

Difficult Journeys Lead to Beautiful Destinations

Michael Kaline
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Since about 2011, I have been dealing with a “finally” identified disease. Before that something was off (since 2008), and I did every test under the sun to find out what it wasn’t. Finally, an answer; Erdheim-Chester Disease (ECD). But what is ECD? I’m still working on that. I do know one thing for sure, it is a game changer.

For several years, I tried different treatments. My physical-being slowly was decaying. I had lost about 40 lbs. Aside from this, I was not able to do the same things that I used to do (like working out, jogging or just about anything outdoors). The other main issue is general fatigue. I had to learn to lower my expectations. My mental-being was also decaying. I was starting to feel unproductive and tired of not really getting better. I started to believe that I was being punished for something really bad that I had done earlier in life.



Sometime in 2015, I was blessed enough to be enrolled in a clinical trial at the National Institute of Health (NIH). For the first 6 months, I felt about the same, but was driven by the thought that the clinical trial could help people in the future. After about 7 months, I started feeling better and that gave me hope.

Apparently, that was the kick in the butt that I needed. Things have been on an upward trend since then. The road has not been easy. And it has been a slow burn. I am about to drop a bunch of clichés. They have changed my life and I wish the same for everybody.

First, ‘Don’t Ever Give Up.’ It is not fair to your family and friends who have supported you. And most importantly, it is not fair to yourself.

Second, ‘Difficult Journeys Lead to Beautiful Destinations.’ Life is not easy but you have to believe that the juice is worth the squeeze. All this BS leads to a beautiful place. Which brings me to my third and final tirade of clichés (for today).

Challenges make life interesting, but overcoming them makes life meaningful. Take the field and face the challenges. Make tomorrow better than today. Treat each other like you want to be treated. And see you in the end zone...

To submit your story, contact us at support@erdheim-chester.org.