Foreword

Joanna Morales: An Unexpected Path

When I started college, I was an international relations major on my way to an international law degree, with dreams of working at the United Nations or The Hague. During my senior year of high school, I started working as an administrative assistant for the John Wayne Cancer Institute’s (JWCI’s) Psychosocial Care Program. Within JWCI was the Positive Appearance Center, a first-of-its-kind, on-site boutique offering items to deal with the comfort and cosmetic side effects of cancer care. At various times during my eight years at JWCI, I managed operations at the Positive Appearance Center, including fitting patients with mastectomy bras and prostheses and billing insurance companies for those items.

When I started at Loyola Law School in Los Angeles, I learned that there was a course on Cancer Rights Law, the only class of its kind in the country. It was the first elective course I chose to take. I was surprised to learn that it was really a survey course, providing brief exposure to many areas of the law that may become an issue after a cancer diagnosis. I was also surprised to learn that I did not have to purchase a very expensive, four-inch-thick casebook to read for the class. No such casebook on cancer rights law existed. While relieved at the time, when I became the professor for this class eight years later, I realized what a challenge it posed in developing lesson plans. And the idea of writing a book started to form.

While taking the Cancer Rights Law class, I learned about the Women’s Health and Cancer Rights Act (WHCRA). It was not a long law, unlike the Patient Protection and Affordable Care Act, but it had a huge impact. An estimated 268,670 women and men will be diagnosed with breast cancer in 2018.5 Forty-two percent of women with breast cancer undergo reconstructive surgery.6

WHCRA requires health insurance companies to cover the costs of reconstructive surgery following a mastectomy for breast cancer or breast prostheses to “achieve symmetry,” if the plan covers the mastectomy. Prior to the law, insurance companies would often deny reconstructive surgery or the prostheses, claiming that they were cosmetic and not medically necessary. The law also required coverage for reconstructive surgery on the breast where breast cancer was not found, in order to achieve a symmetrical appearance in both breasts.

One day, while working at the Positive Appearance Center, I was reviewing the insurance billing and realized that a patient had been denied coverage for her prosthesis. Breast prostheses are not inexpensive and I knew that it would be a hardship for the patient if she were going to have to pay for it out of her own pocket. So, I called the insurance company and was told that the claim was denied because it was not covered under her plan. After a series of questions, I was still at a loss for why she would have been denied coverage. Finally, I asked, “Wouldn’t WHCRA apply to her policy, meaning that her prosthesis must be covered?” There was silence on the other end of the line. After a few moments, the claims representative quietly said, “Yes, I suppose you are right. Please resubmit the claim and we will approve it.”

At first, I felt happiness at being able to get the issue resolved for the patient and then a bit of relief that I would not have to tell her that the insurance company would not pay for her prosthesis. But, as the afternoon wore on, the phone conversation kept gnawing at me. I kept wondering what would have happened if I had not mentioned WHCRA. Very few people are aware of such an obscure law, except, apparently, insurance companies. Yet, despite their knowledge of their obligation under WHCRA, it seemed as if their policy was to deny coverage and hope that no one noticed. And the worst thing that could happen is that someone like me could notice, and then they would just approve the claim.

The whole experience made me realize how important it is for all of us to know about and understand our rights and the options that are available to each of us, so that we can make educated decisions about our lives and get access to the benefits and protections to which we are entitled under the law.

That guiding principle lead me to a career in advocating on behalf of others, focused on educating people about the rights and options afforded to them under the law. And, it has continued to drive my work in the cancer community for more than 24 years. I look forward to a day where advocates, like myself, are no longer needed.

Monica Bryant: A Winding Road

While my career path has been anything but straight, the common theme throughout has been a desire to fight for justice and fairness. As long as I can remember, I have had an interest in the law and how it can both oppress and empower people. I firmly believe that the law touches almost every aspect of our lives and that individuals have to use the law as a tool to become their own advocates. As an undergraduate law and society major, my studies focused on how the law intersected with other disciplines, such as sociology, psychology, anthropology, and biology. Having had the privilege to attend the George Washington School of Law in Washington, D.C., a whole new set of opportunities to interact with the law, in and out of the classroom, were presented. While in law school, and then after graduation, I witnessed and, in some fashion, was able to help formulate public policy on a national level. As Legislative Counsel for Congresswoman Linda T. Sánchez, I frequently observed that lobbyists and large interest groups lead the conversation on policy, rather than the people who were going to be most affected by the policies being debated. It continues to amaze me that the average American tends to be unaware of the power he or she has to effect change using our legislative process.

When I left my job in Congress, I struggled to find a career where I could use my knowledge of the law and the legislative process, as well as my desire to help people find their voices. The stars aligned and my career shifted to that of a cancer rights attorney. Since then, I have found that providing individuals with even the most basic information about the law, in an understandable manner, can change their lives. Over the years, I have had a front row seat to watch people go from despair over the seemingly unavoidable financial devastation caused by cancer treatment, to elation over finding out that their insurance companies had covered a particular treatment. Or that an employer did not have the right to fire them because they needed time off for treatment. It is somewhat of a joke among family and friends that I will never step off my soapbox of encouraging advocacy in its many forms. However, providing that glimmer of hope, in what is often the worst time in someone’s life, continues to drive my work.

This book is simply another tool to help people find their voices as advocates.