

CONQUERING Sjögren's

May/June 2023

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#ThisIsSjögrens



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Sjögren's Awareness Month: Real Patients, Real Advice #ThisIsSjögrens

Every patient has a unique and powerful story to share, which is why Sjögren's Awareness Month 2023 featured 30 real patients who shared their stories to raise awareness about the complexity of the disease.

Although disease awareness is on the rise, Sjögren's is one of the most prevalent but still lesser-known autoimmune diseases. Often described as an "invisible illness," Sjögren's affects patients differently, which is why sharing your story can be an incredibly powerful tool. The Foundation's #ThisIsSjögrens campaign was created to feature you and tell the stories of real patients. It is the collection of your experiences, physically and emotionally, that truly portrays the diversity of this complex disease.

Every day in April, the Foundation featured a different patient on our website and shared insight into their life. This year's campaign focused on both the complexity of symptoms, tips about how self-care can be used to help manage Sjögren's, and advice shared directly between patients. Each daily post gave a small glimpse into what is Sjögren's and together, these 30 stories showcased the complexity of the disease and the strength of this community.

Thank you to everyone who supported this year's campaign and those who shared their Sjögren's journey to help increase awareness of this serious, systemic, and prevalent disease. Even though April is over, every day is an opportunity to start a conversation about Sjögren's and how it affects you. We encourage you to continue to look for ways to connect with the Foundation and add your voice to ours as we work to conquer the complexities of Sjögren's and transform the future for all patients.

Below are some of the stories from this year and we hope you will visit www.sjogrens.org to view all the stories highlighted during Sjögren's awareness month.



Anita 60 (diagnosed at 59)

Sjögren's has taught me to never question people if they don't feel well. Not all diseases are apparent or obvious, someone may be silently suffering.

If you aren't feeling supported, try to get therapy. This is a real disease that is serious. There should be more awareness.



John 44 (diagnosed at 44)

My best Sjögren's tip is to not give up. It's ok to take it one day at a time, or sometimes one minute at a time, or even one breath at a time.

I had to fight for 14 years to get a correct diagnosis and now I am fighting to find a doctor who can adequately treat me for this complex disease that has multi-organ system involvement.



Sharlene 60 (diagnosed at 39)

My most difficult Sjögren's symptoms are muscle aches, fibromyalgia, brain/memory fog, dry eyes/eye health, dryness everywhere, gastrointestinal (GI), neurological and so on.

Sometimes this disease makes me question myself. I know it gets difficult, but we got this. Try to keep living life to the fullest.

“Awareness Month” *continued from page 3* ▼



Sadie 10 (diagnosed at 8)

Sjögren’s has taught me to not give up. Dealing with Sjögren’s takes a lot of help. My best tip is to not to give up on it, because it will get worse if you do. I also sit down when I need to rest and use my water bottle when I’m thirsty.



Darlene 22 (diagnosed at 21)

My most difficult Sjögren’s symptoms are digestion problems, fatigue, and joint/muscle pain.

To help manage my disease, I’ve learned to respect my body’s limitations. I try to avoid things that will trigger symptoms and I don’t

question myself when I’m having a flare. Now, I just accept it and try to calmly deal with it.

Remember to listen to your body. Take care of your physical health, without forgetting the mental health. They go hand in hand.



Natasha 32 (diagnosed at 25)

I had to give up what I thought was my dream job to go on disability because of Sjögren’s, but I’ve realized that dreams change and evolve.

My most difficult symptoms are total body inflammation, widespread pain and dysautonomia.

This disease has taught me to be more confident in advocating for myself and for others.



Gabriella 24 (diagnosed at 22)

Sjögren’s affects me physically, emotionally, and financially. Physically, I am in pain almost every day of my life. It’s sometimes difficult for me to accomplish everyday tasks, like tying my hair or walking up stairs.

Emotionally, I often question why I was chosen to have this condition. And financially, well, we all know that having an autoimmune disease is not cheap by any means with medications, doctor appointments, therapies, and more. Always listen to your body and trust yourself.

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Clinician's Corner: Surgery and Sjögren's

Anesthesia and Sjögren's



by Charles E. Bryant, MD
Board-Certified Anesthesiologist

Q *If you're having surgery with anesthesia, is it important to tell your anesthesiologist that you have Sjögren's?*

A When having surgery with anesthesia, it is important to discuss any systemic manifestation of Sjögren's with your anesthesiologist, particularly if there are any pulmonary issues, autonomic dysfunction, and oral/ocular symptoms. While we take care to protect the eyes during anesthesia, extra care may be required to prevent corneal abrasion.

Q *Before a surgery with anesthesia, why is it important to talk to the anesthesiologist about saliva producing medications like Salagen® and Evoxac®?*

A Products that increase saliva production could increase the presence of saliva while managing the airway, such as placing a breathing tube. This may require additional suction prior to this procedure. Furthermore, medications are frequently used to reverse muscle relaxation that may aggravate dry mouth symptoms. Thus, it is important to discuss these issues and current medications with your anesthesiologist.

Q *Will my general dryness symptoms worsen after surgery with anesthesia? Can I do anything to help with post-surgery dryness?*

A Ideally, prevention of dry eye symptoms through the use of lubricating agents during surgery should minimize dry eye symptoms. However, it is a great idea to have your eye drops available after surgery in the event of dry eye symptoms. I recommend discussing this with your surgeon and anesthesiologist to ensure that it is safe to use these products after surgery.

Eye Surgery and Sjögren's



by Lee Wei Guo, OD
The Johns Hopkins University
School of Medicine,
Assistant Professor of Ophthalmology

Q *Is it possible to have laser eye surgery with Sjögren's? Are procedures like LASIK, PRK or cataract surgery good for Sjögren's patients?*

A When patients inquire about laser surgery, they're usually referring to LASIK or PRK. These surgeries can directly affect the corneal nerve plexus via laser ablation which can potentially attenuate how well these nerves fire in response to environmental stimuli. For example, wind, smoke, fumes, micro foreign bodies, etc will usually stimulate a reflex tearing response.

“Clinician’s Corner” *continued from page 5* ▼

Sometimes after LASIK, the capacity for reflex tearing decreases, leading to post-LASIK dry eye.

When Sjögren’s disease is also comorbid in these situations, lacrimal function is already decreased due to an autoimmune process. That is, Sjögren’s patients on average are already way underproducing tears. Now you have post-surgical decrease in tear production on top of that due to corneal nerve damage. This combination is a recipe for dry eye disaster. The trouble is, often there are Sjögren’s patients who were never diagnosed with Sjögren’s in time, so they went ahead and had LASIK done and developed terrible dry eye sequelae after. Whether it’s LASIK, PRK, or cataract surgery, anytime the corneal tissue is cut or ablated, there is potential for negative effects on the way corneal nerves fire post-operatively, therefore patients should always review benefits and risk with their surgeon before proceeding with any ocular surgery. In the setting of Sjögren’s, there can be a cumulative effect in worse dry eye depending on the type of surgery. Some of my worst cases of dry eye were among patients who did not know they had underlying Sjögren’s at the time of surgical consultation. Later on, what ends up prompting us to investigate for Sjögren’s months to years later

is severe dry eye disproportionate to what we normally observe in post LASIK or post cataract surgery patients. Sometimes patient reported symptoms correlate to dry eye severity but not always; for example, in cases of neurotrophic keratitis or neuropathic pain, both of which can happen after LASIK.

When Sjögren’s patients inquire about their candidacy for LASIK or cataract surgery, we must emphasize the potential for worsening of dry eye post-operatively and carefully consider the risk vs benefit. In addition to preservative-free artificial tears, there’s also medications (cyclosporine, lifitegrast, steroids, antibiotics), tear duct plugs, and Meibomian Gland Dysfunction procedures that we can investigate to optimize the ocular surface as much as possible before cataract surgery so that there is less risk for post operative complications. Just because a patient has Sjögren’s does not mean they cannot have cataract surgery. It’s not an absolute contraindication. Ultimately however, detailed conversations about surgical expectations, risks, benefits, and alternatives must be discussed with your surgeon in order to maximize successful outcomes. The goal of optimizing the ocular surface is to prevent progressive corneal scarring that can lead to vision loss. ■



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

New phase 2 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.



Sjögren’s
FOUNDATION



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



FDA releases Public Safety Notification on Amniotic Fluid Eye Drops

The Sjögren's Foundation remains dedicated to the safety of Sjögren's patients and providing you with the information you need to make important health decisions. On April 10th, the U.S. Food & Drug Administration (FDA) made an announcement to inform consumers that some manufacturers are marketing and distributing amniotic fluid eyedrops to treat, mitigate, or cure diseases or conditions such as dry eye disease without the required premarket review and approval, raising potential significant safety concerns.

There are currently no FDA-approved amniotic fluid eyedrops to treat, mitigate or cure eye diseases or conditions, and in order for a health care practitioner to offer these products to patients, there must be an investigational new drug application (IND) in effect. In addition, as these products are not FDA-approved, the agency does not have information about their manufacture, so no assurance is available showing that the products are safe and effective for any disease or condition.

Examples of Amniotic Fluid Eye Drops include:

Regener-Eyes Professional Strength

Regener-Eyes LITE

StimulEyes

To view the FDA Public Safety Notification, visit [fda.gov](https://www.fda.gov).



Sjögren's Foundation Rings Nasdaq's Closing Bell

On Tuesday, April 11, 2023, the Sjögren's Foundation had the exciting honor of participating in the Nasdaq Closing Bell Ceremony at the Nasdaq MarketSite in Times Square. In honor of the occasion, Janet E. Church, President & CEO of the Sjögren's Foundation, rang the Closing Bell and was joined by Foundation board members, staff, and fellow Sjögren's patients.

It was ideally timed with April being Sjögren's Awareness Month and an amazing opportunity to highlight and increase awareness for Sjögren's. As part of the event, the Sjögren's Foundation logo was displayed on the Nasdaq Tower and Marquee in the middle of Times Square including a live stream on the Nasdaq Webcam, MarketSite Tower in Times Square, and participating television networks such as CNBC, Fox Business News, Bloomberg TV and BNN—reaching millions of viewers worldwide.

“The Sjögren's Foundation was honored to ring the Nasdaq Closing Bell on behalf of all patients living with Sjögren's and to do so during April,” said Church. “Visiting Nasdaq was a highlight of this year's Sjögren's Awareness month. It was an emotional moment being there and an unforgettable experience.”

The Foundation would like to thank the Foundation board members who joined us, Dr. Brent Goodman, Dr. Ava Wu, Dr. Vidya Sankar, Tom Iatesta, and Katie Forte as well as Sjögren's patients Camille Manning, Paula Sosin, Beth Harkavy Axelrod, Christine Iatesta and Antoinette Schielein. The Foundation would also like to thank Nasdaq broadcast events specialist Sabrina Schielein for her help in the Foundation ringing the closing bell. ■



Photography courtesy of Nasdaq, Inc



Photography courtesy of Nasdaq, Inc



Photography courtesy of Nasdaq, Inc

Pictured from left to right: Antoinette Schielein, Beth Harkavy Axelrod, Dr. Brent Goodman, Katie Forte, Dr. Ava Wu, Janet E. Church, Dr. Vidya Sankar, Tom Iatesta, Christine Iatesta, Camille Manning, Paula Yelsey, and Ben Basloe



Photography courtesy of Nasdaq, Inc



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Spring 2023 – Walk for Sjögren's Calendar

June

Virtual Texas Walk for Sjögren's
Saturday, June 10, 2023

Virtual Colorado Walk for Sjögren's
Saturday, June 10, 2023

events.sjogrens.org



Sjögren's Foundation 2023
National Patient Conference

Thank you to everyone who joined us for the
2023 National Patient Conference.

Learn more about this year's Conference in the
next issue of *Conquering Sjögren's*.

My Sister Had Sjögren's, But It Didn't Have Her A Tribute to Jennifer L. Stark

by Amy B. Courchesne

Early in 2022, Jen left me one of her 2021 Walk for Sjögren's t-shirts as she was preparing to be admitted for a hospitalization. (She later told me she gave me the t-shirt because she thought I'd be a good advocate.) Around that time, I received an email from the Sjögren's Foundation about joining Team Sjögren's, which is a fundraising walk/run. Jen took part in many Walk for Sjögren's fundraisers after her diagnosis in 2004, when she was experiencing some of the more common manifestations of Sjögren's. Over the years, as other, more severe symptoms manifested, her annual walks grew shorter, but her resiliency did not. She lived as a courageous, inspiring example of advocacy for her own health condition and that of other Sjögren's patients. It made it easier for me to honor her wishes, especially because I already looked up to her as my big sister.

I completed the Team Sjögren's half-marathon on June 5, 2022, while holding Jen's picture, just as she was preparing for a bone marrow stem cell transplant that might hopefully cure her leukemia. I was resolved to push myself until it hurt because Jen did every day. I was the top fund raiser and she cheered me on during the Team Sjögren's post-run celebration Zoom call.

That wasn't the first time I did something in her stead and honor. In early fall 2012, Jen and I went on a belated 40th birthday trip for her with our mother to the Smoky Mountains National Park. Jen loved national parks, adventures, animals, hiking, and anything outdoors. It was a once-in-a-lifetime trip. I noticed that week that Jen was having trouble with the stairs at the cabin and was slowing down, indicating she was having difficulty. One day at the park, we started a hike up a steep scenic route and she stopped and said she couldn't go any further. I was determined and, though I felt I couldn't make it, I completed the hike. I did it for us. Within weeks after our return home, Jen had permanent bilateral foot drop (foot paralysis) from cryoglobulinemic vasculitis, and they



Jen on her 2021 Walk for Sjögren's around her apartment parking lot.

discovered she also had lymphoma – all severe manifestations of Sjögren's. She endured several years of chemotherapy and plasmapheresis, after learning to walk with newly fitted orthotics and leg braces. Our mother moved in with her to help for a time. Her battle led to career loss following her hard-earned Ph.D. in neuroscience and accomplished research work. From the start, her scientific background gave her the benefit of understanding what was happening in her body and advocating for herself, as many with autoimmune diseases must do.

Thankfully, the Sjögren's Foundation's work resulted in Sjögren's being a qualified disability, as was lymphoma. I helped her through the disability paperwork since she was weak and sick from chemotherapy. I typed when she couldn't, I hiked when she couldn't, I

“Jennifer L. Stark” *continued from page 11* ▼

ran when she couldn’t walk as much; her battle became our battle. When she was too sick, I advocated for her with doctors, but she helped me more than she knew.

The leukemia was chemotherapy-induced from the lymphoma, stemming from Sjögren’s. One of Jen’s dying wishes was that there would be more research, education, and outreach about the severe manifestations of disease and the importance of early diagnostic tests and advocacy. This year’s Sjögren’s Foundation National Patient Conference topic about severe manifestations of the disease was timely, though only a smaller percentage of patients suffer the way Jen did. Jen never stopped fighting until her last breath on February 27, 2023, at 1:07pm. Jen’s hope for her future, turned into hope for someone else’s. The pain of the loss of my beloved sister and friend resulted in a deep desire to do something in her stead and honor her once again. I believe Jen’s life will continue to have meaning and purpose beyond her 52 years. If you are a patient or loved one, friend, researcher, physician, or administrator of a Sjögren’s patient, there is continuous work that can be done as an advocate and supporter, like Jen and me. ■

Disability and Sjögren’s

If your illness has progressed to the point that you can no longer work, you may be eligible for disability benefits through Social Security (Disability Insurance Benefits, Supplemental Security Income, or both), which provide monthly cash as well as access to Medicare after 29 months of disability.

If you’d like to learn more about filing for disability with Sjögren’s, visit our website or use the QR code on the right.



Amy and Jen on her last Walk for Sjögren’s on October 1, 2022, to her beloved bee flower garden and back.



Amy, Jen, and their mother, at the Smoky Mountains in 2012, just prior to Jen’s severe manifestations of Sjögren’s.



An Eyeball Tummy Tuck

What it is and How Could it be Beneficial in Managing a Patient's Dry Eye Symptoms with Sjögren's?



Esen Karamursel Akpek, MD

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Baltimore, Maryland*

Conjunctivochalasis is a chronic ocular surface condition of unknown etiology and a common mimicker of dry eye symptoms. It is defined as the presence of non-edematous folds of loose conjunctival tissue typically located in the inferior and inferotemporal bulbar conjunctiva. The term comes from the Greek “chalasis,” meaning to slacken, and was first used by Hughes in 1942.¹

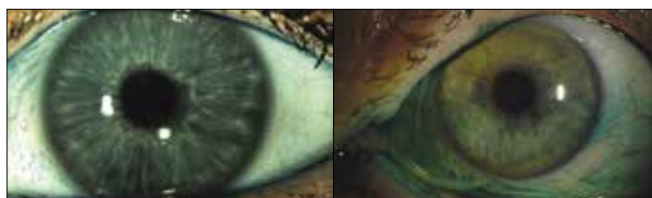
Conjunctivochalasis is a common finding in ocular surface disease practices as well as general ophthalmology and optometry clinics. However, it is often overlooked and underdiagnosed because of underappreciation of the importance of this condition. Although there is a significant variation in presentation, foreign-body sensation, blurring of vision and excessive tearing are the most common patient reported symptoms. Notably, eye dryness is the most common patient-reported symptom in Sjögren's patients but almost never excessive tearing. Patients with Sjögren's related dry eye are particularly susceptible to have conjunctivochalasis due to the severity of the ongoing ocular surface inflammation. Unfortunately, many of these patients are diagnosed with dry eye and treated with a number of conventional dry eye treatments (over-the-counter or prescription medications) for a long time period without improvement of their symptoms.

Diagnosis of conjunctivochalasis requires a high degree of suspicion. Conjunctivochalasis should be anticipated and actively looked for among dry eye patients with foreign body sensation and blurred vision, particularly if they seem to have adequate unanesthetized Schirmer levels. The high lower tear meniscus tends to act as a prism and might blur vi-

sion during downgaze, such as when reading a book or other closeup activities. A careful slit lamp examination shows lid parallel conjunctival folds (Figure 1), which become more apparent with fluorescein or lissamine green dye application. These patients usually have desiccation evident by the staining of the conjunctival epithelium overlying the folds due to the non-wetting by the tear film. Unfortunately, in patients with Sjögren's related dry eye conjunctivochalasis is more difficult to diagnose because of the inherent low tear production and low or absent inferior tear meniscus and high overall conjunctival staining score due to the severity of the inflammation.

Figure 1

Slit lamp appearance of normal bulbar conjunctiva (left) versus conjunctivochalasis (right) after lissamine green dye application. Redundant bulbar conjunctiva with folds staining with the dye are evident.



The exact etiology of conjunctivochalasis is unknown. Prolonged exposure to ultraviolet light and inflammation in the setting of tear film deficiency have been implicated. Clinicopathologic analyses of histopathological samples show mixed results. Some

continued page 14 ▼

“Tummy Tuck” *continued from page 13* ▼

studies found no goblet cell hyperplasia or cells of chronic inflammation. They hypothesized that age-related degeneration was the main cause in the pathogenesis of conjunctivochalasis. Other studies showed evidence of chronic inflammation composed mainly of lymphocytes. In a previous study, we noted stromal edema and fibrosis, chronic inflammation, and dilated lymphatic vessels. Epithelial changes, including goblet cell loss and squamous epithelial metaplasia, were a constant finding in all of our cases, ranging from moderate to severe.²

Although conservative medical therapies such as lubricating drops, topical steroids, and immunomodulating medications can lead to symptomatic relief and some clinical improvement in milder cases, patients with significant chalasis generally do not respond to conservative treatment. Superior limbic keratoconjunctivitis is a similar ocular surface disorder associated with a presumed inflammatory etiology that has been well-studied. Like conjunctivochalasis, it is generally treated conservatively initially with medical management, but surgical resection has been noted to be a definitive treatment for chronic cases.

Several surgical techniques have been described in the literature for patients whose symptoms are significant impacting their quality of life. Ultimately the goal of all these techniques is to remove the redundant conjunctiva, and smoothen the ocular surface. Cau-

terization using high-temperature thermal cautery, surgical excision with primary closure using sutures or fibrin glue, excision with amniotic membrane grafting, and laser or radio-wave electrosurgery are some of the techniques used thus far. Cauterization of the excess conjunctiva is a less invasive technique that can be performed in a clinical setting. However, it only benefits the patients with mild to moderate chalasis and is unlikely to help those with significant folds. In more severe cases, we prefer to perform excision with fibrin glue sealing (paste-pinch-cut technique) because of good clinical results, ease of technique, and a lower cost with reduced invasiveness compared with other techniques.² The surgery is performed in an operating room setting with topical anesthesia and monitoring by the anesthesia team. During the paste-pinch-cut technique (Figure 2), the fibrin glue is injected underneath the conjunctiva in the area(s) of chalasis. The redundant conjunctiva is then grasped with forceps and pinched until the glue solidifies to delineate the area of excision. The excess conjunctiva is then removed using surgical scissors. There is only minimal intraoperative hemorrhaging, and patients are generally comfortable postoperatively. The surgery does not affect vision, and patients can function normally as soon as the sterile eyepatch is removed. The paste-pinch-cut technique seems to be effective, with fast recovery and significant reduction in patient-reported symptoms and ocular surface parameters. ■

Figure 2

Appearance of paste (left), pinch (middle) and cut (right) technique under an operating microscope.



References

- 1 Conjunctivochalasis: a systematic review. Marmalidou A, Kheirkhah A, Dana R. *Surv Ophthalmol.* 2018;63:554-564.
- 2 Clinicopathologic analysis of conjunctivochalasis and paste-pinch-cut conjunctivoplasty for management. Liu T, Siadati S, Eberhart CG, Akpek E. *Can J Ophthalmol.* 2022;57:307-311.

Awareness never looked so good!

World Sjögren's Day is July 23

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Awareness comes in many different forms and this kit is designed to give you items that can create a conversation with family and friends about the disease.

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Summary of Major Findings Document			
(3) "What is Sjögren's?" Brochures			
Awareness Kit #2			
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“Awareness Month” *continued from page 4* ▼**Andrea 42 (diagnosed at 29)**

Fatigue is one of my most difficult Sjögren’s symptoms. When I was first diagnosed, I was so tired that I felt like I couldn’t walk. It was a never-ending feeling of just being extremely exhausted. I compared my fatigue as being hit by a bus!

I wish I had known sooner that I could find a doctor who would take this symptom seriously.

**Maci 21 (diagnosed at 15)**

My three most difficult Sjögren’s symptoms are dry eyes, brain fog, and fatigue. I can’t always do things that others my age can and I’m becoming ok with the fact I’m not always ok.

My go-to Sjögren’s product is a cold eye compress. An anti-inflammatory diet and working out has also helped me. Working out has not only helped with my symptoms, but it helps me mentally work through things and gives me a break for myself. On days when you feel even slightly better than the day before, cherish those small wins with all you have.

**Pooja 31 (diagnosed at 29)**

Sjögren’s has taught me to be a warrior princess and to stay strong to fight this monstrous disease.

Sjögren’s fatigue and pain has been the biggest challenge in my life. I want to do more, but the energy and fatigue won’t let me go anywhere. My best advice is to listen to your body and rest when you feel like you need it the most.

Go-to products: Using the Calm App on my phone to relax when I am not feeling well, drinking plenty of lemon water/carry my Sjögren’s water bottle everywhere, and I use a heating pad to alleviate fatigue and tiredness.

**Miriam 74 (diagnosed at 50)**

My most difficult Sjögren’s symptoms are joint pain, brain fog, inflammation, and neuropathy.

This disease has taught me to get to know my body well. My best Sjögren’s tip is to eat healthy, be active, and attend the Sjögren’s Foundation National Patient Conferences.

**Emily 32 (diagnosed at 31)**

I wish others understood that Sjögren’s has range: in what it can do, how it presents, how it is diagnosed, and its severity. This disease is systemic and can affect the entire body. My most difficult symptoms are neurological (neuropathy and dysautonomia), fatigue, dryness, and muscle pain.

My best tip is to learn to recognize both flares and your different energy “levels” of days, then adjusting early and accordingly.

**Tony 34 (diagnosed at 28)**

Don’t devalue your pain with Sjögren’s. Before I was diagnosed, my dry eyes were excruciating. It’s hard to express just how painful it can get. Your pain is real.

My most difficult Sjögren’s symptoms are dry eyes, dry mouth, fatigue, and swollen lymph nodes.

**Tanisha 43 (diagnosed at 40)**

There isn’t a day that I am not impacted by my disease. I wish others understood that Sjögren’s is a silent disease. A large part of the emotional stress comes from feeling the need to convince or explain to others that I am not feeling well.

I am thankful for my husband and my kids, who have taken the time to become more educated about this disease and help me. They can recognize when I’m in a disease flare and need support.

**Diana 36 (diagnosed at 35)**

Speaking with people and forgetting what you are saying mid-sentence can be humbling. Brain fog and fatigue can remind you to slow down and listen to your body.

This is not a disease you can see, but if you know someone who has Sjögren’s, please educate yourself to better understand them.



Resource Order Form



	Non-Member	Member	Qty	Amount
The Sjögren's Book , Fifth Edition edited by Daniel J. Wallace, MD. The 2022 edition of the Sjögren's handbook has been completely revised and expanded with all new chapters and the latest information on Sjögren's.	\$38	\$32		
The Sjögren's Syndrome Survival Guide by Teri P. Rumpf, PhD, and Kathy Hammitt. A complete resource, providing medical information, research results, and treatment methods as well as the most effective and practical self-help strategies.	\$20	\$17		
The Immune System Recovery Plan: A Doctor's 4-Step Program to Treat Autoimmune Disease by Susan Blum, MD, MPH. This book shares Dr. Blum's four-step program to help autoimmune patients reverse their symptoms, heal their immune systems and prevent future illness.	\$25	\$22		
You Don't Look Sick! Living Well with Chronic Invisible Illness by Joy H. Selak, and Steven S. Overman MD. One woman's journey through the four stages of chronic illness: Getting Sick, Being Sick, Grief, and Acceptance and Living Well.	\$16	\$14		
Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop by Norman Latov, MD, PhD. Peripheral neuropathy is a widespread disease, yet many people do not even realize they have it.	\$19	\$16		
You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life by Mims Cushing and Norman Latov, MD. A compendium of tips, techniques, and life-task shortcuts that will help everyone who lives with this painful condition.	\$19	\$16		
Healing Arthritis: Your 3-Step Guide to Conquering Arthritis Naturally by Susan S. Blum, MD, MPH (Author), Mark Hyman (Foreword).	\$24	\$20		
A Body Out of Balance by Ruth Fremes, MA, and Nancy Carteron, MD, FACR. A Sjögren's patient and a doctor offer their authoritative insight into one of the most common yet most misunderstood autoimmune disorders.	\$16	\$13		
Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain's Silent Killers by David Perlmutter, MD (author) and Kristin Loberg (contributor). A #1 New York Times bestseller – the devastating truth about the effects of wheat, sugar, and carbs on the brain, with a 4-week plan to achieve optimum health.	\$25	\$20		
How to Live Well with Chronic Pain and Illness – A Mindful Guide by Toni Bernhard. The book addresses challenges created from chronic illness to help readers make peace with a life turned upside down.	\$17	\$14		
Shipping and Handling: U.S. Mail: \$7 for first item + \$2 for each additional item				\$7.00
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Membership (new/renewal): Includes <i>Conquering Sjögren's</i> newsletter, member pricing on books and more benefits.		\$36 each		
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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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Exp. Date _____ Security Code _____ Signature _____

“Awareness Month” *continued from page 16* ▼**Caroline 27 (diagnosed at 26)**

Never delay seeking medical treatment if something doesn't feel right.

Sjögren's has taught me to listen to my body. Realizing that I can't be as active as I used to has been tough. My best tip is to recognize when your body needs a break.

Saying no to something can be difficult, but it's important to let your body recover when it needs to.

My go-to Sjögren's products/ tools are scleral contact lenses and preservative free eye drops.

**Maya 63 (diagnosed at 45)**

Sjögren's is invisible, but it is there.

This disease has taught me to be more understanding to others and never give up. To help manage my symptoms, I've incorporated walking and swimming into my self-care routine.

**Jyoti 27 (diagnosed at 21)**

Sjögren's has taught me how strong I am.

My go-to products/tools are yoga, staying positive, eye-drops, hydroxychloroquine, rituximab injections, and being consistent with my food/ medication timing.

**Edward 51 (diagnosed at 51)**

My most difficult symptoms are postural orthostatic tachycardia syndrome (POTS), arthritis pain and fatigue.

People often confuse me being quiet, or assume I'm upset with them, when I'm actually just struggling to cope with random symptoms. This disease has taught me acceptance and that I have to fight to stay ahead.

**Courtney 26 (diagnosed at 22)**

It's important to remember that it's ok to treat yourself. You deserve it!

Living with Sjögren's can be unpredictable, especially as a student. My best advice is to know that this isn't your fault and never stop fighting for adequate care.

My go-to products/tools are an XXL heating pad, a

handicap parking placard, Refresh Optive Mega-3 eye drops, prescription pregabalin, and CBD Epsom salt.

**Madison 23 (diagnosed at 7)**

Sjögren's has taught me to never judge a book by its cover. Someone may be dealing with very complex symptoms that won't show through without looking hard enough.

My best tip is to find a team of amazing doctors who will help you manage all your symptoms and when you need a break, take a break!

**Tawanna 46 (diagnosed at 43)**

I wish people knew that Sjögren's affects everyone differently and it can be hard to find a local doctor who will take your symptoms seriously.

Sjögren's has taught me to listen to my body, have more patience with myself, and have more patience with others.

**Dean 56 (diagnosed at 45)**

You are not alone in your diagnosis.

My best advice is to take care of your body before it forces you to take care of it. It can be difficult to stay positive some days but appreciate the good and great days. Still do what makes you happy!

**Joanie 74 (diagnosed at 71)**

After being diagnosed in 2020, I realized that I likely had some level of Sjögren's going on for decades. I suffered from irritable bowel syndrome (IBS), very dry eyes, dry skin, dry mouth, gastroesophageal reflux disease (GERD), and periodic exhaustion.

Keep the faith, help is on the way. A Sjögren's Foundation membership is the best tool for the latest information and feeling of, "You are not alone." There's hope with more specific-for-Sjögren's drug trials, and slowly, but surely, more doctors are recognizing it earlier for patients like me. ■

#ThisIsSjögrens

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.



IN MEMORIAM

- | | |
|---|---|
| <p>In Memory of Gail Azerrad
Fran Feinman</p> <p>In Memory of Joan F. Bocchino
Patricia Miller</p> <p>In Memory of Heidi A. Burke
John Burke</p> <p>In Memory of Carol Davis
Mary Ratcliff</p> <p>In Memory of Christine Drisgula
Maryann Heisler</p> <p>In Memory of Jan Gordon
Kevin McCaffrey</p> <p>In Memory of Sandra E. Hand
James Hand</p> <p>In Memory of Beatrice Hermann
Kim Ostermeier</p> <p>In Memory of Taryn Lesley Jones
Katy Brownley
Heather Cramer
Karen Galbiso
Mary Nuckols
Debra Ventling
Marilyn and Frank Wolfe
Virginia Wolfe</p> <p>In Memory of Brenda Koplin
Judith Strausberg</p> <p>In Memory of Joan LaPlante
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Bryan Jones</p> <p>In Memory of Dorothy Selleck
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Liz Hall
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Barbara Zaniewski</p> <p>In Memory of M. Joie Webb
Kaci Bishop
Harvest Advisors
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Tammy and JL Stone</p> |
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IN HONOR

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Susan Adley-Warrick</p> <p>In Honor of Monica Dougherty
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Lisa and Steve Shapiro</p> <p>In Honor of Lori Glover
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Ariel Weber</p> <p>In Honor of Lindsay Noble
Patrick Noble</p> <p>In Honor of Liz Perry
Don Perry</p> <p>In Honor of My Family
Richard Bliss</p> <p>In Honor of All My Sjögren's "Colleagues"
Miriam Paradiz</p> |
|---|---|

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



Sjögren's
FOUNDATION



Conquering Sjögren's

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



July 23rd is World Sjögren's Day

On July 23rd, we hope you will join with the Foundation to celebrate World Sjögren's Day. World Sjögren's Day was established to commemorate the birthday of Dr. Henrik Sjögren, the Swedish ophthalmologist who first identified the disease in 1933.

In addition to honoring Dr. Sjögren, World Sjögren's Day gives everyone touched by the disease a vehicle to reach out and educate those close to you about Sjögren's. It is meant to put a face on the millions of people who live with this disease and is the ideal opportunity for you to have your voice heard.

Leading up to World Sjögren's Day, and especially on the day itself, talk about Sjögren's with the people in your life. Share your story and educate others. By doing so, you are helping spread the message that Sjögren's is a serious and complex disease that deserves to be recognized.

We encourage you to visit www.sjogrens.org to learn more about how you can use your voice to join in the celebration of World Sjögren's Day.

