

# My Journey with Fabry Disease and Kidney Disease

By **Travis Kelleher**

My mother had been diagnosed with Fabry disease before I was born so I was informed about the condition I had at a very early age. However, that was in the 1970's when information about Fabry was more difficult to find. I feel my childhood was pretty normal for the most part but did come with some obstacles. The first symptoms of Fabry that I noticed were fatigue, burning pain in my hands and feet and anhidrosis (inability to sweat). In grade school, I was picked on often because I could not play very long outside before the fatigue and pain got to be too much for me to handle. Often I lashed out at the "world" as I felt sorry for myself and wondered why I have this condition.

As I learned more about the condition and how to cope with the symptoms, things started to get better. I went on trying to live as normal of a life as I could. When I was in my mid 20's my doctors started to notice my creatinine level begin to rise. Kidney failure is also a symptom



of Fabry. I knew this day would come eventually; I just did everything I could to keep my mind off of it. I made some changes in my life hoping to push off kidney failure as long as I could.

Right about the time I turned 30 I was notified about a clinical study for a new enzyme replacement therapy drug that was being developed for Fabry patients. The study was being held at Mount Sinai Hospital in New York City (NYC). I began to go to NYC from Wisconsin every other weekend to participate in the study which I did over the next several years until the product was approved by the FDA in 2003. I think being at Mount Sinai had the biggest impact on my life. The clinical study was held in their pediatric department and I met so many young children with a whole assortment of different conditions. It seemed the children with the most severe conditions were the happiest. It was at this time that I realized how foolish I was when I was feeling bad for myself and angry when I was younger. I found out how lucky I had it compared to so many who were/are dealing with a lot worse.

At about this time in my life I had fallen into Stage 3 of kidney disease. With receiving the enzyme replacement therapy, I was hoping to avoid losing my kidneys. In 2008, I met my now wife, Trinh, and we started dating. After I told her about Fabry she really didn't seem to be affected by it, which surprised me. I had noticed my entire life,



once I told somebody that I had a rare condition, they didn't seem to stick around very long. Only two months after marrying Trinh, I had dropped into Stage 4 kidney disease and began the process of finding a donor. After family and friends of mine were tested it turned out none of them were a close enough match to be a donor. Trinh went in and was tested in June and it turned out she was

a perfect match. We started making plans for surgery expecting for it to occur in late 2012 or early 2013 but I quickly slid into Stage 5, or End-Stage Renal Disease (ESRD), so the transplant surgery took place in July of 2012. I am now four years' post-transplant and things are good. Trinh is still as healthy as can be with no issues. The one bad thing about receiving an organ from your wife is that I now have to agree with whatever she says.

I had once heard, "Every curse comes with a blessing" which I take to heart as I look back over my life. I feel everybody living with a chronic disease will feel that way at

some point through their journey with the condition. Fabry disease (and all other health conditions for that matter) is not easy to live with, but I feel it has made me the person I am today. I am very optimistic and very patient. I have empathy for people who are suffering. I don't sweat the small stuff, plus many more attributes that I really don't know I would have if I didn't grow up with Fabry.