

Two Generations Living with Lymphedema

BY LYNN ZIEGLER AND
MARLISE ZIEGLER

Lynn's Story

All parents look forward to the arrival of their child and most expect the baby to be physically perfect. At my birth in 1947, my parents were shocked to see my severely swollen feet and legs. What was wrong?

No one knew the answer. The family doctor in our rural community pointed out that everything else was as it should be and perhaps the swelling would go away in time. My mother cried, the church prayed over me, my feet were kept hidden in the receiving blanket, and life went on.

"Will she walk?" was the next question. I did, and also progressed normally in every other aspect of growing. I had no awareness of disability; no recognition of pain or discomfort. What had always been was normal for me; although, perhaps I welcomed bedtime more than most children, as this was when lymph drainage took place.

School time

I started school wearing shoes that were slit open at the top to accommodate the swelling, but I still didn't feel that I was different from my classmates. Then it was time for my first Christmas concert and I wanted to know why I couldn't have shiny patent leather shoes like the other kids.

Time passed and I still hadn't really realized I had a disability. Then, one day, a teacher stopped me in the hall as I came in from recess. It was hot and the veins were prominent in my legs and my feet were very swollen. "Oh, my goodness," she exclaimed. "How did you hurt yourself?" I looked at her in alarm and then down at my legs. I answered, "They're like this all the time." I'll never forget the look of pity on her face as she patted me on the head and told me to go to my classroom.

Loss of innocence can be devastating, but it usually doesn't happen this way. Afterwards, I put a lot of energy into denying I was different and hiding the ugliness of my lymphedema from others. I became



Lynn and Marlise Ziegler: Two generations living with lymphedema.

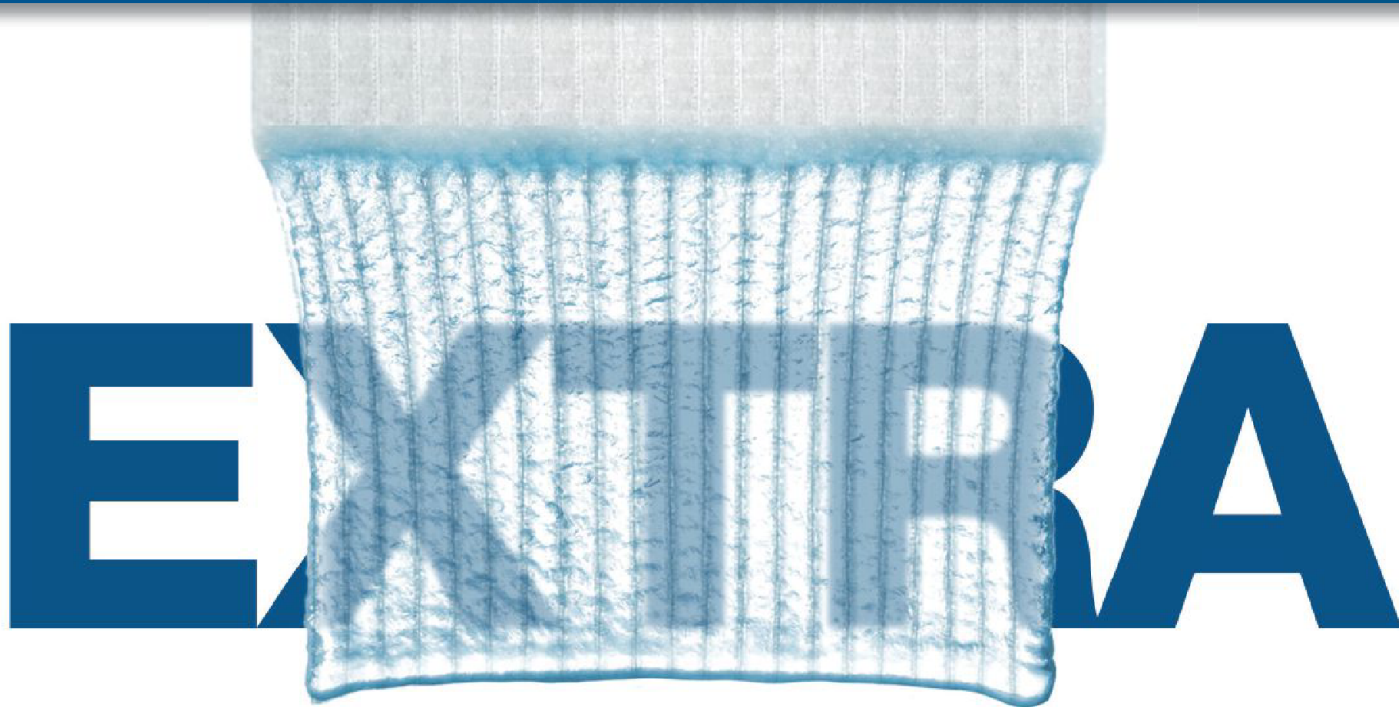
very aware of the other girls' slim legs and feet and pretty shoes, and envied them while feeling ashamed of my own reality.

My parents took me to various doctors. They looked at me and even did tests, but could provide no answers. I shied away from sports because I felt exposed and awkward. I kept my legs tucked behind me and wore long pants when I could get away with it. I didn't cultivate friends and was very introverted.

continued on page 36

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Through the generations

I didn't research my condition, look for compression aids or try to find a support group. I left home at 18, went to university, got married, worked as a teacher and got pregnant. Our first child was born – with lymphedema! I was stunned, but my husband focused on the fact that she was a beautiful baby girl. The doctor said to us, "I don't know what she's got, but she'll have to wear moccasins for the rest of her life."

We went to see a plastic surgeon. He was confident that a z-plasty would solve the problem or at least show the reason for it. My daughter Marlise was less than a year old when the surgery was done. There was no improvement or learning. In fact, the resultant scar tissue made the swelling worse.

Our second daughter arrived – again with lymphedema. This time the disability was less severe. I soon became pregnant again and the doctor offered an abortion. We refused and the new baby had no lymphedema. However, she was 6 weeks premature and a question occurs to me as I write: Did that make a difference? Does the lymph system in the lower extremities develop in the last trimester?

We went for genetic testing and were told there was no hidden or latent sign of lymphedema in our youngest daughter, my parents or my husband. We were told the condition was rare and probably a genetic mutation that had become dominant. Following my parents' example, we treated our children as normal kids and life went on. Luckily we lived on a hobby farm and everyone was busy with chores that required taking many steps during the day.

Unknowingly, we were doing the right thing – working the leg muscles and stimulating the lymph system. We also bought a trampoline. Exercising on it had the same positive effect.

Staying in control

At the age of 44, I decided I should look at wearing compression stockings. My doctor referred me to Alberta Aids to Daily Living (AADL) and I was allotted 2 pairs per year – AADL paid 75% and we paid the rest. Everyone should try to make 2 pairs of stockings last for a year! Everyone should have the experience of legs and feet encased like sausages in lycra, especially on a hot day. But despite the discomforts, I will never give the stockings up!

I'm now 63. I have kept the lymphedema under control and am thankful for my high pain threshold. I have no ulcers or wounds. I have had 1 knee replacement and await the second. I try not to think about whether my lymph system will be further compromised by this invasive surgery. So far, so good. But another question arises: Did the pressure of the swelling in my lower legs contribute to my worn-out knees? Doctors don't speculate on the answer.

At this stage in my life, am I psychologically damaged, afraid to go out and friendless? No. Luckily, I married the perfect person who saw me, not the disability and I "came out!" I am now a widow and I miss my husband of 38 years. But I believe life is good, despite my lymphedema, and I try not to worry about whether it will make aging more complicated than it is for other "normal" people. Again – so far, so good. ☺

Marlise's Story

It has never really bothered me to have lymphedema; after all, I was born this way. It's normal for me. I've mostly been able to ignore it or forget I have it. When I get upset about not being able to find shoes that fit or having to work my way into compression stockings (try it someday...it takes about 15 minutes and at the end I'm all sweaty and ready to go back to bed), it always seems there are worse things that could have happened to me. After all, I can still walk, run and jump, and do everything that "normal" people do.

Other people's problems

I never thought my lymphedema was "that bad" either. Until ... I meet someone who feels compelled to point out that I'm wearing panty hose (and ugly panty hose, mind you) in the middle of summer with shorts and sandals ... or I meet a medical professional who either

doesn't know what congenital lymphedema is or doesn't care, and leaves me with the impression that I'm at fault for having it. One medical professional said, "Well, it can't be that bad if you haven't gotten new stockings for a year." Hmm, I guess he ignored me when I said I wasn't allowed more than 2 pairs a year through AADL, and at that time I was a student and couldn't afford to buy them on my own.

Another doctor said, "I've never heard of someone being born with lymphedema; are you sure you didn't have cancer?" I imagine I would have remembered having cancer. My personal favourite was from a compression-stocking fitter: "Well, you're too fat, you should never have had kids. Look at what you've condemned them to. Really, you should be ashamed of yourself." Imagine yourself the recipient of those comments and then imagine how you would react. Generally, I allow talk like this to flow off me and patiently correct the commenter's erroneous impres-

sion of my disability; then again, sometimes the offence is far too large to ignore.

A disability?

Of course, I never saw lymphedema as a disability. Why should I? I wasn't in a wheelchair, using a multitude of medical aids or sentenced to a shorter life span. I didn't have to take medication or make frequent doctor or hospital visits. My employment and fertility options weren't limited.

Then, one day, my doctor enumerated the multiple ways lymphedema could negatively impact or shorten my life and outlined the limited medical aids available for a person with my condition. He stated unequivocally that I should never have had children because it worsened my lymphedema and I may have passed on a deadly and debilitating abnormality to them. He advised me not to consider employment in which I was required to stand or sit (really?!). It was then I realized I was disabled and had been fooling myself when I thought I was normal. Apparently, not only was I disabled but I was also an incredibly selfish person. I found this realization rather upsetting.

Now, to look at it rationally: My children are normal, with no signs of lymphedema. I will have them genetically tested when they are older to see if they have the gene. I refuse to apologize for my decision to have children and will not accept blame for raising happy, healthy, socially responsible adults who do not see me as abnormal. Having children did worsen my condition, but that was a choice I made and I will live with it and adapt my lifestyle accordingly.

There are limited medical aid options and they are difficult to obtain because of the expense involved. My condition will not disappear, so I will need compression stockings and manual lymph drainage for the rest of my life. Private insurance companies such as Blue Cross won't offer individual insurance to people with lymphedema because of potential complications and because it is an ongoing condition.

Public healthcare assistance consists of AADL, which has stringent conditions and limited coverage. I am now allowed 3 pairs of compression stockings each year. AADL will cover up to \$150 per pair, which is generous. The stockings I wear cost \$275 per pair and are effective in reducing the swelling in my legs for about 2 months. Ideally I should get new stockings every 2 months, but this would cost me \$1,200 per year. Manual lymph drainage, which is done on a weekly basis, is very effective in helping the lymph to drain from my legs; it is also reasonable at about \$120 per visit. Unfortunately, it's not available where I live and the travel cost combined with the massage fee

"I never saw lymphedema as a disability. Why should I?"

– Marlise Ziegler

would be about \$155. Yearly this would be over \$8,000 and that's just not feasible. AADL doesn't currently cover manual lymph drainage. I know these costs are tax deductible, but the money to pay for them still needs to be available up front.

If I am unlucky enough to develop infections and ulcers, then I will be visiting my doctor and the hospital frequently, as well as taking a lot of medications.

As for employment at which I would neither sit nor stand for long periods of time (definition: more than 1 hour) – well, I can't think of what that job might be. So I decided that since I have a disability, I should make it work for me. I have self-defined myself as disabled, requiring some freedom of movement and position changes at my place of employment. My employer wishes to provide equal-opportunity employment for all as well as a healthy work environment, so my situation is working out quite satisfactorily.

A work in progress

It may seem I have adapted quite well to having lymphedema – that I have a good understanding of the negative ways it could impact my life and am developing strategies to deal with them accordingly. Do not be deceived. It has been a long and unhappy road to get to this point. I have felt ugly, humiliated and worthless simply because my legs swell. I feel belittled and ashamed when people comment on my abnormality, particularly those people I am asking for help in making my situation more liveable. It has required a great deal of manufactured self-confidence and self-perception to realize those comments are born of ignorance and arrogance. I do not define myself by my lymphedema and I will not allow other people to do so. ☹

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Systagenix Acquires O2 Insights Inc., Adding a Third Marker to its Wound Diagnostics Pipeline

Systagenix announced today that it completed the acquisition of the assets of O2 Insights Inc., an Ohio based technology start-up developing rapid, reliable and cost effective point-of-care diagnostics for the measurement of transcutaneous tissue oxygenation.

Transcutaneous oxygen perfusion measurement (TCOM), or TcpO₂, is a key marker for chronic wounds where ischemia and/or hypoxia may be playing a role in delayed wound healing. In clinical practice, TcpO₂ is measured to help assess peripheral vascular oxygenation, assist in determining the need for revascularization procedures, and to assess the potential benefits of hyperbaric oxygen therapy.

O2 Insights' technology aims to address many of the shortcomings of current TCOM devices which can be complex to operate, take up to 45 minutes to generate a result, and can require a dedicated technician to operate. The O2 Insights Inc. technology holds the promise of providing easy to use, accurate, and reliable transcutaneous oxygen perfusion measurements in a matter of minutes and at significantly lower capital equipment cost, thus making measurement of TcpO₂ accessible to much larger numbers of patients and health care providers in various clinical settings.

With this acquisition, Systagenix continues to increase its point of care wound diagnostics leadership and footprint by investing in the development of clinically relevant markers and devices to penetrate an untapped potential multi-billion dollar wound diagnostics market.

"We launched WOUNDCHek™ Protease Status – the world's first point of care test for chronic wounds to detect Elevated Protease Activity (EPA) – in Europe, the Middle East and South Africa earlier this year. More recently we reached a very significant milestone by completing the first trial on our wound infection point-of-care test currently in development, and today by joining forces with O2 Insights Inc., we set out to develop an easy to use, rapid, and cost effective point-of-care test for tissue oxygenation" comments Ernest Waaser, Systagenix Chief Executive Officer. "Our goal is to provide physicians better diagnostic tools to help them guide targeted treatment earlier and increase chances of healing more rapidly and cost effectively. We are now well on our way to providing the tools to answer three key questions every clinician would like to know about a chronic wound – does it have elevated protease activity, does infection need to be addressed, and is there adequate tissue oxygenation?"



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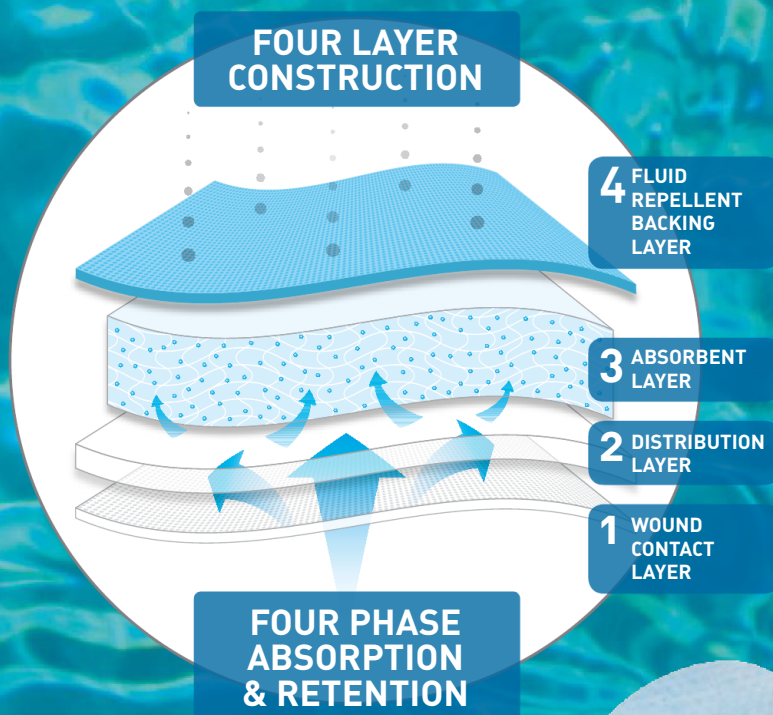
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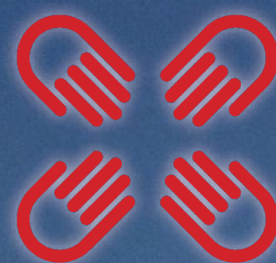
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