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# ENCOMIUM FOR KAREN ROTHENBERG

ELLEN WRIGHT CLAYTON, MD, JD\*

Karen Rothenberg is an extraordinary scholar and leader who changed the course of my career. In law school, I wrote my note for journal on reproductive genetic testing, which appeared in 1978. Then I went to medical school and did a residency in pediatrics. As a young assistant professor, I had given a few talks about genetics and law but was still trying to find my way as an investigator and scholar.

That all changed when Karen and Elizabeth Thomson invited me to give a talk on legal and regulatory issues at an NIH conference on Reproductive Genetic Testing: Its Impact on Women in November, 1991. The conferees consisted of an all-star cast of leading women scholars from a variety of areas including philosophy, history, disability rights, sociology, anthropology, psychology, law, and obstetrics.<sup>1</sup> The conference was both exhilarating and exhausting because it made clear the excitement, the challenge, and the necessity of working across disciplines to understand issues in their full complexity in order to work toward solutions; lessons that have shaped my own work ever since.

This conference also epitomized the essential characteristics of Karen's scholarship – her passion for addressing women's issues, her commitment to understanding from many perspectives what is really at stake, and her insistence on wrestling issues to the ground – no superficial work allowed. I turn first to an example from her work on genetics, our point of first contact. When Jeff Struewing at the National Institutes of Health demonstrated that Ashkenazi Jews had a higher prevalence of specific variants in *BRCA1* and *BRCA2* that created an intermediate risk of cancer,<sup>2</sup> Karen went to work. She worried the results of Struewing's research would stigmatize a recognized and at times disfavored group.<sup>3</sup> Her analysis informed later discussions of how to prevent group harm, a

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1. The participants were Abby Lippman, Ruth Schwartz Cohen, Deborah Kaplan, Mary Mahowald, Ruth Faden, Patricia A. King, R. Alta Charo, Elena A. Gates, Nancy Anne Press, Carole H. Browner, Rayna Rapp, Laurie Nsiah-Jefferson, Barbara Katz Rothman, and Rita Beck Black.

2. J. P. Struewing, et al., *The Risk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 Among Ashkenazi Jews*, 336 NEW ENGLAND J. MED. 1401 (1997).

3. K. H. Rothenberg, *Breast Cancer, the Genetic "Quick Fix," and the Jewish community. Ethical, Legal, and Social Challenges*, 7 HEALTH MATRIX CLEVEL. 97 (1997); K. H. Rothenberg & A. B. Rutkin,

gnarly and still unresolved dilemma.<sup>4</sup> Noting that individuals from whom the tissue samples had been obtained had not given consent for the use of these specimens, Karen helped to coordinate a survey of Jews about their views about the use of stored tissue for this type of research. This survey also covered their views on the acceptability of using different sources of tissues and about whether consent should be required.<sup>5</sup> The investigators found that while the respondents were generally highly supportive of research, they wanted to provide written consent, particularly if the samples were collected in a clinical rather than a research setting.

Karen is also a zealous advocate in the very best sense of the word. After Struewing's article appeared, she wrote an editorial that appeared in multiple newspapers<sup>6</sup> arguing that women with these variants should not lose their insurance.<sup>7</sup> She became deeply involved in the National Action Plan for Breast Cancer, a powerful grass roots organization. Additionally, she became involved at the National Institutes of Health and addressed, often in leadership roles, such issues to develop strategies to prevent genetic discrimination for individuals with variants that increased the risk of developing cancer, to create tools to obtain meaningful informed consent for research, and to govern the use of biological specimens. Her work laid the foundation for the passage of the Genetic Information Nondiscrimination Act<sup>8</sup> as well as the ongoing debate about use of biological specimens for research, most recently instantiated in the changes to the Regulations for the Protection of Human Research Participants that are currently going into effect.<sup>9</sup>

Karen's concern for women was not limited to genetics. Early in her career, she was a vigorous advocate for including women in clinical research, during a time when this surprisingly was a topic of debate.<sup>10</sup> Previously, researchers had

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*Toward a Framework of Mutualism: the Jewish Community in Genetics Research*, 1 COMMUNITY GENET. 148 (1998).

4. K. M. Meagher, et al., *Precisely Where Are We Going? Charting the New Terrain of Precision Prevention*, 18 ANNU. REV. GENOMICS HUM. GENET. 369 (2017).

5. M. D. Schwartz, et al., *Consent to the Use of Stored DNA for Genetics Research: a Survey of Attitudes in the Jewish Population*, 98 AM. J. MED. GENET. 336 (2001).

6. K. Rothenberg, *Miracles of genetics can bear heavy cost Participants in tests sometimes lose privacy and health insurance*, BALTIMORE SUN July 20, 1997, accessed at <https://www.baltimoresun.com/news/bs-xpm-1997-07-20-1997201005-story.html>.

7. K. L. Hudson, et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE 391 (1995); K. H. Rothenberg, *Genetic Discrimination and Health Insurance: A Call for Legislative Action*, 52 J. AM. MED. WOMENS ASSOC. 43 (1997).

8. Genetic Information Nondiscrimination Act of 2008, 42 USC §§ 2000ff et. seq., (2008).

9. Department of Homeland Security et al., *Federal Policy for the Protection of Human Subjects*, 82 FED. REG. 7149 (2017).

10. Karen H Rothenberg, *Gender Matters: Implications for Clinical Research and Women's Health Care*, 32 HOUS. L. REV. 1201(1995); Karen H Rothenberg, *The Institute of Medicine's Report on Women and Health Research: Implications for IRBs and the Research Community*, 18 IRB: ETHICS & HUMAN RESEARCH 1 (1996); Eugene G Hayunga, et al., *Women of Childbearing Potential in Clinical Research:*

usually studied only men because women's hormonal cycles and potential to become pregnant presented too many complications. Her advocacy carried the day, and although progress has been made, parity has not yet been achieved,<sup>11</sup> particularly for pregnant or "potentially pregnable" women.<sup>12</sup> Karen was also deeply concerned about the HIV/AIDS epidemic, focusing both on the obligations of health care providers<sup>13</sup> and also the impact of this disease on women, pointing out their greatly increased risk of domestic violence.<sup>14</sup>

This discussion represents only part of her scholarly and policy impact. Over the course of Karen's career, she has written and spoken extensively about the right to die, medical decision-making for children, research ethics, and access to health care. For the last several years, she has explored in great depth the potential value of using drama to reveal new perspectives on the complexities of advances in genomics,<sup>15</sup> ultimately publishing her book, *The Drama of DNA: Narrative Genomics*<sup>16</sup>, with Lynn Wein Bush. Illustrating the power and wisdom of this endeavor, Jules Odendahl-James, an artist-scholar wrote in his book review "Rothenberg and Bush's narrative . . . scenarios move across time, across professional and personal networks, from the research study to the clinical trial to the medical case. . . . [demonstrating that e]thical and empathetic considerations are not a barrier to cutting-edge research; they are actually key elements to superior, successful medical science."<sup>17</sup> What an important lesson.

What makes Professor Rothenberg's accomplishments all the more remarkable is that she achieved them while creating a leading health law program from scratch at the University of Maryland, then stepping in as dean of the school, and ultimately advising the leadership of the National Human Genome

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*Perspectives of NIH Policy and Liability Issues*, 13 FOOD, DRUG, COSMETIC AND MED. DEVICE L. DIGEST 7 (1996).

11. Louise Pilote & Valeria Raparelli, *Participation of Women in Clinical Trials: Not Yet Time to Rest on Our Laurels\** (Elsevier 2018).

12. Rieke van der Graaf, et al., *Fair Inclusion of Pregnant Women in Clinical Trials: An Integrated Scientific and Ethical Approach*, 19 TRIALS 78 (2018).

13. Karen H Rothenberg, *The AIDS Project: Creating a Public Health Policy—Rights and Obligations of Health Care Workers*, 48 MD. L. REV. 93 (1989).

14. Karen H Rothenberg & Stephen J Paskey, *The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law*, 85 AM. J. OF PUB. HEALTH 1569 (1995); Richard L North & Karen H Rothenberg, *Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection*, THE NEW ENGLAND J. OF MED. 1569 (1993); Karen H Rothenberg & Richard L North, *The Duty to Warn Dilemma and Women with AIDS: Redefining the Foreseeable Victim*, 2 CT. HEALTH SCI. & L. 90 (1991).

15. Karen H Rothenberg & Lynn W Bush, *Genes and Plays: Bringing ELSI Issues to Life*, 14 GENETICS IN MED. 274 (2012); Karen H. Rothenberg, *From Eugenics to the 'New' Genetics: 'The Play's the Thing'*, 79 FORDHAM L. REV. 407 (2010).

16. KAREN H ROTHENBERG & LYNN WEIN BUSH, *THE DRAMA OF DNA: NARRATIVE GENOMICS* (Oxford University Press, USA. 2014).

17. Jules Odendahl-James, Book Review, AM. J. BIOETHICS, Dec. 2016, at W17 (reviewing ROTHENBERG & BUSH, *supra* note 16).

Research Institute for many years, all while doing an almost immeasurable amount of service. And to top it off, she was, and is, an unstintingly generous friend and mentor, for which I am supremely grateful.