

Family Member Profile – Judy Daschuk

Sept., 2007



As I was planning our romantic trip to London and Paris for our 10th wedding anniversary, I jokingly said to my husband Terry, “wouldn’t it be funny if I got pregnant and we had to cancel our trip”. That would never happen to us or so we thought. Well, as the old saying goes...never say never!

Imagine our shock when my doctor confirmed that I was indeed pregnant. What I had thought was just another symptom of Lupus, the chronic disease that I had been suffering from for the past 6 years, turned out to be morning sickness. I was warned that I could easily miscarry but things went well during my closely monitored pregnancy. Nine months later I gave birth to our son, Nicholas, but our joy was short lived as I had been sick with a high fever during the delivery and he was born with a

severe staph infection on his skin. I only held him long enough to take a picture and then he was whisked off to the NICU for 5 days. Surely our troubles were over, but this was not meant to be so.

From the start, Nicholas cried a lot and never slept. As he got older he stopped talking and he made little eye contact. He would go out of control with temper tantrums. Imagine our sadness when he was diagnosed with Autism at the age of three.

The next few years were a nightmare as we muddled through the governments long waiting lists for services and we found there was a huge lack of resources in the schools. As the BC government does not recognize Autism as medical disease, but sees it as a behavioral problem, it means many of the treatments are not covered. We’ve seen other families with autistic children who have gone into debt and sadly marriages have fallen apart because of the strain.

When Nicholas started school I was amazed to see that there were at least ten other special needs children attending the local school. Another mother and I organized a support group to meet once a month for coffee and to discuss how we could get the most out of the school, to exchange knowledge and resources. In the second year I arranged to have speakers come in and we added community partners to the group. After several years of meeting together we all went our separate ways because as our children grew older and attended middle school many mothers went back to work part-time or on to other things. One mother became a school trustee to ensure that the voice of special needs families would be heard at the school board level; another mother became part of the group that spearheaded the movement to take government to court which resulted in the funding that all autistic children across the province receive. Without realizing it, this group actually connected me to Partners Care when one of the community partners received a posting for a job at BC Children’s called the PiC Family Liaison. She recommended one of the groups speakers, Susan Greig, for the position; and as you all know Susan did get the job and the rest is history. Along with those important relationships that I established through the group I learned that networking with other families is important & that you cannot do it alone.

Today Nicholas is 13 years old and attends middle school. Along with Autism he now suffers from severe Obsessive Compulsive Disorder (OCD), being afraid of germs. Our hearts ache for him as he lives in a world that he is afraid of and does not understand.

When I was approached about joining Partners in Care, I felt that I was inadequately qualified to join; after all, Nicholas only periodically uses BC Children’s services. Upon attending a few PIC meetings however, I was struck by all of the members deep commitment to family centred care and I realized that regardless of what our child’s medical issues are, we are all parents who care and want to make a difference. Imagine what we can do.....

PS. As for that 10th Anniversary to Europe, we still did go...but with a baby in tow and minus the romance.

Family Member Profile – Heather Fowlie

May, 2007

“I don’t know how you do it!” has become a familiar phrase to me over the past 10 years. My most frequent response is, “You play the hand you’re dealt”. Some people might think that I have been dealt an unfair hand, but I wouldn’t agree. It started with a routine pregnancy, so normal it was boring. But when my baby Quinn was born, they knew immediately something was wrong. He was blue and his lungs were full of fluid. Every breath sounded like a washing machine. I held my baby for about 30 seconds before he was taken to the BCCH Special Care Nursery.



I wouldn’t hold him again for 10 days.

Quinn was born with Esophageal Atresia with Tracheal Esophageal Fistula, a rare genetic anomaly where the esophagus, instead of attaching to the stomach, attaches to the lungs. He could not swallow and he could not breathe without assistance.

At three days old, he was transferred to BC Children’s Hospital for surgery to try to attach his esophagus where it belonged. The day-long surgery was unsuccessful. While his esophagus was no longer attached to his lungs, it was too short to attach to his stomach. Breathing was better, but swallowing was still impossible. So Quinn would have to stay at BCCH and wait to see if time and growth would make the next surgery a success.

About a month later, the hospital discovered another problem. Quinn had another rare anomaly: a cleft (i.e. hole) between the top of his trachea and his esophagus. Even with a tube placed permanently down his throat to suction out his saliva, he still choked constantly as saliva spilled into his windpipe. At three months of age Quinn got a tracheostomy: a tube in his throat to help him breathe and clear saliva from his airway.

Along with the trach came a move to more permanent quarters in the Technology Dependent Unit of the ICU at BCCH. This would be the Fowlie family home-away-from-home for the next 10 months. Quinn underwent dozens of surgeries to try to close the cleft and to try to reattach his esophagus. In between surgeries the ICU staff did their best to make a tiny 9x9 space seem like home. I commuted to BCCH every day to take my place at his bedside, working to help Quinn achieve the developmental milestones of his first year of life.

After 6 months or so, the Fowlies were a fixture in ICU, well known to all the staff and other families that moved through the unit. Life had become pretty stable and one day I was approached by a staff member who wondered if I knew about the family advisory committee, Partners in Care. Maybe I’d consider coming to a meeting? I was there anyway, so I thought I’d go. I’ve since come to consider Partners in Care to be one of the many gifts my son has given to me.

I was so excited by the work that Partners in Care was doing to improve the lives of families at BCCH that I immediately jumped in with both feet. Within a year I was co-chair, and had made some of the most meaningful friendships of my life. Here I was in a room full of people who understood what it was really like to have a chronically ill child. And here was a group of people who could look outside their own circumstances to see that there were other families who needed to be heard and have their needs met.

That was why I joined PiC. I knew that the skills I had learned from months of advocating for Quinn could be used to help other families who didn’t have those skills or, for one reason or another, couldn’t advocate for themselves.

Quinn was discharged from BCCH at 13 months. He still has a trach and though they were able to attach his esophagus, he's still unable to swallow so he is fed by tube. Today, he is an active and artistic 9 year old, and I have been a member of PiC for over 8 years.



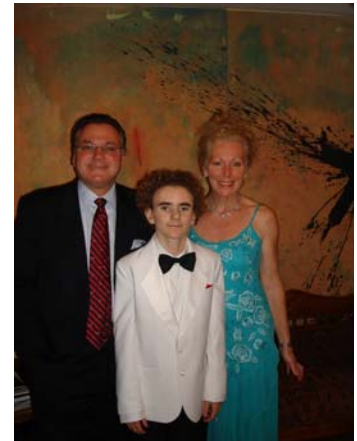
Through PiC, I have been privileged to travel to exciting conferences around North America and learn what is being done to advance the cause of family-centred care in many different places. I sat on a hospital-wide task force which re-wrote the policies regarding families' access to their child's hospital chart. I currently sit on a very exciting new initiative at Women's and Children's Health Centre: a group looking at ways to educate healthcare professionals about working together as an interprofessional team which includes patients and their families. I also sit on the Communications Working Group of InBC, a group dedicated to promoting interprofessional education and patient centred care.

My true passion is education. I believe that family-centred care needs to be at the core of all healthcare education and I'm dedicated to seeing that happen in BC.

So you see, I got a lot of aces in the hand I was dealt.

My name is Lucinda Jones and I have come to be a member of Partners in Care through the extensive amount of time I have spent at Children's Hospital with my son Hunter.

Around the hospital I hardly need to use Hunter's last name for the familiarity he has gained over the course of the last thirteen years, since he was 11 months old, as we have been administered to, it seems, by almost every department. I was about to correct the "we" in that last sentence but it has of course been he and I, and my husband, and Hunter's two older sisters, who have all experienced being admitted once again to hospital, having to cancel once again other plans, feeling the absence of precious family members at meal times and no mother during morning preparations for a new day. But we are hardly alone, unfortunately! Every time I re-enter the world of BCCH I am reminded that our family is just one of the thousands of families who have a hard row to hoe and who come to this institution seeking remedy to a crisis, solace, reassurance, direction and especially, healing!



How can a hospital acknowledge a whole family as it embarks upon caring for one member of that family? This is the consideration of the phrase "Family Centered Care" and is fundamental to the mandate of Partners in Care. Hospitalization can be difficult, even traumatic, the whole family needs support and recognition. How does Partners in Care support the hundreds of well-meaning medical practitioners and staff at BCCH to be as effective as possible? The focused PiC committees have been established with the intention of answering those needs. Participating even to the small measure that I do, on the PiC Family Advisory and Food Services Committees, gives me a place that is concrete to direct my hopefulness.

In my heart, my spirit and my soul, Hunter and I are locked together like two crew members lashed to the helm, braving enormous waves of fear and grief and demoralizing pain. As he quietly holds fast in the face of all adversity we concoct kooky humour to throw at our assailants. He is my inspiration! When Hunter was one and two and three and four and five the gift store in the lobby would be our daily outing; how couldn't it be for a child who suffered so much? But once discharged, his question would be, "what shall we get at the store for me today?" Oops!

Certainly Hunter has taught me the meaning of "carpe diem!" – to seize the day with all of our strength and not let go until that great ball of light has sunk below the horizon and with it, our consciousness. Tomorrow might not come! Today, there is everything! When we are well, we are really, really well! This has been the most wonderful influence for me to direct also to my two daughters, who thrive and live their lives also to the fullest!

Every day my son is not at BCCH is a blessing, yet when we are there, we are blessed. The ability of everyone at BCCH to appropriately address and embrace the child is nothing short of stupendous. It is easy to rally in support of the medical and administrative staff and those who are patients and their families, to help take BCCH forward into new vistas of healing and care.

Family Member Profile – Donna Tack

May, 2007



In September 2001, my then five-week-old son, Spencer, suffered a massive brain injury. The injury was caused by complications due to simple reflux and a tragic mistake at our local hospital. That night, Spencer was transferred to the ICU at BC's Children's Hospital.

After about three weeks in the ICU, we were told that Spencer's brain injury was so catastrophic that he would likely not survive. We were given the opportunity to go to Canuck Place Children's hospice for end of life care. We spent about four weeks at the hospice where Spencer stabilized enough that we were then able to transition home through Sunny Hill Health Centre. It was there I learned how to care for this incredibly complex child, and how to use all the technology that was now a part of our everyday lives.

We did finally make it home, though not for long. The first four years of Spencer's life were a constant battle. Numerous surgeries and even more frequent bouts of pneumonia had us spending up to two hundred days a year at Children's.

It was during this time that I learned of the Family Advisory Committee. I was approached by one of the staff on the group and asked if I would like to join. Those first couple of years, my attendance was, at best, sporadic. However, I was always welcomed, no matter how bad I looked or how many days without a shower I'd been! The other parents always seemed to know when you were 'in' as we'd say, and their quiet support and true understanding meant the world to me. My opinions and ideas were always valued and respected.

As Spencer's health improved, so did my attendance at the meetings. In 2005, I was asked to take on the role as co-chair and I gladly agreed. I still hold that position in the group. I am also a member of the Family advisory Committee at Sunny Hill and also hold a directors seat at my local Child development Centre.

Getting involved with the PiC has helped me have a voice at the hospital and to also try to represent the other families who may not otherwise be heard. I am so proud of all this exceptional group of people has been able to accomplish. We have gone from a small, "under the radar" parents group to a highly respected, valued part of the hospital's inner workings. We have made access to charts for families a reality. We sit on boards and subcommittees and lend the parents point of view to the health care providers and administrators that might otherwise be overlooked. We have found a way to recognize and acknowledge excellence in the practice of family centered care throughout the hospital through our Bravo Star and Family Centered Care wards. We strive to ensure that family centered care is the cornerstone of practice at BC Children's.



I am extremely proud to be a part of this group of exceptional people whose main focus is to make the hospital a better place for families.