



Association québécoise du lymphœdème
Lymphedema Association of Québec

**Activity Report
for the year ended March 31, 2024
(period from April 1, 2023 to March 31, 2024)**

Prepared for members of
Association québécoise du lymphœdème/Lymphedema Association of Québec

and

in conformity with the

Programme de soutien aux organismes communautaires
Ministère de la Santé et des Services sociaux (Québec)

Association québécoise du lymphœdème/Lymphedema Association of Québec
C.P. 152, Succursale Bureau-Chef Saint-Hyacinthe (QC) J2S 7B4
514 979-2463 1 866 979-2463 aql@infolymphe.ca www.infolymphe.ca

Registered charity, No. 81663 0644 RR0001
Company incorporated under the Loi sur les compagnies (Québec)
NEQ: 1166291923

Table of contents

Word from the Interim General Director of the LAQ	3
1. Demonstration of conformity between the activities carried out by the organization and the objects of its charter and the fact that the organization works in the field of health and social services	4
Community Services.....	7
Support in the professional environment	12
Community Awareness.....	14
Refocusing and restructuring operations.....	15
Defense of patient interests and development of a response aligned with patient needs.....	16
Exploration of solutions ensuring the sustainability of the LAQ.....	21
2. Demonstration of the community’s contribution to the achievement of the Association’s activities during the period from April 1, 2023 to March 2024.....	23
3. Demonstration of the dynamism and commitment of the Association in the community and consultation with local resources	26
4. Demonstration of the response provided to the needs of the environment	29
5. Demonstration of the democratic functioning of the LAQ.....	33

Note to readers:

The content of the LAQ Activities Report 2023-2024 was translated with the help of Google Translate.



Word from the Interim General Director of the LAQ

Dear Members and Partners of the Lymphedema Association of Québec,

In office since the summer of 2023, it is with great pleasure that I write this very first word as interim general director of the LAQ. The past year was marked by significant changes and challenges that we met with determination.

We experienced a period of turbulence, but thanks to an energetic new team, a motivated board and loyal, dedicated volunteers, we relaunched our activities and services, restructured our operations, cleaned up our finances and delivered the goods! It is with agility and the joy of contributing that we continue our actions, with the ambition to always better serve the lymphedema community.

When reading the LAQ activity report, you will see the many efforts made to continue to offer essential support to people with lymphedema. Our mission of awareness, information and support remains at the heart of our priorities, and we do everything we can to achieve it with efficiency and humanity.

The year 2025 will launch the 25th anniversary festivities of the LAQ, an exceptional opportunity to celebrate our evolution and our achievements. The year will be punctuated with highlights and a major event to put lymphedema at the forefront and to express our gratitude to all those who have contributed to our success: our members, our volunteers, our donors, our partners and our allies. You will soon receive more information on this major event planned for next March.

I would like to warmly thank all the volunteers for their invaluable commitment and especially our administrators. The proper functioning of the LAQ relies on the unwavering support of our members and the community spirit and goodwill that unite us. Since my arrival, I have been deeply impressed by the resilience of the people we support and the scale of the challenges we help them to overcome.

With the skills of our team and the will of our members and volunteers, we will continue to carry out our mission. Thank you also to our funders and sponsor partners who believe in our cause and give us the means to achieve our goals.

Together, let's continue our commitment to improve the quality of life of people with lymphedema. Because together, it's less heavy.

A handwritten signature in blue ink, appearing to read 'Ginette Bardou'. The signature is fluid and cursive.

Ginette Bardou
Interim General Director
Lymphedema Association of Québec

1. Demonstration of conformity between the activities carried out by the organization and the objects of its charter and the fact that the organization works in the field of health and social services

For purely charitable purposes and without the intention of financial gain for its members:

- Provide support to people with and at risk of lymphedema
- Defend and promote the interests of people affected by and at risk of lymphedema
- Inform and raise awareness among people affected by and at risk of lymphedema, their families and health professionals about lymphedema, its causes, as well as treatments and prevention of this chronic disease and establish an information centre in this regard
- Work in collaboration with the MSSS and its various authorities (RAMQ, PQC) or affiliated organizations (INESSS)
- Encourage scientific research aimed at curative treatment of lymphedema



Receive donations, legacies and other contributions of the same nature in money, securities or real estate, administer such donations, legacies and contributions; organize subscription campaigns with the aim of raising funds for charitable purposes.

Description of activities carried out during the year ended March 31, 2024 (period from April 1, 2023 to March 31, 2024)

INTRODUCTION

Raising awareness of lymphedema and improving access to its treatment drives the mission of the Lymphedema Association of Québec (LAQ). The past year has evolved according to the refocusing, renewal and gathering of the LAQ's strong forces. The relaunch of all services and communications, the return of the printed version of the LAQ Directory, the putting online and promotion of the new website, a shift ensuring a balanced budget, the increased solicitation of donations, strengthening ties with industry partners, and increased outreach on social media have invigorated the entire lymphedema ecosystem. But it is first and foremost, the intensification of the LAQ's presence among its target audiences which has enabled people at risk or suffering from lymphedema to obtain information, education and support.

The last year brilliantly illustrates the achievement of our objectives, despite the challenges posed by the extended sick leave of the General Director, the establishment of agile interim management without competitive salary, the move of the head office, the reorganization of responsibilities and restructuring of operations. Funding from PSOC to build a core team with updated salaries is still awaited. After 12 months of sustained efforts, the LAQ is acting more effectively so that the populations served obtain more concrete help than ever.

The relaunch of monthly education and support groups, as well as online presentations to professionals treating lymphedema, have revived the entire community and made it possible to reach more patients and more stakeholders, improving both the daily lives of patients and the care they receive.

Another important activity in 2023-2024 was the strategy to reach a larger share of target audiences through constant and rigorous written communications, as well as the reevaluation of existing content and the use of social media, which had a major impact. The LAQ broadcast original, relevant and necessary content. Optimizing the distribution of printed LAQ information in CLSCs, GMFs and hospitals has made it possible to support the entire health network in the diagnosis and treatment of lymphedema.



In response to the crisis triggered in February 2024 by the announcement of the permanent closure of the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center), a unique and vital evaluation centre for complex cases from across Québec and an essential scientific partner for the LAQ, we mobilized the entire community to protest and obtain a re-evaluation of this purely administrative decision.

We express our gratitude to all our partners: our public funders, our private donors, our volunteers, our exceptionally dedicated team, and the health NPO community. Thanks to the synergy of these actors, the LAQ was able, for a 25th consecutive year, to reach people suffering from lymphedema and facilitate access to information, care and support essential to living well with this disease. Their support and our resilience have strengthened the organization and generated an unprecedented impact in the community.

As of March 31, 2024, we present this report with pride and satisfaction. The LAQ is more determined than ever to ensure the sustainability of the only organization dedicated to people with lymphedema.

Throughout the last fiscal year, the board of directors, supported by interim management, allowed the LAQ to pursue its mission by increasing its provincial reach, consolidating relationships with its partners, improving the effectiveness of its operations, by regaining budget balance and by implementing ways to meet the needs of all clients affected by or at risk of lymphedema.

Here we report on the LAQ's activities related to this year's **six components**:

- **Community services**
- **Support in the professional environment**
- **Community awareness**
- **Refocusing and restructuring of operations**
- **Defence of patients' interests and development of a response aligned with patients' needs**
- **Exploration of solutions ensuring the sustainability of the LAQ**



Community Services

People with lymphedema have dire needs because they have few access points and resources in the health network to receive the education required to control the disease. Additionally, these people need support to navigate a healthcare system where some types of lymphedema are not covered and most of their care is provided in the private sector.



a) Our virtual education and support groups

- The LAQ's virtual education and support groups make it possible to reach people living in large centres as well as those living in remote regions.
- Virtual meetings meet the needs of participants.
- Patients, their loved ones, therapists and health professionals from the hospital network are invited.
- Meeting topics include: the basics of lymphedema, decongestive exercises, self-massage, lymphedema self-management routine, prevention and management of cellulite, weight control, adapted exercise, etc.
- A therapist specializing in the treatment of lymphedema as well as a person suffering from lymphedema lead the meetings.
- From April 1, 2023 to March 31, 2024, seven (7) education and support meetings were facilitated. The meetings took place over seven consecutive months spanning from September 2023 to March 2024.
- Recorded meetings are available to participants for viewing on demand



In total, more than 613 participants were welcomed during the last fiscal year. Seven volunteers, therapists and patients, led the meetings. Total volunteer hours: 70 h.

b) Therapeutic Support Program: help over the phone

A volunteer directs questions left by patients on our voicemail to one of our certified volunteer therapists. This professional respond and/or directs the patient to appropriate care. The therapist contacts our beneficiary within 24 to 48 hours. The beneficiaries are people affected by or at risk of lymphedema, their families, or health professionals. The volunteer therapist contacts the beneficiary and provides them with the requested information, either on symptoms, risk reduction, treatments, or references to lymphedema treatments. The therapist offers to send the beneficiary the LAQ educational leaflets on risk reduction and treatments, as well as our Lymphedema Guide containing all the services offered in Québec to people affected by or at risk of lymphedema. During the exchange with the therapist, patients are invited to consult our website and participate in our education and support meetings.



The telephone service is democratized thanks to a toll-free telephone number (1 866 979-2463) which is added to the metropolitan line (514 979-2463). Thus, the LAQ has provincial access allowing all residents of Québec to benefit from advice. In addition, this service is coupled with the transcription of messages left on the voicemail, facilitating the transfer of information delivered by the beneficiary to the therapist and ensuring the conformity of the information relayed. Finally, the interview form allows you to document the profile of the callers, the most common questions and the proposed interventions.



From April 1, 2023 to March 31, 2024, a team of 16 certified lymphedema treatment therapists managed 54 initial calls.

c) Therapeutic support program: email support

A volunteer responds to emails requesting support sent by beneficiaries. If necessary, she transfers the emails to our team of volunteer therapists who then proceed as for the telephone service.

From April 2023 to the end of March 2024, the LAQ responded to more than 110 written requests for support (including requests made by email and on Facebook).

A special thank you is addressed to Marie-Thérèse Le Noir, patient volunteer who provided us with more than 300 hours of volunteer support for, among other things, the coordination of the Therapeutic Support Program.

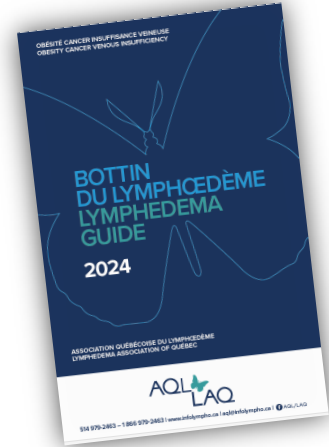


d) Our publications

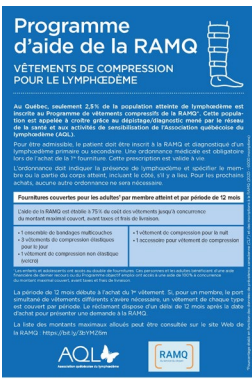
In order to reach customers (patients and professionals) from all administrative regions of Québec, the LAQ relies on a series of educational documents. During the last period, we continued the distribution of our information material.

The LAQ library is made up of the following documents:

The **2024 Lymphedema Guide** (the last printed edition of the Resource Directory took place in 2022, renamed Lymphedema Guide for greater clarity), a free and bilingual resource, offers a provincial compilation of certified therapists, adjustment centres, manufacturers, sources of help, hospital centres with clinic treating lymphedema serving Québec. The 2024 edition includes tools such as *Steps to Take in Case of Suspected Swelling*, a sample *comprehensive prescription for lymphedema*, and *Therapist Code of Conduct*. Published in 6,000 copies on January 1, 2024, the Lymphedema Guide 2024 was mailed on January 18 to 96 clinics and hospital centres and also to the networks of our 30 corporate members (in batches of 25 copies for distribution to patients). We also mailed a copy of the Guide to each of our regular members.



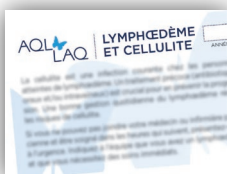
Our **basic leaflets** and our **Booklet on reducing the risks of lymphedema** and methods for living better with lymphedema are still distributed to patients and our partners. The leaflets are given free to everyone. The booklet is given free of charge to LAQ members.



The **sheet on the RAMQ Clothing Program** to promote the program and respond to requests for information from patients and fitters.

The **LAQ sheet** to raise awareness of our mission and services to new patients and front-line healthcare professionals.

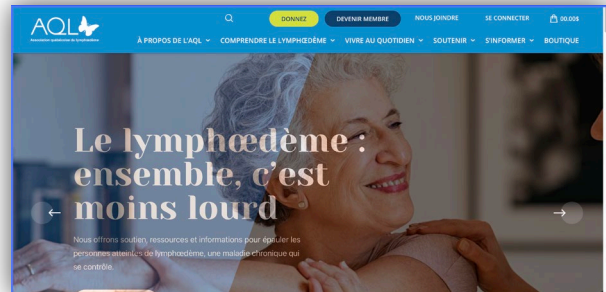
Our **tools for self-measurement** of the lower and upper limbs help the patient measure the progress of their self-measurement.



The **Cellulite card** brings together the symptoms of this infection and key messages for caregivers.

g) Website, Facebook Page, Instagram Page

Online since August 2023, the completely redesigned LAQ website aims to be an encyclopedia bringing together knowledge, tools and testimonials on lymphedema. Advice and scientific articles on lymphedema written by specialists are available on the LAQ website. The new tree structure of more than 70 pages makes it possible to optimize patient self-learning. All our tools are also available there for the general public or by subscription. The LAQ website is the only online lymphedema resource in the world, serving the needs of both French and English-speaking audiences. A site promotion tool was distributed throughout the community to support its launch.



More than 6,800 visitors viewed the LAQ website from April 2023 to the end of March 2024.

The LAQ Facebook page has 1,917 subscribers, an increase of 13%. The total reach is 20,330 people. The page reaches up to 2,066 people per post, an increase of 175%. The LAQ internal team ensured 147 Facebook publications, an increase of 81%, which were published from April 1, 2023 to March 31, 2024.

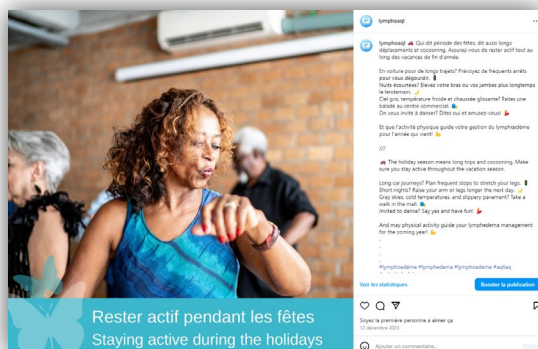
The LAQ Facebook page is used to offer original content on a regular basis. Attractive visual content and reliable informative content are posted regularly. Likewise, provincial, national and global news surrounding lymphedema is broadcast on our Facebook page. The news, research, articles, videos and illustrations shared constitute a first selection of information offered by the LAQ. The Web being a very accessible source of information for patients, the LAQ selection helps Internet users find relevant information. Our partners' initiatives are shared there (studies, tools, recruitment). The LAQ Facebook page also helps stimulate participation in our activities and regularly join the community of therapists.

Facebook Subscribers	1,917 (+13 %)
Publications	147 (+81 %)
Total Scope	20,330
Most viewed post	2,066 persons (+175 %)
Visits	7,500



The LAQ Instagram page has 192 subscribers (+25%). The page reaches up to 1,100 people per publication. 147 publications were posted from April 1, 2023 to March 31, 2024.

Instagram Subscribers	192 (+25 %)
Publications	147 (+81 %)
Total Scope	1,100
Visits	159



Support in the professional environment

Over the last period, we have reached more patients and professionals by continuing to focus on the following elements.

- ProLymph, a peer-to-peer exchange platform for healthcare professionals. ProLymph has two goals: to support lymphedema experts and to reach healthcare professionals new to lymphedema. All in order to improve the screening, diagnosis and treatment of lymphedema. The platform includes a discussion forum, a resource library, an events calendar, and telephone access for peer consultation. This helps create a solid and dynamic network of “learning professionals”. Number of registered professionals: 150 (+56%). **Number of telephone requests for peer-to-peer consultation: 36 health professionals. Number of files recommended to the MUHC Lymphedema Clinic: 4 patient files.**

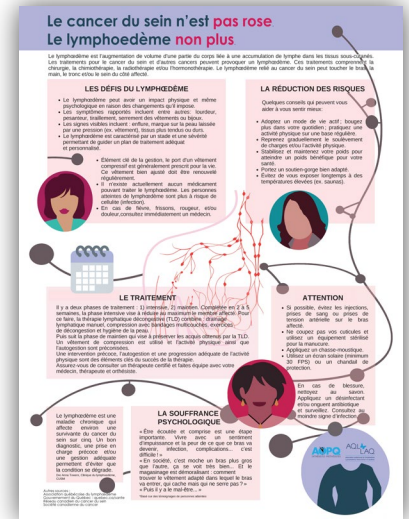
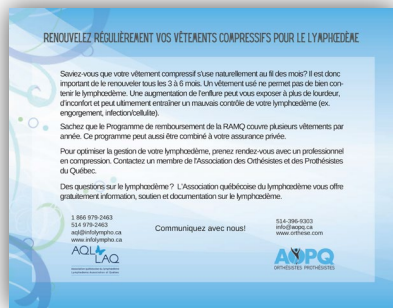


- Joint presentation of the LAQ and compression garment manufacturers to lymphedema professionals. For the first time in March 2024, the LAQ invited health professionals in its network to attend a presentation on lymphedema and compression with a clinical resource from pressure garment manufacturer Essity. Certified therapists, orthotist-fitters, nurses, doctors, physiotherapists, occupational therapists, kinesiologists and massage therapists responded in large numbers to the invitation and requested other webinars of this type for the months to come. **Number of registered professionals: 140**



- Dissemination and promotion of the poster on lymphedema linked to breast cancer, produced in collaboration with the Association of Orthotists-Prosthetists of Québec.

- Dissemination and promotion of the reminder card for the renewal of pressure garments, produced in collaboration with the Association of Orthotists-Prosthetists of Québec.



- Presentation of an official membership certificate for new therapists who are members of the LAQ in good standing, ensuring visibility for the organization and credibility for therapists.



Community Awareness

In order to raise awareness of lymphedema, its impacts and its treatments to people affected and the health professionals who support them, the LAQ uses its permanent awareness material, namely virtual and in-person presentations with detailed and interactive content:

- Presentation to health professionals from the MSSS network as part of the “Allies of the network” lunchtimes
- Presentation of the LAQ to nurses at the CISSS Montérégie Centre
- Presence on the National Committee for Community Cancer Settings
- Distribution of documentation at the conference of the Association of Orthotists and Prosthetists of Québec (AOPQ)
- Discussion on upcoming projects at the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center).
- Meeting and exchange with researchers from Concordia University
- Presence at the CHUM Bravery Day
- Presence at the Congress of Pharmacy Nurses of Québec (IIPQ)
- Renewal of agreements with the Québec Cancer Foundation, the Canadian Lymphedema Partnership and the Regroupement des organismes nationaux en oncologie
- Exchange with the Priorité Cancer Coalition in Québec
- Semi-annual meetings with the Canadian Lymphedema Framework (CLF) and our provincial partners
- Presence at the Exhibitors' Show at the National Lymphedema Congress organized by the CLF
- Presentation of the LAQ ProLymph platform to CLF Congress delegates and Canadian provincial associations
- Participation as a guest organization in the E-Impact project
- Meeting with ROCO organizations



Nathalie Côté, volunteer therapist (left) and Ginette Bardou, Interim General Manager at the IIPQ convention in September 2023.

Delegation of volunteer therapists from the LAQ and Anne-Marie Joncas, president, at the CLF conference in November 2023.



Refocusing and restructuring operations

The prolonged absence of the general director due to illness (10 months as of March 31, 2024) required the sudden establishment of interim management. In addition, the circumstances surrounding this absence combined with the departure of the administrative assistant in September 2023 caused a complex transfer of files and systems management. The office team was recomposed around an experienced interim general director, a volunteer at the reception and data management support, and another volunteer providing strategic support and communications.



The interim general manager, supported by the board of directors, established the list of essential services, put finances and data management in order, restructured all operations, put in place a framework to ensure delivery of services, clarified governance and reviewed the general orientation plan to refocus the objectives according to the means within the organization's reach.

All these steps allowed the LAQ to get through this period of turbulence to emerge stronger, more efficient and even more focused on its mission.

The board of directors set up its four working committees, namely: Governance and human resources, Finance and philanthropy, Science and customers and Communication. Each contributed according to their mandate, either to policies, or to the consolidation of finances, or to the validation of information transmitted to the public and professionals, or to the delivery of the new website and an increased presence of the LAQ among its target audiences.

Defence of patient interests and development of a response aligned with patient needs

With regard to the defence of patients' interests and the development of a response aligned with patients' needs, the LAQ pursued the following actions:

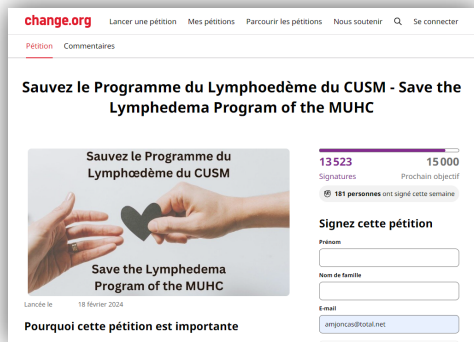
- **Activism:** Defence of patients' rights regarding the announcement of the closure of the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center).

Faced with the announcement on February 1, 2024 by the Cedars Foundation to suspend its charitable funds to the MUHC Lymphedema Clinic and the refusal of the MUHC to supplement this funding leading to the closure of the Clinic on March 31 and the loss of a unique resource in Québec, the LAQ deployed a series of protest and communication actions to defend the interests of patients. Remember that people suffering from lymphedema very rarely obtain the care they need within the public health network.

Note also that the MUHC Lymphedema Clinic is the only evaluation centre dedicated to lymphedema in Québec, the only group conducting research on lymphedema in the province, the only centre of expertise recognized by LE&RN in Canada for its clinical excellence and the leading partner of the LAQ since our founding. And above all, the MUHC Lymphedema Clinic is the only centre that receives hundreds of complex cases each year from the entire Québec health

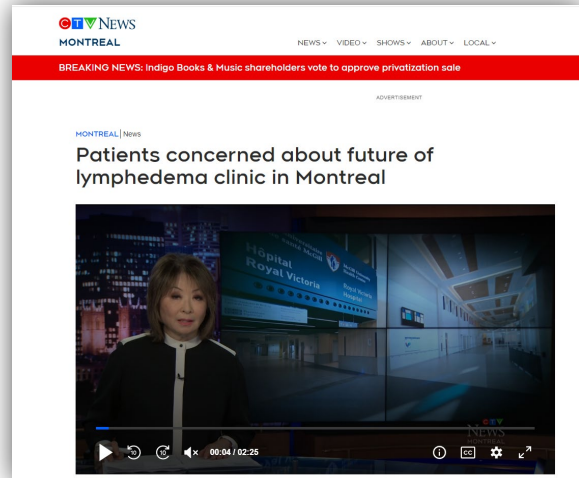
network.

- The LAQ supported by all its means of dissemination a petition protesting against the closure of the MUHC Lymphedema Clinic. The petition has collected more than 13,000 signatures.
- The LAQ sent letters of complaint and officially contacted the managers and organizations concerned.



- The LAQ spread the news in the media, both in print and television, in order to gain public attention and exert pressure to reverse this decision taken on the sly. Testimonials from patients were put forward.

Result as of March 31: The decision has been suspended. Discussions are underway at the MUHC to assess the situation and partial funding has been granted to support the Centre's activities until October 1, 2024. Public operational funding remains required to ensure the sustainability of this essential program. The LAQ continues its representations to the decision-makers concerned.



- **Partnership 1:** Steps for the establishment of systematic early detection with the PQC/MSSS – an essential step for the management of the condition.

Jointly with the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center), the LAQ presented to the MSSS and the PQC a treatment algorithm for lymphedema. The basic algorithm was developed for lymphedema related to breast cancer. As the health network is looking for tools to simplify diagnosis and treatments, this algorithm will reinforce the importance of access to treatments and allow effective dissemination of information.

Context reminder: Since August 2018, and thanks to the LAQ initiative, people suffering from lymphedema in Québec have had access to a

government assistance program for compressive clothing adapted to their needs. However, a very significant number of Quebecers live with the condition without being diagnosed since lymphedema is little known in the medical community.



The implementation of this screening/diagnosis component is crucial for the advancement of lymphedema care whether or not it is related to cancer. Once again, all the human and material resources necessary for this long exercise have been provided until now on a voluntary basis by the LAQ, supported by the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center).

- **Partnership 2:** Renewal of an official agreement with the Québec Cancer Foundation (FQC) – for efficient use of resources.

The LAQ and the FQC have agreed to renew their long-term collaboration with a view to:

- Maximize the benefits for people affected by cancer and/or lymphedema;
 - Participate on a voluntary basis in collaborative projects;
 - Optimize inter-referencing;
 - Participate in FQC fundraising, with royalties to the LAQ;
 - Ensure the visibility of the collaboration.
- **Awareness campaign 1:** March, lymphedema month – a key time to educate patients and raise awareness.



The LAQ has created a series of 62 daily messages on lymphedema. The campaign was broadcast on Facebook and Instagram in March 2024 and reached up to 1,700 people per day. This year, the contact networks of sponsors and partners were particularly leveraged to increase the audience reached.



- **Awareness campaign 2:** Sheet on prevalence, screening, diagnosis, treatment and monitoring for doctors – a tool to enlighten the medical world.



The sheet on the prevalence, screening, diagnosis, treatment and monitoring of lymphedema for doctors is the result of a collaboration between the LAQ and the CLF. The LAQ co-finances the Canadian campaign and assumes 100% of distribution costs in Québec. The LAQ participated in the writing of the communication elements targeted by a committee of experts and carried out the translation into French. Broadcasting continues continuously, reaching new specialized audiences. Funding by the LAQ was necessary to ensure the participation of the French-speaking world in the project.

• **Information campaign 1:** Publicize the new LAQ “encyclopedic” website

The long-awaited launch of the LAQ website had to reach patients and our natural partners, but also to reach new audiences. Remember that this site is the only one of its kind to meet the needs of French-speaking people suffering from lymphedema and leading to self-management. The absence of a printed publication of the 2023 Resource Directory left a void in this regard. A promotion/connection sheet for the new website, including QR code access to a digital version of the Lymphedema Resource Guide 2023, was created, then distributed in the health network, to our partners and disseminated within our list of contacts.



This operation allowed people at risk and affected to directly receive comprehensive information, making them ever more competent in the self-management of lymphedema. These people were also able to receive the promotion/connection sheet through their health professional or the health network.

• **Information campaign 2:** Make LAQ resources known to CLSCs.



The LAQ sends messages to those responsible for wound care in CLSCs to raise awareness of lymphedema, as well as the Association’s materials and resources. The documentation includes: Information intended for nursing staff, RAMQ program, LAQ services.

Requests for renewal of documentation from more than 50 CLSCs in 10 regions of the province.



- **Recognition of volunteers** – the wings of our organization.

Gestures of thanks in writing and in the form of small touches are put in place: Message during Volunteer Week, World Volunteer Day and sending greetings for the holidays.



Exploration of solutions ensuring the sustainability of the LAQ

Concerning the solutions ensuring the sustainability of the LAQ, the organization has laid the foundations of four areas of solution:

- **Analysis of financial potential**

The LAQ received an analysis of its financing potential from the Épisode firm. The report includes, among other things, a portrait of the Association, summaries of interviews conducted with stakeholders in the health and lymphedema sectors and an analysis of comparable organizations. Criteria for success have been identified, as well as targeted strategies in terms of organization, communications and financing, as well as deployment over 3 years. In order to update the recommendations of this report, the board of directors formed working committees which, accompanied by management, share the objectives. The Association will use this report as a compass for the next three years.



- **Grant request**

PSOC: a justification for the enhancement request is sent to the PSOC. It is imperative that the LAQ, whose national mission is accomplished within the framework of a health system that treats lymphedema deficiently, receives funding that reflects the salaries granted for positions in the community setting and allows it to have an impact beyond the cancer sphere to reach populations affected by venous insufficiency and morbid obesity. These last two subgroups still have very limited access to the health network.

- **Fundraising campaigns**

New partnership - **Annual walk for lymphedema** as part of the Grand Défolement of the Québec Cancer Foundation – September 9, 2023.

In order to strengthen the partnership between the LAQ and the FQC, to simplify operations and to stimulate participation through an event at no cost to participants and offering a competition, the Lymphedema Walk took place for the first time within the framework of the Grand Défolement of the Québec Cancer Foundation. The aim of this walk is to raise



awareness of lymphedema as well as fundraising. From all points of view, this activity was a great success.

Participants: 17 walkers
Amount raised: More than \$9,000

Call for employer donations

Members were invited to find out about the existence of such programs in the company where they work or from which they are retired. Special thanks to Lorna Rock, employee of Tenaquip, a company that donated generously to the LAQ for a fifth consecutive year.



Amount collected in 2023-2024: \$5,000
Amount raised since 2019: \$25,000

Invitation to donate during the member membership campaign

Strengthening the call for donations in our communications surrounding member membership.

Strengthening the call for donations during virtual education and support meetings

Results for 2023-2024

Number of donors: 86
Total donations: More than \$53,000
Testamentary gift from Louise Mercure and family: more than \$35,500

- Development of partnerships**

The lymphedema compression garment manufacturer and fitter industry are expected to play an increasingly important role in contributing to a viable long-term financial structure for the LAQ. The price scale with sponsorships introduced in 2022 has been greatly enhanced by offering more visibility and exclusivity to partners in exchange for more substantial funding. The response from clothing manufacturers has been most encouraging. The consolidated links have allowed the Association and partners to better measure the needs and issues of the community, as well as the impact of companies that revolve around the lymphedema community.

The fundamental need of the LAQ highlighted by this approach is to ensure a minimum permanence of 4 employees in order to carry out professional training projects, education and provincial support, government collaboration and defence of patients' interests. The LAQ has the legitimacy that the commercial sector lacks to assert these objectives in the health network.

Number of corporate members: 30
Number of sponsors: 9

2. Demonstration of the community's contribution to the achievement of the Association's activities during the period from April 1, 2023 to March 2024

- **Contribution in terms of human resources**

Doctors, therapists, and patients participated in all our activities: strategic committees, working committees, call return service for professionals and patients, virtual education and support meetings for patients, writing of L'info AQL and L'AQL Express, writing and publishing educational leaflets and the LAQ 2024 Lymphedema Directory, all as representatives, designers, consultants, organizers, facilitators or assistants. The LAQ maintains its recruitment on the I volunteer platform.



Contribution of the LAQ Scientific Committee

The LAQ has the particularity of benefiting from medical and scientific resources through doctors and therapists who conduct cutting-edge research in Canada and who are attached to the Lymphedema Support Center of the FCSQ (MUHC Lymphedema Clinic) and at CHU Sainte-



Centre universitaire de santé McGill
McGill University Health Centre

Justine for pediatric lymphedema. Together, these recognized specialists issue and review

the LAQ recommendations for people at risk and suffering from lymphedema. In addition, they give their opinion for the supervision of our general public and professional activities, as well as for the acceptance of therapists who are members of our association. We also ask them to review our written documentation and presentations. Through their voluntary contribution, these experts contribute closely to the relevance of our actions to the general public and health decision-makers.



CHU
Sainte-Justine
Le centre hospitalier
universitaire mère-enfant
Université
de Montréal



Anna Towers, MD



Marie-Eve Letellier, PhD,
MSC, BSC, KIN, KT, ORT, TAL, TDC (V)



Chantal Lapointe, PHT,
M.Réad., TLC, TAL, ECSA, (CS)

- **Contribution in terms of material resources:**

We benefit from the premises of the Lymphedema Clinic of the MUHC (Lymphedema Support Center of the FCSQ), the Québec Cancer Foundation to meet patients, distribute our educational leaflets, hold support meetings for patients and meetings of the executive committee of the LAQ. The space and sometimes the means of communication (Wi-Fi, computer, projector) are made available to us. We also benefit from reduced rental fees for other premises. We receive donations of lymphedema treatment materials for training courses, provided by the manufacturers of these products.

- **Contribution in terms of financial resources:**

Annual LAQ membership campaign, corporate sponsorships, corporate foundation donations, individual donations, testamentary donations, donations of translation, graphic design and printing services, conference sponsorships, rental/sharing of tables exhibition, exemption from infrastructure and payment processing fees for donations to CanadaHelps campaigns, as well as to the FQC's Grand Défoulement (Lymphedema Walk), and subsidy from the Support Program for Community Organizations of the MSSS.



- **Contribution through a network of volunteers and activists:**

Our dedicated volunteers contribute more than **5,000 hours of volunteer work per year**. Activists from all the organizations that are part of our network were called upon to sign and distribute the petition in response to the announcement of the sudden closure of the MUHC Lymphedema Clinic (FCSQ Lymphedema Support Center). **These are hundreds of people who managed to bring together more than 13,000 signatures in just a few days.**

- **Contribution in the form of free advertising in another network:**

Our education programs have been publicized free of charge by the physiotherapy services/lymphedema clinics of large hospital centres (CHUM, HMR, CUSM, Sacré-Cœur, Cité de la Santé, Jewish General Hospital, etc.) and other patient associations including the Québec Cancer Foundation, the Eastern Cancer Association, Ovarian Cancer Canada, Cancer Saguenay, Cancer Laurentides, Procure. Registration for the ROCO and FQC online portals and directories.

- **Contribution through a leaflet distribution network by other organizations:**

Our educational leaflets and virtual support group calendars are distributed free of charge by other associations and community organizations, foundations and establishments linked to cancer, lymphedema and other diseases, either through their websites, mail, newsletters or during conferences and congresses, or through the media, including social media. **Our educational brochures are available in hospitals, CLSCs, and other public places.**



- **Contribution through references from other organizations:**

Several community organizations, self-help groups, foundations and medical groups refer to the LAQ, disseminate our programs and our educational publications on their websites, social media, publications and newsletters, among others:

- Québec Breast Cancer Foundation;
- Québec Cancer Foundation;
- Cancer Association of Eastern Québec;
- Several CLSCs in Québec
- Therapeutic networks
- Orthopedic adjustment centres
- Vodder and Arborescence: training schools in lymphatic therapy and training for massage therapists
- Priority Cancer Coalition
- The Group of Community Oncology Organizations (ROCO)



3. Demonstration of the dynamism and commitment of the Association in the community and consultation with local resources

On an annual basis, the LAQ collaborates with a large network of natural partners. During the targeted period, from April 1, 2023 to March 31, 2024, the LAQ worked on the annual planning of these collaborations and participation in the various consultation tables.

Collaboration, exchange of resources and activities and participation in conferences of other community organizations including:

- Group of community oncology organizations (ROCO)
- Québec Cancer Program (PQC)
- National Committee for Community Oncology Settings (teleconference)
- Pharmacy nurses of Québec (IIPQ)
- Order of Podiatrists of Québec
- Obesity Canada
- Save your skin
- Québec Breast Cancer Foundation
- Hope & Cope and the Jewish General Hospital Wellness Centre
- CanSupport/Cedars Foundation at the MUHC
- Fondation VIRAGE du CHUM
- HMR Croire Foundation
- Federation of Voluntary Action
- Order of Nurses of Québec (OIIQ)
- Québec Wound Care Group (RQSP)
- Québec Association of Oncology Nurses (AQIO)
- Québec Palliative Care Association (AQSP)
- Association of Orthotists and Prosthetists of Québec (AOPQ)
- Association of Podiatrists of Québec
- Cancer Association of Eastern Québec
- CHUM Bravery Evening
- Priority Cancer Coalition
- Canadian Lymphedema Partnership (CLP) - signing of agreement renewal in January 2024
- PAC (Provincial Associations Community)
- LE&RN (scientific advances)
- International Lymphoedema Framework (ILF)
- FAVA-Multi, rare diseases health sector
- AVML – France (lymphedema)
- MUHC BRA Day and more.



obesity | obésité
canada | canada



LA FONDATION
sauve ta peau



ORTHÉSISTES PROTHÉSISTES



Lymphatic Education
& Research Network
**Centers of
Excellence**



Ordre
des infirmières
et infirmiers
du Québec

Collaboration, exchange of resources and provision of continuing education to hospital centres with a lymphedema program in Québec such as:

- several integrated cancer centres
- the Pediatric Lymphedema Clinic at CHU Sainte-Justine, University of Montreal
- the CHUM physiotherapy service
- the Lymphedema Clinic at Maisonneuve Rosemont Hospital
- the McGill Lymphedema Research Program
- the JGH Lymphedema Clinic at the Segal Cancer Centre
- the FCSQ Lymphedema Support Centre at the MUHC – MUHC Lymphedema Clinic
- the MUHC Breast Clinic
- the Lymphedema Clinic at Cité-de-la-Santé
- Saint-Sacrement Hospital of Québec
- the Physiotherapy Department of Saint-Jérôme Hospital
- the physiotherapy service at the Hôtel-Dieu de Lévis
- the Physiotherapy Department of the Montérégie Integrated Cancer Centre, Charles-LeMoyne Hospital
- CISSS de la Montérégie-Est
- and other hospital programs in Québec



Centre universitaire de santé McGill
McGill University Health Centre

Place occupied by members of the community

The President, Acting Executive Director and several members participate in the McGill Lymphedema Research Program (MLRP) committee.

The president and members are part of the education committee of the MUHC Lymphedema Program. The president is part of a working committee of the Québec Cancer Program (PQC). The president participates in the National Committee for Community Cancer Sectors of the Québec Cancer Program (PQC). The interim general director, the scientific directors, the representatives of the therapists, the members of the council, as well as the president, are part of the activities (meetings, symposiums) of several health organizations, including the Regroupement des organisations communautaires en oncologie (ROCO).

Consultation with various stakeholders from government bodies and others

Close collaboration with the Québec Cancer Program (PQC), the Committee of Community Oncology Organizations, the Régie de l'assurance-santé du Québec (RAMQ - Compression Clothing Program).

Consultation with other community organizations

Active participation in the Grouping of Community Oncology Organizations (ROCO).

Collaboration with the Québec Cancer Foundation to reach the cancer population: information on the risks of lymphedema, on the resources available for cancer and lymphedema

Collaboration with the Se Reconstruction Centre (breast cancer)

Disponibilité pour la communauté lorsque celle-ci est touchée par des événements particuliers

Mobilization of human resources from the Therapeutic Support Program and free provision of documentation for regions without services for lymphedema (for example, Îles-de-la-Madeleine). And also, when a hospital centre loses a lymphedema treatment therapist or the only private therapist leaves the region she covered. The LAQ is able to use all of its communications platforms, including its toll-free line, its human resources and its network of volunteers to relay information communicated by government authorities, to organize a “net” of care and to secure and support people affected by or at risk of lymphedema.

Production and purchase of materials or participation in joint activities with other organizations

Education leaflets and Lymphedema Directory are created, published and distributed free of charge by the LAQ to hospitals, CLSCs and other community and government organizations.

Collaboration with Dense Breasts Canada, an organization that advocates for the recognition of breast density as a risk factor for the development of breast cancer and hinders its detection within the framework of provincial screening programs. In addition to relaying information from Dense Breasts Canada, the LAQ supports investigations into possible links between the prevalence of lymphedema and breast density.

The qualification of tissue density could be an indicator of increased risk of lymphedema in cases of cancer. Proper screening for women with dense breasts could help diagnose cancer earlier and possibly reduce the risk of lymph node damage and lymphedema.

Representation on LAQ services and our philosophy of care for Vodder and Casley-Smith decongestive lymphatic therapy graduating cohorts. Raising awareness of the emotional shock linked to lymphedema, therapeutic support, teaching self-management and the advantages of being a professional member of the LAQ.



Dr. Vodder School™
INTERNATIONAL
Authorized by the original Dr. Vodder Schule - Austria

4. Demonstration of the response provided to the needs of the environment

The LAQ is accessible to clients by telephone, email, website and social media from **9 a.m. to 5 p.m. Monday to Friday, 52 weeks a year.**

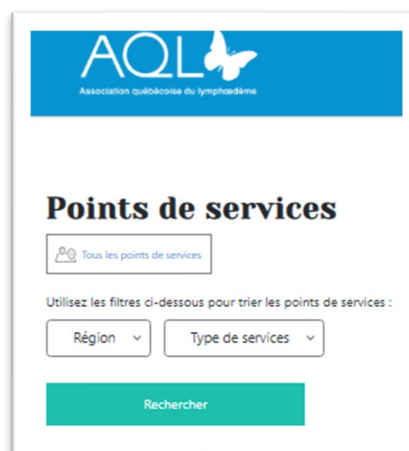
Information and consultation activities and tools

Patients, their family and friends are invited to participate in virtual education and support group meetings. Meeting topics include: Lymphedema 101, meeting a lymphedema expert, lymphedema self-management, exercises, rehabilitation after cancer treatment, new research and treatments, and a discussion of sharing between participants. Therapists specializing in lymphedema as well as a person affected by lymphedema lead the sessions.



Awareness leaflets, newsletters

Each year, the LAQ publishes a “**Lymphedema Guide**” which provides people with lymphedema with the information they need. There is a list of certified lymphedema therapists in all regions of Québec as well as the list of manufacturers, distributors and retailers of lymphedema products, including compression clothing and bandages. Printed in 6,000 copies and available in PDF on our website, as well as in an interactive map version.



AQL
Association québécoise du lymphédème

Points de services

Tous les points de services

Utilisez les filtres ci-dessous pour trier les points de services :

Région ▼ Type de services ▼

Rechercher

The LAQ publishes educational leaflets on lymphedema, in French and English:

- “**Living well with lymphedema**”: learning to manage and living well with lymphedema - informative brochure on treatments, exercise and self-management
- “**Reducing the Risk of Lymphedema**” for people at risk of developing lymphedema – how to avoid complications and learn self-management techniques.



- “Self-measurement of the lower limbs” and “Self-measurement of the upper limbs”
- Sheet on the RAMQ Program
- Sheets on LAQ services and tools
- Profile on the ProLymph network for professionals

The LAQ ensures the translation and distribution of the quarterly Canadian lymphedema journal *Pathways*, in print and online format. Our bilingual newsletter **L’info AQL** distributed online includes articles intended for Québec readers. It contains articles translated into French from *Pathways* as well as targeted content for patients and professionals in Québec. Significant work of managing subscriber lists, translation and layout is carried out by the LAQ team. The **L’info AQL** reaches readers from all over Québec.

In addition to this bulletin, there is a new bulletin: **L’AQL Express**, the upgraded version of existing content. This free newsletter for the general public contains the essentials of L’info AQL without the in-depth articles on lymphedema in order to raise awareness of the needs of the population affected by lymphedema and the activities of the LAQ.

The LAQ publishes two tools aimed at health professionals: the doctor’s reference sheet and the leaflet for nurses.

Newsletters are sent to our members to notify them of news and events. Job offers are sent to our therapist members.

Website

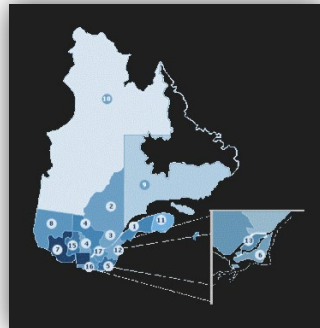
Since August 2023, the completely renewed LAQ website has been presented as an encyclopedia dedicated to lymphedema, bringing together knowledge, tools and testimonials. Advice and scientific articles written by specialists are available there. The new structure of more than 70 pages facilitates patient self-learning. All our tools are also accessible to the general public or by subscription. The LAQ website is the only online lymphedema resource in the world, serving the needs of both French and English-speaking audiences.

Link between the activities carried out and the services offered, and the needs of the community, as identified by the organization

The prevalence of lymphedema is estimated at 238,000 cases in Québec, while 7,000 patients (an increase of 300% over 2 years) are registered in the RAMQ pressure clothing program. To correct underdiagnosis, it is necessary to educate doctors about diagnosis and nurses about lymphedema screening. The LAQ implements its own awareness initiatives among health professionals and collaborates with CLF initiatives targeting this clientele and achieving these objectives. The LAQ organizes, depending on demand, training programs for doctors and nurses. Patients have free access to virtual education and support meetings.

Territory covered from April 2023 to March 2024

The LAQ's activities and programs target all regions of Québec. Our website also attracts professionals and patients from around the world. Our Facebook and Instagram pages have a great influence in Québec and in the global French-speaking world (Europe, North Africa). Our LinkedIn page is increasingly capturing the attention of health professionals and decision-makers. Our ProLymph network reserved for professionals brings together specialized stakeholders from Québec and Canada. We are affiliated with organizations in Canada (CLF), the United States (NLN, LANA) and worldwide (ILF). Virtual education and support groups make it possible to reach all regions of Québec, French speakers outside Québec and help even more people.



Number of people reached by the organization's general public activities

- L'info AQL: Annual readership estimated at 365 people and organizations
- L'AQL Express (new): Readership estimated at 1,555 people and organizations
- New website (new address): More than 6,800 annual visits
- Walk for lymphedema: awareness of 1,500 to 2,000 people and media
- Congresses of other organizations: estimate of 3,000 to 5,000
- Facebook: total reach of 20,300
- Instagram: total reach of 1,100 people
- Digital fundraisers: 10,000 people

Number of people reached by the organization's individual and group activities

- Therapeutic support program (telephone, email, Facebook, ProLymph): **more than 200 people at risk or affected by lymphedema per year**
- Virtual education and support meetings for people affected by lymphedema or at risk of it across Québec: **613 people at risk or affected by lymphedema**
- Presentation to professionals: **140 participants**
- Members: **294**
- Training/information for health professionals and lymphedema therapists: **290 professionals**

5. Demonstration of the democratic functioning of the LAQ

- The category of voting members includes patients and relatives as well as therapists who are members of the LAQ. Together, they participate in the Annual General Meeting.
- The members of the board of directors took part in the decisions of the organization. **Twelve board meetings** were held with a quorum, plus the AGM.
- The president was available to respond to members' requests and suggestions.
- Number of voting members: **264**
- Number of members present at the AGM on June 22, 2023: **12**



Board of Directors and Officers

Anne-Marie Joncas	President, person living with lymphedema
Marie-Eve Letellier	Vice-president, therapist, public sector
Ginette Bardou	Secretary, community representative and interim general manager
Michel Picard	Treasurer, community representative
Maude Jubinville	Administrator, therapist, private sector
Chantal Lapointe	Administrator, therapist, public sector, pediatric
Sylvain Leclerc	Administrator, industry representative
Lynda Ouellet	Administrator, person living with lymphedema
Lorna Rock	Administrator, person living with lymphedema

This Activity Report is filed on June 19, 2024.

Anne-Marie Joncas,
President

Marie-Eve Letellier,
Vice-President

