

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

Ontario, May 2nd 2022: 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, Brynn Clark, and seeks to spread the word about Lupus Awareness Day.

3. Graphics:

- May Lupus Month Graphic
- Lupus Ontario Group Photo

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 Martina Whittick 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 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 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 and was spearheaded by the globally renowned Dr. Murray Urowitz who continues to practice and 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.

A true volunteer-based organization, Lupus Ontario continues to support research and novel approaches to foster discoveries and hope for lupus treatments. A vital component of this initiative is the support Lupus Ontario provides to the physician community. Through the years, Lupus Ontario has established six accredited Lupus Clinics in the Province of Ontario where those living with lupus and their caregivers can seek treatment and support. Crucial to understanding any disease is the commitment of dedicated physicians and researchers, the same is true in the quest to demystify the intricacies of lupus. This is the motivation behind the Geoff Carr Lupus Ontario Fellowship.

Since its creation in 1990, the Geoff Carr Fellowship provided by Lupus Ontario – in honour of the late President of the Association of Commercial Travelers, instrumental in funding the fellowship program – 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 and Geoff Carr Fellows continue to form the bedrock of lupus research initiatives, Lupus Ontario has become involved in advocacy efforts to bring light to an insidious, complicated disease. These efforts helped support 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, Lupus Ontario
April 2022*

Lupus Warrior Article:

“I DIDN’T LIKE THE HAND I’D BEEN DEALT IN LIFE, SO I CHANGED THE GAME.”

Brynn Clark, Lupus Warrior

"I remember it like it was yesterday, not back in 2010. A beautiful September day. 'I don't know how to say this, exactly, but you have lupus,' my doctor informed me. It had taken years...YEARS...to be able to finally have a diagnosis of symptoms that could have been explained away by any part of my made-for-tv-movie kind 'o' life: extreme fatigue (the 'bone-crushing' type kind), deep pain in my muscles and joints...I was 36, working full time, and a mother of five. Of course, I was fatigued. Of course, I was exhausted."

Brynn Clark has become a lupus warrior and advocate in the years since her diagnosis, hoping to bring awareness to this autoimmune disease, and encourage people not to dismiss their symptoms.

Lupus is a chronic, complex autoimmune disease that affects at least 5 million people worldwide.

More than 90% of people with lupus are women; lupus most often strikes during the childbearing years of 15-45. Black, Latino, Asian and Indigenous people are two to three times at greater risk than Caucasians. In lupus, the immune system, which is designed to protect against infection, creates antibodies that can attack any part of the body including the kidneys, brain, heart, lungs, blood, skin, and joints.

“For me, lupus means the full 'systemic lupus erythematosus'. I have had three cardiac infarctions. I have kidney damage. I have had pleurisy,” Brynn recounts how difficult it has been to have her body fight against itself daily.

Lupus is a serious autoimmune disease, which means your immune system attacks healthy cells by mistake. It's also chronic, meaning it lasts a long time and requires long-term treatment. Lupus is one of the most complex autoimmune diseases there is. It affects each person differently with symptoms that are sometimes hard to detect and differ from patient to patient, which is why it is called “the disease with a thousand faces”. This makes the disease hard to diagnose and arriving at effective treatments very challenging. For the vast majority of people going through life with lupus, effective treatment can reduce symptoms, reduce inflammation, and maintain normal bodily functions. It is therefore critical to understand and manage symptoms.

May 10th is Lupus Awareness Day, which serves to call attention to the impact that lupus has on people around the world. Lupus Ontario is joining groups from around the world that have united to lead the annual World Lupus Day observance on 10 May 2022.

Now in its 19th year, World Lupus Day will focus on the need for heightened public awareness of lupus, improved patient healthcare services, increased research into the causes of and desperately needed treatments for lupus, enhanced physician diagnosis of lupus, and better epidemiological data on lupus globally.

Lupus affects more than just the person with the disease -- it also impacts their family, friends, and work colleagues. Still, it is widely under-recognized as a global health problem by the public, health professionals, and governments, driving the need for greater awareness. Early recognition, diagnosis and treatment of lupus help to slow the debilitating effects of the disease. However, lupus is often difficult to diagnose because symptoms frequently mimic common illnesses. Increasing awareness of lupus will save lives.

Brynn shares that “what I needed in the start of my lupus journey was to find somewhere to read about other patients’ experience with lupus. What I did, was start a blog, 'Lupus Interrupted'. It was meant as a place to share my journey for family and friends. My family didn’t read it. Who read it? People from all over the world who wanted a real conversation about what it is like living with this disease. I wrote to become a patient advocate. I wrote to highlight a lupus journey filled with hardships, but rife with positive actions. I wrote for Stanford University’s medical blog, 'Scope', to illustrate to new doctors what living with lupus really feels like.”


Lupus Ontario is the largest Canadian provincial organization focused on improving the lives of lupus patients and their families. 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 with lupus live longer, healthier and better lives. Brynn Clark joined Lupus Ontario as a volunteer and Board Member to continue her impact of advocacy.

"I didn't like the hand I'd been dealt in life, so I changed the game. My epiphany came when I realized that at the end of the day, it's only my choices that will determine whether this life will be remembered and measured in pain, or in memories," says Brynn. "I am an on-my-own mother of five, managing the best that I can with what I've been given. My wish for my children is that they be educated on patient rights, and compassionate to the journey of others, no matter their circumstance or afflictions." Join Lupus Ontario's effort to increase public awareness and understanding of lupus by promoting the annual World Lupus Day observation in your community.

*Written by Lisa Bilodeau, Board Member, Lupus Ontario
April 2022*


Graphics:

1. Lupus Month Graphic



Frustrating right?

If not getting a word until the 6th turn is frustrating, imagine how it feels when it takes an average of 6 years to receive a lupus diagnosis.



2. Lupus Ontario Group Photo

