
Lupus Ontario

September 1, 2011

2900 John St. Suite 301
Markham ON L3R 5G3
Toll Free 1.877.240.1099

☎ 905.415.1099

☎ 905.415.9874

✉ admin@lupusontario.org

<http://www.lupusontario.org>

Dear Friends of Lupus Ontario

Lupus Ontario needs your help again this year. Lupus is an incurable autoimmune disease affecting 1:1000 Canadians. It is a devastating illness that is life altering and sometimes fatal. Lupus is a very unpredictable and difficult illness to live with as an adult, but it brings a whole new set of hurdles for a child. There are hundreds of children with lupus being cared for through the Rheumatology Clinics at the Hospital for Sick Children in Toronto. Yes, children get lupus! To assist these youngsters living with lupus, Lupus Ontario supports an annual Clinical Fellowship awarded to a paediatric physician for specialty training in Lupus Erythematosus and Neonatal Lupus (lupus in newborns). We are in our third year of a five year pledge to raise \$250,000 towards this training and research. Your donation today will make it possible to improve the care of these children living with lupus and increase the hope for a cure.

One of these young people is **Hunter Hogarth**, a 9 year old, living in Barrie. He wants you to know about his lupus journey in hopes that more awareness will lead to more research and a cure. This is his story:

Before I was diagnosed I remember feeling very tired. I couldn't understand why I couldn't keep up with my friends in hockey and while playing outside. Then I started to get very sick and the doctors were not sure what was wrong with me. They told me that I may have some sort of a kidney issue and sent me home from the hospital. I remember sitting in class the first week of school and my legs started twitching and would not sit still. My mom picked me up from school and I told her how I felt. She started asking me why I was making faces and sticking my tongue out... I didn't even know I was doing that.. We went straight to the hospital again and this time I felt very scared. It was getting hard for me to walk and I needed my mom and dad to help me feed myself. I was in the hospital for a long time. I had to do a spinal tap, MRI's, bone marrows, and a whole bunch of ultrasounds and X-rays. There were so many doctors trying to figure out what was wrong with me. It made me very nervous when they talked about brain lesions and heart problems.



Lupus! When I finally had a name for what was happening I felt relieved. I knew that this would mean that maybe they could give me some medicine to make me feel better so that I could get back to school with my friends. My parents and the doctors explained to me that there is not one medicine that will take lupus away. I got a little nervous again so I started asking a lot of questions. I have learned about red and white blood cells and what they do for my body. I have learned that too much sun can hurt me and I have learned that I need to get enough sleep.

Before I got sick I was playing on a AA hockey team. I had been playing with the same friends since I was 4. I did go play with them for a few more games when I got out of the hospital but it was hard for me and I didn't really enjoy it anymore. My hockey friends have

been great through all of this and they held a fundraiser for me. They put red tape on their sticks on the day of the fundraiser and the goalie even put my name on his stick with red tape. They made me feel so good that day. I may try to play hockey again this year but I won't be able to play on that team. I will play on a less competitive team just a couple of times a week. I missed very many school days in my grade 4 year but my teacher was very supportive and even taught my class about lupus. Most kids at my school ask me about it and what lupus is so I try to tell them the best way that I can, but I don't think they really understand how I feel sometimes.

To feel better I take medicine... I make sure that I take my medicine every day. I am on plaquenil, prednisone, a medicine for blood pressure and one for my bladder. I also have to take iron everyday because I am anemic. Other things I do to feel better are just play with my friends and my dog. I also really like to play the guitar.

I see the doctor a lot right now. It has been almost a year since my diagnosis and I still probably go to SickKids at least once a week. I have been hospitalized three more times since my diagnosis and right now I have a stent in my kidney. I get a lot of headaches and fevers and usually have to go to SickKids when this happens too. I sometimes get upset when my parents pack up the car and we head down to Toronto but I know that I have to do it. I really hope that one day I will be like some of those people who only have to do a check up once a year. My mom says I will get there someday and that once they figure out my kidney, things should be better.

When I grow up I want to be an archeologist or a doctor. I love school and I want to go to Yale University. My mom thinks I will become a doctor one day and find a cure for lupus..... maybe I will.

Hunter Hogarth



Please join me, Julia Kane, President of Lupus Ontario and young Hunter as we ask you to share in our efforts to fulfill the \$250,000.00 Lupus Ontario Fellowship commitments at the Hospital for Sick Children. You will receive a full charity tax receipt for your donation and be recognized in our Annual Report along with our premier event, Dance for the Cure, as a Paediatric Fellowship Supporter. If you prefer, you can donate today by visiting www.lupusontario.org and click on the **Make A Donation** button and follow the links in honour of Hunter Hogarth (no card).

Thank you in advance for your generosity.

Sincerely,



Julia Kane, President, Lupus Ontario

PS. Your donation today will help make this incurable autoimmune disease a "life worth living" for many young people like Hunter Hogarth and Kathryn Stewart. Kathryn, who was the heart of our special request letter in September 2010, is in good spirits following hip replacement surgery at age 16, due to complications from her treatment for lupus.