

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

Annual General Meeting

March 11, 2023



Agenda



- Welcome
- The 2021 – 2022 Year in Review
- Looking Forward to 2022 – 2023
- Thank you to our Volunteers
- The Board 2022 - 2023
- Special Volunteer Presentations
 - Donna Chu Award
- Diane Forbes: My Lupus Journey – A Message of Hope
- Questions for the Board
- Adjournment

Celebrating
45 YEARS

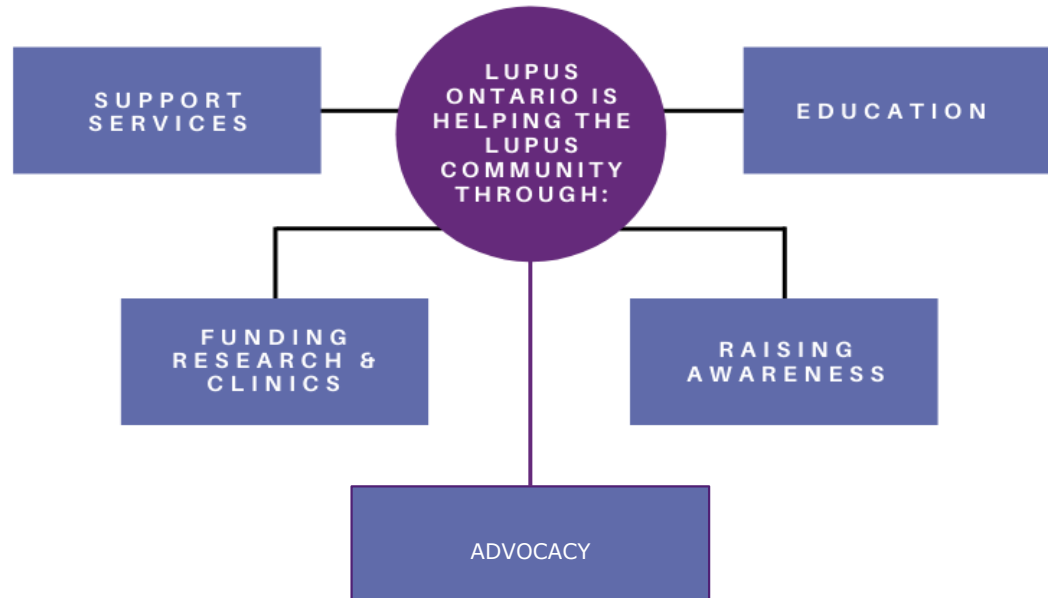
1978-2023



2022 Review & Annual General Meeting

Our 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.





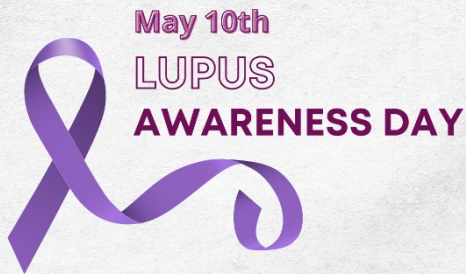
**LUPUS
ONTARIO**
Life Without Lupus

A high-angle, top-down photograph of a diverse group of people standing in a circle on a light-colored wooden floor. Their arms are extended towards the center, and their hands are stacked on top of each other in a unified gesture. The people are wearing various casual and business-casual clothing, including jeans, button-down shirts, and sweaters. The lighting is bright and even, highlighting the textures of the clothing and the wood floor.

Committee Reports

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 supports and services for the lupus community.
- 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 written on both items and shared with multiple organizations such as ORA, pharmaceutical companies, etc.
- Filed with CADTH (Canadian Agency for Drugs and Technologies in Health) to advocate for approval of new biologics: Saphnelo and Benlysta for Lupus Nephritis.



Support Services

Lupus Ontario made a difference in the lives of our members and the community at large

- We have seen growth in our on-line support group meetings. These meetings allow members the opportunity to meet with other lupus patients to share their lived experience & concerns, and to receive information on living with lupus. We currently have 5 Support Groups meeting throughout the month, along with our bi-weekly Dance and Medicine classes.
- Responsibilities for the Support Committee includes working with the newly diagnosed patients as well as responding to emails requiring general information and support.
- The Support Team responded to 98 emails and approximately 60 phone calls for assistance during the last fiscal year. We can be reached by Email at support@lupusontario.org or call the office and your call will be directed to one of our team members.

Education



- Education materials are emailed/mailed upon request. The Lupus Facts Booklet is available on the website.
- Many new educational presentations and webinar videos have been added on our website.
- Monthly/Bi-Monthly virtual webinars are continuing this year. Normally 30-60 people attend. If someone cannot attend at the time of the webinar, it is posted on the website for viewing at any time.
- Lupus Ontario Podcast was launched last year and there are many interesting topics for you to listen to. We now have a worldwide audience learning about topics of interest to 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 under the age of 45

Newsletters

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

Governance



- Working with the Committees to establish or update their Terms of Reference which clearly outlined the purpose of each committee.
- Reviewing and updating our policies to ensure they comply with current legal requirements.
- Review succession planning at Committee level.
- Conducted assessment of Board member satisfaction and overall effectiveness.

Fund Development

- The Italian Dinner Dance was held in a virtual format with an on-line Silent Auction. Thank you to Sabrina Dussin and Anne De Visio for all their hard work to get the auction items and donations. The event raised \$15,000!
- Lupus Ontario held their first ever golf day at the Lebovic Golf Course in Aurora. 132 golfers came out to play and the event raised \$25,000.
- Lupus Ontario was chosen in 2019 as a charity partner for the Hope Volleyball Tournament. The tournament was held in June 2022 raising \$4,500.
- Virtual Walk for Lupus Ontario raised almost \$90,000. It included many new walk locations. A big thank you to our presenting sponsor, Astra Zeneca, and to all our organizers, sponsors and donors!
- Thank you to Glaxo Smith Kline for their grant in support of the Annual Geoff Carr Lupus Fellowship.
- Thank you to our third-party fundraisers: Tom Koor for his Lupus Research campaign, Joni Waiser and Brenda Cardillo for the Ottawa Door-to-Door, Alissa Kipp for the 90's Dinner Dance and Rona Mississauga for raising funds through their Heroes program.



Research

Geoff Carr Fellowship



- Congratulations to Dr. Tala El Tal, who studied at SickKids Hospital under the supervision of Dr. Levy and Dr Knight.
- Dr. El Tal's research topic was Neuropsychiatric Lupus in paediatric SLE patients.
- Dr. El Tal is now a Paediatric Rheumatologist, Assistant Professor of Paediatrics at Children's Hospital of Eastern Ontario in Ottawa (CHEO).
- We wish her every success as she embarks on her new position.

Lupus Ontario Anne Matheson Biobank



- On April 1st, we gathered at McMaster Health Sciences for the official opening of the Lupus Ontario Anne Matheson Biobank. We were delighted that Anne Matheson, Past President of Lupus Ontario and her family were able to join us.
- The 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.***

Dr. Murray Urowitz Chair in Lupus Research

- In March of 2022 we celebrated the career of Dr. Murray Urowitz. Dr. Urowitz is a pioneer in lupus research and globally recognized for his contribution.
- In honour of his retirement, a Research Chair has been established at the University of Toronto to ensure funding for lupus research well into the future.
- Congratulations to Dr. Zahi Touma for his appointment as Chair.
- ***Lupus Ontario has committed \$50,000 in support of this important research project.***

In 2022, we were very pleased to be able to continue to fund the 6 accredited Ontario Lupus Clinics for a total of \$19,000.

All the clinic funding monies were used to keep research databases up to date.

Clinic Funding

Ottawa

London

Hamilton

Toronto Western

SickKids

Mount Sinai



Financial Report

Net Income	September 30, 2022	September 30, 2021
Revenue Expenses	\$269,435 415,371	\$583,465 283,644
Increase/(Decrease) in Unrestricted Fund Balance	\$(145,936)	\$ 299,821

	<u>2022</u>	<u>2021</u>
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 (includes World Lupus Day)	143,136	113,477
Ottawa Door to Door	7,682	7,048
Rona Heroes	6,938	-
Deferred Contributions Recognized	12,600	-
Fundraising Receipts	345,902	239,417
Bequests	-	157,434
Investment and Other Income	(77,872)	176,424
Grants - Federal	-	10,000
Other Activities	1,405	190
Total Receipts	\$ 269,435	\$ 583,465

		<u>2022</u>	<u>2021</u>		<u>2022</u>	<u>2021</u>
Support and Education Programs	\$	52,455	\$ 26,697	Public Awareness	57,017	30,045
Counselling		13%	9%	Advertising and Promotion at Events	14%	11%
Lupus Community Education				Newsletter, Posters, Pamphlets		
Lupus Educational Kits				Social Media		
Newly Diagnosed				Walk for Lupus Campaign		
Ongoing Support and Training				Website: www.lupusontario.org		
Research Funding and Clinic Support	\$	143,747	\$ 153,250	Fundraising	85,563	39,890
Geoff Carr Fellowship		35%	53%	Direct Fundraising Expenses	20%	14%
Anne Matheson Biobank				Event Planning and Execution		
Hamilton Lupus Clinic				Forms, Event Packages		
London Lupus Clinic						
Mount Sinai Lupus Clinic						
Ottawa Lupus Clinic						
Sick Kids Hospital Lupus Clinic						
Toronto Western Hospital Lupus Clinic						
Volunteer Support	\$	18,954	\$ 9,745	Administration	57,635	24,017
Appreciation Awards and Recognition		5%	4%	Audit	13%	9%
Education and Training				Insurance		
				Facilities Rent		
				Office Expenses		
				Total Disbursements	<u>\$415,371</u>	<u>\$283,644</u>



**LUPUS
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Life Without Lupus



Looking Forward

Looking Forward: 2023 Events



The following Events are currently planned:

Registration for the Walk for Lupus Ontario, our largest fundraiser will open in April.

2023

20 March

April

24 June

The Italian Dinner & Silent Auction fundraiser is back. The event is being held virtually with a Silent Auction, Mystery Bag Sale & a 50/50 raffle March 20 - 30.

The Hope Volleyball Tournament will be held on June 24. We look forward to having a few Lupus Ontario teams participate and raise awareness about lupus.

October 2022 – September 2023 Initiatives



Annual Research Campaign

- Kicked off in October 2022 and raised over \$50,000 in support of our research initiatives.

Advocacy

- Continue establishing partnerships with similar organizations to have a larger group representation.
- Support advocacy initiatives led by other organizations such as the ORA and Lupus Canada that are aligned with our objectives of improving medical care access and new medications for lupus patients.
- Provide a patient voice at the provincial and federal government levels.
- Continue to file with CADTH (Canadian Agency for Drugs and Technologies in Health) to advocate for approval of new biologics such as Saphnelo.

Governance

- Review Bylaws to ensure compliance with updated Ontario legislation for not for profits.
- Continue to review all Lupus Ontario policies.
- Review succession planning at Committee level.

October 2022 – September 2023 Initiatives



Public Awareness and Education

- In-person Lupus Awareness Month Event. Join us **May 13th at Rotary Park in Ajax!**
- Upcoming podcasts and webinars to give you more information about not just lupus but navigating the health system.
- Symposium, October 2022 and October 2023, the place to learn all about new research, treatment options, and diseases related to lupus by medical experts.
- More events with partner organizations and at more locations for you to join where you are.
- Planning continues for a more interactive website, providing more resources and information for our community.
- The Living with Lupus Facts Booklet is now available in French. Digital version is on our website.

October 2022 – September 2023 Initiatives



Support Services

- The Windsor Support Group was launched Nov 2022 and has been well received by members in that region.
- The goal for the Support Group is to return to limited in-person meetings/social events this year.
- In December, the Durham group had an in-person meeting where they went out for Dinner and the Young Adults Group had a coffee meet-up in Toronto at a local café in January. Going forward we are encouraging the groups to schedule at least a coffee meet-up 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 group active is very important to Lupus Ontario.
- Online will continue for all the groups and you can email the support team at support@lupusontario.org
- ***We have incorporated the Dance and Medicine group under the Support portfolio as Emma and Katie are committed to continue to volunteer their time with Lupus Ontario.***

Thank you to our Volunteers



Volunteers

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, Podcast
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, Podcast
Julie St. Georges	Ottawa Support Group Facilitator
Michelle Bruxer	Support, Windsor Facilitator
Camille Goobarry	Support, Co-Facilitator
Kiah Reid	Support, Co-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
Alissa Kipp	90's Dance in Princeton

Volunteers: 2022 Walk for Lupus Team Leaders

Location	Organizers and Team Leaders
Brampton	Sherika Bailey
Chatham	Lori Sheppard
Durham	Laura Piccione, Sandra Williams-Reid, Aaren Gillis, Carole Senetchko
Grey Bruce	Jillian Cooper
Halton	Lisa Bilodeau, Sunita Mandi
Hamilton	Jordyn Rigby, Jennifer Allen, Janet Cole, Ashley Cummins, Lindsey Thompson
Kenora	Sue LeBeau
Mississauga	Rupinder Sandhu, Chris Politis
North Simcoe	Heidi Nielsen
Northumberland	Bonnie Leonard

Volunteers: 2022 Walk for Lupus Team Leaders

Location <i>(Continued)</i>	Team Leaders <i>(Continued)</i>
Oakville	Cirissa Sellars
Ottawa	Brent Leonard, Nate Nielson, Glynis Sharpe, Kirsty Hayward, Jennifer Benson
Richmond Hill	Siraj Mehdi
Sault Ste. Marie	Sara Thompson
St. Catharines	Lillian Smith
Stratford	Cathy Stephens
Sudbury	Paulette Macdonald, Josee Morris
Toronto	June Alikhan
Vaughan	Patti Persaud
Windsor	Ashley Naclerio
Woodstock	Jan Ropp

Board of Directors 2021 - 2022

Thank you to the Board Members who will be leaving or have left the Board this year:

- Cheryl Gajadhar
- Faraz Islam
- Jillian Cooper
- Uzair Jalil

Title	Name	Committee
President	Linda Keill	Fund Development, Executive Committee, Finance, Governance, Advocacy
Vice President	June Alikhan	Advocacy, Executive Committee, Finance, Fund Development, Governance
Treasurer	Siraj Mehdi	Finance, Fund development, Executive Committee
Secretary	Uzair Jalil	Governance, Executive Committee
Director at Large	Brynn Clark	Advocacy, Public Awareness, Executive Committee
Director at Large	Cheryl Gajadhar	Fund Development
Director at Large	Sandra Williams-Reid	Support, Executive Committee
Director at Large	Jillian Cooper	Fund Development
Director at Large	Faraz Islam	Fund Development
Director at Large	Brent Leonard	Public Awareness, Advocacy
Director at Large	Lisa Bilodeau	Public Awareness

Thank You to our Office Staff

THANK YOU to **Karen Furlotte, Anne Brooks,** and **Hajra Batool** for their dedication and commitment.

- **Anne Brooks** joined us in July of 2022 as Fundraising and Marketing Manager. We are delighted to now have a team member in the London area
- **Martina Whittick** left Lupus Ontario in May 2022. We thank her for all her work over the past year.
- **Daniel Jiang** *was our* high school Co-op student, who created excellent content for our social media networks. It was a pleasure working with him.
- **Laviza Syed** worked with us over the summer of 2022 on our Social Media team. We thank her for her excellent work and wish her all the best for her year at school.

The Board for 2022-2023



Meet Your New Board Member: Dr. Al Abaie



- Al Abaie is a Doctor of Medicine and lives in Toronto. After graduating medical school, he practiced medicine part-time for a non-profit organization. He has been in the health care industry (mainly pharmaceuticals) starting in sales with giant multinationals and progressing quickly to management positions and eventually to CEO and Board Membership in private companies over the last 16 years. He is Director of Strategic Partnerships at Continuous Medical Education, a Canadian company that provides education to health care practitioners.
- Al first became involved with Lupus patients 30 years ago when he was a medical student at a rheumatology ward in a university hospital. The complexity and extensive impact of rheumatological diseases such as Lupus, persuaded him to take a proactive role in providing patients with better education, easier access to healthcare and better management of their disease to help them live happier lives.
- He will serve on the Advocacy, Fundraising, and Governance Committees. He believes that building bridges between big corporations and government with Lupus Ontario can result in improving service to the Ontario lupus community.

Meet Your New Board Member: Oula Almadoun



- Oula Almadoun obtained her BA in Business Studies with Systems Practice from The Open University in England, and later completed her Master's in Distance Education with a specialization in Instructional Design from Athabasca University.
- Oula's expertise stems from managing, developing educational programs and writing grants proposals for numerous institutions and non-profit organizations. In 2022, Oula joined a private college in Toronto as a Grants Manager and is responsible for scholarship awards for international, citizens, and indigenous students to help support their tuition fees to complete their desired field of study along with assisting them with their work placement to gain the real-world Canadian experience.
- She is looking forward to bringing her experience in diversity, education, and grants, promoting Lupus Ontario's mission through advocacy and awareness about the disease within the community in Ontario for improved access to information, health services, and research.

Meet Your New Board Member: Maneka Kaur



- Maneka Kaur is an internationally trained lawyer who has been advocating for a safer and healthier environment for almost a decade. She has worked closely with not-for-profit organisations and governmental departments to promote access to justice.
- In Canada, Maneka continues to pursue her passion for environmental law and has articulated with specialised environmental legal clinic.
- She believes that although environmental issues, and their impacts in our present world, need to be viewed holistically; one must, however, keep in mind that there is no one-stop solution. It is important to continue to learn about the problems and engineer solutions suitable to the changing times. It was this thought process that intrigued her about the possible co-relation between environmental contaminants and Lupus. She hopes to provide her assistance and support in understanding this co-relation.
- In addition, she is excited to bring all the knowledge acquired by her as an advocate, litigator and researcher and apply it with the same passion to the cause of Lupus Ontario.

Meet Your New Board Member: Dhwani Babla



- Dhwani Babla is a global health consultant who has lived and worked in health systems around the world.
- Over the course of her career, she has developed a deep interest in chronic diseases and a desire to learn more about innovative approaches to achieve health equity.
- Dhwani received her Master of Public Health from Columbia University and BSc from Simon Fraser University in Canada.
- She also currently sits on the Canadian Women in Global Health Steering Committee Board and is looking forward to bringing her experience to the Lupus Ontario committees.
- Outside of work, you will find Dhwani working out, volunteering, spending time with family, taking courses, or planning her next adventure.

Meet Your New Board Member: Kyle Morrow



- Kyle Morrow holds a Bachelor of Arts (Political Science) from St. Francis Xavier University and a Juris Doctor (Common Law) from the University of Ottawa.
- He is currently a lawyer at Fasken Martineau DuMoulin LLP, where he practices public law.
- Kyle also currently teaches in the Clayton H. Riddell Graduate Program in Political Management at Carleton University.
- In his spare time, Kyle enjoys reading, writing, swimming, curling, scuba diving, hiking, and travelling.

Board of Directors Slate

Nominee	Position
One Year Remaining in their Term	
Brynn Clark	Director at Large
Lisa Bilodeau	Director at Large
Sandra Williams-Reid	Director at Large
Elected for a Two-Year Term	
June Alikhan	President
Linda Keill	Secretary
Siraj Mehdi	Treasurer
Al Abaie	Director at Large
Oula Almadoun	Director at Large
Dhwani Babla	Director at Large
Maneka Kaur	Director at Large
Brent Leonard	Director at Large
Kyle Morrow	Director at Large

Donna Chu Award

- The Donna Chu award, established in 1985 in memory of the late Donna Chu, is presented annually, in recognition of outstanding achievement, contribution, dedication or special service to Lupus Ontario.
- **The 2022 winners are Joni Waiser and Brenda Cardillo**

Donna Chu Award

- Approximately twenty years ago, the Ottawa Branch introduced a fundraiser, The Ottawa Door-to-Door Campaign, which over time has raised 10's of thousands of dollars for the Ottawa Lupus Clinic.
- Joni and Brenda are the current organizers of this fundraiser.
- Both Joni and Brenda cite the late Anne Wyse, who founded the Ottawa Branch of Lupus Ontario as their inspiration. They are now the inspiration for new members of Lupus Ontario in the Ottawa area.

Donna Chu Award

- **Brenda Cardillo** has been involved with the Ottawa Branch of Lupus Ontario since its inception.
- Notwithstanding the challenges of living with lupus and other serious health problems, volunteering with several organizations and enjoying an active social life, Brenda has raised significant funds by canvassing for the annual Door-to-Door Campaign. A key motivating factor for her is that the funds raised go directly to the Ottawa Lupus Clinic.



Donna Chu Award

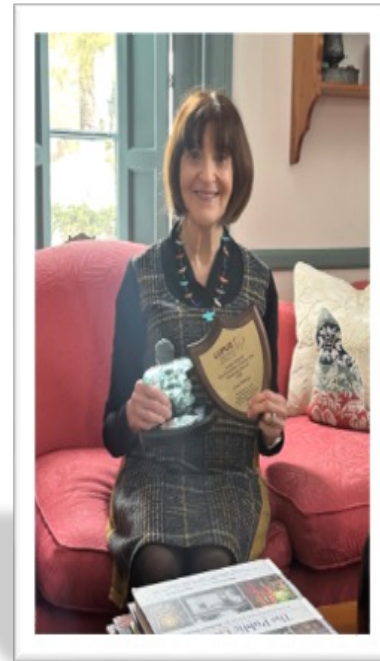
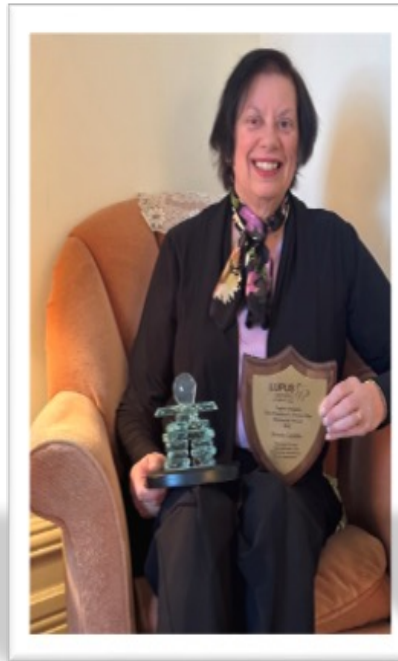
- **Joni Waiser** has been a dedicated and successful fundraiser with Lupus Ontario for many years. Having been involved in the Ottawa Branch of Lupus Ontario since the 1990's, she has also served on the Ottawa Branch Steering Committee.
- Joni and her husband, Dr. David Waiser, are always eager participants in Lupus Ontario's Walk for Lupus.



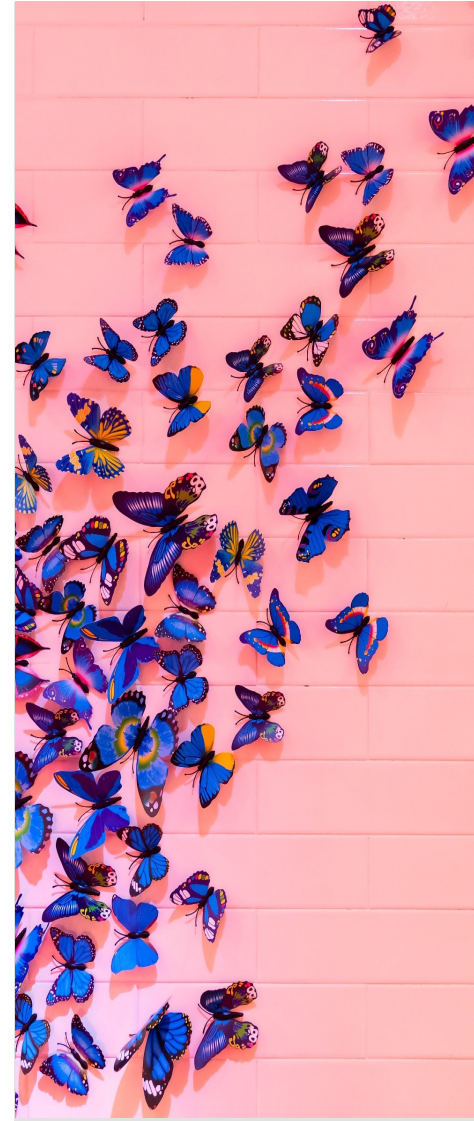
Donna Chu Award

*Thank you, Joni and Brenda, for all your
dedication to raising funds for
the Ottawa Hospital Lupus Clinic.*

You are an inspiration to us all!



My Lupus Journey: A Message of Hope



Diane Forbes



- Diane Forbes is owner of Motivation Through Inspiration, based in Brantford, Ontario.
- She is a motivational workshop facilitator focused on providing support, encouragement, motivation, and inspiration, helping clients discover their pathway to self-empowerment. Diane specializes in self-esteem building, goal setting, life-skills and healing through art.
- Self-employed for 15 years after being on disability with Lupus challenges and in remission now for 18 years, she considers herself “living well with Lupus” maintaining healthy living. It’s what inspires her passion for sharing positive energy and helping people to excel on their own journey to dream it, believe it and achieve their goals.

**Thank you to,
Linda Keill!**



Questions & Comments for the Board



Thank you for attending!

