

# Lupus Ontario

# ANNUAL REPORT

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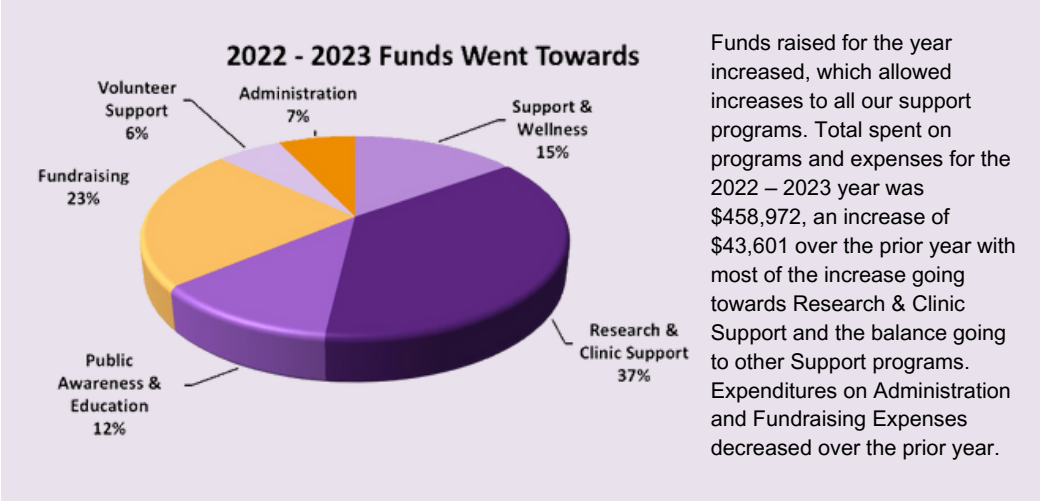
Fiscal Year Ending September 30, 2023



During 2023, we gradually recovered from our locked-in COVID19 pandemic experience and started to once again participate at in-person events. Our events and support group programs were delivered in both a virtual and in-person manner as our immunocompromised community enthusiastically emerged from Covid hibernation. Our joy at being able to gather was showcased at the 2023 WALK for Lupus as the community turned up in huge numbers to support the WALK resulting in extremely successful multiple WALKS across the province therefore surpassing preset goals and raising an incredible \$157,263 for all our programs. The Italian Dinner Dance was still limited by COVID-19 and continued as an online Silent Auction, raising an incredible \$22,955. We are also grateful to everyone who held third party events such as Hope Volleyball Toronto, 90's Dance, Research Fellowship Fundraiser and Ottawa Door-to-Door to raise awareness and funds for lupus. Other non-event-based income sources contributing to revenue included bequests, investment income, memorial and charity donations.

Thanks to the generosity of donors, sponsors and grantors we were able to increase our support for all programs. Research programs funded increased to \$168,385 and included The Geoff Carr Fellowship, The Lupus Ontario Anne Matheson Biobank at the McMaster University Lupus Clinic, The Dr. Murray Urowitz Chair in Lupus Research at the University of Toronto and funding for the six accredited Lupus Clinics. All projects support research by investigating better methods of managing lupus or gathering data for research so that someday we have a Life Without Lupus. Our Geoff Carr Fellow last year was Dr. Stephanie Wong who completed her lupus clinical experience and research project at SickKids Hospital in Toronto. Her project was "Therapeutic drug monitoring of Hydroxychloroquine (HCQ) is feasible in the childhood SLE population, allowing for individualized HCQ treatment with optimal efficacy and prevention of long-term toxicity". She is now practising at Alberta Children's Hospital in Calgary to serve the pediatric lupus community!

From an Education, Awareness and Support perspective, we continued our online support groups and presented valuable educational information through our webinars, podcasts, newsletters and Annual Education Symposium. Through on line programming we were able to serve people living throughout Ontario as well as those living out of province and from all over the world. We increased our advocacy efforts by continuing to forge new partnerships with other organizations, helped improve medical care in northern Ontario and filed with the Canadian Agency for Drugs and Technologies in Health (CADTH) for new biologics for lupus patients.

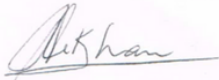


LOOKING FORWARD

We look forward with increased optimism as we realize that research in this area is escalating dramatically with multiple clinical trials under away by various pharmaceutical companies, leading to greater hope for a cure or an improvement in the quality of life for lupus patients. In the meantime, our plans for the coming year include more in person events which will allow us to better increase awareness and understanding of the impacts 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 and dedication to improving life for the lupus community is outstanding and we sincerely thank you.

Sincerely,

  
June Alikhan  
President, Lupus Ontario



# ABOUT US



Our 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.

Lupus Ontario is the largest Canadian provincial organization focused on improving the lives of lupus patients and their families.



In 1978, Honey Agar and Linda Ethier, two lupus patients frustrated by the lack of knowledge and treatment for the disease, joined forces. Their goal was to create awareness and to educate.

# We support the Lupus Community through:

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We provide 6 interactive monthly support groups to lupus patients throughout Ontario. Facilitators guide the meetings based on specific themes or key discussion topics.

**Monthly Support Groups:**

- Durham Support Group
- Ottawa Support Group
- Provincial Support Group
- Windsor Support Group
- Young Adults' Monthly Social

**Bi-weekly Wellness Group:**

- Dance and Medicine classes

**Many supported:**

- 431 attendees to Support Group Meetings and Wellness Classes
- Responded to 178 emails/calls requesting support/information

**CONTACT SUPPORT**

Email the Support team at  
[Support@lupusontario.org](mailto:Support@lupusontario.org)

## We support a variety of research initiatives such as:

- The Geoff Carr Lupus Research Fellowship
- The Lupus Ontario Anne Matheson Biobank
- The Dr. Urowitz Research Chair at the University of Toronto
- 6 accredited Lupus Clinics in Ontario



## 2022 – 2023 LUPUS ONTARIO GEOFF CARR FELLOW

**Dr. Stephanie Wong earned her Doctor of Medicine degree at the University of British Columbia in Vancouver. Subsequently, she pursued a clinical fellowship in Pediatric Rheumatology at BC Children's Hospital. As a Geoff Carr Fellow, she gained clinical experience at SickKids Hospital, focusing on a dedicated SLE Clinic with a multidisciplinary approach. Additionally, she attended transition clinics at Mount Sinai and Toronto Western, as well as the Neonatal Lupus Clinic at SickKids twice monthly.**

**Her research focused on Hydroxychloroquine Blood Concentration in Childhood-onset SLE (cSLE), aiming to explore the feasibility of therapeutic drug monitoring of HCQ in this population for personalized treatment with optimal efficacy and long-term toxicity prevention.**

**Throughout her Fellowship, Dr. Wong was supervised by Dr. Deborah Levy and Dr. Linda Hiraki.**



- Attended Queens Park Lupus Awareness Day recognition ceremony
- Responded to CADTH disagreeing with restrictions placed on new biologic medication
- Worked with St. Joseph's Health Care in Thunder Bay on ACPAC (Advanced Clinical Practitioner in Arthritis Care) shortage
- Set up Hamilton Lupus clinic as an additional resource for northern lupus clinics
- Continued to expand relationships with similar organizations

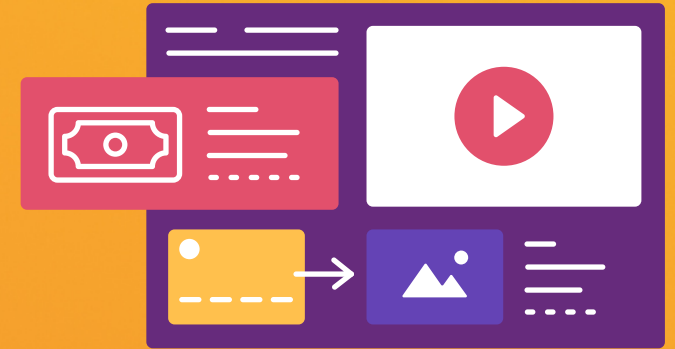


**Lupus Awareness Day  
May 10, 2023  
Queen's Park**



# AWARENESS

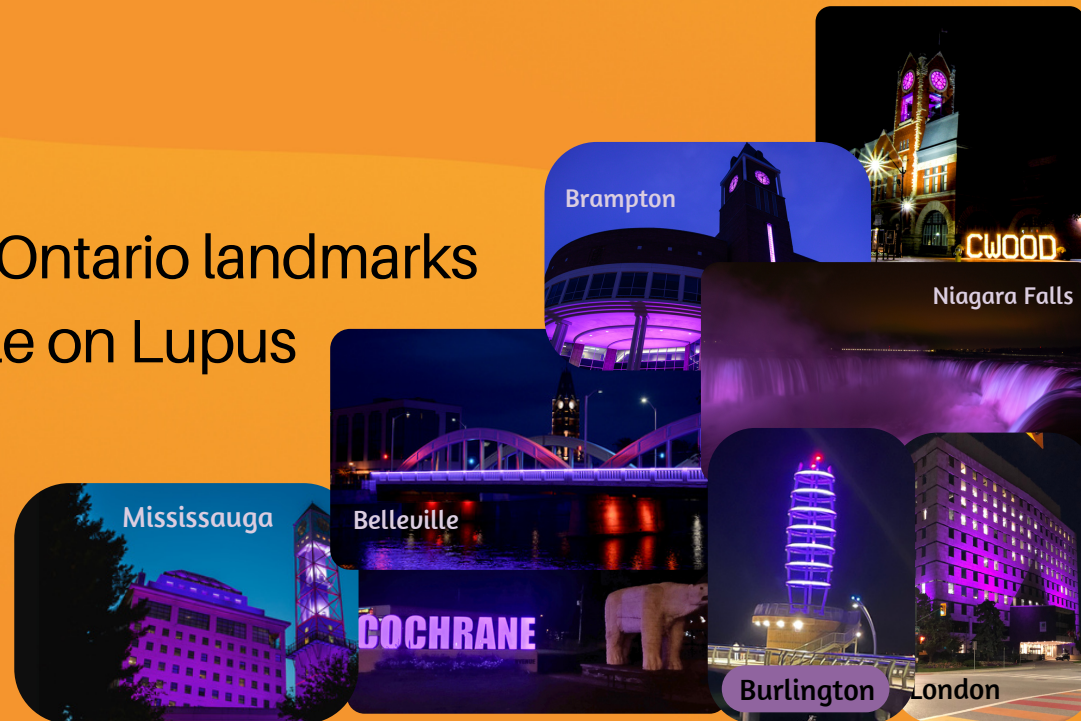
Raise awareness about lupus through social media, website, monthly newsletter, and Lupus Awareness Month in May.



Our recent advocacy efforts led to the recognition of Lupus Awareness Day in Ontario.

41

We also secured 41 Ontario landmarks to illuminate in purple on Lupus Awareness Day.







## Newsletters:

- 1,600 recipients
- Average click rate 54.9%

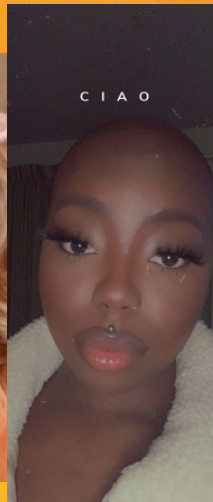
**8 lupus warriors featured in the newsletter and on social media from all across ontario**



*Emily*



*Michelle*



*Jahmeila*



*Olivia*



*Nameerah*



*Aziza*



*Abbey & Vanessa*

We provide education through our monthly support groups, webinars, podcasts, and an annual Lupus Symposium.



#### Podcasts:

- 1,885 listens worldwide
- 32 countries
- 10 Canadian provinces + 2 territories
- 32 US states
- Listeners 76% female, 24% male
- 69% below age of 45



#### Webinars:

- Views between 100- 460 annually



#### New Direction Symposium:

- 61 Registrants
- 890 viewers
- 8 Exhibitors



Lupus Ontario facilitates community members to organize walks, raises money for research initiatives through an annual campaign, and has organized a fundraiser, the Lupus Ontario Gala: Spring Soirée, for April 6, 2024.

## HOPE VOLLEYBALL TORONTO

Thank you HOPE volleyball and all volunteers who participated, raising \$4,600.

## RONA HEROES CAMPAIGN

We were honoured to be selected as the charity of choice for the Mississauga-Dundas store, raising \$5,508.

## 90's Dance

Thank you Alisia Kipp, family and friends for organizing such an amazing event, raising \$8,178.

## AJAX HIGH VOLLEYBALL TOURNAMENT

Thank you Rob Piccione and all who helped put together this tournament in support of Lupus Ontario, raising \$5,475.

## OTTAWA DOOR-TO-DOOR

We are grateful for this annual fundraising initiative led by Jodi Waiser and Brenda Cardillo, raising \$8,596.

## TCS TORONTO WATERFRONT MARATHON

Thank you to those who participated in this great cause, raising \$1,394.

## MILL POND GALLERY ART EXHIBIT

Yuni Ko and her daughter Claire Seo put together an amazing art exhibit in support of Lupus Ontario. Their friends and family helped raise \$24,100.

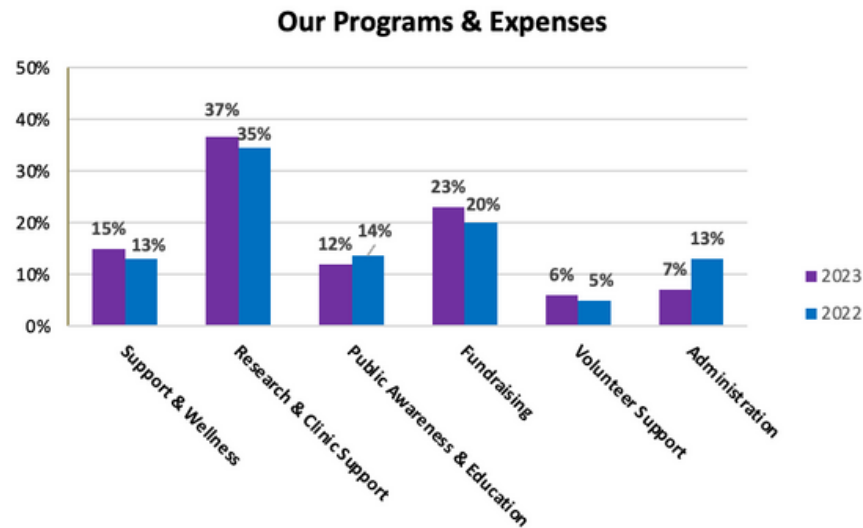
## WALK 2023 STATS

- Over 800 participants
- 1,300 donors
- Media coverage in over 15 regional outlets (tv, radio, online news, social media)
- Raised over \$157,000
- 12 locations:
  - Barrie
  - Durham
  - Hamilton/Halton
  - Kitchener
  - Mississauga
  - Ottawa
  - Richmond Hill
  - Sudbury
  - Thunder Bay
  - Toronto
  - Windsor
  - Woodstock



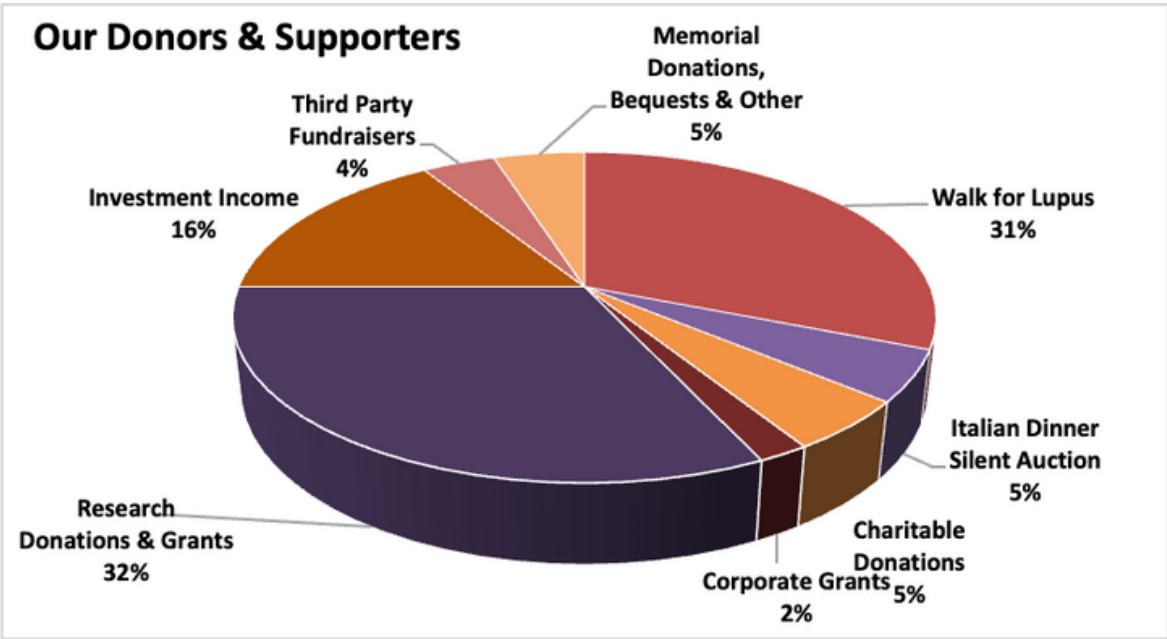
Spending

Spending on programs increased to 70% in 2023 compared to 67% in 2022 with Research & Clinic Support being the largest program. Spending on Fundraising and Administration decreased in 2023 by 3% to 30% as a result of the office going virtual.



Funds received from our generous donors and supporters:

Our largest fundraiser continues to be the WALK for Lupus Ontario and raised an amazing \$157,263 compared to the prior year amount of \$88,983, an increase of almost 77%. This huge success was reflected by the enthusiastic participation of the community at in-person events. Research Donations and Grants also increased as a result of more corporate grants being submitted and corporate recognition of Lupus Ontario research initiatives. Investment Income improved due to better market conditions this year compared to the prior year; which had a market crash as a result of higher interest rates and inflation combined with a worsening economy. The increased donations, sponsorships and grants collected permitted us to increase expenditures on research initiatives and support programs in the 2023 year.





**LUPUS ONTARIO**  
**For the Year Ended September 30, 2023**
**YOUR GENEROSITY AT WORK**
*For the year ending September 30,*
**2023**
**2022**
*Support and Wellness Programs*
**\$ 66,797**
**\$ 52,455**

Newly diagnosed

Ongoing support and training

Counselling

Lupus community education &amp; webinars

Lupus educational kits

*Research Funding and Clinic Research Support*
**168,385**
**143,747**

Lupus Clinics: Toronto Western Hospital, Mount Sinai Hospital, SickKids Hospital, McMaster Hamilton Health Science, St. Joseph's Healthcare London, Ottawa Hospital

Geoff Carr Fellowship

Anne Matheson Biobank

Anne Matheson Biobank

Anne Matheson Biobank

*Volunteer Support*
**27,295**
**18,954**

Education and training

Appreciation awards and recognition

*Public Awareness and Education*
**54,962**
**57,017**

Website: www.lupusontario.org

Social Media: Facebook, Twitter, Instagram

Advertising and promotion at events

Newsletter, posters, pamphlets

*Fundraising*
**110,111**
**85,563**

Direct fundraising expenses

Event planning and execution

Forms, event packages

*Administration*
**31,422**
**57,635**

Facilities rent

Insurance

Office expenses

Audit

**Total Expenses**
**\$ 458,972**
**\$ 415,371**
**Excess (Deficiency) of Receipts over Expenses**
**\$ 46,863**
**\$ (145,936)**
**DONATIONS, GIFTS AND OTHER**
*For the year ending September 30,*
**2023**
**2022**

Walk for Lupus

**\$ 157,263**
**\$ 88,983**

Italian Dinner Silent Auction

**22,955**
**17,041**

Golf

**-**
**25,385**

Charitable Donations

**23,353**
**28,282**

Memorial Donations

**11,616**
**15,855**

Research Donations and Grants

**163,964**
**143,136**
*(includes Research Fellowship Fundraiser)*

Corporate Grants

**10,000**
**-**

90's Dance

**\$ 8,178**
**-**

Ottawa Door to Door

**\$ 8,596**
**7,682**

Rona Heroes

**\$ 5,508**
**6,938**

Other Activities

**1,681**
**-**

Deferred Contributions

**289**
**12,600**

Bequests

**\$ 10,455**
**-**

Investment and Other Income

**\$ 81,977**
**(77,872)**

Books and Merchandise Sales

**-**
**1,405**
**Total Receipts**
**\$ 505,835**
**\$ 269,435**

## SPONSORS



## MAJOR DONORS



Foundation for Human Development



- 1419394 Ontario Limited
- Anthony & Korina Liberta Taylor
- David Ryan & Cirissa Sellars
- The Freddie Liberta Charity Brunch
- Hasnain Panju

- James Samuel
- Ron Bacon Estate
- Ryan Macdonald
- Anonymous (12)

## EXECUTIVE



**June Alikhan**

President,  
Chair Executive Committee  
& Advocacy Committee



**Linda Keill**

Past President, Secretary,  
Chair Governance Committee



**Siraj Mehdi**

Treasurer,  
Chair Finance Committee



**Karen Furlotte**

Office Manager



**Anne Brooks**

Fundraising & Marketing  
Manager



**Hajra Batool**

Digital Marketing &  
Social Media Specialist

## DIRECTORS



**Sandra Williams-Reid**

Director at Large,  
Chair Support & Wellness  
Committee



**Brent Leonard**

Director at Large,  
Chair Public Awareness &  
Education Committee



**Lisa Bilodeau**

Director at Large,  
Chair Fund Development  
Committee



**Dhwani Babla**

Director at Large,  
Advocacy Committee



**Maneka Kaur**

Director at Large,  
Fund Development Committee,  
Governance Committee



**Kyle Morrow**

Director at Large,  
Advocacy Committee,  
Governance Committee

## STAFF

## MEDICAL ADVISORY BOARD

### Dr. Murray Urowitz

Professor Emeritus, Temerty Faculty of Medicine,  
University of Toronto, Schroeder Arthritis Institute,  
Toronto Western Hospital.

### Dr. Zahi Touma

Dr. Murray B. Urowitz Chair in Lupus Research at  
UHN, Director, Toronto Lupus Program at UHN,  
Associate Professor of Medicine, University of  
Toronto, Institute of Health Policy, Management  
and Evaluation, Institute of Medical Sciences,  
Adjunct Scientist, Institute for Work and Health,  
Clinician-Scientist, Rheumatology, University  
Health Network, Scientist, Schroeder Arthritis  
Institute, Krembil Research Institute.

### Dr. Kostas Tselios

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

### 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

### Dr. Catherine Ivory

Assistant Professor at University of  
Ottawa, Division of Rheumatology  
University of Ottawa, Senior  
Clinician Investigator with the  
Ottawa Hospital Research Institute

### Dr. Deborah Levy

Associate Professor, Department  
of Paediatrics University of Toronto

### Dr. Amanda Steiman

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

### Dr. Earl Silverman

Pediatric Rheumatologist at  
SickKids Hospital, Toronto

THANK YOU TO THE BOARD MEMBERS WHO HAVE LEFT THE BOARD



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

## **CONTACT US**

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**905-415-1099**

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