ANNUAL REPORT OF THE SJÖGREN'S SOCIETY OF CANADA INC.

Fiscal Year January 1, 2020 – December 31, 2020

Federal Registered Charity #81858 8956 RR0001

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Working Together to Conquer this Serious Autoimmune Disease!

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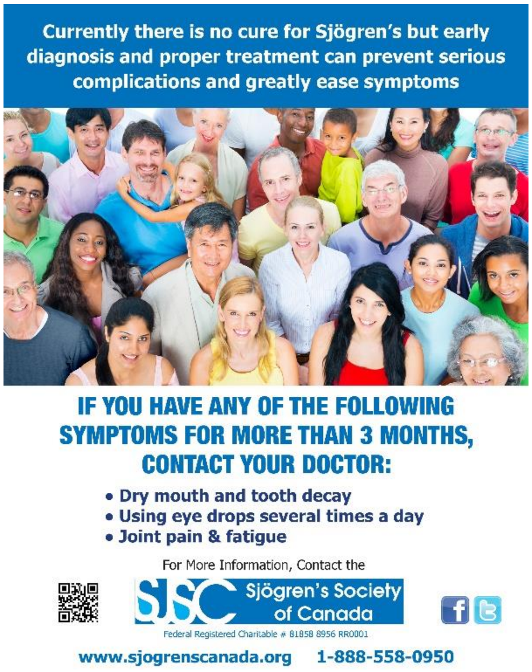
Sjögren's is a chronic, systemic, inflammatory autoimmune disease that usually attacks and damages the salivary, tear and mucous-secreting glands. This results in dry mouth, dry eyes, or even internal organ damage, arthritis, painful weak muscles, neuropathy, and debilitating fatigue. An estimated 1% of Canadians, 90% of whom are women, live with Sjögren's yet it is often misdiagnosed, under-recognized and under-treated.

The mission of the Sjögren's Society of Canada (SjSC) is to provide support and education for diagnosed and undiagnosed Sjögren's patients, to increase professional and public awareness and to promote and fund Sjögren's related research.

The SjSC is a small, primarily volunteer not-for-profit patient organization established in 2006 by Lee Durdon, a Sjögren's patient who realized the need for a Canadian organization to support Sjögren's patients. Our office is located in The Wincey Mills Building in Paris, Ontario. All day-to-day operations of running the organization are provided by the Managing Director, Lauren Vording, our sole paid employee. A Board of Directors and Medical Advisory Board provide the decision-making, guidance, and programming to achieve the objectives and mandates. At the end of 2020 we had 277 members.



Currently there is no cure for Sjögren's but early diagnosis and proper treatment can prevent serious complications and greatly ease symptoms

IF YOU HAVE ANY OF THE FOLLOWING SYMPTOMS FOR MORE THAN 3 MONTHS, CONTACT YOUR DOCTOR:

- Dry mouth and tooth decay
- Using eye drops several times a day
- Joint pain & fatigue

For More Information, Contact the

SjSC Sjögren's Society of Canada

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www.sjogrenscanada.org 1-888-558-0950

A new Board of Directors was formed at our Annual General Meeting in June 2020. We welcomed one new Director, Marc Foisy who joined our current Directors; Leslie Laing, Mary McNeil, Marilyn Thom, Margaret Glasford, Cindy Carter and Annette McKinnon. The Board of Directors said goodbye to Board Members Janet Gunderson and Sandra Anderson. The work of the SjSC is primarily carried out at monthly board meetings and regular committee meetings. All meetings are conducted via Zoom videoconferencing. Our established Committees are: Communications, National Patient Conference, Fundraising/Sponsorship, Recruitment, Grant Writing/Research, Membership Benefits, and Awareness.

Our Managing Director, Lauren Vording, oversees the day-to-day operations of the SjSC. She answers all phone calls and emails for the Sjögren's Society of Canada. In 2020, Lauren responded to hundreds of phone calls from members and non-members and answered more than 2500 emails throughout the year as well. As of March 2020, Lauren began working from home due to the COVID-19 pandemic and has continued to answer all phone and email enquiries for the SjSC. Lauren helps refer patients to Support Group Leaders and Sjögren's specialists across Canada; she coordinates all board meetings and committee meetings along with all events hosted by the SjSC; she handles the day-to-day bookkeeping duties and provides monthly financial reports to the Board of Directors; she provides the Secretary duties at the monthly Board of Directors meetings; she creates the monthly eNewsletters; she updates social media accounts and the website; and she coordinates all peer-to-peer fundraising campaigns. Lauren is our key, first point of contact for everyone who reaches out to the Sjögren's Society of Canada.

COMMUNICATIONS COMMITTEE

The Communications Committee is comprised of Dr. Leslie Laing, Mary McNeil and Annette McKinnon. These are the objectives of the Communications Committee:

- Create quarterly Newsletters for SjSC Membership which provides patient education, research reports and patient profiles.
- Liaise with Medical Advisory Board to write articles for the Newsletter.
- Sell advertising for the Newsletter to cover costs of designing and printing the newsletter.
- Update sjogrenscanada.org website as needed with event, fundraising, and educational information.

The Communications Committee prioritized the Connections Newsletter again in 2020 and distributed four quarterly issues. They also made a commitment to communicating the most up-to-date info on the COVID-19 virus as it related to Sjögren's patients. A formal SjSC statement on COVID-19 relating to Sjögren's disease was sent out in March followed up with related articles in the Connections newsletter.

The Communications Committee also decided to review our current website and made some changes in 2020. They plan to review the website further and make more significant design and content updates in 2021.

In addition to the Connections newsletter, Lauren Vording sends out a monthly e-newsletter to approximately 1500 SjSC members, Facebook page members, and SjSC website registrants. The monthly eNewsletter includes a Tip of the Month, a healthy recipe and the most current events happening at the Sjögren's Society of Canada.

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NATIONAL PATIENT CONFERENCE COMMITTEE

The National Patient Conference Committee is comprised of Dr. Leslie Laing and Marilyn Thom. Objectives of the Conference Committee include:

- Select the date of the Conference by conferring with the Board of Directors, Dr. Arthur Bookman and the Medical Advisory Board.
- Determine if the conference will be virtual or in-person.
- Create an educational theme and find available speakers.
- Contact potential Sponsors/Exhibitors.
- Promote the conference and register participants.

Due to the COVID-19 Pandemic, our National Patient Conference was postponed from our traditional April date until October 17, 2020. The Conference was held virtually this year with 86 attendees from across the country, four expert presenters including Dr. Arthur Bookman, Rheumatologist, Dr. Leslie Laing, Prosthodontist, Dr. Saleel Jivraj, Optometrist and Dr. Ebrahim Sayeh, Laboratory Specialist, and three sponsor presentations. The first Virtual National Patient Conference was a success with much positive feedback. The committee is hoping to hold future meetings in person but will consider more virtual options in the future.

FUNDRAISING/SPONSORSHIP COMMITTEE

The Fundraising/Sponsorship Committee is comprised of Mary McNeil and Cindy Carter. Objectives of the Fundraising/Sponsorship Committee include:

- Work with the Managing Director to schedule and organize fundraising events.
- Expand our Walks for Sjogren's into at least two more major metropolitan areas.
- Create relationships with businesses who could sponsor our newsletter, conference and fundraising events.
- Promote peer-to-peer fundraising and monthly donor giving.
- Expand our Great Canadian Giving Challenge and year-end fundraising campaigns.

The Fundraising/Sponsorship Committee reached out to our membership for several fundraising campaigns during 2020. In June, we participated in the Great Canadian Giving Challenge, a peer-to-peer fundraiser promoted by Canada Helps. We rallied our Board of Directors and Support Group Leaders and set out to raise $5,000. We quickly reached our goal and increased it to $7,500, which we surpassed as well. We ended up raising $14,830, an increase of over $10,000 compared to 2019! In December, we conducted a year-end fundraising campaign consisting of Giving Tuesday and a year-end mailing campaign which brought in a record amount of $8,200, an increase of $1,700 from 2019.

The SjSC held one Walk for Sjögren's in 2020 in London, ON. Plans for an in-person event pivoted to a virtual event with a Zoom kick-off meeting held on August 29th followed by participants walking in their neighbourhoods. The London Walk Committee raised over $12,500 with six sponsors and 140 donors!

RECRUITMENT COMMITTEE

The Recruitment Committee is comprised of all Board of Directors members. Objectives of the Recruitment Committee include:

- Seek qualified members to join the Board of Directors.
- Identify Sjögren's specialists to join the Medical Advisory Board.
- Review the qualifications needed for both boards such as fundraising experience and Sjögren's expertise.

The Board of Directors continues to seek out individuals to complement our current Directors and specifically individuals with a desire and skill for fundraising.

GRANT WRITING/RESEARCH COMMITTEE

The Grant Writing/Research Committee is comprised of Dr. Leslie Laing and Margaret Glasford. Objectives of the committee include:

- Work with the Medical Advisory Board to create research grants for Sjögren's researchers.
- Research and apply for grant opportunities.
- Identify priority areas of research.
- Support Sjögren's-related clinical trials being conducted in Canada.

Research is the key to better treatments and finding a cure for Sjögren's. Since 2009, the Sjögren's Society of Canada has funded thirteen important research studies (twelve student summership grants and one U.S. Canadian collaborative study) which were funded through Walks and designated donations. Although we continue to raise funds for Sjögren's related research, we did not award any research grants in 2020. The Year-End Fundraising Campaign focused on raising funds for future research grants and we are excited to have over $3600 raised for a student summership grant in 2021.

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MEMBERSHIP BENEFITS COMMITTEE

The Membership Benefits Committee is comprised of Mary McNeil. Objectives of the Membership Benefits Committee include:

- Increase membership by enhancing what we provide to members.
- Increase the number of support groups and local contact persons particularly in eastern Canada.
- Conduct meetings with Support Group Leaders to discuss SjSC updates, available resources, and an opportunity to share ideas with other leaders.
- Continue to improve the resources available to support group leaders to help them carry out their essential roles.

Much of our Sjögren's support services are provided through local Support Groups and Contact Persons. We currently have 17 support groups across Canada. We welcomed two new support groups in 2020 including Saskatchewan and Atlantic Canada. We also welcomed a new Support Group Leader in Edmonton, AB. In 2020, we continued to hold our annual meeting of Support Group Leaders to discuss strategies for running meetings and providing patient support. Leaders also shared ideas with each other. We have six local contact persons who are available to support patients who may not have access to a support group. We are very proud and grateful for the work that our team of Support Group Leaders are doing every day to help Sjögren's patients across the country. Many of the leaders held virtual meetings via Zoom with their members due to the Covid-19 pandemic.

AWARENESS COMMITTEE

The Awareness Committee is comprised of Mary McNeil and Marc Foisy. Objectives of the Awareness Committee include:

- Identify ways to increase Sjögren's awareness among all health care professionals and the general public.
- Distribute our new "What is Sjögren's" brochures and posters to Sjögren's specialists to promote the SjSC and our support groups.
- Distribute flyers to all Sjögren's specialists to promote our support groups.
- Grow World Sjögren's Awareness Day across Canada.

The SjSC joined 20 international Sjögren's patient organizations to celebrate World Sjögren's Awareness Day on July 23rd with social media messages and posts. World Sjögren's Awareness Day was created to increase awareness and emphasize the enormous need for Sjögren's research, new diagnostics, and better therapies and treatments. Dr. Henrik Sjögren first identified the disease in 1933 so we commemorate his birthday on July 23rd as World Sjögren's Day.

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In 2020, the SjSC Board of Directors and Awareness Committee made the update of our "What is Sjögren's" brochure a priority. This brochure will be our primary "calling card" to educate patients and the public about Sjögren's and to promote our organization. The SjSC Board of Directors is committed to carrying out this major project and distributing it widely to Sjögren's specialists, Support Groups, patients and the general public.

Our social media presence has steadily increased in 2020. We started the year with **1040** Facebook followers and ended the year with **1185**. Our Twitter page currently has **2192** followers! Thank you to Annette McKinnon for her coordination of the SjSC Twitter account.

The Sjögren's Society website, www.sjogrenscanada.org continues to provide a resource for patients, professionals and the public. The Communications committee began discussions about updating the website which will be a priority in 2021.

FINANCIAL REPORT

Every cent the SjSC spends on our services, programs and staffing has to be raised! We are extremely grateful to our members and donors for their generous donations and continued support throughout the year with total donations at $42,000 and $29,000 raised from fundraising campaigns.

The financial statement included at the end of this report summarizes revenues ($111,414) and expenses ($79,756) for the year 2020 resulting in a surplus of $31,658. This is a major turnaround from 2019 when the SjSC ended the year with a deficit of nearly $29,000. The surplus was due to increases in fundraising, donations, as well as cost cutting particularly downsizing office space. At the end of 2020, the Board created a detailed budget for 2021 and laid out specific plans for how to maintain revenue amounts from 2020 and increase them by 5%.

In 2021, the SjSC Board of Directors will continue to:

- Monitor the profit and loss statements, balance sheets, and budgets at every Board Meeting.
- Reduce expenses where feasible.
- Increase Revenue:
    - Promote peer-to-peer fundraising and monthly donor giving.
    - Increase sponsorships of the National Patient Conference and Walks for Sjögren's.
    - Increase advertising in the Connections and monthly e-Newsletters.
    - Increase memberships by widely distributing the new "What is Sjögren's" brochures.
    - Expand our year-end fundraising campaign.

CONCLUSION

The Sjögren's Society of Canada is intent on improving conditions for Sjögren's patients and putting a human face on this complicated disease. We are grateful to our membership for their support and to our volunteers for all the work they do. We encourage everyone to get involved with the Sjögren's Society of Canada in any way they can. Let's make our voices heard, and together, we will make a difference!

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FINANCIAL STATEMENT

Revenues

Donations	$	42,137
Membership	$	11,842
Conference	$	10,853
Fundraising	$	29,072
CEWS	$	11,928
Advertising	$	4,500
Other	$	1,082
TOTAL	**$**	**111,414**

Expenses

Salaries	$	51,522
Education (Conf.)	$	0
Rent	$	4,029
Office	$	3,702
Prof. Fees	$	5,571
Insurance	$	2,077
Newsletters	$	9,467
Awareness	$	1,225
Telephone	$	479
Dir. Meetings	$	435
Interest/Bank Chrg	$	971
Amortization	$	266
Memberships	$	12
TOTAL	**$**	**79,756**