A therapeutic education program

We asked Dr. Isabelle Quéré to tell us about the first International Lymphoedema Children's Camp, held in Montpellier, France June, 2012

Who is responsible for the project?

The Children's Camp program is administered by the vascular and lymphatic medicine department that I run in Saint Eloi University hospital, Montpellier University, France. Beyond the academic hospital-based administration of the program, the Children's Camp project is primarily the result of a ten year close collaboration between the Association Mieux Vivre le Lymphoedeme (a national support group of patients in France), my team, and more recently the International Lymphoedema Framework.

KEY OBJECTIVES

1) **To implement a structured therapeutic education program for children and their families** Specific objectives and tools had been defined by our previous experiences during weekend camps and on the basis of a qualitative research study of the psychological and social repercussions of lymphedema in children and young adults that we had previously conducted.

2) **To produce video tools** to report on the experience of lymphedema in children and to provide useful tools to the children themselves such as a short film explaining what lymphedema is that they can show at school.

3) **To initiate an international network** dedicated to children and families with lymphedema.

Please share the history with us.

The story of the Lymphoedema Children's camp began five years ago, in 2008, with a first Children's Camp week-end in Montpellier. As a department specialized in diagnostic and treatment of vascular and lymphatic diseases, we developed a dedicated service for children and young people with lymphedema as it became apparent that they had special needs. Children were very happy to meet each other; they became "lymphedema friends".

At the same time, parents were seeking answers and we thought that providing specific and general information on the condition would help families to access quality local treatment and support and also reduce their feelings of isolation and helplessness. The weekends started with an annual multidisciplinary team-based consultation for each individual child, based on scientific and medical care. This was followed by self-management interactive workshops plus creative and social activities that were designed for the participants and professionals to interact.

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Was this the first year the camp was extended to a weeklong event?

Yes, it was. It proved to be successful, yet presented a real challenge as we had to manage simultaneously the implementation of a full therapeutic education program and the international dimension of the project. From my point of view, running the camp during the fourth ILF conference in Montpellier was an exceptional opportunity to share the experience with other countries and to draw attention of all professionals and experts of the field to the needs of children and families on the rare form of the condition.

From your perspective, what was the most remarkable component?

It was having participating families from four different countries (Canada, Denmark, Sweden, France), a multidisciplinary health care team and documentary film makers come together to meet with lymphedema experts at the ILF camp and conference. This experimental project has created a collective dynamism and exceptional confidence which we now hope to share with everyone. For more information about the camp and to access the video tools when they are completed, please visit www.lympho.org.

The reflections of a mother and son’s adventure

By Kim Avanthay

After a long overseas flight, we arrived at the camp in Montpellier, France and met the other families, most of whom already knew each other from previous camps. There were nine youth in total, two girls and seven boys, who came with their parents from Sweden, Denmark, France and Canada. The ages ranged from 6–21, with my son Austin being the youngest. Although Austin “knew” there would be other campers with lymphedema, he really surprised me when he asked the first boy he met why he was wearing a compression sleeve. This was an eye opener for me and validated the key reason for making this trip with Austin – for him to meet other children with lymphedema and understand that he was not alone.

As we were introduced to the camp hosts (International Lymphoedema Framework (ILF), Montpellier University Hospital, the video crew and camp facilitators, Fabienne, Veronique and Florence), I immediately felt that this was going to be a great week! The multidisciplinary team looking after all our health needs included physiotherapists, a psychologist, doctors, angiologists, dermatologists, podologists and dieticians.

Information sessions included a self-bandaging class using different products and techniques. It was great to see Austin take control and do it for himself, along with some guidance. This may be something we can incorporate into our night-time routine, with practice.

> “The best thing was watching the video of the camp...and my birthday cake.” —Austin Avanthay

The self-drainage session was more educational for myself than a six-year-old boy. However as Austin gets older and comfortable in practicing self drainage, it will be an important aspect of keeping his skin soft and the lymphedema under control.

Proper skin care is crucial for lymphedema patients as infection can spread quickly. Therefore we have to be diligent in monitoring changes in Austin’s skin, such as cuts or abrasions. We were taught about the importance of keeping his skin hydrated and the types of products that are best.

Very relevant to us was the foot care session as I am concerned with Austin’s feet and his lack of an arch. We were shown the proper way to cut toenails and learned the importance of wearing proper fitting shoes. A podiatrist pointed out the pressure points on Austin’s feet that I need to keep an eye on.

The children spent many hours frolicking in the pool all week, playing water polo and racing down the water slides. Not only were these activities filled with lots of laughter, but

Kim Avanthay has been on a mission to raise awareness about primary lymphedema. She is an active member of the Canadian Lymphedema Framework (CLF) Advisory Board and Partnership Working Group. She has recently launched a new provincial patient association in Manitoba.

> “Even Austin was overcome with emotion when everyone sang happy birthday.”

very therapeutic for lymphedema, as the water acts like compression.

On Friday, June 29th, Austin woke up excited to be celebrating his 7th birthday in France. We travelled by tram to Le Corum conference venue to join fellow camp families as well as ILF conference delegates for a fitting ending to our week long adventure.

Fabienne Mourgues, the Children’s Camp facilitator, spoke first, followed by Christine Moffatt, Chair of the ILF who presented the findings of her “Quality of Life Study in Children with Lymphoedema”. She targeted so many issues that I felt she was talking directly to me and the other families. After the amazing video was shown of our week’s highlights, we were all invited to come on stage for a round of applause. As I scanned the auditorium, I could see many parents who were touched by our week’s experiences as it appeared there wasn’t a dry eye among the delegates. Even Austin was overcome with emotion when everyone sang happy birthday. His celebrations continued at the conference dinner where his eyes widened with surprise upon presentation of a birthday cake and shiny sparkler. It was an amazing finale to a week that Austin will never forget.

A heartfelt thanks goes to all who made this camp adventure not only a reality but a remarkable learning experience for all the children and parents. I eagerly anticipate the release of the wonderful documentary about children with lymphedema currently in production as a result from this camp. LP

For more information about future International Lymphoedema Childrens Camps, visit www.lympho.org