

## An Orange Socks Story - Phyllis and Keven: Polymicrogyria

Interviewed by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. I was excited to have an Orange Socks interview with Phyllis and Keven about their daughter, Laura. I had the privilege of being their next-door neighbor for several years. Our children became life-long friends, and I consider them extended family. Their youngest daughter, Laura, was diagnosed with polymicrogyria.

Gerald: When did you find out Laura had some problems?

Phyllis: When she was about three or four months old, we went to the doctor because she wasn't progressing. She wasn't making the normal milestones. He checked her and felt there was something wrong with her, so he had us go to the neurologist and that's when we found out.

Gerald: What was the diagnosis?

Phyllis: At first, she didn't know what it was. Then we found out it was polymicrogyria, which means that the brain didn't develop normally. If you look at a picture of a brain, it has little folds in it, and she had lots of little tiny folds but none of them were very deep. It's a lot like lissencephaly, which is a smooth brain. They have a lot of the same symptoms.

Gerald: How did you feel about that diagnosis?

Phyllis: I was crushed. I asked myself, "Why me? Why did this happen to me? I do everything I'm supposed to do. I'm a good person, and I try hard to do what I should do. Why me?" That's how I felt.

Gerald: What were your thoughts, Keven?

Keven: I had a lot of hope, still thinking that the doctors would figure something out. I thought that eventually she would come around and get cured. But then as we kind of learned about what polymicrogyria was, I guess I kind of lost a little of the hope, but I still felt like we'd have a child who we'd love and bring up. We didn't know how it would affect her as she got to be four, five and six. At that age, I just thought, "Well, okay, she's just slow at making sounds and things." I didn't have that full reality that she wouldn't develop.

Gerald: How did it affect her when she was four, five and six?

Phyllis: She couldn't walk, she couldn't talk, she couldn't feed herself, she couldn't do anything for herself, but she could smile, and she could make people happy. She seemed to comprehend what was going on around her. Her body just didn't work to let her do the things that she wanted to do, but she was happy being herself.

Gerald: What were some of the hard parts about having a child with this particular disability?

Phyllis: Feeding her was really hard as she had a hard time eating. She had a tonic bite, she would bite down and then couldn't release her bite. It took forever to feed her. She would gag, and the food wouldn't go down, and it just took forever to feed her so I think feeding her was the hardest thing.

Gerald: Do you have anything to add to that, Keven?

Keven: I don't remember at what age we had the feeding tube installed.

Phyllis: About four years old.

Keven: I guess I worried a little bit about her not growing, but once the feeding tube was in, that was its own little fear of learning how to visually see a tube in her tummy that connected into feed her. Once you do it a couple of times, it's easy to do.

Gerald: What were some of the joys in having Laura?

Keven: As Phyllis stated, she had this killer smile, and you could tell when she was happy, which was usually the case, or when she was sad. You could pick her up like any normal child and put her arms around your neck, she just couldn't move them. There were the joys of just holding her, and she was happy. She would have these, I don't want to say giggle sounds, but you could hear her when she was happy. She was always smiling at you and interested if you would sit and talk with her or read her a story, she was always attentive.

Gerald: What were some of your joys?

Phyllis: Holding and snuggling with her. She was the best kid I ever had. She never talked back to me, she never ran away from me in the store, and she was happy. She was such a happy person. She used a wheelchair, we tried her with a stander as she liked to be upright. We became very creative about finding her different ways to sit up and to be part of the family.

Gerald: How old was she when she passed away?

Phyllis: Ten.

Gerald: How did that affect your family?

Phyllis: That was so hard, so hard. I think we lost a child twice. When she was born and she wasn't a normal or typical child, it was like we lost the vision of that child, and then we accepted her for who she was, and learned to love her and enjoy her. Then we lost her when she died, we lost our child all over again.

Gerald: Tell me, how did she affect your family, your children, your immediate family and your extended family?

Keven: All the kids learned to feed her and take care of her, and it's nice that they were all introduced to the concept of handicapped people so their eyes were opened into accepting others who were of that nature. They all loved her. We all learned to just love her. I liked going out a couple of times to Dan Peterson's school where they work with kids like that. It was fun to go to the Halloween thing because you see all sorts of kids with different types of disabilities, many like her and others who were different. They all were pleased to be able to participate somehow, and Laura would be pushed around in her chair. They had a fishing pond, so we'd stick the rod in her hand. She can't maneuver, so we were attempting to help give her those experiences. It brought joy to all of us to expand our love and to work with her.

Gerald: Phyllis, do you have anything to add?

Phyllis: I think she taught my kids to be more compassionate than they would have been. She helped them to become more open to different people. I feel like Laura came here to teach us. She didn't belong to just us. In our neighborhood, people would think they were so special because they would come up to her, and she would smile at them, and they would think they were so neat because "Laura smiled at me, she likes me." In church, she attended normal classes for children, and the kids loved her. Even those kids were touched by Laura, and their lives have been affected by her.

Gerald: If I came to you seeking advice because I had a child of similar condition, but very young and had just received the diagnosis, what would you tell me?

Phyllis: I don't know if you're lucky, but it took us a long time to realize how blessed we were to have Laura. She brought so much more into our lives than we could have ever imagined. There's a song about how you could have missed the pain, but then you would have missed the dance. She brought so much joy into our lives that I wish she was still with us. The greatest pain was when we lost her.

Gerald: Keven, do you have anything to add?

Keven: I guess I'd explain that life will be little bit different in handling children like this, and there might be a little bit more time that you need to spend taking care of them, but I would tell you it's the best thing in the world. You would miss out so much. I guess it's like any other life decision where you choose to do this or you choose to do that, and there are different consequences. I wouldn't pass up the child.

Gerald: That's wonderful. Thank you. Laura's impact on her family and those who knew and loved her was profound. The family still honors Laura and gathers at her graveside three times a year, at Christmas to place luminaries, at the anniversary of her death, and on her birthday to release balloons symbolizing her freedom.

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