

Lupus Ontario
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LUPUS ONTARIO CREATES MEDIA KIT TO RAISE AWARENESS FOR LUPUS

Ontario, May 1st, 2023: May is Lupus Awareness Month, with May 10th being both World Lupus Day (internationally) and Lupus Awareness Day in Ontario. In an effort to raise awareness Lupus Ontario has created a media kit containing:

1. Lupus Ontario Overview Article:

This article describes a brief summary of lupus, an autoimmune disease, then goes on to briefly explain the efforts Lupus Ontario in making to improve the lives of those living with lupus, its history and research accomplishments.

2. Lupus Warrior Article:

Describes the Lupus Journey of a Lupus Warrior, Rupinder Sandhu and seeks to spread the word about Lupus Awareness Day.

3. Media and Graphics

- Shine a Light on Lupus Video
- Lupus Awareness Month- Fact posts

About Lupus Ontario

Lupus Ontario's mission is to provide vital support, education, awareness, advocacy and research through the fundraising efforts of our staff and volunteer community to help those living with lupus live longer, healthier and better lives.

For any questions, or to reach out for an interview please contact Hajra Batool at (905) 415-1099.

Lupus Ontario Overview Article:

Lupus is a complex autoimmune disease that can impact virtually any organ of the body – skin, kidneys, brain, heart, eyes, and others – with profound life altering and life limiting consequences. Little is known about the disease as each patient presents with a differing array of symptoms. Ninety percent of patients are female, in the prime years of their life.

Lupus Ontario is the largest provincial organization in Canada geared toward providing support, awareness, and education of lupus to patients, caregivers, and health practitioners alike. Since its inception in 1978 Lupus Ontario has been instrumental in development of dedicated Lupus Clinics in Ontario and is an ardent supporter of innovative research.

In 1987 armed with determination to improve the lives of those living with lupus, the founders of Lupus Ontario including Honey Agar and Linda Ethier, and a team of devoted volunteers, set out to raise \$1M to create and launch a program that would be a world first – the Lupus Databank Research Program at Toronto Western Hospital. The Lupus Databank forms the foundation of lupus research through to the present day. This project was spearheaded by the globally renowned Dr. Murray Urowitz who continues to conduct research. The Lupus Ontario commitment to ground-breaking research thrives today in exciting areas including the newly formed Lupus Ontario Anne Matheson Biobank, headed by Dr. Konstantinos Tselios in the Boris Clinic, McMaster Health Sciences in Hamilton. and through the Dr. Murray Urowitz Chair in Lupus Research at the University of Toronto.

Since its creation in 1990, the Geoff Carr Fellowship provided by Lupus Ontario has trained more than 30 Rheumatologists worldwide to specialize in lupus and has motivated each recipient to delve into lupus-based research. The program has funded specialized training through grants totalling more than \$2M.

As the Databank, Biobank the Dr. Murray Urowitz Chair in Lupus Research and the Geoff Carr Fellows continue to form the bedrock of lupus research initiatives, Lupus Ontario has become involved in advocacy efforts to bring light to this insidious, complicated disease. These efforts resulted in the 2021 proclamation by the Government of Ontario proclaiming May 10th as Lupus Awareness Day in the province – the same date recognized globally as World Lupus Day. With awareness dedicated to this single day, and to the month of May as a whole, Lupus Ontario and their partners strive to continue to bring hope to those living with, caring for and treating the disease; shedding light on the causes of lupus and ultimately finding a cure.

The astonishing impacts Lupus Ontario has been able to catalyze are direct results of dedicated partners, volunteers, and physicians. A true volunteer-patient-based organization, our goal has remained constant since 1978: Life Without Lupus.

Partner with us. Volunteer with us. Be part of the cure.

*Written by Brent Leonard, Director at Large, Board, Lupus Ontario
April 2023*

Lupus Warrior Article: Rupinder Sandhu

Lupus Awareness Day is May 10th, and throughout the month of May advocates spread awareness about this less known disease. One of those advocates is Rupinder Sandhu, a volunteer with Lupus Ontario on the Support Committee. She began volunteering for Lupus Ontario in 2020, when she organized the Walk for Lupus Ontario in Mississauga. The Support committee of which she is a member holds regular meetings and the Lupus Ontario website has a wealth of educational information. Please visit www.lupusontario.org for more information.

Rupinder follows the mantra, "I have lupus, but lupus doesn't have me!" She considers having this auto-immune disease as a part of her reality that she has come to accept, but she ensures that it does not become her whole identity. She believes that people living with Lupus deserve the attention and care that she has been fortunate to receive, so works to connect people (newly diagnosed or experiencing symptoms) with rheumatology clinics in their area.

Rupinder shares, "My journey to a lupus diagnosis began in 1996 while at the University of Ottawa. I was suffering from extreme fatigue, inflammation of my joints and symptoms of Raynaud's disease. It only took a couple of doctor's appointments for my diagnosis because I have the anti-Smith antibody which is consistent with a diagnosis of systemic lupus erythematosus." Many people living with lupus have to work through fatigue and other symptoms to manage their daily lives and take rest and breaks whenever possible. Rupinder did just that and completed her placements and degree.

Symptoms continued as she began her work life but she didn't want that to stop her from planned adventures. While working at an international school in England and taking the opportunity to travel she suffered another major flare, episode of Nephritis, kidney biopsies, a hospital stay and new innovative treatment all while living abroad. Lupus Nephritis is when antibodies attack your own tissues in the kidneys which causes inflammation, and the kidneys are unable to do their job (<https://www.lupusontario.org>, 4/26/2023). Also, lupus nephritis is almost twice as frequent in black patients (62%) as in white patients (32%), and the prognosis in black patients with lupus nephritis is significantly worse (<https://journals.lww.com>, 4/26/2023).

Rupinder returned to Mississauga, Ontario in 2002 and with the support of her parents and eventually exemplary care from the Lupus Clinic at the Toronto Western Hospital her health stabilized. Specific lupus care from experts can make all the difference since many physicians are still developing an understanding of the disease. There are other lupus clinics at Hamilton Health Sciences McMaster, Ottawa Hospital, St. Joseph's Healthcare London, and the Hospital for Sick Children. Since receiving effective treatments, Rupinder continues to engage socially, travel, support her family and work as a teacher and now Principal in the Peel District School Board! Rupinder hopes to carve out more time for her volunteerism with Lupus Ontario but for now she says, "I am honoured to serve my community and to support Lupus Ontario because I know to be able to do so is a blessing. The adversity of living with lupus has made me a warrior!"

Lupus Ontario is a volunteer organization which provides support, education and awareness and has raised \$ 4.8 Million in the last 10 years to support innovative research. If you or someone you know needs support, and to get involved in a Walk for Lupus Ontario near you, please visit www.lupusontario.org. Lupus Ontario is thankful to all of our donors and volunteers who support our mission.

3. Media and Graphics

Shine a Light on Lupus: <https://youtu.be/n08wixN26Ik>

Lupus Awareness Month – Facts

Captions:

1. May is Lupus Awareness Month! Join us as we shine a light on important facts about Lupus all month long. Let's work together to achieve a life without Lupus #lifewithoutlupus
2. We're on a mission to raise awareness and find a cure for Lupus. Help us amplify our message by sharing our Lupus facts throughout the month of May. #Lifewithoutlupus
3. We believe in a future without Lupus. Join us this May as we share facts and resources to help educate and raise awareness about lupus. #LupusStrong
4. Lupus Ontario is dedicated to supporting, educating, and raising awareness for those living with this disease. Join us this May to help us shine a light on lupus and make a difference.

DID YOU KNOW?

Women with Lupus can safely get pregnant, have normal pregnancies, and have healthy babies

However all women with lupus who get pregnant are considered to have 'high risk' pregnancies

Let's work together to shine a light on lupus



DO YOU KNOW?



Lupus is estimated to affect over **1 in 1000** Canadians

Let's work together to shine a light on lupus



Lupus is a chronic disease characteristics by inflammation in one or more parts of the body

It belongs in the family of autoimmune diseases which includes rheumatoid arthritis, multiple sclerosis, juvenile diabetes , and scleroderma

Let's work together to shine a light on lupus



DID YOU KNOW THAT...

Genes play a role in the development of lupus. There are dozens of genetic variants linked to lupus. These genes impact both who gets lupus and how severe it is.



Let's work together to
shine a light on lupus


 Share

DID YOU KNOW?

The most common type of lupus is SLE (systemic lupus erythematosus).

Generally, no two people with systemic lupus will have identical symptoms.

Let's work together to
shine a light on lupus

 Share

HOW CAN I HELP?

There are many ways to help:

Donate, Spread Awareness about lupus, amplify our message

Let's work together to
shine a light on lupus

 Share

CAN YOUR DONATIONS MAKE A DIFFERENCE?

They certainly can! Since lupus was first identified as a disease in the 1970s, a lupus patient's rate of survival has improved by almost 85%!

Let's work together to
shine a light on lupus

 Share