



October is Lupus Awareness Month

Lupus remains under-recognized and under-funded

In October, lupus patients and supporters across Ontario will recognize Lupus Awareness Month as a time to reflect on what all Ontarians can do to increase awareness of this under-recognized and under-funded disease. Lupus affects tens of thousands of men, women and children, yet many people are still unaware of the disease. Its symptoms often mimic other illnesses, and it can attack any tissue or organ in the body. Lupus patients often suffer from the disease in very different ways showing various multiple symptoms and it has become known as “The Disease with 1000 Faces”. Common symptoms of lupus include joint pain, skin rashes, sun sensitivity, extreme fatigue, fever, chest pain and seizures (only to name a few). Eighty percent of people diagnosed today are young women. It is a disease that is life altering and sometimes life taking.

Lupus Ontario President Julia Kane says: “While there is no cure yet, with early treatment, most people with lupus can look forward to a normal life expectancy. There are several newer medications that can help to control symptoms, and a new class of drugs is on the horizon. New research brings unexpected findings each year. The progress made in treatment and diagnosis during the last decade has been greater than that made over the past 100 years. Yet so much more is needed to bring about public awareness and better quality of life. Lupus Ontario is dedicated to this task and you can help. Become informed about lupus, become involved, volunteer, be an ambassador, be a donor. Join Lupus Ontario and be part of the solution”.

IN THIS ISSUE

- Lupus Awareness Month
- Special Appeal 2010
- Membership Renewal 2011
- Keeping you in the Loop!
- 4th Annual Durham Walk for Lupus
- Thunder Bay—The City with a BIG Heart!
- The Koski Kup 2010 / Bake Sale for Lupus / Toronto Walk 2010
- Upcoming Events in Support of Lupus Ontario
- Let's Talk Support
- iGive.com
- HBC Rewards
- Shoppers Optimum Points
- Contact Information

OCTOBER IS LUPUS AWARENESS MONTH

- Whereas;** Lupus is an autoimmune disease that can cause severe damage to the tissue and organs in the body and, in some cases, death; and
- Whereas;** More than five million people worldwide suffer the devastating effects of this disease and each year over one hundred thousand young women, men and children are newly diagnosed with lupus, the great majority of whom are women of childbearing age; and
- Whereas;** Medical research efforts into lupus and the discovery of safer, more effective treatments for lupus patients are under-funded in comparison with diseases of comparable magnitude and severity; and
- Whereas;** Many physicians are unaware of symptoms and health effects of lupus, causing people with lupus to suffer for many years before they obtain a correct diagnosis and medical treatment; and
- Whereas;** There is a deep, unmet need to educate and support individuals and families affected by lupus; and
- Whereas;** Increased public awareness, education and research are key to winning the battle against lupus; and
- Whereas;** Lupus Ontario is a nonprofit organization founded in 1978. The primary purpose is to eradicate lupus supporting lupus research, alleviate suffering for those patients through patient services and early detection of undiagnosed cases through awareness promotion.

Now, therefore, Lupus Ontario hereby proclaims **October 2010** as **Lupus Awareness Month**, when we request increases in public and private sector funding for medical research on lupus, targeted education programmes for health professionals, patients and the public, and recognition of lupus as a significant public health issue.

Special Appeal Fall 2010

Dear Friends of Lupus Ontario

Lupus Ontario needs your help today. 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 pediatric physician for specialty training in Lupus Erythematosus and Neonatal Lupus (lupus in newborns). We have pledged to raise \$250,000 towards this training in the next five years. Your donation today will make it possible to improve the care of these children living with lupus and the hope of a cure.

One of these young people is Kathryn Stewart. She wants you to know about her lupus journey in hopes that more awareness will lead to more research and a cure. This is her story:

My name is Kathryn Stewart, I'm 15 years old and I have Lupus.

In December of 2007, when I was 12 years old, I was diagnosed with Systemic Lupus Erythematosus. On the last day of grade six, I came down with the stomach flu. Days turned into weeks, and I wasn't much better. I felt nauseated, tired, cranky and I couldn't eat. I started to lose weight. As an already skinny child, I became dangerously thin.

My family doctor referred me to pediatrician after pediatrician. They all thought I was anorexic or emotionally distressed, but my family stood by me and didn't believe the doctors.

After almost a year, I was diagnosed with Celiac disease, a gluten intolerance. Doctors said I would feel better within a few days of going on a gluten free diet.

Weeks went by and I still felt sick. There was no improvement in my health at all.

A dietician helped me with my gluten free diet. I saw two social workers and a psychologist, getting nowhere close to a real diagnosis.

Finally, a doctor tested me for lupus. After seeing two rheumatologists, lupus was confirmed. It was a few weeks before Christmas. When I first heard I had lupus, I thought I had cancer. As the Doctor explained what lupus was, all I heard was a panicked rushing sound in my ears. "Why me?" was all I could think.

I was put on the medications Prednisone and Plaquenil. Dr. Silverman (my rheumatologist at the Hospital for SickKids) told me I had a mild form of lupus. Within a few months, I had become progressively worse. Things I didn't think of as symptoms **were** symptoms. I got rashes from the sun, (Doctors had said it was sun sensitivity, nothing more), leg pains (Doctors said it was growing pains), and headaches (Doctors said it was just migraines which ran in my family)

The day I was diagnosed was the scariest day of my life. I will never forget the feelings I felt that day; pain, anger, shock, confusion and a feeling that felt like I was falling, falling away from the world.

In the past three years of my lupus journey I have undergone many hospitalizations, pulse prednisone therapy, spinal taps, MRI's, Cat Scans, bone biopsies, allergic reactions to medications, elevated liver enzymes and thirteen months of chemotherapy, which was the hardest thing I have ever had to go through.

Lupus affects my brain. I've had headaches, visual disturbances, hearing problems, concentration issues and some uncontrollable twitching. Because of this, and the stress of being misunderstood at school and even bullied, I missed most of grade 8 and all of grade 9. I did home schooling and still managed to graduate from grade 8 and earned 3 grade nine credits.

I've been on prednisone the whole time I've had lupus. It completely changes how you look. I've been on doses from 10 mg to 60 mg. I have been on prednisone for so long now that I have osteoporosis, avascular necrosis in my right hip, both knees and both shoulders. I will need a hip replacement by the time I am 18 years old.



(Continued)

Lupus changed my life. It changed who I am. I am stronger now than I have ever been before and I am smarter for what I am going through. I am thankful for the care and the Doctors at the Hospital for Sick Children.

Lupus is hard to live with but I choose to live life by these important words,

“Life with lupus is still a life worth living.”



Please join me, Julia Kane, President of Lupus Ontario and young Kathryn Stewart 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 you will be recognized in our Annual Report along with our Premier Event, Dance for the Cure, as a Pediatric Fellowship Supporter. 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 Kathryn Stewart.

MEMBERSHIP RENEWAL 2011

Please consider this note as your membership renewal notice for 2011. Again we are doing this to best control our mailing costs. You may renew your membership with a credit card by phoning Karen in the Lupus Ontario office at 905-415-1099, or toll free in Ontario at 1-877-240-1099, otherwise, we would appreciate receiving the completed renewal and your cheque or credit card information by mail. You may use the addressed envelope included with this edition of Lupus Link. You can indicate on the inside of the envelope where you would like to designate your donation.

Your privacy is protected. Lupus Ontario does not sell or share member lists.

Once again we have had a successful year in spite of the economic stress. We have invested in research and education with the two Fellowships, (Toronto Western and Sick Kids Hospital), increased our support for CaNIOS and the Lupus Data Bank and continued to support the Lupus Clinics across Ontario. We have worked to keep our membership informed and through our partnership with Lupus Canada, we have expanded our public awareness with the PSA airing during Lupus Awareness Month in October on the Slice Network. We participated fully in the May 2010 National Walk a Block event that raised over \$100,000 in support of Lupus Ontario. The success of the *Dance for the Cure* in January, our Italian Dinner Dance, the Durham Walk and Fun Fair and the support of volunteers with golf tournaments, garage sales and carnivals have added to our ability to meet our goals and objectives.

The hard working team in the Markham office of Karen Furlotte, Juanita Butler and Nicole Wright keeps us moving forward and well organized, offering extensive support to the lupus community. Your \$25.00 membership donation helps **Lupus Ontario** to offer further support, education and public awareness programs, including our newsletter **LU-PUS LINK**. **Once again we ask that you consider including a further donation which will assist our commitment to research in the coming year.** This year we were again able to respond to a special research funding request from CaNIOS because of the \$13,000 we raised for research support with our membership renewal. Thank you for your generosity. A full annual report is available on request. Your membership card will be mailed to you with a receipt for the total amount received.

Any total donation of \$75.00 or more (including your membership renewal) will receive a special sponsored gift.

Please cut out, fill in and include the information below in the envelope provided.

MEMBERSHIP RENEWAL: \$ 25.00		Member Name: _____
RESEARCH DONATION: \$ _____ (Optional)		Address: _____
TOTAL AMOUNT: \$ _____		City/Town: _____ P/C: _____
		E-Mail: _____ Tel: () _____

Keeping you in the **Loop!**

The Safety of **Compact Fluorescent Lamps**

More and more Canadians are replacing regular incandescent light bulbs with more energy-efficient products, such as compact fluorescent lamps (CFLs). While CFLs are being promoted because they are energy-efficient, their use has also raised health concerns.

Canadians can be exposed to ultraviolet (UV) radiation from a variety of natural and artificial sources, including the sun, welding equipment, lasers, tanning equipment, and fluorescent lights. UV can be beneficial: it can be used to kill germs and treat various skin conditions, and it is needed to form vitamin D in our bodies. At the same time, there are risks attached to all forms of radiation, and overexposure to UV has been linked to sunburns, premature skin aging, skin cancer, eye problems, and weakening of the immune system.

Although the amount of UV emitted by CFLs poses no problem for the average person, some people are extremely sensitive to UV and may be affected by the amount of UV produced by CFLs. Those who have Lupus or another autoimmune disease and certain skin conditions can be sensitive to the UV from CFLs. If you believe you are suffering from symptoms related to UV, you should consult your health care provider.

Minimizing Your Risk

Although CFLs are considered safe to use, here are some steps you can take to further protect you and your family:

- Always handle CFLs carefully when installing and removing them
- Check with your municipality to see if CFLs can be recycled in your area. Recycling them means that the small amount of mercury they contain will not end up in the environment. If you have skin sensitivities to UV, or have Lupus or another auto-immune disease that makes you sensitive to UV, you can take these steps:
- Buy CFLs that are marked low UV
- Buy CFLs that have a glass cover already added, which will help further filter out UV radiation
- Use additional glass, plastic or fabric materials in your lighting fixtures to act as UV filters
- Increase the distance you are from the CFL, as this will reduce the level of UV exposure

Additional information:

- Remove and install the CFL by handling only the base of the lamp to prevent any unnecessary pressure on the glass that may cause it to break
- Consider using a drop cloth when replacing a CFL to minimize the chance of breakage should the lamp fall or to protect the flooring and assist in clean-up should the bulb drop and break
- Store fluorescent lamps in containers that prevent them from breaking, such as in their original packaging
- Consider avoiding the use of CFLs in areas where the lamps may be easily broken

www.hc-sc.gc.ca

10 Things You Can Control in a Conflict

By Vivian Scott

Dealing with conflict takes energy, and when you're living with lupus, energy can be in short supply. If you've tried your best to resolve a problem, but it still remains, consider using these 10 ways to regain control.

1. Your Plan—Visualizing the future helps you focus beyond temporary problems
2. Your Perspective—Stop and reassess your point of view and find a learning opportunity in the situation
3. Your Responses—Look for ways to respond that don't escalate anxiety
4. Your Investment—Spend less time thinking about it, talking about it, and engaging in it
5. Your Role—it takes two to tango, and if you stop dancing, the conflict has no choice but to diminish
6. Your Expectations—Changing expectations doesn't mean lowering them. Stop holding others to standards they don't know they are being measured against, and get a new yardstick!
7. Your Energy—Direct your energy elsewhere: toward family, classes at the gym, continuing education, or friends
8. Your Own Story—Give accounts without elevating or victimizing anyone. Say, "It's a difficult time right now, but I am learning a valuable lesson," rather than, "Once again, I am the victim."
9. Your Method for Processing Emotions—Talk with a trusted source, keep a journal, get some exercise, or write letters you'll never send
10. Your Character—Show your best side and not an unchecked series of poor reactions

Featured Article: Summer 2010 issue of Lupus Now

Low Level of Vitamin D Does Not Necessarily Result in Bone Disease in People with Lupus

Vitamin D insufficiency in a large female SLE cohort.

Authors: Toloza SM, Cole DE, Gladmann DD, Ibanez D, and Urowitz MB. (2010).

Lupus, 19:13-19

What is the topic?

People with lupus are advised to avoid the sun because the ultraviolet rays can trigger rashes. Some patients experience more widespread flares after sun exposure. However, sun avoidance leads to low levels of vitamin D in the body. Low levels of vitamin D are associated with thinning of the bones, or "osteoporosis." Steroids are often used to treat lupus since they work fast and are highly effective, but they can also increase osteoporosis. For these reasons, among others, people with lupus are at increased risk for osteoporosis.

What did the researchers hope to learn?

The researchers hoped to learn about possible relationships between vitamin D levels in the blood, lupus treatments, and bone mineral density (BMD), a measurement of how thick bones are. BMD is low in people with osteoporosis.

Who was studied?

134 non-pregnant women with lupus were recruited for the study at the University of Toronto Lupus Clinic. The women were mostly Caucasians, an average age of 48, and had lupus for an average of 17 years.

How was the study conducted?

Vitamin D levels in the blood were measured in each woman. About half of the vitamin D measurements were made in the summer and about half in the winter (since there may be more sun exposure in the summer than winter even in people who try to avoid the sun). Vitamin D levels were rated as being "sub-optimal" (if somewhat lower than normal) or "deficient" (if a lot lower than normal).

Most of the women also had their BMD measured by X-rays. BMD measurements were categorized as indicating either "osteopenia" (if BMD was somewhat reduced from normal) or osteoporosis (if greatly reduced from normal).

What did the researchers find?

Vitamin D levels measured in the winter were lower than those measured in the summer even in lupus patients who are usually doing their best to avoid the sun. Sub-optimal levels of vitamin D were found in about 67% of the women, while deficient levels were found in 18%.

Most of the women had normal BMD, but 28 had osteopenia and 12 had osteoporosis.

There was no direct relationship found between vitamin D levels and BMD. However, vitamin D levels were decreased when there was increased "creatinine" (a test that reflects kidney damage) or increased steroid use.

What do the results mean for you?

People with lupus who are treated with steroids are at increased risk of having low levels of vitamin D. This is not new information, of course, and it has been recommended for some time that people taking steroids receive supplements with calcium and vitamin D. Although reduced levels of vitamin D are known to be directly linked to osteoporosis, this study did not show that connection. There can be many reasons for that, including how much milk people drink, their age, their real sun exposure, what kind of vitamin supplements they take, and their age.

MEN & Lupus

- 80% of the people that get lupus are women, but men, of all ages, get both Discoid Lupus and Systemic Lupus
- Men can also get Drug Induced Lupus Erythematosus. In fact they get DILE more often than women. This is likely because some of the medications that trigger DILE are prescribed more often to men
- Hormone levels as well as the way certain hormones are metabolized differs between men with lupus and men without lupus. These hormones include estrogen, androgens, testosterone, and prolactin
- Men may feel less masculine after a diagnosis of lupus seeing it as a "women's disease". This is just not true. Men with lupus are typically as fertile as men without lupus. Lupus does not directly interfere with the ability to perform sexually, however pain, fatigue and depression that sometimes accompany lupus can lead to sexual dysfunction
- Coping with the limitations lupus can put on physical ability can be even more difficult for men than women due to societal expectations on men to be strong and perform physically, and to provide for their families
- Men typically cope better than women with the changes to appearance that can come with lupus but they can still cause loss of self esteem. The changes of most concern to men include hair loss, weight gain and skin changes
- There is conflicting information about the severity of lupus in men versus women
- Some studies have suggested that pleurisy, renal involvement, Discoid Lupus, hemolytic anemia, Lupus anticoagulant, peripheral neuropathy, vasculitis and seizures can be more common in men with lupus than they are in women with lupus

4th Annual Durham Walk for Lupus

On Saturday September 11th, 2010 the Lupus Ontario Durham Branch hosted our 4th Annual Walk for Lupus, Fun Fair & Silent Auction at Rotary Sunrise Lake Park in Whitby.

Approximately **500** people came out to support lupus and close to **\$26,000** was raised for Lupus Ontario. We had many individual walkers and many registered Teams. Close to 100 family and friends walked in Memory of their beautiful angel Ashleigh Prithipaul who lost her battle with lupus at the young age of 18.

Once again Mother Nature was on our side blessing us with beautiful weather. We were very lucky to have the support from our Army Cadets Regiment 1913, Ajax High School, St. John Ambulance, and many wonderful volunteers.

The Trillium College of Massage Therapists and the Career School for Hair & Nails provided wonderful massages and mini manicures to our participants. We were very happy to have Mayor Perkins and members of Whitby Council attend our event and surprise us with an additional donation of \$250.00 to our walk fund.

Some of our sponsors also attended our event and provided event day support. Thank you to Durham Chiropractic Centre, Uweightloss, Vitaminwater, Chatterpaul's Restaurant, Musical Launch Pad and Rogers TV. Thank you ACT-UCT, Canada Cinema Distribution, Ajax Lions Club, Carpenters' Union Local 397, Knights of Columbus St.Jude Council, Borochoch & Associates, Ithai Restaurant in Whitby, Warner Bros Canada, Desjardins Credit Union, Bowmanville Veterinarian Clinic, Mexico Lindo Oshawa, David Roney, Sandra Deering Agency, 6 Degrees, Celebrate Recovery Whitby Group and Gateway Community Church. Thank you to all our silent auction and raffle donors. A special thank you to the Silent Auction Chair, Laura Piccione and Fun Fair/Volunteer Chair, Rob Piccione for all of your hard work. Thank you to Bill Hawthorne and the Donation Bake Crew. Thank you to our Raffle girls Andrea & Kim, Melissa Munn and thank you to my amazing family, friends and volunteers. If not for all of you this event would not be possible.

Seeing how our event fell on September 11th we wanted to do something special. At the beginning of our opening ceremonies our Army Cadet's marched to the front of the gazebo and led everyone in the singing of O'Canada, followed by a moment of silence to remember the victims of 9/11, our troops and all our loved ones past and present. We then had a beautiful butterfly release. We will now have a butterfly release every year!

Our warm-up was a fun Conga-line. Having the Mayor, Whitby Council and everyone take part was great to see. We had Soundmaster DJ, fun fair games, a jumping castle, face painting, balloons, craft station, coloring contest, jelly bean draw, donation bake sale, fundraising table, information booth, raffle, an awesome silent auction – and a doggy booth for all our friendly furry friends. All our walkers received a free meal voucher, door prize ticket and t-shirt.

Our top fundraising team was The Wolf Warriors and the Top Individual Fundraiser was Jaclyn Smith. Both were presented with special plaques.

Juanita Butler and Karen Furlotte were presented awards of appreciation for all their hard work and dedication towards our Walk. Kathryn Stewart was presented with a plaque of appreciation for designing our walk t-shirts for the second year in a row.

I was so proud of everyone. Seeing everyone participate and be as passionate in their support as we all work together to one day squash lupus.

We started with a small group of 20 at a mall. We'd walk for an hour before the stores opened then man a lupus booth for the day. Then my beautiful family agreed to help turn our event into an EVENT. So now with the help of my amazing family, friends and wonderful volunteers we are now taking our Walk for Lupus to new heights.

Please join us next year as we celebrate our 5th Annual Walk for Lupus, Fun Fair & Silent Auction on **Saturday September 10th**. All event details can be seen on www.durhamwalkforlupus.com

Thank you,
Shannon Crawford
Shannon Crawford – Event Organizer & Support Group Facilitator



Mayor John Gray & Durham Lupus Support Group representative Brenda Stewart

October 21, 2010.

On Friday October 15, 2010 the Mayor of Oshawa, John Gray, proclaimed October as Lupus Awareness Month. Members of the Durham Lupus Support Group were in attendance at the flag-raising ceremony at City Hall.

Lupus Ontario would like to thank Mayor John Gray and the City of Oshawa for their continued support. With the involvement of our communities, we can one day bring more awareness and funds to lupus.

Working together to conquer lupus



Shannon Crawford speaking to the participants



Mayor Perkins & Councillor Coe release a butterfly



Group photo



Conga-line starts



Conga-line



All the participants walking in support of lupus



Top Individual pledge earner
Jaclyn Smith



Top Team
Wolf Warriors



Thank you Canada Cinema
Mike Stewart



Tom and Elspeth Koor with their dogs



Mayor Perkins, Whitby Council and Shannon Crawford



Face Painters



Army Cadets 1913



Team Ajax



Team Ashleigh



Thank you ACT/UCT Carol & Charlie

Thunder Bay - The City with a BIG Heart

Paula Courtney.....

On her way to raising \$25,000 In support of Lupus Ontario's SickKids Fellowship

My name is Paula Courtney, I live in Thunder Bay, Ontario and I was diagnosed in 1993 at the age of 28 with Nero SLE Lupus in Toronto by Dr. Keystone. In order to get this diagnosis I had to go through endless tests such as MRI's, blood work, spinal's, bone marrow tests etc. When I was transferred to Toronto I was taken by air ambulance. I had a fever of 106 degrees that would not break and upon arrival I was packed in ice. Anyone that saw me in Thunder Bay prior to my departure to Toronto never thought that I would be coming home alive. Even after being diagnosed with lupus, I was only given 10 years at best to live. I can now say that I have been living with lupus for 18 years and that every day is a miracle that I am determined not to waste.

The reason I am trying to raise \$25,000 for Children's research for Lupus at Toronto SickKid's is simple. Any child that lives with lupus should be able to have the best quality of life possible. The thought of a child having to go through what I endured, makes me shutter. I know the level of pain I have lived through and the thought of babies and children having to go through endless amounts of pain literally makes me sick. I was informed that there has been a steady increase in children being diagnosed with lupus and that Lupus Ontario has a 5 year \$250,000 commitment to Toronto's SickKids Hospital. This served as my platform to bring in the much needed funds to support this partnership.

I've never tried to lead a fundraising campaign before but when you believe in something so much you just take it one step at a time. The campaign's name is "BABY STEPS"! Thunder Bay's children helping children, step by step. This is how I have raised \$14,000 to date. I've had 5 tag days, two at George's Market, one at Metro, one at Quality Market and one at Canadian Tire. I held a Bottle Drive on July 17 & 18 and to this day it continues to bring in money. My latest event was a Benefit which was held at ScuttleButt's with Chris Krienke & Band for live entertainment. This was held on October 1st, 2010, marking the first day of Lupus Awareness Month. A campaign, with purchasing paper baby feet is currently underway in four local businesses, running from October 1 until November 6, 2010. Patrons visiting Taco Time, Rollason Flower's, Global Experience, and D & R Sporting Goods donate a dollar to purchase a baby foot and can then sign their names to be recognized for their contribution.

If you would like to help me reach my goal of \$25,000 please contact Lupus Ontario at 1-877-240-1099

Sincerely,

Paula Courtney

Paula Courtney



Poster for the paper feet campaign



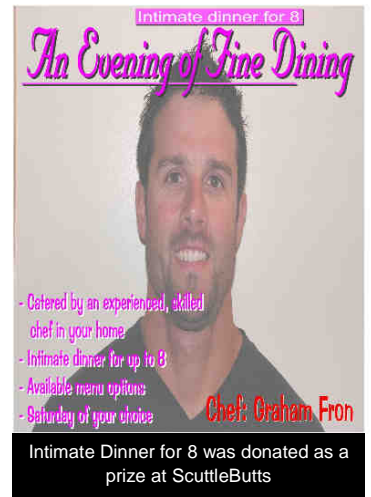
Children at "Step by Step" Daycare centre who helped make the poster



Table of donated items at ScuttleButts



Sherrie and daughter Juliet helping to wrap the donated items for the ScuttleButts event



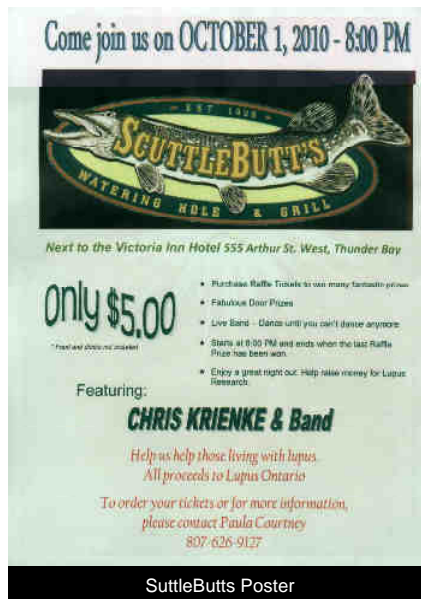
- Catered by an experienced, skilled chef in your home
- Intimate dinner for up to 8
- Available menu options
- Befunday of your choice

Chef: Graham Fron

Intimate Dinner for 8 was donated as a prize at ScuttleButts



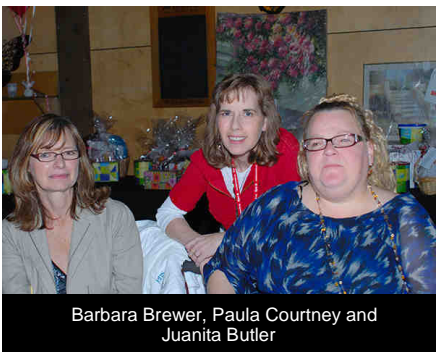
Butterfly door prize



ScuttleButts Poster



Karen Furlotte from Lupus Ontario helping out at ScuttleButts



Barbara Brewer, Paula Courtney and Juanita Butler



Chris Krienke



Paula Courtney and her cousin Cathy Isotalo



Band Singer



Band Singer



Band Drummer

“Donors don't give to institutions. They invest in ideas and people in whom they believe”.

G.T. Smith

The Koski Kup—Raising Money to Combat Lupus Since 2007

Our father had lupus. He was first diagnosed in the mid-1990's and lived with the disease for the last 12 years of his life. After he passed away in September of 2007, my next oldest brother David and I were talking about what we could do to honour our father on our drive back to Toronto from Sudbury. We settled on the idea of an annual ball hockey tournament to raise money to help combat lupus; “The Koski Kup” was borne as an idea. We identified three pillars that could serve as the foundation for the tournament: education, community and sport.

Our father was a teacher by profession (he taught education as a University Professor) and the idea of using the tournament as a means to spread awareness about lupus was a natural fit. The truth is that even though our Dad had the disease for more than a decade, I felt like I still didn't understand it very well.

Community was also an important element of our plan for the tournament; we wanted to bring people together in a fun atmosphere.

Finally, we liked the idea of a sporting event as our father was a big proponent of the power of sport to bring people together; he had been an accomplished athlete when he was younger and had benefited as a player and coach.

We held our first tournament 6 weeks after our Dad passed away and began what has become an annual tradition. That first year, Toronto received heavy rains the day before the tournament and when we arrived at the rink we found two inches of water everywhere! “Ok, who can run to a store and buy some squeegees?” We made it work and the day was a great success having accomplished all of our goals and raising a few thousand dollars for Lupus Ontario.

We recently held our 4th annual tournament in mid-September. You can see a few pictures below. Four years later we continue to focus on the 3 pillars of the tournament, with the underlying mission of raising money for Lupus Ontario. To date The Koski Kup has raised over \$7500.00.

You can see pictures from past years and learn more about the tournament through our website www.koskikup.com So far we've kept the tournament fairly small (averaging 5 or 6 teams) but it may be time to make it bigger! If you are interested in volunteering or putting together a team, we'd love to have you. The 5th Annual Koski Kup is Saturday September 17th, 2011 in downtown Toronto. More details will be provided closer to the tournament day. In the meantime, you can express your interest in participating through the Koski Kup website or through Lupus Ontario.

Thank you for helping spread the word,

Jordy Koski

Jordy Koski, Co-founder, The Koski Kup



“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” *Margaret Mead*

Article by Krista Lattanzio (September 28, 2010)

My name is Krista Lattanzio and my daughters name is Elina. We live in St. Thomas and this is the third year that Elina has done a bake sale with the funds going to Lupus Ontario. The first year Elina raised \$120.00, the second year \$230.00 and this year \$240.00. Elina is ten years old and 4 years ago we participated in Walk a Block for lupus in support of our family friend that has lupus. The next year there was not a local walk, but Elina decided she still wanted to do something. She was only seven years old then, but it really affected her that our friend was sick. She and her little sister Klara—now 8 years old (who is equally dedicated—helps with baking but leaves the selling up to Elina) baked cookies and cupcakes the first two years and added brownies to our sale this year. So over the past three years she has raised \$590.00 and has donated every cent to Lupus Ontario. We are proud of her because she came up with this idea on her own and we are proud of Klara because she is demonstrating interest and enthusiasm in the sale as well. She sets up a table with signs at my parents annual yard sale and people are always so kind, generous and supportive of her efforts. We are super proud of her and Klara, that after three years, they are already planning their next sale.

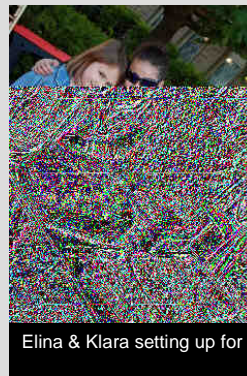
Thanks for hearing our story,

Krista Lattanzio

Krista Lattanzio
(Mom to Elina & Klara)



Elina baking at home



Elina & Klara setting up for



Elina icing a cupcake for the sale

Never too late!!!!

Although the majority of the walks for Walk a Block 2010 took place in May, Cheryl Assivero was determined to gather anyone she could to walk in support of a close friend who was recently diagnosed with lupus.

Walkers assembled at G. Lord Ross Park in Toronto on September 18, 2010. When it was all said and done the walk raised over \$1000.00. Way to go Cheryl and Team Gates! Thank you to Andre Mattera and his wife Mary for attending the walk on behalf of Lupus Ontario and showing your support. Together we can take a step to conquer lupus.



Group photo



Walking through G. Lord Ross Park

Upcoming Events in Support of Lupus Ontario

November 6, 2010

25th Anniversary Italian Dinner at the Riviera Parque in Vaughan

January 29, 2011

Dance for the Cure at the Terrace Banquet Centre in Vaughan

February 23, 2011

Voyage Fashion Show at St. Matthew High School in Orleans

April 15 W/E, 2011

Lupus Ontario AGM and Workshops (New Date)

Throughout May 2011

Walk for Lupus in communities throughout Ontario



VOYAGE

one show, one trip, one cause

Coming February 23, 2011 at 7:00 PM

Ottawa's St. Matthew High School presents their annual Fashion Runway Show this year in Support of Lupus Ontario and their search for a cure. Our Fashion Show's Theme is based on St. Matthew's multicultural week and will be presented as a trip around the world.

My STORY

My name is Bronwyn, and I am helping to raise money and awareness for lupus research because I've been living with the disease since the age of five. This is not just my personal fight, but this event also allows me to make a difference in the lives of others who are affected with lupus.

If you would like to showcase your fashions on the St. Matt's runway please contact Bronwyn Lefebvre at:

bronwyn@answermen.com

If you would like to make a donation in support of the event and Lupus Ontario please contact the Lupus Ontario office at:

905-415-1099 or 1-877-240-1099

25th Silver Anniversary Italian Dinner

SATURDAY NOVEMBER 6, 2010

Riviera Renaissance Parque
2800 Highway #7 West
Concord, Ontario



**Special Performance by
CLUB VIVA DANCE**

PROCEEDS TO LUPUS ONTARIO
(Tax Receipt \$25.00 per ticket)
\$85.00 per Person

Antipasto Bar 6:00-7:00pm
Dinner to Follow

For Tickets and Information
Please call **Juanita at 905-415-1099**
or **Maria at 416-638-6108**



DANCE FOR THE CURE VIVA ITALIA

JANUARY 29TH | 2011
THE TERRACE
BANQUET CENTRE
AN ITALIAN INSPIRED
EVENING TO HELP FIND
A CURE FOR LUPUS

To order tickets or for more information email
tiziana.tolfo@gmail.com or call (905) 415-1099.

ALL PROCEEDS TO LUPUS ONTARIO,
SICKKIDS & THE AARC FOUNDATION



Lupus Canada and our Provincial Partners
are excited to announce the kickoff to the
10th Anniversary
of our National Walk Campaign,
with the launch of our new brand

WALK FOR **lupus** 

It's the same great event... only the name has changed!

Take a step to conquer lupus in May 2011...

visit www.walkforlupus.ca to learn more!

Let's talk **SUPPORT!**

Keep Your Exercise in **Check for Winter**

With the winter months so close, it's time to think about keeping your activities and exercise in check until the warmer weather is upon us once again.

The benefits of physical activity are well known and worth repeating. When you exercise on a regular basis, you:

- Improve your circulation and lung capacity
- Make it easier to reach and maintain a healthy weight
- Help prevent health problems that may be associated with lupus, including type 2 diabetes, heart attacks, strokes and osteoporosis
- Increase your muscle strength
- Strengthen your muscles and prevent your joints from getting stiff
- Reduce fatigue and stress
- Improve your quality of life, overall health and sense of well-being

With all these benefits to be gained, it's not surprising that exercise is strongly encouraged for people with lupus, especially during flare-free periods.

"Regular physical activity" doesn't mean running marathons or intense sessions at the gym. In fact, starting slow and exercising moderately are key. Remember: overdoing it can be as bad as not doing anything at all.

Your goal should be to work towards a total of 60 minutes of physical activity a day. Sound daunting? It needn't be, especially if you tackle those 60 minutes of activity in 10 to 20 minute increments. Remember, every little bit counts.

A few words of caution:

- Always check with your doctor before beginning a new exercise routine
- Listen to your body. Reduce your activity level if you notice unusual or persistent fatigue, weakness, joint swelling or pain after exercising
- It may be wise to limit strenuous exercise during a lupus flare. This is a time when rest is important

Yoga: There are many different styles of yoga, so look for one that is gentle and slow-paced, such as Hatha (whose name suggests "balance" in Sanskrit) and Naram (which means "gentle"). By moving the body into specific shapes, yoga helps increase circulation, which, in turn, nourishes the joints. The meditative aspects of yoga are calming, helping to reduce stress.

Tai chi: This slow and gentle form of exercise encompasses a series of positions strung together into continuous movement. It helps improve strength, balance and flexibility, and can be adapted for people of different abilities, including those using a wheelchair.

Aquatics: Water-based exercises (usually done in the deep end of a pool using flotation belts) are not only gently, they enable you to do things you might not be able to do on dry land. Since water is much denser than air, aquatic exercises provide muscle training with less stress on your joints. Plus it's fun!

Walking: With the winter months so close, walking outdoors can be tricky, so why not bring that walking indoors. By walking on the spot. Invest in good walking shoes and buy a step counter or pedometer. These instruments keep track of every on the spot step you take and help keep you motivated. Make easy to set targets for yourself than gradually take another step then before you know it, you will be walking on the spot for a half an hour. Perhaps you can time your walking with your favourite half our show. When the show is over you have reached your goal.

Take a break: as beneficial as physical activity is, rest is equally important. Fatigue is one of the most common symptoms of lupus. By paying attention to your body, you will learn to recognize fatigue before it becomes overwhelming. Don't ignore these signs, as exhaustion may put you at increased risk for a debilitating lupus flare. You need to schedule time to exercise and you need to schedule a time to rest.

Living Well with Lupus Facts

Useful Websites

- Office of Women's Health—US Department of Health and Human Services: www.couldihavelupus.gov; Great TV commercial about lupus.
- The Arthritis Foundation: www.arthritis.ca
- Osteoporosis Canada: www.osteoporosis.ca
- Lupus Foundation of America: www.lupus.org
- Cleveland Clinic: www.my.clevelandclinic.org/default.aspx;
- Sjögren's Society of Canada: www.sjogrenscanada.org
- MedlinePlus—Blood and Blood Disorders: www.nlm.nih.gov/medlineplus/bloodandblooddisorders.html
- National Institute of Neurological Disorders and Strokes (NINDS): www.ninds.nih.gov
- Public Health Agency of Canada: www.travelhealth.gc.ca
- International Association for Medical Assistance to Travelers (IAMAT): www.iamat.org
- Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS): www.CaNIOS.ca
- Arthritis & Autoimmunity Research Centre Foundation: www.uhn.ca/foundations.aarc/site
- www.ClinicalTrials.gov: Although this is an American site, search "lupus, Canada" for links

iGive.com Help Lupus Ontario When You Search OR Shop!

A penny a search and a portion of each purchase will be donated to **Lupus Ontario** for free. How often do you search or shop online?

Whether it is searching online for the perfect Holiday gift or for your personal wish list make **iGive.com** your search engine for products at over 700+ stores. All you need to do is sign up at www.iGive.com and start your search engines! A penny a search and a portion of each purchase will be donated to **Lupus Ontario**. Searching OR shopping means a donation. It's just that free and easy. As an **iGive** shopper, you have access to exclusive coupon codes, free shipping deals, and sale alerts.

Here are just a few of the stores participating in the donation program:

- Aeropostale
- Cheap Tickets
- Kodak Gallery
- Nike
- Sears
- Travelocity.com
- Apple Store
- eBay
- Lancome
- Nine West
- Sheraton
- Toys R Us
- Bath & BodyWorks
- Expedia.ca
- MattellShop.com
- Old Navy
- Sirius/XM Radio
- Weight Watchers
- Best Buy
- FTD.com
- Microsoft Store
- Payless Shoes
- Sony Style
- Vitamin Shoppe
- Chapters/Indigo
- Home Depot
- Naturalizer
- Scholastic Store
- Starbucks

Make a point of giving.

Donate your Hbc Rewards points to your favourite cause.



Make a point of giving.

Use your Hbc Rewards points to help Lupus Ontario

What if I told you that you could help us make a difference—by shopping?

Well, you can when you join the **Hbc Rewards Community Program**

It's an easy and exciting way to shop your favourite Hbc items and make a contribution to Lupus Ontario.

All you have to do is enrol as an Hbc Rewards member by visiting www.hbc.com/rewards. Once you're a member, you can link your Hbc Rewards account to Lupus Ontario and automatically start contributing your Hbc Rewards points. So that every time you shop at the Hbc family of stores, you can truly make a difference to our cause.

So how do you link your Hbc Rewards account? That's simple. All you have to do is:

1. Visit www.hbc.com/community
2. Go to **Donate to a Community Group**
3. Search for our group by entering our Public ID # 2680757
4. Select the percentage of points you would like to donate (minimum of 10%)

If you have any questions or want to learn more about the Hbc Rewards Community Program, visit www.hbc.com/community. We really think this is a great way to help our great cause and look forward to seeing the results.

PS. If you join the Hbc Rewards Community Program today, Hbc will give Lupus Ontario 2,000 much needed bonus points up to a maximum of 100,000.

Donate your Shoppers Optimum Points

Shoppers Drug Mart offers a charity initiative that can greatly benefit Lupus Ontario.

You can now donate some or all of your Shoppers Optimum Points to Lupus Ontario and help us redeem them for merchandise at Shoppers Drug Mart such as office supplies and fundraising items for auctions, door prizes and raffles.

Here's how you can help:

- Visit www.shoppersdrugmart.ca and click 'Donate Your Points to Charity Today.' A confirmation email will be sent to you as well as to Lupus Ontario.
- Call **1-800-SHOPPERS** and talk to a customer service representative.

* All Shoppers Optimum Points are transferred to Lupus Ontario as anonymous donations.

Lupus Ontario would like to thank all those who have donated to this ongoing program

Lupus Ontario's Board of Directors

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Website: www.lupusontario.org

Provincial Support Centres

Toronto & GTA Region

Toronto West Branch & Support Group
Toronto North Branch & Support Group
Toronto North Support Group
Toronto South Support Group
Toronto Beaches Support Group
Durham Region Support Group
Markham Support Group

Eastern Ontario Region

Ottawa Branch
Lindsay Support Group

Central Ontario Region

Barrie and Area Support Group
Collingwood Support Group

Northern Ontario Region

Sault Ste Marie Support Group
Sudbury Branch & Support Group
Thunder Bay Branch & Support Group
Dryden Information Group

Western Ontario Region

London Support Group
Windsor Support
Bolton Support Group
Brantford Support
Kitchener/Waterloo Support Group
Guelph Support Group
Ridgetown Support/Chatham

South Central Region

Hamilton Branch & Support Group

Ontario Teen & Young Adult Support

Please contact Lupus Ontario for information

**For more information on your
Local Support Centre please contact:**

Juanita Butler, Support Services Coordinator, Lupus Ontario
905-415-1099 or 1-877-240-1099
info@lupusontario.org

Lupus Canada

3555-14th Avenue, Unit 3
Markham, ON L3R 0H5
Toll Free (In Canada): 1-800-661-1468
Tel: 905-513-0004
Fax: 905-513-9516
Email: info@lupuscanada.org
Website: www.lupuscanada.org

Member Organizations

BC Lupus Society

200-1645 West 7th Avenue
Vancouver, BC V6J 1S4
Tel: 604-714-5564
Fax: 604-714-5555
Email: info@bclupus.org

LE Society of Saskatchewan

Box 88, Royal University Hospital
103 Hospital Dr.,
Saskatoon, SK S7N 0W8
Tel: 204-942-6825
Toll Free: 1-877-566-6123
Email: less@sasklupus.com

Lupus Society of Manitoba

105-386 Broadway Ave.,
Winnipeg, MB R3C 3R6
Tel: 204-942-6825
Fax: 204-942-4894
Email: lupus@mts.net

Lupus Foundation of Ontario

294 Ridge Rd. N., Box 687,
Ridgeway, ON L0S 1N0
Tel: 905-894-4611
Toll Free: 1-800-368-8377
Fax: 905-894-4616
Email: lupusont@vaxxine.com

Lupus Ontario

(see contact information at left)

Lupus New Brunswick

c/o Nancy Votour
55 Grant St. Apt 17
Moncton, NB E1A 3R3
Tel/Fax: 506-384-6277
Toll Free: 1-877-303-8080
Email: lupins@rogers.com

Lupus Newfoundland & Labrador

P.O. Box 8121, Station A, Kenmount Rd.,
St. John's, NF A1B 3M9
Tel: 709-368-8130
Email: lupusnfld@nl.rogers.com

Lupus P.E.I. & Lupus Quebec

Toll Free (In Canada) 1-800-661-1468
Tel: 905-513-0004
Fax: 905-513-9516
Email: info@lupuscanada.org

Lupus Society of Nova Scotia

P.O. Box 38038,
Dartmouth, NS B3B 1X2
Tel: 902-425-0358
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Fax: 902-798-0772
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Our Mission:

Lupus Ontario is a team of caring and enthusiastic volunteers and staff who are passionately committed to helping those with lupus live longer and better by raising funds that deliver vital support, education, awareness