

## An Orange Socks Story – Camille and Martin: Seizure Disorder

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I have known Camille and Martin for many years. They were pioneers in getting services for their children. Theirs is a wonderful story in finding joy in their children.

Gerald: So, Camille and Martin, you have four children. How many of them had issues? Tell me your story.

Camille: Three out of four. We had the first, third and fourth children, and they were born with no problems, then developed the problem around 5-7 months of age. They started having seizures. The oldest one was considered a genius. She was able to put a puzzle together at the age of four months, and she was able to walk into the doctor's office three or four steps on her own by the age of seven months, and then she had her first seizure. They think that the problem was exacerbated because of the medication they gave to treat the seizures. However, the children developed retardation from that point on, and they had what was considered the top three percent of people with seizures that were uncontrollable. We've dealt with that ever since, but they never found a specific reason for it, or a name for it. They all had the same issue, and then the learning disabilities on top of that were all slightly different. The typical reaction at the time, and still today, was that the regular pediatricians would start out with Phenobarbital, which will cause retardation. So, the sooner you get to a specialist, and have the neurologist make the assessment, the better. She was seven months old before she had a problem, and they were telling us that we were raising a genius because of what she was able to do.

Martin: It was a similar pattern with the third child. It was at about five months that she started having seizures, and at that point we had a little bit better pharmaceutical help, but it still wasn't where it needed to be, like it is today. They have lots of opportunities with pharmaceuticals that help to suppress the seizures, and at the same time, not do possible damage to development. They're not fully developed at five months, of course, and a lot of development takes a place in the third trimester, which is what we were dealing with. This onset of seizures was taking place during the third trimester, which is a very critical time for the development of a young person. Things didn't go very well, but I wasn't devastated or overwhelmed by that, and we were still looking for a fourth child, and it was a great joy in that it was a boy. But again, we went through the same cycle of seizures and disabilities like the others.

Gerald: How did you react?

Camille: I had a really hard time with the first one, because she had been doing so well and was so bright and cheerful, and then suddenly began having so many problems. The seizures increased, and the doctors' appointments increased, and it was quite difficult. He was working, and I was home and trying to figure out what to do for her, and we talked about it very little. Then I started to talk to the doctor about it a lot, and I started to think, "You know, this is what we've got to deal with, and we'll just figure it out. We'll make it work." I started to kind of investigate it, and instead of worrying so much about it being a huge problem, I started to think, "Okay, how can we make it better for her?" It was interesting because the doctors were always assuming that I was trying to deny that it was a problem or that it was all about me, and it was really frustrating because to me it was always about her and how I could help her be the best that she could be, and be the healthiest that she could be.

Gerald: What was the hardest part?

Camille: The hardest part was maybe also the best part in a way. When we started out, everything was kind of in institutionalized mode. It was special schools, and special places for them, and special this and special that. And with three children with disabilities, we had the opportunity of saying that we wanted to have our kids in regular schools. We can have them in classes with peer tutors and with aides and all, but we want them in a regular school instead of having them bussed from this city to another city. They would say, "Well, you're the only parent that wants that." And we'd say "Well, we have three kids like this, so we have three children that we want this for." And so, by having the multiples, we had a little more push for

them to consider it. It did help to start the local programs in our city that way. So, it was helpful on that side. It was interesting because we often had three kids have seizures five minutes apart, so there were trials that way, but also because they had similar problems. We weren't dealing with three different kinds of problems, three different kinds of disabilities, and so that helped, too.

Martin: Juggling a schedule, keeping work in order, keeping everything in order, making sure to help and support Camille when all three of them would go down within 5 or 10 minutes. We'd discuss what we were going to do, and were we going to take them all to emergency? How are we going to handle it? Often times, because their situation was so unique back then, we would go to emergency, and then we would have to kind of coach the emergency doctor on how to give the best medical support for the situation, because they didn't all know. Often, they thought they had something that was kind of new to them, and they would turn to us and say, "What do they usually do?" or "What is usually done in these particular situations?" Sometimes we'd find some really sharp ones that knew how to take decisive and direct action, but maybe half the time, we'd find somebody who couldn't handle it very well. We'd find the same kind of thing happening in the school district. It was just wonderful that the IDEA bill came along at the federal level, which mandated support for young people with disabilities for services given by the local public school system, but we had to educate the local public school system as to what was best for our kids rather than what was convenient for them to present to us. We found that they had a tendency to say, "Well nobody else has need for these services." We came to the realization that there were others who wanted these same services, but they didn't know or didn't understand that they could make requests, or that services could be made available different from what they were getting. I think the districts were caught in the middle because they had a financial issue with regards to these kinds of services, and at the same time, they were obligated to take care of business by federal law. That was a struggle, too. That was difficult.

Gerald: What were some of the joys?

Camille: Oh, there were a lot of joys. As you know, two of the children have passed away. We look back and laugh and tell stories still about a lot of things that the kids did. Marty was 17, and Carrie was 25. We have neighbors that have left the neighborhood and kids from their schools who we'd run into here and there, and they still tell Marty and Carrie stories. We have a tree across the street that they called the Marty tree that they planted and he dug up, and they planted and he dug up, and they planted. We have a neighbor who moved several years ago, and when I see her, she talks about how in the fall we were cleaning out the yard, and Marty would bring the wagon full of leaves over to her house so that they could throw them away. He would bring our leaves over in the wagon. There are a lot of cute stories in the neighborhood about the kids, too. There are a lot of joys that they brought to their experiences through the neighborhood, and they taught people a lot of tolerance, patience and love through the experiences they had. A lot of people hadn't seen the Marty's and the Carrie's and the Jenny's around the community, and I'd never seen an individual with a disability until I was 16 years old. When we had our children and realized that it's three out of four and we're going to sink if we don't do something differently, we decided we were going to do it differently. So, rather than hide our kids, we had them out in the community. As you probably know, as I did advocacy work, the kids went with me. So, when we did "Sub for Santa," our kids went with us and did "Sub for Santa." When we did community work, the kids went with us and helped us with the community work. They were out there helping and cleaning snow off driveways and whatever. The people in the neighborhood saw that and it made a big difference. People saw them as able and contributing members of the community instead of just folks that were odd or different.

Martin: One of the many joys I'm reminded of today is that we have some snow out there. When the kids were quite young, they were able to do more and participate more. And as they got older, they had those disabilities kind of manifest themselves, and there was less activity. We used to shovel all of the snow off of our driveway and then go across the street as a team and shovel the snow off of the driveway over there. We would do many things together. We'd get out in the community, and Jenny in particular had a great affinity for good manners and "please and thank you," and she trained the adults in the school system that this was needed or they weren't going to get performance from her. One individual who became a great friend to us and to Jenny said that Jenny turned her around in how she handled special ed because of the experiences she had with Jenny. So, Jenny did that for her. Some of the great joys, too, were people in the state. Camille was involved in The Ark, so she would get involved with the governor's counsel and be

invited to a lot of family conferences and such, and our kids were very much there. They were just a joy to be a family, even though they had some limitations, but we still recount phrases that they used, the ones that are passed on that create smiles on our face. They were great! Those are choice memories for us.

Gerald: How were you able to take a break?

Camille: You know when you've got three kids with seizures, it's really hard to find a babysitter, and family never filled up that role either. So, we didn't have opportunities for the two of us to just take off and go very often. We did find one eventually. She had a brother with Down syndrome, and she had parents who were very, very supportive of her, so we did manage in the '90s to get away a couple of times, and we actually took her with us to Disneyland and on a trip for two weeks. Family-wise, extended-family-wise, it was more difficult because of the three. What we did just strengthened us as a family ourselves, so when we took trips, we took them with us, and we had some great times and were probably more like your average family that way. We didn't find it as restrictive as you might think, and we had some great times with the kids.

Gerald: How did her siblings impact your daughter Jackie, who doesn't have a disability?

Camille: We used to just tell Jackie, "This is the way our family is made up," and if the Lord thought that we could handle this, then we'll be able to handle it, we'll find a way to handle it. I used to tell her that I had to work, or if we were going to have extras, we would make that work out as well. In my case, I worked in the disability arena. It gave opportunities to her that we would never have had, and to me as well. We always made her understand that it was a blessing and an opportunity for her. We did the "Sub for Santa" and things where we helped people. She now is such a strong advocate. The first things she did when she graduated as a civil engineer and moved to California was to look up The Ark. The first thing she did when she went to Illinois was look up The Ark. She still does "Sub for Santa," and her kids do it now with her. She's never seen having siblings with disabilities as something that tied her down. She's never seen it that way. She sticks up for people. If she sees somebody who is mistreating someone with disabilities or not, she sticks up for them and she teaches. She's proactive that way. It has not harmed her in any way. It's been a blessing for her, and has made her a better person. People are always telling me how impressed they are with her as a person, both people who know her background and people who don't. It's been a really good experience for her.

Gerald: What have been some other benefits?

Martin: We've met some wonderful people who are kind, caring and giving people, and those are people who have associated with our children and been kind and caring to others, too. I think that's another dimension to the challenge of having three children with some disabilities.

Gerald: Would you do it again?

Camille: I don't know which would be better or which would be worse. I have traced the seizure problem through my line. I had seizures when I was younger, and I've had a couple since. I learned that my mother had a couple when she was younger. I've read my grandmother's diary, I know that my grandfather had them. We've all had different ones. Our kids have had the run of the mill. Martin's father had migraines that used to cause him to black out which probably, combined with my genetics, made it worse. You never know. I've traced the seizure line back to the 1700s. Okay, so knowing what I know now, I could say, "Ugh, maybe we shouldn't have had kids with this problem." However, we could have had perfectly fine children and had a car accident and had kids with brain injuries. We could have had any number of problems down the road. You just never know. People have problems, so do you want to pick one? Or do you just want to have a family and deal with it? I think I'd just choose to deal with it, and you can moan and groan and cry, and to some degree, I did that for a few months. I think the average person would because when you're faced with something different than you're used to, you tend to do that. But at some point, you stop and think, "This is enough, " and "I need to get on with it," and "What can I do? What CAN I do? I can't change it. I can't fix it. It's out of my hands, but it's what I'm dealt." So, pick some books up. Talk to a doctor or two. If you don't like what the one tells you, talk to another one. Make some comparisons, take

some notes, see what you can do and get on with it. That's kind of what we chose to do. With any kid, with any child in any family, that's what you do. You just find another way to deal with it. And as you go on, you make friends with other people, you find groups, you find people who can help you and people who you can help, and on you go. Along the way, with any family, you find joys.

Martin: Again, Camille reminds me of many, many joys and many, many wonderful experiences. And although the cycles of our family are very unique and special, we learned a lot along the way. That's to be appreciated, and we enjoyed it. It was challenging and there were difficult times, but we found that we had answers to overcome those challenges, that others would be puzzled to solve those kinds of problems. We had joy in solving problems, too.

Gerald: I have learned so much from Camille and Martin over the many years that I have known them. They are my heroes in the field of developmental disabilities. In many ways, they are just a normal family, and have acted that way despite a unique set of circumstances.