

Alessandria's Story

When Alessandria was three years old, she started suffering from frequent tummy aches. Her parents thought it was some sort of bug at first but then she started sleeping 12-13 hours a night and napping three hours during the day. Finally when she started losing her appetite, they took her into their family doctor who did some routine blood work. One Friday night at 10:00pm, they received a call telling them that Alessandria's liver enzymes were very elevated and that they should take her to McMaster Children's Hospital right away.

As with many forms of liver disease, it took several more weeks, trips to the ER, hospital stays and countless tests until a diagnosis was finally confirmed. Alessandria had primary sclerosing cholangitis or PSC, a form of liver disease which causes bile ducts outside and inside the liver to become inflamed and blocked eventually causing severe liver damage.



"Everyone was shocked," says Natalie, Alessandria's Mom. "No one in our family had ever heard of PSC before and we did a ton of research to try and learn everything we could." What they learned is that PSC is uncommon in children and that the cause is still unknown.

Since her diagnosis, Alessandria has had to learn to live with her disease but her life is anything but 'normal' compared to other 7 year olds. Having PSC and Crohn's as well as being lactose intolerant, Alessandria can't have any dairy, nuts or popcorn and must avoid certain raw fruits and veggies. She is on a low fat diet and is trying to find a medication that will help with the non-stop itching caused by her liver disease. Her migraines and joint pain means she has to see a neurologist and a rheumatologist who have also prescribed additional medications to treat these conditions. In the past year she's had two MRIs and will have a colonoscopy in May.

"The last four years have been a roller coaster," says Natalie. "Alessandria was originally in a clinical trial with a doctor from California who specialized in pediatric PSC. Then in May 2011 she went on Vancomycin - a drug that cost us close to \$700 per month. We were only able to afford it for seven months and then we had to take her off. The following year she had C-difficile, lost a lot of weight and missed 40 days of school. It's been very stressful on all of us and we spend a lot of time away from home and I miss a lot of work."

When Alessandria was first diagnosed, all she knew was that something was wrong with her tummy. As she's grown older, she understands more about PSC and Crohn's and why she needs so many tests.

"She goes for bloodwork all the time and never cries," says Natalie. "She knows that they're necessary to check on how her liver is doing and if the various medications are working. But there are some days, she just doesn't want to take her meds - and who can blame her?"



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While it's hard to share her daughter's story, Natalie understands that Alessandria's is just one of many that demonstrate how little people understand about liver disease and its impact on a family. "People will say she doesn't look that sick so it can't be that bad," says Natalie. "Yet they don't know how she feels on a daily basis, how many medications she has to take or how many blood tests and hospital visits she must endure. By sharing our story I hope that I can help raise awareness."