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# MY INCREDIBLE JOURNEY WITH KAREN

BARBARA P. FULLER, J.D.\*

There are few people we meet and immediately know they are going to have an impact wherever they go and on whatever they do. This was my initial impression of Karen Rothenberg. However, I never imagined the many positive ways she would have an impact on my life through her roles as professor, mentor, colleague and friend.

I first met Karen in 1975 when we both worked for a large health organization in Washington, D.C. Karen was the assistant to the organization's CEO, and although she was a young (very young) recent college graduate, she gained respect throughout the organization for her reputation of always being prepared and having a command of the issues. This young whirlwind exuded competence and was certainly not intimidated just because someone was older or had a prestigious title. Even when the organization was faced with contentious labor issues, she often represented the CEO in critical meetings because she combined depth of knowledge and a presence that belied her young age. After Karen left this position to go to law school, we did not meet again until many years later when she was a well-respected law professor at the University of Maryland School of Law and I was a "One L."

While I was a student at the law school, I was lucky to have Karen as a professor and to work with her as a research assistant. In both capacities, Karen taught me to look beyond the facts and to consider the future implications of the facts. This was especially evident to me when I began assisting her as she prepared manuscripts on genetic information. She had the unique ability to see the future implications of DNA research and to understand the long-range positive and negative implications for the use of this research. She was passionate about protecting the privacy of genetic information in research and prohibiting discrimination based on an individual's genetic information.<sup>1</sup> I had the privilege of working with her on some of her many articles addressing

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1. See Ben Wilfond et al., , *Cancer Genetic Susceptibility Testing: Ethical and Policy Implications for Future Research and Clinical Practice*, 25 J. L. Med. & Ethics 243 (1997) (advocating for policies to address privacy and discrimination in research involving genetic testing for cancer susceptibility).

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workplace discrimination based on genetic information and genetic discrimination by health insurers.<sup>2</sup> Her boundless energy and efforts to address genetic discrimination were ultimately rewarded in 2008 when Congress enacted The Genetic Information Nondiscrimination Act of 2008.<sup>3</sup> She had diligently worked on this law which offers protections for Americans from both genetic discrimination in health insurance and genetic discrimination in employment.<sup>4</sup>

As Karen's research assistant, I learned tenacity, stamina and perfection first hand – all hallmarks of Karen's work ethic. We spent many hours on manuscripts writing, rewriting, reviewing, rewriting, editing and rewriting. She was never content until all angles of an issue had been explored, sometimes many times over just to be sure there was nothing she had missed that was relevant to the manuscript. She always seemed to have an unending supply of energy, and even when our work sessions went much later than planned, she only stopped when she realized I needed to stop – or more likely, had already stopped. Although I was usually exhausted at the end of these work sessions, they were always enjoyable and rewarding because Karen treated me as a colleague even though I was just her research assistant.

During this time as her research assistant, Karen's enthusiasm extended to possibilities for my future employment. She went out of her way to introduce me to any potential employer – individuals, consumer groups, organizations – anyone or any group with an interest in genetic discrimination. She made sure everyone was aware of my role assisting her behind the scenes. And, of course, Karen's efforts paid off.

Shortly after my graduation from law school, Karen was named Dean. Hiring Karen as Dean was a perfect choice that recognized her love of the law school, her dedication to the law and her positive interpersonal skills. As part of her duties as Dean, she was responsible for fundraising, and I was not immune from her legendary ability to fundraise. While having a conversation about the current state of protections from genetic information in a particular state or in Federal law, Karen would slip in a request that I make a donation – even a small donation - to the Law School. It was impossible to say no to Karen, even then, so I assume I did make a donation but for amounts that certainly paled in comparison to the substantial donations she obtained as part of a multimillion

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2. See Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 SCIENCE 1755 (1997) (providing recommendations for state and federal policies relating to workplace discrimination based on genetic information such as prohibiting employment organization from requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment); See also Karen H. Rothenberg, *Genetic Discrimination and Health Insurance: A Call for Legislative Action*, 52 J. AM. MED. WOMEN'S ASS'N 43 (1997) (advocating to physicians for legislative change to address individuals' fear of being declined health insurance coverage based on the result of genetic testing).

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

4. *Id.*

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dollar campaign. Not surprisingly, her requests for me to donate to the law school continued even after she no longer had fundraising as part of her job description. She continues, even to this day, to fundraise for the law school and the Law & Health Care Program.

Not surprisingly, in addition to more formal roles, Karen and I became friends. At some point, we realized our birthdays were just one day and 10 years apart. This started a tradition of meeting for lunch during our birthday month. These were wonderful occasions, but Karen's negotiation skills were always in play as we perused the menus. Karen likes to share, and me - not so much. We always ended up with a delicious lunch, which we shared, and which I enjoyed immensely.

My incredible journey with Karen has followed an unconventional path and a path neither one of us could have anticipated when we first met in 1975. Karen embodies the gold standard for professors, mentors, colleagues and friends. As professor, she taught me not only to understand all aspects of the legal issues but to look beyond them. As a mentor, she taught me the value of hard work and dedication while maintaining compassion and humanity. As a colleague, she set an example of someone who was always working and always passionate. As a friend, she is always there for meaningful discussions, whether about some current legal news or about grandchildren. I will be forever grateful for the many opportunities provided to me as a result of this incredible journey.