



# Lupus Ontario Annual Report

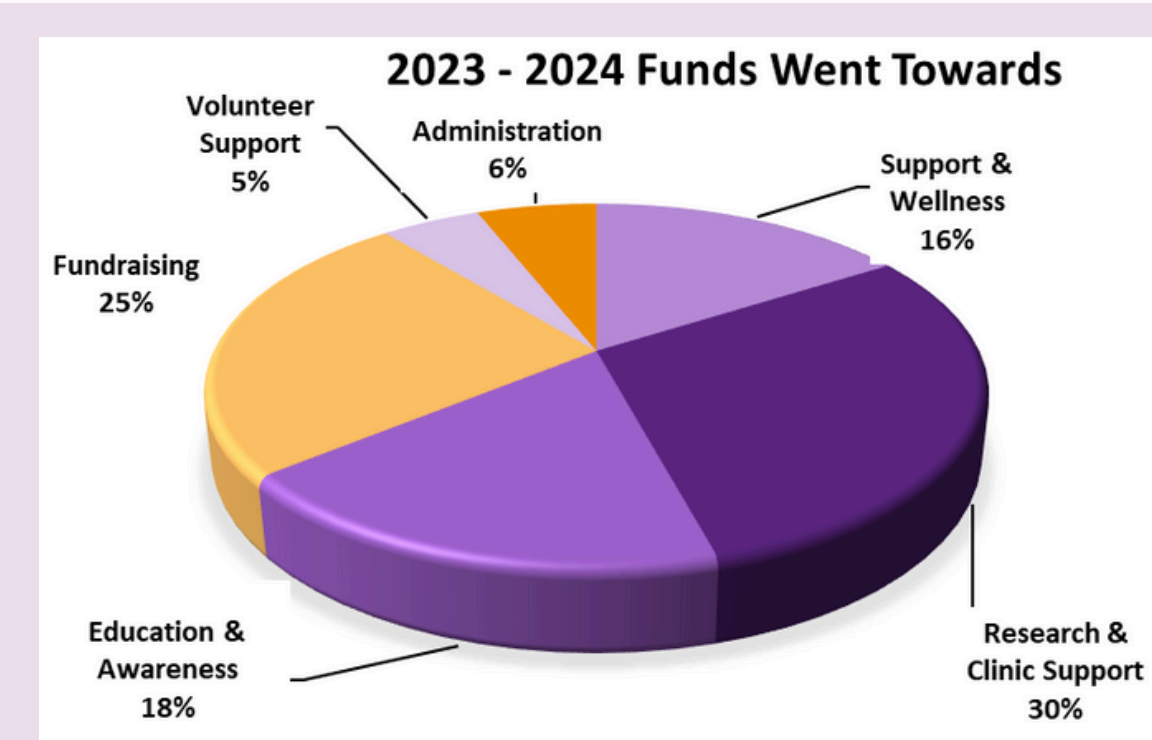
Fiscal Year Ending September 30, 2024



The year 2024 was vibrant and full of enthusiasm. As we wrap up another successful year at Lupus Ontario, we owe our accomplishments to your steadfast support. A sincere THANK YOU to all who devoted their time and energy and generously participated in the Lupus Ontario WALKs, the Silent Auction, and the Spring Gala. We also extend our gratitude to those who organized third-party events to raise awareness and funds, including the Windsor Waterfront Marathon, St. Theresa de Lisieux High School, the Research Fellowship Fundraiser, and Ottawa Door to Door. Revenue from these solicited donors and sponsors for events decreased by 32% from the prior year to \$257,277. We will increase our funding to research by adding the Honey Agar Fellowship for High-Risk Pregnancies in Rheumatic Diseases to our on-going research initiatives such as the Geoff Carr Fellowship.

Other non-event-based income sources that contributed to revenue included bequests, investment income, and donations for memorials and charities. Revenue from these sources increased by 251.5% from the previous year to \$448,851.

Total revenue for the year was \$706,128, reflecting a significant increase of 39.6% driven by contributions from unsolicited donors and investment income. Throughout the year, market conditions steadily improved, as a result of declining inflation and interest rates, which positively impacted the Canadian economy. Consequently, the rise in revenues allowed an increase in program spending. The ratio of spending on program funding compared to fundraising and administration expenses remained consistent with the previous year, maintaining an approximate distribution of 70% for program funding and 30% for fundraising and administration.



Funds raised for the year increased which allowed greater spending on all our support programs. The total expenditure on programs and expenses for the 2023-2024 year was \$472,081, reflecting an increase of \$13,110 compared to the previous year.

The majority of this increase was allocated to Education, Awareness and Support, with the remainder directed towards other expenses.

**LOOKING FORWARD**

We remain optimistic as research in this field is rapidly advancing, with numerous clinical trials currently underway by various pharmaceutical companies. The prospect of finding a cure or enhancing the quality of life for lupus patients through a wider array of medication options, particularly biologics and innovative treatments, is truly exciting.

In the upcoming year, we aim to host more in-person events to enhance awareness and understanding of lupus and its impact on patients, their families, and the broader community. We will continue our educational initiatives, which include new research and medical webinars, personal lupus warrior podcasts, newsletters, a 2025 Symposium, and the unveiling of a new website. We will focus on new advocacy events to raise awareness among Ontario Members of Provincial Parliament regarding the unmet needs of lupus patients. Finally, we will launch the Honey Agar Fellowship for High-Risk Pregnancy in Rheumatic Diseases, a unique new clinical fellowship that will train a rheumatologist in medical and obstetric management of lupus and rheumatic pregnancies.

I would like to express my heartfelt gratitude to all our sponsors, donors, and the dedicated staff and volunteers. Your generosity is essential for us to sustain our high-quality programs for the Ontario lupus community. Your unwavering commitment to our vision of a Life without Lupus plays a crucial role in raising awareness about the disease among a wider audience and in directing additional resources towards research and treatments that improve the lives of lupus patients.

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.

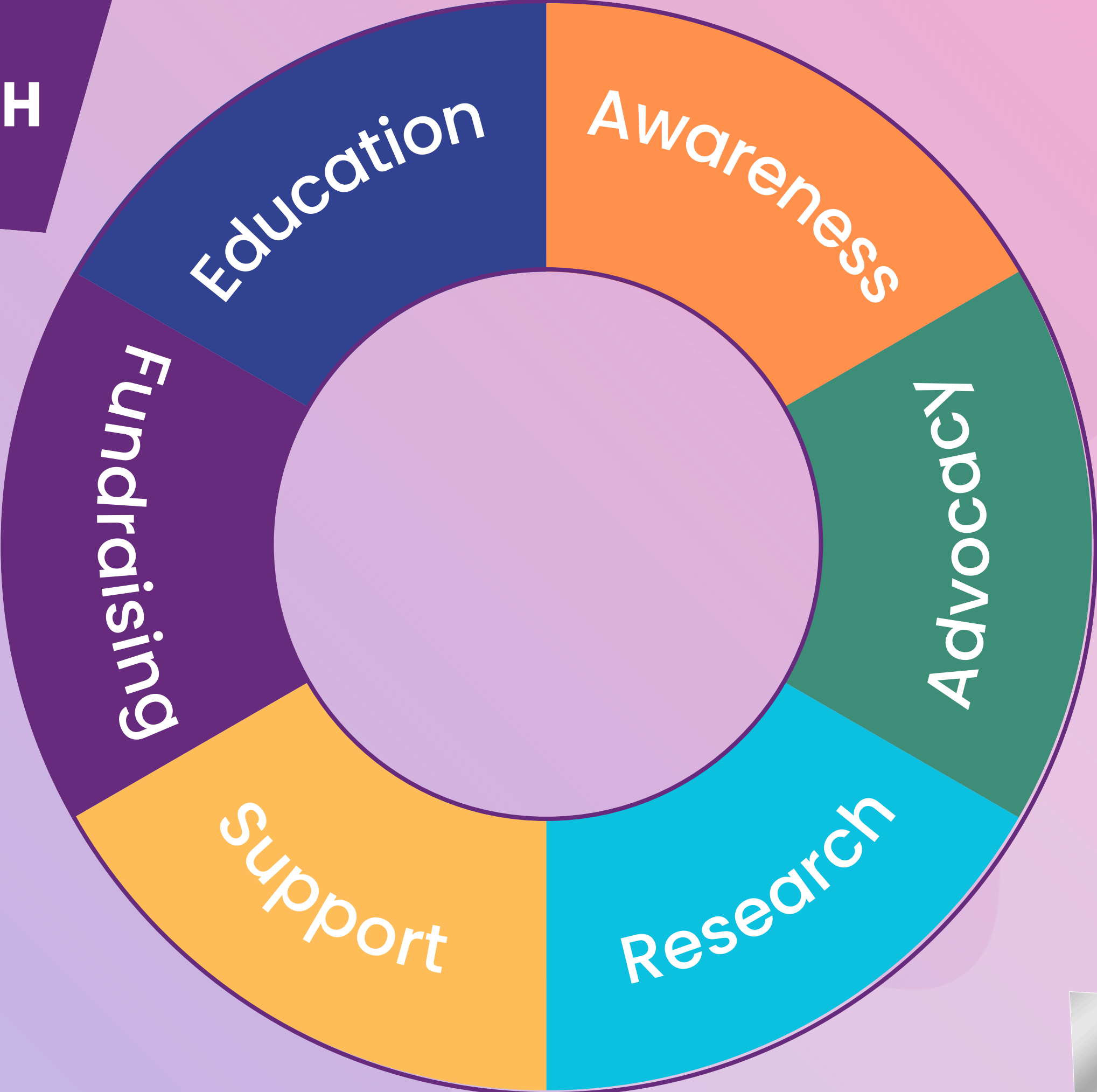
Lupus Ontario is the largest Canadian provincial organization focused on improving the lives of lupus patients and their families.



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





# SUPPORT



We provide 8 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
- Men' Support Group
- Western Support group
- Windsor Support Group
- Young Adults' Monthly Social

## **Bi-weekly Wellness Group:**

- Dance and Medicine classes

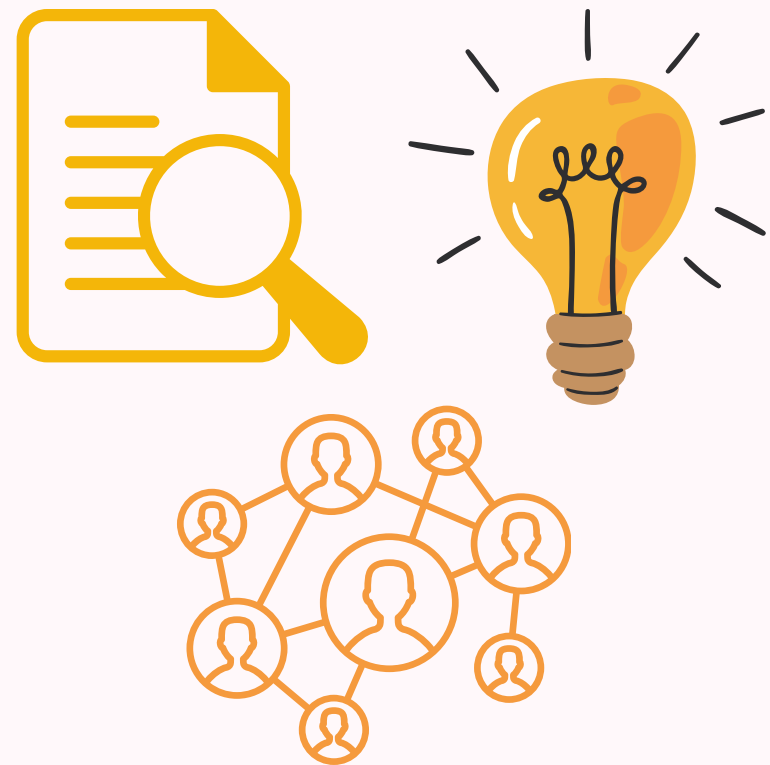
In addition to our support groups, we provide assistance through phone calls, emails, and online resources, ensuring that those in need can access guidance, information, and encouragement. Whether someone is looking for answers to their questions, seeking emotional support, or needing connections to valuable resources, we are here to help.

Our goal is to provide a strong network of support that empowers individuals and their families to navigate life with lupus.

## **CONTACT SUPPORT**

[support@lupusontario.org](mailto:support@lupusontario.org)

905-415-1099 or 1-877-240-1099



# RESEARCH



- The Geoff Carr Lupus Research Fellowship
- The Lupus Ontario Anne Matheson Biobank
- 6 accredited Lupus Clinics in Ontario

## 2023-2024 GEOFF CARR FELLOW

Dr. Teresa Semalulu, a clinical and research fellow at Toronto Western Hospital Lupus Clinic, completed her medical training at McMaster University and Northern Ontario School of Medicine. Specializing in systemic lupus erythematosus she centered her work on bridging pediatric to adult rheumatology care, alongside exploring health disparities. As the recipient of the Geoff Carr Fellowship, her research focused on racial disparities in SLE, pursuing a Master of Science in Clinical Epidemiology and training at the University of Toronto.

Dr. Semalulu's aim is to enhance understanding and address disparities in lupus care.

Throughout her fellowship, Dr. Semalulu was supervised by Dr. Zahi Touma





# ADVOCACY



- Attended Queens Park Lupus Awareness Day recognition ceremony
- Advocated to the Ontario government for better access to CDA-approved biologics
- Secured a new ACPAC (Advanced Clinical Practitioner in Arthritis Care) in St. Joseph's Health Care in Thunder Bay, alleviating a shortage in North Western Ontario
- Gathered signatures for the biologics petition to have the Ontario government approve all lupus-specific biologics/treatments approved by the Canada Drug Agency (formerly CADTH) added to the Ontario Drug Formulary
  - To be tabled at the Ontario Legislature*
- Continued to expand relationships with similar organizations



Lupus Awareness Day May 8, 2024 Queen's Park



# AWARENESS



On April 6th, 2024, we hosted the Lupus Ontario Gala: Spring Soirée. This event raised awareness for lupus with over 250 people in attendance including local politicians, rheumatologists and the lupus community. Thank you to all who attended.



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



# AWARENESS



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

Newsletters:

- 3,023 recipients
- Average click rate 44.4%

**10 lupus warriors featured in the newsletter and on social media from all across Ontario**



# EDUCATION



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



## Podcasts:

- 5 podcasts released in 2024
- 3,175 listens worldwide
- 39 countries
- 10 Canadian provinces + 2 territories
- 32 US states
- Listeners 82% female, 18% male
- 54% below age of 45



## Webinars:

- 6 webinars conducted in 2024
- Views between 500- 600 annually



## Lupus Ontario Education Symposium:

- 175 Registrants
- 1000+ viewers
- 4 Presenters



# FUNDRAISING



## WALK 2024 STATS

- Over 770 participants
- 1,050 donors
- Media coverage in over 12 regional outlets (tv, radio, online news, social media)
- Raised over \$120,000



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## LOCATIONS

- Durham
- Hamilton/Halton
- London
- Mississauga
- Ottawa
- Peel
- Richmond Hill
- Sudbury
- Toronto
- Vaughan (Beach Volleyball)
- Windsor
- Woodstock



# FUNDRAISING



**Lupus Ontario facilitates community members to organize walks, and raise money for research initiatives through an annual campaign**

## **ONLINE SILENT AUCTION**

We appreciate the incredible efforts of our volunteer committee for raising over \$15,000 through the online silent auction.

## **AJAX HIGH VOLLEYBALL TOURNAMENT**

Thank you Rob Piccione and all who helped put together this tournament in support of Lupus Ontario, raising \$ 4,043.

## **ST. THERESA OF LISIEUX CATHOLIC HIGH SCHOOL**

St. Theresa of Lisieux Catholic High School held a business luncheon and fundraiser in December 2023. Special thanks to Anastasia Pinsky for championing Lupus Ontario and sharing her journey with lupus. Their fundraiser raised \$5,121.

## **OTTAWA DOOR-TO-DOOR**

We are grateful for this annual fundraising initiative led by Brenda Cardillo & Joni Waiser raising \$9,595.

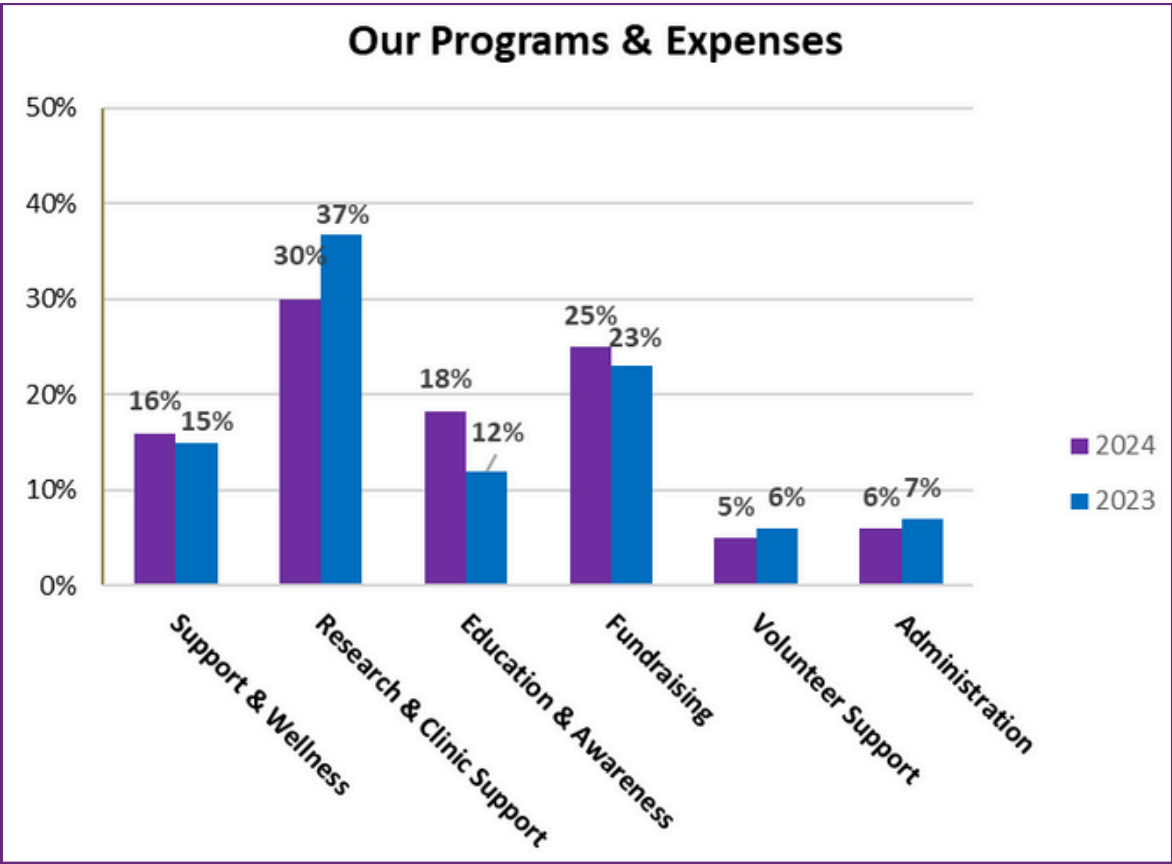
## **RESEARCH FELLOWSHIP FUNDRAISER**

Many thanks to Tom Koor for coordinating the Research Fellowship Fundraiser which raised \$8,173.

Thanks to the generosity of donors, sponsors, and grantors we successfully increased the amount of our support to programs by 2.3% to \$324,798 over last year’s amount of \$317,439. The ratio of spending on program funding compared to fundraising and administration expenses changed marginally compared to the previous year, with approximately 70% allocated to program funding and 30% to fundraising and administration.

Research initiatives funded amounted to \$141,222 and included the Geoff Carr Fellowship, the Lupus Ontario Anne Matheson Biobank at the McMaster University Lupus Clinic, and support for the six accredited lupus clinics. All projects aim to enhance lupus management, support current research and collect data for future research, with the ultimate goal of achieving a Life Without Lupus. Our Geoff Carr Fellow for the year was Dr. Teresa Semalulu who completed her lupus clinical experience and research project at Toronto Western Hospital in Toronto. She is now practicing at St. Michael’s Hospital to serve the lupus community!

Other programs funded were education, awareness, advocacy, support and volunteers which amounted to \$183,576. We continued our on-line support groups and presented valuable educational information through our webinars, podcasts, newsletters and the 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 and organized a Petition for tabling at the legislature for access to current and new biologics for lupus patients.

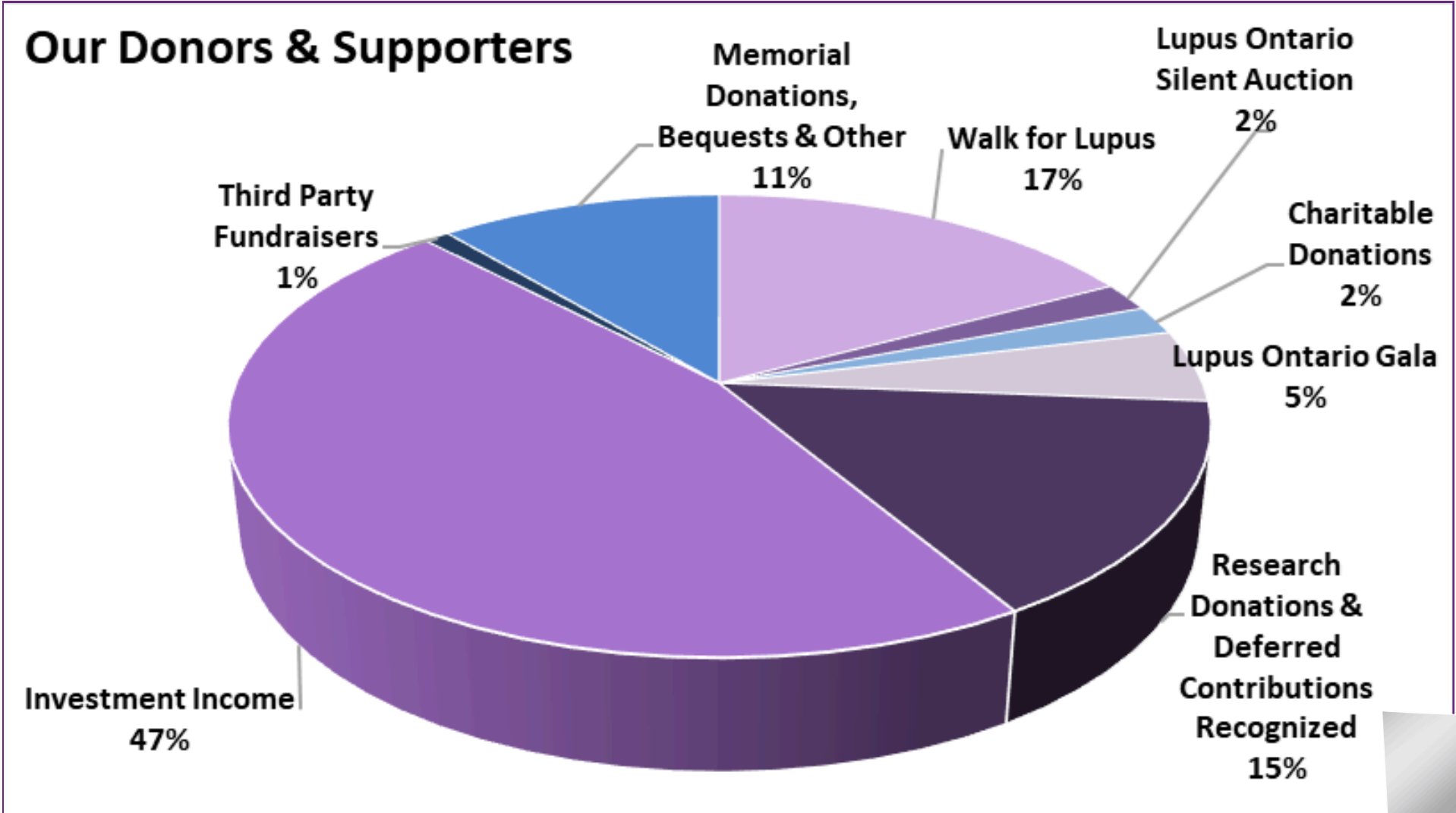


**Funds received from our generous donors and supporters:**

Our largest fundraiser continues to be the WALK for Lupus Ontario which provided 17% of total revenue. The WALKs raised \$122,590 compared to \$157,263 in the prior year, a decrease of 22%. There was enthusiastic participation by the lupus community on all the WALKs with the decline in revenue resulting from lower sponsorship income.

Research Donations and Deferred Contributions Recognized generated 15% of total revenue. Research Donations decreased as a result of corporate cutbacks on grants.

Investment Income produced 46% of total income. This significant increase reflected better market conditions as a result of lower interest rates and inflation. In addition, the investment policy switch to 100% equity holdings was very beneficial and took full advantage of rising Canadian equity market conditions. As a result, total revenue increased to \$706,128 or 39.6% over the prior year compensating for decreased grants and sponsorships





YOUR GENEROSITY AT WORK	For the year ending September 30,	
	2024	2023
<b>Support and Wellness Programs</b>	\$74,015	\$66,797
Newly diagnosed	16%	15%
Ongoing support and training		
Counselling		
Lupus educational kits		
<b>Research Funding and Clinic Research Support</b>	\$ 141,222	\$ 168,385
Toronto Western Hospital Lupus Clinic	30%	37%
Ottawa, London and Mount Sinai Lupus Clinics		
Sick Kids Hospital Lupus Clinic		
McMaster Lupus Clinic		
Geoff Carr Fellowship & Anne Matheson Biobank		
<b>Volunteer Support</b>	\$ 22,991	\$ 27,295
Education and training	5%	6%
Appreciation awards and recognition		
<b>Education and Public Awareness</b>	\$ 86,570	\$ 54,962
Community education: symposium and webinars	18%	12%
Website, podcasts and social media		
Spring Gala, awareness events		
Newsletter, posters, pamphlets		
<b>Fundraising</b>	\$ 120,754	\$ 110,111
Direct fundraising expenses	25%	23%
Event planning and execution		
Forms, event packages		
<b>Administration</b>	\$ 26,529	\$ 31,422
Facilities rent	6%	7%
Insurance		
Office expenses		
Audit		
<b>Total Expenses</b>	\$ 481,879	\$ 458,972
<b>Excess (Deficiency) of Receipts over Expenses</b>	\$ 234,047	\$ 46,863

DONATIONS, GIFTS AND OTHER	For the year ending September 30,	
	2024	2023
WALK for Lupus	\$ 122,590	\$ 157,263
Lupus Ontario Silent Auction	\$ 15,427	\$ 22,955
Lupus Ontario Spring Gala	\$ 36,658	-
Charitable Donations	\$ 15,557	\$ 23,353
Memorial Donations	\$ 5,295	\$ 11,616
Research Donations and Grants (includes Research Fellowship Fundraiser)	\$ 67,698	\$ 163,964
Corporate Grants	-	\$ 10,000
90's Dance	-	\$ 8,178
Ottawa Door to Door	\$ 9,595	\$ 8,596
Third Party Events	\$ 5,309	\$ 7,189
• Rona Heroes		
• St. Theresa de Lisieux High School		
• Windsor Waterfront Marathon		
Deferred Contributions Recognized	\$ 26,000	\$ 289
Bequests	\$ 74,172	\$ 10,455
Investment and Other Income	\$ 327,827	\$ 81,977
<b>Total Receipts</b>	\$ 715,926	\$ 505,835

SPONSORS



MAJOR DONORS



While every effort has been made to ensure the accuracy of this information, we apologize for any inadvertent errors or omissions. We welcome any updates or corrections and appreciate your feedback.



EXECUTIVE



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**Chair: Advocacy Committee,**  
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Governance and Operations  
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**Chair: Fund Development**  
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Education & Awareness, Finance,  
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Advocacy, Finance, Fund  
Development and Operations  
Committees



Siraj Mehdi

**Treasurer,**  
**Chair Finance Committee**

STAFF



Karen Furlotte

**Office Manager,**  
Finance, Fund  
Development and  
Operations Committees



Anne Brooks

**Fundraising & Marketing Manager,**  
Education & Awareness, Finance,  
Fund Development and Operations  
Committees



Hajra Batool

**Digital Marketing & Social  
Media Specialist,**  
Education & Awareness,  
Fund Development and  
Operations Committees



Keriszma Bhargava

**Digital Marketing & Social  
Media Specialist,**  
Education & Awareness,  
Fund Development and  
Operations Committees

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**Chair, Support Committee**



Julian Cappelli

**Chair, Education &  
Awareness Committee**



Dhwani Babla

**Director at Large,**  
Advocacy Committee



Maneka Kaur

**Director at Large,**  
Fund Development and  
Governance Committees

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**Dr. Amanda Steiman**

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

**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. Earl Silverman**

Pediatric Rheumatologist at SickKids Hospital, Toronto

**Dr. Murray Urowitz**

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

**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. 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  
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Kyle Morrow

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Advocacy and  
Governance Committees



Jaime Wilson

**Director at Large,**  
Advocacy Committee





**PARTNER WITH US.  
VOLUNTEER WITH US.  
BE PART OF THE CURE.**

## **CONTACT US**

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