

Karina Eide: how an 11 year old sparked a movement for women with ovarian cancer

In 2006, I was diagnosed with ovarian cancer. I finished my chemotherapy in 2007 about the time that Karina was diagnosed with alveolar soft part sarcoma. I was 49. She was 10. We did not know each other and I had no idea that our lives would become intertwined in a profound way. In 2008, I had begun searching for a way to bring molecular profiling to women fighting ovarian cancer to try to improve the grim survival statistics for this underserved cancer population. As a scientist and later, an executive in oncology drug development, it was routine for us to obtain tumor samples from patients to perform testing that might help inform which tumor characteristics would provide a better response to our drugs. I assumed this was standard procedure for all cancers but was shocked to learn this was not the case for an ovarian cancer diagnosis (and soon learned this was the case for alveolar soft part sarcoma as well). People battling rare cancers still receive trial-and-error treatment as they did decades ago. With hopes of improving outcomes for ovarian cancer, I created Clarity Foundation with friends and colleagues and we began developing a way to address the complexity of providing support to the patients who needed it. How do we put into practice the mission of the Foundation? What was the process of obtaining a piece of someone's tumor, how would the physicians help us, who were the labs that would conduct the analyses and how would these analyses be interpreted? I had suggestions from so many people but none of us knew how to operationalize the ideas. It had never been done.

I'll never forget answering my cell phone one day in early 2008. "My name is Fernette Eide, I got your name from Eric Aguiar, he mentioned that you know how to do molecular profiling, my 11 year old girl has alveolar soft part sarcoma, can you help us?" There were a million things flying through my head - - about how Clarity was only an idea, we had no understanding of what to really do, what was I going to tell this mother fighting for her child? I remember hanging up the phone, taking a deep breath, calling one of the analytical labs that we had visited a few weeks previously, and saying that I needed to send them our first tumor specimen. I asked them to explain to me how to go about obtaining the tumor sample from the pathology lab where it was being stored. I remember the push back that was in that phone call and pleading with them that time was precious, it was an 11 year old child and that we had to all work together to bring hope to Karina. I wouldn't take no for an answer.

Karina was Clarity's ignition. She pushed us from researching and planning into serving and doing. Through the years, from when I first talked to Fernette to her death on May 9, I was so privileged to watch Karina grow into an amazing young woman, help from time to time with additional profiling when her tumor recurred or to suggest out-of-the-box treatments to discuss with their oncologist when options were running low. Each time, we learned something new, each time we applied it to our fight for women battling ovarian cancer.

Needless to say, the processes that we use at Clarity today are much different than back in 2008 when I had to ask Fernette to go to the pathology lab and ship the tumor block herself. That's not all that has changed however, Clarity routinely facilitates testing of tumor samples at three different testing facilities and our ovarian cancer database is made up of almost 400 women. We still have to fight everyday to help women battling ovarian cancer but Karina taught us all a very important lesson: Don't take no for an answer. And because Karina was Clarity Foundation's very first patient and not someone with ovarian cancer, we have never turned away someone battling a different form of cancer that has asked for our help.

We will continue our fight at Clarity to honor the inspiration that she has been to all of us.



Laura Shawver, PhD
Founder