



DISABILITIES MINISTRY

"And when they could not bring [the paralyzed man] to Jesus because of the crowd, they removed the roof above him..." —Mark 2:3-4 (paraphrased)

REFLECTION

Behind the Dark Glasses

He was only 20 months old and had had his fill of caroling at the nursing home. Bored, his little hand reached for my glasses and, before I could stop him, they fell to the floor and the frames broke into several pieces. I pulled out my prescription sunglasses, took my son home and went off to buy a new pair of glasses. It was Saturday evening and I had to have glasses to preach the following day.

My prescription was old, so I needed to see the optometrist. The current prescription wasn't quite doing the trick anyway, so it was probably time for new glasses. As the exam progressed I was focused on my hope that the diagnosis wouldn't include a move to bifocals, so it took me a minute to fully grasp what the doctor was telling me. Bifocals were the least of my worries; I had just been told that I have a rare eye disease that leads to blindness.

With this new knowledge I began noticing changes previously passed off as a need for a new prescription. I started missing steps and falling. I had trouble reading the Bible and began using the Pulpit Bible almost exclusively. (That's a little hard to carry to the hospital!) I began to notice that my eyes were sore and blurry when I first woke-up, but they seemed to clear through the day. I went to an ophthalmologist who gave me a name to attach to what was happening to me – Fuchs Dystrophy. He confirmed that if I lived long enough I would go blind, but that this was a very slow moving disease. OK, then! I tucked that information away and went on with the task of living and serving God.

Five years later we moved to a new state. I was having trouble seeing and again figured I needed new glasses. My new ophthalmologist asked if I knew I had Fuchs Dystrophy, and that I was at least 10 years into the disease. That 10-year timeframe prompted me to do a little searching on the internet. Reading aloud with my family in the room, we learned together that Fuchs can cause sudden blindness, and not just in the elderly. I could see the fear in the eyes of my husband and children, so I once again tucked the information in the back of my mind and moved on with life.

There were many things I was not seeing clearly, but I was extremely good at "faking it," or "compensating" as I preferred to call it. One Christmas, about six years ago, we were playing Rummy

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Cube at my father's house in Michigan. I finally had the tiles to go out, but as I began laying them down I realized I had mixed the red and the orange. "Are these the same colors?" I asked. My nephew laughed and said, "Are you blind or something? Of course not."

"As a matter of fact," I said, "I *am* going blind; that is why I asked." My nephew thought I was kidding until he looked around the table. My youngest son had tears in his eyes as he shook his head no. My sister turned to her son and said, "She is not kidding." My oldest son said something like, "Way to stick your foot in your mouth. That isn't the correct color group, Mom. Now let's play."

In 2009, I sat at the breakfast table with a woman at Annual Conference and talked for a long time. She seemed very familiar, but the light made seeing her face clearly almost impossible. She caught on to the fact that I did not know her and near the end of the conversation she told me who she was. I was very embarrassed, but the situation was also chilling. If you were at that conference in San Diego and thought I ignored you or walked right by you, please forgive me. I did not see you.

The more I found out about Fuchs the more I knew it was time to fully embrace the reality of the situation. Early in August I met with the doctor who pioneered the technique that would be used for a corneal transplant. If my eyesight cannot be fully restored, I hope that something can be learned to aid others in regaining their vision. I need to use what I learn to serve God better.

Following my first partial transplant, called a DMEK, I spent 3 days on my back to allow the cornea to attach. The prayers of my faith community carried me through. It was also helpful to know my surgeon Dr. Price, had a deep faith. The healing process was slow, but there were no major problems. This past December I had a DMEK on my second eye. Things did not progress as they should have, and just before Christmas the severe pain forced me to return to the doctor. I learned that there was a wrinkle in the donor cornea, and the left side of my graft in my left eye had detached. Following the repair I spent five days with my eye closed, on my back praying, waiting. Would I see again? I prayed for a Christmas miracle.

At the beginning of January, I returned twice to see the surgeon. At the first appointment, the contact was removed. I asked Dr. Price about the wrinkle. Would it make the cornea detach again? "What wrinkle?" was his reply. The wrinkle was gone! I had received my Christmas miracle.

I still have some issues and my progression is slow, but I am slowly regaining my sight. Sitting with a friend I suddenly realized I could see his face from across the room! When watching TV I realized the other day I could read the words on the screen.

Lying on my back in the dark, shaking uncontrollably from pain, the story of the blind man ran through my mind constantly. It was the scripture I had chosen for my anointing service. Oh how I wished Jesus would just spit on my eyes and heal me! But I have come to understand that vision is much more than the gift of physical sight. Vision is gift of the heart. Vision is the ability to see God's presence in your life and to act on that vision. Vision is being able to overlook disability and to see ability. Vision is being able to pick yourself up and allow others to pick you up when doors are

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slammed in your face and physical pain paralyzes you. Vision is faith. 'No storm can shake my inmost calm, while to the cross I'm clinging!' (My Life Flows on, from *Hymnal, A Book of Worship*.)

I have been an advocate for others most of my life. I was a special education teacher, pastor, , parent educator, and now I am learning firsthand what it means to have a "disability." It is not always the disability itself that truly holds you back; it is the attitude of others. The most painful and debilitating effects of a disability is the response or lack thereof that comes from the people of God, the church. Areas of support I always thought would be open to me slammed tight, and the lack of response felt cruel, cold, and brutal. But, windows I hadn't seen earlier opened to let the sunshine in and give me a glimpse of hope in my darkness.

One of my goals is to become a support for others who struggle to use their abilities in the face of disability. It is my hope that I can become a mover of barriers that hold us back from being the church of Jesus Christ. I am still on my journey to answer my call to serve God. Wherever my journey leads me, I hope my story will touch someone and bring them hope.

Please open your doors and windows to all God's children. Start today as you celebrate Disabilities Awareness Month. Before we die, we will all most likely experience a disability in our lives. May God's peace be with you always as you seek to use your abilities and the abilities of others.

~~ *Lucinda K. Barnum-Steggerda*
La Porte Church of the Brethren
St. John's United Church of Christ

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