# Rare disease stole her sight at 27

## An interview with Erdheim-Chester Disease patient, Kit McElwee

By Elizabeth Silva Anderson, ECD Global Alliance
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*Photo courtesy of Richard Favinger, Jr.*

"The toughest thing was that I lost my sight within the total of 4 months. It wasn't even that gradual. It was there and then gone."

Spunky Kit McElwee is learning to adapt to blindness. A rare slow-growing cancer seized her health and stole her vision at 27 changing her life forever.

"At first it was hard. Having your sight is a very intricate part of your life."

The southeast Pennsylvania native was diagnosed with Erdheim-Chester Disease in 2007. The characteristic white-blood cells, known as histiocytes, infiltrated her leg and arm bones, heart, brain, and the tissue behind her eyes. The inflammation crushed Kit's eye nerves causing permanent blindness right as her adult life was just beginning.

"I had a lump on my head and I went to my family doctor. She was a breast cancer survivor. So when I said lump she didn't even hesitate. She sent me right for an MRI. She didn't know what she was looking at. So she sent me to my neuro-ophthalmologist. Between him and his two colleagues, they didn't know what they were looking at. And he said, well maybe it's cancer."

"I was 25 at the time and cancer was not a word I wanted to hear. I had a neurosurgeon remove the lump. It turned out to be Langerhans cell-histio. They did another MRI and it came back with something behind my eyes. He did some radiation on the tumor behind my eyes but, the tumors got bigger. He sent me to an ophthalmologic surgeon and she operated in my eye. From a biopsy it turned out to be ECD."

Kit's doctors expediently started her on Interferon-alpha, an immunosuppressant, and chemotherapy treatments. Her doctors believe her ECD is now in remission but she suffers the side effects of the lesions' scar tissue behind her eyes and in her brain, slurring and slowing her speech.

Having ECD and being blind often places Kit in an “in-between” space with people affected with either illness not able to truly sympathize with her condition.

“People from the ECDGA that I’ve met are great but nobody else is blind. It’s nice to at least know people who have ECD. I am part of blind groups and even there they don’t have ECD. So they don’t even know.”

Despite the devastating blow so early in her life, Kit is positive about the familial support she has received and focuses on how she has adapted to life affected by rare disease and blindness.

“I have come to live with the fact that I am blind.”

After losing her sight, Kit with the help of her older brother and younger sister, became a certified SCUBA diver. With the help of friends, she has learned to ride a tandem bicycle. And has taught herself braille.

*Photo courtesy of Richard Favinger, Jr.*

Learning to adapt to a new way of life demonstrates Kit’s resiliency. At the 2015 ECD Patient & Family Gathering in Houston, TX, Kit shared with 30+ patients how she learned to sort coins by feel of the weight, size, and identifying markers. It made no difference that others believed she couldn’t do the task, she proved them wrong.

Kit wants others to recognize that she is a fighter but life as a blind person can still be difficult.

“It’s tough living life as blind person and people should understand that blind people are people too. We have white canes and we do stuff a little differently but that doesn’t mean we aren’t people.”