

This is Ben

A young boy and his family navigate the lymphedema world together

By Katie Nedjelski

Ben is five years old, loves playing outside, skating, swimming, riding a bike, building Lego, going to school and making everyone he meets laugh. Ben also has primary lymphedema in his right arm.



After an uneventful pregnancy and birth, Ben arrived and we noticed his arm was swollen. This marked the beginning of our life with lymphedema—although we did not hear this new word for many months. As new parents we were consumed with finding answers as well as managing life with a newborn. We were followed by a pediatrician and began regular ultrasounds, X-rays, blood tests to rule out any other syndromes associated with larger limbs. We visited many clinics within the Alberta Children's Hospital, including Genetics, Oncology and the Vascular/Birthmark team. Nobody had a clear diagnosis or treatment path for us and we headed down many wrong turns and dead ends. We met privately with a therapist who was the first to confirm that Ben indeed had lymphedema. She trained us in manual lymph drainage, made Ben his first sleeve out of an adult sized garment and taught us how to wrap his arm. His development



and fine motor skills were always foremost on everyone's mind, but we saw no signs that would prevent us from treating him as aggressively as he would let us. At the age of one he had his first custom garments made and we were in a regular routine of manual lymphatic drainage.

Now at almost six, Ben is able to talk about his lymphedema when his friends ask why he has a bigger arm (they always empathize with their own creative story), he's able to tell the camp instructors that he has lymphedema and it's not a broken arm or a bug bite that sends them racing across the park to call his mom. He's able to tell the garment fitter that he doesn't like how it feels on his thumb or his therapist that it feels better or worse or no different at all. We end many evenings together talking about lymphedema, what it is, why he has it and why it makes him unique. Lymphedema will always be a part of our life. Here are some of the lessons we have learned in our short journey through the world of lymphedema with a child.

Be your child's advocate. Read everything: textbooks, blogs, studies, posts, articles. We quickly realized that we know more about the lymphatic system than many doctors or specialists we saw. There is no defined course of treatment, so we sought our own care path which included physical therapists, massage therapists, garment fitters, naturopaths, osteopaths and chiropractic care. We question everything and make



Katie and Ben Nedjelski live in Calgary with dad Sheldon and little sister Finley. Katie is a lymphedema advocate, a school volunteer, small business owner and muffin maker. Ben is a monkey bar master, known for his T-ball home runs and has aspirations to be an astronaut or firefighter.

sure each decision is the right one for Ben. Lymphedema affects people differently in general but with a child, no two cases are the same. What works for someone won't work for another so seeking out and trying different things is OK and I strongly suggest it.

Become a part of the lymph community.

We have met many families on the same journey both locally, across Canada and even overseas who we have connected with through social media and often rely upon for advice. Parenting a child with a rarely diagnosed disorder is lonely and finding others who share the same struggles is an important part of this community. We jumped into the advocacy role and have met with politicians, health care executives, lymphedema associations, Alberta Health Services, media and anyone who will hear our story and will help advance lymphedema care in our province and around the world. Awareness is a huge priority for our family and we hope that more children are properly diagnosed and given appropriate treatment options through our story.



Think outside the box. When self-managing Ben's lymphedema as a baby and toddler, we found unique ways to keep him happy and get his treatments in. MLD was done nightly in the bath and wrapping became a part of our routine. His skin was very sensitive so we experimented with different stockings under his wrap and his dad was fast at getting his short stretch bandages

on. Sessions with our therapist were done in the high chair while he played and ate. Even today we are proud that he will sit for an hour session doing a craft or playing with Lego.

Dual purpose of compression garments.

Daytime garments are for compression and protection for little boys who love the outdoors. Sunburns, wipe outs, scratches and falls, all pose a threat of a skin infection. This risk is minimized by having his garments on.

Take one day at a time. The stress of a chronic condition and a rare disorder was daunting to us as new parents. As the first years passed our anxiety relaxed and we now feel that all we can do is try our best. We are grateful for supportive friends and family and are happy to provide that support to other lymph families! [LP](#)

If you have a child with lymphedema, please contact us at knedjelski@shaw.ca or find me on Facebook or Twitter. We would love to hear from you.



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