CONQUERING Sjögren's

May/June 2024

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CONQUERING
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2024 National Patient Conference

Sjögren's Foundation
National Patient Conference 2024

The Sjögren's Foundation hosted our annual National Patient Conference on April 5th & 6th. Our very first National Patient Conference was 23 years ago in Los Angeles, CA with 200 Sjögren's patients that came together for a weekend of connecting and learning. This year we presented new experiences for our patients and a new platform that enhanced the ability of our patients to connect with one another, providers, and exhibitors.

We had 950 registrants from 49 states and nine countries join our two-day virtual educational experience. Sjögren's experts provided information that 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 ask our experts questions 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. Below is a full list of this year's topics and presenters:

- **Sjögren's Overview** – Dr. Thomas Grader–Beck
- **Oral Manifestations of Sjögren's** – Dr. Vidya Sankar
- **Headaches & Sjögren's** – Dr. Arun Varadhachary
- **Pediatric Sjögren's Update** – Dr. Sara Stern
- **Ocular Manifestations of Sjögren's** – Dr. Sezen Karakus
- **Healthy Sexual Function Throughout Life** – Dr. Cuoghi Edens
- **Stop Bloq Initiative Overview** – Dr. Jill Buyon
- **Dermatology Concerns in Sjögren's** – Dr. Natalie Wright
- **What is on the Horizon for Sjögren's?** – Dr. Darise Farris
- **Empowered Patients!** – Patient Panel with Foundation Board
- A special session of **Ask the Expert** with Dr. Donald Thomas

In addition to learning from experts and asking questions, we provided our attendees with the opportunity to join several communities for virtual discussions, and to share stories and advice with one another.

Overall, patients provided great feedback with the majority of patients stating that their attendance increased their knowledge/understanding of various aspects of Sjögren's. Patients also enjoyed the new event platform and the ability to interact with one another and with providers.

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. Remember that you can view the conference up to 90 days after the event.

2024 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.

2024 Healthcare Professional Award

Sara McCoy, MD, PhD

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.

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Dr. Sara McCoy is an Assistant Professor in Rheumatology and the Director of the University of Wisconsin Health Sjögren’s Clinic. She is both a clinician and researcher who dedicates her time and talents to focus on Sjögren’s and Sjögren’s patients. Dr. McCoy chose to focus her career on Sjögren’s as she recognized the significant gap in care for individuals suffering from the disease, including poor diagnostic tools and lack of approved therapies. Her goal is to critically inform the pathogenesis of Sjögren’s disease toward development of novel targeted therapeutics. Dr. McCoy is considered a rising star in the field of Sjögren’s internationally, and is highly respected for her research, her work with patients, and her leadership in the OMERACT Sjögren’s Working Group.

Dr. McCoy has been awarded three Sjögren’s Foundation grants and was awarded the Foundation’s Outstanding Abstract Award at the 2022 American College of Rheumatology conference. In July of 2022, Dr. McCoy joined the Foundation’s Board of Directors. She serves on the Research committee which reviews new proposals for Foundation grants. She has spoken at many Foundation events including our National Patient Conferences and has been a presenting Rheumatologist for our partner CME programs, which educate other doctors about the serious and systemic nature of Sjögren’s. She has written for us and has been on our Census Expert Panel for both the Pulmonary Clinical Practice Guidelines (CPGs) and our new Peripheral Nervous System CPGs which should be out by the end of 2024. Currently, Dr. McCoy is working with the Foundation as a Sjögren’s expert for our presentation to Centers for Medicare & Medicaid Services (CMS) in May. This year, she has partnered with the parent of a young patient to create and co-chair the Midwest Walk for Sjögren’s to be held June 1st in Madison, Wisconsin.

2024 Volunteer Leadership Award

David Schrader

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.

David Schrader is a patient who continues to make a difference in patients’ lives. David built his career as an entertainment industry financial professional including 20 years at The Walt Disney Company. From 2009 to 2016, he served as Executive Vice President and Managing Director for the theatrical production division, Disney Theatrical Productions, leading domestic and international strategy and business development as well as operational functions, marketing, and merchandising. During his time at Disney, the company produced ten Broadway shows as well as touring and international companies. Disney Theatrical Productions has brought events to a global annual audience of more than 19 million people in more than 50 countries.

David was a member of the Broadway League from 2012-2017 where he served on the Finance Committee and as a Tony Awards voter from 2013-2016. He has served on other Boards, including a continued seat on the Board of Miami New Drama.

In 2013, David was diagnosed with Sjögren’s; in 2016 he realized he could no longer continue with his executive role at Disney and stepped down, founding his entertainment consultancy, Murray & Kean. When David received his diagnosis, he turned to the Sjögren’s Foundation and became a member. He became involved with our programs, attended our events, and was particularly engaged with the New York Sip events supporting fundraising efforts. In 2019, David joined the Foundation’s Board of Directors to bring his governance and finance background and represent male patients. As a Board member, has David served as Secretary of the Board and has co-chaired our New York Walk events.

David has been instrumental in building awareness that men are affected by Sjögren’s! Not only has David directly supported male patients calling in to connect with other men, but he has also served as a patient advocate to pharmaceutical companies so they can better understand the male patient’s perspective. He has also shared his story on video for CME programs to train healthcare providers to think of Sjögren’s as a possible diagnosis for men.

2024 Mission Service Award Recipient

Nishant Gupta, MD

Dr. Nishant Gupta is an Associate Professor in the Division of Pulmonary, Critical Care and Sleep Medicine at the University of Cincinnati. He also serves as the Director of

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Interstitial and Rare Lung Diseases at the University of Cincinnati. An accomplished and recognized researcher in his field, Dr. Gupta's clinical research program focuses on interstitial and rare lung diseases, including Sjögren's-associated lung diseases.

Dr. Gupta has authored dozens of articles published within peer-reviewed scientific journals, including the Foundation's Consensus Guidelines for Evaluation and Management of Pulmonary Disease in Sjögren's (our Pulmonary CPGs). Dr. Gupta was a key contributor and member of the Topic Review Group in the multi-year effort of developing these guidelines and helped facilitate their publication in the prestigious journal, CHEST. Impressively, this article has been downloaded tens of thousands of times since its publication and represents an incredibly important and successful multi-specialty effort that highlights important aspects of Sjögren's that many before Dr. Gupta may not have considered.

The Foundation was excited to welcome Dr. Gupta to our Board of Directors in 2022, where he also serves as a member of our Research Committee. In this role, he helped shape the Foundation's new grant policies and offerings and serves as a reviewer on grant proposals sent to the Foundation. Additionally, Dr. Gupta has volunteered his time and expertise in writing and reviewing content for our magazine, Conquering Sjögren's. This coming May, Dr. Gupta will represent the Foundation at the American Thoracic Society's Annual Meeting when he speaks on the patient experience and burden of respiratory manifestations of Sjögren's, which may be one of the very few times, if ever, that Sjögren's has been a topic of an oral presentation at this meeting.

Dr. Gupta was an early champion of the Foundation's message that Sjögren's is serious and systemic, and that multi-disciplinary care is required to best care for patients. During the inaugural State of Sjögren's event in 2022, he presented on ILD in Sjögren's, a potentially very serious manifestation, and again, emphasized the need for multi-disciplinary care for patients.

We are truly thankful for a successful National Patient Conference and if you have any suggestions for future conference topics, please email us at info@sjogrens.org. ■

StopBloq

Lately, the Foundation has been fielding a lot of questions about pregnancy and Sjögren's, and we wanted to make sure that new and future expecting mothers know about this life-saving initiative. The Stop Bloq Initiative lead by investigators Jill Buyon, MD and Bettina Cuneo, MD is a life-saving research and intervention program for women who are at high-risk of carrying a child with fetal heart block.

Stop Bloq stands for **S**urveillance and **T**reatment t**O** **P**revent fetal atrioventricular **B**lock (AVB) **L**ikely to **O**ccur **Q**uickly. Fetal AVB, also called fetal heart block, is a condition where the fetal heart beats too slowly. In patients with autoimmune disease, specifically Sjögren's patients who are anti-SSA/Ro positive, autoantibodies may attack the heart and cause tissue damage or scarring that affects the way the heart beats. At 11 weeks, Sjögren's antibodies (anti-SSA/Ro and anti-SSB/La) can be detected circulating in the maternal placental transport system.

Fetal heart block occurs between the 17th and 25th weeks of pregnancy. The risk for fetal heart block is relatively low at 2% for mothers with no previously affected children. Mothers that have previous children with fetal heart block have a 7.5-18% chance of having another child with fetal heart block. Unfortunately, there are not a lot of prevalence studies on fetal heart block to have a more accurate range.

Fetal heart block occurs in three degrees of severity: 1°- early damage, 2°- evolving damage, and 3°-complete damage. First and second-degree heart block can usually be reversed, and children usually go on to live with a good quality of life. However, there is a 17.5% mortality rate for those with 3rd degree fetal heart block and most children will require a pacemaker that is needed for life. Currently, fetal heart block cannot be cured, but it can be prevented. A study showed that hydroxychloroquine can reduce the recurrence rate of fetal heart block by half, and currently, no studies have been published on first pregnancy.[1]

The Stop Bloq Initiative is actively enrolling women that are less than 20 weeks pregnant and test positive for anti-SSA (Ro60 or Ro52) antibodies. Other inclusion and exclusion criteria apply. The study lasts about 2 years and will include approximately 10 study visits. You must be within six hours of a study site. The study distinguishes whether mothers who have high or low levels of anti-Ro60 or Ro52 antibodies. If the mother has high levels of anti-Ro antibodies, then they will subscribe to weekly or biweekly echocardiograms to monitor the baby's heartbeat 3x/day. If the baby develops a fetal heart block, then the mother will be treated with dexamethasone and IVIG (intravenous immunoglobulin).

The enrollment for Stop Bloq is currently at 573 participants and split into two groups: Group 1: 261 participants with low Ro52 and Ro60 antibodies, and Group 2: 361 participants with high Ro52 and Ro60 antibodies. Of 573 mothers, 240 sent audiotexts of their fetal monitoring to pediatric cardiologist to analyze what they thought were abnormal echocardiograms. Of those 240 mothers, 10 cases of fetal heart block were found with most participants having higher levels of Ro52 and Ro60 antibodies and exceeding the threshold. There were seven 2° fetal heart blocks which were identified in less than 12 hours from receipt of the audiotext and three 3° fetal heart blocks that were recognized later. Furthermore, fetal heart block was not found in all mothers with higher levels of antibodies nor was fetal heart block found in any mothers with lower levels of antibodies.

Overall, the Stop Bloq presents an opportunity to reverse damage caused by Ro52 and Ro60 antibodies to the fetus preventing lifelong disability and/or mortality.

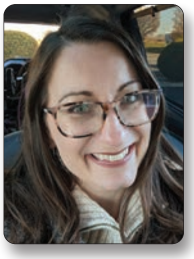
To learn more about the Stop Bloq initiative, please visit Stopbloq.org. To enroll at any site, please contact Mala Masson, Senior project manager by phone: 212-263-032 or email: Mala.Masson@nyulangone.org ■

Citation

[1] Izmirly P, Kim M, Friedman DM, et al. Hydroxychloroquine to Prevent Recurrent Congenital Heart Block in Fetuses of Anti-SSA/Ro-Positive Mothers. *J Am Coll Cardiol*. 2020;76(3):292-302. doi:10.1016/j.jacc.2020.05.045

April Awareness Stories:

This is Sjögren's

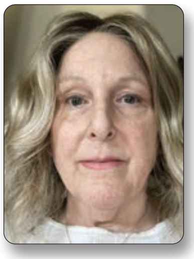


Jenna, 40 (Diagnosed at 29)

I had to resign from my career as a teacher, which really impacted my life in a variety of ways. I've found a way to live a rather normal life now even though I had to change careers.

I pay attention to my body and the signs that tell me I'm getting close to having a flare. I slow down when I need to and do a lot of deep breathing.

I wish people would understand that just because I don't physically look like anything is wrong, you can't see what's going on inside my body.



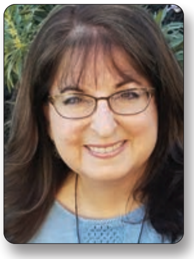
Lisa, 70 (Diagnosed at 37)

In the beginning, I was a research fanatic. In 1990, there wasn't much available so I read medical textbooks and joined my local Sjögrens Foundation to learn. I also met with a counselor who also had an autoimmune disease and she gave it to me straight...You always start each day with at best a quarter tank of gas and must make it last. There will be good days and bad days. Simply hang in on the bad days, follow your health plan, and your days will get better.

Rachel, 28 (Diagnosed at 25)

I feel more limited than friends my age. It's emotionally exhausting having an unseen disability. Balancing my energy that I give at work in hopes that I still have some to give to friends and family tends to be my greatest struggle.

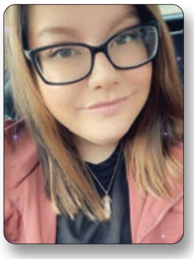
Growth is not always one foot in front of the other. Sometimes growth looks like staying still and weathering a storm. Don't give up on pursuing the right treatment for you. You deserve to life a full life and as much as we can feel limited, we need to continue to pursue life with all we've got and spend our energy on things that matter and bring us the greatest joy.



Lauren, 63 (Diagnosed at 48)

Sjögren's has taught me greater empathy for those struggling with health issues. It has also taught me how to tease apart physical well-being from mental and spiritual well-being. Sometimes my body doesn't feel well, but I am still able to find small wonders and beauty to appreciate each day

We all need to practice self-care, but it's vital when you have a chronic illness. I try to get enough sleep, stretching and exercise, structure some space around activities (as I'm able) and just listen to my body and what it tells me it needs.

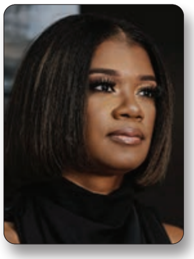


Holly, 31 (Diagnosed at 8)

Sjögrens took a large chunk of my childhood as I was in and out of the hospital for years. I am currently in stable condition but still suffer from chronic fatigue and parotitis.

I take my medications prescribed consistently and make time for self care. I let my body rest when it needs to instead of pushing myself past my limits.

Be gentle with yourself. You have chronic illness and it's okay to acknowledge that.



Cherice, 40 (Diagnosed at 35)

Having a high-risk pregnancy with Sjögrens, during the 2020's pandemic was one of the toughest things I've had to endure (largely alone). I was monitored weekly by doctors to ensure the disease wouldn't impact the growing baby, while most people were trying to stay away from hospitals. A friend told me recently that Sjögren's saved me and my baby's life because I learned how to cope with stress in the toughest conditions.

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“This is Sjögren's” *continued from page 7* ▼

Vince, 23 (Diagnosed at 18)

I was 15 when my symptoms like muscle and neuropathic pain started and was unsure what was wrong with me. I was very lucky to have a good rheumatologist who diagnosed Sjögren’s with a lip biopsy.

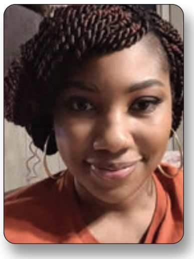
It‘s hard to accept and to move on especially when a new symptom pops up or your body changes due the disease... Sjögren is so diverse, always systemic and much more than just “dry eyes and mouth”.

Stephanie, 62 (Diagnosed at 59)

It has taken a toll on my emotional state. I am a substitute teacher and some days I feel like a failure due to the brain fog. That creates insecurities.

I rely on my wonderful doctors as well as reading and keeping up with the latest information about Sjögren’s.

Just because I look good doesn’t mean that I feel good and that brain fog is real and not just a made up symptom.



Latasha, 36 Diagnosed at 28

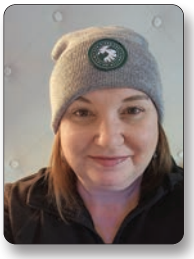
Sjögren’s has impacted my life physically because I’m not able to dance and do cardio like I want to because of the fatigue and joint pain. Emotionally I have gone through periods of feeling anxious about how things will turn out living with Sjögren’s. I have learned to set limits and boundaries so I can make sure I’m taking care of myself.

Tracy, 53 (Diagnosed at 43)

I’ve had people look at me funny when I park in handicapped spots (I have a placard) or use ride-on carts. I look normal, but the constant pain is “invisible.” I share Sjögren’s Foundation on Facebook to help educate people on this.

I’ve learned to pace my activities. I had to give up volunteer work, spread housecleaning over the week, , and keep lotion, nasal spray, chapstick, and gum nearby.

I keep daily track of symptoms for my Rheumatologist. Find a Rheumatologist that is well-versed in Sjögren’s.

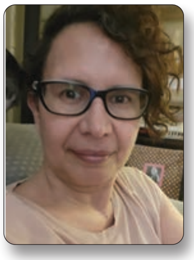


Kathy, 53 (Diagnosed at 52)

It has impacted my life by creating a sense of confusion, fear and anxiety, and isolation. It is really frustrating to feel like I am navigating this alone. I feel guilty and ashamed often.

I have not yet learned to cope with Sjögren’s. But I do have a Sjögren’s journal that is helping me track symptoms and triggers. Joining this Foundation has helped me, as well, as I am beginning of learning more about what I am experiencing and that I am not alone.

I wish people knew that my symptoms seem to change weekly and that when I finally say I need to rest my eyes and/or body it means I have already been “pushing through” for too long and really need to rest.



Yvette, 59 (Diagnosed at 49)

This is a disease so few people know about or understand. You have be prepared to advocate for yourself. It’s been 10 years and every time I’ve mentioned I have Sjögren’s, I have to tell them what it is.

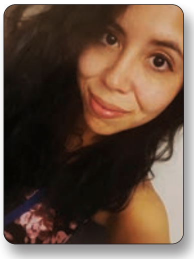
I have a hard stop. I listen to my bodily cues and stop whatever I’m doing. My family, friends, and coworkers know when I say I’m done, I am.

Be good to yourself. Your best is your best.

JayLyn, 37 (Diagnosed at 37)

I was a single mom for many years while navigating misdiagnosed and unmedicated Sjögren’s. It was so difficult, and my mental health took a dive. I found therapy, a support system, and tools to navigate my symptoms and situation.

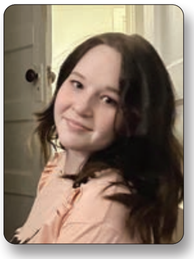
Never give up. You are stronger than you realize, and you deserve peace. Never stop trying to find a solution to your symptoms.



Daniela, 34 (Diagnosed at 25)

I have a variety of different symptoms and have a lot of specialists I see. At one point I was seeing 13 different doctors... I incorporate exercise to manage my Sjögren’s. It helps me to not only stay sane but it makes me feel physically better.

I wish that people knew that it affects all ages. Most people believe it is only in your 40s but I was in my early 20s with issues due to Sjögren's. I also wish that people understood that it is so much more than “dry mouth”. Dry mouth is the least of my concerns with this disease.



Taylor, 22 (Diagnosed at 21)

Sjögren's isn't my primary illness. It's one of three illnesses I have. My Sjögren's amplifies all my other symptoms to a new extreme.

I have POTs and Rheumatoid Arthritis. Sjögren's makes me hurt so much more. It works directly against my POTs, and has made my fainting much worse.

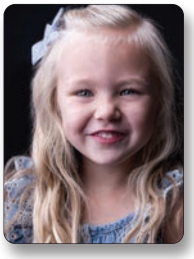
Take it one day at a time. Somedays I can move mountains, others I can't even move myself.

Philippa, 44 (Diagnosed at 39)

I used to be this whole other person, I was a very competitive show-jumper and rower. Now, I have lost that high level of fitness I had, and that has been difficult to take on board, I'm this whole other person that I didn't know was there.

I didn't understand or want to understand before that I can't burn the candle at both ends. I didn't want to recognize the glass ceiling above my head, I wanted to shatter it and be my old self. Now I know that if I push too hard or do one thing too much I will start to have symptoms. So I try to eke out the little battery I wake up with, out all day.

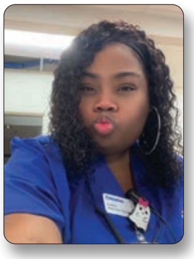
Skarlett, 4 (Diagnosed at 4)



I wish people knew that little kids can have Sjögrens too. Even some of my pediatric doctors haven't seen someone my age with Sjögrens. It's more than just dry eyes and mouth. I don't even have those symptoms. It affects my whole body.

It's a lot to manage, and I'm still learning how Sjögrens is affecting me. I currently have appointments with or referrals put in to see 5 different specialists each dealing with a different part of my body.

I keep having pain in my cheek (parotitis), and sometimes I can't taste the food I'm eating. That's really frustrating, especially when I'm eating ice cream... I have hypermobility issues. I want to be active and do things like gymnastics, but my body feels too tired.



Kyaira, 29 (Diagnosed at 27)

I make sure to rest as much as possible and remind myself to cut myself a break. I make sure to dedicate at least one day of self care and low maintenance to myself per each work week.

Create a strong support system. Bad days don't last that long when you have one. I join groups of alike peers to vent and support others in a safe space.

Christi, 48 (Diagnosed at 39)

Although I look healthy, I am often tired and in pain. When I plan for an activity/event, ALOT of preparation goes into making it work, so when I turn down last minute invitations it's truly just to keep from the possibility of being a burden.

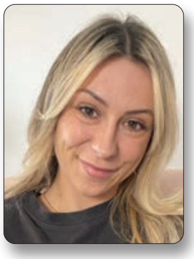
I always plan ahead, carry liquids with me all the time and never leave home without meds or eye drops.

The Porto Vino handbags are a lifesaver. They are meant for wine but great for ice cold water as well.

Robert, 30 (Diagnosed at 28)

After experiencing a severe flare-up in early 2020, I became largely bedbound and lost most of my strength. At first, none of the doctors I saw had useful advice on how to exercise with chronic pain and severe fatigue. One doctor even told me I was hopeless if I couldn't follow his simple exercise protocol. After cycling through many practitioners for over a year, I found care providers willing to look at all my challenges, build a plan specific to me, and give ongoing support.

I cannot predict how disabled I will be day to day, so it's challenging for me to plan ahead. On some days, I'm in the gym with my physical therapist, lifting heavy weights. On others, I cannot get out of bed.



Michelle, 30 (Diagnosed at 18)

It's changed my world. I recently had months long flare up that has made me not be able to wear contact lenses, I had to leave my serving job and went through my life savings just to pay my bills living alone. I had to learn to love who I see in the mirror again and to save accordingly. I have my own swimwear business I taught myself to sew and some days my hands are in so much pain and I'm exhausted. But I make my own hours and I set myself up for success so I can still thrive!

It's not the end of a good fulfilling life. You can manage your symptoms once you're aware of them (after diagnosis) and thrive! In my 20's, I didn't fully give 100 percent and it caught up with me.

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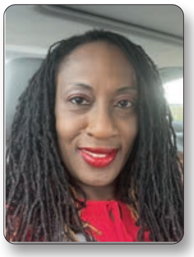
“This is Sjögren's” continued from page 9 ▼

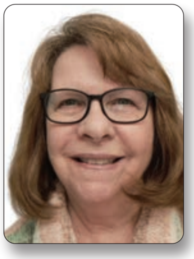


Demetra, 46 (Diagnosed at 42)

After months of physical therapy, I’ve discovered the importance of maintaining mobility despite the challenges of joint pain. Rather than fixating on past abilities, I’ve shifted my focus to achievable daily goals.

Investing in senior-friendly workout equipment has been a game-changer, offering gentle yet effective mobility support on tough days.

This balanced approach, coupled with consistency, has significantly improved my overall well-being, allowing me to embrace each day with renewed vitality.

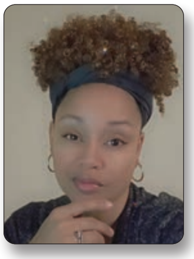


Penny, 71 (Diagnosed at 43)

Since I’ve dealt with Sjögren's and two other autoimmune diseases for twenty-eight years, I developed a philosophy early on that essentially is acceptance that things will change and when they do, I make a new plan and keep moving.

Sjögren's was far less known and understood when I was diagnosed, and no one understood how much it affected me. I hid a lot of the effects and did more than I should have too often.

Do what works for you and don’t compare yourself to others. What works for each person may be different even for the same symptoms.

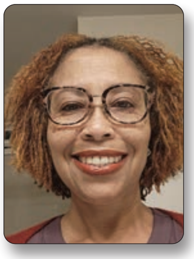


Vicky, 39 (Diagnosed at 34)

I take each day as it comes. My symptoms have a wide range and I have to do what’s best for me. Use eye drops, try to stay active even if it’s just a tiny bit, rest when I need rest, and take my medication without fail to prevent flare-ups.

Not all providers understand the real complexity of Sjögren's and that it's more than just dry eyes and mouth.

I wish people knew it’s invisible. Sometimes even tests come out normal and no one can figure out what’s happening.



Eudine, 55 (Diagnosed at 35)

I think I have been suffering with Sjögren’s since I was 11 years old, and no one knew then what it was. It has impacted my life with all sorts of medical and psychological issues.

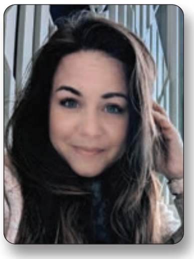
My self care is to take one day at a time and to love myself by doing what I can to feel better.

Most importantly I tell myself every day that I am not crazy. I do what I can to listen and pay attention to the signs when a flare up is about to start.

Pooja, 24 (Diagnosed at 22)

I moved to Germany to pursue my dreams, even though dealing with the symptoms of Sjögren’s, like fatigue, muscle pain, dehydration, and eye swelling, has been challenging for the past two years.

Some people have doubted my illness, thinking I’m pretending or lying about being sick. But I know the truth. I don’t need to prove anything to anyone. I’m determined to keep chasing my dreams despite the obstacles Sjögren’s may bring.



Lena, 42 (Diagnosed at 40)

I have to schedule my day a bit differently. Mornings are difficult and I have learned to listen more to my body and give it what it needs. Even if that means resting more than usual or adjusting my schedule.

I try to record how I’m feeling each day to get a better understanding of how to manage my symptoms.

Share your story with others so they can see how strong you are. It may inspire them to feel strong too.

Jennalee, 35 (age of diagnosis not provided)

Sjögren's has impacted me the most physically as the fatigue is so overwhelming. Some days I just want to lay in bed and sleep.

I have a supporting husband who realizes when I’m going through a flare and reminds me to take my medications. Also, I love to run which helps my mood.

I say this every year, and I’ll say it again. Sjögren's in pregnancy! A lot more monitoring, appointments.

Jd, 33 (age of diagnosis not provided)

I may look normal on the outside, but my body is fighting every day. Sjögren’s is an invisible illness that attacks every part of my body. It’s not just dry mouth & eyes. It’s a full-time job managing debilitating symptoms. So, I never know what my day will look like. When you see me, just know it took a lot for me to show up. When I get home, recovery is a different story.

continued next page ▶

Eva Plude

We are deeply saddened to learn of the loss of our long-time volunteer, Eva Plude, and we wanted to honor her many contributions to the Sjögren's community.

After being diagnosed with Sjögren's, Eva started the Bel-Air Support Group- just outside Baltimore, MD- in 1999 to help fellow patients in her area. She spent nearly 20 years as the Support Group Leader and retired in 2017. As a Support Group Leader, Eva recruited top-rated physicians, dentists, and other healthcare professionals to volunteer to speak to her group. She also put together a monthly newsletter that was distributed to her group members, which included information about upcoming meetings.

Eva served as a Patient Support Volunteer for several years accepting calls from hundreds of patients a year. She was also an Awareness Ambassador bringing materials to local physician's offices to educate them about Sjögren's. As if that wasn't enough, Eva represented the Foundation at various health fairs and community events in her local area.

In 2007, her incredible dedication and efforts as a volunteer were recognized when the Foundation awarded her with the 2007 Volunteer Leadership Award at the National Patient Conference.

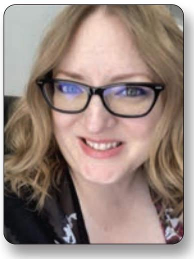
Eva was an amazing woman who was so warm and welcoming. Those that worked with her would say that you rarely meet a person so selfless and devoted. The Sjögren's Foundation was extremely fortunate to have Eva's support and we will surely miss her energy, passion, and heart. Eva made an impact on so many lives and we are incredibly grateful for her dedication and support! We offer our deepest condolences to her family and friends, and we thank them for sharing her with us. ■

“This is Sjögren's”

continued from page 10 ▼

Self-care is a must. It has become a lifestyle and a daily choice. Every day looks different. Whatever my body & spirit needs, I prioritize that.

If you want to pour yourself onto others & the things you love, you have to fill your cup.



Michelle, 42 (Diagnosed at 41)

The initial Sjögren's diagnosis was overwhelming. Rampant symptoms left me feeling my worst, battling fear, anxiety, and depression. But with the help of exceptional doctors, consistent follow-ups, and dedicated research, I've gained control of my symptoms and reclaimed a relatively normal life.

It's a continuous challenge, each day presenting new experiences. However, with the unwavering support of loved ones, a fantastic medical team, and invaluable support groups, I navigate this journey one day at a time. With the right support system and a proactive approach, you can take control of your condition and reclaim your life, one day at a time. There is hope, and you are not alone. ■

40 Years Sjögren's FOUNDATION

16th Annual International Symposium for Sjögren's Disease (ISSjD)

In April, the Sjögren's Foundation attended the 16th annual International Symposium for Sjögren's Disease (ISSjD) in Egmond aan Zee, located in North Holland. ISSjD hosted world-renowned experts and was themed "Looking Forward", with a focus on new research, diagnostic tools, and cross-disciplinary collaboration.

This was the first year that the conference has changed its name to use Disease in the title rather than Syndrome, reflecting that Sjögren's is also recognized internationally as a serious and systemic disease. At the welcoming presentation for ISSjD, Hendrika Bootsma, MD, PhD updated the international community on Sjögren's nomenclature and asked that all presenters use "Sjögren's disease" during the conference.

Kathy Hammitt, MA, VP of Scientific and Medical Affairs at the Sjögren's Foundation and Alan Baer, MD, Chair of the Medical and Science Advisory Council at the Sjögren's Foundation

Overview of ISSjD

The symposium included 38 oral and over 180 poster presentations from new and veteran investigators on a wide array of topics covered under nine overarching topics, which included:

- *From a patient's point of view*
- *Glands and imaging*
- *Pathogenic aspects I*
- *Trials and tools*
- *Extra-glandular involvement*
- *Pathogenic aspects II*
- *Outstanding abstracts presentations*
- *Classification and stratification*
- *Looking forward*

The number of presentations and research topics increased from previous years signifying the rise in Sjögren's research.

Foundation Presentations

The conference opened with a special presentation on "Aligning Patient and Clinician Perspectives" presented by Kathy Hammitt, MA, VP of Scientific and Medical Affairs at the Sjögren's Foundation and Alan Baer, MD, Chair of the Medical and Science Advisory Board at the Sjögren's Foundation and Director of Jerome Greene Sjögren's Clinic at John's Hopkins University. This presentation discussed the different perspectives patients and clinicians have on the priorities of a treatment plan. It also addressed the types of questions the patient and clinician should ask each other to ensure the treatment plan is appropriate from both perspectives and helps the patient receive the best care.

The Foundation also gave five different presentations: one oral talk and four poster presentations. We partnered with prominent Sjögren’s experts to help present this information.

The Foundation, facilitated by Robert Fox, MD, PhD, presented an oral talk focusing on the new clinical practice guidelines for the peripheral nervous system (PNS). He described the systematic review process and reviewed the new recommendations for the management and treatment of peripheral neuropathy in Sjögren's patients. Overall, the clinical practice guidelines include 28 Best Practices and 23 Recommendations amongst three categories of PNS manifestations: mononeuropathy (cranial neuropathies, peripheral nerve neuropathies), polyneuropathy (large fiber neuropathy, small fiber neuropathy, demyelinating polyradiculoneuropathy, ganglionopathy (neuronopathy), vasculitic neuropathy) and autonomic neuropathy (autonomic ganglionopathy, orthostatic intolerance, and gastrointestinal dysmotility). These guidelines will be submitted for publication later this year.

Nancy Carteron, MD and Ghaith Noaiseh, MD

One of the biggest hurdles from developing our PNS clinical practice guidelines was the disconnection between the nomenclature used by rheumatologists and neurologists to describe peripheral neuropathies. Rheumatologists Ghaith Noaiseh, MD and Nancy Carteron, MD presented the Foundation’s poster on aligning nomenclature titled: “Alignment Between Rheumatology and Neurology of Nomenclature for Peripheral Nervous System Neuropathies”. This poster was derived from our experience navigating the differences in nomenclature when creating the PNS clinical practice guidelines. We hope that this work will continue to establish better multi-specialty collaboration between rheumatologists and neurologists— something that our patients greatly need.

Other posters on the following topics were also presented and well-received: postural orthostatic syndrome (POTS) and Sjögren’s, respiratory manifestations in Sjögren’s, and our 40th year timeline to highlight the progress made in Sjögren’s.

Several members of the Foundation’s Board of Directors were invited to give oral presentations along with many current and past recipients of the Foundation’s grant awards, who presented their research that the Foundation helped to fund. Here’s a list of a few of their presentations:

- *Sjögren’s Disease Endotypes: Towards Precision Medicine*, Dr. Sara McCoy (University of Wisconsin), Sjögren’s Foundation Board of Director’s Member, 2021/22 Sjögren’s Foundation High Impact Grant Recipient
- *Dysautonomia in Sjogren's Disease*, Dr. Brent Goodman (Metrodora Institute), Sjögren’s Foundation Board of Director’s Member
- *TYK2 is required for salivary and lacrimal gland inflammation in a mouse model of Sjogren's disease*, Dr. Scott Lieberman (University of Iowa), Sjögren’s Foundation Board of Director’s Member
- *Sjögren and non-Sjögren Dry Eye Patients Have Similar Transcriptional Expression Patterns Involving Immune Pathways in the Conjunctiva*, Dr. Cintia de Paiva (Baylor College of Medicine), 2021/22 Sjögren’s Foundation High Impact Grant Recipient
- *Spatial Transcriptomics Implicates Glandular Cell Involvement in Pathophysiology of Sjögren’s Disease*, Dr. Christopher Lessard (Oklahoma Medical Research Foundation), 2023/24 Sjögren’s Foundation Dynamic Grant Recipient

Overall, the Foundation had a great time at ISSjD and we learned so much from the international Sjögren's community. We look forward to seeing the impact of the research presented at ISSjD on Sjögren's and will provide updates on the impact of this research as it becomes available. ■

ISSjD 2024 Opener – Hendrika Bootsma, MD, PhD

World Sjögren's Day

AMGEN

Doubling Down on Donations for World Sjögren's Day– Amgen will Match up to $40,000 for 40 years of Progress!

Help us Celebrate World Sjögren's Day on July 23rd by donating to the Sjögren's Foundation. Amgen, a corporate sponsor, will generously match up to $40,000 of donations made in honor of World Sjögren's Day. This year's Amgen match is an increase from last year to $40,000 to celebrate our 40th anniversary.

Why do we celebrate July 23rd as 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.

In 1929, Dr. Sjögren met a patient who complained of dry eyes, dry mouth, and joint pain. Each of these symptoms were already well known, but it was the combination of them that Dr. Sjögren noticed and decided to investigate. Dr. Sjögren could have dismissed his patient that "just had dry eyes", but his open mind led him to the discovery of an unknown clinical entity that was later named after him.

World Sjögren's Day celebrates the man who has helped all patients find answers to their health questions. As many Sjögren's patients still have a hard time getting diagnosed, World Sjögren's Day is a great 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.

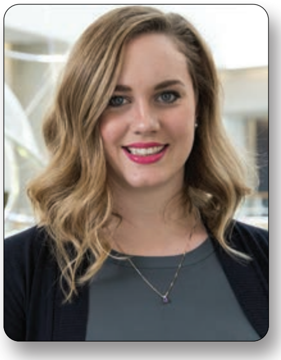
Please consider giving a donation in honor of World Sjögren's Day. Your support has allowed researchers to build on Dr. Sjögren's work, making the recent scientific breakthroughs in the field possible.

Together we can conquer the complexities of Sjögren's!

If you would like to make a donation, please visit www.sjogrens.org/world-sjogrens-day-donations or scan the QR code to the left.

Research Outcomes Series-
Sjögren's Grant Recipients

The Sjögren's Foundation is proud to present a new series of articles that update you on the research from recipients of our Pilot and High Impact Research Awards. We are truly grateful not only to the researchers that share their contributions with us, but also the incredible work they are able to do with our support!



Kimberly Jasmer, PhD (2018/2019 Pilot Research Award Grantee)

Assistant Research Professor University of Missouri | Department of Biochemistry, Vice President for the International Association for Dental Research (IADR) Salivary Research Group

P2Y2 Receptor as Therapeutic Target in a Sjögren's Mouse Model

Generally, we think of the roles of nucleotides within the cell in the form of genetic material or energy currency, but **nucleotides** also serve as transient extracellular signaling molecules. Released by damaged or dying cells, extracellular nucleotides act as a specific class of damage-associated molecular patterns (DAMPS) known as **alarmins** that initiate inflammatory responses. Essentially, extracellular nucleotides set off an alarm, indicating nearby cellular damage and mount an immune response to that damage. If that alarm never shuts off, the persistent immune invasion can lead to tissue destruction. We study the receptors that sense and respond to these extracellular nucleotides, along with other enzymes and transporters that mediate that response. Together, we refer to this set of proteins as the extracellular **purinome**. We investigate

Editor's Brief Summary

The Jasmer research group studies the influence of the P2Y2 nucleotide receptor (P2Y2R) in chronic inflammation of the salivary and lacrimal glands and the contribution of P2Y2R signaling to the increased risk of developing B cell lymphomas in Sjögren's. They used two different mouse models to study the role of P2Y2R in the development of Sjögren's.

In their first study, they used a mouse model that mimics Sjögren's and spontaneously develops B cell lymphoma. They looked at the difference in glandular inflammation and function as well as the development of B cell lymphomas in mice with and without the P2Y2R. They found that Sjögren's mice lacking the P2Y2R did not develop inflammation in salivary or lacrimal glands and retained glandular function. The mice lacking the P2Y2R also did not develop pulmonary inflammation or B cell lymphomas.

In a different study, they investigated whether an antagonist— a drug that prevents function of a receptor— for the P2Y2R could also improve inflammatory symptoms in a Sjögren's mouse model. They found that there was a decrease in lymphocytic infiltration in the salivary and lacrimal glands and that salivary flow was improved. The Jasmer research group also demonstrated that the P2Y2R in B cells was important for B cell migration, which contributes to B cell infiltration and activity in the salivary and lacrimal glands.

Overall, the work by the Jasmer research group lays a foundation for potential new therapies against the P2Y2R in the prevention of B cell lymphomas caused by glandular inflammation and tissue damage.

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"Research" continued from page 15 ▼

the purinome in the context of diseases that impact the salivary glands, namely autoimmune Sjögren's Disease (SjD). SjD has many hallmarks of **B cell hyperactivation** and dysregulation. One such example is the elevated risk of developing marginal zone B cell lymphomas of the mucosa-associated lymphoid tissue (MALT) origin. The overall hypothesis of this project was that the P2Y2 nucleotide receptor (P2Y2R), which we had previously shown is found on B cells within the salivary glands of multiple mouse models of SjD, contributes to chronic inflammation present in the glands and contributes to the increased risk of developing B cell lymphomas. We used two mouse models to test the hypothesis that targeting this receptor may be a novel therapeutic strategy.

Using a mouse model that spontaneously develops B cell lymphomas by 15 to 18 months of age, we found that Sjögren's mice that lacked P2Y2R never developed salivary gland or lacrimal gland inflammation and retained glandular function. We also found that our mouse model had significant inflammation in the lung, which many SjD patients experience as well. The mice that lacked P2Y2R did not develop this pulmonary inflammation. Importantly, none of the mice that lacked P2Y2R developed obvious B cell lymphoma masses. However, one question this project raised for us was what defines the differences between lymphocytic foci (organized masses of immune cells), lymphoepithelial lesions (referred to as **lymphoepithelial sialadenitis**, or LESA, when found in the salivary glands), and malignant B cell lymphomas that are present in affected tissues. To determine the mechanisms by which P2Y2R contributes to this progression and ensure we are effectively identifying B cell lymphomas at early stages, we needed to arrive at a definition of these stages and the markers and characteristics we use to identify them. This effort is ongoing as we revisit data from the project.

In another mouse model, we utilized a pharmacological approach by administering a P2Y2R antagonist called AR-C118925. This resulted in significantly fewer lymphocytic foci in the salivary and lacrimal glands and improved salivary flow. We further demonstrated that P2Y2R expression on B cells was important for B cell migration and production of immunoglobulins, suggesting that P2Y2R helps B cells migrate to inflammatory sites within the gland and contributes to B cell function.

Together, we found that P2Y2R may serve as a promising target for new therapeutics to resolve inflammation, restore glandular function, and ameliorate the risk of developing B cell lymphomas. Unfortunately, the compound we used to inhibit P2Y2R in mice, AR-C118925, does not have the **pharmacokinetic properties** that make it suitable to translate to the clinic. Thus, we are working with a chemical biologist to screen compounds to find suitable **antagonists** to target human P2Y2R. We have narrowed the list to 100 candidate drugs, which we will begin testing to determine their efficiency in binding to and modifying the function of human P2Y2R. At the same time, we are working to understand better the development of B cell lymphomas in affected mucosa-associated tissues (e.g., salivary glands, lungs) and test AR-C118925 treatment at various disease stages in multiple animal models. Finally, with the explosion of robust transcriptomic datasets, we are investigating the cell-specific expression of purinome genes in the minor salivary gland biopsies from SjD patients compared to those without SjD. This will allow us to identify potential cell-cell communication and provide a better idea of the overall purinome landscape rather than investigating one receptor at a time to assess its suitability as a therapeutic target. ■

Glossary

- **Alarmins**- immune activating proteins or peptides
- **Antagonist**- a substance that inhibits or interferes with the normal function of a protein or enzyme
- **B cell hyperactivation**- higher activity and infiltration of B cells caused by inflammatory stimulation of the B cell receptor, CD40 receptor, and/or the toll-like receptor, which can lead to increased antibody production, resulting in hypergammaglobulinemia, elevated levels of β2-microglobulin and production of autoantibodies directed against SSA/Ro and SSB/La autoantigens and rheumatoid factor.

  Citation
  Kroese FG, Abdulahad WH, Haacke E, Bos NA, Vissink A, Bootsma H. B-cell hyperactivity in primary Sjögren's syndrome. *Expert Rev Clin Immunol*. 2014;10(4):483-499. doi:10.1586/1744666X.2014.891439
- **Lymphoepithelial sialadenitis**- benign autoimmune lesion characterized by acinar cell destruction, infiltration of lymphocytes, and ductal cell overproduction in the salivary glands; however, the lesions have a higher risk to become malignant in Sjögren's

  Citation
  Chi Y, Zhang Q, Qin Z, et al. Molecular pathology assists the diagnosis of lymphoepithelial sialadenitis, Sjögren's syndrome and extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue. *J Dent Sci*. 2024;19(1):130-138. doi:10.1016/j.jds.2023.05.018
- **Nucleotides**- the basic structural unit of nucleic acids; DNA and RNA are made up of chains of nucleotides
- **Pharmacokinetic properties**- "what the body does to the drug"; contains four processes: absorption, distribution, metabolism, and excretion
- **Purinome**- contains all sets of proteins— including enzymes, transporters, and receptors— involved in nucleotide signaling ■

Sjö-off Your Sjögren's Swag and Raise Awareness in your Community!

With Dry Eye Awareness month and World Sjögren's Day in July, spark conversations with those in your community about Sjögren's by displaying your Sjögren's awareness items. We have created different bundles for whichever collection of awareness items fits your style. Whether you're driving around, running to the grocery store, or writing notes at work, you can raise awareness by showing off your Sjögren's items!

Sjögren's Soft T-Shirt

Back

Front

Sjögren's Car Magnet

Sjögren's Pen

Sjögren's Shopping Tote

Sjögren's Bookmark

Order your kit by calling (301) 530-4420, online at sjogrens.org/shop or use the form below

	Qty.	Size: S-2XL	Total
Full Awareness Kit **Member: $34 Non-Member: $39** Shopper Tote, Pen, Car Magnet, 40th Anniversary Timeline with Major Milestones in Sjögren's, 40th Anniversary Bookmark, Awareness T-shirt, The "This is Sjögren's" Flyer, Living with Sjögren's Summary of Patient Survey and 3-brochures: "What is Sjögren's", "Dry Eye", and "Dry Mouth" *Shipping $9.00*			
Shoppers Tote & Magnet Bundle **Member: $12 Non-Member: $15** Shopper Tote, and Car Magnet *Shipping $9.00*			
Shoppers Tote **Member: $9 Non-Member: $10** Shopper Tote *Shipping $6.00*			
Car Magnet **Member: $5 Non-Member: $6** Car Magnet *Shipping $6.00*			
Shipping and Handling: U.S. Mail: $9 or $6 for first item + $2 for each additional item			
		Total Amount Due	

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

Name ______________________ Member # __________

Address ______________________

City ______________ State ______ Zip ________

Telephone ____________ E-Mail ____________

40 Years Sjögren's FOUNDATION

☐ 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 ________ Security Code ________ Signature ______________________

You Stood Up!

Our Creative and Silent Fundraising Supporters

The Foundation is tremendously grateful to our many dedicated donors and fundraisers throughout the year. We often share our gratitude with supporters that we know have participated in Foundation-organized fundraisers, including our Walk for Sjögren's and the World Sjögren's Day donation match. However, there is a large group of fundraisers that we don't often hear about. Other fundraising platforms do not always notify us of who set up fundraisers and/or their donors. So, we'd like to thank the innovative fundraisers that leverage digital platforms like Twitch and YouTube to fundraise for the Foundation.

Twitch and YouTube are two of the most popular platforms for content creation and community engagement. As the technology age is evermore present, there are multiple ways to utilize it for fundraising, including live streams to raise awareness for Sjögren's or using their donation integration tools to set up an automatic donation button for followers. Utilizing these platforms creates a connection to millions of people across the world to offer unique opportunities for fundraising and raising awareness.

Here are several ways in which these platforms can be effectively utilized for such purposes:

Educational and Awareness Campaigns

Twitch and YouTube can be used to create a variety of educational and awareness content for viewing. The channels can be used to host live discussions or presentations as well as posting informative videos that detail the daily life of a patient with Sjögren's or describing the symptoms, clinical manifestations, and burden of this invisible disease. Using digital platforms like this can help amplify your voice, provide valuable information to the world, and inspire others to take action.

Donation Challenges and Charity Livestreams

Creating content for charity challenges can be fun and interactive. Many people host talent shows, live performances, or question and answer sessions. Content creators can set up donation challenges during their streams, where certain milestones trigger specific actions or incentives. For example, reaching a certain donation amount might lead to the creator performing a song, hosting a giveaway of donated items, or initiating gamer challenges.

An example of this has been done by one of our community members, Alexis (online alias: SqueeeQueen), on Tiltify. Tiltify is a fundraising platform for the digital

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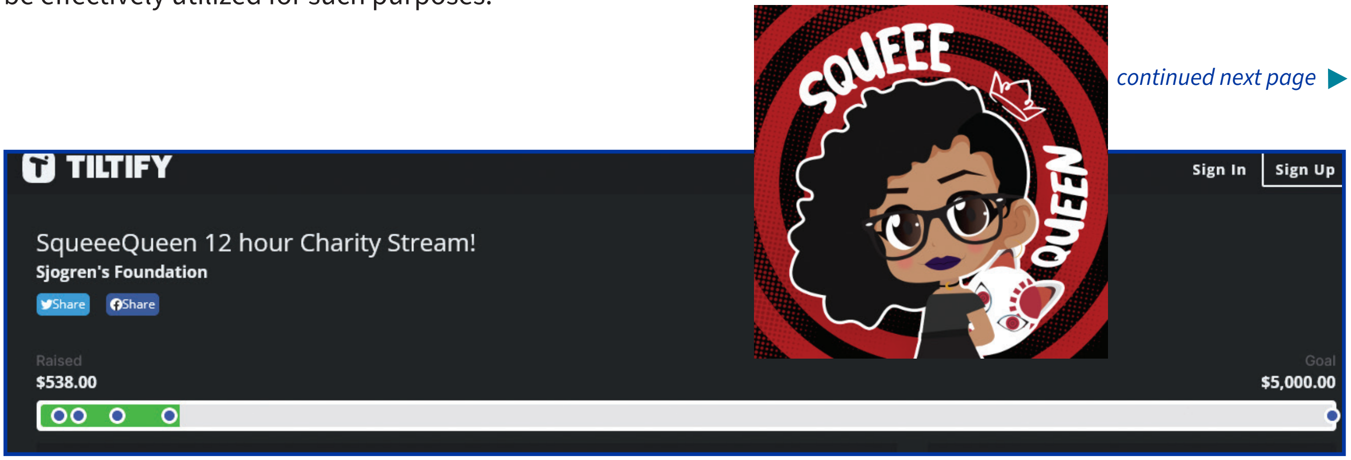

SqueeeQueen 12 hour Charity Stream!

Sjogren's Foundation

Raised
$538.00

Goal
$5,000.00

IN MEMORIAM

In Memory of Heidi Ann Burke
John Burke

In Memory of Inas Clark
Barbara Hoover
Amy Hoover Wren
Jacqueline Blount
Ken and Pat Burger
Pamela Butcher
Patty Hoover
Ron and Kathy Morgan
Carl Rohrs
Madonna Woodrey

In Memory of Kathleen Crawford
Anthony Varcallo

In Memory of Jacquelyn Ann Crosby
Chester Crosby
Lisa Crimaldi
Victoria Robb
Cory Ross
Terry and Jean Roberts
Charles and Martha Thomas
Sandalwood South Association
James Davis
Gene and Diane Gaudino
Kenneth and Sandra Pape

In Memory of Al DeVries
Judith Machtel

In Memory of Cindy Dickerson
Gerald Bergum

In Memory of Ida Dombi
Mercedes Dombi

In Memory of Marlene Dunham
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In Memory of Sharon Dutcher
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James Burson
Aaron Dutcher
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Brian Schultz
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Sandra Thomas
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In Memory of Marilyn Fusco
Helen Chaing

In Memory of Guadalupe Garcia
Ellen O'Brien-Garcia

In Memory of Jan Gordon
Kevin McCaffrey

In Memory of Sandra Hand
Stephen Clarridge

In Memory of Martha C. Hernandez
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Mardi Smith

In Memory of Patricia Knight
Gary Coenen

In Memory of Brenda Koplin
Judith Strausberg

In Memory of Bonnie Litton
Naomi and Neil Arnold

In Memory of Maxine Marshall
Beverly Graham
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In Memory of Joan Polcari
Elyssa Barbaro
Lisa Nantsis

In Memory of Ellen Peterson
Carl Peterson

In Memory of Eva Louise Plude
Maria Nally

In Memory of Chanda N. Powell
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In Memory of Carol Richards
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In Memory of Edward and Lillian Shore
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In Memory of Ella Whitten Sisler
Darla Rae
Joe Sisler

In Memory of Jennifer L. Stark
Amy and Shawn Courchesne

In Memory of Claude Watson Wilson, MD
Laurel Point Property
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IN HONOR

In Honor of Susan Barajas
Judith Hooyenga

In Honor of Sara Cashen
Celia Baldwin

In Honor of Beth Chase
Don and Mary Schock

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Miriam Paradiz

In Honor of Ken and Anne Economou
Mary Rosenfeld

In Honor of Jenny Fan
Andrew Gottlieb

In Honor of Cecile Haley
Alvin Haley

In Honor of Erica Hanson
Rebecca Hanson

In Honor of Kathy Hammitt
Janet Schwartz

In Honor of Carol Hrvatin
Ron Hrvatin

In Honor of Katherine Lawrence
Christopher Moench

In Honor of Richard Levy
David Levy

In Honor of Lari Lopp
Isabelle DesFontaines
Sarah Garretson

In Honor of Cynthia Neubecker
Lauren Young

In Honor of Lindsay Noble
Patrick Noble

In Honor of Liz Perry
Don Perry

In Honor of Adam Robinson
Joseph Harrington

In Honor of Nancy Sarow
Donna Reinardy

In Honor of Pat Shouse
Jacquelyn Staron

In Honor of Dr. Donald Thomas
Miriam Paradiz

In Honor of Nancy Visocki
Barb and Randy Bovin

In Honor of Kathleen Whittaker
Leroy Whittaker

generation that uses streaming platforms like Twitch, YouTube, and Facebook to provide interactive telethon-style technology to engage donors. Alexis reached out to the Foundation to ask us to be added to the list of organizations on Tiltify. She is a Twitch streamer that uses her love of video and computer games to create content and milestone challenges for her gaming streamer community and followers. She has raised over $850 for Sjögren's by doing something that she loves to do. Thank you, Alexis, for including us in your charity streams and raising awareness for Sjögren's!

Direct Donation

For those that want to remain anonymous or do not want to create content, there is an easy option for you! Both Twitch and YouTube offer features that allow creators to integrate donation buttons directly into their streams or videos. Viewers can make donations with just a few clicks, making the process seamless and convenient. Additionally, creators can set up recurring donations or reward donors with special perks or recognition, fostering a sense of appreciation and community engagement. ■

Again, the Foundation would like to thank every fundraising supporter and hope that you continue to find fun ways to fundraise and spread awareness for Sjögren's.

Conquering Sjögren's
Sjögren's Foundation Inc.
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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

Conquering Sjögren's One Step at A Time!

Join us in a Fall Walk as we celebrate 40 years of Progress!

Walk for Sjögren's is a national awareness and fundraising program that takes place across the country every spring and fall. But the walks are so much more! They are an amazing series of events where patients build community together, interact with Sjögren's experts, educate family and friends, and raise funds for important initiatives and research. This year, we are commemorating 40 years of Sjögren's progress with our theme: Conquering Sjögren's, One Step at a Time! Join us at one of our fall virtual events, we had a great set of spring walks and look forward to seeing you in the fall. If you're interested in attending and would like to learn more, please contact Jessica Levy at jlevy@sjogrens.org, visit **events.sjogrens.org**, or scan the QR code below.

Fall 2024 – Walk for Sjögren's Calendar

July	**Virtual Fall Kick-off** *Thursday, July 11, 2024*
September	**Virtual Texas Walk for Sjögren's** *Saturday, September 28, 2024*
October	**Virtual Northeast Walk for Sjögren's** *Saturday, October 19, 2024* **Virtual West Coast Walk for Sjögren's** *Saturday, October 19, 2024*

events.sjogrens.org

40 Years Sjögren's FOUNDATION