

Lymph Science Advocacy Program (LSAP) Participants Review 8th International Conference



KIM AVANTHAY

My interest in the LSAP program stems from my 3 year old son who has LE in his right leg and arm, so as you can imagine I want and need to learn as much as possible about LE.

To sum up the conference in one word, overwhelming. It was such an amazing experience to network and join conversations with the professionals in attendance. My eyes were opened up to a world of knowledge about Lymphedema that I didn't know existed. I realized that there are actually people out there actively working to advance Lymph Science and LE.

A huge bouquet and congratulations to you all!

The conference consisted of research paper presentations and break out sessions, topic specific. Some of the research presentations were well over my head but even so, I still managed to take away with me bits of knowledge. The abundance of appealing topic break out sessions made it hard to narrow down the ones I would sign up for but I was happy with the presentations I attended. All of the speakers were amazing and to my pleasant surprise, approachable. They were interested in the questions asked and responded to them in as much detail as possible. Time was a factor throughout the conference but the organizing committee did a tremendous job keeping it moving.

Specific Canadian "round tables" and meet and greet sessions were an awesome opportunity for networking. Hearing the other Canadians speak about their trials and tribulations were a great way to see what has been done and what is being done in neighboring provinces. This networking has opened up a whole new opportunity to gain wisdom and knowledge with support, closer to home.

As an LSAP participant, it was go,

go, go. There was little time to stop for a break and the days were very full. Being able to meet the other LSAP participants and discuss together the information we heard throughout the conference made the world of difference to have a better understanding and a look at the information through the eyes of someone else. It was a wonderful group to be a part of and each participant was special in what they could offer to the rest of the group.

My son is full of energy and people are drawn to him. The thing they notice after his bright smile is his compression garments. Their question is always, "oh, did he burn himself?"

My response is always, "no, he has a condition called Lymphedema." They get that look on their face that says they have no idea what I'm talking about, they try to pronounce it back to me, and then I've got them...I say, Lymphedema, it is a condition...You can bet that once I'm done with them, they will not forget what LE is.

Thank you Saskia and the NLN team. Thank you so much for this wonderful opportunity. I am forever grateful and I will be spreading the word about LE.



JANICE GOLDBERG

I was thrilled to receive an email in early July 2008, informing me that I had been selected as an LSAP participant! I have a ten-year-old daughter who has primary lymphedema in her right foot and lower leg, diagnosed at age four. Thankfully, she suffers from relatively mild swelling and disfigurement. However, we have struggled with various troubling complications over the past year and a half.

I had been acting as her tireless advocate during our navigation of the medical system. Various medical team members often told me that I was the lymphedema "expert." As I knew that I had very limited knowledge and

understanding of lymphedema and the lymphatic system, I found this assertion very troubling indeed.

Unable to find satisfactory answers to our daughter's difficulties, I became interested in promoting lymphedema and lymphatic research in Canada. Attending the NLN conference was an important goal in order to educate myself about the current state of scientific knowledge.

From our first LSAP group meeting with Saskia on Wednesday (pre-conference day), until the conference wrap-up morning on Sunday, I felt privileged to be participating in an event where everyone attending pre-conference day was passionate about lymphedema: its treatment, management, and scientific investigation and understanding. Certainly, I was even busier than I had anticipated. As a member of a select group of patient advocates, I felt a responsibility to learn as much as I could through full attendance at the early morning roundtable seminars, plenary sessions, and educational workshops.

I listened, wrote, and tried to absorb the constant stream of knowledge and information being presented. (I felt a new appreciation that I had at least completed high school math and science!) I can now rhyme off phrases such as "axillary lymph node dissection," "measurement thresholds for sub-clinical identification," and "bio-impedance analysis" with confidence.

I was particularly excited by the imaging research. Perhaps I am biased towards the importance of imaging in understanding the physiology of LE and the lymphatic system (I am married to a radiologist), but I cannot forget the words of a well-meaning physician describing the following conundrum to me with respect to my daughter's case: "We cannot treat what we cannot see."

Although there was limited information pertaining to primary lymphedema

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in particular, I gained valuable understanding of the different modalities of research that contribute to the understanding of this disease. For example, prior to attending this conference, I had never once thought about how a data management study might be designed, or that patient attitudes and subjective findings about their condition could be quantified and analyzed, thus leading to scientific impact.

On Sunday "wrap-up" morning, I realized that for me, the stated objectives of the LSAP program had been absolutely met. I felt that as the "gate-keeper" to so much information, it would be morally wrong for me not to share this knowledge. As I told Saskia that morning, I now felt a profound impetus to act on my intentions of promoting awareness, change and research. Moreover, during the conference, I developed friendships with the other LSAP participants and I derived inspiration from their remarkable stories of strength, tenacity, and hope.

Post-conference, I am thrilled to have recently been elected to the Board of Directors of The Lymphovenous Association of Ontario. I will focus on promoting research with the help and direction of LAO Executive Director Anna Kennedy and the other board members.

Friends and family have asked me if I learned anything specific at the conference that could make a significant difference towards my daughter's treatment and management. My reply has been that I learned that we are doing everything right for now, but that I was buoyed by the evidence of the growing numbers within the scientific and treatment community who are advancing the state of knowledge and awareness



JAN HASAK

As a lymphedema patient advocate, I perceived the 2008 NLN conference to be an incredible eye-opener. From the presentations at the first plenary session to the concluding talks I gleaned

invaluable insights into the latest research and development on the lymphedema front. Especially enlightening were the presentations with encouraging news about pre-surgery measurements.

All surgeons who perform axillary node dissections and sentinel node biopsies should be informed that comparing such measurements with those post-surgery may be an important factor in diagnosing lymphedema. If a clinic can afford it, the bioimpedance device is a superior measurement tool. Sessions on the psychosocial aspects of lymphedema were intriguing. Speakers on this subject discussed the value of a solution-based approach to patient adherence rather than a more controlling approach that discourages compliance.

At other plenary sessions I learned that pumps may benefit some patients, and that the Flexitouch system may help those at home who cannot perform self-MLD effectively. A Flexitouch representative treated me to a soothing and relaxing half-hour session. ➔

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At a workshop presentation by an M.D., I discovered a host of popular medications that can cause edema to varying degrees. The speaker recommended that doctors of patients with lymphedema consider alternatives to these drugs, if medically possible. A pharmacist then summarized studies of supplements for lymphedema patients, including horse-chestnut extract, selenium, Butcher's broom, and Pycnogenol. Butcher's broom was a promising herb with which I was previously

and threw beach balls to upbeat music. We were having too much fun to notice that this also benefited our LE!

The exhibit booths overflowed with exciting products, including the latest in bandages, decorative garments, gauntlets, devices for massage and pumping, supplements, and more. Of course, a visit to the NLN booth was in order.

Upon returning home I met with local doctors and my lymphedema therapist who also attended the conference to

lymphedema field: researchers chasing the next hopeful angle with the excitement of a surfer out after the perfect wave; doctors whose fists clench in empathy as they seek out answers for their patients with lymphedema; therapists proud of the hours they spend reducing not only the swelling but also the self-loathing of their lymphedema patients; product suppliers and designers who strain to hear the small, discouraged voices of lymphers unable to find the right fit, the right feel, the one



Janice Goldberg, Bonnie Pike, Kim Avanthay, Saskia Thiadens, Bob Weiss, Jan Hasak and Kathie Vaughn

unfamiliar. In a separate workshop a panel discussed the current NLN position papers (available from the NLN website). Air-travel tips for lymphedema patients included avoiding alcohol and coffee, drinking plenty of water, and stretching frequently. Also, we were advised, if possible, to seek newer airplanes with reduced cabin pressure to lessen the swelling risk. I also learned tips on how a patient can pass through airport security when he/she must bandage or wear a bandage alternative on airplanes. If the individual prefers not to bandage after passing security, the speaker suggested that he/she arrive at the airport early to allow time to be wanded, and to bring a laminated prescription script from the doctor. We LSAP participants regularly met with mentors to ask questions about the lectures. One early morning we were treated to a Lebed exercise program where we laughed, blew bubbles,

formulate a plan to integrate the new developments into a patient awareness program. What an incredible honor to be among the attendees and serve as an advocate to my community. Thanks to the NLN for a most informative and engaging conference.



BONNIE PIKE

*Riding The Wave of Discovery
San Diego 2008*

Here's a riddle: What do San Diego and lymphedema have in common?

Nothing, you say? Think again. The answer may surprise you: **PASSION!**

San Diego, sure. It's a lively, happening place. But – *lymphedema?*

The 2008 NLN Conference for Professionals in San Diego was five packed days of discovering the passion that fills every player in the

clever and comfortable solution to their awkwardness and pain.

And right in the middle of all those passionate, empowered professionals were five awed lymphedema patients, this year's participants in the NLN's Lymph Science Advocacy Program. Together, we five were there to represent the whole range of our fellow lymphers. Primary and secondary. Young and old. Arms, legs, and everything in between.

We can certainly do that. We all share the pain and frustration of freak-ing out over the infection risk of a mosquito bite or a hangnail. We taste the humiliation of hiding from the glare of public exposure wearing stiff and stuffy compression garments. We know the discouragement of giving up and paying cash we can't afford for critical products and services our insurance repeatedly denies. That empathy and

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KATHIE VAUGHN

shared experience is the easy part.

What's harder is to find ways to communicate our shared experience. At the Conference I was overwhelmed with the passion of so many professionals from all over the world. I had no idea there were so many people who cared so much about us. But clearly, all the good that's flowing from their passion has been generated almost exclusively by them.

The input from lymphedema patients is just about zero. It's certainly not because these professionals aren't struggling to listen to us, but because we aren't talking to them. We haven't yet found a united voice that can match their passion and commitment. Instead, when the diagnosis of lymphedema hits, we each retire to our own small corner and lick our wounds in silence.

As an LSAP patient advocate, what I take from the Conference is the challenge of drawing my fellow-lymphers out of our mutual isolation and into this community of encouragement, hope, and empowerment. Working together, we can spark the ideas our researchers need to solve the twin puzzles of prevention and cure. We can help our doctors learn about this last frontier of biological science, the human lymph system. We can express our appreciation for the hard-earned skills and experience of our therapists, influence the direction and quality of new product development, and demand needed legislative changes.

San Diego, lymphedema: passion.

My journey to the 2008 NLN conference began in 2007 when I attended the patient conference sponsored by Lighthouse Lymphedema in Atlanta, GA. To that point, I had not personally known a single other person with lymphedema despite being an 18-year breast cancer survivor and a member of three breast cancer support groups in Sacramento.

I came away from the 2007 conference with a renewed interest in finding out even more about lymphedema, alternative treatments, and efforts to raise awareness and funding for research and treatment improvements. I joined the National Lymphedema Network, attended meetings that were hosting lymphedema speakers, and continued my online networking on sites dedicated to lymphedema. In the course of these activities I learned about the NLN Lymph Science Advocacy Program (LSAP) and applied for consideration to attend the 2008 NLN Int'l Conference in San Diego. I was thrilled to be selected as a 2008 LSAP participant.

My inclusion in LSAP far exceeded my expectations. The caliber of conference presenters was exceptional, each presenting the most recent research or thinking about lymphedema. The discussion was more scientific, medically oriented, and at a much higher level than I had experienced at the patient conference. As a consequence, I deepened my understanding of

lymphedema in general, rather than focusing so specifically on my individual circumstances.


The exhibitors were numerous and exciting, demonstrating the level of innovation that is occurring in the field and showing the range of people interested in contributing to the management of lymphedema. It was truly exhilarating to see the variety of bandages and compression garments; donning tools and measuring devices; and clothing options that are improving the appearance of lymphedema garments. There was so much to see and learn and I came away with tremendous appreciation for what the entrepreneurial spirit is creating for those dealing with this condition.

The ability to attend sessions and to interact with the physical therapists who are dedicating their skills to the treatment of lymphedema patients was a rare privilege. From personal experience, I know what a difficult job lymphedema treatment is – it is time intensive and demanding, both physically and emotionally. Hearing the comments and questions of treatment professionals only reinforced my respect for the skill, the dedication, and the caring that is making such a difference for all of us.

The LSAP program is well organized, with preparatory sessions in advance of the conference, mentoring sessions during the conference with doctors and other lymphedema experts, and ongoing networking opportunities with other LSAP participants and alumni.

I appreciate that this was a rare experience that few lymphedema participants will ever experience and I am grateful for the opportunity.

It was a special privilege to attend the 20th anniversary of the establishment of the National Lymphedema Network (NLN) and to see Saskia Thiadens honored for her vision in beginning the NLN and her leadership in fostering its growth to the impressive organization that it is today. What a meaningful demonstration of how one individual CAN make a difference!

For me, LSAP is a journey, a journey that is just beginning! 
www.lymphnet.org/patients/LSAP.htm

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