SJSC Sjögren's Society of Canada

Annual Report

2021

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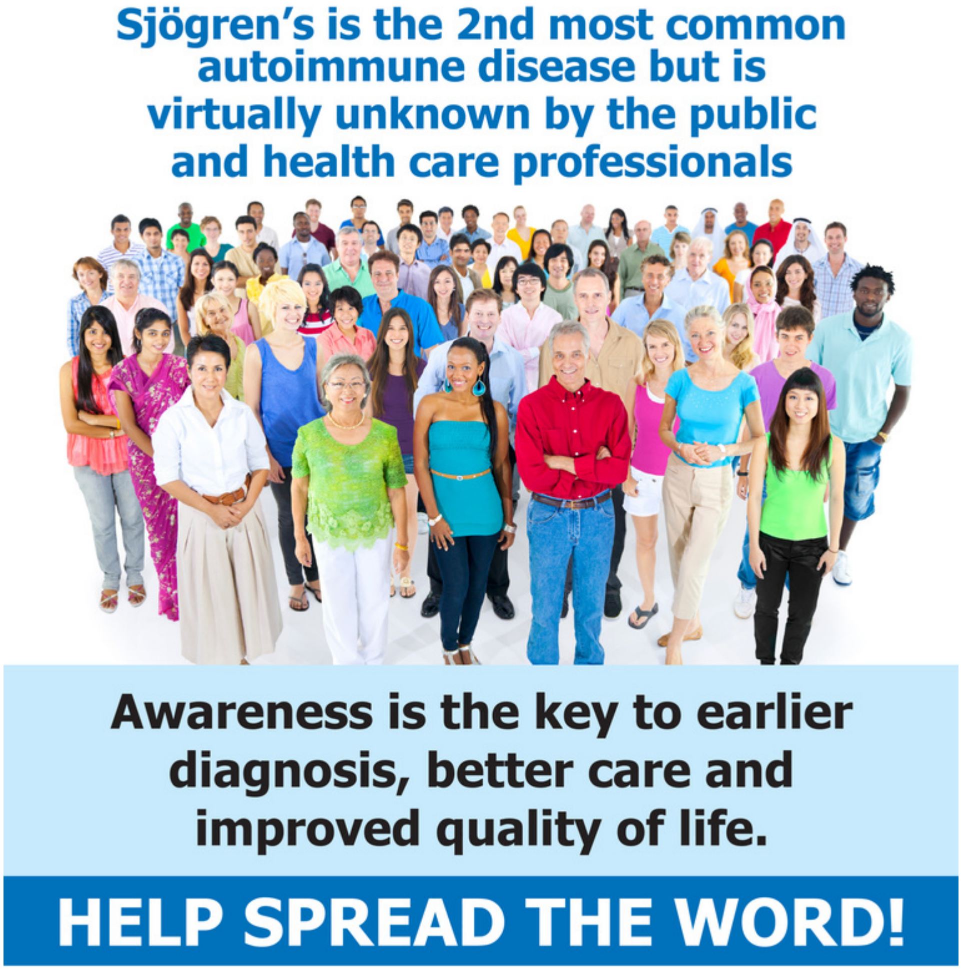

Introduction

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 2021 we had 358 members which is a 29% increase in membership over 2020.

A new Board of Directors was formed at our Annual General Meeting in June 2021. We welcomed two new Directors, Christin McGinn & Julie Yoshikuni who joined our current Directors; Leslie Laing, Marc Foisy, Mary McNeil,, Margaret Glasford, and Cindy Carter. The Board of Directors said goodbye to Board Members Marilyn Thom and Annette McKinnon. 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, is our key first point of contact for everyone who reaches out to the SjSC. She oversees the day-to-day operations of the SjSC including:

- Responding to hundreds of phone calls from members and non-members.
- Answering more than 2500 emails throughout the year.
- Referring patients to Support Group Leaders and Sjögren's specialists across Canada.
- Coordinating all board meetings and committee meetings along with all events hosted by the SjSC such as conferences and town halls.
- Handling the day-to-day bookkeeping duties and provides monthly financial reports to the Board of Directors.
- Taking care of the Secretary duties at the monthly Board of Directors meetings as well as agendas and minutes.
- Creating the monthly eNewsletters and compiling the quarterly newsletter.
- Updating social media accounts and the SjSC website.
- Organizing all peer-to-peer fundraising campaigns.

SjSC Committees

Communications Committee

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

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

The Communications Committee prioritized the Connections Newsletter again in 2021 and distributed four quarterly issues. They also continued to communicate the most up-to-date info on the COVID-19 virus as it related to Sjögren's patients.

In 2021, the Communications Committee also decided to overhaul our current website and to make significant updates in 2021. They decided on a new website designer and started the process of re-designing and re-writing the SjSC Website. They plan to launch the new site in 2022.

In addition to the Connections newsletter, Lauren Vording sent out a monthly e-newsletter to approximately 1900 SjSC members, Facebook page members, and SjSC website registrants. The monthly eNewsletter includes strategies for living well with Sjögren's, a healthy recipe and the most current events happening at the Sjögren's Society of Canada.

National Patient Conference Committee

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

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

Our National Patient Conference was held on April 24, 2021. After our successful Virtual Conference in 2020 and with the continuing Covid-19 pandemic, the National Patient Conference Committee decided to hold our conference virtually in 2021. We welcomed 99 attendees from across the country and four expert presenters including Dr. Arthur Bookman, Rheumatologist, Dr. Will Ngo, Optometrist, Dr. Hagan Klieb, Oral Pathologist, and Phillip Hudson, Pharmacist. 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 Christin McGinn. Objectives of the Fundraising/Sponsorship Committee include:

- o Work with the Managing Director to schedule and organize fundraising events.
- o Expand our Walks for Sjogren's into at least two more major metropolitan areas.
- o Create relationships with businesses who could sponsor our newsletter, conference and fundraising events.
- o Promote peer-to-peer fundraising and monthly donor giving.
- o 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 2021. 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 $15,000. Although we did not reach our goal, we ended up raising $12,300! In December, we built off of our successful 2020 year-end fundraising campaign. All donations through our Giving Tuesday and year-end mailing campaign were matched by a generous donor up to $10,000. We raised a record amount of $11,280 (plus $10,000), an increase of over $3000 from 2020.

The SjSC held two Walks for Sjögren's in 2021: A Virtual Walk in London, ON and an in-person Walk in Paris, ON. The London virtual event began with a Zoom kick-off held on October 2nd followed by participants walking in their neighbourhoods. The London Walk Committee raised over $8,355 with two sponsors and 80 donors! The Paris Walk was held on September 25th. After missing a year due to COVID-19, the Paris Walk Committee rallied to raise $1,795.

Recruitment Committee

The Recruitment Committee is comprised of all Board of Directors members.Objectives of the Recruitment Committee include:
o Seek qualified members to join the Board of Directors.
o Identify Sjögren's specialists to join the Medical Advisory Board.
o 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:
o Work with the Medical Advisory Board to create research grants for Sjögren's researchers.
o Research and apply for grant opportunities.
o Identify priority areas of research.
o 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 our fundraising Walks and designated donations. Although we continue to raise funds for Sjögren's related research, we did not award any research grants in 2021 due to COVID-19 restrictions. In 2021, the SjSC committed to allocating 5% of all donations received in the fiscal year to go towards research. With $4446 raised in 2021, we look forward to awarding summership grants in 2022.

Membership Benefits Committee

TThe Membership Benefits Committee is comprised of Mary McNeil. Objectives of the Membership Benefits Committee include:
o Increase membership by enhancing what we provide to members.
o Increase the number of support groups and local contact persons particularly in eastern Canada.
o Conduct meetings with Support Group Leaders to discuss SjSC updates, available resources, and an opportunity to share ideas with other leaders.
o Continue to improve the resources available to support group leaders to help them carry out their essential roles.

The Membership Benefits Committee introduced our Members Only Virtual Town Halls in 2021. We welcomed 4 guest speakers to give a short presentation and then opened the floor to our members to ask questions. This event was established when the committee realized that there is not much time for Q&A during our National Patient Conference and wanted to give our SjSC members special access to Sjögren's specialists. 361 members joined us in 2021 for this inaugural year of the Members Only Virtual Town Halls and increased our membership by over 80 members!

Much of our Sjögren's support services are provided through local Support Groups and Contact Persons. We currently have 17 support groups across Canada and 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 our leaders continue to hold virtual meetings via Zoom.

Awareness Committee

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

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

In 2021, the SjSC launched "July is Canadian Sjogren's Awareness Month". Every day during the month of July, a Sjogren's information graphic was posted on Facebook, Instagram and Twitter. Members were encouraged to share the postings with friends and family.

In 2021, the SjSC Board of Directors and Awareness Committee completed our new "What is Sjögren's" brochure. This brochure is our primary "calling card" to educate patients and the public about Sjögren's and to promote our organization. The SjSC mailed over 8000 brochures to Sjögren's specialists, Rheumatologists, Support Groups, patients and the general public in 2021.

What is Dry Eye Disease?

Dry Eye Disease is an inflammatory condition in which either the tear film evaporates too quickly, or tear production is too low. The result is irritation, blurred vision, grittiness, burning, pain, corneal ulcers, redness, photosensitivity, and infections. Although up to 30% of Canadians suffer from dry eyes, over 90% of people living with Sjögren's deal with the most severe symptoms of dry eye.

The tear film is made up of three main components: The watery portion of the tears comes from the lacrimal glands and contains lubricants and special proteins that fight off infection and maintain the health of the surface cells. The mucous portion thickens the tear film and helps maintain a slippery surface so that the lids can move over the surface easily. The oils from the meibomian glands in the eyelids sit on the surface of the tear film to prevent evaporation. Inflammation occurs when these three components become compromised and unstable.

Monitoring Dry Eye Disease

It is essential that individuals with Sjögren's see an optometrist and/or ophthalmologist on a regular basis. These eye-care specialists are trained to perform diagnostic tests to assess tear production, tear stability, tear distribution and overall health of the eyes. They may consider prescribing anti-inflammatory drops designed to help increase natural tear production.

Self-Care Treatment of Dry Eyes

There are many treatment options that people with Sjögren's should consider for relief of dry eye symptoms. Regular and proactive use of moisturizing drops throughout the day is the foundation of dry eye treatments. Other important strategies include taking 2000 mg per day of omega-3 supplements, cleaning your eyelids, using warm compresses, taking blinking breaks, humidifying your home and workplace, and wearing sun and moisture chamber glasses. Special attention to overnight eye care such as using gels, ointments, eye masks, and humidifiers will allow eyes to heal.

What is Dry Mouth?

Sjögren's patients frequently complain of dry mouth or lack of saliva particularly in the throat and lips. Saliva, with its watery and mucous components, is produced by three pairs of major salivary glands and hundreds of minor salivary glands located on the tongue, palate, lips and cheeks. Saliva preserves and maintains oral health and function. Prolonged dry mouth may result in difficulty speaking, tasting, chewing, swallowing, and digesting food, as well as an increased risk of dental decay.

How Do I Manage My Dry Mouth?

Dry mouth is not the same as thirst. While drinking water can satisfy a thirst, it does not relieve dry mouth over an extended period and can make the mouth feel drier: when the water is swallowed, so is the saliva. Some techniques to stimulate saliva release include:

- massaging of glands in the cheeks or under the tongue;
- chewing gum (xylitol-containing);
- sucking on a hard object (cherry pit, smooth button, pebble, or xylitol-containing lozenge);
- applying dry mouth relieving products (gels, sprays, adherent discs, or rinses);
- taking prescribed medications

All of these may help on a temporary basis. No one product or technique works for everyone. To rehydrate the mouth, oil-pulling with virgin coconut oil may help.

How Do I Take Care of My Teeth?

Good oral health is essential. Brushing the teeth/mouth with a soft toothbrush upon waking, after meals and before bed are key techniques along with daily flossing, use of either a fluoride-containing or remineralizing toothpaste, use of fluoride rinses, and regular 3 to 6 month visits to dental teams. Your dentist may also suggest the application of silver diamine fluoride (SDF) to reduce oral decay-causing bacteria and remineralize the teeth. Since a dry mouth tends to be more acidic, rinsing with baking soda in water (5 mL per litre of water) can raise the pH and reduce acidity.

What is the Sjögren's Society of Canada (SjSC)?

Formed in 2006, the SjSC is a national, non-profit organization dedicated to improving the lives of Sjögren's patients in Canada.

Mission

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.

How Will the Society Work for You?

Join today and receive the following benefits of membership:

Patient Support: Access to an expanding network of local support groups and contact persons.

List of Sjögren's Specialists: The SjSC maintains and makes available to its members, a list of rheumatologists, dentists and ophthalmologists who are experts in Sjögren's.

Newsletter: Our quarterly Connections newsletter is filled with educational information from diagnosis to treatment, hints for daily living, upcoming events, research, and much more.

eNewsletter: Our monthly eNewsletter features tips for living with Sjögren's along with upcoming events and fundraisers.

Discounts: On National Patient Conferences and books.

Education:

- Annual National Patient Conference featuring presentations from experts about Sjögren's-related topics, as well as exhibitors showcasing the newest products.
- Educational brochures and posters for patients and professionals.
- Support group meetings often feature expert speakers.

Advocacy & Research: With the help of our Board of Directors and our Medical Advisory Board, the SjSC is committed to monitoring Sjögren's-related issues in Canada, encouraging research into Sjögren's, and informing patients about new treatments and research updates.

Join the Sjögren's Society of Canada TODAY!
www.sjogrenscanada.org or call 1-888-558-0950

Sjögren's Society of Canada,
31 Mechanic Street, Suite 201 Paris, ON N3L 1K1
Toll Free: 1-888-558-0950 • Local: 519-302-0051
Email: info@sjogrenscanada.org
www.sjogrenscanada.org
Federal Registered Charity #81858 8956 RR0001

What is Sjögren's?

Dry eyes, dry mouth, fatigue, and joint pain are the hallmark symptoms of one of the most prevalent autoimmune diseases that affects an estimated 1% of Canadians, 90% of whom are women.

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is Sjögren's Treated?

e are numerous over-the-counter products that provide symptomatic relief for various aspects of disease. There are a few prescription medications may be helpful in treating dry eyes, dry mouth and symptoms depending on the type and severity. unosuppressive medications are used to treat serious n complications. Learn more about treatment options your doctor and by participating in a local support p. Educating yourself is very important in managing ren's.

e is currently no cure for Sjögren's. It is a serious and ntially progressive disease but is generally not fatal. phoma (lymph node cancer) may occur in up to 10% of nts with Sjögren's, but it is generally slow growing and ed with effective drug protocols. It is also important for ren's patients to be monitored for organ involvement, as in the liver, kidney and lungs. In 30% of patients, ren's will co-exist with other autoimmune diseases as rheumatoid arthritis or lupus.

Who Does Sjögren's Affect?

- Approximately 1% of the population
- 9 out of 10 patients are women but the number of men is increasing
- Average age of onset is between 35-65 although it can occur in all age groups including children

greatly impair their quality of life. Undiagnosed patients consult several specialists about Sjögren's-type symptoms not knowing these symptoms are connected by a common disease. Sjögren's can mimic other diseases such as rheumatoid arthritis, lupus, multiple sclerosis or fibromyalgia, further complicating diagnosis. Early diagnosis and proper treatment is essential to prevent serious complications associated with Sjögren's.

What Kind of Doctor Treats Sjögren's Patients?

Talk to your health care provider if you experience dry eyes and/or dry mouth for more than three months and have other commonly associated Sjögren's-type symptoms. Rheumatologists usually have primary responsibilities for managing Sjögren's patients. Eye practitioners (optometrists or ophthalmologists), dentists, or ear, nose and throat specialists (otolaryngologists) are usually the first to detect Sjögren's and can treat the site-specific symptoms. It is recommended that patients see their rheumatologist, eye care and dental care providers every 6 months to monitor symptoms and potential complications.

There are several other blood tests which your doctor may use as part of your evaluation:

- ANA (Anti-Nuclear Antibody): Found in 70% of Sjögren's patients and those with other autoimmune diseases.
- SS-B (or LA) antibodies in Sjögren's: 40% of Sjögren's patients are positive for SS-B.
- RF (Rheumatoid Factor): 60-70% of patients with Sjögren's are positive for RF.

Ways Sjögren's Can Affect Your Body

Headaches
Altered taste and smell
Swollen salivary glands
Increased dental decay
Heartburn, gastro-esophageal reflux disorder (GERD), dry cough
Digestive issues, stomach upset, gastroparesis, autoimmune pancreatitis
Vaginal dryness, painful intercourse
Dry skin, skin rashes, cutaneous vasculitis, Raynaud's phenomenon, digital ulceration
Peripheral neuropathy (numbness and tingling in the extremities)
Neurological problems including impaired memory and concentration (brain fog)
Dry, gritty, painful, burning eyes, corneal ulcerations, blurred vision
Dry nose, recurrent sinusitis, nose bleeds
Dry or burning mouth, mouth sores, oral yeast infections
Difficulty speaking, eating, chewing, swallowing
Lymphoma
Recurrent bronchitis, pneumonia, interstitial lung disease
Liver abnormalities, primary biliary cholangitis, chronic active hepatitis
Arthritis, muscle pain, joint pain
Extreme fatigue

Our 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.

In 2021, the SjSC Board of Directors committed 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

The financial statement included in this report summarizes revenues ($90,657) and expenses ($84,224) for the year 2021 resulting in a surplus of $6,433. This is a continuing trend from 2020 when the SjSC ended the year with a surplus for the first time in many years. The surplus was due to an ongoing focus on fundraising, donations, as well as cost cutting wherever possible. At the end of 2021, the Board created a detailed budget for 2022 and, again, committed to 5% of all donations be allocated to research.

2021
Financial Statement

REVENUES	
Donations	$31,655.00
Fundraising	$24,447.00
Memberships	$13,129.00
Events	$12,254.00
CEWS/CERS	$7,970.00
Advertising	$2,000.00
Interest Income	$202.00
TOTAL	$90,657.00

EXPENSES	
Salaries	$51,118.00
Awareness	$9,195.00
Newsletters	$6,336.00
Professional Fees	$5,031.00
Office	$4,078.00
Rent	$3,959.00
Insurance	$2,550.00
Telephone	$676.00
Interest & Bank Charges	$592.00
Directors' Meeting Expences	$476.00
Amortization	$213.00
TOTAL	$84,224.00

We thank you for your ongoing support of the SjSC!

Board of Directors

Dr. Leslie Laing, SjSC President

Mary McNeil, SjSC Vic President

Marc Foisy, Treasurer

Margaret Glasford, Director

Christin McGinn, Director

Julie Yoshikuni, Director

Medical Advisory Board

Arthur Bookman, MD, FRCP, Chairperson

Barbara Caffery, M.S., O.D., F.A.A.O

Miriam Grushka, MSc, D.D.S., PhD

Leslie P. Laing, B.Sc., B.Ed., M.Sc., Ph.D., D.D.S., M.Sc. (Prosthodontics), FRCD(C)

Shalu Pal, O.D., F.A.A.O., F.S.L.S

Janet Pope, MD, MPH, FRCPC

C. Lisa Prokopich, O.D., MSc

Allan Slomovic, M.A., MD, FRCSC

Sjögren's Society of Canada
31 Mechanic Street, Suite 201
Paris, ON Canada
888-558-0950
www.sjogrenscanada.org
info@sjogrenscanada.org