

Tina's Story



In her early 20s, Tina Aswani Omprakash was a busy, young professional living in New York City. Her life was then derailed and “the rug pulled out from under her” when she began a 10-year journey to find a treatment for her Crohn’s disease. After undergoing 20 surgeries and trying countless medications, Tina enrolled in a clinical trial. Today, Tina’s Crohn’s is in remission, and though she still lives with the emotional and physical scars of her journey, she is a fierce advocate for reducing the stigma around Crohn’s and the need for increased education about clinical trials.

In 2006 I was diagnosed with Ulcerative Colitis (UC). However, both my father and his sister (my aunt) had suffered from aggressive Crohn’s that turned into colon cancer. As they both died from this condition, I worried that I may also have Crohn’s and aggressively searched for a specialist who would confirm my diagnosis. After seeing six or seven specialists and being put through a battery of testing while suffering through numerous flare-ups, I was finally diagnosed with Crohn’s.

At the time, I was in my 20s with a busy life working in finance in New York City, and while I was relieved to finally have a diagnosis, things got worse. For a number of years, I struggled with medication after medication and underwent 20 surgeries for the Crohn’s disease that resulted in complications including recurrent fistulas, or abnormal connections between organs that were both physically and emotionally painful. When I had run out of medications to try, I was put in a phase III trial. Clinical trials had been proposed early in my journey and I did not take the opportunity because of the same fears that many patients have. Now I was facing the worst of possible consequences and weighed my fears against the potential of saving my life. I participated in the trial, and within several months, my fistulae had closed and I was in remission for the first time in 10 years. I am still on the same medication, and I haven’t had surgery since.

Today, I am healthy, but I still live with the emotional trauma and the stigma of Crohn’s disease. For everything Crohn’s disease took from me, it also gave me something – today I am a patient advocate and speak to individuals struggling with these same physical and emotional issues. I realized my story could really help people, so if life has given me these lemons, why not make lemonade out of them?

The main lessons I share are:

1. As a condition, Crohn’s often hits people in their 20s when they are in the prime of their lives. I had no idea of the stigma that would come with Crohn’s or what it would be like to live with a chronic condition. Even in my own family, I experienced hesitation to talk about my condition and to share my experiences. As an advocate now, I see what power there can be in community, and how important it is to connect with others who have the same condition and understand the many obstacles and challenges. I found that this added fuel to my fire - when I saw how people responded, it helped me become a fiercer advocate. I was speaking about things that others have been afraid to speak about – and there is tremendous power in that.
2. I also see that people sometimes wait too long to get treatment or to push for the right treatment. Many times, this is because they are scared and don’t understand the background of the drugs that are being studied. The industry and physicians need to make sure patients feel comfortable with considering clinical trials. Understand that it is scary for patients, but that there is a bridge where we can meet each other to make them feel comfortable. I know that because I participated in a clinical trial, doctors have learned more about this disease. There is a lot of learning that can be done from trials and a lot of hope.

To learn more about Tina and her story visit Own Your Crohn’s (<http://ownyourcrohns.com>)

“Tina’s story and the many struggles she went through remind us that there are many patients out there who are waiting for us to push the boundaries of research trying to find new answers to an old disease and its challenges.”

- Andreas Reiff, M. D., Vice President and Therapeutic Area Head, Rheumatology and Immunology, Parexel

A clinical trial is not just a trial, but a path to answers that lie within us all. For each share of Tina’s story, Parexel will make a donation to raise awareness of clinical research. #parexelwithheart