

Thank you for joining us

Please note:

- Today's presentation is in a webinar format which has been chosen for its enhanced security features
- All attendees' cameras and chat features have been disabled
- Please use the Q&A button to submit questions
- Questions will be addressed at the end of the presentation



Lupus Ontario ANNUAL GENERAL MEETING March 9, 2024





AGENDA

- Welcome
- The 2022 2023 Year in Review
- Looking Forward to 2023 2024
- Thank you to our Volunteers
- The Board 2023 2024
- Dr. Murray Urowitz: Which Lupus Do You Have? Type 1 or Type 2 Lupus
- Questions for the Board







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.

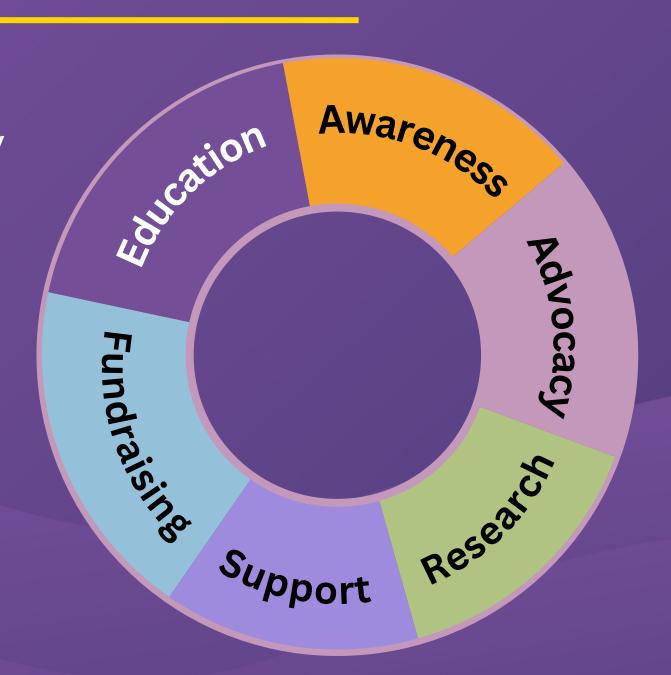




In 1978, Honey Agar and Linda Ethier, two lupus patients frustrated by the lack of knowledge and treatment for the disease, joined forces. Their goal was to create awareness and to educate.

YEAR IN REVIEW - 2022-2023

We support the Lupus Community through:





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

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



Lupus Awareness Day May 10, 2023 Queen's Park

- Set up Hamilton Lupus clinic as an additional resource for northern lupus clinics
- Continued to expand relationships with similar organizations

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.



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



Brampton

Niagara Falls



Newsletters:

- 1,600 recipients
- Average click rate 54.9%

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

Abbey & Vanessa Aziza Nameerah Olivia Jahmeila Michelle **Emily**

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

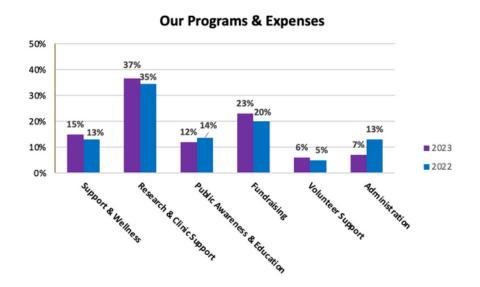




FINANCIALS

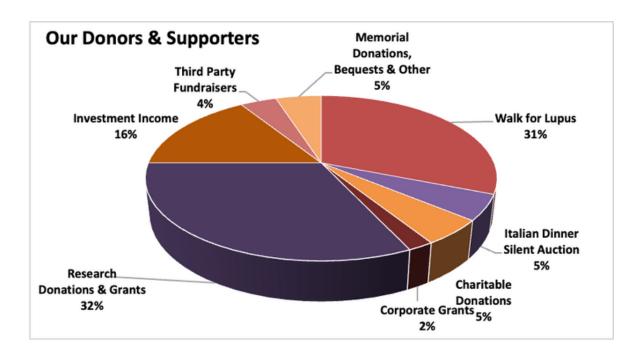
Spending

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.



ANNUAL GENERAL MEETING March 9, 2024



FINANCIALS

LUPUS ONTARIO For the Year Ended September 30, 2023

OUR GENEROSITY AT WORK	For the year ending September 30,		DONATIONS, GIFTS AND OTHER	For the year ending September 30,	
	2023	2022		2023	2022
Support and Wellness Programs	\$ 66,797	\$ 52,455	Walk for Lupus	\$ 157,263	\$ 88,983
Newly diagnosed Ongoing support and training Counselling			Italian Dinner Silent Auction	22,955	17,041
Lupus community education & webinars Lupus educational kits			Golf	-	25,385
Research Funding and Clinic Research Support	168,385	143,747	Charitable Donations	23,353	28,282
Lupus Clinics: Toronto Western Hospital, Mount Sinai Hospital, SickKids Hospital, McMaster Hamilton Health			Memorial Donations	11,616	15,855
Science, St. Joseph's Healthcare London, Ottawa Hospital Geoff Carr Fellowship			Research Donations and Grants (includes Research Fellowship Fundraiser)	163,964	143,136
Anne Matheson Biobank			Corporate Grants	10,000	-
Volunteer Support Education and training	27,295	18,954	90's Dance	\$ 8 ,178	-
Appreciation awards and recognition Public Awareness and Education	F4.062	57,017	Ottawa Door to Door	\$ 8 ,596	7,682
Website: www.lupusontario.org Social Media: Facebook, Twitter, Instagram	54,962	57,017	Rona Heroes	\$ 5,508	6,938
Advertising and promotion at events Newsletter, posters, pamphlets			Other Activities	1 ,681	-
Fundraising	110,111	85,563	Deferred Contributions	289	12,600
Direct fundraising expenses Event planning and execution			Bequests	\$ 10,455	-
Forms, event packages Administration	31,422	57,635	Investment and Other Income	\$ 81,977	(77,872)
Facilities rent Insurance Office expenses Audit	31,422	37,033	Books and Merchandise Sales	-	1,405
Total Expenses	\$ 458,972	\$ 415,371	Total Receipts	\$ 505,835	\$ 269,435
Excess (Deficiency) of Receipts over Expenses	\$ 46,863	\$ (145,936)			

LOOKING FORWARD



Lupus Ontario Gala - Spring Soirée

- Saturday, April 6, 2024
- The Avenue Banquet Hall, 1600 Steeles Avenue West, Vaughan ON, L4K 4M2
- Tickets available for purchase now
- Online Silent Auction, Mystery Bags & 50-50 Tickets
- Online Silent Auction opens March 27, 2024

WALK for Lupus Ontario

- 12+ locations looking for coordinators
- May-September 2024
- Registration will open in April





Webinars & Podcasts

- Look for a variety topics on monthly webinars /podcasts
- Have an idea or connection for a topic? Let us know!

Symposium

 Taking place over two evenings, October 22-23, this event will feature a variety of experts in the lupus field

Support & Dance Groups

- 5 Monthly Support Groups ongoing: Provincial, Durham,
 Ottawa, Windsor, Young Adults
- Dance & Medicine biweekly classes



Volunteers are the life blood of our organization. We would not exist without your dedication and commitment.

You help us with:

- Public Awareness
- Advocacy
- Governance
- Finance
- Education

- Fundraising
- Support Groups
- Administration
- Board Directors

We sincerely thank you for all you do!



VOLUNTEERS

VOLUNTEER	ROLE / COMMITTEE
Sara Ramnarine	Support, Young Adults
Rupinder Sandhu	Support, Facilitator
Stephanie Byfield	Support, Co-Facilitator
Ange-Lynca Kantungane	Support
Laura Piccione	Durham Support Group Facilitator
Beth Beaven	Ottawa Support Group Facilitator
Joy Phillips	Young Adults Social, Support
Julie St-Georges	Ottawa Support Group Facilitator
Michelle Bruxer	Support, Windsor Support Group Facilitator
Camille Goobarry	Support, Co-Facilitator
Kiah Reid	Support, Co-Facilitator
Andrea Ou-Hingwan	Support, Facilitator



VOLUNTEERS

VOLUNTEER	ROLE / COMMITTEE
Emma Neary	Dance and Medicine
Katie Healey	Dance and Medicine
Joni Waiser	Ottawa Door-to-Door Campaign
Gloria Checkley	Ottawa Door-to-Door Campaign
Brenda Cardillo	Ottawa Door-to-Door Campaign
Tom Koor	Lupus Research Campaign Fundraiser
Pauline Duquette-Newman	French Translation of the Lupus Facts booklet
Carolyn Pancham	Newsletter
Brianna Green	Newsletter
Utkarsh Sood	Public Awareness
Ibrahim Mohamed	Public Awareness
Joseph Gallagher	Public Awareness
Nameerah Hasan	Volunteer Committee



VOLUNTEERS: 2023 WALK CO-ORDINATORS

LOCATION	CO-ORDINATORS
Barrie	Jan Gillis, Hunter Hogarth & Heidi Neilsen
Durham	Laura Piccione & Sandra Williams-Reid
Hamilton-Halton	Lisa Bilodeau
Kitchener	Yolande Charest & Michelle Mortensen
Mississauga	Rupinder Sandhu
Ottawa	Elizabeth Beaven & Julie St-Georges
Richmond Hill	Siraj Mehdi
Sudbury	Nicole Lamirande
Thunder Bay	Vanessa Cava & Abbey Hunter
Toronto	June Alikhan & Linda Keill
Windsor	Riley Desjarlais
Woodstock	Alisia & Wendy Kipp, Jan Ropp & Joyce Watson



MEET THE NEW BOARD MEMBERS FOR 2023-2024

DIRECTORS



Director at Large, Advocacy Committee, Governance Committee

Deni s a versatile policy professional with a background in leading strategic initiatives across energy, infrastructure, and health regulation.

Driven by her own experiences with chronic health conditions, particularly autoimmune and digestive issues, Deni is passionate about advocating for chronic illness awareness, especially for those with lupus.

A lifelong learner, she holds degrees in Biology (Honours), Molecular Biology, and Public Administration from Queen's University.
Outside of her professional pursuits, Deni enjoys dancing, weight-lifting, reading, and exploring local coffee shops.



Director at Large, Co-Chair Support and Wellness Committee

Sabrina is currently an MD/MBA candidate at the University of Toronto and holds a Graduate Diploma in Health Research and a Bachelor of Health Sciences.

She currently serves as the Fundraising Coordinator at the Stevens-Johnson Syndrome Canada, and sits on both the Board of Directors at the Halton-Peel Community Aphasia Program and the Academic Board at the University of Toronto.

She has particular interests in patient education, healthcare strategy, and systems-level change. She is looking forward to leveraging her experience to advance the mission of Lupus Ontario.



Director at Large, Co-Chair Support and Wellness Committee

Jacqueline Meeks is an experienced leader, author, and disability advocate. Her journey is guided by a sincere commitment to understanding trauma and fostering meaningful connections through relationship-driven leadership.

Jacqueline is motivated towards creating a more inclusive world, acknowledging the collaborative effort needed for positive change.



LEADERSHIP

EXECUTIVE



President,
Chair Executive Committee
& Advocacy Committee



Vice President, Chair Fund Development Committee



Past President, Secretary, Chair Governance Committee

THANK YOU TO THE BOARD MEMBERS WHO WILL BE LEAVING OR HAVE LEFT THE BOARD THIS YEAR.



Treasurer, Chair Finance Committee

DIRECTORS



Director at Large, Advocacy Committee



Director at Large,
Fund Development Committee,
Governance Committee



Director at Large,
Advocacy Committee,
Governance Committee



Director at Large,
Advocacy Committee,
Governance Committee



Director at Large, Co-Chair Support and Wellness Committee



Director at Large, Co-Chair Support and Wellness Committee



LEADERSHIP

THANK YOU to Karen, Anne, and Hajra for their dedication and commitment.

STAFF



Office Manager Fur



Fundraising & Marketing Manager



Digital Marketing & Social Media Specialist

- **Anjola Asubiojo** was our high school Co-op student. She Assisted with social media and mailing print newsletters.
- Laviza Syed worked with us over the summer of 2023 on our Social Media team.

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

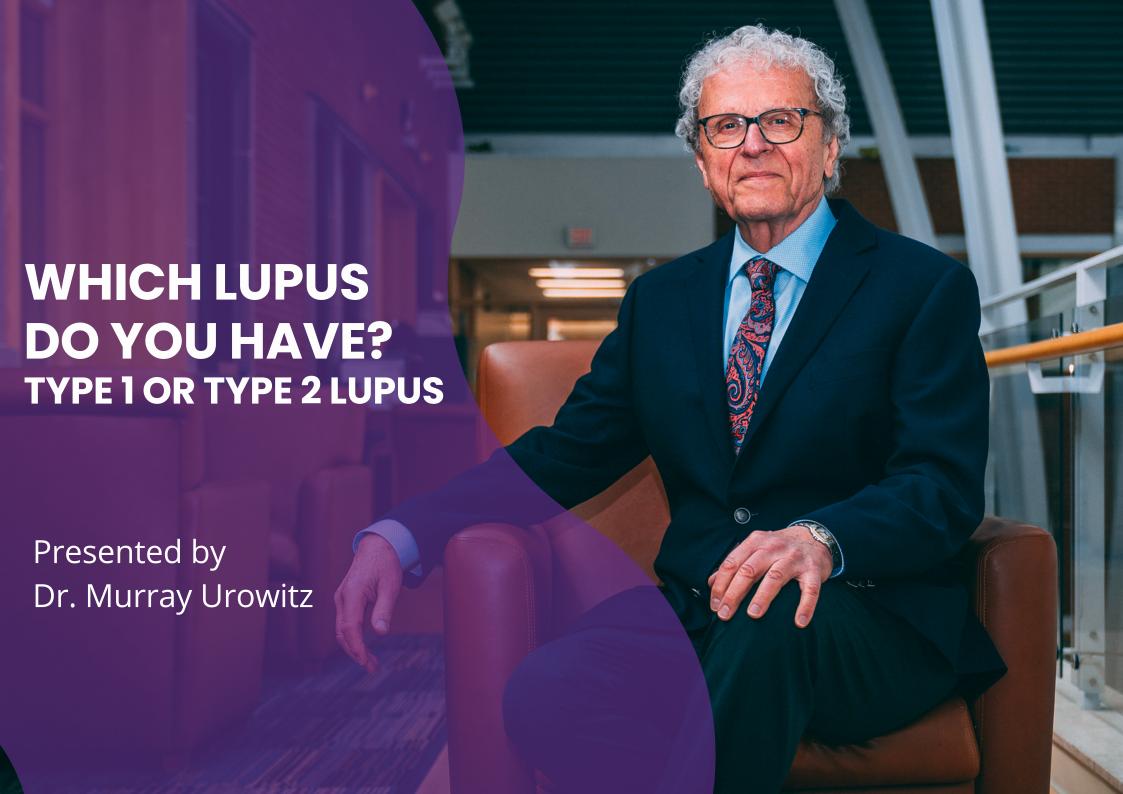
Dr. Earl Silverman

Pediatric Rheumatologist at SickKids Hospital, Toronto



BOARD OF DIRECTORS SLATE

NOMINEE	POSITION		
ELECTED FOR A TWO-YEAR TERM			
Lisa Bilodeau	Vice President		
Jacqueline Meeks	Director at Large		
Sabrina Hundal	Director at Large		
ONE YEAR REMAINING IN THEIR TERM			
June Alikhan	President		
Linda Keill	Secretary		
Siraj Mehdi	Treasurer		
Dwhani Babla	Director at Large		
Maneka Kaur	Director at Large		
Kyle Morrow	Director at Large		
Deni Ogunrinde	Director at Large		



QUESTIONS FOR THE BOARD





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

