CELEBRATING LUPUS ONTARIO'S FIRST 40 YEARS

In 2018, Lupus Ontario celebrates its 40th anniversary. This remarkable milestone is a testament to the dedication and generosity of the organization's many volunteers and supporters. It's also an opportunity to reflect on how things have changed, what the lupus community has achieved, and what we need now.

Lupus Ontario was created the same way it's run today—by people who know intimately the challenges of living with the incurable autoimmune disease known as systemic lupus erythematosus, and who are passionate about improving lupus support, education and awareness.

The year was 1978. Pierre Trudeau was prime minister of Canada. In Ontario, minimum wage was $2.85 per hour. The year's top-grossing movie? *Grease*. And, at a hospital ward in downtown Toronto, two patients decided to start a lupus support organization.

Honey Agar and Linda Ethier were roommates in 6 North, Wellesley Hospital's unit for patients with lupus. The two women often discussed the lack of support and information available for patients, their families and medical professionals. "We were both confined to bed, and we spent a lot of time talking," says Agar. "We were really angry that doctors didn't understand what we had and didn't know how to treat it. We were angry about the drugs, the isolation. We said, 'If we ever get out of here, we'll teach the doctors how to do this.'"

Agar was diagnosed with lupus in 1970, at age 28, after years of distressing symptoms that started when she was pregnant with her daughter, Michelle, seven years earlier. She continually sought medical help for fevers, chills, intestinal problems, fatigue and other symptoms, but doctors dismissed her concerns. Some even accused her of faking or imagining her illness.

By the time Agar was diagnosed with lupus, the disease had attacked her heart, lungs, gastrointestinal system, joints, eyes and brain. She was given a 50-percent chance of surviving the next three years. Facing these frightening odds, and suffering debilitating side effects from the drugs that were meant to save her life, Agar became determined to help herself and others with the disease.

Autoimmune disease exacted another terrible toll on Agar. Her mother died of scleroderma in 1972, and one of Agar's close friends died of lupus in 1975. By then, Agar herself had spent 13 years moving in and out of hospitals.

By 1978, she had turned her focus to finding educational materials about lupus and establishing a support and information group for fellow patients of her rheumatologist, Dr. Murray Urowitz at Toronto Western Hospital. She and Ethier, following through on the promise they'd made on 6 North, organized a meeting for April 8. They and other volunteers spread the word with phone calls, flyers, newspaper ads and radio announcements. They anticipated that 50 people might attend. More than 400 showed up.

"It was a dream," says Agar. The overwhelming demand for information became a catalyst for the founding of the Ontario Lupus Association (OLA), with Agar as president and Dr. Urowitz as medical advisor—a role he fulfills to this day. The group operated under the Arthritis Society, which Agar had approached for guidance. Over the next five years, the OLA established 12 branches across the province, providing a much-needed resource for people with lupus and their families.

"Our goal, from the beginning, was to create awareness and to educate. At that time, there was no information on lupus. Even the doctors knew very, very little about it," says Agar, who is now 76. "Lupus was very difficult to diagnose—people were usually diagnosed upon dying."

The health-care system was also deeply patriarchal, and young women—the population most affected by lupus—were frequently dismissed, disbelieved or misdiagnosed. "Remember, in the '60s and '70s, we weren't listened to very much. Doctors said, 'Now, now, don't worry, just do what I tell you,'" says Agar. "They put a lot of us on Valium. A side effect of that is paranoia, so then they said we were crazy. We were young women, so doctors would say, 'What's wrong, did you have a fight with your husband or boyfriend?' Lupus can be triggered after giving birth, so they said, 'Are you having postpartum depression?' And when you showed up at emergency half-dead, they said, 'Why didn't you come before?'"

With the Arthritis Society as its home base, the OLA launched self-help groups and raised funds to support lupus research. Families in the lupus community stepped up to offer their support: the Chu family held an annual Chinese Dinner fundraiser from 1982 to 2002; the Colagiovanni family started their annual Italian Dinner fundraiser in 1984; and the Risi and Tolfo families started their annual Dance for the Cure in 1992.

The OLA held its first conference in 1983, the same year that Agar's sister, Frances Gotkin, became the organization's second president. Agar continued to lend her support to others with lupus, despite serious ongoing health problems of her own. In 1985, she shared her lupus story in a CBC documentary called I'll Get There Somehow'. the public awareness it generated led to the creation of more OLA branches and support groups.

In 1985, the OLA was also fortunate to partner with ACT (Associated Canadian Travellers), a fraternal benefit society that became the organization's first sponsor (it funded a two-day seminar on lupus epidemiology). Geoff Carr, then president of ACT, was instrumental in the partnership, and he also founded the OLA's North Bay branch.

In 1985, October became Lupus Awareness Month. Each year in October, several city halls around the province raise a flag in its honour.

There were developments in the wider lupus community, as well. In 1986, members of the OLA and other Canadian lupus organizations began discussions to form Lupus Canada. In January 1987, OLA President Frances Gotkin hosted a meeting in Toronto for lupus groups and members across Canada. This meeting resulted in the formation of Lupus Canada, whose first AGM was held later that year.

In 1987, Honey Agar, with the help of volunteers from OLA and others, raised over $1 million to help Dr. Urowitz and Dr. Dafna Gladman launch the Lupus Databank Research Program, the first of its kind in the world, at Toronto Western. Canadian talk-show host Dini Petty became a spokesperson for both the OLA and the project. To date, the Databank has provided data for hundreds of research projects aimed at better management of lupus. “As the database has grown, what we can learn from it has grown immensely,” says Dr. Urowitz. “We’re discovering things that change the way we treat lupus.”

Also in 1987, with fundraising support from the Association OF Commercial Travellers (ACT), the OLA began to fund four lupus clinics at Ontario hospitals (today, Lupus Ontario continues to fund five clinics). Stewart Stainton of the Lindsay Branch was elected the third president of the OLA, and he was instrumental in developing a group for youth with lupus. Founded by Andrea Ou-Hingwan, it was originally called TOLL (Teens in Ontario Living with Lupus); it was renamed TLC (Taking Life as a Challenge) in 1994.

In 1990, Geoff Carr, a member of ACT, passed away. The OLA Fellowship, launched earlier that year to provide bursaries to medical professionals to study lupus for a year at an Ontario lupus clinic, was renamed the Geoff Carr Lupus Fellowship in his honour. To date, the fellowship has funded research and education for over 27 medical fellows, including physicians from Canada and around the world.

In 1998, following two decades of support from the Arthritis Society, the OLA became an independent organization with its own charitable number, office and full-time office coordinator. “The Arthritis Society gave us room and board, basically,” Agar says gratefully. “We would not be here without them.”

The new millennium has seen the launch of the OLA’s Walk A Block fundraiser, the organization’s amalgamation with the Lupus Society of Hamilton (also founded in 1978), improved governance, and a new mission statement and vision. In 1987, the Donna Chu Memorial Award was established to recognize outstanding achievement and contributions, dedication or special service to the lupus community. In 2007, the Lupus Ontario Hope Award was established to recognize leadership and dedication to the lupus community.

Currently, Lupus Ontario continues to fund Ontario lupus clinics and the annual Geoff Carr Lupus Fellowship. We raise money via the annual Walk for Lupus Ontario in approximately 20 communities across the province. We leverage digital tools such as our new website, social media and online support group meetings to reach more patients and donors.

Honey Agar looks back on Lupus Ontario’s first four decades with pride. “We’ve come a long way in 40 years. We have made a difference,” she says. “Lupus is much better known. There is help available, on all different levels. Quality of life for lupus patients has improved tremendously. We've come a million miles. I think our biggest goal now is research to find better treatments with less side effects."

Linda Keill has been Lupus Ontario's president since 2014. Speaking about the organization's 40th anniversary, she says, "I think we have a history we can be very proud of. What Honey Agar managed to do is absolutely remarkable. Looking to the future, I think our challenge is to keep flourishing in a really competitive marketplace. It's tough for charities to raise the money they need, and we need to focus on raising awareness and getting funding for research."

Dr. Urowitz also believes that research funding is now the greatest priority, especially as Canada's traditional funding agencies tighten their budgets. "There's a major shortfall. Only one out of 10 grants receive funding," he says. "We should celebrate Lupus Ontario's past—a lot of wonderful things have happened. We should also anticipate a successful future. The next phase is to really promote research by raising funds and raising awareness at government levels, which might result in more expenditures in lupus research. The next big steps are going to require that support."

Written by Jaclyn Law

The History of Lupus Ontario

1978 Ontario Lupus Association formed by group of patients seeing a need for support and education for those living with this little known disease

- First meeting was held at Wellesley Hospital. Honey Agar, one of the founding members was first president.
- Hamilton Lupus Society and Lupus Foundation all formed that year.
- OLA Operated under auspices of Arthritis Society as their first Specific Disease Group, established 12 branches in the next 5 years
- The first branch of the OLA began in Sudbury with branches soon to follow in Windsor, London, Kitchener, Ottawa, Lindsay, Soult Ste. Marie, Thunder Bay, Timmins, North Bay, Kingston and Peterborough.

1982 Inaugural Chinese Dinner fundraiser hosted by the Chu family in Toronto. The Donna Chu Chinese dinner was later to be named in memory of their daughter. (Continued until SARS in 2002)

1983 First Lupus Conference held in Toronto. Frances Gotkin, Honey Agar's sister, became second OLA President

1984 First Italian Dinner fundraiser hosted by Colagiovanni family

1985

- CBC documentary "I'll Get There Somehow" directed by John Zaretsky was produced. One of four segments was on Lupus and featured Honey Agar and her family. Great public awareness produced more branches and support groups
- First in the world, Lupus Databank Research Program was inspired by Honey Agar, Dr. Murray Urowitz and Dr. Daphna Gladman
  Over one million dollars was raised in numerous events. Dini Petty, a Canadian talk show host became the spokesperson for both the OLA and the Databank
- ACT (Associated Canadian Travelers) became first OLA sponsor. Geoff Carr, President, was instrumental in the partnership and also founded the North Bay Branch of the OLA. October became Lupus Awareness Month and a 2-day seminar on Lupus Epidemiology was funded by ACT

1986 Members of Canadian Lupus Organizations met at a conference in Cleveland Ohio and began discussions to form Lupus Canada. First AGM in 1987

1987 OLA and ACT partnered to fundraise. The first project raised $23,000.
OLA began funding in four lupus clinics in Ontario

1988 Stewart Stainton of the Lindsay Branch was elected third President of OLA and was instrumental in developing a junior group. Founded by Andrea-Ou Hingwan it was originally called TOLL (Teens in Ontario Living with Lupus) but was changed to TLC in 1994 (Taking Life as a Challenge).

1990 President of ACT, Geoff Carr, passed away and the OLA Fellowship was named the Geoff Carr Lupus Fellowship in his honour. The Geoff Carr Fellowship continues today with annual applicants from around the global.

1992 Risi and Tolfo families host first Halloween Dance. Renamed “Dance for a Cure” became Lupus Ontario’s largest single fundraiser. Held at the end of January each year it has raised over $750,000. to date

1993 Shelagh Purcell became 4th President OLA. The second Lupus conference was held in Toronto

1996 OLA applied for own Charitable Number
The Centre for Prognosis Studies in Rheumatic Disease opened at Toronto Western Hospital under the direction of Dr. Murray Urowitz and Dafna Gladman.

1998 Julia Kane became 5th President, OLA, facilitated Charitable # and incorporation. Office was relocated to Markham. Full time office coordinator hired

2000 Karen Guest becomes sixth president. Julia Kane was hired as the first Executive Director.

2002 First Walk a Block was help

2003 OLA and Lupus Society of Hamilton complete negotiations to amalgamate, Lupus Foundation chooses not to be part, but would continue to collaborate.

2004 Amalgamated groups hold first formal AGM in London. Named officially changed to Lupus Ontario, Kevin Stannard becomes 7th President

2006 Lupus Ontario declines division status with Lupus Canada

2007

- Julia Kane gets recycled as President of Board, LO
- Lupus Canada reverts board composition to MO representation.
- First Lupus Ontario HOPE award was given to Tiziana and Lois Tolfo and Tony and Connie Risi for “outstanding leadership in improving the lives of people with lupus”
- Lupus Ontario backs Walk a Block by hiring coordinator Juanita Butler
- Outstanding success in October Walks raise $256,000 shared with Lupus Canada

2008

- Walk-a-Block was moved to May 10th in conjunction with World Lupus Day… “Walk the World for Lupus”
  Raised $188,000, shared revenue with Lupus Canada, in Ontario
- Lupus Ontario Hope Award presented to Dr Earl Silverman, Hospital for Sick Kids at “Dance for the Cure”
- Anne Matheson receives Donna Chu award
- Lupus Ontario awarded over $250,000 in education fellowships, research and clinic support

2009

- Improved Governance through Strategic Planning process with Wayne Hussey Consultants
- New Mission Statement and Vision

- Attempted to put in consistent leadership through hiring process for new position of Executive Director. Our First candidate hired did not meet expectations, and the second resigned following health issues at the end of 2009. Our reduction in income of 14% led us to defer filling this position until future finances allow.
- $213,000 awarded in strategic partnership and research funding
- Walk a Block revenues down partially due to inclement weather $178,236 shared revenue
- Dr. Murray Urowitz honored as the Lupus Ontario Hope Award recipient

2010

- Colagiovanni Family receives Donna Chu Award
- Dr. Zahi Touma receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Dr. Paul Fortin honored as Lupus Ontario Hope Award recipient

2011

- Kathryn Stewart receives Donna Chu Award
- Dr. Amanda Steiman receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Dr. Janet Pope honored as Lupus Ontario Hope Award recipient

2012

- Anne Matheson elected President
- Tiziana Tolfo receives Donna Chu Award
- Dr. Barry Sheane receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Honey Agar honoured as Lupus Ontario Hope Award Recipient

2013

- Michael Stewart elected as President effective June 2013
- Lupus Symposium organized by Anne Matheson held at Liuna Station in Hamilton
- Paula Courtney receives Donna Chu Award
- Dr. Kim Legault receives Geoff Carr Fellowship to study at McMaster Health Sciences

2014

- Linda Keill, Vice President, takes President role in August
- Dr. Konstantinos Tselios receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Vince Blosser receives Donna Chu Award

2015

- Linda Keill elected as President

- Lupus Ontario takes over running Walk for Lupus from Lupus Canada
- Strategy for Board recruitment changed to more competency focus
- Board Committees established to set direction and support office staff
    - Finance and Audit
    - Business Process and IT
    - Fund Development
- Dr. Jorge Medina Rosas receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Elspeth Koor receives Donna Chu Award
- Lupus Ontario renews commitment to Ontario Volunteer Service Awards to recognize service of our volunteers

2016

- Head Office moves to 25 Valleywood Drive
- Dr. Julie Couture awarded Geoff Carr Fellowship to study at SickKids
- Gloria Checkley receives Donna Chu Award
- Anastasia Koutsidis receives special award for her on-going support and commitment to Lupus Ontario

2017

- Lupus Ontario changes logo and official colour to purple to align with Lupus Canada
- Linda Keill re-elected as President
- Dr. Konstantinos Tselios receives Geoff Carr Fellowship to study at Toronto Western Hospital
- Strategy approved to move to more digital communications
- Full slate of Board Committees established
    - Finance and Audit
    - Business process and IT
    - Support and Education
    - Public Awareness and Communication
    - Strategic Planning
    - Volunteer Management
    - Fund Development
    - Governance