



Lymphedema Matters

Association of Ontario

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Our journey so far...

This time last year we were anxiously awaiting test results for our daughter Emily in the hopes of getting a diagnosis to explain her puffy little feet. We have learned a lot since then...

We welcomed our sweet baby girl into the world on October 16, 2013. I was blessed with a very healthy pregnancy and a quick and natural labour. While the midwives were checking over Emily, they shared some concerns about the swelling in her little feet. After consulting with the nurse practitioner, we were referred to the pediatrician that was on call that day. While we waited to speak with the doctor, my husband consulted Dr. Google (which is never a good idea) and our concerns were elevated to a whole new level. We read about Turner Syndrome, Milroy Disease, kidney and cardiac complications. I tried to remain calm and optimistic, as I didn't want to be robbed of this beautiful moment. My husband who is naturally a worrier was very concerned. After speaking with the pediatrician, she mentioned many of the same possible causes and so the testing began. Within the first week of her life, Emily had blood work taken, an ultrasound of her kidneys done and a urine sample to check her protein levels. Fortunately all the test results came back normal so we continued to monitor her over the next couple months.

At six weeks of age, Emily's care transferred from the midwives to our family doctor. We shared with him all of the testing that had been done so far and our concerns about what we might be dealing with. At this point in time, it had been mentioned to us that Emily might have Turner Syndrome. Edema in the feet is a common symptom of Turner Syndrome, but no testing had been done at this point. Our family doctor recommended that we get the necessary tests done so that we could confirm or eliminate this possibility. He sympathized with us, saying that we would never be able to rule out the possibility unless we knew for sure. Since it would only require some blood work, he suggested proceeding.

After much confusion about where to have the blood-work done and which forms to fill out, we were informed that this type of testing can be quite in-depth and, given the backlog of work, it could take months to receive the results. We waited for 6 long weeks to hear the results. During that time, we were trying to learn more about Turner Syndrome and prepare ourselves for a positive diagnosis, all the while trying to remain hopeful. Emily also had another ultrasound of her abdomen and pelvis. Then, at one of Emily's doctor appointments, our family physician shared that the results had come back negative for Turner Syndrome. We were delighted with the news but we were also left wondering what it was that was causing this swelling in her feet. We were also beginning to wonder if we would ever know. *Continued on page 7*



The Stephens Family

Lymphedema Association of Ontario

Committed to improving the lives of people living with lymphedema

416-410-2250

Toll Free: 1-877-723-0033

info@lymphontario.ca

Charitable Registration number

87165 5049 RR0001

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LAO Conference Cancelled

As you are aware, the LAO conference that was scheduled for March 6 & 7, 2015 was cancelled due to low registration. The decision was made by the LAO Board and team after lengthy deliberation and the realization that the registration numbers would not be expected to increase significantly. The low registration meant that the event would become too costly to host.

We sincerely apologize for this outcome as there were numerous supporters and we believed that there was interesting information to be shared and an opportunity to network. However, despite our ongoing promotion and registration encouragement, we were not successful in reaching registration numbers that would support a successful and cost effective event.

To assist with future planning, we will be sending out a survey to get your feedback. We encourage you to complete the survey as we value your input.

We send a tremendous THANK-YOU to all who have been involved in the planning (planning committee members) and to the presenters who have put time into preparing presentations. Perhaps in the future we can plan for an alternate venue/presentation method to share your material. Also a tremendous THANK-YOU to our sponsors and exhibitors, and to those who registered for the conference.

We are grateful to all who have expressed their understanding. We plan to take this information to plan for the future. And we are also extremely grateful to all the sponsors, exhibitors and registrants who donated all or a portion of their conference registration fees to the LAO.

Our apologies for any inconvenience that the conference cancellation has caused and thank-you again for your support.

Respectfully,

The LAO Team and Board of Directors

LAO membership sign up or renewal options:

 **Online:** Go to www.lymphontario.ca, click on the "BECOME A MEMBER" button and begin your membership affiliation or renewal process.

 **Phone:** Call 416-410-2250 or 1-877-723-0033 to join/renew by credit card.

 **Mail:** Fill out a membership form and remit a cheque or credit card information by mail. Please make your cheque payable to: Lymphedema Association of Ontario. The membership form is located on the back page of this *Lymphedema Matters* insert.

Benefits include:

- Newsletters
- Information updates
- Quarterly national Lymphedema magazine "*Pathways*"
- Discount for the LAO conference
- Voting right for individual members at the LAO Annual General Meeting

The pediatrician that we were seeing recommended that we see a plastic surgeon at McMaster University Medical Centre. I was very confused as to why the referral would fall under this area of specialty but she explained that there isn't exactly an area of specialty for the lymphatic system and so the specialist with the most experience would be a plastic surgeon. My family doctor also thought that this was a strange referral but we decided to go to the appointment. At this point, we wanted to speak to as many people as possible to see if anyone knew what was going on with Emily. Looking back on that appointment now, I am still confused by the information that they shared with me, an experience we now understand is quite common with lymphedema patients and the parents of lymphedema patients. I know that they never used the words "primary lymphedema" to explain Emily's condition; in fact, they didn't give her a diagnosis at all. Rather, they recommended that I have custom compression garments made for her and sent me home with a list of local shops that could help me coordinate her first pair.

So, in search of a solution, I called around to a few of the shops and shared our situation. After speaking to our local shop, the sales person was in shock that they would recommend compression garments for a 5 month old. I was too, but I thought "Hey, who am I to have a medical opinion on the matter?" She offered to call around to some of her colleagues who have worked in the field for thirty-plus years, and she did. When she called me back, she said that after consulting with her colleagues, they all agreed that Emily was still too young to be fitted for compression garments, especially, since they didn't have a diagnosis as to what was causing the swelling in the first place. I was completely frustrated at this point. If the experts in the field didn't know what to do for Emily, I was starting to wonder if we would ever have any answers. I felt so helpless! She recommended that I contact Pam Hilliard, who is a physiotherapist at Sick Kids who has a lot of experience working with infants and children with lymphedema. I tracked down Pam's number immediately and left her a message. When she called me back, I was almost in tears. Finally, I was talking to someone who was familiar with Emily's condition. I felt such relief and joy to know that we were no longer alone in this.

When we first met with Pam, we shared Emily's medical history and Pam knew just how much information to share with us at that point. Most importantly, she explained that primary lymphedema is a condition that is diagnosed by elimination. Since we had already gone through the necessary testing, she set up an appointment for us to meet Dr. Clarke at Sick Kids. She sent me home with elastogrip and showed me how to make little stockings for Emily to wear. She also explained the benefits of manual lymph drainage and showed us where to find qualified massage therapists in our area. She explained

the importance of proper skin care and we talked about which types of footwear would be most appropriate for Emily to wear. She was the first person who seemed to be able to answer any of the questions that were keeping me awake at night.

Over the next few months, we did lots of reading about primary lymphedema. I learned how to do manual lymph drainage and was massaging Emily daily. We purchased some adorable soft-soled leather shoes for her to wear around the house and outside to help keep her stockings on and to add some light compression. It felt really good to have things that we could do to help. As Emily grew and became more mobile, the swelling came down.

As the summer approached, I purchased lightweight leggings in almost every colour for Emily to wear under her summer dresses. One day our family went on a hike in the forest and I thought it would be nice for Emily to wear shorts on such a hot day. I knew that the trees would shade her but what I didn't consider was how bad the mosquitoes would be in the woods. Our anxiety heightened as we swatted at every bug. Our leisurely walk in the forest was anything but. We learned that day to be more prepared. Sunscreen, bug spray, leggings and shoes were really important in reducing Emily's chances of getting a skin infection that could develop into cellulitis.

Emily began walking just after she turned 11 months old and she has been trying to keep up with her brother William ever since. She is a very active little girl. She loves to swim and she loves to dance. She is quick on her feet and has become quite the climber. We are relieved and so happy to know that she will be able to do all of these things and many more.

A big thank you to Janet Stephens for organizing an auction fundraiser and donating some of the proceeds to the LAO.

Last spring, I was longing to do more. I wanted to help generate funds for research but I knew that I couldn't make a significant donation on my own. I contacted my crafty friends and family to see if they could make a few items that I could auction off. Using social media, I organized a 5 day online auction in late November, just as people were getting ready to start their Christmas shopping. I was overwhelmed by peoples' generosity, and before I knew it I had approximately 90 items to auction off. Donations included knit and crocheted mittens and hats, hand-turned wooden pens, a stained-glass and wooden cabinet, jewelry, baby bow-ties and homemade cards to name a few. I am delighted to share that we were able to raise \$2347 and the funds were donated to SickKids Foundation and the Lymphedema Association of Ontario. ■