



The Voice of Liam's Light

Spring 2010

Newsletter

Yeah Spring is finally here!

Dear family & friends;

Well, thank goodness the warm weather is finally here and we all get a chance to get outdoors and enjoy the weather.



It has been almost 6 months since we last updated you on Liam and the activities of Liam's Light. We have many new exciting developments to share with you all and we will take this time to bring you all up to speed on the most recent activities.

To begin with, we had some very exciting news in November 2009, when **Liam's Light was asked to be an Olympic Torch Relay participant.** Liam was so excited, but a tad disappointed when he learnt that he had to be 13 years of age to carry the torch, so instead Deborah carried the torch on his behalf and Liam and Doug ran beside her. We had some friends out cheering us on and taking pictures as we made our way through Pickering on an early brisk December morning. Words can't quite describe the feeling of being handed the torch and the moments when the flame was passed to light my torch. To me, it represented hope and life and the belief that anything is possible. We feel the same way in regards to Liam's Light. We chose the name "Liam's Light"

because to us, the "light" is the hope for tomorrow. So yes, it was very emotional as Doug and Liam ran beside me and we traveled as a family on our journey down the road together with the torch.

We will have some pictures of the run and the Olympic torch on display at our next gala night on Sept 17, 2010 back again at The Academy of Spherical Arts. Please read more about this event on the next page, BUY your tickets and mark your calendar..

We were thrilled with the amazing outcome from the Pegasus Dance Studio fundraising even on Feb. 20th at the Betty Oliphant Theatre. The company performed some amazing dances and the evening was very exciting. Liam loved sitting in the box seat with his friend Jeremy and enjoying the cool hip hop dancers from Pegasus Dance group. That evening, the company raised \$5900 towards Liam's Light and we wanted to once again thank all of them for the amazing efforts and thinking of Liam's Light as their charity of choice.

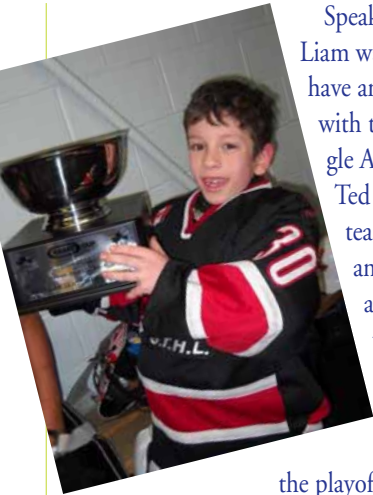
We also wanted to thank Andrew Dorovenis a friend of Liam's from his hockey team, who decided to opt out of presents this year at his birthday party and instead ask for donations towards Liam's Light. That party, Liam's Light received \$900, what a beautiful gesture and we thank you again Andrew for being so thoughtful.



On Thursday, December 17th 2009 on a very cold crisp morning, Deborah Moore carried the Olympic Torch in honour of Liam's Light.

The excitement and honour was a life time experience for both Liam, Deborah & Doug.





Speaking of hockey, Liam was thrilled to have an amazing season with the GTHL, Single A, Minor Atom, Ted Reeve Thunder team. The families and kids were amazing, and the team won their eastern division in the regular season,

the playoff season, as well they won the Kraft Cup for their division. What a ride and a thrilling year. Liam has made many friendships that he will continue to enjoy and foster for years to come. He will still see many of his friends as he will be on the ice next year playing in net, with the Leaside Flames AA Atom division.

So what about Liam. How is he? Well, as you can imagine he is thriving with the hockey, and loving it. He will be on the greens this summer teeing it up with Nani, playing tennis in the beach and continuing hockey with 3 on 3 this summer. So he is busy and athletic and never lets his illness stop him from pursuing things that he loves.

Medically Liam is still dealing with an ongoing chronic illness. He is managing his blood pressure and portal hypertension with medication and we are happy to say that he still remains asymptomatic of those enlarged nodes in his pancreas. He has been dealing with some aching and pain in his back due to his kidney involvement, and we are trying different methods for helping him cope with that pain. Due to the medication he has been on since birth, Liam has developed very enlarged gums in his mouth, which are not allowing the teeth to come through. So in May, Liam underwent a procedure to remove some gum tissue on 8 teeth which allowed the teeth to come through. This was very difficult and painful for Liam and he was incredibly brave throughout it all, sitting with frozen pees on his face for a week. He is happy to show off soon his big smile with teeth.

We have an amazing group of individuals at SickKids who we continue to support through the Liam's Light research initiatives which we awarded last fall. Their area of study covers the spectrum of basic science, clinical research, quality of life research and educational projects in transplantation. Of course we still continue to fund the music therapist on the Liam's Light Step Down unit.

We also have some very exciting news regarding our plans for future money raised from fundraising events.

We have been trying to get specific research into Liam's illness at SickKids but it has been a challenge due to the rarity and interest level. However, our hard work over the years has paid off and we are thrilled to announce that **LIAM'S LIGHT will be funding in the near future a research grant for Translational Studies of Liver Disease in Autosomal Recessive Polycystic Kidney Disease.** This grant will bring together two investigators from different pediatric disciplines, which perfectly mirror the organ involvement in ARPKD/CHF.

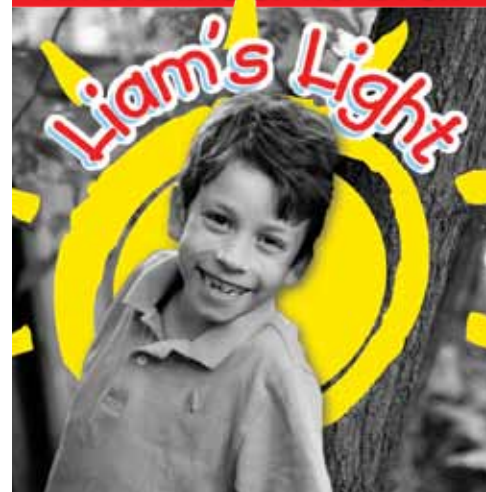
We hope to see many of our family and friends at our fifth GALA night SEPT. 17, 2010 at THE ACADEMY OF SPHERICAL ARTS. We wish you all continued health and as always we are forever grateful for the support and kindness that we have been blessed with over the years.

Love and best wishes,
Deborah, Doug & Liam Moore



Announcing Ticket Sales for

AN EVENING OF HOPE FOR



Supporting Research and Care for Pediatric Transplants

Buffet, cocktails, silent and live auctions

"great fun for a great cause"

FRIDAY, SEPT. 17TH 2010

Cocktails & Buffet 6:30 p.m.

The Academy of Spherical Arts
38 Hanna Ave., (see map on reverse) (416) 532-2782

\$150/pp

www.liamslight.org

For ticket information please contact Lynda Wadsworth @ 416 934 1834



Miles Faber and Liam at Pegasus Event which raised \$5,900 for Liam's Light.