his day-to-day job and substantial evidence indicates that mental or physical deficits have played a major role in the governance of previous presidents.¹⁶¹ While there may be a presumption that someone does not use drugs unless evidence suggests the contrary, there is no underlying legal presumption that someone is in good health unless evidence is presented to the contrary.

Genetic information carries its own stigma, but it is not clear that this type of health information would be more stigmatizing than the revelation that a politician used cocaine. Just how stigmatizing the genetic information would be depends on factors such as how the related phenotype is treated, whether it is socially discriminated against, how prevalent it is, and where the individual is in her own personal and social development. It might be more stigmatizing for an unmarried man who is a relative rookie on the political scene to have genetic mutations disclosed, as he has not had a chance to prove his prowess absent the public's knowledge of his genetic lottery. It also might affect his ability to fundraise, marry, or otherwise interact with friends and family.

Communitarian scholar Amital Etzioni has written a great deal on privacy rights and the flexibility inherent in the Fourth Amendment. He has argued "that which is considered reasonable changes as the social climate changes."¹⁶² Perhaps this explains the loosening of the once rigid ban on warrantless searches. In the period following September 11, 2001 and the Patriot Act,¹⁶³ the government has advanced theories of permissible warrantless wiretaps, and courts may now be

160. A phenotype describes any quality of an organism that can be observed by direct examination, whereas the genotype refers to all the genes an organism carries. W. Johannsen, *The Genotype Conception of Heredity*, 45 AM. NATURALIST 129, 132-34 (1911).

161. This will be explored further in the next section, but many authors have documented this proposition. See discussion *infra* Part III.B. "[T]he international list of those who have carried great responsibility while ill is a long one and there are fleeting glimpses of decisions which good health might have turned another way." Dean Rusk, *The President*, 38 FOREIGN AFFAIRS 353, 366 (1960); see also Jerrold M. Post & Robert S. Robins, *The Captive King and His Captive Court: The Psychopolitical Dynamics of the Disabled Leader and His Inner Circle*, 11 POL. PSYCHOL. 331, 332 (1990) ("Woodrow Wilson's stroke and the immobilization of his presidency, the Shah's lymphatic cancer and the victory of the Islamic Revolution, and Mao's arteriosclerosis and the Cultural Revolution are only a very few examples of the effect of a leader's medical impairment on major political events."). Additionally, President Johnson's gall bladder surgery "had a negative impact on his congressional leadership" and his absence from the center state encouraged Congress to vote against a rent subsidy program that Johnson supported, as well as filibustering against repeal of a section of the Taft-Hartley Act that Johnson wanted repealed. Robert E. Gilbert, *The Political Effects of Presidential Illness: The Case of Lyndon B. Johnson*, 16 POL. PSYCHOL. 761, 772 (1995).

162. Etzioni, *supra* note 28, at 215.

163. USA Patriot Act of 2001, Pub. L. No. 107-56, §§ 201-25, 115 Stat. 272, 278-96 (codified as amended in scattered sections of 18, 22, 28, 50 U.S.C.).

more likely to agree with such measures as being reasonable based on national security interest. Relevant to our inquiry, Etzioni later said that in this context, “DNA searches once considered a matter of science fiction and entirely unreasonable are now becoming reasonable[,] [a]s their service to the common good becomes better known, their intrusiveness declines. . . .”¹⁶⁴

The *Chandler* precedent provides a roadmap for allowing genetic testing of presidential candidates, however murky the road to success. In keeping with the Fourth Amendment standard of reasonableness, any law requiring genetic testing of presidential candidates would need to ensure that the search is not overly broad in scope, and not more intrusive than necessary to achieve its stated purpose. The special need must be articulated carefully so that the motivation for the search is clearly couched in terms of the nation’s safety and public interest. Any genetic testing requirement would need to be automatically applied in specified situations to eliminate the chance of abuse of discretion by administering personnel.¹⁶⁵ This may provide fodder for testing all candidates, even if no evidence of compromised health exists for any one person.

5. *Non-Discrimination Statutes as a Constraint on Disclosure*

Various forms of statutory protection exist to prohibit genetic discrimination by employers and insurers. Most states have implemented some type of protection from genetic discrimination, but exactly what is protected varies from state to state.¹⁶⁶ Forty-four states and the District of Columbia do not allow insurance eligibility to be determined based on either genetic traits or some grouping of genetic traits.¹⁶⁷ Twenty-seven states’ privacy laws restrict certain parties such as insurers and employers from using the individual’s genetic information without their consent.¹⁶⁸ Eighteen states have established civil, criminal, or some combination of each type of penalty for violating genetic privacy laws.¹⁶⁹

164. Etzioni, *supra* note 28, at 216.

165. *Cf.* South Dakota v. Opperman, 428 U.S. 364, 383 (1976) (Powell, J., concurring) (explaining that law enforcement officers do not make discretionary determinations during automobile inventory searches because such searches are conducted in accordance with established police department rules and are not conducted for criminal investigation purposes).

166. *E.g.*, Nat’l Conference of State Legislatures, Genetics and Health Insurance: State Anti-Discrimination Laws [hereinafter Genetics and Health Insurance], <http://www.ncsl.org/programs/health/genetics/ndishlth.htm> (last visited Apr. 21, 2008); Nat’l Conference of State Legislatures, State Genetics Employment Laws, <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last visited date); Nat’l Conference of State Legislatures, State Genetic Privacy Laws [hereinafter State Genetic Privacy Laws], <http://www.ncsl.org/programs/health/genetics/prt.htm> (last visited Apr. 21, 2008).

167. Genetics and Health Insurance, *supra* note 166.

168. State Genetic Privacy Laws, *supra* note 166.

169. *Id.*

Federal law has been protective as well. HIPAA clarified that protected health information included genetic information, and therefore HIPAA prohibits unauthorized disclosure or discrimination of such information by group health insurance plans and employers.¹⁷⁰ President Clinton signed Executive Order 13145 on February 8, 2000, which expanded this protection to federal civil employees.¹⁷¹ The order prohibited federal employers from discriminating in employment hiring, promotion, firing, or benefits based on the employee's protected genetic information or a request for receipt of genetic information.¹⁷² Interestingly enough, the definition of federal civil employees carved out elected public officials.¹⁷³ While HIPAA provides some protection to group health care plan recipients, and the executive order extends that to federal civil employees, gaps still remain in protection. HIPAA does not, for example, preclude employers from denying coverage altogether. Most importantly, HIPAA "only applies to employer-based and commercially issued group health insurance plans and not to private individuals seeking health insurance on the market. . . ."¹⁷⁴

To close some of these loopholes, the House introduced H.R. Bill 493, the Genetic Information Non-Discrimination Act (GINA), which passed the House in April of 2007.¹⁷⁵ After the Senate made a few revisions to the bill to prevent frivolous employee lawsuits, the Senate passed a slightly different version in April of 2008.¹⁷⁶ President Bush has indicated that he will sign this bill into law.¹⁷⁷

170. 29 U.S.C. § 1182(a)(1)(F) (2000) ("[A] group health plan, and a health insurance issuer offering group health insurance coverage . . . may not establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on . . . [g]enetic information."); Deborah Kohn, *Who is Covered by HIPAA*, AIIM, Aug. 19, 2004, <http://www.aiim.org/article-docrep.asp?ID=28503>.

171. Exec. Order No. 13145, 3 C.F.R. 235 (2000), available at <http://www.eeoc.gov/abouteeoc/35th/thelaw/13145.html>.

172. *Id.* at 236.

173. *Id.* ("The term 'employee' shall include an employee, applicant for employment, or former employee covered by section 717 of the Civil Rights Act of 1964, as amended."). Under Section 717 of the Civil Rights Act, the "term 'employee' shall not include any person elected to public office in any State or political subdivision of any State by the qualified voters thereof . . ." 42 U.S.C. § 2000e(f) (2000).

174. Karen Eltis, *Genetic Determinism and Discrimination: A Call to Re-Orient Prevailing Human Rights Discourse to Better Comport with the Public Implications of Individual Genetic Testing*, 35 J.L. MED. & ETHICS 282, 282 (2007).

175. H.R. 493, 110th Cong. (2007) (as passed by House, Apr. 25, 2007).

176. The Senate passed GINA on April 24, 2008, approving unanimously an amended version of H.R. 493. The passage of the Bill "end[ed] a 13-year odyssey for the bill, first proposed in 1995 by Louise Slaughter, a House Democrat from western New York, who ha[d] been promoting it ever since." Andrew Pollack, *Genetic-Discrimination Ban Moves Ahead in Congress*, N.Y. TIMES, Apr. 23, 2008, at C1. While the House still needs to approve the changes made by the Senate, it is expected that the bill will pass and be signed by the President into law. Will Dunham, *Experts See Boost to Genetic Testing From U.S. Bill*, REUTERS NEWS, Apr. 27, 2008, available at <http://www.reuters.com/article/healthNews/idUSN2639236620080427>.

Specifically, the bill proposes prohibiting disclosure of an employee's genetic information unless it is made to a labor organization at the written request of the employee, for public health research conducted pursuant to federal law, or in response to a court order.¹⁷⁸ Genetic information is defined as information about "(i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) . . . the manifestation of a disease or disorder in family members of such individual."¹⁷⁹ Genetic information also includes genetic services such as genetic testing, counseling or education, but does not include information about the age or sex of an individual.¹⁸⁰ The term "genetic test" is defined to mean an "analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes," but excludes analysis of proteins or metabolites that do not detect genotypes, mutations, or chromosomal changes.¹⁸¹ Under the bill, as currently drafted, discrimination based upon genetic information is likewise an "unlawful employment practice."¹⁸² Specifically, it is actionable to fail or refuse to hire, to discharge an employee, or otherwise discriminate with respect to pay, terms, or privileges of employment based upon the employee's genetic information.¹⁸³ GINA also provides that separate treatment or classification of employees based upon their genetic information would be illegal if it deprived an employee of opportunities or adversely affected an employee's status.¹⁸⁴

The Americans with Disabilities Act of 1990 (ADA), could theoretically provide some basis for protection against genetic discrimination.¹⁸⁵ Title I of the ADA prohibits private employers, state and local governments, employment agencies, and labor unions with more than fifteen employees from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, promotion, compensation, or training.¹⁸⁶ It is not immediately clear whether this applies to genetic disorders or abnormalities unless the phenotype would

177. OFFICE OF MGMT. & BUDGET, EXECUTIVE OFFICE OF THE PRESIDENT, STATEMENT OF ADMINISTRATION POLICY: H.R. 493 – GENETIC INFORMATION NONDISCRIMINATION ACT OF 2007 (2007), *available* at <http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/SAPonHR493.pdf>.

178. H.R. 493 § 206(b)(1)–(3).

179. *Id.* § 201(4)(A).

180. *Id.* §§ 201(4)(B)–(C), (6).

181. *Id.* § 201(7).

182. *Id.* § 202(a).

183. *Id.* §§ 202(a), 207.

184. *Id.* § 202(a)(2).

185. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified at 42 U.S.C. § 12101–12203 (2000)).

186. § 102, 104 Stat. at 331 (codified at 42 U.S.C. § 12112).

amount to a “disability” under current ADA precedent.¹⁸⁷ On May 8, 2002, the Equal Employment Opportunity Commission (EEOC) instituted a lawsuit against Burlington Northern Santa Fe Railway Company (BNSF).¹⁸⁸ The EEOC alleged that BNSF engaged in unlawful employment practices in violation of the ADA by requesting that certain employees who claimed that they had developed work-related carpal tunnel syndrome submit to a diagnostic blood test for a genetic marker.¹⁸⁹ The EEOC further alleged that BNSF retaliated against those employees who refused to submit to genetic testing.¹⁹⁰ In return for the claimants’ release of charges, BNSF agreed to pay the claimants \$1,750,000.¹⁹¹ They also agreed never to request that their current or past employees submit to genetic tests.¹⁹²

Even if not couched in terms of genetic non-discrimination, the ADA has been invoked to prevent other types of inappropriate workplace testing for genetic diseases, such as sickle cell anemia. In 1998, a California laboratory was charged with violating the ADA by requiring, encouraging, or assisting in testing for sickle cell anemia in its employees “that was neither job-related nor consistent with business necessity.”¹⁹³ The Ninth Circuit held that the employees had failed to state a claim under the ADA, as the ADA imposes no restriction on the scope of employee entrance exams.¹⁹⁴ However, the employees had made out a successful claim based on Title VII of the Civil Rights Act of 1964 as well as the right to privacy guaranteed in United States and California Constitutions. The ability of employers to test employees before making hiring decisions is precisely the type of gap that the proponents of GINA hoped prohibit. The ADA analysis will no longer add much as the employees would now be protected from employment genetic discrimination under many state statutes, HIPAA, and GINA.

187. Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?*, 42 VILL. L. REV. 613, 626–28 (1997); Brian R. Gin, Note, *Genetic Discrimination: Huntington’s Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406, 1417–18 (1997); Deborah Gridley, Note, *Genetic Testing Under the ADA: A Case for Protection from Employment Discrimination*, 89 GEO. L.J. 973, 991–92 (2001); Susan M. Wolf & Jeffrey P. Kahn, *Genetic Testing and the Future of Disability Insurance: Ethics, Law and Policy*, 35 J.L. MED. & ETHICS 6, 7 (2007).

188. Equal Opportunity Employment Comm’n v. Burlington N. & Santa Fe Ry. Co., No. 02-C-0456, 2002 WL 32155386, at *1 (E.D. Wis. May 8, 2002).

189. *Id.*

190. *Id.*

191. *Id.* at *2.

192. *Id.*

193. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1265 (9th Cir. 1998).

194. *Id.* at 1273.

a. *Permissible Disclosures Under the Anti-Discrimination Statutes*

There are several statutory definitions of the term “employee” incorporated into GINA and the other anti-discrimination statutes discussed herein.¹⁹⁵ Of note, none of the definitions include elected public officials, and the oft-recycled definition of employee in the Civil Rights Act of 1964 specifically carved out those elected for public office.¹⁹⁶ Presumably, this is because the “employer” in this situation is the public and the act of voting is intentionally and inherently discriminatory. For First Amendment reasons, the motivations for “hiring” one candidate over another cannot be subject to review under either the Civil Rights Act of 1964 or GINA.¹⁹⁷ This means that a candidate for public office could not make a claim under any of the non-discrimination statutes as he or she is not considered a covered employee.

Therefore, if GINA does go into effect, the only population that may have compromised benefits or who may be denied employment based on their genetic information is the U.S. military.¹⁹⁸ The practice of genetic discrimination against

195. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 201(2) (2007) (including the definition of: (1) an “employee” as set forth by the Civil Rights Act of 1964, 42 U.S.C. § 2000e(f) (2000); (2) a “State employee” as set forth by the Government Employee Rights Act of 1991, 42 U.S.C. § 2000e-16c(a) (2000); (3) a “covered employee” as set forth in Congressional Accountability Act of 1995, 2 U.S.C. § 1301 (2000); and (4) an “employee or applicant to which section 717(a) of the Civil Rights Act of 1964 (42 U.S.C. § 2000e-16(a)) applies”). The term employee does not include elected public officials. 42 U.S.C. § 2000e(f). (“The term ‘employee’ means an individual employed by an employer, except that the term ‘employee’ shall not include any person elected to public office in any State or political subdivision of any State by the qualified voters thereof, or any person chosen by such officer to be on such officer’s personal staff, or an appointee on the policy making level or an immediate adviser with respect to the exercise of the constitutional or legal powers of the office.”) However, the public official exemption “shall not include employees subject to the civil service laws of a State government, governmental agency or political subdivision.” *Id.* Further, an “employee” only includes an “individual who is a citizen of the United States.” *Id.*

196. H.R. 493, § 201(2); 42 U.S.C. § 2000e(f) (excluding elected public officials from the definition of “employee”); 42 U.S.C. § 2000e-16c(a) (prohibiting discrimination against employees or applicants for employment in the military, United States Postal Service and the Postal Regulatory Commissions, judicial branch of the federal government, the Government Printing Office, the Government Accountability Office, and the Library of Congress); 2 U.S.C. § 1301(3) (defining the term “covered employee” as any employee of the following: (a) the House of Representatives, (b) the Senate, (c) the Capital Guide Service, (d) the Capital Police, (e) the Congressional Budget Office, (f) the Office of the Architect of the Capitol, (g) the Office of the Attending Physician, (h) the Office of Compliance; or (i) the Office of Technology Assessment).

197. *See Price Waterhouse v. Hopkins*, 490 U.S. 228, 249 (1989) (“[O]nce the plaintiff had shown that his constitutionally protected speech as a ‘substantial’ or ‘motivating factor’ in the adverse treatment of him by his employer, the employer was obligated to prove ‘by a preponderance of the evidence that it would have reached the same decision as to [the plaintiff] even in the absence of the protected conduct.’”) (quoting *Mt. Healthy City Sch. Dist. Bd. of Educ. v. Doyle*, 429 U.S. 274, 285–86 (1977)).

198. *See* 42 U.S.C. § 2000e-16c(a). The staff of elected public officials was previously not included under the definition of “covered employees,” but now is incorporated into GINA under 2 U.S.C. § 1301(3).

members of the military is particularly egregious. One publicized example relays the story of a pregnant military pilot who developed a blood clot after being assigned to desk duty. The military then refused her retirement benefits when they tested her for a rare genetic blood-clot disorder that was probably not the cause of her particular clot.¹⁹⁹

B. Analogies to Financial Disclosures as Required by State and Federal Election Commissions

Congress has the constitutional power to regulate federal elections.²⁰⁰ The Federal Election Commission (FEC) is an independent regulatory agency established in 1975 to administer and enforce the Federal Election Campaign Act (FECA).²⁰¹ FECA limits the sources and amounts of contributions used to finance federal elections.²⁰² It also requires public disclosure of campaign finance information and provides for the public funding of presidential elections along with the Primary Matching Payment Act and the Presidential Election Campaign Fund Act.²⁰³ FECA requires candidates and their committees to file monthly or quarterly reports disclosing the money they raise and spend.²⁰⁴ These campaign finance reports are available on the FEC website and from the FEC's public records office.²⁰⁵

Opponents to FECA have challenged the Act, alleging, *inter alia*, that it violates the First Amendment. Specifically, opponents of the limits on campaign contributions felt that such restrictions violated the donor's freedom of speech.²⁰⁶ Although First Amendment protections for political speech are exacting, the Supreme Court found that the governmental interest in preventing actual or apparent corruption of federal candidates and officeholders was sufficiently

199. See Karen Kaplan, *U.S. Military Practices Genetic Discrimination in Denying Benefits*, L.A. TIMES, Aug. 18, 2007, at A1; Genetics & Pub. Policy Ctr., Genetics Perspective on Policy Seminar—Genes in Uniform: Don't Test, Don't Tell, http://www.dnapolicy.org/news.past.php?action=detail&past_event_id=25 (last visited Apr. 21, 2008).

200. U.S. CONST. art. I, § 4.

201. Fed. Election Comm'n, About the FEC, www.fec.gov/about.shtml (last visited Apr. 21, 2008).

202. Federal Election Campaign Act, 2 U.S.C. §§ 431–441j (2000 & Supp. 2007).

203. See *id.* § 434; Presidential Election Campaign Fund Act, 26 U.S.C. §§ 9001–9003 (2000); Presidential Primary Matching Payment Account Act, 26 U.S.C. § 9031 (2000). For more information on campaign finance law and the role played by the FEC in regulating federal elections, see FED. ELECTION COMM'N, THE FEC AND THE FEDERAL CAMPAIGN FINANCE LAW (2007), available at http://www.fec.gov/pages/brochures/fec_feca_brochure.pdf.

204. 2 U.S.C. § 434(a)(3).

205. Fed. Election Comm'n, Campaign Finance Reports and Data, <http://www.fec.gov/disclosure.shtml> (last visited Apr. 21, 2008).

206. See *Buckley v. Valeo*, 424 U.S. 1, 6, 11 (1976) (per curiam) (challenging provisions of the Federal Election Campaign Act and the Internal Revenue Code that limit campaign contributions on the grounds that limiting money for political purposes also restricts communication).

important to justify campaign contribution limits.²⁰⁷ The Court has also found that it is constitutional to enact laws preventing circumvention of such limits.²⁰⁸ The Court has repeatedly stressed the value of public discussion and debate on the qualifications of candidates, stating that it is an integral part of the operation of the system of government established by our Constitution.²⁰⁹ The First Amendment affords the broadest protection to such political expression in order “to assure [the] unfettered interchange of ideas for the bringing about of political and social changes desired by the people.”²¹⁰ Although First Amendment protections are not confined to “the exposition of ideas,”²¹¹ “there is practically universal agreement that a major purpose of that Amendment was to protect the free discussion of governmental affairs. . . . [which] of course include[s] discussions of candidates”²¹² Because the First Amendment protections of political speech are so strong, it is that much more relevant that the mandatory financial disclosures were upheld.

The mandatory disclosure of financial data has also been challenged on Fourteenth Amendment privacy grounds.²¹³ In addition to the federal regulations requiring disclosure of certain financial facts, many states have passed laws or added provisions to their constitutions that require candidates for public office to disclose their financial interests and associations, and sometimes those of family members as well.²¹⁴ However, if the required financial disclosures are considered too broad, courts may find that they violate the privacy rights protected under the federal constitution. In *Carmel-by-the-Sea v. Young*, a California court invalidated a statute, which directed every public officer and candidate for public office to file a statement disclosing the nature and extent of investments in excess of \$10,000 that were held by the candidate, his spouse, or his minor child, except for real property which was used primarily for personal or recreational purposes.²¹⁵ The court found that the statute was an overbroad invasion of the right to privacy and reasoned that there must be a balancing of interests between one’s right to privacy while seeking or holding public office and the government’s need to expose or minimize possible conflicts of interest of public officials.²¹⁶ The court pointed out that the statutory requirements applied indiscriminately to persons holding office regardless of the

207. *Id.* at 26, 29.

208. *McConnell v. Fed. Election Comm’n*, 540 U.S. 93, 144 (2003).

209. *See, e.g., Buckley*, 424 U.S. at 14; *Mills v. Alabama*, 384 U.S. 214, 218–19 (1966).

210. *Roth v. United States*, 354 U.S. 476, 484 (1957).

211. *Winters v. New York*, 333 U.S. 507, 510 (1948).

212. *Mills*, 384 U.S. at 218.

213. *See Brown v. Socialist Workers ’74 Campaign Comm.*, 459 U.S. 87, 94 n.9 (1982); *Plante v. Gonzalez*, 575 F.2d 1119, 1128–29 (5th Cir. 1978); *Carmel-by-the-Sea v. Young*, 466 P.2d 225, 230–322 (Cal. 1970).

214. *E.g., COLO. REV. STAT. §§ 1-45-110, 24-6-202* (West 2001); *GA. CODE ANN. § 21-5-50* (2003 & Supp. 2007); *MASS. GEN. LAWS ANN. ch. 55, § 18* (West 2007).

215. 466 P.2d at 227.

216. *Id.* at 232, 227.

nature of their function and questioned why no effort had been made to relate the disclosure requirements to financial dealings or assets that might be expected to give rise to a conflict of interest.²¹⁷

This case has often been questioned or distinguished by later state courts; the majority of mandatory financial disclosure laws have been upheld despite challenges that they violated a candidate's constitutional privacy rights.²¹⁸ In *Snider v. Thornburgh*, the court held that the law requiring public officials to publicly disclose financial information, and to some extent the financial affairs of their families, did not violate the officials' individual rights of privacy.²¹⁹ While recognizing that the privacy interest possessed by an individual extended to his financial reports, the court held that public officials must abdicate some measure of their privacy interests in their financial histories which might, under different circumstances, be successfully invoked by private persons.²²⁰ In *County of Nevada v. MacMillen*, the court found a 1973 California statute constitutional that applied to officers, county supervisors, city council members, planning commissioners and chief administrative officers, and required an annual disclosure of business investments in excess of \$1,000, real estate investments in excess of \$1,000, and sources of loans and gifts exceeding \$250.²²¹ The California Supreme Court held that these disclosure provisions were sufficiently narrow to avoid any potential constitutional infirmities.²²²

Lastly, a state constitutional provision requiring public officials and candidates to disclose personal financial information was held not to violate the

217. *Id.* at 232.

218. In *Evans v. Carey* 385 N.Y.S.2d 965, 965-66 (N.Y. App. Div. 1976), state officers and employees were required to list income sources for the period during which they held office, specifying amounts in excess of \$1,000, and to disclose all assets and liabilities. However, in upholding the disclosure requirement, the court found that recent federal precedents involving privacy claims had tended to look narrowly at the specific complaint and the immediate impact of the governmental intrusion rather than making categorical assertions about privacy rights. *Id.* at 968, 971. The court in *Kenny v. Byrne*, 365 A.2d 211, 213-14, 218-19 (N.J. 1976), held that an executive order requiring executive officers of state government to disclose financial interests held by themselves and their spouses, in statements subject to public inspection, was not an unconstitutionally overbroad invasion of the right to privacy. In *Lehrhaupt v. Flynn*, 356 A.2d 35, 38-39, 41, 46 (N.J. 1976), the court rejected claims that a township ordinance which imposed comprehensive requirements on local officials for the disclosure of their economic interests constituted an overbroad invasion of the officials' right to privacy. Privacy rights are not absolute, and must be balanced against the right of the public to acquire knowledge relevant to the actual or potential performance of its officials and the legitimate public interest in preserving the integrity of the democratic process. *Id.* at 41-42.

219. 436 A.2d 593, 598-99 (Pa. 1981).

220. *Id.* at 599.

221. 522 P.2d 1345, 1348, 1350 (Cal. 1974).

222. *Id.* at 1350-51 ("The statute . . . requires that a person seeking public office make available to those who vote . . . information regarding the property interests which he holds and which, if elected, he might be expected to protect.").

right to privacy under the federal Constitution in *Plante v. Gonzalez*.²²³ The court did find that financial privacy was part of the right to confidentiality, an element of the right to privacy.²²⁴ However, it held that the interests served by the disclosure in deterring corruption, developing an informed electorate, and restoring public confidence in state officials were strong enough to outweigh the privacy interests of officials and candidates whose legitimate expectations of privacy were less than those of private citizens.²²⁵ The court rejected a claim that the state's interests would be similarly served by limiting disclosure to an ethics commission, stating that the needs of an informed electorate justified public disclosure of the financial data.²²⁶ Interestingly, the court relied in part on the fact that such disclosure requirements did not come at all within the branch of the constitutional right to privacy concerned with autonomy, which had been invoked and developed in cases involving government interference with intimate decisions.²²⁷

Many state cases permit mandatory disclosure of a candidate's financial information. The question then becomes, "how is financial information any different from information regarding a candidate's health, and specifically her genetic information?" Financial privacy is protected in our society, as evidenced by legislation like the federal Gramm-Leach-Bliley Act of 1999²²⁸ and the Right to Financial Privacy Act.²²⁹ Many people prefer not to speak about their finances publicly, and would consider it quite rude to ask a stranger outright how much money she had in her bank account or how much she had saved for her retirement. Even so, the universe of people who can access our financial data is far larger than those who can ask about our dental records. When we apply for a loan for a house or a car, the bank will demand to view our credit report and perhaps ask detailed questions about our assets. When we seek to rent an apartment, landlords may ask to see a current pay-stub as evidence of ability to pay. Applications for licenses to professional associations will also ask whether you have ever filed for bankruptcy or defaulted on your student loans. All of these things severely discriminate against individuals who are financially less stable. Why then, are so many institutions allowed to ask about stigmatizing financial information, when we cannot inquire into any information about health? Might it be tied to our concepts of fault, where we still believe that most people who are poor deserve it, whereas unhealthy people do not deserve to be sick?

223. 575 F.2d 1119, 1128–29, 1136, 1138 (5th Cir. 1978).

224. *Id.* at 1132.

225. *Id.* at 1135 ("Plaintiffs in this case are not ordinary citizens, but state senators, people who have chosen to run for office. That does not strip them of all constitutional protection. It does put some limits on the privacy they may reasonably expect." (citation omitted)).

226. *Id.* at 1137.

227. *Id.* at 1128–1132.

228. Gramm-Leach-Bliley Act of 1999, 15 U.S.C. §§ 6801–6827 (2000 & Supp. 2007).

229. Right to Financial Privacy Act of 1978, 12 U.S.C. §§ 3401–3422 (2000 & Supp. V. 2006).

Perhaps we have grown more private as our society becomes more splintered and sophisticated, or perhaps we do not want to miss this opportunity to prevent yet another type of social discrimination.²³⁰ Whatever the sociological reasons, there is no obvious reason why predictive health information should be treated any differently than other types of potentially discriminatory information. However, if we think critically about the population of people passing these laws, then we can understand why older gentlemen might be interested in protecting health information, or specifically be interested in laws like GINA. Unlike other types of private information that could be successfully masked, legislators are for once presented with a possibility that they too will be discriminated against.

Newly discovered genetic information is not obvious to the naked eye, and cannot be reduced to status symbols like nice cars or huge houses. Genetic information is therefore largely behind the veil of ignorance for now, to use a Rawlsian distributive justice term.²³¹ When groups are confronted with the possibility of receiving the short end of the stick, this may motivate them to pass anti-discrimination laws that would not be passed if there were no such veil. Still, the plethora of state opinions permitting disclosure of a candidate's personal financial information include reasoned and articulated state interests that could most certainly be applied to permit access to a candidate's private health information.

C. Background on the Types of Genetic Tests and Their Limitations

1. Chromosomal Genetic Testing

There are many types of genetic tests, depending on which aspect of the genetic process is being studied. At a high level, scientists will engage in

230. Steven Nock, *Too Much Privacy?*, 19 J. FAM. ISSUES 101, 101 (1998) ("A general increase in privacy has occurred for the past century.").

231. Distributive justice principles are designed to direct the allocation of the benefits and burdens of economic activity in a society. See John Rawls, *The Law of Peoples*, 20 CRITICAL INQUIRY 36, 62 (1993) [hereinafter Rawls, *The Law of Peoples*]. One popular theory developed by John Rawls asks members of a society to ask what allocations or rules they would agree to if they were under a "veil of ignorance" as to their own socio-economic lottery. See *id.* at 44-45. The idea is that if we can assume an original position where we do not know how resource-rich or lucky we will be, we should allocate goods in a way that seeks to provide fair conditions for free and equal citizens. *Id.* When we discuss genetic information, it is typically not required to pretend to be under a veil of ignorance, as most of us, in fact, are naïve about our genetic information and risks. The de facto veil of ignorance surrounding genetic information may explain the greater support given to genetic non-discrimination bills than to similar non-discrimination bills for people who are homosexual, or who have certain mental illnesses. However, unlike the true veil of ignorance that Rawls envisioned where the parties making decisions did not know their social status or "final ends," the Congress, who proposed GINA, know precisely how powerful they are. See John Rawls, *Kantian Constructivism in Moral Theory*, 77 J. PHIL. 515, 522-23 (1980) [hereinafter Rawls, *Kantian Constructivism*]. This type of information asymmetry provides for prioritization of self-interested policies. *Id.* at 523.

cytogenetics studies that analyze the number and structure of entire chromosomes to study chromosome deletions or translocations.²³² In congenital disorders, such as Down or Turner syndrome, cytogenetics can determine the nature of the chromosomal defect—whether it be a repeat of genetic data, a translocation, a deletion, or an insertion of genetic information in either or both of the parents, or in the fetus.²³³ Chromosomal defects are often discovered at birth and can lead to mental retardation. Examples of these defects include Down syndrome or Edwards syndrome.²³⁴ Even in these classic chromosomal abnormalities, there is considerable phenotypic variability. Mosaicism is a condition where an individual has a mixture of cells with different genotypes in the body. This can lead to milder expression of a genetic trait and is being uncovered as another biological cause for congenital malformations.²³⁵ The majority of known chromosomal abnormalities are discovered either through prenatal or newborn screening, or in response to children who exhibit severe developmental delay or retardation.²³⁶ Even so, there are some chromosomal disorders that are not tested for in newborns and for which adult onset is possible. Examples of these disorders include distal leg myopathy and neurodegenerative disorders such as myoclonic epilepsy and leukodystrophy.²³⁷ Leukodystrophy results from widespread myelin loss in the central nervous system and is similar to the phenotype for multiple sclerosis.²³⁸ Testing for particular chromosomal neurodegenerative disorders with adult onset may be warranted in the case of presidential candidates, as even when there is considerable variation in expression of the disorder, it is still quite likely that the affected person will experience some dysfunction. Discretionary problems would arise when determining which disorders to test, but this would be true of every genetic testing

232. JORDE ET AL., *supra* note 88, at 107, 122, 124. Chromosomes are the organized bundles of a single strand of DNA found in each of our cells. *Id.* at 6. Humans have 23 pairs of chromosomes, for a total of 46 per cell. *Id.*

233. March of Dimes, Chromosomal Abnormalities (Oct. 2006), http://www.marchofdimes.com/pnhec/4439_1209.asp; *accord* JORDE ET AL., *supra* note 88, at 106, 113.

234. JORDE ET AL., *supra* note 88, at 106, 113, 116; March of Dimes, *supra* note 233.

235. KRISTINE BARLOW-STEWART & GAYARTHI PARASIVAM, CTR. FOR GENETICS EDUC., FACT SHEET 13: MOSAICISM – COMPLEX PATTERNS OF INHERITANCE 1 (2007), *available at* <http://www.genetics.com.au/pdf/factsheets/fs13.pdf>; JORDE ET AL., *supra* note 88, at 115.

236. JORDE ET AL., *supra* note 88, at 281, 288; Mohamed N. Ahmed et al., *Postnatal Developmental Delay and Chromosomal Abnormalities*, 39 CLINICAL PEDIATRICS 233, 233–35 (2000); KidsHealth for Parents, Prenatal Tests, http://www.kidshealth.org/parent/system/medical/prenatal_tests.html (last visited Apr. 22, 2008).

237. J. Aicardi, *The Inherited Leukodystrophies: A Clinical Overview*, 16 J. INHERITED METABOLIC DISEASE 733, 733–42 (1993); Patricia K. Crumrine, *Degenerative Disorders of the Central Nervous System*, 22 PEDIATRICS REV. 370, 370–78 (2001); John M. Shoffner, *Oxidative Phosphorylation Disease Diagnosis*, in OXIDATIVE/ENERGY METABOLISM IN NEURODEGENERATIVE DISORDERS, 893 ANNALS N.Y. ACAD. SCI. 42, 50 (John P. Blass & Fletcher H. McDowell eds., 1999) (stating that myoclonic epilepsy can begin at ages ranging from childhood to adulthood).

238. Univ. of Cal., S.F., Laboratories of Neurogenetics (2006), <http://www.ucsf.edu/humgene/adld.htm>.

schema. A relatively new method, dubbed molecular karyotyping,²³⁹ diagnoses chromosomal aberrations at a genome-wide level. Unlike traditional karyotyping,²⁴⁰ molecular karyotyping does more than reveal structural or numerical errors on a particular chromosome, because it can pinpoint the precise genetic sequence involved and with a high resolution.²⁴¹

Because the Y chromosome is passed exclusively from father to son,²⁴² this chromosome can also be tested for ancestry purposes. Men who share a common paternal ancestor will have virtually the same DNA on their Y chromosome.²⁴³ This is true even if that male ancestor lived many generations ago, as the DNA on the Y chromosome does not mutate very frequently.²⁴⁴ Progress in identifying single nucleotide polymorphisms (SNPs) on the Y-chromosome was initially slow, until recently.²⁴⁵ Testing the presidential candidate's Y chromosome would not paint the entire genealogical picture as the maternal line would be absent. Additionally, one wonders how relevant this is to the candidate's decision-making or governance, and whether information on ancestry may only reinforce racial or ethnic discrimination.

239. Molecular karyotyping is a genetic disease screening technique that has a higher-resolution than traditional karyotyping and can therefore more easily identify genetic diseases that have smaller chromosomal abnormalities. Joris R. Vermeesch et al., *Molecular Karyotyping: Array CGH Quality Criteria for Constitutional Genetic Diagnosis*, 53 J. HISTOCHEMISTRY & CYTOCHEMISTRY 413, 413, 419 (2005).

240. Karyotyping is a test "based on staining chromosomes [that] aim[s] to identify chromosomal aberrations by screening the genome," or in other words, identify the genetic cause of a disorder or disease. *Id.* at 419; accord Medline Plus, Karyotyping, <http://www.nlm.nih.gov/medlineplus/ency/article/003935.htm> (last visited Apr. 22, 2008).

241. The method receives its name from conventional karyotyping, as both technologies are based on staining of the chromosomes to visualize errors that may lead to a genetic disorder, such as mental retardation. Vermeesch et al., *supra* note 239, at 419.

242. JORDE ET AL., *supra* note 88, at 6.

243. Sorenson Molecular Genealogy Found., Y-Chromosome DNA, <http://www.smgf.org/pages/ychromosome.jsp> (last visited Apr. 22, 2008).

244. *Id.*; WILLIAM S. KLUG ET AL., CONCEPTS OF GENETICS 81 (8th ed. 2006).

245. Mark A. Jobling & Chris Tyler-Smith, *New Uses for New Haplotypes: The Human Y Chromosome, Disease and Selection*, 16 TRENDS GENETICS 356, 358 tbl.1 (2000). Linda Hellborg & Hans Ellegren, *Y Chromosome Conserved Anchored Tagged Sequences (YCATS) for the Analysis of Mammalian Male-Specific DNA*, 12 MOLECULAR ECOLOGY 283, 284 (2003) ("Because [the Y chromosome] is mainly a nonrecombining chromosome, analysis of Y chromosome SNPs allows the construction of specific haplotypes defining patriline. Using this approach, a number of studies have recently attempted to dissect the evolutionary history of modern humans With the access to Y chromosome haplotyping, it is therefore possible to compare directly the relative contribution of fathers in shaping the genetic signatures of populations." (citations omitted)); Silvia Paracchini et al., *Hierarchical High-Throughput SNP Genotyping of the Human Y Chromosome Using MALDI-TOF Mass Spectrometry*, 30 NUCLEIC ACIDS RES., at e27, e27 (2002).

2. Mitochondrial Genetic Testing

Mitochondrial DNA (mtDNA) is not transmitted through cell nuclei like chromosomal DNA but rather through the energy-generating mitochondria.²⁴⁶ Chromosomal and mitochondrial DNA are thought to be of separate evolutionary origin, with mtDNA being derived from the genomes of bacteria that were internalized by our nucleus-containing ancestor cells.²⁴⁷ Mitochondrial inheritance challenged our traditional thinking of genetics as Mendelian inheritance presumes that half the genetic material of a fertilized egg derives from each parent, and mtDNA is virtually all inherited from the mother's ovum.²⁴⁸ This type of DNA is thought to have less non-coding "junk," and therefore most mitochondrial DNA mutations lead to functional problems.²⁴⁹ Even so, much of the mtDNA testing that goes on today is for DNA ancestry testing as one thread of the maternal line can be traced this way due to its passing via the mother's ovum.²⁵⁰

Men and women inherit mtDNA from their mothers.²⁵¹ mtDNA disorders were once considered so rare that they were only of academic interest, but now are believed to be much more common. Mitochondrial diseases are due to deficiencies in the generation of cellular energy and respiratory function.²⁵² Common related phenotypes include stroke-like episodes, exercise intolerance and muscular weakness.²⁵³ Due to the complexity of mitochondrial inheritance and inter-family variability, clear genotype-phenotype correlations are difficult to demonstrate.²⁵⁴ This is complicated by the fact that mtDNA related diseases may be caused by nuclear genome defects as well.²⁵⁵ Other examples of mtDNA related diseases include diabetes, blindness and deafness.²⁵⁶ In the most common cases, the onset for the mtDNA related disorder is well before age twenty, but with the case of

246. BRUCE ALBERTS ET AL., *MOLECULAR BIOLOGY OF THE CELL* 767 (4th ed. 2002).

247. Siv G. E. Andersson et al., *On the Origin of Mitochondria: A Genomics Perspective*, PHIL. TRANSACTIONS ROYAL SOC'Y BIOLOGICAL SCI., Jan. 29, 2003, at 165–66.

248. ALBERTS ET AL., *supra* note 246, at 816–18.

249. See Miria Ricchetti et al., *Continued Colonization of the Human Genome by Mitochondrial DNA*, 2 PLOS BIOLOGY 1313, 1314 (2004); *Mitochondrial Genes Cause Nuclear Mischief*, SCI. DAILY, Sept. 8, 2004, <http://www.sciencedaily.com/releases/2004/09/040907082844.htm>.

250. DNAAncestry, *Maternal Lineage Test*, <http://dna.ancestry.com/learnMoreMaternal.aspx> (last visited Apr. 22, 2008).

251. KLUG ET AL., *supra* note 244, at 227.

252. See Douglas C. Wallace, *Mitochondrial Diseases in Man and Mouse*, 283 SCI. 1482, 1483 (1999).

253. Cleveland Clinic Ctr. for Consumer Health Info., *Mitochondrial Disease* (2008), <http://www.clevelandclinic.org/health/health-info/docs/1600/1678.asp?index=6957>.

254. Sarah White et al., *Genetic Counseling and Prenatal Diagnosis for the Mitochondrial DNA Mutations at Nucleotide 8993*, 65 AM. J. HUM. GENETICS 474, 474–75 (1999).

255. Andrea L. Gropman, *Diagnosis and Treatment of Childhood Mitochondrial Diseases*, 1 CURRENT NEUROLOGY & NEUROSCIENCE REPS. 185, 189 (2001).

256. KLUG ET AL., *supra* note 244, at 221–22; Cleveland Clinic Ctr. for Consumer Health Info., *supra* note 253.

mitochondrial encephalomyopathy (stroke-like episodes), the onset is typically around age 40.²⁵⁷ This means that most of the mtDNA-related diseases would become present before a candidate ran for presidential office. Even so, to the extent that the phenotypes have not yet been expressed, the genotype-phenotype correlations are too unpredictable to be very useful in measuring the possibility that a president would develop mtDNA-related stroke-like episodes. What is more, the “[c]linical features are usually extremely heterogeneous because [mtDNA-related diseases] may involve several tissues with different degrees of severity.”²⁵⁸ So mtDNA genotypes will not tell us very much about the development of disease.

mtDNA testing can tell us something about the individual’s ancestry, in that it can trace distant maternal relatives. However, as with Y chromosome testing, it cannot tell us about all of the maternal ancestry as it only looks at one single genetic line.²⁵⁹ Because we are a genetic mixture of many of our ancestors, these tests do not tell the entire story. But more importantly, confirming or debunking a presidential candidate’s family history is likely never in the public interest, as it is near impossible to imagine a scenario where the President’s deep ancestral roots are at all relevant to governance or political decision-making.

3. *Marker, Linkage, and Enzyme Dysfunction Testing*

We can test DNA directly and indirectly. If we know the gene that we want to study, we can analyze the DNA error (deletion, duplication, etc).²⁶⁰ If we do not know the precise gene implicated in a certain disease, we can study the DNA indirectly by looking to “markers” to determine whether someone has inherited a crucial region of the genetic code that is typically passed through families exhibiting the disease.²⁶¹ Markers are helpful when the precise gene implicated in the disease has not yet been identified, but the marker is adjacent or contained within the targeted gene of interest. Due to its proximity to the target gene, the marker is likely inherited in tandem with it.²⁶² Indirect studies usually rely on blood samples from many family members who both exhibit and do not exhibit the disease. Linkages are then created based on the pattern of inheritance of these

257. See Genetics Home Reference, Mitochondrial Encephalomyopathy, Lactic Acidosis, and Stroke-Like Episodes (Feb. 10, 2008), <http://ghr.nlm.nih.gov/condition=mitochondrialecephalomyopathy+lacticacidosisandstrokelikeepisodes>.

258. Massimiliano Filosto et al., *Neuropathology of Mitochondrial Diseases*, BIOSCIENCE REPS., June 2007, at 23–24.

259. See DNAAncestry, *supra* note 250; DNAHeritage, mtDNA Test for Maternal Ancestry, <http://www.dnaheritage.com/mtdna.asp> (last visited Apr. 22, 2008).

260. KRISTINE BARLOW-STEWART, CTR. FOR GENETICS EDUC., FACT SHEET 21: DNA TESTING – SCREENING FOR GENETIC CONDITIONS AND GENETIC SUSCEPTIBILITY 2 (5th ed. 2007), available at <http://www.genetics.com.au/pdf/factsheets/fs21.pdf>.

261. KLUG ET AL., *supra* note 244, at 128.

262. BARLOW-STEWART, *supra* note 260, at 4.

markers, and can be used to test relatives to determine if they inherited the region that is reflected in those who exhibit the disease.²⁶³

In addition to studying the gene mutation that caused the abnormality, we can also study abnormal enzyme production. Enzymes are proteins that regulate the variety of chemical cascades occurring in our bodies.²⁶⁴ Enzymes may be deficient, absent, unstable, or behave in ways that lead to clinical manifestations in humans.²⁶⁵ As genes code for the production of proteins, we can also study proteins to see if they are longer or shorter than they should be and this can indirectly assess genetic anomalies.²⁶⁶

4. SNP Genotyping and Whole Genome Sequencing

The above methods are used to investigate genes or proteins associated with specific diseases. But what if we have no target gene, and instead just want to know what our entire set of genes look like? This question has been answered in part by high-density SNP (single nucleotide polymorphism) genotyping and whole-genome sequencing, which have taken off recently.²⁶⁷ To understand what an enormous feat this is, it is important to understand both how the genome is sequenced and just how complex it is.

Inside *each* of the 100 trillion cells in our bodies is a nucleus that contains the entire genome (forty-six human chromosomes) that regulates human development through protein transcription.²⁶⁸ Each chromosome is one long string of tightly bundled DNA that is coiled in a double helix.²⁶⁹ Chromosomes are made up of millions of base pairs, consisting of copies of the four letters of the genetic code A, C, G, and T, which are arranged into genes and non-coding sections.²⁷⁰ The aim of genomics is to figure out the order, or sequence, of these four letters.²⁷¹ Since routine sequencing of the genomes of thousands of individuals is still impractical,

263. *See id.* at 4–5.

264. ALBERTS ET AL., *supra* note 246, at 76–78, G:12.

265. Muscular Dystrophy Ass'n (MDA), *Metabolic Diseases of Muscle, Facts About Metabolic Diseases of Muscle*, <http://www.mda.org/publications/fa-metab-qa.html> (last visited Apr. 22, 2008). In fact, enzymes that metabolize drugs are being studied rigorously in order to tailor pharmaceutical drugs to certain populations. Sharon Gardiner & Evan Begg, *Pharmacogenetic Testing for Drug Metabolizing Enzymes: Is it Happening in Practice?*, 15 PHARMACOGENETICS & GENOMICS 365, 365 (2005).

266. Par K. Ingvarsson, *Gene Expression and Protein Length Influence Codon Usage and Rates of Sequence Evolution in Populus Tremula*, 24 MOLECULAR BIOLOGY & EVOLUTION 836, 842–43 (2007); *see also* Vivek Mittal & Daniel J. Nolan, *Genomics and Proteomics Approaches in Understanding Tumor Angiogenesis*, 7 EXPERT REV. MOLECULAR DIAGNOSTICS 133, 138 (2007) (using proteomic testing to target tumor vessels).

267. KLUG ET AL., *supra* note 244, at 128, 485.

268. JEREMY M. BERG ET AL., *BIOCHEMISTRY* 36, 118 (5th ed. 2002).

269. KLUG ET AL., *supra* note 244, at 246, 246 fig.10-14.

270. ALBERTS ET AL., *supra* note 246, at 198; BERG ET AL., *supra* note 268, at 3.

271. KLUG ET AL., *supra* note 244, at 8.

many studies have attempted to systematically test the majority of human genetic difference that is due to common variations, and map this genetic variance on to the presence of disease.²⁷² This method results in genome-wide association studies. Replication of these disease association studies has proven to be difficult and the interpretive power of the association is not robust.²⁷³ Still, they provide an initial method of making weak associations between diseases and particular SNPs in large populations.

At a larger population level, the ambitious HapMap Project aimed to produce a subset of SNPs to evaluate genetic variation in four discrete subpopulations: Ibadan, Nigeria; Tokyo, Japan; Beijing, China; and Utah, U.S.A.²⁷⁴ SNPs occur when one base replaces another in what is known as a point mutation. Usually, T replaces A, G replaces C, and vice versa.²⁷⁵ Compiling all of the SNPs in one person can tell us something about her genetic profile, as SNPs have been used as markers in the association studies of complex human diseases.²⁷⁶ In one method, certain relevant SNPs are tagged, each being carefully chosen so that together they hopefully represent underlying related genetic variants. A sample of SNPs may then be used to represent a patchwork of the individual's genotype for a certain disease.²⁷⁷ The commercial genomic company, 23andMe, relies primarily on high-density SNP genotyping for its services, looking at nearly 600,000 SNPs to survey a large chunk of the genetic difference between people.²⁷⁸

272. See *id.* at 485 (acknowledging that identifying all genes in a genome is “a time consuming endeavor, which led to the beginning of recombinant DNA technology for genetic analysis”); Genome News Network, Genome Variations (Jan. 15, 2003), http://www.genomenewsnetwork.org/resources/whats_a_genome/Chp4_1.shtml.

273. Paul I. W. de Bakker et al., *Efficiency and Power in Genetic Association Studies*, 37 NATURE GENETICS 1217, 1217 (2005); see also J. Raphael Gibbs & Andrew Singleton, *Application of Genome-Wide Single Nucleotide Polymorphism Typing: Simple Association and Beyond*, 2 PLOS GENETICS 1511, 1511–12 (2006) (describing another variant of the disease association technique used to retrieve the same results, but one that is still problematic).

274. de Bakker et al., *supra* note 273, at 1217. A haplotype is a set of linked alleles that can be compared with haplotypes from other individuals. Nat'l Human Genome Res. Inst., International HapMap Project, <http://www.genome.gov/10001688> (last visited Apr. 22, 2008).

275. TARA RODDEN ROBINSON, GENETICS FOR DUMMIES 282 (2005).

276. Huanyu Zhou et al., *Combining Association Tests Across Multiple Genetic Markers in Case-Control Studies*, 65 HUM. HEREDITY 166, 166 (2008).

277. Int'l HapMap Consortium, *A Haplotype Map of the Human Genome*, 437 NATURE 1299, 1309–10 (2005). Many researchers question the methodological validity of genetic association studies as differences exist in allele frequency by population and genes interact with environmental factors. See Sarah J. Lewis & Eric J. Brunner, *Methodological Problems in Genetic Association Studies of Longevity—The Apolipoprotein E Gene as an Example*, 33 INT'L. J. EPIDEMIOLOGY 962, 962, 965 (2004); Scott F. Saccone et al., *Power-Based, Phase-Informed Selection of Single Nucleotide Polymorphisms for Disease Association Screens*, 30 GENETIC EPIDEMIOLOGY 459, 469 (2006).

278. 23andme.com, Our Service: How the Process Works, <https://www.23andme.com/ourservice/process> (last visited Apr. 22, 2008).

By observing variations in the sequence of the base pairs, geneticists can identify areas that may be linked to specific diseases.²⁷⁹ The entire human genome is made up of about 3.5 billion bases;²⁸⁰ therefore, to map the genome properly when comparing sections from various donors, complex algorithms must be used to pick apart and reassemble puzzle pieces from different versions of the same chromosomes.²⁸¹ Geneticists are getting better at this, and are now able to understand to some degree the genetic variation within a single genome. As the process of gene sequencing is expensive and time-consuming, scientists are rushing to find cheaper technologies that can sequence just the protein-coding regions of the genome while discarding the irrelevant data.²⁸² Although thousands of tests are available for a variety of genetic diseases and there is great *potential* for gene sequencing to reveal detailed information about the risks someone may carry for a number of diseases, many involved caution patients from jumping into genome-sequencing blindly. The president of the National Society of Genetic Counselors challenges consumers to ask, "What is this going to tell me, is it going to give me information that's helpful right now?"²⁸³

As the controversial genomics pioneer, Craig Venter, has sequenced his own genome, we have found out that Venter is likely to have wet earwax and lactose intolerance.²⁸⁴ However, Mr. Venter reports that he is, in fact, lactose tolerant, so the genotype does not match the predicted phenotype.²⁸⁵ There are potentially many other discoveries on genetic expression to come from analyses of both Venter's genome and another celebrity genome, that of James Watson. In partnership with scientists at Baylor College of Medicine, 454 Life Sciences Corporation completed "Project Jim," an endeavor to sequence the genome of Mr. Watson, co-discoverer

279. See Genome News Network, *supra* note 272.

280. Bijal P. Trivedi, Genome News Network, Sequencing the Genome (June 2, 2000), http://www.genomenewsnetwork.org/articles/06_00/sequence_primer.shtml.

281. See J. Craig Venter et al., *The Sequence of the Human Genome*, 291 Sci. 1304, 1310–13 (2001) (describing a complex algorithm).

282. Chao-Qiang Lai, *Speed-Mapping Quantitative Trait Loci Using Microarrays*, 4 NATURE METHODS 839, 839–40 (2007); Gregory J. Porreca et al., *Multiplex Amplification of Large Sets of Human Exons*, 4 NATURE METHODS 931, 931 (2007); Andreas Sundquist et al., *Whole-Genome Sequencing and Assembly with High-Throughput, Short-Read Technologies*, PLOS ONE, May 30, 2007, <http://www.plosone.org/article/fetchArticle.action?articleURI=info:doi/10.1371/journal.pone.0000484>.

283. John Lauerman, *Cheap, Detailed Genetic Testing Soon May be Ready for Market*, BLOOMBERG.COM, Oct. 14, 2007, <http://www.bloomberg.com/apps/news?pid=newsarchive&sid=arSzBEc17W34>.

284. Samuel Levy et al., *The Diploid Genome Sequence of an Individual Human*, 5 PLOS BIOLOGY 2113, 2114, 2131, 2134 tbl.13 (2007); accord Heidi Ledford, *All About Craig: The First 'Full' Genome Sequence*, 449 NATURE 6, 6 (2007).

285. Levy et al., *supra* note 284, at 2131.

of the double-helix structure of DNA.²⁸⁶ The press release on 454 Life Science's website stated:

The mapping of Dr. Watson's genome was completed using the Genome Sequencer FLX™ system and marks the first individual genome to be sequenced for less than \$1 million. . . . Today, we give James Watson a DVD containing his personal genome—a project completed in only two months. It demonstrates how far sequencing technology has come in a short time.²⁸⁷

There is big business behind this technology, as the cost will likely drop and more routine human sequencing will become affordable. An executive vice president at Applied Biosystems predicted that the market for personal genomic testing could reach \$500 million by 2011.²⁸⁸

5. *Complex Behavioral Genetics*

Behavioral genetics measures the genetic influence on complex human traits that “traditionally have come within the purview of psychologists (and psychiatrists).”²⁸⁹ This has been a particularly controversial area of research in part because of its mixed history with eugenics.²⁹⁰ The American eugenics movement of the late nineteenth and early twentieth century sought to cleanse the race of impurities such as violence, disability, or mental retardation through sterilization or restrictive marriage laws for individuals with these perceived negative traits.²⁹¹ As doctor and author Leonard Fleck points out, “these are not benign intellectual errors.”²⁹² The “studies” looked at families with shared traits and environments, and thus failed to isolate genetic causation.²⁹³ Measurement of the phenotypes was less than scientific as well. Perhaps, partially in response to the embarrassingly unethical eugenics movements, and partially in response to behaviorism, the thinking in the 1950s shifted from biological explanations of behavior to social ones.²⁹⁴ According to these socially loaded constructs, bad behavior was caused by

286. Eliot Marshall, *Sequencers of a Famous Genome Confront Privacy Issues*, 315 SCI. 1780, 1780 (2007).

287. Press Release, 454 Life Scis., 454 Life Sciences and Baylor College of Medicine Complete Sequencing of DNA Project (May 31, 2007), <http://www.454.com/news-events/press-releases.asp?display=detail&id=68>.

288. Lauerman, *supra* note 283.

289. Erik Parens, *Genetic Differences and Human Identities: On Why Talking About Behavioral Genetics is Important and Difficult*, HASTINGS CTR. REP. (SPECIAL SUPP.), Jan.–Feb. 2004, at S4, S6.

290. Anne Kerr et al., *Eugenics and the New Genetics in Britain: Examining Contemporary Professionals' Accounts*, 23 SCI., TECH., & HUM. VALUES 175, 175–77 (1998).

291. KLUG ET AL., *supra* note 244, at 659.

292. Leonard Fleck, *Creating Public Conversation about Behavioral Genetics, in WRESTLING WITH BEHAVIORAL GENETICS* 256, 259 (Eric Parens et al. eds., 2006).

293. KLUG ET AL., *supra* note 244, at 659.

294. NELKIN & LINDEE, *supra* note 90, at 33–34.

bad environments.²⁹⁵ The variance in traits were explained based on parenting, nutrition, or education.²⁹⁶

Even when molecular genetics developed a better understanding of the possible inheritance of behavioral traits, early pronouncements were reported as a “gene for” addiction or aggression.²⁹⁷ The problem with this reporting is beyond mere semantics. Stating the genetic cause in this way reiterated genetic reductionism and divorced genes from the environment as two independent variables.²⁹⁸ Modern behavioral geneticists understand that genes interact with each other,²⁹⁹ genetic variation can exist outside of Mendelian models of inheritance,³⁰⁰ and the environment greatly affects expression of genes.³⁰¹ Put differently, there is no “gene for” any given complex behavior. Rather, there is almost always a group of genes that together may increase the chance of a behavior being exhibited in response to certain environmental stressors.

Although behavioral geneticists employ the genetic tests and methods that were described above (linkage studies, genome-sequencing), much of behavioral genetics rests on a wholly different set of methods that employ epidemiological, psychosocial, and longitudinal studies.³⁰² These studies often look at the individual differences in behavior between monozygotic (genetically identical) and dizygotic (fraternal) twins reared apart, between siblings, and across generations.³⁰³ Twin studies have resulted in interesting attributions of genetic variance. For example, the famous Minnesota Twin Study by Thomas Bouchard found that about 70% of the variance in IQ between the twins was associated with genetic variation.³⁰⁴ However, later researchers found that the significance of genetic differences in

295. Kenneth F. Schaffner, *Behavior: Its Nature and Nurture, Part 1*, in *WRESTLING WITH BEHAVIORAL GENETICS*, *supra* note 292, at 3, 4.

296. *See id.*

297. *See* Jonathan Beckwith, *Whither Human Behavioral Genetics?*, in *WRESTLING WITH BEHAVIORAL GENETICS*, *supra* note 292, at 74, 90; Rick Weiss, *Behavioral Genetics and the Media*, in *WRESTLING WITH BEHAVIORAL GENETICS* *supra* note 292, at 309, 310–11.

298. *See* Beckwith, *supra* note 297, at 84–85.

299. KLUG ET AL., *supra* note 244, at 659.

300. Kenneth F. Schaffner, *Behavior Its Nature and Nurture, Part 2*, in *WRESTLING WITH BEHAVIORAL GENETICS*, *supra* note 292, at 40–41.

301. Fleck, *supra* note 292, at 259.

302. *E.g.*, Ayman H. Fanous, *A Longitudinal Study of Personality and Major Depression in a Population-Based Sample of Male Twins*, 37 *PSYCHOL. MED.* 1163 (2007); A.C. Heath et al., *Evidence for Genetic Influences on Personality from Self-Reports and Informant Ratings*, *J. PERSONALITY & SOC. PSYCHOL.*, July 1992, at 85; Jonathan S. Raymond, *Behavioral Epidemiology: The Science of Health Promotion*, 4 *HEALTH PROMOTION INT'L* 281, 281 (1989).

303. Parens, *supra* note 289, at S10–11.

304. Thomas J. Bouchard et al., *Sources of Human Psychological Differences: The Minnesota Study of Twins Reared Apart*, 250 *SCI.* 223, 224 (1990). This data is based on more than one hundred sets of reared apart twins. *Id.* at 223.

explaining variation in IQ scores depends heavily on the socioeconomic status (SES) of the person taking the test.³⁰⁵

Interpreting behavioral genetics information has therefore been thorny. Legitimate questions have been raised of reporter bias in measuring the behavior as well as an inability to completely control or quantify the shared and non-shared environmental factors. History has taught us to temper our reports of any clear genetic cause for complex behavioral traits, as many of the reductionist predecessor claims have fallen by the wayside.³⁰⁶ Even still, recent replicated methods have produced target genes associated with many complex traits such as attention-deficit/hyperactivity disorder (ADHD),³⁰⁷ depression,³⁰⁸ alcoholism,³⁰⁹ and schizophrenia.³¹⁰ Nevertheless, it is not yet possible to leap from a genetic association to prediction or cause at an individual level.

Behavioral genetics data provides the framework for some of the more interesting questions about presidential candidates. After having suffered a war-mongering, alcoholic, language-confused executive chief, some members of the public may react by wanting to test presidential candidates for several behavioral traits such as aggression, alcoholism, or dyslexia. But the truth is, they cannot – not with any useful degree of certainty. This does not mean that behavioral genetics

305. Parens, *supra* note 289, at S9 (“Genes appear to help explain the differences in test scores among high SES children, but not among low SES children.”); cf. Eric Turkheimer et al., *Socioeconomic Status Modifies Heritability of IQ in Young Children*, 14 PSYCHOL. SCI. 623, 627 (2003).

306. See Beckwith, *supra* note 297, at 74–75 (“Initial optimistic and widely publicized molecular genetic studies reporting genes predisposing to schizophrenia, bipolar manic depressive illness, alcoholism, homosexuality, risk taking, and others have been retracted, rebutted, or have yet to be replicated successfully.”).

307. ADHD is also highly heritable. Josephine Elia & Marcella Devoto, *ADHD Genetics: 2007 Update*, 9 CURRENT PSYCHIATRY REPS. 434, 434 (2007) (“Several epidemiologic studies point to a strong influence of genetic factors in susceptibility to . . . ADHD.”).

308. While heritability estimates of depressive symptoms range widely, there is a growing consensus that genes and their interaction with the environment play a large part in the development of depression. Minna Happonen et al., *The Heritability of Depressive Symptoms: Multiple Informants and Multiple Measures*, 43 J. CHILD PSYCHOL. & PSYCHIATRY 471, 475 (2002); Klaus Peter Lesch, *Gene-Environment Interaction and the Genetics of Depression*, 29 J. PSYCHIATRY & NEUROSCIENCE 174, 181 (2004).

309. Matt McGue, *The Behavioral Genetics of Alcoholism*, 8 CURRENT DIRECTIONS PSYCHOL. SCI. 109, 109–11 (1999). Recent studies have discovered the complex genetic components of certain alcohol-metabolizing enzymes that moderate tolerance and likelihood of dependence. Yasuhiko Mizoi et al., *Involvement of Genetic Polymorphism of Alcohol and Aldehyde Dehydrogenases in Individual Variation of Alcohol Metabolism*, 29 ALCOHOL & ALCOHOLISM 707, 707, 709 (1994).

310. Researchers have found that the concordance rates for schizophrenia (i.e., the likelihood that one twin will develop the disorder that the other twin has) is somewhere around 41–65% for monozygotic twins, which is much greater than the average population’s risk. See Alastair G. Cardno & Irving I. Gottesman, *Twin Studies of Schizophrenia: From Bow-and-Arrow Concordances to Star Wars Mx and Functional Genomics*, 97 AM. J. MED. GENETICS 12, 13 (2000); Jehannine C. Austin & H.L. Peay, *Applications and Limitations of Empiric Data in Provision of Recurrence Risks for Schizophrenia: A Practical Review for Healthcare Professionals Providing Clinical Psychiatric Genetics Consultations*, 70 CLINICAL GENETICS 177, 177 (2006) (“Schizophrenia affects approximately 1% of the population.”).

science is junk, but rather that it is “science at an early stage.”³¹¹ We can test for genes that are associated with greater susceptibility to alcoholism, ADHD, depression, etc. And even if causal alleles are identified, we cannot know whether someone will become an alcoholic, attention-constrained, or suffer from depression until we know much more about that individual’s unique environmental stressors and the causative role of the group of genes associated with the behavior. Once you acknowledge that heritability of certain behavioral phenotypes changes over an individual’s life,³¹² the information becomes even more speculative. Confusing the prospect of a “genetic test for alcoholism” more is that the definition of the phenotype in this continuum is not at all clear. As Steve Hyman noted, “there is no bright line between normal behavioral variation and disease.”³¹³

D. The Importance of Assessing the Clinical and Analytic Validity of Genetic Tests

Over a thousand clinical genetic tests are currently available for specific disorders or diseases. For purposes of this paper I am interested mostly in presymptomatic genetic testing, in which there is a genetic mutation that is at least somewhat predictive of risk of developing a certain disease as an adult. Not all genetic tests have equally clinical or analytical validity or usefulness. “Analytic validity” refers to a test’s accuracy in detecting a genetic variant when it is present, and not detecting it when it is not present.³¹⁴ “Clinical validity” refers to the correlation between the genetic variant and a particular health condition or risk.³¹⁵ Both of these measures are important to know before receiving any type of test: the first asks whether the test will yield false positives or negatives,³¹⁶ and the second asks whether this information will tell us anything useful about our future health.

One way to measure the predictive value of a genetic test is to assess the penetrance of the gene that is thought to cause the disease. Penetrance is the percentage of individuals with a specific genotype who express an associated

311. Schaffner, *supra* note 300, at 40, 60.

312. Sarah E. Bergen et al., *Age-Related Changes in Heritability of Behavioral Phenotypes Over Adolescence and Young Adulthood: A Meta-Analysis*, 10 TWIN RES. & HUM. GENETICS 423, 423, 429–30 (2007); see also Tinca J.C. Polderman et al., *A Longitudinal Twin Study on IQ, Executive Functioning, and Attention Problems During Childhood and Early Adolescence*, 106 ACTA NEUROLOGICA BELGICA 191, 204 (2006) (“Moreover, the same genes that influence IQ at age 12 also influence attention problems at age 5.”).

313. Stephen E. Hyman, *Using Genetics to Understand Human Behavior*, in WRESTLING WITH BEHAVIORAL GENETICS, *supra* note 292, at 109, 119.

314. Kathy Hudson et al., *ASHG Statement on Direct-to-Consumer Genetic Testing in the United States*, 81 AM. J. HUM. GENETICS 635, 635 (2007).

315. *Id.* at 635–36.

316. Glenn E. Palomaki et al., *Analytic Validity of Cystic Fibrosis Testing: A Preliminary Estimate*, 5 GENETICS MED. 15, 15 (2003).

phenotype.³¹⁷ The greater the penetrance, the more useful the test (i.e., the better it is at predicting the risk of developing a particular disease).³¹⁸ Some of the diseases with highly penetrant causal genes are Huntington's disease,³¹⁹ BRCA1 breast cancer,³²⁰ sickle cell anemia,³²¹ polycystic kidney disease,³²² retinitis pigmentosa,³²³ Marfan's syndrome,³²⁴ and early onset Alzheimer's disease.³²⁵

317. Jacques S. Beckman et al., *Copy Number Variants and Genetic Traits: Closer to the Resolution of Phenotypic to Genotypic Variability*, 8 NAT. REV. GENETICS 639, 640 (2007). For example, Huntington's disease is 95% penetrant, meaning that 5% of those with the dominant allele for Huntington's disease will *not* acquire the disease and 95% will. DAVID B. RESNIK, *OWNING THE GENOME: A MORAL ANALYSIS OF DNA PATENTING* 23 (2004). Penetrance does not measure how strongly the phenotype (in this case, Huntington's disease) is expressed; only that it is acting. See HELEN V. FIRTH & JANE A. HURST, *OXFORD DESK REFERENCE: CLINICAL GENETICS* 6 (Judith G. Hall ed., 2005).

318. See Neil A. Holtzman & David Shapiro, *Genetic Testing and Public Policy*, 13 BRIT. MED. J. 852, 852 (1998) ("Variable expressivity, incomplete penetrance, and genetic heterogeneity all reduce the ability of genetic tests to predict the future.") (emphasis added).

319. Anne Maradiegue & Quannetta T. Edwards, *An Overview of Ethnicity and Assessment of Family History in Primary Care Settings*, 18 J. AM. ACAD. NURSE PRAC. 447, 450 (2006).

320. Jane E. Lacovara & Jessica Ray, *Deciphering the Diagnostics of Breast Cancer*, 16 MEDSURG NURSING 391, 395 (2007). It is important to note that there are multiple types and causes of breast cancer. MayoClinic.com, *Types of Breast Cancer* (Dec. 28, 2007), <http://www.mayoclinic.com/health/breast-cancer/HQ00348> (last visited Apr. 22, 2008).

321. Jamie A. Grodsky, *Genetics and Environmental Law: Redefining Public Health*, 93 CAL. L. REV. 171, 183–84 (2005).

322. HAROLD CHEN, *ATLAS OF GENETIC DIAGNOSIS AND COUNSELING* 797 (2006).

323. Retinitis pigmentosa (RP) is a group of inherited disorders with various causes and penetrance levels. Sarah Bunday & S. James Crews, *A Study of Retinitis Pigmentosa in the City of Birmingham: II Clinical and Genetic Heterogeneity*, 21 J. MED GENETICS 421 (1984). RP causes gradual degeneration of the ocular rods and cones or the retina, resulting in progressive visual loss. Thomas Rio Frio, *Premature Termination Codons in PRPF31 Cause Retinitis Pigmentosa Via Haploinsufficiency Due to Nonsense-Mediated mRNA Decay*, 4 J. CLINICAL INVESTIGATION 1519, 1519 (2008). Many mutations that lead to RP are autosomal dominant and highly penetrant, while other forms of RP have lower penetrance and are recessive. See Bunday & Crews, *supra*, at 412, 427; Hiroyuki Kondo et al., *Diagnosis of Autosomal Dominant Retinitis Pigmentosa by Linkage-Based Exclusion Screening with Multiple Locus-Specific Microsatellite Markers*, 44 INVESTIGATIVE OPHTHALMOLOGY & VISUAL SCI. 1275, 1278 (2003).

324. Nicola C. Y. Ho et al., *Marfan's Syndrome*, 366 LANCET 1978, 1978 (2005).

325. See, e.g., K. Taddei et al., *Association Between Presenilin-1 Glu318Gly Mutation and Familial Alzheimer's Disease in the Australian Population*, 7 MOLECULAR PSYCHIATRY 776, 776 (2002) (indicating there is a high penetrance in the PSEN 1 gene for early onset Alzheimer's). Similar to breast cancer, there are multiple types and causes Alzheimer's disease. See Judith L. Benkendorf et al., *Impact of Genetic Information and Genetic Counseling on Public Health*, in *GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY* 361, 370–71 (Mun J. Khoury et al. eds., 2000). For example, three genes have been associated with the rare forms of Early Onset Familial Alzheimer's Disease (EOFAD, also known as Alzheimer's disease type 3 or AD3). *Id.* at 370. Lab Tests Online, *Alzheimer's Disease* (Aug. 19, 2005), <http://www.labtestsonline.org/understanding/conditions/alzheimers.html>. Mutations in each of the genes (PSEN1, PSEN 2, and APP) cause Alzheimer's in *anyone* who carries the mutation. See Taddei et al., *supra*, at 776; MayoClinic.com, *Alzheimer's: Is it in Your Genes?* (Feb. 28, 2007), <http://www.mayoclinic.com/health/alzheimers-genes/AZ00047>. See generally C. L. Lendon et al., *Exploring the Etiology of Alzheimer Disease Using Molecular Genetics*, 277 JAMA 825, 826–28 (1997)

Huntington's disease presents an interesting case for the testing of presidential candidates because it is highly penetrant.³²⁶ The mutation follows autosomal dominant inheritance, meaning that if the candidate has one copy of the mutant Huntington gene and more than forty copies of the expanded CAG repeat, he or she possesses a near 100% chance of developing the disease in some form.³²⁷ Further, the disease affects important processes such as memory and decision-making.³²⁸ While there is a highly predictive genetic test, there is also no cure. Adult onset Huntington's disease does not typically appear until between the ages of 30 and 50,³²⁹ and it is not routinely tested for in newborn genetic screens.³³⁰ Huntington's disease impairs skills such as planning, cognitive flexibility, abstract thinking, rule acquisition, initiating appropriate actions, and inhibiting inappropriate actions, as well as speech and motor function.³³¹ When present, these symptoms would be quite significant to an individual's ability to effectively govern. However, most diseases that significantly affect cognitive functioning do not have such a simple and well understood genetic contribution.

(discussing the three genes that cause Early Onset Alzheimer's and how they cause the disease). However, this is a very rare form of the disease and susceptibility to the more common late onset Alzheimer's disease is attributed to different mutations on different genes. Robert L. Nussbaum & Christopher E. Ellis, *Alzheimer's Disease and Parkinson's Disease*, 348 *NEW ENG. J. MED.* 1356, 1356-57 (2003).

326. Maradiegue & Edwards, *supra* note 319.

327. See Nagehan Ersoy, *Molecular Genetics of Huntington's Disease: When Size Does Matter*, 6 *J. CELL & MOLECULAR BIOLOGY* 1, 1-3 (2007); Anneke Maat-Kievit et al, Letter to the Editor, *New Problems in Testing for Huntington's Disease: The Issue of Intermediate and Reduced Penetrance*, 38 *J. MED. GENETICS*, at e12, e12 (2001) ("Penetrance of 36 to 39 repeat alleles may be higher in persons with confirmed ancestry of HD than those from collateral branches with new mutations. Penetrance is also dependent on the expression of the disease in the parent with the expanded repeat, but reliable empirical penetrance risks are not yet available [for low intermediate CAG repeat levels].").

328. Michael Morris & Jane Scourfield, *Psychiatric Aspects of Huntington's Disease*, in 31 *HUNTINGTON'S DISEASE* 73, 107 (Peter S. Harper ed., 2d ed. 1996) (finding that Huntington's Disease impairs recent and remote memory); Jane S. Paulsen & Rachel A. Conybeare, *Cognitive Changes in Huntington's Disease*, in 96 *BEHAVIORAL NEUROLOGY OF MOVEMENT DISORDERS* 209, 215 (Karen E. Anderson et al. eds., 2d ed. 2005) (indicating that Huntington's Disease impairs decision-making).

329. KRISTINE BARLOW-STEWART & GAYARTHI, CTR. FOR GENETICS EDUC., *FACT SHEET 44: HUNTINGTON DISEASE - NEUROLOGICAL CONDITIONS 1* (2007), available at <http://www.genetics.com.au/pdf/factsheets/fs44.pdf>.

330. See U.S. GEN. ACCOUNTING OFFICE, *GAO-03-449, NEWBORN SCREENING: CHARACTERISTICS OF STATE PROGRAMS* 8, 9 tbl.1 (2003) (citing that the most common newborn screening programs focus on the following disorders: phenylketonuria, congenital hypothyroidism, galactosemia, sickle cell diseases, congenital adrenal hyperplasia, biotinidase deficiency, maple syrup urine disease, and homocystinuria).

331. Paulsen & Conybeare, *supra* note 328, at 210 tbl.15-1, 212; JIM POLAND, *A CAREGIVER'S HANDBOOK FOR ADVANCED-STAGE HUNTINGTON DISEASE* 6 (Jim Pollard ed., 2003), available at http://www.hdac.org/caregiving/pdf/Caregiver_Handbook.pdf; Juri D. Kropotov & Susan C. Etlinger, *Selection of Actions in the Basal Ganglia - Thalamocortical Circuits: Review and Model*, 31 *INT'L J. PSYCHOPHYSIOLOGY* 197, 206 (1999); Carol Brown Moskowitz et al., *Palliative Care for People With Late-Stage Huntington's Disease*, 19 *NEUROLOGIC CLINICS* 849, 854 (2001).

In some cases, an implicated gene has been extensively studied and appears to show signs of increased susceptibility to a certain disease, or is associated with disease development, but there is little data to accurately predict expression. One example is the exon 41 mutation on the LRRK2 gene that is responsible for some forms of familial and sporadic Parkinson's disease.³³² The penetrance for this exon 41 mutation is not as high as that of Huntington's disease, but it is higher with people who had two copies of the mutated gene.³³³ No clinical genetic tests exist for this mutation, as it remains outside of clinical use and is still being studied for clinical and analytic validity. This example illustrates that there is often a gap between the discovery of a tight genotype-phenotype causal association and the development and availability of a related clinical genetic test. Some bench scientists believe that these types of findings are "reliable and useful enough to disclose to participants even prior to the development of a validated clinical program for delivering the information."³³⁴ However, as there is no common nomenclature or shared standards for determining when a genetic test has analytic validity, clinical validity, or clinical utility, it remains that much trickier to assess when genetic testing is clinically appropriate.³³⁵

Not all sequence variations will have clinical significance, which is to say that not all sequence variations will inform health decisions in any way. The certainty that any given variation *is* of clinical significance falls along a continuum of interpretations.³³⁶ To help clinicians in reporting results to families, the American College of Medical Genetics (ACMG) published recommended categories for reporting sequence variations.³³⁷ The first category consists of variations that were previously reported in the Human Gene Mutation Database or the locus-specific database, and this variation is widely recognized to be the cause of a disorder.³³⁸ The second category exists when a "[s]equence variation is previously unreported and is of the type which is expected to cause the disorder."³³⁹ This is based on the

332. Hiroyuki Tomiyama et al., *Clinicogenetic Study of Mutations in LRRK2 Exon 41 in Parkinson's Disease Patients From 18 Countries*, 21 MOVEMENT DISORDERS 1102, 1103 (2006).

333. Compare Robert Marongiu et al., *Frequency and Phenotypes of LRRK2 G2019S Mutation in Italian Patients With Parkinson's Disease*, 21 MOVEMENT DISORDERS 1232, 1233 (2006) ("[T]he age-related penetrance of the LRRK2 disease . . . has been shown to increase from 17% at age 50 up to 85 % at age 70 years"), with Maradiegue & Edwards, *supra* note 319, at 450 ("Another example of a highly penetrant gene is the gene for Huntington's disease, where those with the Huntington mutation will manifest the disease 100% of the time if they live long enough.").

334. Lynn G. Dressler & Eric T. Juengst, *Thresholds and Boundaries in the Disclosure of Individual Genetic Research Results*, 6 AM. J. BIOETHICS 18, 18 (2006).

335. *Id.* at 19.

336. Am. C. Med. Genetics Lab. Practice Comm. Working Group, *ACMG Recommendations for Standards for Interpretation of Sequence Variations*, 2 GENETICS MED. 302, 302 (2000).

337. *Id.*

338. *Id.*

339. *Id.*

type of mutation and the predicted shifting of the messenger ribonucleic acid (mRNA) that encodes the blueprint for a protein's product.³⁴⁰ The third category exists when the variation is unreported and may or may not be of the type that causes the disorder.³⁴¹ The fourth is when the sequence variation is previously unreported and probably not the cause of the disorder.³⁴² The fifth and final category exists when the sequence variation is reported, but is recognized as a variant with a neutral effect.³⁴³ The ACMG acknowledged that while the causative link may be influenced by many other parameters such as family history or the sensitivity or specificity of the test being performed, it is important to have a framework for differentiating the possible clinical significance when reporting sequence variations to individuals.³⁴⁴

E. The Method of Disclosure Is Not One-Size Fits All

In the case of "Project Jim," 454 Life Sciences and the Baylor College of Medicine decided on a "data release pathway," delivering a DVD to Watson that contained his completed genomic sequence.³⁴⁵ Watson would then accept responsibility for discussing the risk with his family members, and decide what should be kept private and how the sequence ought to be made public.³⁴⁶ This release pathway seemed appropriate after "rigorous consent" was obtained, and after Watson requested that his ApoE gene status, which can indicate an elevated risk for Alzheimer's disease, be redacted.³⁴⁷ Watson is a Nobel Prize winner and revolutionary geneticist.³⁴⁸ The disclosure vehicle that might work for him cannot be generalized to the rest of the population, as he has very sophisticated knowledge about the way genes work and the limits of genome sequencing. What about those of us who are not scientists, much less geneticists? Should the presidential candidates receive every possible type of genetic information and then have a committee review it? Even if we answer yes to these questions, we still must evaluate how best this information might be communicated to the public, and whether it should be done so voluntarily.

340. *Id.* Messenger ribonucleic acid (mRNA) is a molecule that encodes a chemical blueprint for producing a gene's protein product. JORDE ET AL, *supra* note 88, at 11–12.

341. Am. C. Med. Genetics Lab. Practice Comm. Working Group, *supra* note 336, at 302.

342. *Id.*

343. *Id.*

344. *Id.*

345. Marshall, *supra* note 286, at 1780.

346. *Id.*

347. *Id.*

348. *Id.*

III. SHOULD THE BACKDROP BE MANDATORY OR VOLUNTARY DISCLOSURE?

A. Benefits of Voluntary Disclosure: Privacy and Confidentiality

With voluntary disclosure, the candidate would decide which information to make public or keep private, and would be furnishing the data herself. Anything released would have her imprimatur, and this would remove the problematic issues discussed above. First, this maintains patient confidentiality and physicians will not divulge confidential information about their patient. There would be no HIPAA concerns, as the covered entity cannot prevent a patient from disclosing her own health data. There could be no action in court for a violation of the candidate's privacy right, so long as the information is not eventually presented in a way that the publisher knows to be false or contradictory to the voluntary disclosure. As the government did not mandate any test as a condition on running for office, there also could be no Fourth Amendment claim. Similarly, the non-discrimination statutes do not apply, as their chief purpose is to preserve and protect the near exclusive rights of individuals to share their genetic information.

It is possible that even under a voluntary disclosure scheme, individuals may file Freedom of Information Act (FOIA) claims to obtain any information that was not disclosed by the candidate.³⁴⁹ However, unlike the privacy tort regime where public figures are afforded less privacy protection, FOIA protects personnel information from disclosure that was determined to be private at the time it was obtained by the government.³⁵⁰ Title 5 of the U.S. Code, Section 552(b)(6) provides that records are exempt from FOIA requests if they are personnel files, the disclosure of which would constitute "clearly unwarranted invasion of personal privacy."³⁵¹ In construing the federal provisions of FOIA, the Supreme Court has determined that the federal privacy exemption was designed to protect individuals from the "injury and embarrassment that can result from the unnecessary disclosure of personal information."³⁵² Courts also look to whether the individual thought the information would be considered private at the time when they originally provided

349. Freedom of Information Act, Pub. L. No. 89-554, 80 Stat. 383 (1966). The Act was subsequently amended. Pub. L. No. 93-502, §§ 1-3, 88 Stat. 1561-64 (1974) (codified as amended at 5 U.S.C. § 552 (1982)) (adding measures to compel agency compliance).

350. See *Painting Indus. of Haw. Mkt. Recovery Fund v. U.S. Dep't of the Air Force*, 26 F.3d 1479, 1483-84 (9th Cir. 1994) (demonstrating that once a party establishes privacy in the information, disclosure only results if the information fits within a FOIA exception); *Judicial Watch, Inc. v. Rossotti*, 285 F. Supp. 2d 17, 19-20, 31 (D.D.C. 2003); *Fine v. U.S. Dep't of Energy*, 823 F. Supp. 888, 894, 897 (D.N.M. 1993) (mem.) (explaining that a defendant must demonstrate a "substantial privacy interest" for information to be withheld from disclosure under FOIA).

351. 5 U.S.C. § 552(b)(6) (2000 & Supp. V 2006).

352. *Dep't of State v. Washington Post Co.*, 456 U.S. 595, 599 (1982).

the information to the government.³⁵³ While the Supreme Court has repeatedly held that the First Amendment “embodies the right to receive and gain access to information and ideas,”³⁵⁴ federal courts have “explicitly rejected the proposition that government officials, by virtue of their positions, forfeit their personal privacy for FOIA purposes.”³⁵⁵

B. Problems with Voluntary Disclosure: Cover-ups, Captive Kings, and the Twenty-Fifth Amendment

The main problem with voluntary disclosure is that history demonstrates that we cannot trust our candidates to reveal important information about their health.³⁵⁶ As there are no requirements for presidents to reveal their health information in any particular way, they often do so strategically, and many candidates and presidents have knowingly deceived the public about their health. There are many examples of presidents and presidential candidates who have outright lied to the public about their health information. It is therefore worth considering the frequency and depth of this phenomenon below.

The first major medical cover-up in the White House for which there exists ample evidence occurred during Grover Cleveland’s second term in office.³⁵⁷ President Cleveland secretly underwent upper jaw surgery to remove a cancerous node while aboard a yacht in the New York harbor.³⁵⁸ Out of concern that the news of Cleveland’s surgery would cause serious national financial damage, the attending surgeons cooperated with the President in his attempt to cover up the fact that he was having any surgery at all.³⁵⁹ The operation was in fact quite serious as there was danger of stroke as well as explosion from the large amount of ether that

353. *Painting Indus.*, 26 F.3d at 1483; *Judicial Watch*, 285 F. Supp. 2d at 31; *Fine*, 823 F. Supp. at 897.

354. *Lieberman v. Bd. of Labor Relations*, 579 A.2d 505, 513 (Conn. 1990) (citing *Press-Enterprise Co. v. Superior Court*, 464 U.S. 501, 508–10 (1984)); *Globe Newspaper Co. v. Superior Court*, 457 U.S. 596, 606–07 (1982); *Nixon v. Warner Comm’ns, Inc.*, 435 U.S. 589, 597–98 (1978).

355. *Fund for Constitutional Gov’t v. Nat’l Archives*, 656 F.2d 856, 864 (D.C. Cir. 1981); *accord Nix v. United States*, 572 F.2d 998, 1006 (4th Cir. 1978) (protecting the identity of an FBI agent from public disclosure).

356. Jerrold M. Post, *The Health of Presidents and Presidential Candidates: Dilemmas and Controversies*, 16 POL. PSYCHOL. 757, 757 (1995) (“[M]any candidates for the highest office had suffered serious illness before running for high office, the existence or gravity of which had been concealed from public view.”).

357. Carlos Gomez & Kenneth Crispell, *The Cover-Up of Presidential Illness, the President’s Physician, and the Twenty-Fifth Amendment*, in 3 PAPERS ON PRESIDENTIAL DISABILITY AND THE TWENTY-FIFTH AMENDMENT 3, 7 (Kenneth W. Thompson ed., 1996).

358. CRISPELL & GOMEZ, *supra* note 21, at 204; Gomez & Crispell, *supra* note 357, at 7.

359. Gomez & Crispell, *supra* note 357, at 7 (“W.W. Keen, Mr. Cleveland’s chief surgeon, withheld public comment until 1917, 24 years after the operation. . . . One of the attending surgeons, John F. Erdmann said that he did more lying during that time period than in all the rest of his life put together.”).

his doctor needed to use on Cleveland's hefty frame.³⁶⁰ The *New York Times* reported that, at the time "Doctor Bryant sa[id] the President [was] absolutely free from cancer or malignant growth of any description . . . [n]o operation ha[d] been performed, except that a bad tooth was extracted."³⁶¹

Perhaps more brazen was the cover-up of President Woodrow Wilson's multiple strokes. Wilson suffered his first stroke in 1896, and experienced three more strokes throughout his life as researched and recorded by Edward Weinstein.³⁶² Historians have extensively investigated Wilson's health problems by using primary documents provided by his doctor Cary Grayson.³⁶³ These documents indicate that Wilson indeed had cardiovascular disease, producing severe disabling neurological symptoms.³⁶⁴ Some political commentators have argued that Wilson's neurological symptoms affected his mental functions during the signing of the Treaty of Versailles *and* during his failed campaign to rally support for the League of Nations.³⁶⁵ During the famous conference in Paris, Prime Minister Lloyd-George noted that Wilson had "suffered something like a stroke," while others noted that Wilson seemed less alert.³⁶⁶ Herbert Hoover observed that Wilson's normally quick mind had to "grope for ideas."³⁶⁷ The President confided in his physician, Grayson, that he was having trouble in the evening remembering what happened each afternoon,³⁶⁸ and Dr. Grayson noted that Wilson had "trouble arranging his thoughts."³⁶⁹ In 1919, while making a speech to support the creation of the League of Nations in Pueblo, Colorado, the President "showed signs of a massive embolism," and a few days later, he suffered from a severe stroke that kept him incapacitated until his death.³⁷⁰ The President's wife and doctor continued to "shroud the true extent of the President's illness in secrecy," as the first lady denied

360. ROBERT H. FERRELL, *ILL-ADVISED: PRESIDENTIAL HEALTH AND THE PUBLIC TRUST* 6 (1992) (describing the risk of stroke associated with the President's operation and explaining that because ether is highly volatile, "its use with the primitive electrical equipment for cauterization could have caused an explosion").

361. *Id.* at 8 (quoting an excerpt from an article that appeared in the *New York Times* on July 7–8, 1893).

362. Gomez & Crispell, *supra* note 357, at 8–9.

363. *Id.*; Michael Alison Chandler, *A President's Illness Kept Under Wraps*, WASH. POST, Feb. 3, 2007, at B1.

364. Gomez & Crispell, *supra* note 357, at 8.

365. See CRISPELL & GOMEZ, *supra* note 21, at 15 ("By the time he arrived in France to undertake the most arduous and dangerous political task of his life, Woodrow Wilson was suffering from the sequelae of a series of maladies which have been diagnosed as both neurological and psychosomatic in origin.").

366. *Id.* at 64.

367. *Id.*

368. *Id.*

369. *Id.* at 65; accord Edwin A. Weinstein, *Woodrow Wilson's Neurological Illness*, 57 J. AM. HIST. 324, 345 (1970).

370. CRISPELL & GOMEZ, *supra* note 21, at 65–67 accord Weinstein, *supra* note 369, at 345–46.

aides access to the President for *four months*; during that time she took affairs into her own hands.³⁷¹ Dr. Grayson informed the cabinet that Wilson “had suffered a nervous breakdown, indigestion, and a depleted nervous system,” but he cautioned the cabinet not to bother the President, because “any excitement might kill him.”³⁷² When Robert Lansing, then Secretary of State, pointed out that the Constitution provided for the Vice President to assume the duties of the President in case of some incapacity, Grayson was “incensed and said that he would never certify that the President was disabled.”³⁷³ During the several months after Wilson’s stroke, the executive office went almost completely “out of business—[b]ills were left unsigned, policy left undecided.”³⁷⁴ Mrs. Wilson did all she could to hide her husband’s serious illness, and to “keep the burden of government from hindering his recovery.”³⁷⁵ Up until Wilson’s death, Grayson continuously issued his “reassuring, and patently false, press releases” about the President’s health.³⁷⁶

Likewise, it is now well known that Franklin D. Roosevelt had medical problems throughout his life. He had typhoid, stomach distress, appendicitis and lumbago, pneumonia and severe influenza, tonsillitis, and sinusitis.³⁷⁷ Of course, he also developed polio in 1921, from which he never fully recovered.³⁷⁸ In addition to the paralysis of his legs as a result of the polio, Roosevelt had many other problems such as severe coughing and heart failure, perhaps due to an enlarged left ventricle.³⁷⁹ The President had to take long naps during the day and slept for approximately ten hours a night.³⁸⁰ Roosevelt once left the White House for five weeks to rest, leaving major world events to occur in his absence: he was nominated for the Democratic Party ticket, the Russians captured Riga and invaded Warsaw, and the American troops captured Brittany in France.³⁸¹ Roosevelt was aided in his health cover-up by a cooperative media that was deferential to his image management.³⁸² The image management ran deep, involving misleading disclosures by his doctors and staged speaking platforms that would disguise the President’s disability.³⁸³ When Roosevelt hosted dinner parties, his aides would wheel him into the dining room first so that guests would not witness this as they

371. CRISPELL & GOMEZ, *supra* note 21, at 70.

372. *Id.* at 70–71.

373. *Id.* at 71.

374. *Id.* (citation omitted).

375. *Id.*

376. *See id.* at 72.

377. GILBERT, *supra* note 37, at 43–44.

378. Bruenn, *supra* note 53, at 579.

379. *Id.* at 579–82, 590–91.

380. *Id.* at 581–82.

381. *Id.* at 587.

382. GILBERT, *supra* note 37, at 47–48.

383. *Id.* at 49–50, 53–54.

filed into the room.³⁸⁴ The President engaged in other types of “presidential theatrics” to camouflage his severe physical disability, including sitting on a bicycle that was cloaked in ferns so that he would appear to be standing while addressing a group.³⁸⁵ He often disguised his inability to walk by having his aides escort him to the podium, which he would grasp for support as he spoke.³⁸⁶ “Unknown to the public until recent years was the fact that [Roosevelt]. . . had visited the National Naval Medical Center in Bethesda at least 29 times” from 1941 to 1945, using false names.³⁸⁷ In 1970, Roosevelt’s physician, Dr. Howard Bruenn, published an account of the President’s health history.³⁸⁸ This history revealed that Roosevelt had hypertensive heart disease, heart failure, and high blood pressure, and was in frequent need of bed rest due to his poor health.³⁸⁹ Dr. Bruenn stated: “[I]n most instances not only have the details [regarding the illness of a president] been obscure[d] but the very fact that illness existed has been not infrequently denied.”³⁹⁰ He closed by acknowledging the reason for his long-awaited publication: “Many people rightfully attach much importance to the health records of the men whom they have considered and elected to the office of President of the United States.”³⁹¹

President John F. Kennedy successfully concealed that he had Addison’s disease, a potentially fatal adrenal illness, by managing the debilitating effects with regular shots of cortisone.³⁹² As the 1960 presidential campaign approached, the question of Kennedy’s health became front-page news for the first time.³⁹³ Stories circulated that Kennedy had more than just back pain—rumors spread that he had some incurable “malady.”³⁹⁴ The Kennedy camp lied about what they knew of Kennedy’s adrenal function at the time, stating that “[John F. Kennedy] does not now nor has he ever had an ailment described classically as Addison’s disease, which is a tuberculosis destruction of the adrenal gland. Any statement to the contrary is malicious and false. . . .”³⁹⁵ Kennedy’s campaign team created the image of a “young, heroic politician, full of vital energy,” an image that the media and general public accepted, and which catapulted Kennedy into the White House,

384. *Id.* at 49–50.

385. *Id.* at 50.

386. *Id.* at 48, 50.

387. Gomez & Crispell, *supra* note 357, at 15.

388. Bruenn, *supra* note 53, at 579.

389. *Id.* at 580–81.

390. *Id.* at 579.

391. *Id.* at 591.

392. Robins & Post, *supra* note 17, at 846 (suggesting that Kennedy was receiving some cocktail of amphetamines and steroids to treat his Addison’s disease).

393. Gomez & Crispell, *supra* note 357, at 20.

394. *Id.*

395. *Id.* at 21 (citation omitted).

despite his serious health problems.³⁹⁶ In a clever spin, Kennedy's doctor, Dr. Janet Travell, suggested that to call Kennedy an Addisonian would be a misdiagnosis, as he did not exhibit one of the disease's main symptoms—pigmentation of the skin or mucous membranes.³⁹⁷ Travell failed to mention that the cortisone treatments that he was taking would clear up the discoloration.³⁹⁸ Further, his "depletion of adrenal function" was said to be due to malaria,³⁹⁹ and his back pain appeared after he swam to rescue fellow military men when his boat was blown up in World War II.⁴⁰⁰ Later, his spokesperson would say that they did not use the term "Addison's disease," even though they knew that to be what it was, because the public wrongly thought that Addison's was fatal, and it would give a false impression to use the term.⁴⁰¹ When deciding who should run alongside Kennedy in the event that he were to step down, Kennedy famously told one of his aides, Kenny O'Donnell: "I'm the healthiest candidate for President in the United States. . . . [and] I'm not going to die in office. So the vice presidency doesn't mean anything."⁴⁰²

There have also been examples of presidential candidates deceiving the public about their health. Paul Tsongas was diagnosed with non-Hodgkin's lymphoma in 1983,⁴⁰³ and in his 1992 presidential campaign he attempted to counter the image of a recovering cancer patient by releasing ads where he vigorously swam the butterfly.⁴⁰⁴ During this campaign, he lied to the public, characterizing himself as "cancer-free" when in fact he was fully aware that he was no longer in remission.⁴⁰⁵ The doctors who treated Tsongas at the Dana-Farber Cancer Center were complicit in this dishonesty, as they masked the fact that the bone marrow transplant that Tsongas received did not cure him of cancer.⁴⁰⁶ They knew that the cancer recurred in 1987, which required excising a cancerous node.⁴⁰⁷ Instead of confronting this recurrence directly, the medical team used euphemistic and misleading language to describe Tsongas' health to the press.⁴⁰⁸ The cancer was referred to as "suspicious

396. *Id.* at 21–22.

397. CRISPELL & GOMEZ, *supra* note 21, at 195.

398. *Id.* at 195–96.

399. *Id.* at 195.

400. *Id.*

401. *Id.* at 199.

402. This was in response to O'Donnell's opposition to choosing Johnson as the Vice President, should Kennedy die in office. KENNETH P. O'DONNELL ET AL., "JOHNNY, WE HARDLY KNEW YE," at vii, 192–93 (1972).

403. Editorial, *Cancer in a Presidential Candidate*, N.Y. TIMES, Nov. 26, 1992, at A26.

404. Karen De Witt, *Tsongas Pitches Economic Austerity, Mixed with Patriotism*, N.Y. TIMES, Jan. 1, 1992, at A10.

405. See Lawrence K. Altman, *Tsongas's Health: Privacy and the Public's Rights*, N.Y. TIMES, Jan. 17, 1993, at A26.

406. Robins & Post, *supra* note 17, at 854.

407. *Id.*

408. *Id.*

cells” and the radiation he received was labeled “precautionary.”⁴⁰⁹ There are no doubt countless others who have run for office under false pretenses about their health, and the examples listed above only highlight some of those for whom we have documented evidence of extensive cover-ups.

Many presidents who were sick or died in office have left inspiring and fruitful legacies in United States government.⁴¹⁰ This point underscores that presidents need not be completely healthy to be effective leaders. However, the degree to which presidents and presidential candidates have been able to dupe the public regarding their health through obfuscation, secrecy, and cover-ups is somewhat mind-boggling. The quality of the data presented through voluntary means cannot be verified. It also cannot be sufficiently relied upon as the physicians providing the summaries may be close friends of the candidate, or they may have a conflict of interest that runs counter to the desire for full and accurate disclosure.⁴¹¹

Another problem with voluntary disclosure lies in the political structure of the executive branch and the ways in which power is transferred should a president become unable to discharge her duties. This is where the critical link is made between what information is divulged during the run up to the White House and how this disclosure may be relevant once the successful individual is inaugurated. If we had a clear mechanism for diagnosing disease in presidents and assessing when a president is too diseased to effectively govern, then information gathered during the campaign stage would be less relevant. But as we will see below, the Constitutional mechanisms for transferring power when the President is disabled are not described in great detail.

The only formal, legal method for the transfer of presidential power due to presidential disability is the Twenty-Fifth Amendment.⁴¹² The Twenty-Fifth Amendment to the Constitution was ratified in 1967 in the wake of Eisenhower’s cardiac problems and the growing concern of presidential disability and uncertain procedures for succession.⁴¹³ The Amendment provides a method for the President to certify to his disability, transfer his duties to the Vice President, and then resume

409. *Id.* Paul Tsongas eventually apologized for the cover-up in an editorial for the *New York Times*. Paul Tsongas, *The Cancer Freed Me. It Freed Me.*, N.Y. TIMES, May 6, 1992, at A29.

410. Herbert L. Abrams, *The Vulnerable President and the Twenty-Fifth Amendment, with Observations on Guidelines, a Health Commission, and the Role of the President’s Physician*, 30 WAKE FOREST L. REV. 453, 461–62 (1995) (listing the fourteen presidents of the twentieth century who suffered from significant illnesses while serving the Presidency).

411. One of Paul Tsongas’ physicians at the Dana Farber Cancer Center, Dr. Tak Takvorian had contributed money to Tsongas’ campaign and thus had not only a personal but a financial investment in presenting a rosy picture about the candidate’s health. Abrams, *supra* note 37, at 801, 803. Also, Tsongas was a trustee of the Dana Farber Cancer Center, posing its own conflict of interest. *Id.* at 803.

412. U.S. CONST. amend. XXV.

413. William F. Brown & Americo R. Cinquegrana, *The Realities of Presidential Succession: “The Emperor Has No Clones,”* 75 GEO. L.J. 1389, 1393, 1399–400 (1987).

his duties when no longer disabled.⁴¹⁴ The flaw of the Amendment is twofold. First, it vests initial authority in the President to certify to his disability.⁴¹⁵ For obvious reasons, evidenced throughout history, presidents loath to give up their power voluntarily, and particularly if they are disabled and grasping at straws.

The second flaw in the amendment is its provision that allows the Vice President and a majority of the cabinet to determine disability in the event that the President is unable to certify to his disability.⁴¹⁶ This is a problem because a physically or psychologically impaired president “might cling to office, concealing the extent of his impairment behind a protective cordon of aides whose loyalties as ‘president’s men’ lie primarily to the person rather than to the office.”⁴¹⁷ If a leader is totally disabled by heart attack or gunshot wound, it is quite difficult to cover up or ignore. A more insidious and subversive problem is that of a partially disabled or neurologically impaired president, such as President Wilson.⁴¹⁸ If the President is fully aware of his disability, this allows his principal advisors, cabinet members, and the Vice President to “become co-conspirators in their efforts to deny or minimize the extent of the disability.”⁴¹⁹ Conversely, it could lead to clever

414. The third section of the Twenty-Fifth Amendment states:

Whenever the President transmits to the President pro tempore of the Senate and the Speaker of the House of Representatives his written declaration that he is unable to discharge the powers and duties of his office, and until he transmits to them a written declaration to the contrary, such powers and duties shall be discharged by the Vice President as Acting President.

U.S. CONST. amend. XXV, § 3.

Section four provides:

Whenever the Vice President and a majority of either the principal officers of the executive departments or of such other body as Congress may by law provide, transmit to the President pro tempore of the Senate and the Speaker of the House of Representatives their written declaration that the President is unable to discharge the powers and duties of his office, the Vice President shall immediately assume the powers and duties of the office as Acting President. Thereafter, when the President transmits to the President pro tempore of the Senate and the Speaker of the House of Representatives his written declaration that no inability exists, he shall resume the powers and duties of his office

Id. § 4, cl. 1–2.

415. *Id.* § 3.

416. *Id.* § 4; Jimmy Carter, *Message from Former President Jimmy Carter*, in *PRESIDENTIAL DISABILITY*, at xv (James F. Toole & Robert J. Joynt eds., 2001).

417. Edwin M. Yoder Jr., *Determining Presidential Health Under the Twenty-Fifth Amendment*, 30 *WAKE FOREST L. REV.* 607, 608 (1995).

418. See Mohr, *supra* note 59, at 785 (“In obvious situations, such as a massive stroke, a medical disability determination should be quite easy. In other medical conditions, such as Alzheimer’s disease, alcoholism, AIDS, or insidious mental illness, astute clinical judgment and considerable courage may be required to make such a determination.”); see *supra* notes 362–76 and accompanying text.

419. Post & Robins, *supra* note 161, at 341; see also Louis A. Gottschalk et al., *Presidential Candidates and Cognitive Impairment Measured from Verbal Behavior in Campaign Debates*, 48 *PUB. ADMIN. REV.* 613, 617 (1988) (“The impaired brain can sometimes not critically evaluate its own malfunction.”).

manipulation of the leader by his close advisors. A conflict presents itself when the very person who would receive the transfer of power is the one to initiate it. Researchers looking at the effects of a leader's disability on political decision-making determined that particularly in less transparent leadership models where there is "no clear succession mechanism, the intricate relationship between the disabled leader and his inner circle can be of crucial significance."⁴²⁰ The aide or vice president who acts too assertively to invoke the Twenty-Fifth Amendment when the President is incapacitated may find himself alienated if the President recovers.

Adding to this, presidents are special patients and because of that, they may receive especially *bad* treatment.⁴²¹ Research shows that celebrity patients often receive worse care because their medical team is often too many or too few, comprised often of inexpert physician-friends, and the referral channel is typically indirect and unusual, which can lead to a lack of continuity in care.⁴²² Celebrity patients more frequently call the shots in the delivery of their care, which can lead to improper treatment where the providers are too deferential and may not advise the cabinet of the President's truly failing systems.⁴²³

The Twenty-Fifth Amendment has not been invoked when it ought to be.⁴²⁴ This leaves the efficacy of the Amendment largely untested as *only* one President has ever invoked it for the transfer of presidential power to the Vice President due to the inability of the President to perform his functions.⁴²⁵ This is remarkable given the life-threatening and temporarily incapacitating events that have taken place since the passage of the Amendment. After Ronald Reagan was shot and seriously wounded, it was not clear that he was going to live.⁴²⁶ Even so, the Vice President did not initiate the transfer of presidential power temporarily to himself

420. Post & Robins, *supra* note 161, at 333.

421. See Anastasia Kucharski, *On Being Sick and Famous*, 5 POL. PSYCHOL. 69, 79–80 (1984).

422. *Id.* at 70.

423. Often the inner circle will cater to the leader's denial of ill health, and this will prevent direct and timely treatment of the disease. Post & Robins, *supra* note 161, at 341. There are many examples of this throughout history. When Ataturk suffered from liver disease, his staff shared in his denial by repeatedly exterminating the palace for the "insects" biting at him. *Id.* "It was only when [Ataturk] left the country that a physician whose view was not clouded by idolization saw the obvious stigmata of terminal liver disease." *Id.*

424. *E.g.*, Abrams, *supra* note 410, at 460–62 (noting that President Reagan refused to invoke the Twenty-Fifth Amendment when he underwent surgery to remove his colon cancer even though he delegated the power of the presidency to the Vice President).

425. Mike Allen, *Bush Resumes Power After Test*, WASH. POST, June 30, 2002, at A13. On July 21, 2007, President George Bush wrote to the Speaker of the House of Representatives and the President Pro Tempore of the Senate indicating that he planned to invoke the Twenty-Fifth Amendment and pass his duties off temporarily to the Vice President, as he was undergoing sedation for a routine procedure. Jim Rubenber, *Bush Has 5 Polyps Removed in Colon Cancer Screening*, N.Y. TIMES, July 22, 2007, at A20.

426. Abrams, *supra* note 410, at 455–458.

according to the Twenty-Fifth Amendment.⁴²⁷ Again, Reagan underwent surgery on July 13, 1985 to have a polyp removed from his colon.⁴²⁸ The President was under anesthesia for several hours, and slept from 11:28 a.m. until about 7:00 p.m.⁴²⁹ Although he transferred the duties of his office to the Vice President, he wrote a letter before surgery stating:

I am about to undergo surgery during which time I will be briefly and temporarily incapable of discharging the Constitutional powers and duties of the office. . . . I am mindful of the provisions of Section III of the 25th Amendment. . . . *I do not believe that the drafters of this Amendment intended its application to situations such as the instant one.*⁴³⁰

The means by which the Twenty-Fifth Amendment should be invoked are thus not abundantly clear, and as this is the case, it becomes even more important for voters to have information on the health of the President. If we cannot rely on the President to step down when disabled, or on his cabinet and inner circle to invoke the Twenty-Fifth Amendment when necessary, we really ought to know more about the underlying health of the President *before* he is elected.

C. *Benefits of Mandatory Disclosure: Standardization and Openness*

The benefits of mandatory disclosure mirror the disadvantages for voluntary disclosure. Even so, mandatory disclosure would have to involve adequate regulation and enforcement to ensure that it is not voluntary disclosure dressed up in the clothes of compliance with a required Congressional form. If Congress were to mandate some sort of regulated health disclosure before a candidate could receive federal matching funds for his campaign, the candidate could not cover up any potentially serious health issues by providing careful summaries of his health or no summaries at all. Each candidate would be held to the same standard, and the same information would be released for each person, yielding better comparative information. Voters would be able to be as informed as possible about the candidate's health, rather than relying on photo-ops of the candidates running around picturesque Camp David, eating salads, or sailing on the Chesapeake. Having a more concrete idea of the presidential candidates' health risk factors could prompt voters to evaluate more closely the vice presidential candidate if the President's health appears to be diminished in some way. In addition, with

427. *Id.* at 460.

428. JOHN R. BUMGARNER, *THE HEALTH OF PRESIDENTS* 284 (1994); accord Gerald M. Boyd, *On the Mend: White House Prepares for a Post-Surgical Presidency*, N.Y. TIMES, July 21, 1985, available at <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9C01E3D91538F932A15754C0A963948260>.

429. See BUMGARNER, *supra* note 428, at 284.

430. *Id.* at 284–85 (internal citation omitted).

mandatory disclosure, we would not need to worry as much about a secretive and protective cabinet shielding the public from the truth about the President's health, or manipulating his poor health to advance a puppet-style agenda.

D. Problems with Mandatory Disclosure: Third Parties, Stigma, and Privacy

While the benefits of regulated mandatory disclosure are legion, the obstacles confronted by such a scheme are as well. In addition to the legal framework discussed above, there are ethical problems with disclosing the results of a presidential candidates' genetic test. First of all, to the extent the President has any living family members, they will learn something about their own genetic profile that they may not want to know. Unlike tests for pregnancy or kidney function, genetic tests would convey information that could be clinically extrapolated to the candidate's extended family.⁴³¹ We may learn that the President is a carrier for genetic diseases that he does not express, but that his children might. This is not a trivial bit of information, and could impact the family member's day-to-day behavior, pregnancy planning, and psychological well-being.⁴³² Much of the invasion of privacy doctrine rests on the distinction between public and private people and the fact that public people hold themselves out for public scrutiny.⁴³³ The children or siblings of presidential candidates did not choose to be thrust into the public sphere. We need to think critically about whether they should have their health privacy compromised on behalf of a third-party's actions. It is one thing to communicate the genetic results to family members privately, it is another thing entirely to make this publicly available.⁴³⁴

The effect on stigmatization of disease could cut either way, depending on the facts of each case and public reception of each candidate's illness. On the one hand, a successful candidate who has depression could erode the stigma of this disorder by exposing its prevalence and the benefits of drug therapy. However, if the candidate is never given the chance to prove that someone with depression can effectively manage his professional life and mood, the stigma will attach.

Another ethical problem with mandatory disclosure is that even if the candidate is herself consenting to increased scrutiny by running for office, it is not

431. John Balint, *Issues of Privacy and Confidentiality in the New Genetics*, 9 ALB. L.J. SCI. & TECH. 27, 29 (1998); Nancy Kreiger et al., *A Qualitative Study of Subject Recruitment for Familial Cancer Research*, 11 ANNALS EPIDEMIOLOGY 219, 219 (2001).

432. See e.g., Janene Holzberg, *Genetic Counselor Shows Patients the Options; Neighbors*, BALT. SUN, Dec. 21, 2007, at 3G.

433. *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 344–45 (1974).

434. The American Society for Clinical Oncology (ASCO) believes that obligations to at-risk family members are best fulfilled by communicating the familial risk to the person who is being tested, where the provider will stress the importance of sharing this information with family members so that they too can benefit. Am. Soc'y of Clinical Oncology, *American Society of Clinical Oncology Policy Statement Update: Genetic Testing for Cancer Susceptibility*, 21 J. CLINICAL ONCOLOGY 2397, 2403 (2003).

clear that we want to expose the candidates to *every possible type* of scrutiny. There might be some types of information that are so private and so personal that we might even want to protect the most public people from being forced to disclose them.⁴³⁵ As a society, we must ask ourselves whether we want to discourage reasonable people from running for office because we make disclosure so unwieldy and intrusive. In a democratic society that supports free speech, we cannot control the tabloid-type obsession with silly details about public figures' lives. But we do not have to encourage it with statutes mandating disclosure. In fact, we might want to consider the long-term effects of focusing on what might be considered peripheral information about candidates.

A theoretical problem with disclosure is that the list of diseases or disorders for which testing is mandated will inevitably be both over and under-inclusive. Due to the universe of possible neurological or cardiac diseases that could debilitate the President's decision-making capacity, it would be impossible to tailor a subset of genetic tests that captures everything without including some that are less relevant. There would necessarily be a point of diminishing returns, where each additional genetic test would add little probabilistic value of detecting significant health risk. To the extent the list is under-inclusive, disclosure at the candidacy stage may reduce vigilance in monitoring presidential health as it may be perceived that anything relevant would have been captured by the pre-presidential screening.

Another ethical hurdle exists due to the poorly regulated market for commercial genetic tests. If a genetic test is administered as part of a package of clinical services, the clinical laboratory performing the test is subject to the Clinical Laboratory Improvement Act, (CLIA) which imposes basic requirements regarding personnel qualifications, quality-control standards, and documentation and validation of testing procedures.⁴³⁶ Since the Centers for Medicare and Medicaid Services (CMS) "has not created a genetic testing 'specialty' for molecular and biological tests. . . specific proficiency testing for genetic tests is not mandated under CLIA."⁴³⁷ Genetic tests performed using a kit of purchased reagents and protocols are regulated by the FDA as in vitro diagnostic devices, much like the kits used to diagnose HIV.⁴³⁸ However, of the roughly one thousand commercially available genetic tests, less than a dozen are sold as kits and have been reviewed by

435. *See* *Time, Inc. v. Hill*, 385 U.S. 374, 383 n.7 (1967).

436. Pub. L. No. 90-174, § 5, 81 Stat. 533, 536-39 (1967), *amended by* Clinical Laboratory Improvement Amendments of 1988, Pub. L. No. 100-578, 102 Stat. 2903 (codified at 42 U.S.C. § 236a (2000)). CLIA is enforced by the Centers for Medicare and Medicaid Services (CMS). Ctrs. for Medicare & Medicaid Servs., Clinical Laboratory Improvement Amendments (CLIA): Overview (Nov. 8, 2007), <http://www.cms.hhs.gov/clia/>.

437. Gail H. Javitt & Kathy Hudson, *Federal Neglect: Regulation of Genetic Testing*, ISSUES SCI. & TECH., Spring 2006, at 59-61.

438. Audrey Huang, Genetics & Pub. Policy Ctr., Who Regulates Genetic Tests? (Sept. 27, 2007), http://www.dnapolicy.org/images/issuebriefpdfs/Who_Regulates_Genetic_Tests_Issue_Brief.pdf.

the FDA.⁴³⁹ This means that the FDA does not regulate the overwhelming majority of genetic tests. Labs that assemble their tests in-house are subject to minimal CLIA oversight, and CMS cannot conduct pre- or post-market surveillance of the analytic validity or utility of these tests.⁴⁴⁰ The FDA has stated publicly that it lacks statutory authority to regulate in-house assembled genetic tests.⁴⁴¹ Presumably the problems with lack of clinical laboratory quality controls could be mitigated when it is a public figure receiving the test as part of a Congressional mandate; however, it is worth highlighting the lack of uniformity in laboratory and test regulation as another compounding factor in test reliability. Lack of FDA standards or oversight further compromises the clinical and analytical validity of the test. It intensifies the potential of confusing consumers and leading them to believe that the test is a more accurate predictor of disease than it is.

In order to mandate some type of health disclosure, such a scheme would need to overcome challenges under state laws, federal statutes, and the Constitution. As we saw from the discussion above, there are many safeguards that protect an individual's health information from being disclosed, including the physician-patient privilege, HIPAA, tort law, GINA, and the Fourth Amendment. However, if disclosures were legally mandated, we would eliminate the problems with unauthorized disclosure of protected health information under HIPAA, as there is a carve-out for disclosures as required by law.⁴⁴² A careful look at each of the employee categories covered by GINA and the other existing non-discrimination statutes reveal that public officials such as the President are not currently defined to be protected "employees." Federal agency employees, the military, and public employees in group insurance plans are statutorily protected, but not presidential candidates or presidents themselves.⁴⁴³ The remaining constraints on disclosure hinge on whether the presidential candidate's health information is considered a matter of public interest. If it is, then it is likely there will be no successful tort of invasion of privacy, as the precedent holds that private information may be publicly disclosed about public figures when it is newsworthy, i.e., in the public interest.⁴⁴⁴ The physician-patient privilege is not inviolate.⁴⁴⁵

439. *Id.*

440. Javitt & Hudson, *supra* note 437, at 61.

441. *Id.*

442. 45 C.F.R. § 164.512(a) (2007).

443. *See supra* Part II.A.

444. *See Smith v. Daily Mail Publ'g Co.*, 443 U.S. 97, 103 (1979) ("[I]f a newspaper lawfully obtains truthful information about a matter of public significance then state officials may not punish the publication of the information, absent a need to further a state interest of the highest order."); *Florida Star v. B.J.F.*, 491 U.S. 524, 533 (1989) (adopting the standard from *Daily Mail*).

445. *See Mohr*, *supra* note 59, at 789 ("I choose to believe that physicians must maintain confidentiality within the context of the doctor-patient relationship unless a *compelling* legal or ethical reason exists to release information without a patient's consent in the interest of the public welfare. Any

Physicians have in fact been obligated to breach their patient's privilege if it was squarely in the public interest⁴⁴⁶ (and it might be possible to tailor the disclosure in a way so that a physician is not complicit and the information comes only from the candidate herself). The balancing test under the Fourth Amendment depends greatly on the degree to which the search is considered part of the public interest.⁴⁴⁷ If the government's purpose in the search greatly advances the public interest or national security, it is much more likely to be upheld. Thus, everything depends on just how much the public interest is served by knowing more about the President's health, and specifically his genetic information. To know whether disclosure of the genetic information would be in the public interest, we need to look more deeply at what type of genetic information is being shared.

E. Which Types of Genetic Information May Be Appropriate for Mandatory Public Disclosure?

So how then might we decide which battery of genetic tests would be appropriate to employ in any mandatory presidential health test? Some of the options are: (i) tests for linkages at certain loci associated with behavioral traits; (ii) genome sequencing; (iii) high-density SNP testing; (iv) SNP genotype testing for a defined group of cognitive diseases such as Alzheimer's, Parkinson's or dementia; or (v) genotype testing for only those diseases with strong genotype-phenotype correlations. This section will analyze each of these in turn.

Behavioral genetics traits may be the most interesting to potential voters, but they are also the most difficult to test. Even whole genome sequencing cannot diagnose or even predict any increased risk for expressing these behaviors,⁴⁴⁸ as we have only scraped the surface in identifying some of the genes associated with complex behavioral traits. Perhaps one day we will have batteries of genetics tests for behaviors such as autism or alcoholism, but for now behavioral genetics still operates largely in a world of loose associations in large populations. What is more, we have a much better predictor of a presidential candidate's behavioral traits, that is, his demonstrated behavior. Put differently, why rely on a grouping of genotypes that indicate greater likelihood for risk-taking when voters can ostensibly assess the candidate's risk-taking behavior directly by reviewing his record? If this is the case, the public simply needs more vigilant media scrutiny on information that matters, namely the candidate's health and health behavior.

The next option is whole-genome sequencing. As was discussed above, Venter's genome report tells us some interesting things, but not all of it is currently

such release of medical information in the public interest must only be done through properly established channels . . .").

446. *E.g.*, *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 346–47 (Cal. 1976) (en banc).

447. *See supra* notes 113–40 and accompanying text.

448. *See supra* notes 297–301 and accompanying text.

relevant to his health, and much of it is useless in his clinical care.⁴⁴⁹ We learn from his genomic sequence that his parents were not closely related.⁴⁵⁰ He has the short form of the DRD4 III Exon SNP,⁴⁵¹ which indicates he is less likely to be novelty seeking,⁴⁵² but he also has the C/C genotype on the DRD4 gene,⁴⁵³ which conversely indicates the “highest novelty seeking scores.”⁴⁵⁴ How do we interpret this apparent contradiction? While it seems that this information may be interesting to some voters, the roughly \$1 million price of the genome sequence combined with the two months of full laboratory support that it would take to create each profile makes this impractical.⁴⁵⁵ The public and Congress are not likely to endorse this method in order to find out information such as whether Rudy Guliani’s parents were closely related or that John McCain is genetically predisposed to be a night owl. While the information that whole genome sequencing could provide would no doubt satisfy some morbid curiosity, it is not of great public value when weighed against its cost. This is especially true given that most clinically and publicly relevant data found through high-density SNP testing could specifically be tested, such as appearance of the ApoE e4 allele as a predictor of elevated risk of Alzheimer’s disease.⁴⁵⁶

As 23andMe and Navigenics, Inc. now provide the second option of high-density SNP testing for under \$1000 per pop,⁴⁵⁷ it might be more cost-justified to test presidential candidates for this information. While the online commercial providers claim that their information is currently meant for novelty purposes,⁴⁵⁸ in the hands of a skilled geneticist some predictions could be made about risk of certain types of cancer, diabetes or Alzheimer’s disease. Not all of the information that is provided would be in the public interest, and so some winnowing down of the 600,000 SNPs provided would perhaps be necessary in advance of any public

449. See *supra* notes 284–87 and accompanying text.

450. See Levy et al., *supra* note 284, at 2115, 2118 (“[W]e identified heterozygous alleles within the HuRef sequence. This variation represents differences in the maternal and paternal chromosomes.”).

451. *Id.* at 2134 tbl.13.

452. *Id.*

453. *Id.*

454. *Id.*

455. Press Release, 454 Life Scis., *supra* note 287.

456. Ertekin-Taner, *supra* note 24, at 628 (demonstrating that longitudinal studies have concluded that the presence of ApoE is a predictor of future Alzheimer’s Disease development, but also stating that its use in the clinical setting is not substantiated).

457. Mike Macpherson et al., 23andMe, White Paper 23-01 (Nov. 18, 2007), https://www.23andmeobjects.com/res/2273/pdf/23-02_Incidence_And_Ethnicity.pdf; 23andme.com, Build Your Order, <https://www.23andme.com/store> (last visited Feb. 8, 2008) (showing price of \$999.00 per kit).

458. E.g., 23andMe, About Us: Core Values, <https://www.23andme.com/about/values/> (last visited May 4, 2008) (stating that the company was “founded to empower individuals”); About Navigenics: What Do We Do?, <http://www.navigenics.com/corp/About/> (last visited May 4, 2008) (“[N]avigenics brings genetics out of the lab to help you live a longer, healthier life.”).

disclosure. The reliability of the predictions may not be great, but in some sense there may be value to the public in mere elevated risk, regardless of whether this risk materializes.

Rather than test a veritable sea of SNPs, it might be preferable to determine a subset of diseases that are most relevant to presidential governance, and then test only for those. This could include chromosomal, mtDNA, or smaller groupings of SNP mutations that are associated with such things as cognition or memory. While it would not be a trivial task to get the policymakers to agree on which genotypes should be assayed, it is theoretically possible to narrow the field to those disorders that would significantly impair the individual's decision-making or executive functioning on average. The benefit from this type of genetic test is that there will be less noise from presenting data that is completely unrelated to a president's ability to govern. However, the same caveats apply that were discussed above. Depending on the specific genotype that is being studied, there may not be great statistical data as to likelihood of the disease being expressed and how severe it would be.

In general, the tighter the causal link, the more the public interest is served by possessing the genetic information. Think back to our discussion of Huntington's disease and how the candidate's possession of one copy of a mutant gene would almost always predict development of that neurological disease in some form.⁴⁵⁹ This type of genetic information would better fit in with information in the public interest, as there is no conjecturing about the potential of developing a disease and the information takes on less of a gossip, novelty flare. However, the majority of traits we have discussed herein are not inherited in this way. Only certain diseases can be predicted based on a single mutation or single gene, and yet we would be under-inclusive if we only tested for such disorders. Further, testing only certain diseases based on a single known phenotype with demonstrated single-allele causal genotypes would perhaps be an under-inclusive approach as many of the multifactorial neurological or disabling diseases would not be captured.⁴⁶⁰

Specific determinations as to which tests ought to be employed based on current clinical utility or validity is beyond the scope of this paper and the expertise of its author. However, if genetic testing of candidates is pursued, an expert panel of clinical human geneticists should then provide recommendations to Congress on which tests would be appropriate in any given campaign cycle. Should genetic tests predicting the likelihood of developing dementia, Parkinson's, Alzheimer's or serious cardiovascular disease become reliable and valid, information on the risk of developing these types of diseases would be particularly useful to voters. As was discussed in brief above, there is psychological value in the genetic data that exists apart from any clinical value or diagnosis. It might not have true public import, but

459. Maradiegue & Edwards, *supra* note 319.

460. *See supra* Part II.D.

it might have public value based on old-fashioned curiosity surrounding celebrities. Whether this is a laudable justification will be discussed further below.

1. Even If This Is Legal, Is It Ethical to Fully Disclose, and How Might This Be Done?

Even if we waive the confidentiality of genetic information when speaking of presidential candidates, this does not mean we should waive the rest of the ethical safeguards implemented for private individual tests. There is no public interest served by prohibiting the candidate from accessing other clinically relevant information about the test. Irrespective of the method of disclosure, the candidate should have access to genetic counseling. The candidate should also be provided information about the therapeutic options or lack thereof, the sensitivity and specificity of the test, and the strength of susceptibility predictions. This would typically occur before one can consent to the test, but in a mandatory framework, it should still be part of the testing and disclosure process.

There is quite a gulf between full disclosure and keeping the records entirely private. The appropriateness of the disclosure of course depends on its purpose. A private panel reviewing Watson's or Venter's genome sequence and then discussing the results privately with either scientist would not serve the group's aim of broadening access to comparative genomic data. Similarly, reporting genetic test results only to the presidential candidate does not directly serve the public interest if there is no mechanism by which this information is publicized. There may be some public good in the candidates' knowing what their genetic test results are so that they can minimize whatever environmental factors exacerbate development of genetic disease. Because we have no way of knowing how the candidates will respond to this information, if at all, the public interest component is severely diminished if the information is not publicly shared. The true value in the information comes from voters being able to predict the health of the presidential candidate in some way and to use this to inform their decision-making.

If the point of departure in this section is mandatory genetic testing, at least some information should be communicated to the public in order to justify the test. The question then becomes what would be most useful. One possible option is confidential review of certain genetic tests by a skilled medical panel, which would then provide either a "medically fit" or "medically unfit" assessment based on the candidate's genetic information. Assuming for a second that the panel was approved by Congress, the value of this "fit" for the job stamp of approval would be highly suspect and probably politically very dicey. Sympathizers to anyone who was deemed "medically unfit" could argue that the panel had been hijacked, and questions about the legitimacy of the clandestine and binary decision would no doubt ensue. To counter these questions of legitimacy, surely there should be medical geneticists as well as population geneticists, counselors, neurologists, cardiologists and internists; but how would these people be selected? If they are

appointed by the executive branch for political reasons, then speaking practically, there might as well not be mandated public disclosure. Some sort of bipartisan committee might meet the goals of fair and standardized disclosure, where each party selects four members from particular medical disciplines, and then the Director of the Institute of Medicine or some other respected CMS or NIH representative could break the tie.⁴⁶¹ The candidate's personal primary care physician could serve in a consultative role, but probably should not draft or comment on the final statement that would be issued. The details of such a committee's composition are subject to additional research and review, and will not be investigated in depth here. Suffice it to say that some type of confidential reviewing panel is one option.

There could also be a tiered disclosure option to promote the autonomy of the candidates while at the same time screening them for relevant health risks. This approach has been suggested in the context of revealing genetic test results to participants in research protocols, but could be applied to this situation as well, as the data would not be primarily used for the individual's clinical care.⁴⁶² Here, the presidential candidate could choose what type of information he would want to have personally communicated to him, and the other information would be destroyed once the testing took place. The candidate could then be required to comment on the information that was disclosed to him in a public setting, choosing whatever means of communication he so chooses, but with the understanding that if he contradicts what an independent panel finds, that they could go public with the contradiction. While this option favors the autonomy of the President, it is practically not that useful. If the candidates can choose what information they want to know, and this will become the universe that can be commented upon in the public media, then the candidates will just choose to know nothing or very little about their genetic test results.

Another option is review by a confidential, bipartisan medical panel as loosely described above, which would publish a health report rather than a mere statement that the candidate is either medically fit or not fit for the job. This report would outline any significant present health issues, as well as highlight any significant potential future health risks based upon the candidate's genetic data. It would not be detailed, and would consist only of "comments" in each of the selected medical disciplines. With the exception of the President's personal physician, it seems that the same panel should oversee each of the candidates, for consistency and fairness. Of course, what would be considered significant is a

461. Some variations on this type of review panel have been suggested elsewhere. For example, Dr. Bert Park contemplates a medical panel to review the health of the President generally. Bert E. Park, *Presidential Disability: Past Experiences and Future Implications*, 7 POL. & LIFE SCI. 50, 57 (1988); accord Abrams, *supra* note 410, at 464–65.

462. Mark A. Rothstein, *Tiered Disclosure Options Promote the Autonomy and Well-Being of Research Subjects*, 6 AM. J. BIOETHICS 20–21 (2006).

pivotal question, and would no doubt be roundly debated. There are many possibilities to get the debate going as to what may register as “significant.” One definition could include anything that the panel thinks could reasonably and foreseeably lead to an event that could give rise to a Twenty-Fifth Amendment transfer of power. However, we have seen that presidents differ in terms of what would trigger a Twenty-Fifth Amendment event.⁴⁶³ Another possible definition could have a temporal prognosis attached, and include any information that indicates an increased likelihood that the candidate may develop a physical or mental disability in the next four years that would negatively affect his day-to-day executive functioning, decision-making, or general ability to govern. These are only two of many potential definitions.

Another option would be for the specific genetic mutations that the candidates possess to be disclosed, along with statistical data about how likely it would be for the candidate to develop the phenotype for the disease. Embedded within this option could be the idea that only those tests that are clinically and analytically valid and yield useful data about risk susceptibility would be administered. It is not necessary that the test have any clinical utility, in that we are not exclusively concerned here with whether interventions or therapies exist; this is where the role of patient and president are quite divorced. If the test is not clinically valid, or if there is insufficient replicated data to support the susceptibility prediction, then the genetic information should not be disclosed. The problem with this method is that as the presidential candidates approach celebrity status, anything associated with them can become an advertisement or endorsement for use. A candidate’s genetic test may serve somehow to encourage inappropriate consumer genetic tests. It would not be irrational for private individuals to confuse the purpose of the candidate’s test (information dissemination of comparative risks) with the potential for clinical benefit. The reasons for testing the candidate would not be wholly to intervene or improve her care. The chief reason may be to share the genetic data in the hopes that this may inform voters’ decisions. This is quite distinct from any clinical goals, and yet as the candidate’s genetic test may operate as an advertisement, the public may inflate the value of genetic testing for clinical care. The public nature of the test may also lead to perpetuation of deterministic thinking about the relationship between genes and disease. Lastly, disclosing the candidate’s genetic information may reinforce associations between diseases and specific ethnic groups, and may increase stigma if certain polymorphisms are considered too deleterious or risky for public life.⁴⁶⁴

Theoretically, another option would be to post the candidates’ SNPs or sequence data on a website without any accompanying statistical or descriptive

463. *See supra* notes 412–30 and accompanying text.

464. Sarah E. Gollust et al., *Limitations of Direct-to-Consumer Advertising for Clinical Genetic Testing*, 288 JAMA 1762, 1764 (2002).

information. However, this will not help if the goal is to provide voters with information that will assist them in their decision-making. Merely posting data about an individual's genetic polymorphisms or sequence absent any idea of how this mutation increases risk would be virtually meaningless. It would be like handing sheet music to someone who does not play an instrument, and then telling them to transpose the notes to a different key. Genetic information in a vacuum will likely only confuse the voter, as he will not be able to interpret what the mutations mean. Is this mutation the only way to develop the disorder, or is it even the most common way? Does the SNP interact with other mutations? Is it highly penetrant? Does this mutation only increase the risk by a small percentage? What kind of environmental influences increase the risk of developing the phenotype? Without these kinds of answers, the information is practically useless.

IV. CONCLUSION

The legal principles that protect the privacy of individuals generally, and those that relate to genetic information specifically, could be applied in new but not doctrinally inconsistent ways to allow for the mandatory testing of public figures such as presidential candidates. The physician-patient privilege would not be an absolute bar, as the testing could occur outside of a clinical setting.⁴⁶⁵ Even if a personal physician conducted the blood draw, a strong public interest (and prevention of harm) argument could *perhaps* militate disclosure. HIPAA does not preclude disclosure, as a Congressional requirement that candidates be tested prior to receiving FEC public funding may provide the legal exception that HIPAA permits.⁴⁶⁶ The larger obstacles are the Fourth Amendment arguments and privacy causes of action. Here, the key question is how well the public interest would be served by the mandatory testing. According to the *Chandler* precedent and the voluminous case law on the privacy of public figures, this inquiry rests on balancing individual privacy interests with the public interest arguments in favor of disclosure.⁴⁶⁷ In theory, we make this determination based on the political candidates having reduced expectations of privacy.

It may be possible to test presidential candidates by conditioning their receiving public funding on whether they undergo genetic tests for disorders that would affect their governance or decision-making. Of course, there may be other constitutional incentive structures that could work, but the point here is this *could* happen legally so long as the public interest weighs mightier than the intrusion into

465. 23andme, *supra* note 278 (describing how one only need spit in a tube, mail it in, and obtain the results with no physician involvement).

466. 45 C.F.R. § 164.512(a) (2007).

467. *Chandler v. Miller*, 520 U.S. 305, 313–14 (1997); *see also supra* notes 126–40 and accompanying text.

the presidential candidate's privacy.⁴⁶⁸ We now must ask, assuming that courts recognize a sweeping public interest in knowing the presidential candidates' genetic information, whether mandatory genetic testing and disclosure is a good thing.

A. The Public Interest Is More Than What the Public Is Interested In

As genetic testing currently stands, the public interest would *not* be sufficiently served by intrusion into the presidential candidate's privacy. This is true for all types of genetic tests, and has been hinted at throughout the article. It becomes clear once we thoroughly investigate the global risks and benefits of such a mandatory testing program that much personal damage could be caused to the candidate and her family, with very little countervailing informational benefit to voters. Thus, genetic testing and mandated disclosure is not warranted in the public interest *at this time*. This conclusion rests on four factors.

First, the genetic tests that currently exist are poor predictors of most health outcomes. With the exception of a relatively small number of diseases like Huntington's disease, genetic tests are not reliable and valid predictors of the onset of most disorders.⁴⁶⁹ Further, the genetic information that would be most relevant to a presidential candidate's governance is largely behavioral, and behavioral genetics has produced no clinically valid tests for the complex traits.⁴⁷⁰ Although there may be psychological value in merely knowing a candidate possesses some elevated risk for developing a disease, this information is not justified by the intrusion into the candidate's privacy and the airtime it would take away from more pressing substantive concerns. Genetic tests with low clinical validity could be used as a distraction from meaningful policy distinctions and measures.

Second, because many of the tests are poor predictors of clinical outcomes, and most tests exist purely in research stages, broadly testing the candidates and then publicly disclosing the results misleads the public about the present value of genetic testing for individuals who are not at risk.⁴⁷¹ This confers more scientific and clinical legitimacy on the data than it currently deserves. It may encourage private citizens to canvass their genomes without understanding the clinical relevance of the results, or it may implicitly perpetuate deterministic thinking about genetics, as no comparable information on the candidates' environments could be simultaneously shared.

Third, the families of political candidates have not agreed to have their genetic information tested or disclosed.⁴⁷² Even if it remains unknown whether the

468. See *supra* Parts II.A.1-4.

469. See *supra* notes 290-313 and accompanying text.

470. See *supra* Part II. C.5.

471. See *supra* Part II.D.

472. See *supra* Part III.D.

relative possesses a certain genotype, once the results are public, the informational burden may be on the relative to prove that she is not “affected.” The public interest justification underlying disclosure of a candidate’s health information does not hold for a private individual, as we are not voting on the executive functioning of the President’s children.

Finally, what we see when we embark on this inquiry into specific types of health information is that we really need to clarify the Twenty-Fifth Amendment mechanisms for the transfer of power, rather than inundate voters with quasi-useful information about the candidates.⁴⁷³ In the absence of a predictable method for transferring power from the President when he becomes unable to discharge his duties, much more health information should be made available to voters. However, it would be better to work within our existing Constitutional construct and elucidate what we mean by “unable to discharge the powers and duties of his office” under the Twenty-Fifth Amendment. Put differently, it might be useful to test presidential candidates for Huntington’s disease as the genetic test is highly predictive and the disease impairs decision-making and planning (two functions critical to the leader of the free world). However, if we had a better method for detecting and tracking the development of the disease once the successful candidate enters the White House, then the value of the genetic test results wanes dramatically. It seems both less ethical and efficient to discourage someone from becoming president based on increased probability of developing a disease. However, voters then need to be assured that once that disease materializes, the media, his cabinet, and the Vice President will scrutinize the President’s health, and the Twenty-Fifth Amendment will be invoked if appropriate. Under the current framework, this expectation is unrealistic. Unless the media takes on a much more aggressive role inquiring into the President’s health, any resulting disease that *could* be kept from the public *will* be kept from the public.

B. A Possible Double Standard Developing in Public Officials’ Privacy Rights

In practice, and by design, we see that the privacy of public figures should be greatly reduced.⁴⁷⁴ However, for reasons that are not superficially obvious, candidates for high public office have been granted greater privacy rights than many private figures when it comes to mandatory testing of their biological samples.⁴⁷⁵ Privileging their privacy in this way is particularly egregious given that private people have not been endowed with countervailing protections when it comes to genetic testing.

473. See *supra* Parts III.B–D.

474. *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 344–45 (1974).

475. See *supra* notes 141–51 and accompanying text.

The DNA Fingerprint Act, effective July 27, 2006, allows the Attorney General to collect DNA samples from individuals who are neither charged nor convicted of any felony.⁴⁷⁶ While one may support the creation of a database to identify future suspects from past offenders, it is a huge invasion of privacy rights to include those who were merely *arrested* in this registry, as the Federal DNA Act and some states have done.⁴⁷⁷ In California, individuals who are arrested on mistaken information and later completely cleared could still have their genetic information warehoused.⁴⁷⁸ This promotes indiscriminate detentions because police can use a database match even when the initial arrest is invalid.⁴⁷⁹ The statutes that require arrestees to provide genetic samples are not clear as to what sort of behavioral genetics research could be conducted on the samples that were obtained purely for identification purposes.⁴⁸⁰ Further, police can conduct “DNA dragnets” to take DNA samples from dozens to hundreds of persons who are not suspects, but who are guilty only of living or working near a crime scene.⁴⁸¹

This data on the mandatory DNA testing of innocent civilians is provided to demonstrate (i) the shifting of our Fourth Amendment privacy rights doctrine away from its roots, and (ii) the potential implications this has for searches of private

476. Pub. L. No. 109-162, § 1004, 119 Stat. 3084, 3085 (2006) (codified as amended at 42 U.S.C.A § 14135a(d)(1) (Supp. 2007)).

477. With little public comment, President George W. Bush signed comparable federal legislation into law. Pub. L. No. 109-162, §§ 1001–05, 119 Stat. 3084, 3084–86 (2006) (codified as amended in scattered sections of 42 U.S.C.); TANIA SIMONCELLI & SHELDON KRIMSKY, AM. CONSTITUTION SOC’Y, A NEW ERA OF DNA COLLECTIONS: AT WHAT COST TO CIVIL LIBERTIES I (2007). DNAresource.com maintains a database of state statutes and the conditions under which samples may be collected. DNAresource.com, State DNA Database Laws: Qualifying Offenses, <http://www.dnaresource.com/documents/statequalifyingoffenses2008.pdf>.

478. Robert Berlet, Comment, *A Step Too Far: Due Process and DNA Collection in California After Proposition 69*, 40 U.C. DAVIS L. REV. 1481, 1487 (2007) (“Louisiana and California refuse to overturn a conviction based on DNA obtained by mistake. California is the only state that specifies that failure to follow its DNA database act does not invalidate a database match.”).

479. *Id.* at 1510–11.

480. *E.g.*, KAN. STAT. ANN. § 21-2511 (Supp. 2006) (“[A]ny person convicted as an adult or adjudicated as a juvenile offender because of the commission of an unlawful sexual act . . . shall be required to submit specimens of blood or an oral or other biological sample authorized by the Kansas bureau of investigation to the Kansas bureau of investigation in accordance with the provisions of this act.”).

481. “[D]ragnets are conducted on a supposedly voluntary basis; but since refusing to consent raises suspicion, there is little an individual can do to avoid having their DNA sampled.” Aaron B. Chapin, *Arresting DNA: Privacy Expectations of Free Citizens Versus Post-Convicted Persons and the Unconstitutionality of DNA Dragnets*, 89 MINN. L. REV. 1842, 1846 (2005); see also Matejik, *supra* note 123, at 62 (“DNA Dragnets, also known as DNA sweeps, occur when police officers ask citizens to voluntarily submit DNA samples for the purpose of eliminating suspects in an unsolved case. . . . Described by critics as ‘warrantless searches administered en masse to large numbers of persons whose only known connection with a given crime is that authorities suspect that a particular class of individuals may have had the opportunity to commit it,’ the use of DNA Dragnets is largely unregulated by the legislature” (citation omitted)).

people's DNA in criminal as well as non-legal contexts.⁴⁸² The Fourth Amendment "special needs" doctrine began as a narrow exception to the rule that searches by the government should *not* be conducted without individualized suspicion and a warrant predicated on probable cause.⁴⁸³ The expansion of this doctrine permits warrantless searches of New York subway riders, low-level state employees, probationers, and unlucky folks who live near crime scenes.⁴⁸⁴

Despite being the most influential leader in the United States with power to send troops to war and veto spending on important social programs, we somehow do not see our president or the presidential candidates as being as "public" in this regard as a sixteen year old who plays basketball on his local high school team. While some may argue that national security concerns often require increased government surveillance over greater populations, the way that the doctrine has been articulated over time has created perverse incentives. The less tied to law enforcement the search, the more likely it is it will satisfy the "special needs" loophole, meaning that individualized suspicion is not necessary.⁴⁸⁵

About a decade after the Supreme Court protected the privacy rights of public gubernatorial candidates in opposition to Georgia's interest in making sure its leaders were not high on drugs,⁴⁸⁶ the Patriot Act massively reduced the privacy rights of private civilians by allowing applications to the Foreign Intelligence Surveillance Court ("FISC") for warrantless eavesdropping orders.⁴⁸⁷ Unlike law enforcement agents who utilize grand jury subpoenas and judicially approved search warrants, counterintelligence officials issue "National Security Letters" and obtain "surveillance orders for searches and wiretaps from the secretive [FISC]."⁴⁸⁸ As one legal commentator put it, "[t]he notion seems to be that there can be no 'unreasonable search or seizure' when conducted in the name of national security. . . . [and] if this is so, the Fourth Amendment is hardly much of a protection of

482. *Vernonia Sch. Dist. v. Acton*, 515 U.S. 646, 669–76 (1995) (O'Connor, J., dissenting) (discussing a brief of the history of the Fourth Amendment); see *supra* notes 141–65 and accompanying text.

483. *Acton*, 515 U.S. at 669–76.

484. See *supra* notes 141–46 and accompanying text.

485. See *supra* note 125 and accompanying text.

486. *Chandler v. Miller*, 520 U.S. 305, 309 (1996).

487. Pub. L. No. 107-56, § 218, 115 Stat. 272, 291 (2001) (codified as amended at 50 U.S.C.A. §§ 1804(a)(7)(B), 1823(a)(7)(B) (2007)) (allowing applications to the FISC for eavesdropping orders where foreign intelligence was "a significant purpose" of the surveillance). The court in *In re Sealed Case*, 310 F.3d 717, 735 (Foreign Int. Surv. Ct. Rev. 2002), ruled that the primary purpose could be a criminal investigation, as "the Patriot Act amendment, by using the word 'significant,' eliminated any justification for the FISA court to balance the relative weight the government places on criminal prosecution as compared to other counterintelligence responses."

488. Michael German, *Trying Enemy Combatants in Civilian Courts*, 75 GEO. WASH. L. REV. 1421, 1431 (2007). Instead, the surveillance orders come from the secretive FISC. *Id.*

privacy.”⁴⁸⁹ It is an anathema to the privacy doctrine that protects public officials from disclosure of private facts, while more and more private civilians are exposed to warrantless searches and seizures. The information and privacy asymmetry appears to be growing in many ways.⁴⁹⁰ While it is clear that we should not stand in the way of legitimate national security concerns, we need to be vigilant in working to close the privacy asymmetry as it relates to good faith surveillance of our presidents’ decisions and decision-making capacity.

As genetic testing currently stands, access to a candidate’s complete genetic results will not close this widening gap. What we need is better scrutiny by the press of candidates’ health generally and predictable guidance as to how the Twenty-Fifth Amendment operates. However, this begs the question of whether clinically valid information about a presidential candidate’s neurological or cardiac health may be appropriately disclosed in the public interest. This is something that should be addressed in further detail elsewhere. What can be said at this point is that genetic information would only serve as a petty distraction from the broader goal of empowering voters with relevant information about the person they are electing to office. As the clinical validity of genetic information improves, we should revisit the potential of genetic testing of political candidates as part of a larger mandated health screen. Without better public surveillance or mandated health disclosures, presidents will continue to cover up disorders that may significantly impair their leadership ability.

489. Stephen A. Saltzburg, *A Different War: Ten Key Questions About the War on Terror*, 75 GEO. WASH. L. REV. 1021, 1041 (2007). The questionable protection of the Fourth Amendment is especially true following the Patriot Act’s blurring of the line between intelligence gathering and law enforcement. *Id.*

490. This year the National Intelligence Director Mike McConnell confirmed for the first time that telephone and internet companies lent a hand to President Bush’s warrantless surveillance program. See Bruce E.H. Johnson & Sarah K. Duran, *Recent Developments in Commercial Speech and Consumer Privacy Interests*, 918 PLI/PAT 499, 505 (2007).