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NARRATIVE GENOMICS: CREATING A STAGE FOR INQUIRY AND BIOETHICS EDUCATION

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I. SETTING THE BIOETHICS STAGE

Many bioethical challenges surround the promise of genomic technology and the power of genomic information,[1] providing a rich context for critically exploring underlying bioethical traditions and foundations as well as the practice of multidisciplinary advisory committees. Karen and I long appreciated, independently and together, that the teaching of contemporary bioethics with creative approaches provides a significant opportunity to re-examine our disciplines' underpinnings while addressing thorny issues by casting light on the implications of genomics. Of particular interest to Karen, and me, are

* Division of Genetics and Genomics, Boston Children's Hospital; Center for Bioethics, Harvard Medical School. I would like to thank Sue McCarty of the Thurgood Marshall Law Library at Maryland Carey Law for her expertise and patience in helping to format the references included in this piece. All of the material in this article was inspired by my collaboration with Karen, who so generously shared her scholarship, insights, and friendship with me this past decade. Segments from this article were paraphrased from my 2014 OUP Blog, *Illuminating the Drama of DNA: Creating a Stage for Inquiry*, https://blog.oup.com/2014/10/drama-dna-genomics-instruction/; or our book, *The Drama of DNA: Narrative Genomics*.

1. Eric D. Green & Marl S. Guyer, Nat'l Human Genome Research Inst., *Charting a Course for Genomic Medicine from Base Pairs to Bedside*, 470 NATURE 204 (2011); PRESIDENTIAL COMMISSION FOR THE STUDY OF BIOETHICAL ISSUES, PRIVACY AND PROGRESS IN WHOLE GENOME SEQUENCING (2012), https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/PrivacyProgress508_1.pdf; PRESIDENTIAL COMMISSION FOR THE STUDY OF BIOETHICAL ISSUES, ANTICIPATE AND COMMUNICATE: ETHICAL MANAGEMENT OF INCIDENTAL AND SECONDARY FINDINGS IN THE CLINICAL, RESEARCH, AND DIRECT-TO-CONSUMER CONTEXTS (2013), https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/FINALAnticipateCommunicate_PCSBI_0.pdf; Robert C. Green et al., *Exploring Concordance and Discordance for Return of Incidental Findings from Clinical Sequencing*, 14 GENETICS MED. 405 (2012); Lynn W. Bush et al., *Professional Responsibilities Regarding the Provision, Publication, and Dissemination of Patient Phenotypes in the Context of Clinical Genetic and Genomic Testing: Points to Consider—A Statement of the American College of Genetics and Genomics*, 20 GENETICS MED. 169 (2018); Karen L. David et al., *Patient Re-Contact After Revision of Genomic Test Results: Points to Consider—A Statement of the American College of Genetics and Genomics*, 21 GENETICS MED. 769 (2019).

controversial issues that call into question core values and assumptions inherent in bioethics analysis and necessitate interprofessional inquiry[2]—such as determining whether, what, to whom, when, and how genomic findings ought to be discovered and disclosed to individuals and their families,[3] and whose voice matters in making these determinations, especially when children or pregnant women are involved.[4]

Soon after we met a decade ago, Karen and I became a team, in scholarship and friendship, and developed *narrative genomics*.[5] Using drama with fictionalized characters and dialogue as an engaging pedagogical approach, *narrative genomics* brings to life the diverse voices, varied contexts, and complex processes that encompass genomics as it evolves from research to clinical practice.[6] Our interdisciplinary educational technique focuses on inherent challenges currently posed by the comprehensive interrogation and analysis of DNA and illuminates ethical, legal, social, psychological, and policy issues[7], providing a stage to reflect on the controversies together.

As a bioethics teaching method,[8] *narrative genomics* highlights the breadth of individuals affected by next-gen technologies—the conversations among professionals and families—bringing to life the spectrum of emotions and

2. James P. Evans, *Finding Common Ground*, 15 GENETICS MED. 852 (2013); Robert C. Green et al., *ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing*, 15 GENETICS MED. 565 (2013); American College of Medical Genetics and Genomics, *Incidental Findings in Clinical Genomics: A Clarification*, 15 GENETICS MED. 664 (2013).

3. Amy L. McGuire et al., *Point-Counterpoint: Ethics and Genomic Incidental Findings*, 340 SCIENCE 1047 (2013); Susan M. Wolf et al., *Point-Counterpoint: Patient Autonomy and Incidental Findings in Clinical Genomics*, 340 SCIENCE 1049 (2013); Catherine Gliwa & Benjamin E. Berkman, *Do Researchers Have an Obligation to Actively Look for Genetic Incidental Findings?*, AM. J. BIOETHICS, Feb. 2013, at 32; Gail E. Henderson et al., *What Research Ethics Should Learn from Genomics and Society Research: Lessons from the ELSI Congress of 2011*, 40 J.L. MED. &ETHICS 1008 (2012).

4. Lynn Bush, *In the Best Interest of the Child: Psychological and Ethical Reflections on Traditions, Contexts, and Perspectives in Pediatric Clinical Genomics*, AM. J. BIOETHICS, Mar. 2014, at 16; James P. Evans, *Return of Results to the Families of Children in Genomic Sequencing: Tallying Risks and Benefits*, 15 GENETICS MED. 435 (2013); Ellen Wright Clayton et al., *Addressing the Ethical Challenges in Genetic Testing and Sequencing of Children*, AM. J. BIOETHICS, Mar. 2014, at 3; Christine C. Grady & Colleen C. Denny, *Ethical Issues in Research Involving Women*, *in* THE OXFORD TEXTBOOK OF CLINICAL RESEARCH ETHICS 407 (Ezekiel J. Emanuel et al. eds., 2008).

5. KAREN H. ROTHENBERG & LYNN WEIN BUSH, THE DRAMA OF DNA: NARRATIVE GENOMICS (2014).

6. Eric D. Green, *Foreword*, *in* ROTHENBERG & BUSH, *supra* note 5; Teri A. Manolio et al., *Implementing Genomic Medicine in the Clinic: The Future Is Here*, 15 GENETICS MED. 258 (2013); Laura L. Rodriguez et al., *Research Ethics: The Complexities of Genomic Identifiability*, 339 SCIENCE 275 (2013).

7. Karen H. Rothenberg & Lynn W. Bush, *Genes and Plays: Bringing ELSI Issues to Life*, 14 GENETICS MED. 274 (2012); Lynn W. Bush & Karen H. Rothenberg, *Dialogues, Dilemmas, and Disclosures: Genomic Research and Incidental Findings*, 14 GENETICS MED. 293 (2012).

8. METHODS IN MEDICAL ETHICS (Jeremy Sugarman & Daniel P. Sulmasy eds., 2d ed. 2010); Jules Odendahl-James, Book Review, AM. J. BIOETHICS, Dec. 2016, at W17 (reviewing ROTHENBERG & BUSH, *supra* note 5).

challenges that envelope genomics. Controversies over sequencing in children[9] and consent issues[10] have brought fundamental ethical theses to the stage to be re-examined,[11] further fueling our belief in drama as an interdisciplinary pedagogical approach to explore how society evaluates, processes, and shares genomic information that may implicate future generations. With a mutual interest in enhancing dialogue and understanding about multi-faceted implications raised by generating and sharing genomic information, and with our diverse backgrounds and perspectives, we have been collaboratively weaving dramatic narratives to enhance the bioethics educational experience within varied professional contexts and academic levels.[12]

Dramatizations of fictionalized individual, familial, and professional relationships that surround the ethical landscape of genomics create the potential to stimulate bioethical reflection and new perceptions amongst "actors" and the audience, sparking *the moral imagination*[13] through the lens of others. By casting light on all "the storytellers" and the complexity of implications inherent with this powerful technology, our dramatic narratives create vivid scenarios through which to imagine the challenges faced on the genomic path ahead, critique the application of bioethical traditions in context, and re-imagine alternative paradigms.

Building upon the legacy of case vignettes in clinical teaching, and inspired by "readers' theater,"[14] "narrative ethics,"[15] and "narrative medicine"[16] as approaches that helped us expand the analyses to implications of genomic technologies, our experiences suggested similar value for bioethics education within the translational research and public policy domain. While drama had

9. Laine Friedman Ross et al., *Technical Report: Ethical and Policy Issues in Genetic Testing and Screening of Children*, 15 GENETICS MED. 234 (2013); ROTHENBERG & BUSH, *supra* note 5; Green et al., *supra* note 2; American Academy of Pediatrics, Committee on Bioethics, Committee on Genetics, American College of Medical Genetics, *Ethical and Policy Issues in Genetic Testing and Screening of Children*, 131 PEDIATRICS 620 (2013).

10. Lynn W. Bush et al., *Pediatric Clinical Exome/Genome Sequencing and the Engagement Process: Encouraging Active Conversation with the Older Child and Adolescent: Points to Consider—A Statement of the American College of Genetics and Genomics*, 20 GENETICS MED. 692 (2018).

11. Wylie Burke et al., *Recommendations for Returning Genomic Incidental Findings? We Need To Talk!*, 15 GENETICS MED. 854 (2013).

12. A Summary of MOLLY COOKE ET AL., EDUCATING PHYSICIANS: A CALL FOR REFORM OF MEDICAL SCHOOL AND RESIDENCY (2010), http://archive.carnegiefoundation.org/elibrary/educating-physicians-summary.html.

13. R.S. DOWNIE & JANE MACNAUGHTON, BIOETHICS AND THE HUMANITIES: ATTITUDES AND PERCEPTIONS (2007).

14. TODD L. SAVITT, MEDICAL READERS' THEATER: A GUIDE AND SCRIPTS (2002); Nancy King & Richard Robeson, Dramatic Arts Casuistry in Bioethics Education and Outreach (paper presented at ELSI Congress; 2011; Chapel Hill, NC).

15. STORIES MATTER: THE ROLE OF NARRATIVE IN MEDICAL ETHICS (Rita Charon & Martha Montello eds., 2002); Martha Montello ed., *Narrative Ethics: the Role of Stories in Bioethics*, 44 HASTINGS CTR. REP. (Special issue 2014).

16. RITA CHARON NARRATIVE MEDICINE: HONORING THE STORIES OF ILLNESS (2006).

often been utilized in academic and medical settings to facilitate empathy and spotlight ethical and legal controversies such as end-of-life issues, professionalism, and health law,[17] we realized there were few dramatizations focusing on exome/genome sequencing.[18]

We initially collaborated on the creation of a short vignette-play in the context of genomic research and the informed consent process that was performed by colleagues at the NHGRI-ELSI Congress, followed by excerpts selected from existing theatre.[19] The response by "actors" and audience fueled us to present additional original dramatic scenarios as well as expand upon Karen's already significant contributions to the field exploring existing theatrical dialogues, with both methods continuing to engage interdisciplinary professionals at conferences and academic institutions, nationally and internationally.

Since a growing number of colleagues inquired about using our plays in their classrooms, we authored a book based on adaptations of six original and twelve existing plays.[20] Designed to enhance teaching, *The Drama of DNA: Narrative Genomics* was structured to provide an analytical foundation to reinforce the fact that many complex bioethics issues surface repeatedly in varying contexts and can become increasingly more controversial, for example as experienced with ethical-legal debates surrounding the initial ACMG recommendations on the return of incidental findings.[21]

17. Melissa McCullough, *Bringing Drama into Medical Education*, 379 LANCET 512 (2012); Johanna Shapiro & Lynn Hunt, *All the World's a Stage: The Use of Theatrical Performance in Medical Education*, 37 MED. EDUC. 922 (2003); THE PICTURE OF HEALTH: MEDICAL ETHICS AND THE MOVIES (Henry Holt et al. eds., 2011); Matthew J. Czarny et al., *Bioethics and Professionalism in Popular Television Medical Dramas*, 36 J. MED. ETHICS 203 (2010); Karl Lorenz et al., *End-of-Life Education Using the Dramatic Arts: The Wit Educational Initiative*, 79 ACAD. MED. 481 (2004).

18. Lynn W. Bush & Karen H. Rothenberg, *It's So Complicated! Genomic Research & Incidental Findings*, online supplement to Lynn W. Bush & Karen H. Rothenberg, *Dialogues, Dilemmas, and Disclosures: Genomic Research and Incidental Findings*, 14 GENETICS MED. 293 (2012), https://www.nature.com/articles/gim201172#s1 [hereinafter Bush & Rothenberg, *Complicated*]; Lynn W. Bush & Karen H. Rothenberg, *It's Not That Simple! Genomic Research & the Consent Process*, online supplement to Karen H. Rothenberg & Lynn W. Bush, *Genes and Plays: Bringing ELSI Issues to Life*, 14 GENETICS MED. 274 (2012),
https://staticcontent.springer.com/esm/art%3A10.1038%2Fgim.2011.47/MediaObjects/41436_2012_BF gim201147_MOESM1_ESM.pdf [hereinafter Bush & Rothenberg, *Simple*]; MAHALA YATES STRIPLING, BIOETHICS AND MEDICAL ISSUES IN LITERATURE: EXPLORING SOCIAL ISSUES THROUGH LITERATURE (2005); KIRSTEN SHEPHERD-BARR, SCIENCE ON STAGE: FROM DOCTOR FAUSTUS TO COPENHAGEN (2006).

19. Jill M. Oliver & Amy L. McGuire, *Exploring the ELSI Universe: Critical Issues in the Evolution of Human Genomic Research*, 3 GENOME MED. art. no. 38 (2011); Gail E. Henderson et al., *What Research Ethics Should Learn from Genomics and Society Research: Lessons from the ELSI Congress of 2011*, 40 J.L. MED. & ETHICS 1008 (2012).

20. ROTHENBERG & BUSH, *supra* note 5.

21. *See* Evans *supra* note 2; Green et al., *supra* note 2; American College of Medical Genetics and Genomics, *supra* note 2.

Because narrative genomics is a pedagogical approach intended to facilitate discourse as well as provide reflection on the interrelatedness of the cross-disciplinary issues posed, we begin with a content analysis of critical issues, then ground our original dramatic scenarios in current scholarship and consult with experts to ensure scientific accuracy. We also provide extensive references in the book and pose focused bioethics questions to complement and enhance the classroom experience.

Bioethical issues and controversies can also be brought to life when teaching incorporates dramatizations from existing theatre whether to highlight thematically, or illuminate the historical path to the genomics revolution from an ethical, legal, societal perspective as Karen had previously done, including "From Eugenics to the "New Eugenics: The Play's the Thing," and with our broader analysis of 46 plays across three centuries for our monograph-anthology, Manipulating Fate: Medical Innovations, Ethical Implications, Theatrical Illuminations.[22] Varying iterations of these theatrical narratives have been experienced internationally to enhance bioethical insight and facilitate interdisciplinary dialogue largely thanks to Karen, who has particular expertise using theatre as a platform for teaching and inquiry over decades, perhaps most notably at the Smithsonian.[23]

II. PROCESS IN CONTEXT AND CONTROVERSY

As our bioethical exploration of the drama of DNA focuses the imagination on exome/genome sequencing, the complexities and processes of integrating genomic research and medicine are illuminated in a variety of contexts. These contemporary bioethical issues are brought to life through fictionalized characters and their dramatic narratives, illustrating potential benefits and decision-making dilemmas facing individuals, families, and professionals with comprehensive genome technology and the information it generates. Our characters cover thorny ethical terrain traversing from prenatal testing[24] to

22. Karen H. Rothenberg, *From Eugenics to the 'New' Genetics: "The Play's the Thing,"* 79 FORDHAM L. REV. 407 (2010); Karen H. Rothenberg & Lynn W. Bush, *Manipulating Fate: Medical Innovations, Ethical Implications, Theatrical Illuminations*, 13 HOUS. J. HEALTH L. & POL'Y 1 (2012).

23. Raymond MacDougall, *NHGRI Workshop Spotlights the Connection Between Genomics and Theater*, NAT'L HUM. GENOME RES. INST. (Apr. 30, 2014), https://www.genome.gov/27557019/nhgri-workshop-spotlights-the-connection-between-genomics-and-theater.

24. WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGIES (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994); PRENATAL TESTING AND DISABILITY RIGHTS (Erik Parens & Adrienne Asch eds., 2000); Ilana R. Yurkiewicz et al., *Prenatal Whole-Genome Sequencing—Is the Quest to Know a Fetus's Future Ethical?*, 370 NEW ENG. J. MED. 195 (2014); Diana W. Bianchi, *Cherchez la Femme: Maternal Incidental Findings Can Explain Discordant Prenatal Cell-Free DNA Sequencing Results*, 20 GENETICS MED. 910 (2018).

newborn screening and sequencing healthy infants on a population-level[25] to whole genome sequencing children.[26]

Through narrative genomics, we aim to raise awareness that preferences and tolerance for uncertainty vary within and across families, and depending on cultural and other demographic variables, the way in which genomic information is received and shared will differ, as will expectations.[27] Moreover, cognizant that perspectives can dramatically shift depending on the nuances and context presented, we purposefully select characters' age-ranges to highlight the additional responsibility required when considering sharing genomic information attained from families that include pregnant women and fetuses, newborns, and children[28] with varying levels of assent.[29]

By highlighting variation of voices on issues and contextual nuances, including the commonalities and distinctions between research, clinical, and

25. Karen and I have presented on ELSI issues in Newborn Screening and Sequencing in many venues over the past decade. For example: Navigating the Thorny Landscape on the Path from Newborn Screening to Genome Sequencing. ASHG 2014 Evening Premiere, Presenter. actor-panelists E Green, H Rehm, J Evans, B Koenig, R Truog, W Burke, R Nussbaum, C Bustamonte, J Botkin; Script/Video ASHGweb, open access NHGRI. ROTHENBERG & BUSH, *supra* note 5, at 31–56; Ellen Wright Clayton, *Currents in Contemporary Ethics. State Run Newborn Screening in the Genomic Era, or How to Avoid Drowning when Drinking from a Fire Hose*, 38 J.L. MED. & ETHICS 697 (2010); Jonathan S. Berg et al., *Newborn Sequencing in Genomic Medicine and Public Health*, 139 PEDIATRICS e20162252 (2017); Aaron J. Goldenberg et al., *Including ELSI Research Questions in Newborn Screening Pilot Studies*, 21 GENETICS MED. 525 (2019); Josephine Johnston et al., *Sequencing Newborns: A Call for Nuanced Use of Genomic Technologies*, HASTINGS CTR. REP., July/Aug. 2018, at S2.

26. Wylie Burke & Douglas S. Diekema, *Ethical Issues Arising from the Participation of Children in Genetic Research*, 149 J. PEDIATRICS S34 (2006); Isaac S. Kohane, *No Small Matter: Qualitatively Distinct Challenges of Pediatric Genomic Studies*, 3 GENOME MED. art. no. 62 (2011); Colleen M. McBride & Alan E. Guttmacher, *Commentary: Trailblazing a research Agenda at the Interface of Pediatrics and Genomic Discovery—a Commentary on the Psychological Aspects of Genomics and Child Health*, 34 J. PEDIATRIC. PSYCHOL. 662 (2009).

27. Karen and I serve in an advisory role (to H3Africa IFGeneRA PI Jantina De Vries), helping adapt our narrative genomics approach for a Cape Town-Botswana research context. The study examines ethical issues regarding feedback of individual genetic research results, exploring preferences of parents whose children have neurodevelopmental conditions, mostly autism, using our Drama of DNA method to foster engagement and understanding of ethical challenges, incl strong ancillary care expectations, belief in witchcraft as explanatory illness model, and resource-limited setting impacting medical actionability.

28. Additional protections for pregnant women, human fetuses, and human neonates involved in research. 45 C.F.R. § 46.201-46.207 (2012).

29. Benjamin S. Wilfond & Douglas S. Diekema, *Engaging Children in Genomics Research: Decoding the Meaning of Assent in Research*, 14 GENETICS MED. 437 (2012); Lynn W. Bush et al., *Pediatric Clinical Exome/Genome Sequencing and the Engagement Process: Encouraging Active Conversation with the Older Child and Adolescent: Points to Consider—A Statement of the American College of Genetics and Genomics*, 20 GENETICS MED. 692 (2018).

public health domains,[30] screening and diagnostic testing,[31] and the quality of information and counseling[32] generated by genomic technologies, our narrative genomics approach encourages interprofessional communication and collaboration[33] whether in the classroom or large professional conference, locally or globally.

We reflect on the reality that as the evolution of exome/genome sequencing progresses exponentially from research to clinical medicine and public health screening, so too does the discovery of incidental/secondary findings and ethical complexities.[34] Further complicating the decision-making and return of results process, it often is the case that the original question for which genomic study was indicated will go unanswered or be uncertain.[35]

Our scenarios also illuminate that, unlike some diagnostic or screening methods, comprehensive genomic sequencing can reveal information that extends beyond the individuals to include blood relatives and ancestral groups, and thus, anticipation of the implications necessitates additional forethought.[36] The sharing of secondary results amongst individuals, professionals, and families that are attained in both genomic research and clinical medicine remains controversial,[37] and the need to clarify definitions such as variable penetrance and susceptibility is essential. There is great debate as to what revelations constitute urgency for disclosure and who should decide, as well as what findings are deemed clinically relevant, actionable, or predictable.[38]

The fictionalized characters are designed to represent many perspectives, spotlighting less than ideal professional practices in somewhat caricature-fashion

30. Christine Grady & David Wendler, *Making the Transition to a Learning Health Care System. Commentary*, HASTINGS CTR. REP., Jan./Feb. 2013, at S32; Emily A. Largent et al., *Can Research and Care Be Ethically Integrated? Commentary*, HASTINGS CTR. REP., July/Aug. 2011, at 37; Mildred Z. Solomon & Ann Bonham, eds., Special Issue, *Ethical Oversight of Learning Health Care Systems*, HASTINGS CTR. REP. Jan./Feb. 2013, at S2.

31. Wylie Burke et al., *Genetic Screening*, 33 EPIDEMIOLOGIC REVS. 148 (2011).

32. Barbara A. Bernhardt et al., *An Exploration of Genetic Counselors' Needs and Experiences with Prenatal Chromosomal Microarray Testing*, 23 J. GENETIC COUNSELING 139 (2013).

33. Diane R. Bridges et al., *Interprofessional Collaboration: Three Best Practice Models of Interprofessional Education*, 16 MED. EDUC. ONLINE art. no. 6035 (2011). doi:10.3402/meo.v16i0.6035.

34. James P. Evans, *When Is a Medical Finding "Incidental"?*, 15 GENETICS MED. 515 (2013); Susan M. Wolf, *The Past, Present, and Future of the Debate over Return of Research Results and Incidental Findings*, 14 GENETICS MED. 355 (2012).

35. Rachel B. Ramoni et al., *The Undiagnosed Diseases Network: Accelerating Discovery About Health and Disease*, 100 AM. J. HUM. GENETICS 185 (2017).

36. Ben Chan et al., *Genomic Inheritances: Disclosing Individual Research Results from Whole-Exome Sequencing to Deceased Participants' Relatives*, 12 AM. J. BIOETHICS, no. 10, 2012, at 1.

37. Rachel B. Ramoni et al., *Experiences and Attitudes of Genome Investigators Regarding Return of Individual Genetic Test Results*, 15 GENETICS MED. 882 (2013).

38. Leslie G. Biesecker, *Incidental Variants Are Critical for Genomics*, 92 AM. J. HUM. GENETICS 648 (2013); Christopher A. Cassa et al., *Large Numbers of Genetic Variants Considered to be Pathogenic Are Common in Asymptomatic Individuals*, 34 HUM. MUTATION 1216 (2013).

as well as all-too-real procedural challenges. Our dialogue emphasizes that neither the clinician-researcher nor the individual can always predict whether their preferences for the return of results will change or who will bear the burden and distress from the return of unanticipated findings.[39] Furthermore opt-out/in clauses to receive genomic findings are not always provided, with little consensus regarding under what circumstances, if any, a consent form's request "not to know" may go un-honored.

Karen and I feel strongly, mirrored by some of our characters, that next-generation sequencing raises particular challenges when children,[40] especially otherwise "unaffected" children, are faced with findings that raise novel concerns about their future.[41] As investigations involving minors engender even more complex ethical and psychological challenges, the need for heightened sensitivity by professionals becomes magnified, as does the unsettling nature for researchers and clinicians.[42] Differential approaches must be weighed not only to consider whether, but to whom and when, results may be disclosed.

III. THE DRAMA OF DNA

With these debates and dilemmas as our backdrop, the scenario for one of our vignette-plays and book chapters[43] spotlights Whole Genome Sequencing and the need for ethics consultations in a variety of contexts, including IRBs and genomics advisory committees. The drama particularly highlights the roles professionals should play within each group to minimize psychosocial harm, ideally in advance of genomic testing. This dialogue brings to life significant challenges with the process and systemic questions raised when "a plan" does

39. Laura M. Beskow & Wylie Burke, *Offering Individual Genetic Research Results: Context Matters*, 2 SCI. TRANSLATIONAL MED. 38cm20 (2010); James P. Evans & Barbra B. Rothschild, *Return of Results: Not that Complicated?*, 14 GENETICS MED. 358 (2012); Amy L. McGuire et al., *Returning Genetic Research Results: Study Type Matters*, 10 PERSONALIZED MED. 27 (2013).

40. Anya E.R. Prince & Benjamin E. Berkman, *When Does an Illness Begin: Genetic Discrimination and Disease Manifestation*, 40 J.L. MED. ETHICS 655 (2012); Jennifer M. Kwon & Robert D. Steiner, *"I'm Fine; I'm Just Waiting for my Disease": The New and Growing Class of Presymptomatic Patients*, 77 NEUROLOGY 522 (2011); Bush, *supra* note 4.

41. Christopher H. Wade et al., *Effects of Genetic Risk Information on Children's Psychosocial Wellbeing: A Systematic Review of the Literature*, 12 GENETICS MED. 317 (2010); Annelien L. Bredenoord et al., *Next-Generation Sequencing: Does the Next Generation Still Have a Right to an Open Future?*, 14 NATURE REVS. GENETICS 306 (2013); Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, HASTINGS CTR. REP., Mar./Apr. 1997, at 7.

42. Kristien Hens et al., *The Return of Individual Research Findings in Paediatric Genetic Research*, 37 J. MED. ETHICS 179 (2011); Ruqayyah Abdul-Karim et al., *Disclosure of Incidental Findings from Next-Generation Sequencing in Pediatric Genomic Research*, 131 PEDIATRICS 564 (2013).

43. ROTHENBERG & BUSH, *supra* note 5, at 11–30; ROTHENBERG & BUSH, *supra* note 5, at 61–80. Karen and I used iterations of these plays and ethical analysis in 2013-2015 as invited faculty presenters at Advancing Ethical Research, PRIM&R Annual Conference. Actor-panelists include C Grady, P O'Rourke, R (Skip) Nelson, J Botkin, S Joffe, S Kornetsky, B Bierer, M Barnes. All videos and scripts available for educational purposes at PRIM&R (context peds rare disorder; autism).

not adequately consider potential risks. Along with exploring reactions toward planning protocols in anticipation of results generated from the genomic study, the narratives illustrate inherent tensions among professionals and the need for guidance from institutional boards, advisory committees, and professional societies.

We showcase the practical application of the issues with distinctions that are context-driven and relationship-oriented. Our earliest play and sequel[44] sheds light on the complexity of emotions, reactions, and implications throughout the informed consent process and during disclosure of genomic information. The vignette illuminates some of the challenges that may arise from the multidimensional role of the clinical geneticist-researcher when recruiting a long-standing patient and family for participation in a genomic study. The narrative commences by illustrating *It's Not That Simple!*,[45] with dialogue that focuses on decision-making dilemmas often facing family members during the informed consent process for genomic research and medicine, and concludes with some of the professional, personal, and familial dilemmas surrounding the reporting of genomic findings to illuminate that *It's So Complicated!*[46] Such issues considered in the play include the blurring of boundaries between genomic research and clinical practice, the therapeutic misconception, privacy and confidentiality, biobanking, reporting incidental findings to *unaffected* children, the role of assent, and broader implications for blood relatives and ethnic communities.

IV. REFLECTIONS

Whilst Karen and I are often vocal regarding our differing perspectives on these issues, which in part shapes some of our characters and dialogue, we fully share the belief that the sensory and visceral impact of experiencing dramatic narrative is powerful, and the synergy between the application of genomic technologies and the value-laden choices these innovations create raise fundamental questions that center on complex ethical dilemmas for individuals, families, and society. Because values among individuals are so diverse and fluid, the powerful role of relationships within a family varies across a continuum, and different judgments about "what is *normal*?" are shaped by our experiences and cultural expectations, which directly impact how we frame our identities and

44. ROTHENBERG & BUSH, *supra* note 5, at 31–45; Karen and I used iterations of the play and ethical analysis in 2015 at Johns Hopkins University-Berman Institute of Bioethics. Presentation-panel with videoed play for teaching. Session open access on JHU Berman website. We also presented at The Presidential Commission of Bioethics Lunchtime Speaker Series for an invited interactive play and lecture as co-commentators.

45. *See* Bush & Rothenberg, *Simple*, *supra* note 18.

46. *See* Bush & Rothenberg, *Complicated*, *supra* note 18.

those of others, including constructs of dis-abilities – all powerful issues influenced by genomics and ripe for teaching bioethics with dramatic scenarios.

We strongly endorse the position that the complexity of decision-making and these contemporary bioethical issues is powerfully brought to life through narratives, "just because it is not our life, places us in a moral position that is favorable for perception and it shows us what it would be like to take up that position in life."[47] As Karen is uniquely poised to know given her past role as senior advisor on Genomics and Society to the NHGRI Director, by facilitating discourse and raising more questions than answers on difficult issues, narrative genomics links the opportunities and concerns of next-gen technologies with a creative bioethics pedagogical approach for learning from one another.

47. MARTHA C. NUSSBAUM, LOVE'S KNOWLEDGE: ESSAYS ON PHILOSOPHY AND LITERATURE (1990).