Karen Rothenberg: Prescient, Perceptive, Persistent and Passionate

Diane E. Hoffmann

Follow this and additional works at: https://digitalcommons.law.umaryland.edu/jhclp

Recommended Citation
Available at: https://digitalcommons.law.umaryland.edu/jhclp/vol22/iss2/2

This Tribute is brought to you for free and open access by the Academic Journals at DigitalCommons@UM Carey Law. It has been accepted for inclusion in Journal of Health Care Law and Policy by an authorized editor of DigitalCommons@UM Carey Law. For more information, please contact smccarty@law.umaryland.edu.
KAREN ROTHENBERG: PRESCIENT, PERCEPTIVE, PERSISTENT AND PASSIONATE

DIANE E. HOFFMANN, J.D., M.S.*

This issue of the Journal of Health Care Law & Policy is dedicated to the legacy of Professor Karen Rothenberg as a health law scholar, teacher, mentor and founder of the Law & Health Care Program (L&HCP) at the University of Maryland Francis King Carey School of Law. The issue includes twelve articles/essays from individuals whose professional careers have been touched by Professor Rothenberg in some way. They are from former students (Fuller, Ulrich, and Walman), senior health law professors who Karen mentored early in their careers (Charo and Clayton), mid-career health law professors who benefited from Karen’s sage advice when they were just starting out (Roberts and Rebouche), current colleagues (Pasquale), co-workers or collaborators on policy and educational initiatives (Berkman, Brody, Collins, Green, Faden and Schwartz), and co-authors (Bush, Charo, Fuller, Rebouche, and Ulrich). They are just a small sampling of the many people who have had the good fortune to interact with Karen during her time in the academy.

I write this introductory essay as someone who was mentored by Karen, who has benefited from Karen’s wisdom and advocacy throughout my career, collaborated with her on policy initiatives, co-authored articles with her, worked for her as Associate Dean when she was Dean, co-taught courses with her, and who has been her colleague and friend for over 30 years. I met Karen in 1987 when I was interviewing for a faculty position at Maryland. At the time I was practicing at a law firm in Washington, D.C. and was not quite sure that I was ready to go into academia. But after meeting Karen, there was no way I could give up an opportunity to work with this brilliant, creative and passionate woman. I was offered the position and immediately accepted it and have never regretted that decision for an instant.

I. KAREN ROTHENBERG IN FOUR “P”S

The title of this article has two origins. First, it stems from one of the many things Karen taught me: people will remember what you have to say much better
if you use alliteration; thus the four “P”s: Prescient, Perceptive, Persistent and Passionate. In fact, every year when Karen was Dean and spoke to the incoming class at orientation, she would talk about the five “P”s that you need to have a successful experience in law school and in a legal career: People, Professionalism, Participation, Perspective, and Passion. Second, it grew out of the common characteristics that the authors of the dozen essays in this tribute highlighted about Karen.

Karen has been prescient about health law since before the area was a field of practice and the authors in this issue consistently mentioned Karen as both forward looking and as able to see into the future, at least as to what the future might bring in health law. Karen went to law school at the University of Virginia and was a student of the late Professor Walter Wadlington. Wadlington had this to say about Karen when she became Dean at Maryland: “While she was at Virginia, Karen was one of my favorite students because of her effervescent personality and her keen interest in developments in medicine and medical practice and what they might hold for law in the health care field.”¹ After graduating from law school, Karen worked for the law firm of Covington & Burling, in Washington, D.C., where Charles Miller was her mentor. Reflecting on her time at the firm, Miller said:

I always knew that Karen was destined to be a leader in health law when she joined our firm in 1979 and told me she wanted to develop a health law practice before we knew there was such a field as health law. Karen had the vision to see that we were then on the brink of a great development in this field, and the energy to convert that vision into reality. Her decision to join the UM faculty and head up the Law & Health Care Program when no one could have told you what such a program really would or should entail further illustrates that she was a true pioneer and destined for great accomplishments. It all looks inevitable now, but it did not seem so then.²

The second “P” about Karen is that she is very perceptive, a good quality to have as a law professor and scholar and the reason many people sought her out as a mentor. She is able to simplify complex legal and scientific issues and see things that are not obvious to others. She can cut through all the weeds quickly and skillfully and get to the heart of an issue. She sees the need for nuanced solutions and is able to see a problem from multiple perspectives. She

---

¹ E-mail from Professor Walter Wadlington, University of Virginia School of Law, to Diane E. Hoffmann, Jacob A. France Professor of Health Law, Director, Law & Health Care Program, University of Maryland Francis King Carey School of Law, circa 1999, on the occasion of Prof. Rothenberg stepping down as Director of the Law & Health Care Program and becoming Dean.

² E-mail from Charles Miller, Senior Counsel, Covington, to Diane Hoffmann, Jacob A. France professor of Health Law, Director, Law & Health Care Program, University of Maryland Francis King Carey School of Law, circa 1999, on the occasion of Prof. Rothenberg stepping down as Director of the Law & Health Care Program and becoming Dean.
Karen Rothenberg: Four P’s

is a master at solving problems that others find intractable. An example of this was her work on genetic discrimination. Her insights that genetic test results could ultimately be used by insurers and employers to deny individuals insurance or employment and thus discourage individuals from participating in genetic research ultimately led to the passage of the Genetic Information Nondiscrimination Act (GINA). Without this law, as pointed out by Berkman, Brody, Collins and Green, the field of genomics research may have been much slower to develop.

While prescience and perceptiveness are two of Karen’s strengths, she is also persistent about making her point. She never gives up trying to get you to see her perspective nor backs down when challenged. This persistence may stem from the character trait that comes up most often when people talk about Karen, i.e., her passion. This trait was mentioned by a number of the tribute authors. Whether it is a passion for women’s issues, genetic privacy, or theater, passion seems to ooze through her veins. She uses that passion to zealously advocate for a position or person with the intensity of a dog with a bone, not willing to stop until she has gotten you to agree with her, and the amazing thing about her is that she gets you to think it was your idea in the first place!

Two additional words that describe Karen, that I did not include in the title simply because it would have been ridiculously long but that are in keeping with the alliteration theme, are “partner” and “pal.” Several commenters in this issue mention how Karen mentored them not so much as a teacher, but rather as an equal or partner. That was especially the case when she was co-authoring a piece with a junior faculty member or with a student research assistant. But the word partner also describes Karen’s penchant for collaboration not only with individuals, but also with institutions. As the founding Director of Maryland’s Law & Health Care Program, she sought to collaborate with the health science schools on our campus, as well as with Johns Hopkins University, on both educational and research initiatives. As Dean, she channeled her love of theater to partner with Baltimore theaters on a program called “Linking Law & the Arts.” After her Deanship, she developed partnerships between the L&HCP and the Berman Bioethics Institute at Johns Hopkins University, helping to establish a dual degree program in law and bioethics, and between the L&HCP and the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH), offering an innovative new course and externship for law students.


The final word that describes Karen is “pal” or, more appropriately, friend. Even after meeting Karen for the first time, you feel as though you have made a new friend. She not only wants to know what you are writing about, she wants to know what is important to you – your family, your children, your friends, your ideas and beliefs. She effortlessly makes a connection with you and once she does, she is there for you in good times and bad.

II. A CAREER IN THREE PARTS

Part One

Karen started at the law school in 1983, just a few years before me, with a plan to develop and grow a law and health care program. In large part, I was hired to help her. For the next dozen years, we worked closely together as colleagues building the program, teaching and working on our scholarship. As an assistant professor, Karen was incredibly prolific and, it seemed to me when I arrived, had already made a name for herself in the health law and policy academy. In the first four years of her professorship she had been a legal consultant for the American College of Nurse-Midwives, served on an NIH consensus panel on the use of diagnostic ultrasound imaging in pregnancy, and led a Task Force to plan a forum held by NIH and the International Childbirth Education Association on Medical Malpractice Issues in Obstetrics. After I started, she somehow seemed to pick up the pace of her work. During the next eight years she served on numerous boards, advisory and planning committees, and as an officer or leader in a number of health law organizations. These positions included the Board of Directors of the National Health Law Program; Chair of the AALS section on Law, Medicine & Health Care; and member of the Institute of Medicine’s (IOM’s) Committee on Legal and Ethical Issues Relating to the Inclusion of Women in Clinical Studies. Ruth Faden, in her essay, recounts meeting Karen when they both served on this IOM Committee. She remarked that “[t]wo of Karen’s abiding passions, advancing the rights and interests of women and advancing more ethical public polices, were front and center in the work of this committee.”

While in this nascent phase of her career, Karen was an active researcher and scholar. Her early scholarship focused on the right to forego life-sustaining treatment, medical decision-making for children, the rights of health care workers when treating individuals with acquired immunodeficiency syndrome (AIDS), and the evolution of the legal duty to provide emergency care. She served as the principal investigator on a grant from the American Foundation for AIDS Research to examine the connection between partner notification, violence, and women with AIDS or Human Immunodeficiency Virus (HIV).

Through two cases handled at the law school’s AIDS/HIV clinic, where the clients were women who had tested positive for HIV, Karen learned that notification by physicians or public health officers to the sexual or needle-sharing partners of such individuals led to domestic violence (shooting) in one case and abandonment in another. Such notification was recommended by the CDC at this time. However, Karen’s research and scholarship informed and supported changes in partner notification protocols at the federal and state levels.

Early on in her career, Karen developed a relationship with a number of researchers and policy makers at NIH and spent several sabbaticals and leaves (under the Intergovernmental Personnel Act) at different Institutes there. The first was in the spring of 1991 when she worked at the National Institute for Child Health and Human Development. In the course of her work there, she met Elizabeth Thompson and became very interested in newly available prenatal genetic tests and the profound issues they raised for pregnant women. This experience was to be the foundation for much of her early and long-term scholarship. During this time, Karen was focused primarily on women’s health and reproductive issues and published articles on surrogacy, low income women and medical malpractice, the “good mother”, and women in clinical trials. With the coming of the genetic revolution, Karen became embroiled in the world of prenatal genetic testing, co-editing her first book (with Elizabeth Thomson) on that topic. It was this work that led to what has become the scholarship for which she is most well-known: legal issues in research and clinical practice involving genetic testing and treatment.

At this time, Karen was also a member and then President of the Board of Directors of the American Society of Law, Medicine & Ethics (ASLME). During her tenure as President, Karen oversaw a milestone leadership transition and worked with other members to establish a peer review process for articles published in the Journal of Law, Medicine & Health Care (now the Journal of Law, Medicine & Ethics). Although having only been a health law professor for a decade, in 1994 she was selected as one of the earliest recipients of ASLME’s prestigious Jay Healey Health Law Teacher’s Award.

7. CTR. DISEASE CONT. PREVENTION, DATA SECURITY AND CONFIDENTIALITY GUIDELINES FOR HIV, VIRAL HEPATITIS, SEXUALLY TRANSMITTED DISEASE, AND TUBERCULOSIS PROGRAMS 20 (2011).
8. MD. CODE ANN., HEALTH–GEN. § 18-201.1(d)(1)(i) (West 2019). Prior to Karen’s research, Maryland law required physicians to contact needle-sharing and sexual partners of their patients who were HIV positive. After it came to light that women were being abused when their male partners were informed of the HIV status of their female partner, the Maryland General Assembly changed the law to give physicians the discretion as to whether to notify their female patients’ male partners. Id.
In the early 1990s, Karen also worked closely with me as I led a coalition of stakeholder groups to change and expand the law in Maryland regarding decision-making for life sustaining treatment when patients are terminally ill, in a persistent vegetative state or have an “end-stage condition.” We developed a legislative proposal that was the subject of significant debate and controversy in the Maryland General Assembly. Karen’s guidance and advice during this monumental effort was both inspired and strategic. Jack Schwartz, in his essay, describes how Karen had a clear “reading of the legislative and public mood at a time when end-of-life policy making was in flux.” She was able to see what was at issue for families under the prior law that required them to go to court in order to disconnect a loved one from a ventilator or feeding tube. She realized such a requirement was emotionally heart wrenching for them and knew no one wanted to go to court at the time a beloved family member was dying. She successfully and passionately made that argument in her testimony before the Maryland General Assembly, which then passed the Health Care Decisions Act.

Subsequently, she spent an academic year (Sept. 1995 – May 1996) at NIH’s Office of Research on Women’s Health as a Special Assistant to the Director, Vivian Pinn. There she continued her work on the inclusion of women in clinical trials and expanded her scholarship on genetic issues. From 1995 to 1999, Karen published numerous articles on such topics as genetic discrimination and health insurance, the challenge of too much genetic information, genetic information and the workplace, cancer genetic susceptibility testing, privacy in genetics research, and cloning. While writing in this area she also served on a number of relevant panels and work groups. For example, she served on the Working Group on Ethical, Legal and Social Implications of Human Genome Research, on the Ethical Issues Committee on Tissue Banks and the Biological Resources Working Group for the National Action Plan on Breast Cancer, and as a member of the Recombinant

---

DNA Advisory Committee at NIH. During this time, she also developed and honed certain positions on significant ethical issues created by genetic testing and genetic research. These included the idea that not all medical/genetic information is a good thing. This idea ran counter to the general medical view at the time that more information is better. However, Karen persuasively argued in a number of forums that sometimes people might not want to know that they are likely to develop a certain disease or disabling condition such as Huntington’s or Alzheimer’s, particularly when there is no cure for the disease. Subsequent research on this question continues to build on Karen’s early research and insights.

Karen also had strong concerns about discrimination based on the results of genetic testing and published several articles in the prestigious journal, *Science*, about the potential use of genetic test results by health insurers to deny individuals insurance and by employers who might choose not to hire someone with a predisposition to a serious genetic disease. But Karen came to see that genetic testing could also lead to another type of discrimination, that against groups of individuals. For example, when it became clear that Ashkenazi Jewish women were more likely to carry the BRACA 1 gene that often leads to breast cancer, some may have assumed that all Ashkenazi Jewish women will develop the disease when, in fact, only a small percentage will do so. Ellen Clayton describes in her essay how Karen’s analysis on this topic “informed later discussions of how to prevent group harm, a gnarly and still unresolved dilemma.”

**Part Two**

Karen’s concerns about the use of genetic test results to discriminate led her to help lay the groundwork for legislation at the federal and state levels that would prohibit the use of such test results by insurers and employers. However, her work on this important legislation was put on hold, but only momentarily, as she took over as Interim Dean (1999–2000) and then Dean (2000–2009) of the law school. During this time, Karen, still full of boundless energy, kept up her

22. While the work of Prof. Rothenberg as Dean was also noteworthy for her many accomplishments, this aspect of her time at the law school has been written about in a special issue of the Maryland Law Review. Tributes were published by Martin J. O’Malley, former Governor of Maryland and former student of Prof. Rothenberg; Senator Benjamin Cardin (U.S. Senator for Maryland and Maryland alum); Robert M. Bell, former Chief Justice of the Maryland Court of Appeals, and Andre M. Davis, former United States Circuit Judge of the United States Court of Appeals for the Fourth Circuit and Maryland alum. Martin J. O’Malley, Benjamin L. Cardin, Robert M. Bell, & Andre M.
work on legal and policy issues arising out of the developments in genetics. In particular, she continued her advocacy for GINA, which was ultimately passed by Congress in 2008, and worked with members of the Maryland General Assembly to pass similar legislation in Maryland. Several of the contributors to this issue describe Karen’s role in getting the federal legislation passed. Jessica Roberts describes her as the “fairy godmother of genetics and the law.”

While Karen was Dean and I was Associate Dean, we also worked together on a major empirical project looking at how health-related genetic test results were being used in the court room. We saw these as “second generation” genetic tests following on the heels of DNA tests used for determining identity in paternity and in some criminal litigation. We designed and conducted a survey of all state circuit court judges and federal district court judges in Maryland. Judges were asked about their prior use of genetic tests for identity purposes and whether they had had any requests to admit or compel health-related genetic tests in their court rooms. We then gave them a series of hypothetical cases where they were asked to respond to requests by one of the litigants to admit or compel such tests results. Through Karen’s role as Dean and her relationship with many judges in the state, we were able to obtain a very good response rate (72%). Collaboration with Karen on the interpretation of the data and writing of the article was an amazing experience. As Barbara Fuller, Karen’s former research assistant, stated in her essay for this issue about collaborating with Karen, “she was never content until all angles of an issue had been explored.” And the data we generated had many angles from which it could be interpreted. Truly the analysis and the article were much better for my collaboration with Karen.

While serving as Dean, Karen somehow managed not only to sit on the newly established Maryland Stem Cell Commission, but also to chair it – a time consuming and demanding job. It was a significant role that required establishing all the procedures, protocols and policies by which the Commission would


allocate a several million-dollar budget to Maryland scientists performing stem cell research. Jack Schwartz writes in his essay about the controversy that enshrouded a similar effort in California that “Karen had the discernment to know that the best path forward for the Maryland effort would be . . . quiet and steadfast professionalism – a scientifically sound grant review process, free of conflicts of interest and political agendas . . .”29 As the person who took Karen’s place on the Commission after her term of service, I can see the beneficial impact that Karen’s vision and characteristic strategic acumen had on the workings of the Commission.

Part Three

In the last phase of her career, since stepping down as Dean, Karen has married her love of theater with her passion for the ethical, legal and social issues arising out of research and clinical practice related to genetics and has devoted much of her scholarship to the use of plays to explore and mine those issues. She has written articles about plays that many of us have read or seen performed examining the scientific and ethical questions they raise, often foreshadowing some of the current dilemmas we face as a society regarding whether and how to regulate science.30 But she also sees them as vehicles for examining relationships in ways that the study of science alone may not allow. In his essay for this volume, Frank Pasquale writes about how “Rothenberg’s turn to literature recognizes that our plays and poems, stories and films, reveal patterns of power and meaning in the world by exploring the ramifications of critical relationships. They illuminate fundamental aspects of human experience.”31 While Karen explored the depths of existing literature to illustrate aspects of the human condition affected by science, she was not content to simply analyze the writings of others. In addition to her analysis, she co-authored several original plays designed specifically to examine some of the intractable dilemmas that current genetics research and clinical practice raise; issues like return of incidental findings,32 informed consent,33 discrimination,34 privacy,35 and relationships

33. Wilfond, supra note 16, at 244.
34. Rothenberg, supra note 15, at 1755.
35. Fuller, supra note 17, at 1359–60.
between family members. Often enlisting colleagues to play the actors in her theatrical productions, Karen used these plays as a way to generate conversations among scientists, bioethicists and health law academics, and to help researchers understand the difficult decisions patients must make as a result of new genetic information and technologies. Lynn Bush writes eloquently in her article for this issue about her collaboration with Karen on many of these plays and on their co-authored book, *The Drama of DNA.* And, in personal correspondence to me, Professor Abbe Gluck described Karen’s work “using theatre as a pedagogical tool to inspire discussions on issues of genetic ethics and to engender empathy” as “groundbreaking.”

Also, in this phase of her career, Karen was given a joint appointment at the Johns Hopkins Berman Institute. In her essay, Ruth Faden, former Director of the Institute, shares the role that Karen has played at the Institute over the last decade and the impact that she has had on many of the faculty and Fellows that have spent time there. And last but not least, over the time since her Deanship, Karen spent several years at NIH, as Senior Advisor to Eric Green, Director of NHGRI, and at the Clinical Center working with Ben Berkman and others. In their contribution to this issue, Green and Berkman, along with NIH Director Francis Collins and NHGRI Senior Investigator Lawrence Brody share the roles Karen has held at, and contributions she has made to, NIH. One of those roles is “educator.” They describe how Karen developed “the idea for an intensive workshop where students would research and analyze a range of ethical, legal and policy questions raised by the increasing prevalence of human genome sequencing in research.” Karen enlisted several colleagues at NIH to serve as supervisors for law students in a non-traditional law school course that was part externship, part seminar and part clinic.

Michael Ulrich, a former student in this innovative class, writes about how empowered he felt as a student to have the opportunity to work with these genetic experts on cutting edge genetic policy issues. He is just one of the many students Karen empowered and inspired in her years of health law teaching.

III. Conclusion

Just as each of the writers in this volume have been touched by the generosity, creativity, encouragement and friendship of Karen Rothenberg, so have I. As her colleague and friend for the last 32 years I have truly been

39. For a description of the course, see *Karen H. Rothenberg and Benjamin E. Berkman, Teaching Law Students to be Policymakers: The Health and Science Workshop on Genomic Research, 40 J.L. MED. & ETHICS* 147 (2012).
fortunate. I agree wholly with Ruth Faden who says in her essay, “Karen is the best kind of colleague to have, and the best kind of friend.”40 Her friendship is something I treasure and hope will continue for many years to come.