

# Lupus Ontario

# ANNUAL REPORT

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Fiscal Year Ending September 30, 2022

Celebrating  
45 Years

## PRESIDENT'S MESSAGE

We are delighted to present this new format for our Annual Report. With this new version we are able to provide more information about the services of Lupus Ontario and our many activities. We hope you find it informative.

During our fiscal year 2021 -2022 we continued to experience the effects of the COVID-19 pandemic. Our events and support group programs were delivered in a virtual manner as our immunocompromised community continues to avoid personal contact at large events. Despite these challenges, we held a very successful 2022 WALK for Lupus, adapted our Italian Dinner Dance to an online Silent Auction, and held our first ever Lupus Ontario Golf Day. We are also grateful to everyone who held third party events to raise awareness and funds for lupus.

We were able to increase our research funding to include the Lupus Ontario Anne Matheson Biobank at McMaster University and the Dr. Murray Urowitz Chair in Lupus Research at the University of Toronto. Both of these projects will support research to investigate better methods of managing lupus and maybe someday even finding a cure. Our Geoff Carr Fellow, Dr. Tala El Tal, is now at The Childrens Hospital of Eastern Ontario (CHEO) after serving her Fellowship at SickKids. How wonderful to now have a lupus specialist to serve the paediatric lupus community in the Ottawa area!

From an Education and Support perspective, we continued our Support Groups online and presented valuable information through our webinars and podcasts. We learned that through online programming, we are able to serve people from out of province and from all over the world. We increased our advocacy efforts by forging partnerships with other organizations and conducting focus groups which have provided valuable information that was used as a basis of our support for new medications for lupus patients.

We look forward to 2022 - 2023 with increased optimism as we plan for more in-person events which will allow us to better increase awareness and understanding of the impact of lupus on patients, their families and the community in general. I would like to thank all our sponsors, donors and dedicated staff and volunteers. Without your generosity we could not continue to provide high quality programs for the Ontario lupus community. Your commitment to improving life for the lupus community is outstanding and we sincerely thank you.



**Linda Keill**

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## ABOUT LUPUS

Lupus Ontario is the largest provincial organization in Canada 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 the development of dedicated Lupus Clinics in Ontario. We are also an ardent supporter of innovative research.

In 1987, Lupus Ontario 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. The Lupus Ontario commitment to ground-breaking research thrives today in exciting areas including the newly formed Lupus Ontario Anne Matheson Biobank.

Through the creation of the Geoff Carr Research Fellowship, Lupus Ontario has trained more than 30 Rheumatologists from across the world 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.

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## MISSION

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.

**Our Vision is a Life without Lupus**

## BOARD OF DIRECTORS

### EXECUTIVE



**Linda Keill**

President, Chair Fund Development Committee



**June Alikhan**

Vice-President, Chair Executive Committee & Advocacy Committee



**Siraj Mehdi**

Treasurer, Chair Finance & Audit Committee



**Uzair Jalil**

Secretary, Chair Governance Committee

### DIRECTORS



**Sandra Williams-Reid**

Chair Support Committee



**Brent Leonard**

Chair Public Awareness and Education Committee



**Brynn Clark**

Director at Large, Advocacy, Public Awareness, Executive Committee



**Lisa Bilodeau**

Director at Large, Public Awareness



**Jillian Cooper**

Director at Large, Fund Development

### THANK YOU TO THE BOARD MEMBERS WHO HAVE LEFT THE BOARD



**Faraz Islam**

Director at Large, Fund Development



**Cheryl Gajadhar**

Director at Large, Fund Development

## MEDICAL ADVISORY BOARD



McMaster Lupus Clinic  
*Hamilton, ON*

### Boris Clinic/McMaster Lupus Clinic

#### Dr. Konstantinos Tselios

Rheumatologist at Hamilton Health Sciences Centre, Assistant Professor McMaster University, Hamilton



Saint Joseph Health Care  
Rheumatology Clinic  
*London, ON*

### St. Joseph's Health Care London

#### Dr. Janet Pope

Chair/Chief of Division of Rheumatology, Professor of Medicine in the Division of Rheumatology at the University of Western Ontario (UWO), Schulich School of Medicine, London, Ontario, Canada



Mount Sinai Lupus Clinic  
*Toronto, ON*

### Mount Sinai Hospital- Young Adult SLE (YASLE) Clinic

#### Dr. Amanda Steiman

Assistant Professor, Rheumatologist at Sinai Health/University Health Network, Toronto

#### Dr. Earl Silverman

Pediatric Rheumatologist at SickKids Hospital



Toronto Western  
Lupus Clinic  
*Toronto, ON*

### UHN - Toronto Western Hospital

#### Dr. Murray Urowitz

Senior staff rheumatologist at the Toronto Western Hospital, Senior Scientist at the Krembil Research Institute, Professor of Medicine at the University of Toronto and Director of the Centre for Prognosis Studies in the Rheumatic Diseases and the University of Toronto Lupus Clinic

#### Dr. Zahi Touma

Rheumatologist & Clinical Epidemiologist, Director, Toronto Lupus Program at UHN, Associate Professor of Medicine, University of Toronto

#### Dr. Dafna D. Gladman

Deputy Director, Centre for Prognosis Studies in the Rheumatic Diseases, Professor at the University of Toronto Faculty of Medicine, Senior Scientist at the Krembil Research Institute

## RESEARCH

### Lupus Ontario Support for Research

- Dr. Urowitz Chair in Lupus Research – Lupus Ontario has committed \$50,000 in support of this important research project.
- The Lupus Ontario Anne Matheson Biobank is now up and running and gathering samples to be used for ongoing lupus research. Lupus Ontario has committed \$150,000 over 3 years to support this important project.
- Clinic Funding for research and education – Lupus Ontario continues to fund six accredited Lupus Clinics in Ontario.
- The Lupus Ontario Geoff Carr Research Fellowship – The annual fellowship trains a Rheumatologist in the best practices for diagnosing and treating lupus. Each fellow participates in critical lupus research.

### 2021-2022 GEOFF CARR FELLOW

A lupologist, lupus-specific paediatric rheumatologist, in the making at The Hospital for Sick Children (SickKids) for children and young adults, as a recipient of the Geoff Carr Fellowship Award. She obtained her medical degree in 2016 and completed her paediatric and adolescent medicine residency at the American University of Beirut (AUB) in 2019, in Lebanon.

Recently completed a paediatric rheumatology fellowship at SickKids in June 2021, during which Dr. El Tal helped lead the Canadian paediatric surveillance program for Multisystem Inflammatory Syndrome in Children (MIS-C) at a national and hospital level in the COVID pandemic. During her lupus fellowship, Dr. El Tal hopes to apply her QIPS skills to improve routine mental health screening for depression and anxiety in childhood systemic lupus erythematosus (cSLE) clinic to ultimately enhance patient mental health outcomes. In addition, her current lupus research focuses in neuropsychiatric (NPSLE), specifically examining the longitudinal prevalence of cognitive impairment and relationship to disease and health-related quality of life in cSLE.



**Dr. Tala El Tal**

# OCTOBER 2021– SEPTEMBER 2022 RECAP

**PROVIDING 6 ONLINE SUPPORT GROUPS  
THROUGHOUT THE YEAR**



**OCTOBER 2021 –  
OTTAWA DOOR-TO-DOOR**  
Organized by Brenda Cardillo  
& Joni Waiser



**NOVEMBER 2021 – LUPUS ONTARIO  
SELECTED AS THE CHARITY OF CHOICE BY  
RONA OF MISSISSAUGA-DUNDAS**



**OCTOBER 2021 –  
SCOTIABANK MARATHON**

**APRIL 2022 – LUPUS ONTARIO ANNE  
MATHESON BIOBANK PLAQUE CEREMONY**



*Plaque Ceremony with Dr Judah Denburg,  
Lupus Ontario President Linda Keill,  
Dr. Tselios, and Anne Matheson*

**MARCH 2022 – 35TH ANNUAL ITALIAN  
DINNER & SILENT AUCTION FUNDRAISER**  
Organized by Anne Di Vizio &  
Sabrina Dussin

**May 2022 – Annual Research Fundraiser**  
Organized Tom Koor

# OCTOBER 2021- SEPTEMBER 2022 RECAP

## MARCH 2022 - TRIBUTE TO DR. UROWITZ



## JUNE 2022 - HOPE VOLLEYBALL TOURNAMENT



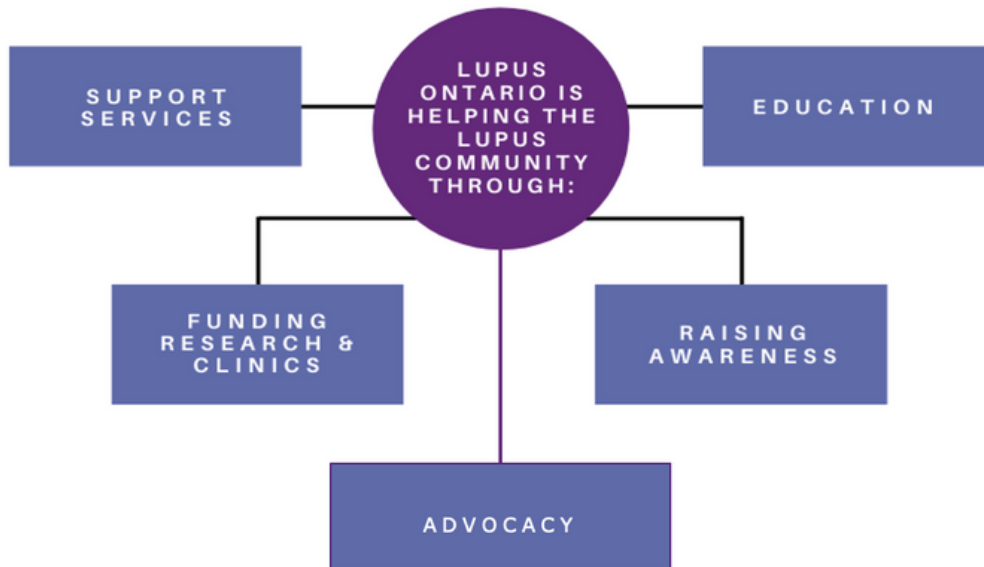
## JUNE 2022 - #FORELUPUSONTARIO GOLF DAY



## JUNE-SEPTEMBER 2022 - WALK FOR LUPUS



## OUR COMMITTEES



The Lupus Ontario Board has set up a committee structure in order to carry out the mission of the organization. Each committee has its own mandate to follow and makes recommendations to the Board which is then discussed and a course of action determined.

### **Advocacy**

- The Lupus Ontario Advocacy Committee focuses on advocating for the Lupus community by providing strategic, inclusive, and evidence-based information to engage with key healthcare institutions and professionals, all levels of government, and other patient-based organizations in order to improve the lives of people living with Lupus.

### **Executive Committee**

- The Executive Committee provides strategic direction for Lupus Ontario's Board and all stakeholders to ensure the organization focuses on achieving its mission. In addition, the Executive Committee is responsible for making recommendations to the Board for any major risks encountered by the organization and for overseeing staff compensation.

### **Finance Committee**

- The Finance and Audit Committee's purpose is to provide Lupus Ontario's donors, members, and other stakeholder's assurance on the integrity of financial information, clarity in reporting, transparency in disclosure, as well as, stewardship of all assets owned and managed by Lupus Ontario.

## OUR COMMITTEES

### Fund Development Committee

- The Fund Development Committee creates, directs, and monitors a comprehensive and tactical fund development plan for revenue generation in order to fulfil the strategic direction set by the Board of Lupus Ontario.

### Governance Committee

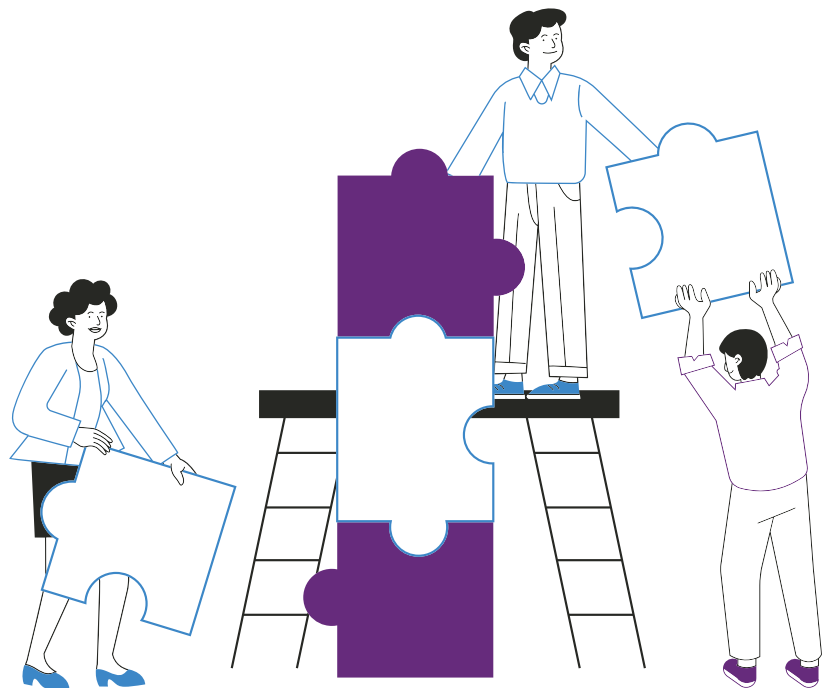
- The Governance Committee's objectives are to oversee and evaluate compliance with legal regulations and guidelines applicable to not-for-profits; ensure the Board is in compliance with its' Charter and all By-Laws; and determines nominating subcommittee for board development (subcommittee may be comprised of both current and past Board Members).

### Public Awareness Committee

- The Public Awareness Committee's focus is to increase awareness of Lupus Ontario, lupus as an illness, its impact on individuals and their families, research, and treatments within the public in order to better understand the needs of the lupus community and the efforts and programs offered by Lupus Ontario.

### Support & Education Committee

- The Support & Education Committee provides relevant and factual information, support services and education to Ontario lupus patients, their families, health care professionals and organizations.



## SUPPORT

- We currently have 5 Support Group meetings throughout the month along with our bi-weekly Dance and Medicine class.
- The Windsor Support Group was launched in Nov 2022 and has been well received by members in that region.
- The Support Team responded to 98 emails and approximately 60 phone calls for assistance during the last fiscal year.
- The goal for the Support Groups is to return to limited in-person meetings and to organize social events this year.
- We encourage groups to schedule in-person meet ups (such as a coffee meet) with the goal of starting some in-person meetings when members are comfortable.
- **We are always looking for volunteers to join our committee**, as keeping these groups active is very important to Lupus Ontario
- We have incorporated the Dance and Medicine class into the Support portfolio as these volunteers are committed to continue to volunteer their time with Lupus Ontario.



**ONLINE SUPPORT WILL CONTINUE FOR ALL THE GROUPS.  
EMAIL THE SUPPORT TEAM AT [SUPPORT@LUPUSONTARIO.ORG](mailto:support@lupusontario.org)**

## ADVOCACY

The Advocacy Committee has been focused on building relationships with other organizations who are working to improve the lives of patients with inflammatory arthritis conditions. This will give us a stronger voice when we petition the government and other institutions for better support and services for the lupus community.

We held multiple sessions with a Provincial Focus Group consisting of 10 lupus patients spread across Ontario to determine: 1) Medical Care Access in Northern Ontario and 2) Effectiveness of Current Lupus Medications. Reports were written on both areas and shared with multiple organizations such as ORA, pharmaceutical companies, etc.

These reports were filed with CADTH (Canadian Agency for Drugs and Technologies in Health) to advocate for approval of new biologics Saphnelo and Benlysta for LN.

## EDUCATION

- Education materials are emailed/mailed upon request. The Lupus Facts Booklet is available on the website and in hard copy upon request.
- Many new educational presentations and webinar videos have been added on our website and Youtube channel.
- Monthly/Bi-Monthly virtual webinars are continuing this year. Typically 30-60 people attend each presentation. If someone cannot attend at the time of the webinar, it is posted on the website for viewing/available on Youtube.
- Lupus Ontario Podcast was launched last year and there are many interesting topics for your listening. We now have a worldwide audience learning about topics of interest for lupus patients and their caregivers.



## PUBLIC AWARENESS

### Social Media

- Incredible engagement on all platforms
- Record new followers/shares in May
- Delivered more videos, reels and interactive posts

### May Lupus Awareness Month

- Record number of illuminations in May
- Media coverage: articles, news interviews (CHIN, Global)

### Podcasts

- Launched in 2021
- 13 episodes, 1400+ listeners, 25 countries worldwide
- >50% of listeners are under the age of 45

### Newsletters

- Updated newsletter format, including Research News
- Electronic newsletter released monthly



## FINANCIALS

### LUPUS ONTARIO

For the Year Ended September 30, 2022

#### YOUR GENEROSITY AT WORK

For the year ending September 30,  
2022 2021

#### **Support and Education Programs**

Newly diagnosed

Ongoing support and training

Counselling

Lupus community education & webinars

Lupus educational kits

\$	52,455	\$	26,697
	13%		9%

#### **Research Funding and Clinic Research Support**

Toronto Western Hospital Lupus Clinic

Ottawa, London and Mount Sinai Lupus Clinics

Sick Kids Hospital Lupus Clinic

Geoff Carr Fellowship

143,747	153,250
35%	53%

#### **Volunteer Support**

Education and training

Appreciation awards and recognition

18,954	9,745
5%	4%

#### **Public Awareness**

Website: [www.lupusontario.org](http://www.lupusontario.org)

Facebook, Twitter, Instagram

Advertising and promotion at events

Newsletter, posters, pamphlets

57,017	30,045
14%	11%

#### **Fundraising**

Direct fundraising expenses

Event planning and execution

Forms, event packages

85,563	39,890
20%	14%

#### **Administration**

Facilities rent

Insurance

Office expenses

Audit

57,635	24,017
13%	9%

#### **Total Expenses**

\$	415,371	\$	283,644
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#### **Excess of Receipts over Expenses**

\$	(145,936)	\$	299,821
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## FINANCIALS

### DONATIONS, GIFTS AND OTHER

*For the year ending September 30,*  
**2022**                      **2021**

Walk for Lupus	88,983	89,479
Italian Dinner	17,041	-
Golf	25,385	-
Charitable Donations	28,282	17,698
Memorial Donations	15,855	11,715
Research Donations Membership & Research World Lupus Day	143,136	113,477
Ottawa Door to Door	7,682	7,048
Rona Heroes	6,938	-
Deferred Contributions Recognized	12,600	-
Bequests	-	157,434
Investment and Other Income	(77,872)	176,424
Federal Government Grant	-	10,000
Books and Merchandise Sales	1,405	190
<b>Total Receipts</b>	<b>\$ 269,435</b>	<b>\$ 583,465</b>

## LOOKING FORWARD

- Upcoming podcasts and webinars to give you more information about not just lupus but navigating the health system.
- Attend more events with partner organizations at a variety of locations for you to join wherever you are.
- Planning continues for a more interactive website, providing more resources and information for our community.
- The Living with Lupus Facts Booklet will be available in hard copy and digitally in French.
- Lupus Symposium Re-Launched!



**In-person Lupus Awareness Month Event. Join us May 13th at Rotary Park in Ajax!**

## SPONSORS

### PRESENTING SPONSORS



### COMMUNITY PACE SETTERS



### COMMUNITY POWER WALKER



### COMMUNITY STROLLER



## MAJOR DONORS



Yvonne Bailey



Catharina  
Birchall



Foundation for Human Development



Murray Hedges



Linda Keill



James Samuel

David C.  
Stevens



Anonymous (3)

# THANK YOU FOR YOUR SUPPORT

## CONTACT US

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