

Liam's Light

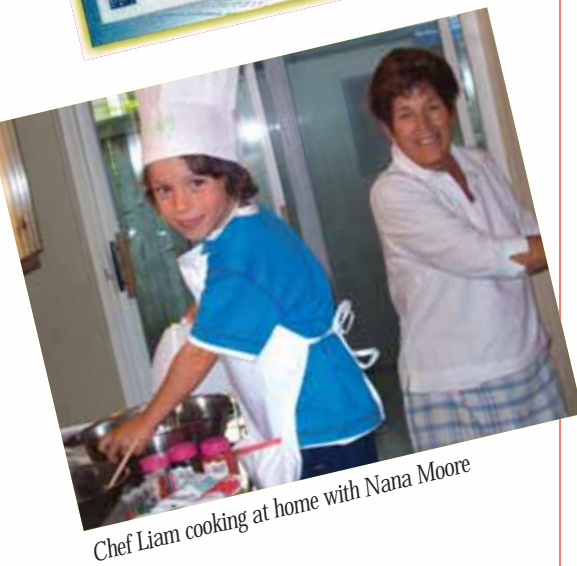
The Voice of Liam's Light

Newsletter Winter 2007

Supporting Research and Care for Pediatric Transplants



Liam, goes for speed when tubing at the cottage



Chef Liam cooking at home with Nana Moore

Holiday Greetings.... To all of our family and friends!



We apologize that we have been somewhat silent in the past year, but it has been a year of many exciting as well as sad event's in our family. In January 2007 the Moore, Campbell, Wadsworth families had a very big shock, when Peter Wadsworth (Liam's Gampi) passed away suddenly. Peter and Liam had a special bond and Liam will always know he has a true "angel" sitting on his shoulder, his beloved Gampi.

As hard as this has been for our families, we continue to keep our heads up and our spirits positive, as this would be what Peter would have wanted for us to do.

In May 2007, we did learn of some very exciting news. Liam's Light was awarded \$10,000 from the Today's Parent "For Kids-Sake Award". This award is for outstanding charities in Canada who are making an impact in the lives of children. We felt extremely honoured to be recipient's of this tribute and we are thrilled to announce that with this money, we have invested into a music therapist for the Liam's Light step down unit and 6A floor at SickKids. The music therapist will start on the floor in January 2008.

In June, Liam, Doug, Deborah and Nani headed to the National Institute of Health in Washington (NIH) to partake in an exciting protocol for research into ARPKD/CHF children. Liam went through a series of tests at the NIH and the results were shared with his dedicated team at SickKids. We all stayed at

the Children's Inn and Liam met many children living with rare illnesses from around the world. We met two other families with children with ARPKD/CHF. Liam really had a great time with these kids, and it was nice for him to identify children going through the same illness as he is. We will continue to go back yearly.



Liam, battling for the lead in his first X-Country run.

Research News:

In November 2007, we finalized the exciting news that Liam's Light will be helping to fund a dynamic program and research scientist named Stacey Pollock-BarZiv within the Pamot Program at SickKids. We are pleased to introduce you to this amazing woman.

"My name is Stacey Pollock-BarZiv, and I am near completing a 2-year post-doctoral research fellowship with the Heart Transplant Program at the Hospital for Sick Children evaluating outcomes after pediatric heart transplantation. Prior to that, I completed a PhD from the University of Toronto, Institute of Medical Sciences studying quality of life and health outcomes in lung transplant recipients. I have been involved in research studies with the Heart Transplant Program since 1999, working alongside the PAMOT Program and it has been my long-term objective to undertake similar research across all solid organ transplant recipients.

My research expertise is on health outcomes, quality of life, and behavioral aspects of life after organ transplantation. My humanistic view remains that research must ultimately be useful to individuals and as a

"Research Scientist" in the PAMOT Program I would be committed to the research and advocacy of psychosocial and behavioral outcomes that influence the day to day quality of life of the pediatric transplant recipient and their families. Life after transplant involves rigorous medical care, multi-drug therapy, and profound psychosocial, medical and economic consequences. My research questions are focused on the following three areas:

- 1) Psychosocial factors (physical, social, and emotional aspects);
- 2) Issues that have a particular impact on pediatric patients (developmental, academic, peers, compliance and coping);
- 3) Developing a framework for evaluating transplant recipients at risk, and integrating medical management and psychosocial factors for interventions.

Transplantation is an exciting field with great changes and a vibrant future. The PAMOT program is well positioned to be a world-leader in multi-organ transplant outcomes, quality of life, and behavioral research. With the help of PAMOT and LIAM'S LIGHT, I hope to be able to help develop a comprehensive research program that addresses both the health and psychosocial components involved in the solid organ transplant process, to promote positive health outcomes and to champion collaborative research on the behavioral health of transplant patients and their families; with the aim of improving the quality of life for pediatric recipients of solid-organ transplantation."

We are very excited to be able to welcome Stacey and introduce her to Liam's Light. We know and are confident that we will be hearing wonderful news in the area of transplantation with Stacey on our side.

An Evening of HOPE 2008



We are working toward another exciting "Evening of Hope" for Liam's Light. This event will be held sometime in the fall of 2008 back at our regular spot at The Academy of Spherical Arts.

The evening will be full of amazing silent and live auction items, drinks and food. We are looking for a Title Sponsor as well as Corporate Sponsors, if you are interested in being a sponsor please contact Deborah and Doug Moore 416 690 6229.

We also need to SELL OUT the evening! We need your help!

TICKETS can be purchased directly by contacting Lynda Wadsworth at 416 934 1834 or Deborah and Doug Moore at 416 690 6229.

***We will confirm the date in our June newsletter, so stay tuned!**

Finally to Liam. Liam continues to do well medically. We feel so blessed to have such a dedicated team looking after him at SickKids. We have learnt this past summer, that his liver has more cysts than we originally thought, as well the cysts are not just contained in the right lobe of the liver but also into the left. We continue to monitor his liver and kidneys in clinic, and keep hoping that his health will remain stable.

Liam emotionally is thriving! He loves grade 2 at his school and has many friends. He is enjoying the learn to play hockey program at St Michael's arena, and he won a bronze medal in track and field this fall running 2km which he was very proud of!

So dear friends, this newsletter has many updates and information for you all, but the most important information and one that is constant to Doug Liam and Deborah is that we **AREN'T** a charity without you. The support, care and generosity of our family and friends always amazes us and you should all feel that you are **ALL HERO'S** helping us reach our goal in research and care for Pediatric Transplant's at SickKids.

So on behalf of Deborah Doug and Liam, we wish you a very happy, healthy and joyous Holiday Season and a wonderful New Year!

*With great love,
Deborah Doug and Liam Moore*

