CONQUERING Sjögren's

March/April 2022

Help Spread Awareness During Sjögren's Awareness Month

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April is Sjögren's Awareness Month

Sjögren's FOUNDATION

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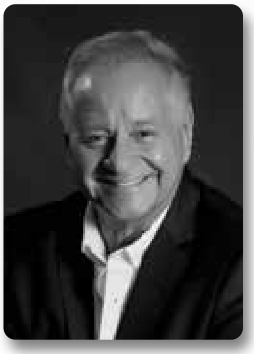
Ask the Doctor: Your Questions Answered



Stephen Cohen, OD

"What are the advances in treating corneal disease?"

by Stephen Cohen, OD, Optometrist

While this is a very broad topic, we can focus on the impact that dry eyes has on the cornea (the clear "cap" over the colored part of our eye). Corneal health impacts dry eyes and conversely, dry eyes can cause injury, damage, or instability of the cornea.

An unstable tear film (common with Sjögren's patients) can adversely affect the surface of the eyes and vice versa. The cornea can swell, which may cause blur, fluctuations and/or haziness of vision. With an inadequate tear film, the cornea also loses some of its protective barrier from the environment, so patients may experience irritation and increased susceptibility to allergies and infections. Therefore, while the overall topic about corneal disease is expansive and treatments can vary depending upon the source of the corneal problem, Sjögren's patients can help to treat corneal issues by having the underlying dry eye problems addressed.

When the cornea is involved with dry eye problems, sometimes treatment is needed first to get the resultant inflammation under control. This could involve lubricating drops, eye masks, cool compresses, allergy eye drops, and/or steroid eye drops. While steroids have potential side effects (some people experience increases in eye pressure and prolonged use can increase cataract development and decrease protection from infection), short-term treatment can be safe and effective to reduce inflammation that often accompanies corneal involvement from dry eyes.

An ongoing and inadequate tear film can lead to corneal inflammation and, potentially, damage. There are some options that can help to create a healthier corneal surface. For example, amniotic tissue has been used for wound healing for a long time, and for the eyes, can help with healing from injuries and ulcers. In recent years, it has been effectively used with dry eye patients, particularly those with Sjögren's disease. In one form, a disk which holds the amniotic tissue is placed on the eye for several days, restoring the corneal surface. "Prokera" is the leading product used for this treatment, but a number of other forms are on the market. There is a liquid form called "Regener-Eyes®," which your doctor can prescribe that will provide these restorative cells.

One of the effects of long-term corneal inflammation (e.g. from chronic dry eyes) is that nerve sensitivity decreases. While this might help to reduce the discomfort associated with dry eyes, it also neutralizes the nerve pathway that tells the brain to tell the eyes to produce more tears. There is a 6-week eyedrop treatment called "Oxervate" that helps to restore this nerve pathway so that they messaging to produce new tears can continue. Getting approval for this treatment takes some time and cooperation with your eye doctor, but the treatment can be effective and long-lasting. A new treatment on the market is called "Tyrvaya," which is a nasal spray that provides another way to stimulate this nerve pathway. This is the same premise as another treatment device that came on the market a few years ago called "TrueTear."

The ability to increase tear production can also assist in maintaining corneal health. There are now three U.S. Food and Drug Administration (FDA)

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approved prescription eye drops for dry eyes that are used chronically to improve tear production and tear quality. The three are: Restasis®, Xiidra, and Cequa™. All three have been found to be safe for long-term use (one drop in each eye twice a day). The first step is to slow or stop the progression because a well-lubricated eye will help to keep the cornea healthy and clear.

To maintain corneal health and integrity, we need a stable tear film that doesn't evaporate before you have the chance to naturally blink again and coat the eyes with new tears. Keeping the glands in the lids healthy (called "meibomian glands," which produces the oils that stop the tears from evaporating too quickly) can help to protect the cornea from irritation, inflammation, and damage. Moist heat has been effective in keeping these glands flowing, and an at-home treatment with "Tranquileyes" goggles can be effective. There are also in-office treatments (e.g., "Lipiflow," "TearCare") that help to clear out these glands and help them to function more effectively. over-the-counter (OTC) products like "Ocusoft" can help clear debris that can block the gland openings, and some OTC lubricating drops provide some additional benefit to the lids and gland health (e.g., "Systane Balance," "Systane Complete," and "Retaine MGD"). Also, a "triglyceride" form of Omega-3's (e.g., "PRN De3" or "Nordic Naturals Omegas") is more naturally absorbable to provide full benefit.

By no means is this an exhaustive list of available options and considerations, but it hopefully provides a basis for additional research and/or discussion with your eye doctor. The issue is more than just producing more tears. Quality tear production can help to maintain corneal health which can then play a critical role in the stability and quality of vision and ocular health. Please remain optimistic as there are many new options on the horizon, and the Sjögren's Foundation is dedicated to the health and well-being of the Sjögren's community.


Nancy Carteron, MD, FACR

"If my family member has Sjögren's, should I get tested?"

by Nancy Carteron, MD, FACR
Rheumatologist

Not under most circumstances. Testing should be driven by the presence of symptoms that suggest an autoimmune disease, like Sjögren's. However, if a family member has symptoms such as, joint pain, severe fatigue, dry eye, dry mouth, vaginal dryness, nerve pain, etc. the possibility of Sjögren's should be considered, and appropriate consultation and testing performed. The presence of Interstitial Lung Disease (ILD), mucosal associated lymphoid tissue (MALT) Lymphoma, or Primary Biliary Cholangitis (PBC) in the family member should raise suspicion for Sjögren's if any of the wide range of possible Sjögren's symptoms are present.

The one situation where a female family member of a Sjögren's patient might seek testing is prior to pregnancy to screen for the presence of the SSA (Ro) and/or SSB (La) autoantibody. These autoantibodies are associated with neonatal lupus and fetal heart block, and preventive strategies can minimize risk. However, there are no studies that assess the risk/benefit of performing these screening tests on family members of a Sjögren's patient. Individual cases should be discussed with a treating physician, rheumatologist, and/or possibly a high-risk fetal medicine specialist.


Esen K. Akpek, MD

"What is the difference between Cequa™ and Restasis® eye drops?"

by Esen K. Akpek, MD
Director, Ocular Surface Disease and Dry Eye Clinic, The Wilmer Eye Institute, Johns Hopkins University School of Medicine

A hallmark of Sjögren's is exocrinopathy, which often results in disabling dry eye and dry mouth. According to the 2016 Sjögren's Foundation *Living with Sjögren's* survey findings, 97% of about 3,000 patients with Sjögren's complained of dry eye: the most common complaint among these patients.[1] More than half (53%) experienced significant dry eye symptoms daily or almost daily with major impact on their quality of life.[2] Corresponding proportions for dry mouth and fatigue were 48% and 45%, respectively. A great majority of the patients in this series (97%) acknowledged having used nonprescription eye drops such as artificial tears or ointments. However, only three quarters (76.2%) were ever given a prescription for a therapeutic eyedrop. Currently, there are several U.S. FDA approved prescription topical treatments [Restasis® (cyclosporin 0.05%), Cequa™ (cyclosporin 0.09%), Xiidra (lifitegrast 5%) and Eysuvis (loteprednol etabonate 0.25%)] available for treatment of dry eye. However, none is specific for treatment of patients with underlying Sjögren's.

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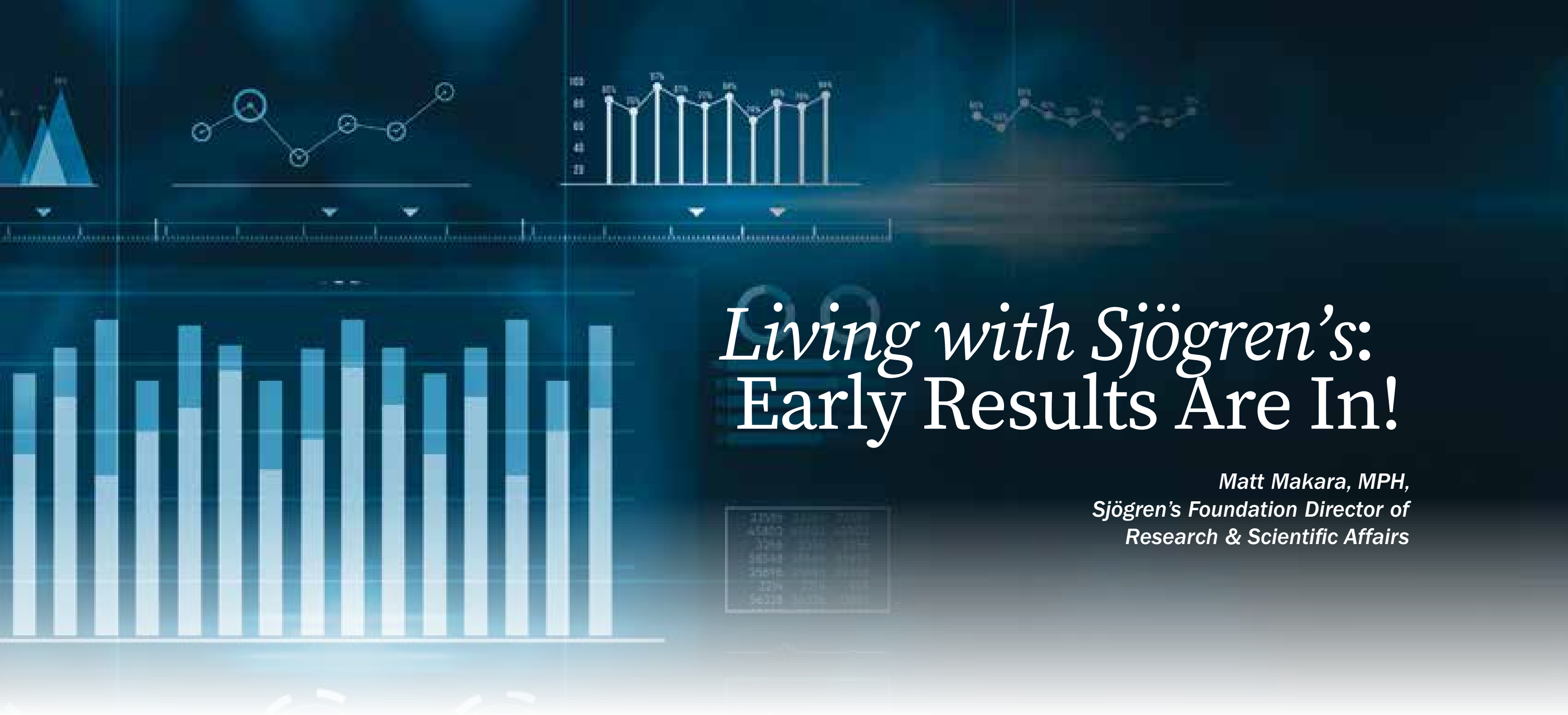

Living with Sjögren's: Early Results Are In!

Matt Makara, MPH,
Sjögren's Foundation Director of
Research & Scientific Affairs

We're excited to share some key, early, results from our recent *Living with Sjögren's* patient survey – a project that many of you contributed to by sharing your experience of living with this serious and systemic disease.

This insight will provide researchers with valuable information about the variety and severity of experiences patients with Sjögren's live with; create greater awareness in the Sjögren's community at large about the complexities of the disease; and educate regulatory agencies and pharmaceutical companies about the need for new and systemic therapeutics for Sjögren's.

The online survey was available between October 13, 2021, and November 8, 2021, and open to both Foundation and non-Foundation members.

What Did We Learn?

A total of 3,622 completed responses were received which met the inclusion criteria (i.e., 18+ years old, living in the U.S., with a Sjögren's diagnosis). Table 1 provides detail on who took part in the survey.

Diagnosis

On average, the majority of respondents (63.1%) indicated that they were diagnosed within the last ten years, with 338 respondents having received a diagnosis in 2021. To receive a diagnosis, 77% of respondents indicated they underwent a blood workup and 21% underwent lip biopsy. The average time between seeking and receiving a Sjögren's diagnosis was 47 months, however, the median time for diagnosis was 12 months, indicating a more promising turnaround time between seeking and receiving a Sjögren's diagnosis.

Table 1: Demographics (n=3,622)

Gender		Age	
Type	**%**	**Range**	**%**
Male	3.3	18-29	1.8
Female	96.7	30-39	5.9
		40-49	13.2
		50-59	24.6
		60-69	30.3
		70-79	20.7
		80+	3.5

In this survey, we asked a new question about when you first believe you had Sjögren's, looking back, and more than half of respondents (54%) believe they first had Sjögren's in childhood (<18) or as a young adult (18-35). We also learned that 66% of respondents have blood relatives with Sjögren's and / or another autoimmune disease.

Symptoms

Participants were provided a list of 48 symptoms and asked to indicate how frequently they were experienced and how impactful each had been over the prior year. Frequency rates ranged from 6% to 95%, with 21 symptoms being experienced by >50% of survey respondents. The top ten symptoms experienced weekly or more frequently were dry eyes (90.5%), dry mouth (89.6%), fatigue (80.9%), dry or itchy skin (72.8%), joint pain (71.8%), eye discomfort (70.9%), dry nose (66.6%), trouble sleeping (64.1%),

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This unmet need is recognized by patients[3] as well as treating eye care providers.[4]

Cyclosporin is an immunomodulating drug that has been used since the early 1980s to prevent solid organ rejection after transplantation such as a liver or kidney. Although the exact mechanism of action of cyclosporin is not known, it is thought to be due to inhibition of the intracellular enzyme calcineurin.[5] This results in specific and reversible inhibition of T-lymphocytes with T-helper cells as the primary target. Cyclosporin also inhibits lymphokine production and release, which results in halting the activity of the existing T cells. T helper lymphocytes are well-known to be the major player cells in Sjögren's as well as non-Sjögren's dry eye.[6]

Currently, there are two commercially available cyclosporin eyedrops, specifically approved by FDA to be used in the treatment of dry eye: Restasis® (Allergan Inc., Irvine, CA) and Cequa™ (Sun Pharmaceutical Industries Ltd., Mumbai, India). Restasis® is a cyclosporin 0.05% emulsion (whitish liquid) with castor oil as its vehicle. Cequa™ is a cyclosporin 0.09% solution (clear liquid) with propriety NCELL technology that increases the solubility. Just recently, a generic form of cyclosporin 0.05% emulsion was also approved, although not yet in market. In addition, another cyclosporin product, (Verkazia® 0.1% cyclosporin emulsion, Santen Pharmaceutical Co. Ltd. Osaka, Japan) recently became available to treat a chronic allergic conjunctivitis condition, vernal keratoconjunctivitis, in children and adults. These preparations differ in the concentration of the cyclosporin, the vehicle used, the pH and the osmolarity of the drops as well as whether in solution or emulsion form all of which can play a role in the bioavailability and efficacy as well as tolerability. With the exception of Verkazia (4 times daily), all of them are used twice daily. Also, all of these drops are supplied in preservative free, single use droppers. Unfortunately, thus far there have been no head-to-head studies comparing any of the topical cyclosporin drops in patients with Sjögren's or non-Sjögren's dry eye. Therefore, it is not known whether one brand is superior to the other. The one well-known issue with any topical cyclosporin is the discomfort upon instillation. Some patients might tolerate one brand better than the other, therefore it is reasonable to switch brands if tolerability is an issue. Lastly, some brands might have broader insurance coverage, which might play a significant role in access to treatment. Of note, a compounded

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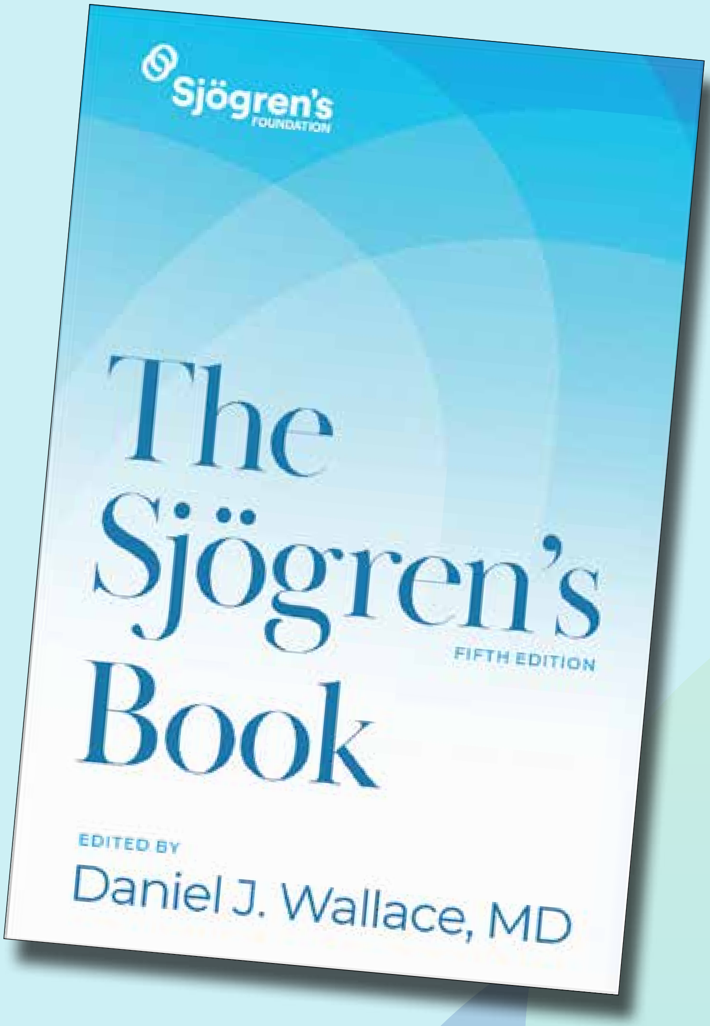

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All books will ship the end of May

The Sjögren's Book, Fifth Edition is a comprehensive and authoritative guide, produced by the Sjögren's Foundation and its medical advisors and edited by a leading authority on autoimmune disorders.

This expanded edition provides readers with the best medical and practical information on this disease, bringing together current thinking about Sjögren's in an easily readable and understandable book and providing important new content on areas not covered in previous editions.

With more than fifty chapters written by leading experts, this book illuminates the major clinical aspects of the disease and is loaded with practical tips and advice as well as scientific advancements in the field.

Recognized as the bible for Sjögren's sufferers, this reliable and informative guide is the first place for patients to look when they have questions about this disabling disease. It is a valuable aid that patients can use while discussing their illness with their physician and an excellent resource for family members.

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cylosporin 1% is also used frequently and might be a cheaper option in the case on non-coverage. Although, the compounded drops are preservative free and can only last a month at a time and need refrigeration in between instillations.

Sjögren’s-related dry eye is a progressive condition that has major negative impact on the quality-of-life of afflicted patients, due to significant ocular discomfort as well as blurred/fluctuating vision. Cyclosporin is a disease modifying agent that has a track record of efficacy in many inflammatory diseases. Long-term topical cyclosporin can be an effective mode of treatment in many dry eye patients with improvement or complete resolution of symptoms and ocular findings.[7,8] ■

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muscle pain (62.2%) and eye fatigue (60.6%)

Respondents were also given the opportunity to rate the impact of each symptom that they had indicated experiencing during the previous year. The top ten most impactful symptoms were fatigue (79.3%), dry eyes (74.7%), dry mouth (73.1%), joint pain (64.8%), trouble sleeping (64.3%), eye discomfort (59.6%), muscle pain (55.6%), brain fog (54.2%), eye fatigue (49.8%) and dry or itchy skin (48.2%).

Once categorized by impact, respondents were asked to consider all of the symptoms they have experienced and indicate which one of these symptoms had the greatest negative impact on their life. Here, fatigue (25%) had the largest percentage, followed by dry eyes (10%), joint pain (8%), dry mouth (7%) and neuropathy (5%).

In addition, the survey examined subjective responses to symptom severity on a scale of 0-10 for dryness, fatigue and pain. Since the responses are subjective, it is important to note that something that is considered mild to one person may be moderate or severe to another. Within the group as a whole, dryness had an average of 6.6, fatigue had an average of 6.4 and pain had an average of 5.0.

Comorbidities

Most Sjögren’s patients experience at least one related health condition in addition to their Sjögren’s, with 95% of patients experiencing at least one related eye condition and 85% having at least one related oral condition. The majority of respondents also indicated having at least one health condition related to the nervous system (83%), reproductive system (72%), immune system (70%), GI tract (66%), blood (64%), respiratory system (57%), cardiovascular system (53%), and urinary/excretory system (50%).

In addition to high rates of dryness-related diagnoses (dry eye, 94%; dry mouth leading to major dental work, 64%; vaginal dryness, 56%); a high percentage of respondents indicated having received a diagnosis of gastroesophageal reflux disease (GERD) (55%), anxiety/depression (50%), neuropathy (45%), sinusitis (40%), irritable bowel syndrome (38%), Raynaud’s syndrome (37%) and hypertension (36%).

Care & Treatments

The majority of patients (61%) say they see between 3-5 different healthcare providers at least once annually and currently use, on average, 3.7 over-the-counter (OTC) treatments and 3.3 prescription treatments to help with their disease.

Respondents were also asked to rank the importance of a new therapy to address a wide range of disease manifestations. When using the top two responses – extremely important or absolutely

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Awareness Ambassadors – *You Stood Up!*

Sjögren's Foundation Awareness Ambassadors are volunteers who go out in their communities, to help the Foundation achieve our mission and vision of providing credible resources and conquering the complexities of Sjögren's through awareness. They do this by implementing Foundation campaigns, targeted at educating healthcare providers in their area about the various manifestations of the disease, new science and current information. Together, these Awareness Ambassadors have reached thousands of healthcare providers throughout the country, making a tremendous impact on the landscape of Sjögren's in the medical community. Ambassadors have done important work over the past year, including bringing both the Sjögren's Foundation Clinical Practice Guidelines for Pulmonary Manifestations in Sjögren's and the newly updated ICD-10 codes for Sjögren's to providers in their communities.

During the spring of 2021, Awareness Ambassadors were provided with 3 copies of the Clinical Practice Guidelines for Pulmonary Manifestations in Sjögren's. While the main purpose of this campaign was to get these guidelines in the hands of rheumatologists and pulmonologists, Ambassadors were also encouraged to share them with their primary care providers. Ambassadors will reach over 150 providers with this campaign!

Sjögren's Foundation

CLINICAL Update

Sjögren's Foundation Clinical Practice Guidelines

Pulmonary Manifestations in Sjögren's

Sjögren's Foundation

Awareness Ambassadors went out into their communities again this fall to deliver information on the new ICD-10 codes for Sjögren's. These new ICD-10 codes took effect in the U.S. beginning October 1, 2021. For this campaign, a handout was created with a brief explanation of the change and a listing of all the new codes. Each participating Ambassador was supplied with 5 handouts and asked to bring them to their healthcare providers when they go for an appointment. Every type of provider and specialty needs to be aware of these new codes. This campaign is still ongoing due to the large number of providers needing the information and timing of patient visits. So far, the handouts have been well received by providers and they appreciate the easy-to-read format.

We are grateful for our Awareness Ambassadors and appreciate their role in helping us reach our mission. Thank you for standing up to support Sjögren's! ■

Want to learn more about these resources?

“Living With Sjögren's”

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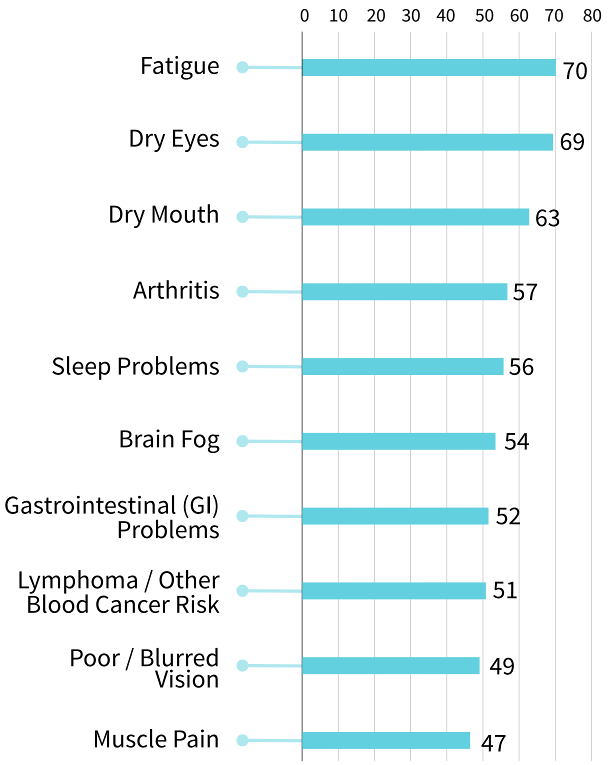
essential – fatigue (70%) was the most highly ranked symptom in need of a therapy. Figure 1 shows the top ten disease manifestations that patients felt were in the greatest need for new treatments.

Importantly, nearly all respondents (97%) stated they wished there were additional treatments available for their Sjögren’s.

Importance of New Therapies (Extremely Important / Absolutely Essential) (%)



Aspects of Home Life & Work

The majority of respondents have needed to make at least one day-to-day change around the house (79%) or at work (64%), and 78% stated their disease gets in the way of things they need to do each day. More than half of respondents reported that Sjögren’s has had a great deal or a lot of negative impact on their ability to exercise (55%) or participating in hobbies, social activities, and extracurricular activities (52%). An inability to concentrate, whether on a single task (39%) or more than one task (46%), was greatly impacted, as was the ability to find the correct word during conversation (45%) and remembering details at home or work (40%).

Emotional Burden & Ability to Cope

A large percentage of respondents indicated experiencing a significant emotional burden (81%), that living with the disease makes everyday a challenge (79%) and that they struggle to cope with their disease (66%). Encouragingly, 69% of respondents said that they are able to live a fulfilling life despite their Sjögren’s.

Financial Burden

Respondents shared that living with Sjögren’s adds a significant financial burden to their life (67%), with dental care listed as the highest annual spending category ($1,580), followed by prescription medications ($1,165) and healthcare appointments/co-pays ($1,050). The average total healthcare cost for Sjögren’s patients per year was $6,769.

Summary

Sjögren’s is a serious and systemic disease, which can have a substantial impact on the physical, social, financial and emotional well-being of patients. Sjögren’s patients are in need of improved treatment and care and experience significant barriers to daily living, with many feeling that living with the disease makes every day a challenge. The data obtained through this survey will be used to inform a variety of Foundation-led efforts geared towards patients, providers and researchers. The data shared within this article is representative of the unweighted group as a whole, except the statements related to costs, and is meant to provide a high-level overview of the findings. More comprehensive and detailed analyses will be shared in the future. ■

The Foundation is grateful to all who contributed to the development of this important work, including The Harris Poll, medical, scientific and patient reviewers, and, of course, to all of the patients who took the time to share their personal experience living with Sjögren’s!

Inaugural State of Sjögren's

Focus on Multidisciplinary Collaboration

> *"Communication and collaboration among the many different specialists who see Sjögren's patients is key." – Janet E. Church, Sjögren's Foundation President & CEO*

Healthcare professionals from a broad range of specialties as well as an array of professional stakeholders joined the Sjögren's Foundation on January 28, for the inaugural State of Sjögren's, which focused on the need for multidisciplinary communication and collaboration in Sjögren's clinical trials and patient care.

Janet E. Church, Sjögren's Foundation President & CEO, began the meeting with an update on the Foundation and highlights from the Foundation's *Living with Sjögren's* national patient survey conducted this past fall. Alan Baer, MD, Chair of the Foundation's Medical and Scientific Advisory Council, and Professor of Medicine and Director of the Jerome L. Greene Sjögren's Syndrome Center at the Johns Hopkins University School of Medicine, then moderated the day's program. This included an overview of the current state of Sjögren's, in depth discussions on how Sjögren's may present in certain specialties, a panel discussion on creating a multidisciplinary team and an overview of the state of research in Sjögren's.

During the overview, Dr. Baer stressed that Sjögren's is, indeed, a disabling, systemic autoimmune disease. Patients also carry a significant burden in terms of financial costs, and this should be a consideration when determining management strategies. He emphasized that accurate diagnosis is key and a multidisciplinary team with expertise in Sjögren's is required for effective patient management. An accurate diagnosis is also key to developing and prescribing effective and safe therapy.

Following Dr. Baer, expert speakers shared insights into both pulmonary and neurological complications seen in Sjögren's, and what others can be looking for that might hint at a Sjögren's diagnosis. The panel portion of this event, which included all of the day's speakers, provided a platform to discuss various successes and barriers faced when trying to coordinate care for patients with Sjögren's with a multidisciplinary team, including advice for others on how to get started.

Because Sjögren's may involve any body organ or system, including other specialists in the management of a Sjögren's patient is critical. Making connections among the different clinicians involved in Sjögren's can be rewarding and motivating for all involved, and integrated care with regularly scheduled communication leads to better patient care and more successful clinical trials. Not all clinicians are knowledgeable about and experienced in Sjögren's, so State of Sjögren's speakers emphasized the need to educate and share experiences with one another and engage in a continued, interactive dialogue.

When talking about the event, Janet Church stressed the need for all healthcare professionals to advocate for Sjögren's and the Foundation with their peers, "Communication and collaboration among the many different specialists who see Sjögren's patients is key. We want to deepen the conversation about engaging multiple disciplines in Sjögren's to enable the best patient care and ensure successful clinical trials. We also want to share the inspirational stories from some of our healthcare professionals who have created positive multidisciplinary partnerships so that others might learn from their successes." ■

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Do you like to be a part of a team that is making a difference?

Then our virtual Team Sjögren’s program is for you!

We are looking for walkers or runners to join our Virtual Team Sjögren’s Training Program. Follow our program and we will prepare you to walk or run either a 5K, 10K, Half or Full Marathon distance over the weekend of June 4-5, 2022, in your hometown!

If you have been looking for an opportunity to set a goal with the support of this community, then our program is for you! Team Sjögren’s allows you to train at your speed with the support of team members and our Team Trainer.

All of our runners and walkers will take part in regular training calls with their fellow team members and also get personal training advice from our experienced members. Then between June 4-5, our runners will all head out to complete their distance!

If you don’t feel you can walk or run in this event, do what so many other patients have done and recruit someone to walk or run in your honor.

To learn more, please contact Kalla Ford, Team Coordinator, at kford@sjogrens.org.

We Run in Honor of the 4 Million Americans with Sjögren’s… We are Team Sjögren’s!

Why I Walk…

I walk to contribute to our path in finding a cure! – Mary

I walk because my life has changed so much since I was diagnosed with Sjögren’s thirteen years ago. When my symptoms started, I typed them into “Google” and found the Sjögren’s Foundation. I shared the information with my Primary Care Physician and was diagnosed with Sjögren’s after blood work was performed.

To no longer be alone in this fight, provides momentum and purpose in my life. I believe it’s my obligation to educate and spread awareness about Sjögren’s with all of my doctors and I have asked each of them to both sponsor and attend our Walk for Sjögren’s event. ■

Walk for Sjögren’s 2022

CELEBRATING OUR STRENGTH

Participate in one of the Spring Walk for Sjögren’s events. To learn more visit: events.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218.

April	**Mid-Atlantic & National Virtual Walk for Sjögren’s** *Saturday, April 9, 2022*
May	**Philadelphia Tri-State Virtual Walk for Sjögren’s** *Saturday, May 7, 2022*
June	**Colorado Virtual Walk for Sjögren’s** *Saturday, June 11, 2022* **Texas Virtual Walk for Sjögren’s** *Saturday, June 11, 2022*

events.sjogrens.org

Awareness never looked so good!

Limited Edition April Awareness Kit


Sjögren's Eyeglass Cloth

Sjögren's Eyeglass Case


Sjögren's Soft T-Shirt

Show your support during April Awareness Month by purchasing a limited-edition awareness kit. Awareness comes in many different forms and this kit is designed to give you items that can create a conversation with family and friends about the disease.

These kits will only be available in April and supplies are limited. Order your kit by calling (301) 530-4420, online at www.sjogrens.org or use the form below.


Sjögren's FOUNDATION

CLINICAL Update

Sjögren's Foundation Clinical Practice Guidelines

Pulmonary Manifestations in Sjögren's

THIS IS Sjögren's

WHAT IS Sjögren's?

Get Sjögren's Support!

	Qty.	Size: S-2XL	Total
April 2022 Awareness Kit $38 ea. • New Sjögren's Foundation Cotton T-shirt • New Sjögren's Foundation Eyeglass Case • New Sjögren's Foundation Eyeglass Cloth • ICD-10 Clinical Update Flier • Sjögren's Pulmonary Clinical Practice Guidelines Sheet • This is Sjögren's Flier • Sjögren's Foundation Referral Tear-Off Sheets • (3) "What is Sjögren's?" Brochures			
Shipping and Handling: U.S. Mail: $7 for first item + $2 for each additional item			
		Total Amount Due	

Mail to Sjögren's Foundation: 10701 Parkridge Blvd., Suite 170
Reston, VA 20191 or Fax to: 301-530-4415

Name ______________________________

Address ______________________________

City ____________ State ______ Zip ________

Telephone ____________

E-Mail ______________________________

☐ Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren's Foundation.

☐ MasterCard ☐ VISA ☐ Discover ☐ American Express

Card Number ______________________________

Exp. Date ________ Security Code ________

Signature ______________________________

IN MEMORIAM

In Memory of Alice Glupe
Karin Blaney

In Memory of Angeline Reeder
Jo Maddox

In Memory of Ann Buffie Pavey
Lisa Buffie

In Memory of Ann Meritt
Deborah Parker

In Memory of Archie Bullard
Hettie Bullard

In Memory of Betty Belbas
Diane McClain-Inman
Laverne Chastain
Bob Smith

In Memory of Betty Hardgrave
Kathy Sivils

In Memory of Bonnie Litton
Linda Phillips

In Memory of Carol Ann Grenko
Edgar Smith

In Memory of Carol Schenkel
Al Wallin

In Memory of Deborah Bales Magill
John Magill

In Memory of Ella Sisler
Joe Sisler
Darla Rae

In Memory of Evelyn Cudney
David Whittaker

In Memory of Florence Fox
Janis Fox

In Memory of Henri Bromberg
Robert Wald

In Memory of Hollie Smith
Martha Brown

In Memory of Jan Gordon
Kevin MccCaffrey

In Memory of Jane Gates
Michael and Diane Corbine

In Memory of Jeanne St-Pierre
Normand Lavoie

In Memory of Joan Fellows
Michael and Betty Lou Aihoshi
Shawn Winters
Kevin Mulcahy

In Memory of Joan Horne
Rebecca Young-Marquardt
Caroline Nowak
Marian Mennella

In Memory of John Pike
Joon Moy Chin

In Memory of Margaret Hartman
Sarah Hartman

In Memory of Marie Branda

In Memory of Marie Driscoll
Charles Musson
Stephanie Wilkinson
Pauline Bishop
Ann Marie Piantedosi

In Memory of
Marta Huerto Frenandez
Juliet Snay

In Memory of Mary Barbato
Stacey Small

In Memory of Mary Holechko
Todd Gould
Robert Robey
John and Barbara Gallina
Jeremy McCallum
Sofia Rodriguez
Donna Mazanowski
Jim and Judy Scott
Mike and Linda White

In Memory of Mary Holechko
Peter, Barbara and Jason Volk
Ryan and Nichole Volk
Susan Keegan
Ellen Wycoff
Michael and Cheri Flanagan
Courtney Nichols
John Schumaker
The Pilgrim Family
Lana Whaley
Sheila Behr
Teresa Hamilton
Jan Miller
Deborah Goetz
Dennis and Mary Gallagher

In Memory of Maureen Hanlon
Marcy Baker
Alicia Pratt
Anne Noonan
Steve Hanlon

In Memory of Mazelle Baird
Emily Borden

In Memory of Nancy Dobert
Bunny Bitner
Jane Kana
Amy Spitzer

In Memory of
Patricia and Elfrida Frank
Diane Stadtmiller

In Memory of Paulette Williams
Mary Lou Custer and the Marlette Class of 1964
Louise and Garth Glazier

In Memory of Richard Haemmerle
Arlene Haemmerle

In Memory of Roosevelt Blackburn
Louise Blackburn

In Memory of Rose Fasone
Jill Greuling
Debra Martinez
Kathryn Polson
Rosemary Egkan
Tim Holmes
Sheila Matteau
Karen Braun

In Memory of Ruth Ann Beach
Lisa and Alison Henry Vasquez

In Memory of Sandra Flesner
Lesley Hicks

In Memory of Sandra Saner
Bank of America match

In Memory of Scott Allen Squires
Connie Holmes

In Memory of Sharon Meyer
Elizabeth Benson

In Memory of Shirley Kaplan
Rochel Kaplan

In Memory of Susan Barb
Barbara Henry
Ray and Betty Vanasse

In Memory of Teresa Vitale
Thomas Vitale

In Memory of Theresa Butler
Catherine Johnston

In Memory of Valetta Nead
Nelda Carpenter

In Memory of Viola Ferrigno
Michael and Sharon Lala
Joanne Medori
Andrea Abdo
Josephine Gagliardi

IN HONOR

In Honor of Adah Stock
Myra Bahme

In Honor of Ann Smithey
Harriet Swift

In Honor of
Anne Denny and Steven Stromberg
Barbara Evans

In Honor of Ardetha More
Mckinnon Family Women With Sjogren's

In Honor of Ariel Weber
Adrienne Jones

In Honor of Aryeh and Alison
Dr. Baraf

In Honor of Barbara Bernheim
Elaine Levin

In Honor of Benjamin Butler
Linda Champion

In Honor of Beth Ann Hatfield
Lindsey Hatifeld

In Honor of Brandon Dunn
Teri Dunn

In Honor of Catherine Siegl
Lindsey Hatfield

In Honor of David Rolader
Joanne Finnick

In Honor of
Debbie and Bob Rosenfeld
Ken and Anne Economou

In Honor of Diane Ott
Myrtle Ott

In Honor of Don Perry
Liz Perry

In Honor of
Dr. Guada Respicio Duque
All your patients with Sjogren's

In Honor of Edythe McPherson
Al and Debbie Herman

In Honor of Elizabeth Hamel
Alexandra and Charlene

In Honor of Ellen Campbell
Stefanie Campbell

In Honor of Ellen O'Brien-Garcia
Dr. Robert Fox

In Honor of Georgia and Sylvester Hobbs
Sam and Paulette Delk

In Honor of Hannah Kaplan
Mr and Mrs Levin

In Honor of James Hand
Sandra Hand

In Honor of Jennifer Brennan
Sheryl Crum

In Honor of Jimmy Dominguez
Barbara Chapman

In Honor of Jocelyn Davis
Judy and Glenn McDowell

In Honor of Joseph Harrington
Adam Robinson

In Honor of Kacie McManus
Shauna Hansen

In Honor of Linda Harris
Elaine Harris

In Honor of Linda Wisch-Davidsohn
Dr. Scott Jeffrey Zashin

In Honor of Lucy March
Judy Rabinovitz

In Honor of Lui and Shirley Sha
Theresa Wong

In Honor of Marilyn Middaugh
Shawna Behnsch

In Honor of Meredith Moses
Gloria Moses

In Honor of Neil Tow
Rachel Schwartz

In Honor of Oscar Ojeda
Norma Mota

In Honor of Robin Burns
Beverly Taylor

In Honor of Scott Elias
Rona Elias

In Honor of Sean Adcroft
Patrice Adcroft

In Honor of Stacey Gallant
Annika Rosenberg

In Honor of Stacey Silberzweig
Joan Fanwick

In Honor of Susan Horst
Carol Watson

In Honor of Thomas Doyle
Diane Doyle

In Honor of Thorne Research
Noah Syndergaard

In Honor of TN
April Danielle

In Honor of Will and Patricia Prout
Sjogren's Researchers

2022 Virtual National Patient Conference

Conquering Sjögren's Together

The 2022 Virtual National Patient Conference

Delivered to you in the comfort of your own home!

Friday, April 29th – 1:00 pm - 5:00 pm (EDT)

Saturday, April 30th – 1:00 pm - 5:30 pm (EDT)

This two-day online educational experience will help you understand the complexities of Sjögren's so you can take control of your health. Learn more about the disease from leading Sjögren's experts to better manage symptoms you have today and issues you need to watch for in the future.

Register online at www.sjogrens.org

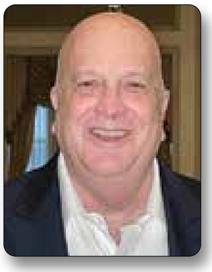
Sjögren's
FOUNDATION

Friday, April 29, 2022 *All times are Eastern Time*

1:00pm Welcome and Opening Remarks

Janet E. Church
Sjögren’s Foundation President & CEO

1:10pm Sjögren’s Overview



Daniel J. Wallace, MD, FACP, MACR

Dr. Wallace will present a comprehensive review of Sjögren’s disease including the range of symptoms that patients experience. He will give special attention on issues not covered by other presentations and will offer thoughts on treatment options, practical tips for managing symptoms, labs needed for best care, and when to add specialists to your medical team.

Dr. Daniel J. Wallace is a Rheumatologist and Internist in Beverly Hills. He is the Director of the Lupus Clinic at Cedars-Sinai. Dr. Wallace also serves as a professor of medicine at the David Geffen School of Medicine at UCLA and the Associate Director of the Rheumatology Fellowship Program at Cedars-Sinai Medical Center. He is an Associate Member of the Foundation’s Medical & Scientific Advisory Board, Sjögren’s OMERACT and the FNIH Sjögren’s Committee. A key leader in Sjögren’s, he is both the editor and author of multiple chapters in the fifth edition of *The Sjögren’s Book*.

2:00pm Exploring Sjögren’s Spotlight

2:10pm Gastrointestinal Issues in Sjögren’s

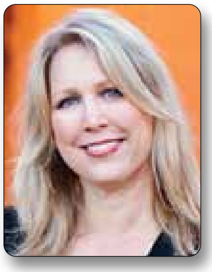
Lucinda Harris, MD

Dr. Harris will discuss the different gastrointestinal issues associated with Sjögren’s including dysmotility, gastroesophageal reflux disease, gastroparesis, irritable bowel syndrome, and more. This session will help you understand how to decipher your symptoms and get the correct care and treatment needed for best management.

Dr. Lucinda Harris is a Gastroenterologist and Associate Professor of Medicine in the Division of Gastroenterology and Hepatology at Mayo Clinic in Scottsdale, AZ. A current fellow with the American Gastroenterological Association she has spent over 30 years treating patients with digestive diseases including Sjögren’s. Throughout her career Dr. Harris has published extensively on IBS and other digestive diseases.

2:50pm Exploring Sjögren’s Spotlight

3:00pm Foundation Update



Janet E. Church
Sjögren’s Foundation President & CEO

Janet Church will present the results from our recent patient survey, Living with Sjögren’s, as well as share current Foundation updates.

3:30pm Exploring Sjögren’s Spotlight

3:40pm Ocular Manifestations of Sjögren’s

Vatinee Y. Bunya, MD, MSCE

Approximately 95% of Sjögren’s patients experience dry eye. Dr. Bunya will share how Sjögren’s impacts eyes and what you need to know about caring for your dry eyes. Understand the tests that your doctor needs to perform and the available treatments to help keep your eyes as healthy as possible. She will also share what is on the horizon for dry eye therapy.

Dr. Vatinee Bunya is the Co-Director of the Penn Dry Eye & Ocular Surface Center. She cares for patients with dry eye, Sjögren’s, and other disorders that affect the ocular surface. Dr. Bunya has extensive experience in the study of dry eye and diseases that affect the ocular surface and eyelids. She also has a special interest in the study of Sjögren’s. Dr. Bunya has been the principal investigator for several dry eye clinical trials and receives funding from the National Eye Institute. She currently is working to develop better ways to measure dry eye and to screen patients for Sjögren’s.

4:20pm Product Showcase

Kimberly Kelley, PharmD

Sjögren’s patients use a number of over-the-counter and prescription products to treat their various complications. This session, presented by Dr. Kimberly Kelley, will highlight an array of products that help Sjögren’s patients live more comfortably.

Dr. Kimberly Kelley has been a Doctor of Pharmacy in Arizona for 35 years. She has had an expansive career as a Director of Pharmacy, Operations Manager for a Specialty Pharmacy, Faculty Associate with the University of Arizona and Midwestern University Colleges of Pharmacy, and as a business owner providing Pharmaceutical Consulting across the United States. She is a member the Sjögren’s Foundation Board of Directors and a patient.

4:50pm Day One Wrap-up

Saturday, April 30, 2022 *All times are Eastern Time*

1:00 pm Opening Remarks & Awards

Janet E. Church
Sjögren's Foundation President & CEO

Donald E. Thomas, MD, FACP, FACR
Chair of the Board of Directors

1:30pm Oral Manifestations of Sjögren's

Ava Wu, DDS

Approximately 93% of Sjögren's patients have dry mouth and it's important to understand the daily care needed to minimize the impact to your oral health. Dr. Wu will share the range of issues that can be caused by dry mouth, offer recommendations for successful management, and share tips on how to work with your dentist for best long-term management. She will also share what's new on the horizon for dry mouth and oral care.

Dr. Ava Wu is an oral medicine specialist in San Francisco, CA. She cares for patients experiencing the oral component of Sjögren's, in which the body's immune system mistakenly attacks its own moisture-producing glands, causing a dry mouth among other possible symptoms. In her research, Wu studies how Sjögren's develops and ways to treat the complications of dry mouth. She is a current member of the Foundation's Board of Directors and is author of a chapter in the fifth edition of *The Sjögren's Book*.

2:10pm Exploring Sjögren's Spotlight

2:20pm The Impact of Sjögren's on Organs – Kidneys, Liver, Pancreas

Chadwick Johr, MD

We all know that Sjögren's is a serious and systemic disease, but how involved are your internal organs? We will take a closer look at how Sjögren's can involve your kidneys, liver and pancreas. Dr. Johr will share what we need to know, tests we need to be aware of, and how we need to work with our medical team to ensure proper management and/or treatment for these organs.

Dr. Chadwick Johr is an Associate Professor of Clinical Medicine in the Division of Rheumatology at the University of Pennsylvania and the Director of the Penn Sjögren's Center. He is a current member of the Foundation's Board of Directors and is author of a chapter in the fifth edition of *The Sjögren's Book.*

3:00pm Exploring Sjögren's Spotlight

3:10pm Musculoskeletal Pain and Sjögren's

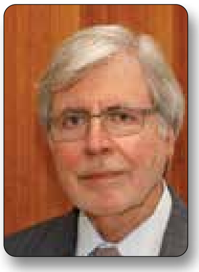
Sara McCoy, MD

Joint and muscle pain are common symptoms of Sjögren's patients. In fact, approximately 83% of patients suffer from musculoskeletal pain. In this presentation, Dr. McCoy will share how Sjögren's impacts the musculoskeletal system, how doctors determine the root of the pain, then she will offer ideas on treatment and management.

Dr. Sara McCoy is a rheumatologist and the Director of the University of Wisconsin Health Sjögren's Clinic. She is also a faculty member in the Division of Rheumatology within the Department of Medicine at the UW. Dr. McCoy is a current recipient of the Foundation's High Impact Research Grant and was also a 2021 recipient of the Foundation's Outstanding Abstract Award. She publishes frequently on Sjögren's-related topics and has helped lead a team in the publication of the 2016 *Living with Sjögren's* survey data. Additionally, Dr. McCoy served on the Consensus Expert Panel for the Foundation's pulmonary clinical guidelines for Sjögren's.

3:50pm Exploring Sjögren's Spotlight

4:00pm Research That Will Change Sjögren's



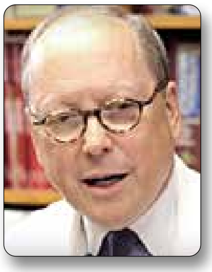
Steven Carsons, MD

We are at an exciting time in Sjögren's research! There are new projects looking at Sjögren's and autoimmune disease in new ways. Dr. Carsons will share some of the most interesting research happening today, what we might learn, and how it could change the way Sjögren's is diagnosed and treated in the future.

Dr. Steven Carsons is a rheumatologist and Professor in the Dept. of Medicine and Senior Associate Dean- Research, at the NYU Long Island School of Medicine. He is also the Chief of Rheumatology, Allergy and Immunology, NYU Langone Hospital-Long Island. He has been a long supporter and friend of the Foundation, previously serving on the Board of Directors and currently serves as Chair of the Foundation's Clinical Practice Guidelines Committee. He is a highly sought-after clinician and leader in Sjögren's and is author of a chapter in the fifth edition of *The Sjögren's Book*.

Saturday, April 30, 2022 *(continued)*

4:40pm Clinical Trials: What Every Patient Should Know



Herbert S. B. Baraf, MD, FACP, MACR

This session will give an overview of clinical trials: how they are managed and analyzed, the process and timing between trial phases, and why patient participation is critical to get new Sjögren's therapies to market. Dr. Baraf will also highlight what patients need to know about participating in clinical trials and help you understand your patient rights.

Dr. Baraf is a founding member and former managing partner of Arthritis and Rheumatism Associates, one of the country's largest private practice rheumatology groups. He founded and directed his practice's clinical research division, the Center for Rheumatology and Bone Research, where he has served as principal investigator for over 400 clinical trials. He is a Clinical Professor of Medicine at The George Washington University School of Medicine and a Clinical Associate Professor of Medicine at the University of Maryland School of Medicine. He is a Master of the American College of Rheumatology and a recipient of the College's Paulding Phelps Award. Dr. Baraf also previously served on the Sjögren's Foundation Board of Directors.

5:20pm Conference Recap and Closing Remarks

Janet E. Church
Sjögren's Foundation President & CEO

Donald E. Thomas, MD, FACP, FACR
Chair of the Board of Directors

5:30pm Conference Adjourns

QUESTIONS?

Please visit our National Patient Conference page at www.sjogrens.org or call 301-530-4420

Register online at www.sjogrens.org

2022 Virtual National Patient Conference

Conquering Sjögren's Together

Registration Form

Registrant

Name ____

Street Address ____

City ________________________ State __________ Zip ____________

Telephone ______________ E-mail ________________________________

Fees – please check appropriate fee

☐ **Member $80.00** ☐ **Non-Member $100.00**

Payment – Mail to Sjögren's Foundation, 10701 Parkridge Blvd., Suite 170, Reston, VA 20191

☐ Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren's Foundation.

☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx

Card Number __________________ Exp. Date ________ CC Security Code ______

Signature ____

Please Note

Registrants must have a device with internet access to join the conference. Recorded videos of each lecture will be available to registrants for 60 days after the conference.

Conquering Sjögren's
Sjögren's Foundation Inc.
10701 Parkridge Blvd., Suite 170
Reston, VA 20191
Phone: (301) 530-4420
Fax: (301) 530-4415

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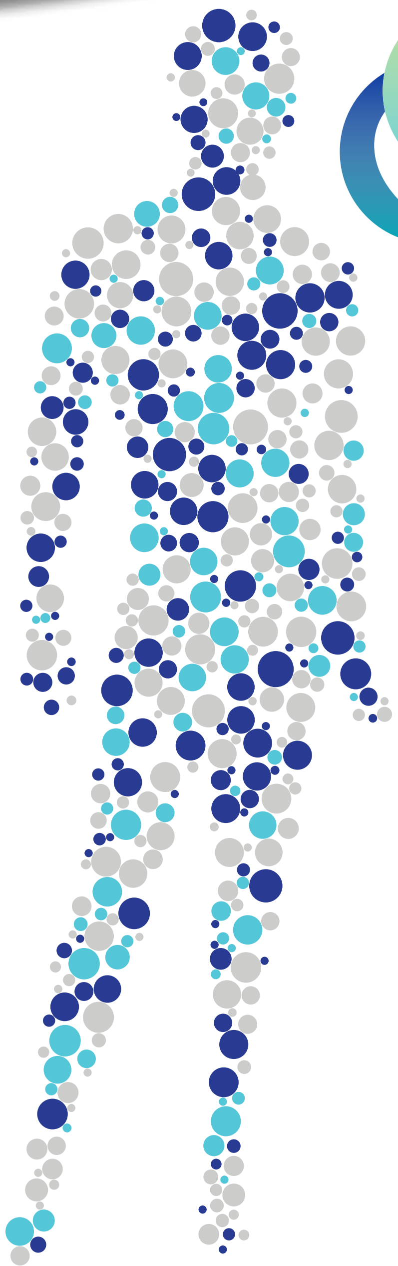

April is Sjögren's Awareness Month

Sjögren's Awareness Month was first established in 1998 when New York Congresswoman, Louise Slaughter, read it into the Congressional Record. Each year the Foundation works to keep the spirit of national awareness alive every April. As we pass the two-year mark into a the COVID-19 pandemic, it is even more important that we come together as a virtual community to raise awareness of the complexities of Sjögren's.

In our online #ThisIsSjögrens campaign, we are highlighting you. You are the voice and the face of the Foundation, and it is the collection of your experiences that portrays this complex disease. During these past two years apart, we not only want to raise awareness of Sjögren's, but also come together to share how patients are effectively coping with the disease and offer advice for others, including self-care tips.

Every day in April, we will highlight a different patient on our website and social media accounts and share a glimpse into their life with Sjögren's. While each daily post will only give a small insight into what is Sjögren's, by the end of the month, we believe these 30 posts will showcase the complexity of the disease.

Visit www.sjogrens.org to learn more about our #ThisIsSjögrens campaign.

Sjögren's
FOUNDATION