



Newsletter

Season's Greetings

Dear family & friends;

It has been a very busy past year with many exciting developments to share with you all. To begin with we would like to update you on Liam and his health this past year. We are amazed that our little boy is nine and still managing to thrive despite a not so great "plumbing system".



Roxy our new member of the family.



Liam is still dealing with the ongoing medical issues surrounding his high blood pressure and portal hypertension. He has now developed what is known as pruritus (itch) which occurs when there is poor bile flow (cholestasis). It is thought that the itch is due to the excessive amounts of harmful bile acids circulating in the blood stream. This happens when the liver disease prevents these bile acids from being excreted effectively. He is tolerating a new med which he takes daily to help him relieve this ongoing itch. As well, in August a routine ultrasound detected some very large periportal and pancreatic lymph nodes, which caused us to be concerned as Liam is at high risk for cholangitis, which is a serious bacterial infection in the bile duct. To date, his medical team continues to do follow up ultra sounds to monitor these nodes and we have been asymptomatic and hope we stay that way.

Liam was thrilled to be chosen to be a goalie for the Ted Reeve Thunder, GTHL Hockey league, and he is loving it. He has been to two tournaments, many games and loves his new friends that he has made with hockey. To Liam this is a chance to just hang with the kids and be social. Many of these boys know about his illness and are fiercely protective of Liam when he is in net. They are great kids and we are so happy that Liam is well enough to be able to play the game he so loves.

Liam continues to go to school at Kew Park Montessori where he finds the homework, in his words, "too much" but he loves all his friends. It's hard to believe that he is now in grade four.

We were thrilled that three separate companies came forward this year to raise funds on behalf of Liam's Light. We would like to thank these companies from the bottom of our hearts for considering Liam and his charity. This is a wonderful and beautiful surprise for us all.

The first company is **Pegasus Dance Studio** and they have chosen Liam's Light to be their official charity this year and will be hosting a very large dance concert on Feb 20th at the Betty Oliphant Theatre.

If you would like further information regarding this event please contact Deborah Moore @ 416 690 6229.

The second company was **Fly Girl Fitness** and in October many friends got together to pump up with pumpkins with the owner and trainer expert Briar Munro. The workout was an hour and together raised over \$340.00 for Liams Light. Well worth the sore arms and bodies the next day.

The third company was **Retina Entertainment** and on Oct 31st they held an event named "Thriller" at the Hyatt Regency and raised over \$1,000.00 for Liam's Light. Many wonderful performances and fun costumes.



frishmennellphotography



Liam's stops the big one for Ted Reeves Thunder, Minor Atom, GTHL A.



Liam's Light would like to update you on the ongoing work we are supporting and funding, so we have asked the Transplant Centre to provide us with some updates.

"We are thrilled to provide Liam's Light with an update on research initiatives, works-in-progress and dissemination efforts. It has been a productive year and we are proud of our many significant accomplishments. The year started out with a bang at the 2009 Canadian Society of Transplantation (CST) Annual Meeting and Scientific Sessions, where our program of research examining 'quality of life and psychosocial implications following pediatric transplantation' was awarded the Canadian Transplant Academy Training Day Research Prize and both the Pediatric Special Interest Group and Associate Members Clinical Research Awards. At the CST we were invited to present our findings from our study exploring "transitioning from pediatric to adult care: strategies for improvement" and were awarded a CST research grant for our investigations on the "impact of participation in the World Transplant Games on physical fitness, activity patterns and quality of life". In April, findings from several research studies were presented at both the International Pediatric Transplant Association and the International Society for Heart and Lung Transplantation, including an oral presentation with results from our study on 'ABO-incompatible heart transplantation – a parents' perspective' and an invited presentation entitled 'Quality of life and adherence - do we underestimate their importance?'. Awards were received from several sources including the Canadian Institute for Health Research in order to facilitate the knowledge transfer and exchange of these exciting research programs. Additional dissemination efforts included the publication of our article 'Perceptions of Transitional Care Needs and Experiences in Pediatric Heart Transplantation' in the American Journal of Transplantation and our manuscript 'Child and Parental Perspectives of Multidimensional Quality of Life Outcomes after Kidney Transplantation' was accepted to the journal of Pediatric Transplantation. We are also pleased to report that we have been asked to write a chapter on 'quality of life after pediatric solid organ transplantation' for an upcoming edition of Pediatric Clinics of North America.

At the start of the 2009 academic year we expanded our academic and clinical network by embarking upon a collaborative partnership with McMaster University, with an interest in developing a theoretical framework for quality of life in children with chronic illness. This initiative presents us with a forum to collaborate with other scholars, engage with internationally recognized experts in the field of quality of life inquiry and enrich our knowledge base. More recently, several innovative research proposals have been submitted to various internal and external granting bodies. With strong multi-disciplinary co-investigation teams, we have submitted propos-

als on 'the experiences and perceptions surrounding participation at a transplant camp, 'multidimensional quality of life and behavioral adjustment in pediatric kidney transplant recipients' and 'experiences and perceptions of pediatric health professionals providing end of life and palliative care'. Our success over the past year is due in part to the on-going support of Liam's Light. We look forward to another productive year in 2010 and appreciate the generosity of the numerous Liam's Light donors. With this partnership, we will continue to strive toward creating the necessary evidenced-based foundation from which strategies for successful psychosocial adaptation and enhanced quality of life can be built.

— Wanda Schoonheydt, Director,
Clinical Programs, Transplant Centre

SickKids Transplant Centre

– Report on the First Call for Seed Research Funding Generously Supported by Liam's Light

THE INAUGURAL FIRST CALL FOR APPLICATIONS

The first call for applications was widely disseminated across the Transplant Centre during the summer 2009 and encouraged applications of high quality, innovation, and supporting the Transplant Centre vision of premier international excellence. The Transplant Centre Funds Advisory Committee was chaired by Dr. Lisa Robinson (staff nephrologists and associate scientist), and consists of 10 members of the interprofessional team representing all areas of solid organ transplantation. A standardized rating system was created to allow for scoring of the proposals and focused on innovation, potential for future development, measures of impact, feasibility, and strategic fit with Transplant Centre goals. Proposals were required to include timelines and metrics for success. Results

There were 11 outstanding applications received that covered the spectrum of basic science, clinical research studies, quality of life research and educational projects in transplantation. Applicants encompassed the breadth of interdisciplinary staff from within the Transplant Centre including staff physicians, Scientists, social workers, members of rehabilitation medicine and nursing. We are thrilled to announce the successful award recipients of the first Grant Competition:

1 **Robin DeLiva BScPT** (Physiotherapist, Rehabilitation Sciences, Heart and Lung Transplant Program). In collaboration with Samantha Anthony MSW, PhD (candidate), Catherine Patterson BScPT, Stephanie So BScPT, Cedric Manlhiot BSc, Stacey Pollock-BarZiv PhD, Alison Drabble RN, Anne Dipchand MD.

Research Title: "Impact of participation in the World Transplant Games on physical fitness, activity and quality of life: A study of pediatric solid organ transplant recipients".

Study Objective: To seek how training for and participation in sporting events such as the World Transplant Games affects health-related physical fitness, exercise behaviors and measures of quality of life in a group of pediatric transplant recipients to optimize outcomes by informing post transplant exercise rehabilitation interventions.

2 **Dr. Valerie Langlois** (Physician, Renal Transplant). In collaboration with Vivian Cornelius RD, Degen Southmayd BScPT.

Research Title: "Comprehensive multidisciplinary approach to reduce overweight and obesity post-renal transplantation".

Study Objective: Implementation of a novel multidisciplinary approach utilizing physician, dietician and physiotherapy services including individualized home exercise programs, nutritional counseling, motivational interviewing and standardized monitoring to optimize overall health after transplantation.

3 **Clifford Lingwood, PhD** (Senior Scientist, Research Institute, Program in Molecular Medicine and Pathobiology) and Dr. Upton Allen (Senior Scientist, Division of Infectious Diseases).

Research Title: "Verotoxin as a diagnostic adjunct to post-transplant lymphoproliferative disease (PTLD) prediction"

Study Objective: The development of an assay for early detection of circulating lymphoma cells after transplantation, may allow for prediction of PTLTD development.

We will enjoy hearing from these three in the spring when they will share a short abstract on their work for our next newsletter.

We wish all our family and friends a wonderful holiday season with continued good health. We are always grateful for the support and kindness that we have been blessed with over the years.

Peace to you all, with hope for a wonderful New Year ahead.

Love and best wishes,
Deborah, Doug & Liam Moore

