

CONQUERING Sjögren's

July/August 2023

Inside this Issue

National Patient Conference Recap

Clinician's Corner: Corneal Abrasions

Dry Eye Awareness Month

Educating Providers

Patient-to-Patient



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Table of Contents

National Patient Conference Recap	3
Dry Eye Awareness Month	9
Clinician's Corner: Corneal Abrasions	11
Patient-to-Patient	13
Educating Providers	17
In Honor and Memoriam	19

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CONQUERING Sjögren's

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Sjögren's Foundation 2023 National Patient Conference



Alan Baer, MD



Cole Sterling, MD



Michael Brennan, DDS, MHS



Janet E. Church, CEO



Brent Goodman, MD



Esen Akpek, MD



Monique Vaughan, MD



Ghaith Noaiseh, MD



Blake M. Warner, DDS, PhD, MPH, ABOMP

The Sjögren's Foundation hosted our annual National Patient Conference on April 21st & 22nd. This year marked 22 years since our first conference! We have grown so much since that first conference in Los Angeles in April of 2001 when 200 Sjögren's patients came together for two days of learning and connection. This year, over 1,200 people joined us virtually from all around the world! We are proud to say we had attendees from all 50 United States and 20 different countries including Australia, Belgium, Canada, Cyprus, the Czech Republic, England, Germany, Greece, India, Ireland, Italy, Mexico, New Zealand, Scotland, South Africa, Taiwan, Trinidad and Tobago, and the United Arab Emirates!

Our two-day virtual educational experience helped attendees understand the complexities of Sjögren's and learn more about their disease and how best to manage symptoms. Attendees had the opportunity to learn from leading Sjögren's experts and were able to ask them questions, right from the comfort of their own homes, in real time. Topics included information about the most common symptoms of Sjögren's disease as well as manifestations patients should be aware of to protect their health. The following is a full list of this year's topics and presenters:

- **Sjögren's Overview** – Alan Baer, MD
- **Lymphoma and Other Cancers in Sjögren's Patients** – Cole Sterling, MD
- **Oral Manifestations in Sjögren's** – Michael Brennan, DDS, MHS
- **Sjögren's Foundation Update** – Janet E. Church, CEO
- **Autonomic Dysfunction in Sjögren's** – Brent Goodman, MD
- **Ocular Manifestations in Sjögren's** – Esen Akpek, MD
- **Interstitial Cystitis and Recurrent UTIs** – Monique Vaughan, MD
- **Vasculitis in Sjögren's** – Ghaith Noaiseh, MD
- **Understanding Research in Sjögren's** – Blake M. Warner, DDS, PhD, MPH, ABOMP

In addition to learning from experts and asking questions, our attendees also learned from each other by engaging in supportive and lively conversation using the conference platform's chat feature. We saw a bountiful and uplifting sharing of experiences, peer tips, and

“2023 NPC Recap” *continued from page 3* ▼

support and connection happening between attendees in the chat. Our board chair, Dr. Donald Thomas, even surprised attendees by popping in the chat and graciously answering questions and providing tips.

We are proud to say that 97% of those completing the post event survey stated that their attendance at the conference increased their knowledge/understanding of various aspects of Sjögren’s! Those who registered can review the conference recordings until April 30, 2024, to revisit topics they wanted to hear again or perhaps missed due to a schedule conflict during the live conference. This ability to revisit presentations will continue to increase knowledge and understanding beyond the conference and we are excited to be able to offer this wonderful benefit to attendees as part of their registration. If you attended the conference and wish to revisit it, you can find easy instructions on how to do so in the day-of-event guide you received for the conference via email on April 20th, as well as in the recap emails sent both Friday and Saturday of the conference.

Did you miss the conference and would still like to see the information? Visit page 7 to find out how to purchase the 2023 National Patient Conference replay.

2023 Volunteer Award Recipients

The Sjögren’s Foundation hosts our annual volunteer awards celebration every year at the National Patient Conference. This year we honored three amazing volunteers with awards. We are so grateful for their contributions to the world of Sjögren’s and the work of the Foundation.



2023 Healthcare Professional Award

Donald E. Thomas, Jr., MD, FACP, FACR

This award recognizes a healthcare professional who has given their time and talents to educate their community about Sjögren’s while also promoting the mission of the Sjögren’s Foundation.

Donald E. Thomas, Jr., MD, has a special interest in systemic autoimmune diseases, especially Sjögren’s and lupus. He has served as Chair of the Board of Directors of the Sjögren’s Foundation for the past two years and will transition to Immediate Past Chair

continued page 5 ▼

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on July 1, 2023. He is in private practice in Greenbelt, Maryland, and he also enjoys teaching other healthcare providers about lupus and Sjögren's in his capacity as an Associate Professor of Medicine at the Uniformed Services University of the Health Sciences in Bethesda, Maryland. He is passionate about empowering people to learn to combat their medical problems, which eventually drew him to write the highly acclaimed patient education book "The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families." Although he has written a book on lupus, he is equally knowledgeable in Sjögren's, and the Foundation has turned to him many times as a speaker at our patient conferences, including co-hosting with Janet. Don has also delivered an outstanding primary care CME course through Pri-Med. This course trained over 4,500 PCPs, the vast majority of whom (94%) reported that they would change their practice because of his course. This course was so popular and successful that Don is teaching a second CME course with Pri-Med on the systemic nature of Sjögren's and how to care for Sjögren's patients. He is an incredible educator and supporter of patients, and we are grateful for his leadership and honored to have worked with him so closely for the past several years!



2023 Volunteer Leadership Award

Nancy Crabbe

This award recognizes a Foundation volunteer who has helped to increase awareness, supported patients and their families, and fully supported the mission of

the Sjögren's Foundation.

Nancy Crabbe was diagnosed with Sjögren's nearly 40 years ago. Prior to and for some time after her Sjögren's diagnosis, she enjoyed a long career as a public librarian. Unfortunately, complications of her Sjögren's forced her to retire a bit earlier than expected. After her retirement, in addition to spending more time researching Sjögren's, Nancy also connected with the Sjögren's Foundation and was eager to help others.

Nancy has been a member of the Foundation for almost 20 years. During that time, she has been an

amazing supporter of our programs, services, and events. Most notably, Nancy served as the Sjögren's Support Group Leader for the San Francisco Bay Area for the past 15 years, only recently retiring from this role. During her time as leader, she took calls, led meetings, helped countless patients find the information they needed, and provided comfort in knowing they were not alone in dealing with their disease.

In addition to the support group, Nancy has been a regular annual supporter of the Foundation. Over the years she has participated in and donated to Walk for Sjögren's events, Sip for Sjögren's events, and seasonal campaigns. She has also attended nearly all the Foundation's patient conferences and educational events and we can always count on her to share her voice during our impact calls and while raising awareness in her medical community. We are truly grateful for Nancy's continued support over the years and we are so proud to name her our 2023 Volunteer Leadership Award!

2023 Development Award

Carroll Petrie Foundation

This award recognizes an individual or group that has contributed to increasing fundraising for the Foundation.

The Carroll Petrie Foundation is a private family foundation that was established in 1996 by Mrs. Carroll Petrie to continue her support of initiatives important to her and her late husband Milton Petrie. Carroll passed away in 2015 and the Foundation is currently led by a board of directors including her grandchildren and her niece, Camille Manning. The Foundation has generously supported museums, hospitals, and non-profit organizations, as well as assisted smaller and individual charitable causes. Today, it invests in the care and protection of animals and the natural world and individual causes supported by its Board of Directors. The Sjögren's Foundation was introduced to the Carroll Petrie Foundation more than a decade ago through Camille who is also a fellow Sjögren's patient. The Sjögren's Foundation is proud to have built such a wonderful relationship over the past 10 years with Camille and the Carroll Petrie Foundation. We are incredibly grateful for their continued support and the impact they have had on increasing Sjögren's awareness and education. ■



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Sjögren's Foundation 2023 National Patient Conference

The 2023 Sjögren's Foundation National Patient Conference is Now Available for Purchase!

Did you miss the 2023 National Patient Conference? We've got you covered! We've made it easy for you to still get the vital information that you need by offering post-conference access to the 2023 National Patient Conference presentations. With your purchase, you will have the entire conference lineup available to replay, including:

- **Sjögren's Overview** – Alan Baer, MD
- **Lymphoma and Other Cancers in Sjögren's Patients** – Cole Sterling, MD
- **Oral Manifestations in Sjögren's** – Michael Brennan, DDS, MHS
- **Autonomic Dysfunction in Sjögren's** – Brent Goodman, MD
- **Ocular Manifestations in Sjögren's** – Esen Akpek, MD
- **Interstitial Cystitis and Recurrent UTIs** – Monique Vaughan, MD
- **Vasculitis in Sjögren's** – Ghaith Noaiseh, MD
- **Understanding Research in Sjögren's** – Blake M. Warner, DDS, PhD, MPH, ABOMP
- **Sjögren's Foundation Update** – Janet E. Church, CEO
- **Product Showcase** – Susan Barajas, Sjögren's Foundation Chair-Elect

Your post-conference access will be available until April 30, 2024. During that time, you can watch and rewatch the conference and presentations as many times as you'd like. You can leave and come back, watching one presentation at a time, or watch it all the way through from start to finish! It's up to you!

*Full access to the post-conference recording
is available for \$125*

Access can be purchased in our store.

If you have any questions or need additional information you can contact the Foundation office at (301) 530-4420.

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July is Dry Eye Awareness Month: *Dry Eye & Sjögren's*

Chronic dry eye affects millions of Americans and 95% of Sjögren's patients identify with having dry eyes, according to the recent 2021 *Living with Sjögren's* patient survey, conducted by The Harris Poll on behalf of the Sjögren's Foundation.

In 2005, the Sjögren's Foundation, along with coalition partners, asked Congress to officially declare July "Dry Eye Awareness Month" to help increase awareness of dry eye, while also educate the public about symptoms and treatment options for dry eye. The declaration of July as Dry Eye Awareness Month helps ensure that a primary symptom of Sjögren's gets widespread recognition. This is why every July the Foundation works to help educate the public about dry eye symptoms and the possible cause being Sjögren's.

Chronic dry eye has two main causes: decreased secretion of tears by the lacrimal (tear-producing) glands and loss of tears due to excess evaporation. Both can lead to ocular surface discomfort, often described as feeling of dryness, burning, a sandy/gritty sensation, itchiness, visual fatigue, sensitivity to light and blurred vision.

In honor of July being Dry Eye Awareness Month, below are popular dry eye tips from leading Foundation experts aimed to promote dry eye education. To learn more about dry eye awareness month, visit www.sjogrens.org.

Dry Eye Tips:

- Dry eye is a chronic, progressive disease. To help manage and treat your dry eye, it's important to communicate with your eye care professional that you have Sjögren's. You should be checked annually or more often depending on the severity of your dry eyes.
- The mainstay of treatment for blepharitis, a chronic condition that accompanies dry eye and Sjögren's, is warm compresses, lid massage and lid hygiene. If the blepharitis is acute, you might need a prescription antibiotic ointment.
- Apply a warm, wet washcloth or a microwaveable mask to the closed eyes at bedtime and upon awakening for 5 minutes or more to stimulate the oil glands in the eyelids.
- If your eyes are bothered by light, wear sunglasses or try lenses with a FL-41 filter.
- Use non-preserved artificial tears frequently and regularly, even when your eyes feel good. The goal is to keep your eyes comfortable, not to wait until they are uncomfortable.
- Avoid applying anything to the eyelids that can irritate your dry eye; products placed on the eyelid will get into the tear film.
- Dry eye patients often develop or aggravate their environmental allergies. An over-the-counter (OTC) allergy drop (even if preserved) used twice daily may help.
- Eye ointments and gels can blur your vision and are usually reserved for overnight use. If your vision is blurred with artificial tear use, try a less thick (viscous) drop or ointment.
- Try moisture chamber glasses, wrap-around sunglasses, or other glasses, goggles or shields to prevent moisture evaporation and offer protection from air currents that irritate your dry eye.
- When you are reading or looking at a computer screen or TV, take blink breaks to give your eyes a rest and to stabilize the surface of your eyes.
- Consider taking Omega-3 supplements to help the glands in your eyelids produce better quality oil. You may wish to check with your eye doctor first.
- Avoid environmental stresses that worsen dry eye, such as low humidity, drafts from air conditioners or fans, smoke, dust, or excessive makeup. ■

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Stay updated on current Sjögren's clinical trials and how they can benefit you.

New phase 2 and phase 3 trials are happening now!


Clinical trials are a crucial element in medicine and healthcare to help develop drugs that will treat or possibly cure certain diseases. Researchers use clinical trials to test if a drug works, how well it works, how safe it is and how it compares to any currently available treatments.

The Sjögren's Foundation has a section on its website devoted to clinical trials in Sjögren's and a listing of clinical trials that are currently recruiting Sjögren's patients.



To learn more visit:
www.sjogrens.org/living-with-sjogrens/clinical-trials





Clinician's Corner: Corneal Abrasions: Now what? What to do when you get a corneal abrasion



Stephen Cohen, OD

The “cornea” is the clear cap over the colored part of the front of the eye. It has many free nerve endings, so when there is an injury, we feel it quickly and notably. An injury or irritation to the cornea can cause tearing, pain, difficulty keeping the eye open, redness, and a higher sensitivity to light (“Photophobia”). The bad news about an injury to the cornea is that it can be very painful. The good news is that it typically heals very quickly, often within just a few days.

There are many things that can cause an abrasion to the front of the eye. Often, it is traumatic, coming from things like a branch, a fingernail, a papercut. Often, people fail to put protective eyewear on when doing yard work (like mowing or edging) or when doing work with drills and saws where flying debris can cause an eye injury.

Knowing what caused the abrasion can impact how it is treated, based upon what exposure there might be (e.g., possible bacterial contamination from hand or fingernail if poked in the eye). Once the corneal surface is injured, our susceptibility to other complications can increase. Most people immediately feel the injury. With Sjögren’s, the underlying dryness of the eyes can exacerbate the injury or can even cause the injury. For example, dryness associated with Sjögren’s can cause the back of the eyelid to “stick” to the surface of the cornea and then, when opening the eye, the cornea can be injured/irritated (like pulling

a scab off). In this scenario, it is often diagnosed because patients will note that the pain started as soon as they opened their eyes in the morning.

Once an abrasion is diagnosed, a “tincture of time” can help, but we want to facilitate healing, prevent scarring, and prevent a secondary infection that can occur with a corneal abrasion. Your eye doctor will often prescribe an antibiotic eye drop, not because there is an infection, but to prevent one from setting in while the eye is healing. Once the outer surface is healed, your doctor might add an anti-inflammatory drop to further reduce symptoms and facilitate healing. A “bandage” contact lens or a “pressure patch” might be used to protect the surface while it is healing, and to decrease discomfort. Some doctors have access to treatment with “amniotic tissue” that can be safely placed on the ocular surface to accelerate healing. Cool compresses can be used to help reduce pain and inflammation.

A critical part of treatment is what should be done once healing has occurred. While the eye may look and feel better, it takes time for the healed tissue to fully “anchor” itself, so there is a risk of irritation to the healed cornea from dryness or rubbing the eyes. To help prevent a secondary injury/irritation, patients often increase the use of artificial tears/lubricating drops to help protect the surface of the eyes, as well

“Clinician’s Corner” continued from page 11 ▼

as opening the eyes slowly in the morning so as not to irritate the healing tissue due to the lid sticking to the ocular surface.

For Sjögren’s patients, prevention is more critical because the tear film provides a bit of a protective barrier for the cornea, and a lack of tears can make the cornea more susceptible to injury, irritation, or re-injury. There is not much that can be done to prevent a traumatic injury, but prompt attention can help with healing and prevent secondary issues.

Keeping the eyes as well-lubricated as possible can prevent non-traumatic injuries to the cornea in addition to helping with healing. Corneal abrasions can be quite painful and debilitating when it occurs, but they tend to heal quickly and fully. As always, prevention (where possible) is the best treatment. Use protective eyewear. Use lubricating drops. Wear sunglasses, especially in windy conditions. However, if an injury occurs, call your eye doctor to have your eye promptly checked and treated. ■

Dry Eye Tip!

If you have severe dry eyes and trouble opening your eyes in the morning because your lid is sticking, try to keep your eyes closed when you wake up and use the heels of your hands to gently massage your lids. What this will do is break any of those adhesions that may be there, and it stimulates a little tear production so that you can actually open up your eye safely. But if you wake up and open your eyes right away, you run the risk of – ouch – pulling that adhesion off, again, like pulling a scab off of a wound.

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Patient-to-Patient

The Foundation wants to thank everyone who shared their story during Sjögren's Awareness Month. To keep strengthening this community, we are going to continue to publish real patients giving real advice.

Patient-to-Patient is an opportunity for Sjögren's patients to share their real experiences and advice. Each Patient-to-Patient story discusses a specific symptom or aspect of living with Sjögren's. They are a unique look into how individuals manage their disease.

These stories will be shared once a month for patients to share directly how they are effectively coping with the disease and offer advice for others. Current Patient-to-Patient topics include:

- POTS & Sjögren's
- Joint Pain & Chronic Fatigue
- Being a mom with Sjögren's
- Gastrointestinal (GI) & Constipation Symptoms
- Dry Eyes & Sjögren's
- Fatigue, Brain Fog & Sjögren's

We encourage you to go to our Patient-to-Patient page to see how you can be featured by visiting www.sjogrens.org.



Antoinette (diagnosed at 52)

Patient-to-patient topic

Gastrointestinal (GI) & Constipation Symptoms & Sjögren's

When first dealing with digestive symptoms and Sjögren's, I didn't have the right doctor advising me.

I wish someone had told me to seek a specialist and make sure that all my organs were functioning correctly. Thanks to the Sjögren's Foundation, I understand the disease can have multi-organ involvement and have various doctors as part of my medical team.

Best advice

Keep a journal and track your triggers. You can live a healthy life if you understand your issues and take care of each issue individually.

Listen to your body. For me, this disease has affected my eyes, mouth, teeth, muscle pain, GI complications and vaginal dryness. Having a team of specialists has kept my disease under control. I've learned so much through the Sjögren's Foundation. I encourage all patients to get educated and get involved in the Sjögren's community.

Go-to products/tools

Xiidra for dry eyes, Nexium for Gerd/reflex, Advil for muscle pain, Oral-B Dry Mouth Oral Rinse for dry mouth.

“Patient-to-Patient” *continued from page 13* ▼**Destinee 25 (diagnosed at 21)****Patient-to-patient topic**

Fatigue, Brain Fog & Sjögren’s

I may look normal on the outside, but I’m fighting debilitating fatigue. I’ve learned that our bodies have a way of making us rest. I used to try and “power through,” but I’ve

learned it only makes things worse. In the end, going at my own pace has a better outcome. It’s okay for us to be tired because our bodies are fighting every day.

How do you effectively cope with symptoms: I go to therapy to help handle my stress better and take daily vitamins. It’s important to take days off when you aren’t sick too. You don’t want to become stressed and trigger more sickness.

Best advice

I sometimes worry about not having the energy to conquer my goals in life, but it’s important to give yourself a break. Don’t beat yourself up when your body and mind want you to rest. Rest is necessary and deserved.

Go-to products/tools

Taking days off when you aren’t sick! You don’t want to become stressed and trigger more sickness. I also take Vitamin D3, magnesium, omega-3, and turmeric.

**Mimi 58 (diagnosed at 47)****Patient-to-patient topic**

POTS & Sjögren’s

I wish I knew earlier about a possible overlap of Sjögren’s and POTS.

I began to experience a very fast heart rate whenever I tried to do any activity. I felt like I was going to faint

and would have to lie down to get relief. I saw three doctors before I was finally diagnosed. It is important to be patient because it takes a while to figure out what treatment is going to help you the most.

Most difficult Sjögren’s symptoms

Fatigue, pain, and gastrointestinal (GI) symptoms.

Best advice

Know that there are still doctors who don’t know about this condition and it’s important to advocate for yourself. Prepare for your doctors’ visits by writing down ahead of time what you want to discuss. Review notes again while in waiting room. Living with Sjögren’s and POTS is challenging, remember to focus on the small victories.

Go-to products/tools

A refillable water bottle, a collapsible stool that has a strap to carry it like a purse, a cooling towel for when outside in heat, following a FODmap diet, taking breaks when needed and exercising three times a week.

**Ira 39 (diagnosed at 37)****Patient-to-patient topic**

Being a mom with Sjögren’s

Sjögren’s fatigue is real, and the pain is real. Take the bad days step-by-step and don’t judge yourself for not being the “perfect mom full of energy.”

Best advice

It’s okay to ask for help and fill your own cup. You are important in your life!

Most difficult Sjögren’s symptoms: Muscle pain, fatigue, joint pain, dry skin, and feeling sick.

Go-to products/tools

Anti-inflammatory supplements and rest.

**Rachel 27 (diagnosed at 25)****Patient-to-patient topic**

Joint pain and chronic fatigue

I struggled with joint pain for years in complete defeat. I would finish my workday in tears because my body was in so much pain. It’s okay to have days like that, but those days shouldn’t be your normal. Advocate for yourself, do your own research and try different treatment plans.

I had no hope that I could live a somewhat normal life; sure I still have flares and bad days, but my quality of life has changed dramatically, and this was not handed to me. I fought for it. Keep the fight inside of you!

Best advice

There are solutions to symptoms. Know that there are doctors who are proactive and will want to find the right treatment plan for you. It is important to try different things and don’t be discouraged if/when a medication or treatment plan doesn’t work for you. What works for some people, won’t work for everyone, but you will find things that work for you.

Go-to products/tools

Epsom salt baths, Advil Dual Action, a heating pad, and hydroxychloroquine.

All stories come from the patient’s voice. The listing of any products does not constitute as an endorsement of those products. We strongly advise that you consult with your physician, dentist and/or pharmacist regarding your treatment plan and finding what is right for you. ■

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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.

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Use Your Voice to Celebrate World Sjögren's Day



World Sjögren's Day was created to commemorate the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who discovered Sjögren's.

World Sjögren's Day, July 23, celebrates the man who has helped all patients find answers to their health questions and is the ideal opportunity for you to have your voice heard. We encourage you to celebrate this day by using your voice and educating those close to you that Sjögren's is serious, systemic, and prevalent.

Please consider giving a donation in honor of World Sjögren's Day. Your support has allowed researchers to build on Dr. Sjögren's work, making the recent scientific breakthroughs in the field possible. Together we can conquer the complexities of Sjögren's!



*Horizon Therapeutics is proud to help the Foundation raise more funds in honor of World Sjögren's Day and further efforts to make a meaningful difference for Sjögren's patients. Thanks to their generosity, your gift will have **DOUBLE** the impact!*



Donate online



- Enclosed is my gift of \$ _____ to support the Foundation's initiatives and programs.
- I am interested in learning more about how to make a stock donation.
- Please send me information about listing the Sjögren's Foundation in my will.

Thank you for your support of the Sjögren's Foundation.

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

Name _____

Address _____

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Sjögren's Foundation In Action!

Provider Education Program Update: In-Person Conference Recap



Foundation booth
at the American
Academy of
Neurology's (AAN)
23rd annual meeting.

The most frequently asked question we hear at the Sjögren's Foundation is: "Can you recommend a doctor who is Sjögren's-knowledgeable?" Last year, the Foundation strengthened the strategic focus on provider education, which includes outreach and interaction with providers at in-person professional conferences. In the last 12 months, the Foundation has attended several conferences aimed at different professional audiences and specialty areas including the American College of Rheumatology (ACR) Annual Meeting, with over 7,000 rheumatologists in attendance, and the American Autonomic Society (AAS) Conference, which included clinicians and researchers who engage with the autonomic nervous system, such as neurologists.

At each conference the Foundation attends, we provide messaging to providers to emphasize that Sjögren's is systemic, serious, and prevalent and much more than dry eyes and dry mouth. We provide materials and resources, and we share valuable data from our *Living with Sjögren's* patient survey to drive our messaging and speak to specialists in more depth about how Sjögren's affects their patients. We encourage providers to learn more about how best to treat Sjögren's patients and encourage providers to get involved with the Foundation.

Most recently, the Foundation attended the American Academy of Neurology's (AAN) 2023 Annual Meeting in Boston and the American Thoracic Society's (ATS) 2023 International Conference in Washington, D.C. Each

conference drew more than ten thousand attendees including providers, researchers, medical and graduate students, and industry leaders. At the AAN meeting, the Foundation participated as an exhibitor (see above for a photo of our booth) and shared educational materials, patient survey data, and ways for providers to be involved with the Foundation. We also asked neurologists and autonomic specialists to serve on our expert voting panels for new Foundation-led guidelines for peripheral nervous system and autonomic nervous system complications in Sjögren's. Additionally, the Foundation presented findings from the *Living with Sjögren's* patient survey – our poster included data and findings relevant to AAN attendees, as it emphasized neurological complications and their impact on Sjögren's patients' quality of life.

At the ATS conference, the Foundation participated as an exhibitor and again shared materials and survey findings relevant to pulmonologists and researchers in attendance. We also promoted the Clinical Practice Guidelines for Pulmonary Manifestations in Sjögren's, which were completed in 2020 and published in the journal CHEST. The Foundation is excited about and dedicated to increasing the visibility of these guidelines among pulmonologists and rheumatologists.

The Foundation continued our provider education program in June by attending the Nurse Practitioners (ANP) National Conference. Next we will be attending the Rheumatology Nurses Society (RNS) Annual Conference in August – stay posted for updates from these and subsequent conferences later this year! ■



COVID-19 Booster & Sjögren's

Ask the Doctor:

Does it matter when I receive my next booster?

by Cassandra Calabrese, DO

Have you been wondering when to receive your next COVID-19 booster and/or what COVID-19 vaccines are still available? Since the authorization of the bivalent booster in Fall 2022, the bivalent vaccine offered by Pfizer or Moderna is now the only available COVID-19 vaccine in the United States.

All persons aged six months and older are recommended to receive a bivalent vaccine.

Updated guidance recommends persons aged 65 years and older and immunocompromised persons have the option to receive a second bivalent vaccine four months after their first dose. However, there are no strong data supporting the effectiveness of a second vaccine for these populations, so persons in these groups may instead want to wait to receive a reformulated vaccine later this year in the fall or winter.

Patients who have had a COVID-19 infection in the past six months can delay any subsequent vaccine for six months. To view the latest information on the COVID-19 vaccine and Sjögren's, please visit www.sjogrens.org.



Cassandra Calabrese, DO



IN MEMORIAM

In Memory of Joan Marie Arruda
Leslie Kelley

In Memory of Joanne C. Baker
Sideny Baker

In Memory of Frankie Bissette
Dave and Pam Belote
Stephen Boyce
S Grey Folkes Jr.
Susan Landry
Don Parr
Susan Perry
Marion Rosenow
Suzy Whelan
Michael Williams

In Memory of Heidi Burke
John Burke

In Memory of Shirley Crecca
Gerard Crecca, MD

In Memory of Hyonmi DelFerro
Marie Kilpatrick

In Memory of Christine Noel Drisgula
Cathy Bosland

In Memory of Nancy Gardner
Laura Gaddis

In Memory of Alice Glupe
Karin Blaney

In Memory of Jan Gordon
Kevin McCaffrey

In Memory of Sarah Hand
Sarah Clarridge

In Memory of Susan Hansen
Bruce Hansen

In Memory of Taryn Lesley Jones
Mary Antonides

In Memory of Suzanne LaFleur
Paul LaFleur

In Memory of Joan LaPlante
Butcher Boy Meat Market
Kristy Dickinson
Debra McAuley
Ella Riley
Ann and Ed Wilk

In Memory of Clotilde Parra Lechuga
Consuelo Castro

In Memory of Debbie Magill
Sara Dayton

In Memory of Betty McMinn
Billy McMinn

In Memory of Ramona Sue Johnson Nash
Melanie Gillum
Walter Kastner
Christopher McHugh

In Memory of Janet Nichols
Janine Bensman
Melissa Wayne

In Memory of Michelle Quigley
Ruth Hoffmann
Gloria Olsen

In Memory of Cathryn Robertson
Linda Chessman
Nancy Heller

In Memory of Rose Marie Shartle
Danny Davis
Jeanne Lewis

In Memory of Camille Silliman
Mary-Alice Thompson

In Memory of Ella Jane Sisler
Joe Sisler
Darla Rae

In Memory of Jennifer Stark
Janet Hatch

In Memory of Rose Marie Shartle
Danny Davis

IN HONOR

In Honor of Erin Bloomsburgh
Terry Bloomsburgh

In Honor of Stephanie Cote
James Casilli

In Honor of Donna David
E.D. David

In Honor of Yolanda Gales
Esther Perryman

In Honor of Cecile Haley
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In Honor of Mary Anne Hines
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In Honor of Lari Lopp
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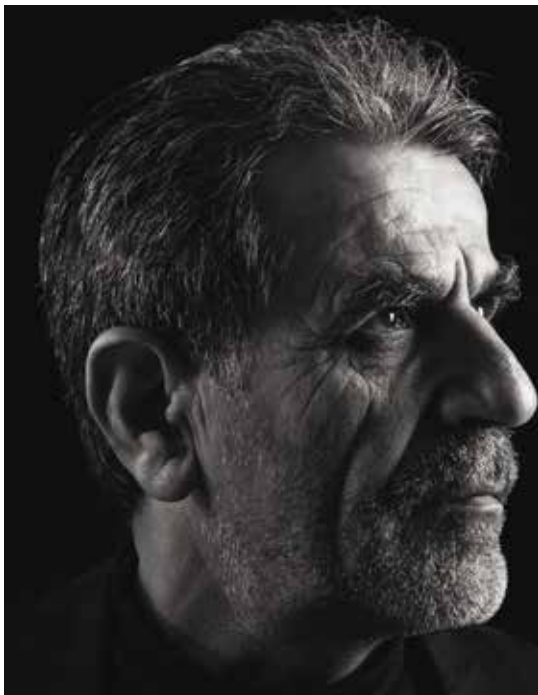
In Honor of Lindsay Noble
Patrick Noble

In Honor of Liz Perry
Don Perry

In Honor of Cathie Robertson
Leanne Berge

In Honor of Edward Tacher
Edward Tacher

In Honor of Juli Thomas
Heather Williamson



Remember your loved ones and special occasions with a donation to the Sjögren's Foundation in their name.





Conquering Sjögren's

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

If you would like to receive this newsletter but are not currently a Member, please contact us at (301) 530-4420

Team Sjögren's

Congratulations Team Sjögren's Runners and Walkers!

On June 3rd and 4th, 40 Team Sjögren's runners, including 38 patients, stepped up to train for a virtual 5K, 10K, or Half-Marathon. Representing 25 states, these runners raced in their hometowns. Congratulations to all of our Team Sjögren's runners for your tremendous efforts and accomplishments in honor of all patients.

The Team Sjögren's running program is only one of the Foundation's many events.

Sjögren's Foundation events are a great way to join fellow patients, family, and friends as we gather to raise awareness and crucial funds! The funds raised make a difference and support Sjögren's research and education.

The Foundation is committed to conquering Sjögren's, but we can't do it alone! We hope you will join us at one of our many upcoming fall 2023 events and be a part of conquering this complex disease. To learn more about upcoming Foundation events, please email info@sjogrens.org or visit www.sjogrens.org.

We Run in Honor of the 4 million Americans with Sjögren's, We Are Team Sjögren's!

