



October is Lupus Awareness Month

Lupus remains under-recognized and under-funded

- 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 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 and research

Now, therefore, Let it be proclaimed that **October 2011** is **Lupus Awareness Month**

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Dr. Daphna Gladman, Mark Brunswick, Tina Sarta, Tiziana Tolfo, Dr. Murray Urowitz

Dance for the Cure

On June 16, 2011 Tiziana Tolfo, Tina Sarta and Mark Brunswick Dance for the Cure Chair and Committee Members presented a cheque for \$35,000 to the AARC Foundation. The funds were raised through the 16th Annual Dance for the Cure held on January 29th, 2011.

Each year funds raised through Dance for the Cure are divided amongst Lupus Ontario, the AARC Foundation and a Fellowship with the Paediatric Lupus Clinic at the Hospital for Sick Children. Lupus research

continues to be tremendously under-funded, and these three, very deserving organizations depend on this support.

The **17th Annual Dance for the Cure** will be held **February 25th, 2012** at the Terrace Banquet Centre in Vaughan. If you would like to attend, volunteer or donate please contact the Lupus Ontario Office. **1-877-240-1099** | events@lupusontario.org

www.lupusontario.org

Keeping YOU in the loop!

President's Message

from Julia Kane

This is just a short note to keep you up to date on the workings of Lupus Ontario over the past three months.

Firstly we need to acknowledge the generous support received from the Dawe Family Foundation. The \$10,000 grant will be instrumental in our ability to meet our support commitments this fiscal year.

Secondly, we would like to thank the Member Organizations and Lupus Canada for responding to our August request for \$10,000 to help in funding our Paediatric Research Fellowship at the Hospital for Sick Children. The new Fellow is Dr. Senq Lee from Australia under the supervision of Dr. Earl Silverman. We are almost half way through the \$250,000 commitment for this Fellowship which is sponsored in half by the proceeds from The Dance for the Cure, and half by fundraising at Lupus Ontario. (This includes the dedicated fundraising by Paula Courtney of Thunder Bay earlier this year) The Lupus Clinic at the Hospital for Sick Children (SickKids) is one of the largest in the world and is full of young people coping with lupus.

One of these youngsters is Hunter Hogarth who is pleased to tell his story (see page 4 & 5) in hopes that we can raise funds and awareness for lupus. Hunter is facing a second surgery in October for a stent placement to improve his kidney function.

You can be part of our solution. Please give generously and know that every dollar is gratefully received for this worthwhile Lupus Ontario Paediatric Fellowship.

There have been several resignations from our Board and we are very appreciative of their gifts of time, energy and talent that have benefitted Lupus Ontario. Our best wishes to Tom Mather (VP) and Janice Locke (Secretary and Lupus Canada Representative) and Ruth Tarvudd our Board Member covering Thunder Bay and the North who has moved to Sudbury.

This leaves us with some pretty big vacancies to fill as we look for someone to be a representative and liaison in the north. Passion, time and commitment are needed for the Executive Positions open, namely Vice President and Secretary. After almost 12 years as President of the Board, I look forward to mentoring the next VP into the position.

As we do this mailing, we have a 2012 Calendar available "**Butterflies for Lupus**" in a CD type case for sale. I sold about 20 at my Art Show in Unionville over the Labour Day weekend and you really need to open one to show people how they work in the CD stand, otherwise many people thought they were CD's. At \$5.00 each they are a great fundraiser. (Stocking stuffer)

Thank you to everyone who had events this summer, both large and small, anniversaries and bake sales and a special thank you to Hunter Hogarth for his courage to be the face and story of our Fall campaign. Please remember every penny counts with Lupus Ontario and of every dollar donated over 80 cents is spent on programmes and research. Please give generously if you are able. Donate online @ www.lupusontario.org or by calling 1-877-240-1099

GSK/HGS' Benlysta gets Canadian OK for lupus

WORLD NEWS | JULY 13, 2011.

KEVIN GROGAN

GlaxoSmithKline and Human Genome Sciences have been boosted by another approval for their lupus drug Benlysta, this time in Canada.

Health Canada has given the green light to Benlysta (belimumab) for use in addition to standard therapy for reducing disease activity in adults with active, autoantibody-positive systemic lupus erythematosus (SLE). GSK will sell the drug in Canada and it is expected to be available in September.

It is the first time in almost 50 years that Canadians living with lupus will have a new treatment option, GSK noted. One in 1,000 people in the country suffer from the disorder where the body's immune system creates autoantibodies that attack normal healthy tissue, leading to inflammation in many parts of the body.

Murray Urowitz, a lupus expert in Toronto was quoted as saying that the drugs currently used were not originally developed for the intent of treating lupus, so Benlysta "is a much-needed addition to the treatment paradigm." The drug got the green light in the USA in March, while in May, the European Medicines Agency's Committee for Medicinal Products for Human Use recommended approval.

Toward an understanding of **remission in lupus**

Systemic lupus erythematosus (SLE) is referred to as the “Disease with 1000 Faces;” every patient presents uniquely. Increases in anti-double stranded DNA antibodies (anti-dsDNA) are thought to be related to disease flare. Similarly, decreased levels of complement suggest that these immune components are being expended in the body’s misguided attack on itself. Some patients with SLE have anti-dsDNA and/or complement levels which are highly suggestive of active disease, but their clinical presentation suggests otherwise: they are perfectly well. These patients are referred to as “serologically active, clinically quiescent” or “SACQ.” In SACQ patients, there is no clinical evidence of disease; their anti-dsDNA and complement levels suggest otherwise. In these cases, does a clinician expose a patient, by all accounts healthy, to the risks associated with treatment?

Indeed, there has been debate among rheumatologists over how to best manage these patients. Some clinicians treat with steroids or immunosuppressive drugs, intending to avoid disease flare; others watchfully wait, relying upon close clinical monitoring at regularly scheduled clinic visits to ensure that there is no evidence of SLE flare. Our recent research has revealed that, while 60% of SACQ patients flare, they do so only after an average of three years, and that SACQ patients do not accrue lupus-related organ damage during a SACQ period. This suggests that the elevation in anti-dsDNA and/or consumption of complement do not cause harm in these patients. We have also determined that no reliable clinical predictors for disease flare exist among SACQ patients.

Since organ damage in lupus stems from both disease- and treatment-related effects, the ability to confidently identify which patient will achieve a remission state is important not only for its disease-related consequences, but for minimizing treatment-related organ damage. The next phase of our study seeks to identify fundamental differences in gene expression and levels of effector cells in the blood of SACQ, as well as serologically quiescent, clinically quiescent (SQCQ) patients. These will be compared to levels in active lupus patients who were flaring at the time the blood sample was taken. If reliable differences are found between clinically quiescent and clinically active patients, these may aid in the ability to predict imminent flare, not only in SACQ or SQCQ patients, but in all lupus patients. An understanding of the mechanism of remission among lupus patients has yet to be elucidated. It is our hope that this work will further our understanding of this important and desirable disease state.

Amanda Steiman, Geoff Carr Lupus Fellow

Principal Investigators: Drs. Dafna Gladman and Murray Urowitz

Amanda Steiman was born and raised in Toronto. She obtained her MD degree from the Schulich School of Medicine at the University of Western Ontario in 2006, and completed her Internal Medicine and Rheumatology residency training at the University of Toronto. Amanda has commenced a clinical research fellowship under the supervision of Drs. Dafna Gladman and Murray Urowitz at the Toronto Western Hospital, investigating predictors of remission in SLE. She will concurrently pursue a Masters degree in Clinical Epidemiology at the University of Toronto.



Amanda Steiman

ClinicalTrials.gov

ClinicalTrials.gov offers up-to-date information for locating federally and privately supported clinical trials for a wide range of diseases and conditions. A clinical trial (also clinical research) is a research study in human volunteers to answer specific health questions. Interventional trials determine whether experimental treatments or new ways of using known therapies are safe and effective under controlled environments. Observational trials address health issues in large groups of people or populations in natural settings.

ClinicalTrials.gov currently contains **113,270 trials** sponsored by the National Institutes of Health, other federal agencies, and private industry. Studies listed in the database are conducted in all 50 States and in **176 countries** ClinicalTrials.gov receives over **50 million** page views per month **65,000 visitors** daily.

For specific clinical trials on Systemic Lupus Erythematosus (SLE) in Canada please visit the following link:

http://clinicaltrials.gov/ct2/results?term=SLE&recr=&rslt=&type=&cond=&intr=&outc=&lead=&spons=&id=&state1=&cntry1=NA%3ACA&state2=&cntry2=&state3=&cntry3=&locn=&gndr=&rcv_s=&rcv_e=&lup_s=&lup_e=

Special Appeal Fall 2011

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 oneday 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.

(Continued)

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

MEMBERSHIP RENEWAL 2012

Please consider this note as your membership renewal notice for 2012. Again we are doing this to best control our mailing costs. You may renew your membership with a credit card by phoning 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 the Hospital for Sick Children), increased our support for CaNIOS and the Lupus Data Bank and continued to support the Lupus Clinics across Ontario. We would like to thank the Dawe Family Foundation for the \$10,000 Grant which will be instrumental in our ability to meet our support commitments. We participated fully in the May 2011 National Walk for Lupus event that raised over \$98,000 in support of Lupus Ontario. The success of *Dance for the Cure* in January, The 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 **LUPUS LINK**. Your membership makes you part of the team that is making a difference in the lives of those living with lupus. **Once again we ask that you consider including a further donation which will assist our commitment to research in the coming year.** 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:	\$ _____	Address: _____
(Optional)		City/Town: _____ P/C: _____
TOTAL AMOUNT:	\$ _____	E-Mail: _____ Tel: () _____

Ignite your *PASSION!*

October is Lupus Awareness month and Lupus Ontario is requesting your support to bring more awareness to this under recognized disease.

Invite your workplace and your local businesses to show how passionate they are about finding a cure for lupus. Once you have their commitment pick a date in October and start the creative ball rolling. See below for suggestions and more details.

Let's help those with lupus live longer and live better!

Dress in **RED** fundraising ideas:

- Donate and wear red for a day
- Red hair/Red highlights/Red wig
- Bake sale with red goodies
- Ugliest red tie contest
- Car wash
- BBQ
- Potluck
- Pumpkin carving contest

*Challenge your
neighbouring business!!!*

Be creative!

Customize a poster to promote your fundraising day

Keep pledges available for donations

Ask Lupus Ontario for a donation box to keep in your business for the month of October

Make a personal donation to show your support

Ask your employer to make a "matching gift" donation



YES!

Our organization will be participating in "Dress in Red for Lupus"

_____ (provide date)

Organization's Name: _____

Dress in Red Coordinator: _____

Street Address: _____

P.O. Box: _____ City: _____ Province: _____ Postal Code: _____

Phone: _____ Fax: _____

Email: _____

Number of pledge forms required: _____ Coordinator's Signature: _____

By mail Lupus Ontario
2900 John St. Suite 301
Markham, ON L3R 5G3
By fax 905-415-9874
By phone 1-877-240-1099 or 905-415-1099
By email nwright@lupusontario.org

Thank you

For making Lupus Ontario your charity
of choice throughout the year

Charitable tax receipts will be issued for donations of \$20 or more.

Please make all cheques/money orders payable to: Lupus Ontario

Charitable Registration #88333 1472 RR0001

In honour of 30 years

This past July my Mom and Dad, Jane and Jim, celebrated their 30th wedding anniversary. My brother, James, sister Jess and Brother-in-Law Dan, along with my Husband Mike, and I, Jennifer, threw a party to celebrate our parents' 30 years together. Our Mom and Dad are such amazing role models of what love is. In their 30 years together they have overcome many of life's challenges, and through it all have remained deeply in love, committed to each other and taught us about what it means to be a family.

In throwing a party, we wanted to honor them for all that they have accomplished in their years together. My parents are the most positive people I know. No matter what life throws their way, they always stay so strong. One of the challenges that my parents have endured is living with Lupus. My Mom was diagnosed in 1989. We had just moved to a new house in a new town, and spent the summer outside in the sun down by the water. It was then that my Mom began to get sick, which eventually led to her diagnosis of Lupus. In the true spirit of my parents, life continued pretty normal for us kids. In fact, if you met my parents, you would never know that my mom was sick.



Together, they deal with this disease every day. As I grew up, I began to understand how much the disease affected, and continues to affect, my mom, even though she never utters a complaint. Over the years I have seen her many struggles, as she seems to always be dealing with a new symptom or problem. She amazes me with her strength, as does my Dad with his constant support. Lupus does not slow them down, but it does take its toll. My mom refuses to let lupus control her life. Through this, she has taught us that life really is about the attitude you take when dealing with circumstances.

When we decided to throw the anniversary party, we chose to ask for donations to Lupus Ontario in lieu of gifts. Lupus affects so many people, and hurts the whole family. We need a cure. We need to keep researching to find ways to ease the symptoms and struggles of patients and families living with Lupus. The donations from our friends and family for the party is a beautiful gift to give our parents because it is helping to bring researchers one step closer to finding the answers we need. We have hope that one day our Mom, and the many others living with Lupus, will live without pain and the constant challenge of chronic fatigue. We hope that they will feel happy, healthy and strong. Thank you to all of our friends and family who continually donate to such an important cause.

Jennifer McNorgan

Butterflies for Lupus 2012 Calendars

The holiday season is fast approaching and Lupus Ontario has a great gift idea... "**Butterflies for Lupus 2012 Calendars.**" The Calendars include 12 different images of monarch butterflies along with a lupus fact for each month. Calendars may be purchased through the Lupus Ontario office at a cost of \$5.00 each, plus \$2.00 shipping and handling. Order yours today!

1-877-240-1099 | 905-415-1099 | info@lupusontario.org

DONATE NOW feature at www.lupusontario.org

Lupus Ontario has implemented a new "Donate Now" feature on our website. It's quick, easy and safe!

- Click on the "Donate Now" button
- Select the "Donation Type"
- Select "Gift in Honour" or "Gift in Memory" (if applicable). Cards will be mailed to the recipient by Lupus Ontario
- Fill out the donor information
- Fill out the payment information (secured)
- All donations over \$20.00 will be issued a tax receipt

"A day will never be anymore than what you make of it"

Josh S. Hinds

The Inside Story

What happens in your body that makes exercise so good for you?

When Tara Manna, 35, started working out with a personal trainer last fall, her goal was to trim 25 pounds by Christmas. But the fatigue from her lupus made exercising almost impossible. "I just couldn't do it," recalls the stay-at-home mom from Myrtle Beach, SC.

Manna was having trouble keeping up with her exercise plan, and the lack of results was frustrating. "I wasn't losing weight," she says. "The numbers weren't going down, so I was getting upset and discouraged."

Manna and her trainer decided she needed to adjust her workout routine—and her goals. She still wants to lose the 25 pounds, but the timeframe is less important. "My main goal is I want to exercise to feel better and healthier," she says.

Once she began taking it slow and working at her own pace, Manna eased into a regular fitness routine. She has a lot more energy as a result. A few months ago she felt so drained that she'd have to nap for three hours a day. Today, she's down to less than an hour of napping every other day. "I feel more awake," she says. "I just feel like I have more of the day."

To understand why fitness is so important, it helps to understand how. What exactly is going on in your body when you work up a sweat?

The Body Gets to Work

Every time you work out, exercise sets in motion a cascade of events in your body that collaborate to help you lose weight and get healthier. When you exercise—whether it's walking, biking, or lifting weights—your muscles contract. To contract, muscles need oxygen. "The benefit of exercise is it stimulates the body to deliver more oxygen to the muscles that are contracting," explains Robert Robergs, Ph.D., F.A.S.E.P., professor of exercise physiology at the University of New Mexico, Albuquerque.

The need for extra oxygen makes you breathe faster. Every time you inhale, a rush of oxygen-rich air flows into your lungs. Oxygen makes its way into red blood cells, where a molecule called hemoglobin transports it to the muscles—and everywhere else in your body it needs to go. Your heart must pump harder to send all that oxygen-rich blood to your muscles. The more the heart works, the more efficient it gets at its job. "Over several weeks the heart becomes a better pump," Robergs says. Meanwhile, your body produces new blood vessels to help carry all the extra blood the heart is pumping. Those extra vessels take some of the work off your exercising blood vessels, thus reducing your blood pressure.

That's not all exercise does for you. "Because exercise burns calories, it can help reduce body fat. It can raise the good cholesterol—the HDL cholesterol," Robergs says. HDL—or high-density lipoprotein—cholesterol is the "healthy" form that helps sweep the low-density "bad" cholesterol to the liver for removal, before it can build up in the arteries and lead to coronary artery disease.

It's hard to argue with the long list of benefits of exercise.

"There's evidence to show that exercise helps prevent and manage chronic illnesses like diabetes, obesity, and depression," explains Rosalind Ramsey-Goldman, M.D., Dr. P.H., Solovy/Arthritis Research Society Professor of Medicine at the Northwestern University Feinberg School of Medicine in Chicago. This is important for people with lupus because these conditions can be side effects of corticosteroid use.

How Exercise Helps you and Lupus

Working out when you have lupus might seem like an insurmountable obstacle, but it's worth the effort. "Taking care of your body doesn't come second. It's the first thing you should be concerned about," says Cassandra Corum, a California-based wellness expert and strength and fitness coach.

Corum, who has a connective-tissue disorder, knows what it's like to live with a chronic illness. "When there's something you have that you can't control, it's extremely frustrating. It can make you feel like your life is over," she says. Exercise gives her the chance to work out some of those frustrations. "I feel like I can control my body, rather than my body controlling me."

Exercise doesn't just improve your overall fitness; it can also help relieve many of the symptoms of lupus by fighting fatigue, relieving stiff and painful joints, and releasing chemicals that improve your mood. But, be sure to talk with your physician before starting an exercise program to make sure it's appropriate for you.

Fatigue Fighter

One of the biggest problems people with lupus face is debilitating fatigue. When you're exhausted, the last thing you probably want to do is exercise, but getting moving is actually one of the best ways to replenish your energy supplies. "Exercise is an overall stimulant," Robergs explains. "It directly combats fatigue."

Joint Stabilizer

Joints are like hinges. If you don't move them, eventually they'll get rusty and stiff. "Our joints need to be moved," says Robergs. "Moving our joints facilitates the natural lubrication." It's like oiling a rusty hinge on a gate to allow it to open more smoothly and easily. You'll also take some of the pressure off your joints by strengthening the muscles surrounding them. "Flexible, strong muscles will help protect the joint," says Ramsey-Goldman.

Inflammation Eraser

Lupus is an inflammatory disease. As such, people with lupus tend to have higher levels of inflammatory proteins such as interleukin-6 (IL-6) and C-reactive (CRP) in their blood. These substances, which have been linked to heart disease, are also elevated in people who are obese. Exercise can simultaneously fight obesity and inflammation, packing a double punch against heart disease.

Mood Lifter

When you're tired and in pain all the time, you feel miserable. "Tied up into the fatigue are stress, anxiety, depression, and poor sleep," Ramsey-Goldman explains. Exercise lifts your mood, in part by triggering the release of feel-good chemicals in the brain, called endorphins. "They actually stimulate feelings of greater comfort, pleasure, and confidence," Robergs says.

Redefine Exercise

Exercise can only help you if you do it. Ideally, you need at least 30 minutes of exercise a day, five days a week, to get the maximum health benefits, but that goal can be entirely unrealistic for many people with lupus. How can you even think about walking outside for 30 minutes when you can barely drag yourself out of bed and walk to the kitchen?

People with lupus need to change their perception of the word "exercise," says Ramsey-Goldman. "Exercise can mean moving, which is OK. It doesn't have to only mean that you have to work out hard at the gym."

It doesn't matter how or when you exercise, just that you do it. "Leave the hardest chores to your gardener and start mowing your own lawn. Choose a room or two to paint in your house. Instead of driving three blocks to the grocery store, walk," Corum suggests. "Anything that gets you moving, go do it."

You will want to combine some type of cardiovascular exercise to get your heart pumping, weight training to strengthen your muscles, and stretching to improve your flexibility and range of motion— but all at a level that suits your abilities and is workable for you. Again, it's important you speak with your physician about beginning a new workout routine.

"You can't go from 0 to 100 overnight," Ramsey-Goldman says. "Don't try to do too much too quickly, because then you'll hurt yourself and you won't want to do anymore." If you can only exercise for five minutes at a time to start, or you can only do gentle slow stretches, that's fine. Gradually build up the length and intensity of your routine when you feel ready.

Manna, who has had two total knee replacements and numerous stress fractures in her feet, takes her workouts slowly and keeps her exercise short, about a minute each. She does only what she can handle. "I don't necessarily have to do aerobic exercise," she says. "If I'm sitting on the couch, I'll lift my leg up and hold it for as long as I can and out it

down."

While you're redefining what it means to exercise, you also need to redefine your attitude about fitness. "If you don't think you can exercise, that's going to be a barrier to being able to do it," Ramsey-Goldman says. "Cast off the mindset of, 'I'm sick; I can't do anything.' When you move, you actually feel better."

Get Help

Don't try to launch into a new fitness program alone. First, talk to your doctor to find out how much exercise you can manage. Then work with a physical therapist, or a personal trainer, who can help you create a program that fits your abilities and goals. "You need to work on balance and flexibility and posture, and all of those things could be part of a workout program with a physical therapist while you learn to move in a way that isn't harmful," Ramsey-Goldman says. It's not an easy out. The person has to change themselves and how they feel about exercise," she continues. "It's a lifetime commitment to being physically active, and this is just the start."

Best Ways to Exercise With Lupus

Go for a swim at your local pool or health club. Not only will the buoyancy of the water cushion your inflamed joints, but it will also keep you cool and comfortable while you exercise. Walking, bicycling, yoga, and Pilates are other good low-impact options. Avoid exercises that can aggravate your joints, like running or high-impact aerobics.

Begin very slowly. If all you can do is lift your arms or legs at first, do that for a couple of minutes at a time. Then add light weights. Gradually increase the length and intensity of your workout and add in new exercises when you're ready.

Vary your routine so you don't get bored, and change up your exercises so you're always working different muscle groups.

Wear sturdy sneakers or shoes when you work out, so you don't fall.

Never work out to the point of pain or exhaustion. You could injure yourself or make your condition worse.

Because exercise burns calories, it can help reduce body fat. It can raise the good cholesterol—the HDL cholesterol.

Lupus Now (Spring 2011)

Useful Links

Lupus Foundation of America

www.lupus.org

Lupus Research Institute

www.lupusresearchinstitute.org

Clinical Trials

www.clinicaltrials.gov

MEDLINEplus Lupus Patient Education Page

www.nlm.nih.gov/medlineplus/tutorials/lupus/html/_no_100_no_0.htm

Arthritis & Autoimmunity Research Centre Foundation

www.uhn.ca/foundations/aarc/site

Public Health Agency of Canada

www.travelhealth.gc.ca

Alliance for Lupus Research

www.lupusresearch.org

The Arthritis Foundation

www.arthritis.ca

Ways to get involved



YOUNG ADULT, HEALTH AND EMPLOYMENT STUDY

How does the transition to adulthood with lupus influence employment? *YHES! The Young Adult Health & Employment Study*

The transition from adolescence to adulthood includes a number of important of life changes like graduating from high school and attending university or college, finding a career, moving away from home and forming lifelong relationships. This transition can be a stressful process for any young person, especially those living with lupus.

Although, past research has stressed the importance of being employed on the health and quality of life of people living with lupus, little is known about the transition to adulthood and its impact on working. Focusing on the experiences of young adults can be very important to service providers, clinicians and policy-makers who aim at improving employment outcomes. By identifying the problems and needs of young adults, programs and work polices can be designed to improve early career success and help young people with lupus find employment and remain employed throughout their adult life.

To better understand the employment experience of young adults living with lupus, researchers and clinicians at the University Health Network, Dalla Lana School of Public Health at the University of Toronto and British Columbia Children's & Women's Hospital have developed an online research study on the experience of finding and maintaining employment among young adults living with lupus. *YHES! The Young Adult Health & Employment Study* is funded by the Canadian Institutes for Health Research.

To contribute to this important area of research, young adults ages 18 to 30 years living with lupus, are invited to take part in an online survey. The survey asks about the types of work activities and conditions that may create problems for young people living with lupus, perceptions of work and the changes to work that might help young people remain employed. In addition, questions will ask about a participant's life and health.

All young adults living with lupus are encouraged to participate, whether they are employed, not currently working or have never held a job.

For more information on how to participate, please contact:

Arif Jetha

Toll Free at 1-855-469-4540

By, email at yhes@uhnresearch.ca

And visit our website at www.yhes.ca



Wedding Celebration Program

If you are planning a wedding and would like to make a meaningful donation in lieu of traditional wedding favours (bomboniere), why not choose Lupus Ontario as the recipient? You can celebrate and support a good cause at the same time.

To thank you for your donation, we offer cards/place cards for your guests for a donation of \$2.00 per guest. We can work with you to personalize the wording.

For more information please contact the Lupus Ontario Office:

1-877-240-1099 | info@lupusontario.org

Italian Dinner Dance and Silent Auction

SATURDAY NOVEMBER 12, 2011

*Riviera Renaissance Parque
2800 Highway #7 West
Concord, Ontario*

**ANTIPASTO BAR 6:00 - 7:00 PM
DINNER TO FOLLOW
OPEN BAR**

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

\$85.00 per Person



Lupus Ontario

(Charitable #88333 1472 RR0001)

For Tickets and Information
Please call Nicole at 905-415-1099
Or Juanita at 1-877-240-1099
You can also email events@lupusontario.org

Upcoming Events in Support of Lupus Ontario

Month of October	Lupus Awareness Month
October 8, 2011	Butterfly Masquerade Ball at the Thornhill Community Centre
October 16, 2011	Scotiabank Toronto Waterfront Marathon (see pg 14)
October 20, 2011	Bowl for Lupus in Ottawa at Walkley Bowling Centre
November 12, 2011	Italian Dinner at the Riviera Parque (see pg 11)
February 25, 2012	Dance for the Cure at the Terrace Banquet Hall
May 2012	Walk for Lupus in Communities throughout Ontario
May 10, 2012	World Lupus Day

If you are interested in hosting a third party event in support of Lupus Ontario please contact Nicole Wright:
events@lupusontario.org | 1-877-240-1099

In Memory of Traci Gard



Mike Bissonnette, Corinne Bissonnette and Traci's sister Jodi

Traci passed away July 26th, 2010 at the age of 39. She was a daughter, sister, wife and mother of 3 children. She had a very wide circle of good friends.

She also battled Lupus for over 15 years. Her last 8 years were spent 3-times a week in dialysis and her last 6 months saw her using oxygen full time.

In spite of Traci's limitations, she still liked to see her friends whether it be at the local Tim Horton's for her favourite coffee or attending a party.

One of her good friends, Shawn Hodge, held "Bonfire Parties" for many years and this year his annual summer party was held "In Memory of Traci" There was a \$5.00 entrance donation and Hawaiian leis with Traci's picture attached, were given out to everyone in attendance. Shawn was happy to be able to donate \$600.00 dollars to Lupus Ontario given generously by all of Traci's friends.

There was a lot of dancing to Traci's favourite genre, country music and everyone remembered that when she could, she danced right along with us. We were sure that night she was doing so from "up above". Some tears were also shed remembering happier times but knowing Traci is pain free now helps ease our pain. Rest in Peace dear Traci.

Corinne Bissonnette



Traci Gard is in the back left.
This is the last bonfire she attended.

WOODYSTOCK 2010 & 1/2

On June 18, 2011. **WOODYSTOCK 2010 & 1/2** took place at the Legion in Newmarket. Numerous musicians and bands (see poster below for complete list) rallied together under the direction of Woody.

Lupus Ontario and the Sunshine Foundation were the two designated charities. A cheque for \$3000.00 was presented to Julia Kane, President, Lupus Ontario.

PROUD TO PRESENT

Multiple Maple Blues and Juno Award winners from Fathead - Al Lerman and John Mays
Yonge Street Toronto Music Scene Icons - Donnie Meeker, Sonny Milne, Virgil Scott,
Joe Agnello, Frank Gennuso, Dave Breckels and Doug Pettigrew and Mystery Guests

Always A Big Rock Ending - Neil Chapman

As well as Johnny Rock Wright, Johnny Cox, Mikey Roland, Too Tall Paul Jones, Jessie T,
Rick Anderson, Shawn Kerrigan, Al Sare, John Lemme and Graham Young

Bands included are:

Fireball - George Sheffield, Dan D'Andrea, John Dolan and Alan Ribeiro

Eddy Blues Band - Eddy G, Colin Fletcher and Paul Watson

US - Marlene Clark, Paul Pitchuck, Geoff Moorehouse and Corey Richardson

Laura Lee and the Tequila Rocking Birds

Vinyl Candy

Abstract Gypsies - Steve Ford, Shane Sares and Brent Bartley

Domino Horn Section - Michael Braun - Trombone, Sandy Taylor - Sax and Jim Brereton - Trumpet
and Woody

Listing of musicians and bands for WOODYSTOCK 2010 & 1/2



Cheque Presentation at Woody's home
Woody, Julia, Mel and Nicole



Woody sitting in the front with all the musicians
who came out to the benefit

Bake sale in support of Lupus Ontario

My name is Krista Lattanzio. Our daughter (my husband Frank and I) Elina started her Annual Bake sale for Lupus 4 years ago after the Walk a Block for Lupus that we participated in in 2007 here in St Thomas didn't take place again in 2008. Elina was only 7 years old when she decided on her own to hold a bake sale instead. Our family friend is affected by the disease and this really stuck with Elina as something she truly wanted to raise money for. The first year the bake sale raised a very respectable \$100. The second year, the variety of goodies expanded and it doubled to \$200 and the third year (with the weather not fully cooperating) it raised almost \$250. With word of mouth spreading and repeat supporters returning each year with stories of their own, or with their family members struggles with Lupus --we felt it was a year to expand a little. This year we took to Facebook to spread the word. We had friends offer to contribute baked goods and their time to this cause. Elina also baked dozens of cookies, cupcakes and brownies. (with a little help of course). Elina made all of the signs, put an announcement on the school PA system and hand made 50 fliers (each one different) to hand out at her school (Elgin Court Public School) just in case some kids didn't hear the announcement. On May 28th Elina set up her stand at her grandparents yard sale at 7am and was completely sold out of EVERY last treat by 10am. There were hundreds of little goodies and they were GONE. Friends, strangers, neighbours, teachers, classmates and family came to support this cause and when the three hours of fun chaos were over she had raised \$535 for Lupus, bringing her 4 year total to over \$1000. With more plans to expand in May 2012 and countless people offering to help her expand this into a BBQ/bake sale, Elina has already started to plan her sale for next year. Elina has a sister Klara and a brother Giustin that help out a little with the sale, but this is really Elina's passion project. From the organization, to the signs and all of the "customer" interaction on the day of the sale, Elina makes us so proud with her determination and selflessness. We look forward to letting you know about our 2012 successes-Elina's plan is to raise \$600 next year.....I bet she surpasses that .



Elina with her bake table all set up



Elina with her cousins, sister and Aunt

Info, INFO, iNfo

Infections and Immunizations

When you have lupus, you are at increased risk for all kinds of infections. There are two main reasons for this higher risk. First, lupus itself can make infections occur more often: the way lupus affects the immune system can sometimes limit the body's ability to fight off foreign invaders, such as bacteria and viruses. Second, people with lupus often take immunosuppressive medicines to control their overactive immune system. These drugs limit the ability of the body's immune system to respond, and can leave a person more open to infectious agents.

The most common infections seen with lupus involve the respiratory system (lungs and heart), the skin, and the urinary tract. You are also at an unusually high risk for developing Candida (yeast) infections and shingles (the same viral infection as chicken pox).

These types of infections tend to last longer and so require a longer period of treatment with antibiotics. Sulfa antibiotics, a class of drugs commonly used to treat infections, should be used very carefully to treat infections in anyone with lupus because these drugs can increase sensitivity to light and skin rashes, and can lower white blood cell counts.

You should do your best to avoid anyone who has a cold or other contagious condition. During cold and flu season, wash your hands often to cut down transmission of infectious germs. Also, talk to your dentist and surgeon about preventive antibiotics before you have dental work or surgery.

Sometimes what appears to be an infection—with fever and inflammation—may not be an infection, but a lupus flare. Therefore it is very important to check with your doctor if any sign of an infection appears.

Fever

If you have a fever of 100 degrees Fahrenheit (F) or higher, you should contact your doctor promptly, as a fever can be a warning sign of a lupus flare or an underlying infection. A high fever can be especially serious if you are taking steroids or chemotherapy drugs.

Vaccines and Immunizations

Most people with lupus are able to be vaccinated against a variety of diseases with no problems. However, because your immune system may be weakened, you should always talk with your doctor before receiving and vaccine.

If you cannot receive vaccines for common illnesses you can still protect your health in many ways.

Avoids crowds or wear a mask to prevent respiratory infection.

Wash your hands well and often.

Avoid touching your mouth or eyes.

Consider asking close contacts, such as family members or caregivers, to be vaccinated for influenza, measles-mumps-rubella, and chicken pox if they aren't already immunized.

Wear a medical alert bracelet or carry a wallet card that explains that you have a suppressed immune system.

Frequently Asked Question

Are people with lupus more prone to infections even if they are not taking immunosuppressive drugs?

There is some evidence that people with lupus are more likely to get infections than completely healthy people, even when they are not taking corticosteroids (prednisone and similar medications). The most common infections are in the respiratory tract (colds, sore throats, sinusitis, bronchitis, and pneumonia), the urinary tract (bladder or kidney infections), and the skin (boils, cellulitis, and infected cuts).

If a person with lupus is taking corticosteroids every day, particularly more than 10 mg a day, the risk of infection goes up considerably. However, if a person can take corticosteroid doses once in the morning every other day—instead of every day—there is not much, if any, increase in the risk for infections. Of course, every-other-day treatment does not control active lupus as well as every day.

Other medications used for moderate to severe forms of lupus, such as azathioprine (Imuran), mycophenolate mofetil (CellCept), and cyclophosphamide (Cytoxan), increase infections even more than having the disease does. Herpes zoster outbreaks (shingles) - with painful blisters along the course of a nerve—are particularly increased by the immunosuppressive medications. In general, the more severe the lupus is, the higher the risk for infection, partly because of being sick and partly because of the treatments. In contrast, the anti-malarials (hydroxychloroquine, Plaquenil, is the most commonly prescribed) do not increase infections.

There are excellent strategies to reduce your risk for infection. You should have your vaccinations up to date, including Pneumovax to prevent pneumococcal pneumonia. You should take a flu shot every year. Most women can tell accurately that a bladder infection is present, and you should ask your doctor about taking medications to prevent pneumocystis pneumonia.

If you have frequent urinary tract infections, there are antibiotics taken once at bedtime and agents that change the acid in the urine that are effective at reducing urinary tract infection rates. If you suffer from outbreaks of herpes virus lesions/ulcers in your mouth, on your lips, or in genital areas, discuss preventive antiviral treatment with your doctor. If you have been exposed to tuberculosis, you should have a PPD skin test (tuberculin) and consider taking six months of anti-tuberculosis antibiotics if the test is strongly positive. Finally, if it possible to avoid people with bad colds or other communicable infections, you should do so. Of course, you cannot protect yourself from participating in life, so use your common sense.

www.lupus.org

Biomarkers Predict Success of Lupus Nephritis Drug Therapy

Identification of biomarkers that predict response to treatment of lupus nephritis with mycophenolate mofetil or pulse cyclophosphamide. Dall'Erà, M Stone D, Levesque V, Cisternas M, and Wofsy D. (2010). *Arthritis Care and Research (Hoboken)*: epub ahead of print

What is the topic?

Kidney involvement (nephritis) can be one of the more serious complications of lupus. Even though outcomes have improved with more aggressive treatments in recent years, many patients still develop significant damage to the kidneys within 10 years of nephritis diagnosis.

Since lupus nephritis can be severe and the therapy can be toxic, it is important to be able to predict which patients would most benefit from long-term treatment. It would be particularly useful if specific factors could provide some advanced predictions about whether or not there would be successful responses to treatments for lupus nephritis.

What did the researchers hope to learn?

The researchers hoped to identify factors that might be seen after 8 weeks of treatment for nephritis that might predict whether or not the treatment would be successful after 24 weeks.

Who was studied?

The participants were mostly women, aged 20-41 who had lupus nephritis for 1-6 years. Patients were only included if nephritis was active by having a certain level of protein spilling into the urine (2 grams of protein in the urine during a 24-hour period) and the diagnosis of nephritis needed to be proven a kidney biopsy (a procedure in which a small piece of kidney tissue is removed for purposes of diagnosis).

The following patients were excluded from the study: those who had recently received aggressive treatment for nephritis (cyclophosphamide or CYC) or mycophenolate mofetil (MMF) within the previous year, people who were on dialysis for more than two weeks prior to study entry, and those who had received steroids within the past two weeks.

How was the study conducted?

The information came from 306 patients who participated in a clinical trial that compared CYC with MMF after study entry. The patients included were those who completed the first six months of the Aspreva Lupus Management Study (ALMS). ALMS was an international clinical trial for the treatment of lupus nephritis and included patients from many different countries and of different races.

Patients received either CYC or MMF. All patients received prednisone starting at a maximum dose of 60 mg per day. The dose was gradually decreased every two weeks until a dose of 10 mg per day was reached. Patients could be taking ACE inhibitors (drugs used to treat protein spilling from the kidney and/or high blood pressure) but the doses had to remain stable throughout the study.

A number of factors were tested to try to see if they would predict response to drug therapy for lupus nephritis at 24 weeks after initiation. These include the following: age, age at the time that lupus nephritis started, time since diagnosis of lupus nephritis, time since diagnosis of systemic lupus, whether the patient was a man or a woman, severity of lupus nephritis, how well the kidney was actually functioning, how much protein was spilling from the kidney, levels of antibodies such as anti-double stranded DNA, complement protein levels, whether or not anti-cardiolipin antibodies were present, and the different background medications being used (including ACE inhibitors, hydroxychloroquine, and drugs to lower cholesterol levels in the blood).

What did the researchers find?

Improvement in lupus nephritis was evaluated after 24 weeks

of treatment. About half the patients receiving drug treatments for lupus nephritis met the criteria for a reasonable level of improvement after 24 weeks.

Three things that were measured before the patients started the study predicted a successful response to drug therapy (regardless of whether the patients were taking CYC or MMF) after 24 weeks. These were kidney function upon entry to the study, the time since diagnosis of lupus nephritis, and the complement protein levels (C3 and /or C4). 58% patients with good kidney function when they started improved after treatment as compared to 19% whose kidneys already showed some significant damage at the beginning of the study. 36% of patients who were diagnosed with lupus nephritis 1-5 years before entry into the study responded to drug therapy while 61% who were diagnosed less than a year before the study responded. Of those patients who started the study with low levels of C3/C4 complement proteins, 59% responded to therapy but only 47% of those with normal levels of C3/C4 responded.

The investigators also looked at how the patients were doing at 8 weeks and if this could predict how they were doing at 24 weeks. If the protein spilling from the kidney decreased by 25% or if complement proteins C3 and C4 went back to normal by 8 weeks, then it was more likely that the patient would be considered significantly improved at 24 weeks. A decrease in levels of anti-double-stranded DNA after 8 weeks of treatment did not predict treatment response after 24 weeks.

What were the limitations of the study?

The study looked at responses to treatment for lupus nephritis after 24 weeks. 24 weeks may not be sufficient time to see maximal responses to therapy for lupus nephritis for all of the patients. On the other hand, if a person does not respond by 24 weeks, then it is optimal for the long-term health of the kidney. Still, it is important to keep in mind that if a longer treatment time is considered, additional factors could become predictive of responses to treatment. Also, this study was a "post-hoc analysis," meaning that the statistical analyses performed on the study results were not pre-determined at the start of the study. This makes it an exploratory analysis. The rules of statistics would require this information to be confirmed by another study before a final conclusion can be made. Nevertheless, this information could be very important, on a practical level, for lupus patients and their doctors by providing some guidance at the earlier stages of treatment about whether to consider increasing treatments or whether or not steroids should be tapered.

What do the results mean for you?

At the start of treatment for lupus nephritis, the complement protein levels and kidney function, as well as the time since diagnosis of lupus nephritis, predicted the chances that standard treatments would work. These factors can thus help physicians and patients decide how aggressive to be in the choice of therapies. Once 8 weeks of treatment have passed, this study suggests that improvement in the complement and levels of protein in the urines might serve as a valuable guide to how well things are going with the current treatment and help in the decisions about whether to increase treatments, hold a steady course, or start to taper steroids. Because this is an exploratory study, no statistical conclusions can be drawn. However, with the lack of guidance about these issues that we currently have, and the fact that these findings make clinical sense, this study provides a critically important milestone that physicians are likely to take very seriously.

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www.lupusmanitoba.com

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Ridgeway ON L0S 1N0
ON only: 1-800-368-8377
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Lupus Ontario

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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 and research