

Patient Stories, continued

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Calgary, AB

Pediatric dysmotility problems

By: Joan, Saskatchewan, Canada

Mark was born on July 6, 1983. At seven pounds, five ounces, he was perfect in every way. A contented baby, he slept well and cooed and smiled, meeting all his developmental markers as he should. He was exclusively breast fed until he was at least six months old, when he started to experiment with some soft and pureed foods. However, I continued to breast feed him long after his first birthday.

Once Mark's diet progressed to solid foods, he was one who had to be watched carefully anytime he had food in his mouth. He often gagged and choked. His older brother kept a close eye on him and patted his back to help him get the food up and out when he was in trouble. Mark was never allowed to eat without someone near.

Overall, Mark had a pretty healthy start, with the odd hiccup, an inguinal hernia, three surgeries for blocked tear ducts, facial cellulites, and a period of time when he had asthmatic symptoms, probably related to chemicals sprayed on a field near our home. When he was having breathing difficulties, Mark's doctor decided to test him for cystic fibrosis. The result was negative.

As I reflect back on those early years, I remember Mark saying "I have a head egg in my stomach". He used that expression numerous times in those pre-school days.

By the age of six years, Mark was having difficulty swallowing his own saliva. He was constantly in the bathroom, spitting. He said his mouth tasted bad. Soon, he was not just bringing up bubbly saliva, but undigested food was coming up with it. Because he was embarrassed and ashamed, he would take a tissue and hide behind the couch or table to purge. The garbage cans were always filled with Kleenex tissues.

He began to lose weight rapidly and became severely dehydrated. He was admitted to hospital and IV was started right away. Within hours, he was his old playful self. At that time most of his admissions were for only about three days. Each time, he would feel better soon after the IV was started. He eventually figured out that he felt better while in the hospital. When he became horribly nauseous and weak at home, he would ask to go back to the hospital to "get that needle in my arm." The doctors and nurses determined that his condition was psychosomatic. We were questioned about the possibility of abuse at the hands of family, friends or neighbours. After all, it was obvious that every time he went home, he just got sick again.

We finally met with a pediatric gastroenterologist, who was very kind, but had no answers for us. However, he called some months later and asked to see Mark. He said, "I just found H pylori in a thirteen year old and knowing it is possible for someone so young to have this bacteria present, perhaps it is possible that a six year old could also have it." He had an endoscopy and

the result was positive for H pylori. Now we understood why Mark felt better on IV. It was because there was no food in the digestive tract feeding the bacteria. They would starve while Mark was on IV. He would feel better, go home, eat, feed the bacteria, get sick, and the cycle would continue. Hence, Mark began taking antibiotics each and every time the symptoms would appear. They worked, and he felt better than he had for some time. However, by the age of ten years, he was not thriving. The antibiotics were prescribed frequently. Nausea and pain were a constant. It appeared that every time he sat down to eat and his digestive juices started working, he felt that overwhelming nausea and urge to move his bowels. The bathroom light was on more than it was off, with Mark sitting in there for hours trying to void.

His teachers expressed concern about the time he spent in the school washroom. His brother asked me to tell doctors that he had been inside every washroom from British Columbia to Halifax. Of course, he was the one who had to accompany Mark to the bathroom every time we travelled away from home.

A new local pediatrician was very concerned when he first met Mark who had symptoms of pneumonia. He was so wasted looking, and his breathing was so shallow, that he was convinced he had cystic fibrosis. Again his test result was negative. From the age of ten years until age fourteen years, Mark failed to thrive. I would describe how he felt in terms of good weeks and bad. Then it came down to good days and bad. As he became more ill, his good times were limited to hours. He was thin, weak, exhausted, cold, tired and had almost constant nausea and pain in the area of the small bowel. His greatest pressure point was to the right of the navel where he said "it feels like there is a match burning in there". His gastro thought perhaps his trouble was motility, and prescribed various drugs, including Propulsid, Cisapride, Buscopan and Losec. These did not improve Mark's condition significantly.

When Mark was thirteen, he developed 'Shingles'. Needless to say, that was difficult and enhanced his pain. He missed so much school that it was necessary to do most of his work at home with Tutors for Math and Sciences.

Mark started grade seven in 1997, but would see little of the classroom that year or the next. He had many hospital admissions, some that lasted for several weeks. Initially, the doctor thought it was related to the recent death of his grandmother. Again, he was looking for the psychosomatic link. I explained that his grandmother lived hundreds of miles away and was not a constant in Mark's life. It was unlikely that her loss would affect him in such a way. His weight dropped from one hundred and fourteen pounds to a low of seventy-eight pounds, frighteningly thin for someone five foot seven. That entire year was a bit of a blur. I know that when the gastro did the endoscopy, he determined that "there was quite a lot of inflammation and swelling in the duodenum, looks like Celiac or Crohn's." He told me to call the intern in charge if he got into big trouble. He would be away at a conference but knew it was possible Mark would need attention before his return. As it was, Mark deteriorated quickly and had to be admitted once again. The Barium was forced down his throat because Mark was non-compliant. He couldn't keep water down and certainly couldn't swallow the Barium. The radiologist summoned me in to view the path of the Barium. It was trapped in the stomach, barely trickling down through the

duodenum. There was some panic and then phone call to his specialist who was on course down east. The decision was made to pump his stomach. I am uncertain that was ever done. Based on this test, the diagnosis was made. "Crohn's Disease". He was immediately started on Solumedrol. The following week was horrendous. Mark's pain had him literally screaming. I pleaded with nurses to request an x-ray. I was certain that the Barium had solidified in his bowel. Hospital staff were insistent that the Barium had passed long ago, but I knew it wasn't so. Finally, x-rays revealed that his bowel was full of Barium. He was administered enema after enema, more x-rays, more enemas. He was infirm for several weeks. Finally, he was released with prescriptions for prednisone and Zoloft. He could not tolerate the Zoloft and discontinued after a few days. He had collected a cup full of lorazepam tablets in the top drawer of his hospital room, which he turned back to nurses on his release. He said they made him feel fuzzy. During the next two years, Mark was in and out of emergency rooms. He had a few more lengthy admissions. Each time they would up his steroids. He never did respond well to them and was becoming visibly depressed. Many different anti-depressants were prescribed. Mark always said "the anti-depressants don't make me feel any better; I just don't CARE as much that I am sick". Eventually, his gastro told us that he was sorry about the fact that Mark had lost his 'growth' opportunity due to steroids taken during his teens. He was concerned that his depression was related to the use of the prednisone. It was also noted that his symptoms were not diminished. Mark was then put on Imuran, an immunosuppressive. That treatment worked very well for just over a year. He responded positively and was able to resume a pretty normal lifestyle. Unfortunately, his white cell count dropped below acceptable levels and the drug had to be discontinued.

We were back to square one. His doctor had accepted the diagnosis of duodenal Crohn's and tried everything available to help reduce symptoms. Nothing worked. During his treatment, it seemed we were constantly giving him something to increase peristalsis and something else to reduce cramps. Other drugs were given to help control the nausea. It seemed that nothing helped control the symptoms. I cannot recall all of the drugs, but he reacted very badly to some of them, especially the 'stemtil' and 'reglan'. During one of his admissions, Mark was given enteral feedings. He tolerated them well for a short time, then the tube kept blocking and eventually he was unable manage the nausea.

By the time Mark was 17 years old (2000) he was in big trouble again. This hospitalization would last four months. He was referred to another gastro, who after studying his medical history, announced that he was quite certain that Mark did not have Crohn's disease. He thought it was likely to be neuro-muscular and suggested that I get on the internet and check it out. The hospital was far from home, so I had no access to a computer. I called a friend who worked in the lab at the hospital and asked her to do some research. She did. Having known Mark his entire life, she was certain that she had come up with an absolute diagnosis. She met me for lunch and presented an article on 'Chronic Intestinal Pseudo-Obstructive Disorder. This was it!!! It described Mark perfectly. The gastro took the article, read it, acknowledged it, and asked to make a copy. By now, Mark had been on TPN for some time. He was not even able to

tolerate water. The nausea was out of control. It appeared that initially there was a standoff. The doctor was simply waiting for Mark to decide to eat and drink. That would not happen. Finally, the doctor told us that he did not know what to do with Mark. Would we consider taking him to the Mayo Clinic for a consultation. He had consulted several experts across Canada that indicated they had nothing to offer in terms of treatment. Mark was eventually referred to pediatrics in Rochester Minnesota. He flew air ambulance and remained a patient for ten days. We were told that his liver function tests were a concern and that they would have to remove the PIC line. His urine was dark brown. He needed help to get out of bed. His weight was dangerously low and his spirits were even lower. They tried the enteral feedings again, but could not even run a teaspoon per hour without Mark retching and heaving. Eventually, he pulled the tube right out. Ever so apologetic, he broke down and cried. He just could not tolerate it and begged them not to put it in again. They were unable to run the test which involved placing a tube down his throat and having him eat a chicken dinner. My husband thought they were nuts. He said "he hasn't eaten in four months. What makes you think he will eat a chicken dinner with a tube down his throat?" The pediatric gastro came in and assured Mark that his endoscopy revealed a healthy duodenum and that everything looked healthy. This was five days before he was to be released. We realized by now that the Mayo Clinic had no miracles for Mark. The doctors prescribed many drugs, including domperidone, reglan, celexa, laxatives and anti-nauseants. They recommended a transfer back to the University Hospital in Saskatoon, where Mark had been living for the past four months. We decided to take him home. Mark, my husband and I flew home on a commercial flight. We were all depressed, exhausted and beaten down, recognizing that we had been to what was considered the 'top of the Medical pyramid' and had come home empty handed. Within three days, we were back in the emergency ward, seeking IV rehydration. That night I said to Mark, " I think you are actually getting worse on all of these drugs". He responded, "I do too".

I suggested that we flush all the drugs and take a complete about face. I asked if he wanted to seek help from Dr. Amell, a Naturopath whose practice was right here in our town, Moose Jaw, Sask. He agreed that we had nothing to lose. Now we had a new direction. Dr. Amell devoted many many hours to Mark's care. He was very slowly introduced to liquid nutrition and then simple foods. Mark took support for his adrenals and his liver. He took enzymes for stomach and bowel. Natural products were introduced to reduce inflammation. Dr. Amell was troubled with Mark's inability to absorb nutrients. Testing was sent to North Carolina to determine what happened to the food from the time it was consumed to the time it was eliminated. Results indicated that he was not getting the nutrients from the food, they were simply passing through. From 2001 through to 2005, Mark was holding his own. He managed to complete High School, get a driver's license and held down a part time job for awhile. He was never strong and healthy, but at least able to participate in life. Some days he could only tolerate liquid nutrition, some days he could manage a bit of pureed food, and some days he would actually eat solids once or twice a day. His mainstay has been a nutritional supplement manufactured by Metagenics called InflammX. He has been drinking this at least twice daily for seven years. Besides supplements,

Mark had Cranial Sacral Massage, Chiropractic, Physio and worked faithfully to restore his emotional health through an audio-video program 'Understanding Anxiety and Depression'. He joined the gym, lifted weights and eventually purchased equipment for home use, which he uses daily, even on the really bad days.

In the fall of 2005, for reasons unknown, Mark had a downturn. He was projectile vomiting water when we finally had him admitted to hospital. His body temp was low, heart rate low, and BP was very low. He had lost a substantial amount of weight and was again well below 100 pounds. His fingers were blue and even a heated electric blanket would not stop the shivering. He was in and out of the hospital for several months. A referral to another gastro in Regina, Sask. gave us new hope. However, numerous tests did not bring forth a definite diagnosis. This gastro did not acknowledge the information I offered on Chronic Intestinal Pseudo Obstructive Disorder. He suggested that he continue to take his 'Effexor'. For approximately eighteen months Mark continued taking the Effexor, but did not like how it made him feel. He decided to gradually reduce his dosage and eventually went off it completely. The withdrawal of this drug brings on extreme anxiety. It is a tough one to kick, but Mark has determined that he will never be convinced to take it again.

Today Mark is twenty-five years old. He spends most of his days on the computer, watching TV and reading. He exercises daily and walks outside when the weather permits. His loyal friends come by most days to hang out for awhile. When Mark feels energized and his nausea and pain are under control, he gets up and out. He shares that whenever he feels good, he knows he must get going and do something because he feels like the 'meter's running'.

The time when he feels good is limited to minutes or on rare occasions, hours. He weighs in at about 95 pounds and stands five foot seven. His debilitating nausea and that constant feeling that he describes as 'backed up' and the 'plugged drain, continue to haunt him daily. He used to enjoy swimming, snow skiing and karate, but those activities are now out of the question. He is too cold, too weak and too ill to participate. Recently, he purchased a program to learn the Japanese Language. It is challenging, but gives him something new to think about. He has been working at home on a complex Math program. This is good brain exercise. One day he came home with an electric guitar and announced that he wanted to add some variety to his activities. Whenever Mark has some enthusiasm for anything, it brings hope that there will be better days ahead for him.

I attended the GPDA presentation in Calgary on June 21st, 2008. I was moved to tears when I recognized that there were actually gastroenterologists who understand and acknowledge Mark's symptoms. Until that time, I felt that our family was an island fighting this disease.....alone. One of the presenters at the forum, a renowned and respected gastroenterologist invited me to contact him regarding my son. He said that 'Hoping and Praying is just not working' and he is right. Mark deserves to enjoy a better quality of life and we are hopeful that he will. Our family is very thankful for the gifted professionals who have come together to offer hope for a brighter future to all those who suffer from these GI disorders.

I invite anyone who is interested in contacting me to use my email address j.cathcart@shaw.ca