

Lymph Science Advocacy Program at 9th NLN Conference

Review - 2010 LSAP Graduates



2006, 2008, 2010 LSAP Graduates

HEATHER FERGUSON

I scarcely know where to begin, but I will start by saying it would be wonderful if every patient and caregiver could have the LSAP experience! The warmth and compassion that exists within the lymphedema community is truly remarkable and, although it may sound cliché, there really is a sense of family. I wish every person with lymphedema could experience the camaraderie which has arisen from a disease which all too often leaves its sufferers feeling isolated.

Our LSAP experience began with three "webinars." All were excellent, but I was particularly excited to hear from Dr. Kathleen Francis about the latest research and breakthroughs. I have always had faith that significant advances would occur during Dylan's lifetime (Dylan is my child who has lymphedema), but this was the most insight I had been given into exactly what these breakthroughs will likely be. There is reason indeed to be hopeful for what the future holds for persons with lymphedema!

Upon arrival we had a meeting for LSAP members with Saskia Thiadens, which gave me my first taste of how rewarding

this experience would be. Despite my extensive advocacy work and communication with countless individuals by email, there is no support group in my area, and I have had very little in-person contact with other lymphedema patients. Those who have had the experience know how therapeutic it can be just to be in the physical presence of others with similar experiences.

The next day was the first day of the main conference and I was the key note speaker during the opening ceremony. I shared my experience of raising a child with lymphedema and how his being denied coverage for garments set me on my journey as an advocate. I also talked about obtaining a state mandate, getting the federal bill HR 4662 introduced, and finally, how everyone can and must work for passage of that bill. I am very appreciative of all the enthusiasm and support expressed to me during the conference, which continues by e-mail as I write this.

Our days were jam-packed, and although I was completely exhausted by the conclusion of the conference, I was also sad to see it come to an end. I cannot even begin to list within the confines of this article all

that I learned. Since my connection is through my son's primary lymphedema, I was especially interested in presentations including genetics, pediatrics, and care giving. The work being done with near-infrared fluorescence imaging was also of particular interest to me. The still photos and movies shown using the fluorescence imaging to assess lymphatic architecture, dynamic flow, and response of lymphatic function to MLD, were fascinating!

All of the presentations were informative and interesting, and I found great value in the countless conversations which spontaneously occurred amongst attendees between sessions. In some ways I found this informal information-sharing as helpful as the lectures themselves. I came home with gems of wisdom that I can utilize as a caregiver and patient advocate, and I also hope that in sharing my experiences I have, in turn, helped others.

My participation in this conference has no doubt helped to further my ability to not only be the best caregiver possible for my child, but to also be the best advocate I can to help better the lives of all those who suffer from lymphedema.

I came home so filled with ideas and enthusiasm, and I wish there were more hours in the day to implement them all. But for the present time, my priority will remain devoting myself fully to working toward passage of the HR 4662 federal bill. After all, advances in diagnosis and treatment methods only matter when patients have access and coverage for these services. Please support this effort to ensure that lymphedema sufferers are no longer denied coverage for the medical treatment they need and deserve. To learn more, visit www.LymphedemaTreatmentAct.org.

To any reader who contemplates participating in a future conference as an LSAP member, I cannot emphasize enough how rewarding the experience will be. The conference was everything I had hoped for and more, and I am so grateful to have had the opportunity. As I said in the beginning, it is an experience I wish every patient and caregiver could have.

JANE A. DWECK

The NLN conference in Orlando was quite the experience for me. Thanks to Dr. Mei Fu for nominating me and to Saskia Thiadens for accepting me into the program. Meeting my fellow "LSAP'ers" and LSAP graduates and hearing their stories of how their newly acquired knowledge has made a real difference in their local lymphedema community was truly moving. Breakfasts with our mentors were great. I especially enjoyed Michael Bernas discussing the LLLT. He stated that one treatment can actually excite cancer cells into activity, while further treatments appear to calm them back into dormancy. I had never heard of this before and think we need to learn more about this. I also enjoyed speaking with professionals whom I had met at the American Lymphedema Framework Project (ALFP) stakeholders meeting in Chicago.

The NLN Conference lectures were fantastic. I especially enjoyed the Point/Counter Point session on LLLT and Risk Reduction with Drs. Ridner and Cheville. Dr. Sheila Ridner said, "I don't care what studies show what; when I am in a room with 20 LE patients and 18 tell me they got their LE after an air flight, I am going to listen to that, period." Jodi Winicour's presentation on Axillary Web Syndrome was outstanding. I also really enjoyed the presentation on breast lymphedema (which I have), a condition which is entirely overlooked by our physicians.

Meeting the vendors was quite the experience. I had spoken on the phone and/or e-mailed so many of them, and it was really nice to meet them in person. I Love the breast swell spot and other samples I received. And the biggest fun was when a group of therapists asked if they could take my picture with my patterned LymphedIVAs sleeves on. They said they had many patients who just refused to wear their

sleeves because they were so ugly. When they saw how fashionable I looked, they were sure they could convince their patients to wear LymphedIVAs!

All the information regarding pumps, bandaging, liposuction, and de-bulking, will help me in my work at Step Up, Speak Out, and in my talks before various lymphedema support groups and student nurses.

Again, thank you all for this wonderful opportunity!

TALIA FROMBACH

The 2010 National Lymphedema Network Conference was such an amazing experience for me. I have lived with lymphedema in both arms since I was six months old. It has always been a major struggle finding valuable and reliable information that could help me. Having to live with this condition everyday does have its setbacks, but right when I arrived in Orlando and saw hundreds of people there for the same reason, I knew I couldn't be in a better place.

The conference widened my eyes to lots of new technologies and discoveries that are happening in the world of Lymphology. Everyday the conference was full of energy and non-stop information. It did get overwhelming at times, but in a good way. By the end of the day, I was always full of new information.

The conference consisted of plenary research sessions, breakout sessions, vendors and my favorite part, round table discussions. I wish I could have attended all the sessions, but I'm very happy for the ones I chose. The speakers were excellent and presented beautifully. The pediatrics class, taught by Mary Kathleen Kearse and Dr. Feldman, was my favorite. The presentation was very interesting and informative. I had no clue that genetics play such a big role with primary LE. I loved how open everyone was to questions and comments. The plenary sessions had great new research that was interesting to hear about. I didn't realize so much lab based research was being done in regards to the lymphatic system. It's reassuring to know that people are helping to find out more about the lymphatics and maybe one day treating lymphedema will be as easy as treating a common cold. Wouldn't that be nice!

It was a great pleasure to sit down with amazing doctors, therapists and surgeons to talk about their opinions and experiences working with LE. I am so appreciative that they took that time to spend every morning with the LSAP participants. The best part of my day was listening to the discussions, and asking the experts questions.

The conference was a wonderful place to meet new people who had common stories and backgrounds. The other patient advocates were amazing and I know that I will always have their support and friendship. I loved talking to them and hearing their LE story. It felt reassuring to me that I'm not going through this alone. There are actually others out there that are going through the same struggles and adventures everyday. These ladies have inspired me to be who I am and never give up. I know that I'm not only taking away valuable information from the conference, but also a group of new lifelong friends.

My goal is to teach the people in my community about lymphedema and the risk factors. I want to share new information about lymphedema with the pediatricians at area hospitals. No child should have to go through the misdiagnoses process like I did, and should not be without the proper help they need. I want to set up a local support group in my community for anyone with LE. I think it is very therapeutic to be around others who are sharing the same experiences.

I am getting in contact with my congressmen to get on board with HR 4662. I continue to spread the word about lymphedema every chance I can get.

Thank you, Saskia and the NLN, for letting me have this wonderful opportunity that I will never forget. The conference was beautiful and couldn't have been done any better. I am so grateful to have had this experience. I can't wait for more to come!

MELANIE VALENTINE

First I would like to express my gratitude to the NLN and Saskia Thiadens for allowing me to participate in such an eye-opening and educational experience. I came to the 9th annual National Lymphedema Network International Conference as a person with lymphedema in my right

leg, as an Occupational Therapist, and more importantly, as a patient advocate. I joked with my hotel roommates that the conference left me feeling a bit 'bipolar.'

Like most of the other LSAP participants, I initially felt overwhelmed attending the conference (this being my first one), but extremely excited to be part of a gathering of such amazing people. From our first meeting with Saskia on Wednesday evening, to Bob Weiss's lecture on the LE Bill HR 4662 on Sunday, I was eagerly soaking up as much information as possible. As LSAP participants, we also met daily with designated mentors who were very gracious in sharing their insights with us, and readily answered all of the questions we asked.

On our first full day, our mentor was Dr. Nancy Hutchison. One of the topics discussed with the LSAP group was regarding lymphedema, allergies and inflammation. Dr. Hutchison stated that in her experience, some lymphedema patients present what she called an 'allergy' type constitution. They are more prone to localized immune responses in their LE limb and have a generalized redness that sometimes looks like cellulitis. I've noticed a similar phenomenon in my patients and in my own LE extremity. Later in this first full day, the plenary session by Jane Armer on the Assessment of Genetic Predisposition to Secondary Lymphedema as a Potential Tool in Education for Risk Reduction and Individualizing Cancer Treatment also caught my attention. I feel this study is a unique and much needed approach to identify which breast cancer patients are at a highest risk for developing lymphedema based on specific genetic mutations associated with LE.

On our second full day, our mentor for the morning was Steve Norton. Steve stressed how important good manual lymphatic drainage is in the proper treatment of lymphedema. It was an interesting juxtaposition, as in the late-afternoon plenary sessions the day before; there were quite a few presentations on the use of pneumatic compression devices in treating LE. As a therapist myself, I tend to go back and forth on this issue. I know that the newer generations of pumps are not damaging like the older versions, but I still feel the pump can be over-used by patients, even when given

proper training and education. Also, as a person with lymphedema, I think pumps can be very isolating. Although for some patients the pump can be a good tool, for me, it would make me feel less like an active participant in my self-care. One theme I was grateful to hear throughout the conference was that, despite having LE, a person must live his/her life and not the disease. I know first-hand how much time and energy goes into performing a good self-care program at home. Taking the most active role possible gives me a feeling of empowerment in treating my LE and living my life.

I would be remiss if I did not mention the exhibitors and the exhibit hall. I spent quite a bit of time going to each booth, talking to the many helpful vendors. I met some amazing people, quite a few of whom I realized live and work close to my hometown. It was great making these connections, knowing that I have a whole host of new resource people who are educated in lymphedema, and whom I can call upon if needed for myself or my patients. One product that stood out to me was a line of compression garments by an Italian manufacturer. I believe they are new to the United States. This product was exciting for me as a younger person with LE. They are beautifully designed with an eye towards fashion, with many color and fabric choices. I know I sound like a spokes person here, but for younger people with arm and lower extremity LE, it offers us a more fashionable alternative!

I also must mention how 'wowed' I was by the Plenary sessions regarding Near-Infrared Fluorescence Imaging given by John Rasmussen, I-Chih Tan, and Erik Maus. The images presented of both normal and abnormal functioning lymphatic systems were amazing. Their accompanying findings and images of lymphatics crossing watersheds and developing through scars were also exciting. As a therapist and a lymphedema patient, being able to visualize the lymphatic system in this way, gives me another piece of the puzzle in terms of knowing what effect manual lymphatic drainage has on the system. At one point in their lecture, they showed a patient receiving the imaging tracer then receiving MLD. Watching the response of the lymphatic system to the

therapists' hands was no less than incredible. So exciting!! Not to mention the possible far-reaching uses for this new imaging technique.

Overall, it was an honor to attend the conference and to be an LSAP participant. The caliber of conference presenters, organizers, and attendees was exceptional. The passion of the professionals for LE was clearly evident, and this gives me great hope for the future. I would also like to mention how wonderful it was to meet the other LSAP participants, past and present. I know that they will continue to be a great resource, as they are all quite amazing individuals.