

# CONQUERING Sjögren's

March/April 2021

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## CONQUERING Sjögren's

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# Gynecologic Health and Sjögren's

by Dana Shanis, MD, FACOG

## *How Sjögren's affects the pelvic organs*

**S**jögren's is an autoimmune condition that can affect many tissues in the body, including the vagina and vulva. Inflammation and injury to the glands and blood vessels in the pelvic tissues in women with Sjögren's leads to a high rate of dryness, pain, infection and sexual dysfunction. Women with Sjögren's are more likely to have symptoms of vaginal atrophy prior to menopause than the general population, with effects that can greatly impact quality of life. The aim of this article is to review different issues that women with Sjögren's can face, and give some helpful tips on how to start feeling better.

## *Perineal Hygiene*

For many women, with or without Sjögren's, the vulvar skin can be very sensitive to irritants. This can cause itching and burning that may be difficult to distinguish from infections, atrophy or other vaginal skin changes. To decrease the likelihood of exposure to irritants, here are some recommendations for good perineal hygiene that all women should follow.

### **Laundry**

- Avoid detergents with dyes and fragrances
- Use drier balls instead of dryer sheets or fabric softener
- Try white vinegar instead of bleach

### **Clothing**

- Wear all cotton underwear (not just cotton liner)
- Avoid tight clothing

### **Bathing**

- Try using just warm water to clean vaginal area
- If you need soap, avoid ones with dyes and perfumes

- Trim pubic hair rather than shave (or better yet, leave it alone)
- DO NOT DOUCHE!!!

## *Infections*

Chronic yeast infections are more common in women with Sjögren's, which can cause significant itching, burning and discharge, and may be difficult to treat. It is important that a vaginal culture be performed by your doctor prior to treating a chronic yeast infection, as there are resistant strains of yeast, and the symptoms can overlap with other infections, as well as other non-infectious conditions. There is little evidence of a benefit of probiotic foods or supplements in treatment of chronic yeast infections, however, anecdotally many women report decreased frequency of infections with addition of probiotics. A healthy anti-inflammatory diet, with limited amounts of sugar, in general, may help prevent some yeast infections.

Once diagnosed by culture, various treatments are available, with prolonged treatment of fluconazole being the preferred option. Many women will opt to continue fluconazole suppression once yeast has been treated to prevent a recurrence. Gentian violet and boric acid suppositories are helpful for some, but have failed to show adequate treatment responses in many studies. If you suspect chronic yeast infections, you should talk with your gynecologist or see a specialist with training in difficult to treat vaginal infections.

Human papillomavirus (HPV) infections of the cervix and vagina are also more commonly active in women with Sjögren's. If untreated, these infections can lead to cancer. It is important that women with Sjögren's see their gynecologist to keep up on their annual pelvic exams, and obtain appropriate pap and HPV testing. HPV vaccination is now recommended in women

## “Gynecologic Health” *continued from page 3* ▼

up to 45 years old, and should be strongly considered in women with Sjögren’s.

### Vulvar Dermatoses

Autoimmune vulvar skin conditions, such as lichen planus and lichen sclerosus, are more common in women with Sjögren’s than in the general population. It is worth mentioning these conditions as often the symptoms overlap with infections or atrophy and can take a long time to diagnose. Correctly identifying these conditions are important, as the treatment is different to get relief, and there can be long-term consequences of this additional chronic inflammation.

Lichen planus is a condition that most commonly occurs as ulcerations, with symptoms of soreness, pain and itching. It can occur in other locations, such as mouth, skin or scalp. 70% of women with vulvar lichen planus will have involvement of the vaginal tissue, which helps to distinguish it from other dermatoses.

Lichen sclerosus most commonly presents as chronic, severe itching, with development of white, thickened patches of skin on the vulva. This condition is important to recognize and treat aggressively, as fusion of the labia and skin changes can lead to issues with urination and sexual activity. In addition, this condition increases the risk of vulvar cancer, so frequent monitoring and intermittent biopsy is recommended. Treatment of this condition with potent topical steroids is important, and may be needed even when you are not symptomatic.

### Vulvar and Vaginal Atrophy/Dryness

Vaginal dryness is common in all women after menopause, however, women with Sjögren’s are more likely to experience this at younger ages. There are several different theories on why this occurs, and is likely related to Sjögren’s attack on both exocrine glands and blood vessels in the vaginal tissue. Atrophy of the vaginal tissue that occurs with lowering of estrogen levels can worsen these symptoms and lead to increased risk of urinary or sexual dysfunction. This dryness and atrophy can cause discomfort in daily life, but is especially bothersome during sexual activity.

Vaginal estrogen is the most effective treatment for vaginal atrophy. It comes in various forms, such as a cream, tablet, capsule or ring. The absorption of vaginal estrogen is much lower than when taken orally, and does not typically require a progestin to protect the uterine lining. Many women shy away from estrogen supplementation due to their concern of breast cancer risk, however, there is a lot of research showing that that risk is either very low or non-existent.

Even women who have had breast cancer in the past may be candidates for this treatment, if they have failed non-hormonal options. There are some hormonal, non-estrogen options, such as Ospemifene, an oral agent or vaginal DHEA, which can be discussed with your provider if you want to avoid estrogen.

For women who are not candidates for hormonal treatment, there are lubricants and moisturizers that may help to alleviate symptoms of dryness or pain with sex. There are hundreds of brands of moisturizers and lubricants on the market, and differ in their pH, osmolality (concentration) and ingredients. The difference between moisturizers and lubricants is shown in this table:

Moisturizers	Lubricant
Rehydrate mucosa	Reduce friction
Typically bioadhesives	Improve comfort with penetrative intercourse
May help with dryness symptoms	Start with water-based
Use 2-3 times per week	Silicone or oil-based can last longer (use with caution on silicone sex toys)
Containing hyaluronic acid and/or vitamin E may be more effective	

The best way to find which option and brand is right for you is trial and error. Many companies and doctors can give you samples of various formulations for you to test out. If you have any skin sensitivities, ingredient lists should be reviewed and are, fortunately, available for most brands.

### Pain Syndromes

Women with Sjögren’s are more likely to suffer from a pelvic chronic pain syndrome than the general population, likely due to inflammatory effects. 1 in 10 women with Sjögren’s suffer from a condition called interstitial cystitis or painful bladder syndrome (IC/PBS). In this condition, women experience pain in the bladder, especially when full, and frequent need to urinate. Since most women with IC/PBS also have involvement of the nerves and muscles of the pelvic floor, urinary incontinence, pelvic pain and pain with sex are common.

Pelvic pain from other conditions, such as endometriosis, may be 4-times as common in women with Sjögren’s compared to the general population. Endometriosis is a condition where cells similar to the uterine lining are found elsewhere in the body, these cells bleed and secrete irritating chemicals that cause local inflammation, leading to pain. This pain is often

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## **“Gynecologic Health”** *continued from page 4* ▼

progressive over time, as the central nervous system and musculoskeletal system become involved.

Nerve issues, such as pudendal neuralgia and vulvodynia are also more common in women with Sjögren's and can be difficult to treat. Seeing a provider who specializes in these pain syndromes is important, as the treatment usually requires multiple modalities. Opioids are not typically effective for these pain conditions, and should be avoided.

### **Sexual Dysfunction**

Issues with all stages of the sexual cycle are common in women with Sjögren's, and are typically multifactorial. Many women experience dryness, which can cause discomfort with penetrative intercourse. Pelvic floor spasms and chronic pain syndromes can also lead to pain with sex. Both the inflammation of chronic illness and higher rates of depression can lead to issues with libido and arousal. Decreased vaginal blood flow, along with the problems in libido, arousal and pain, also can affect the ability to orgasm.

Unfortunately, many healthcare providers do not ask patients about issues with sexual function, and many patients and doctors do not feel comfortable discussing it. This is a shame, since many treatment options exist that can help with all aspects of the sexual cycle. It is important not to ignore these issues, which can have a great impact on your sense of self, quality of life, as well as your relationships. If you do not feel comfortable with your provider's ability to comfortably discuss these personal issues, I would seek out another provider, ideally one who specializes in sexual health. These issues are really common and there is no need to feel embarrassed!

### **Mental Health**

Chronic illness and pain increase the likelihood of depression and other mood disorders, so any emotional symptoms you are experiencing should routinely be addressed with your healthcare providers. Talking to a psychologist or counselor, or joining a support group can be really helpful to gain tools to cope with your symptoms. Treating symptoms with an anti-depressant can be really helpful to reset the neurotransmitter abnormalities that can affect your mood. Since depression can worsen the perception of pain and worsen long-term outcomes of chronic illness, in addition to affecting your quality of life, it is so important to address these issues.

### **Recommendations**

- Discuss concerns with your gynecologist! If you don't feel comfortable talking with your current doctor, or they are untrained in this area, find a specialist.
- Keep up on preventative gynecologic care. Annual exams and pap smears are important to prevent developing cervical or other gynecologic cancers in the future.
- Practice good perineal hygiene to avoid worsening any discomfort you may have.
- Experiment with different moisturizers or lubricants, trial and error may be the best way to find what works best for you.
- Talk to your doctor about vaginal estrogen if you are experiencing dryness or atrophy symptoms.
- Talk with your partner about your concerns, especially in regards to intimacy.
- Consider counseling and/or a support group. Dealing with chronic illness is hard, but you are not alone. ■



### **Are You a Spouse or Partner of Someone Living with Sjögren's?**

The Foundation knows how supporting and/or caring for someone with a chronic illness, like Sjögren's, can be very rewarding but it also has a significant impact on your life, too.

Please contact the Foundation at (301) 530-4420 or send an email to [info@sjogrens.org](mailto:info@sjogrens.org) and sign-up to receive specialized mailings, educational information, and notices about teleconference support group meetings for spouses and partners of Sjögren's patients.



## The Sjögren's Foundation Welcomes Janet E. Church as President and Chief Executive Officer



*Janet E. Church  
Sjögren's Foundation  
President and CEO*

The Sjögren's Foundation is proud to announce Janet E. Church as the organization's new President and Chief Executive Officer. Church will succeed Steven Taylor, who served nearly 18 years as President and CEO. Taylor will be joining the Arthritis Foundation as Executive Vice President.

Church was named after a comprehensive search led by a Search and Transition Committee, comprised of a diverse group of Foundation volunteer leaders and supported by the Board of Directors. "Janet's experience as a dynamic leader, along with her deep understanding of the disease, makes her the ideal person to lead the Foundation in our critical efforts," said Donald Thomas, MD, FACP, FACR, and Chair of Sjögren's Foundation Board of Directors.

Church is a seasoned technology marketing executive with a unique combination of corporate, agency, consulting, and non-profit experience acquired within the Fortune 50 technology sector—as well as with global non-profits and early-stage technology/service startups. Church, who is a Sjögren's patient, has served on the Sjögren's Foundation Board of Directors for the last eight years, holding the position of Board Chair for the past three years. She has a B.A. Degree in Communications from the University of Washington in Seattle, WA and is a Certified Professional Leadership Coach.

"Janet is the perfect choice to be the next President and CEO. She is not only authentic but is also a strategic leader who believes in the mission and vision of the Foundation. Her passion is easy to recognize and I know the Foundation is in great hands under Janet's leadership. We will continue to see incredible achievements on behalf of, and for, Sjögren's patients," said Steven Taylor.

"I'm honored to be entrusted with this important leadership position. The Sjögren's Foundation has a rich history as a trusted organization advocating for Sjögren's patients. I like to take on new challenges and have no trepidation moving boldly into the future of the Sjögren's Foundation. I look forward to joining the dedicated staff and working with our members and volunteers as we continue to move towards our shared vision of creating a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's," said Church. ■

# A Letter from Steven Taylor 18 Years of Service as President and CEO



*Steven Taylor  
Sjögren's Foundation  
Past President and CEO*

**F**or the past 18 years, I have been extremely honored to lead the Sjögren's Foundation. It has been the most incredible journey for me and my family.

As you know, my mother is a Sjögren's patient and I fully believe in the Foundation's mission and vision for the future. And that is why it is with mixed emotions I am departing the Sjögren's Foundation to join the Arthritis Foundation to serve as their Executive Vice President.

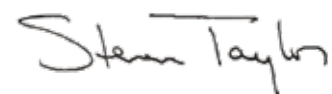
During my tenure at the Sjögren's Foundation, I have met so many wonderful patients, families, and caregivers – who each inspired me to forge on and fight for them. As our founder Elaine Harris said, “the Foundation was founded by a patient, for patients.” And that is how the staff and I have always led this organization.

The good news is that the organization continues to have the most remarkable and committed staff, an amazing Board of Directors, and hundreds of dedicated volunteers who help us each day to achieve our mission. And as patients and members of the Foundation, you are and will continue to be the heart of this organization.

I am also thrilled to be able to announce that the incoming President and CEO has already been named. Janet E. Church, past Board Chair and Sjögren's patient, has been by my side for the past eight years and I couldn't ask for a better successor. She is an outstanding leader who understands the disease and the Foundation's vision. She has helped lead this organization as our volunteer Board Chair for the past 3 years and she will do a remarkable job as the new President and CEO.

I want thank you from the bottom of my heart for allowing me to be a part of this wonderful community for so long. As a son of a Sjögren's patient myself, I will continue to support the Foundation in any way I can. I look forward to watching the Foundation continue to achieve its mission while creating a community that will conquer the complexities of Sjögren's together.

With heartfelt gratitude,





## Clinician's Corner:

# Oral Health and Sjögren's

by Shaila Kabani, DDS



*“My gums are very sore and appear to be receding. Is this common with Sjögren's and what are my treatment options?”*

**X**erostomia is a cardinal symptom of Sjögren's and is common in patients with periodontitis (gum infection/disease) and gingivitis (gum inflammation). Xerostomia can increase the chances of gum disease in a healthy mouth due to the lack of salivary flow, bacterial growth and sometimes followed by gum disease.

### *Most common types and causes of gum disease:*

#### **Gingivitis**

Gingivitis is inflammation of gums caused by retained food particles on teeth and around the gum areas due to lack of proper oral hygiene that turns into plaque and tartar, and causes irritation, swelling and bleeding of gums. This condition is reversible. It is treated by thorough debridement of gums by a hygienist and by using proper oral hygiene regimen to keep gums clean and healthy.

#### **Periodontitis**

Periodontal disease or Periodontitis is caused by bacterial growth over tartar and plaque, which causes bleeding, swelling and loss of bone that surrounds the root structure. Due to irreversible loss of bone, gums detach from the tooth surfaces causing recession and deeper pockets. Periodontitis is an irreversible condition and has to be managed on a regular basis. A deeper scaling and root planning (deep cleaning) is done initially by a hygienist or periodontist (specialist

of gum diseases) followed by 3-4 months periodontal maintenance to keep bone levels stable. As per studies, if periodontal maintenance is not performed every three months, bacterial growth recurs in the same areas that were infected initially. Therefore, timely management of the disease is very crucial and so is proper oral hygiene regimen at home.

### *Gum disease and Sjögren's:*

As per some studies, people who suffer from Sjögren's have a slightly higher risk of getting periodontal disease due to Xerostomia. Some studies have also indicated that the risk could be bidirectional. There is some evidence available showing that treatment of periodontal disease and elimination of bacterial infection may boost the salivary flow, improve clinical and immunological parameters and quality of life. An association may exist between Sjögren's and periodontal disease, and the topic needs further research and studies.

Xerostomia can also cause irritation of gums due to lack of moisture and lubrication. This may manifest as soreness of the oral tissues and gums, which causes gingivitis.

Gum recession due to gingivitis, periodontitis or other causes, exposes the root surface and structure. Root surface is a comparatively fragile part of the tooth and is not protected by enamel. If exposed due to recession combined with xerostomia, root surfaces can get decayed very quickly and cause sensitivity, pain and nerve infection if the decay progresses to the deeper structure.

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**“Clinician’s Corner”** *continued from page 9* ▼

**Treatment options for gum disease and at-home care:**

- Proper examination and evaluation of gums is very crucial, especially in patients who are suffering from xerostomia. Treatment of gum infection should be considered and should not be delayed if indicated. Proper periodic monitoring of gums should be performed by dentist and hygienist.
- If there are signs of gum recession, dentist may recommend gum grafting procedure to recover the lost tissue over root surfaces depending on the degree of recession. Gum grafts are generally performed by periodontist (specialist of gums).
- Proper oral hygiene routine including brushing with soft toothbrush and regular flossing will keep the plaque and tarter away from the gums and will prevent gum diseases. Adding over-the-counter (OTC) mouth rinses with fluoride or anti-inflammatory agents will keep the bacterial damage at bay. Dentist may recommend dental topical creams like MI paste or extra strength fluoride toothpaste to prevent damage to tooth and root structures.

- Lubrication of mouth consistently will decrease the chances of gum diseases, decay, sensitivity, stomatitis and inflammation. There are many OTC lubrication agents available, which can be beneficial for oral symptoms associated with Sjögren’s. To learn more about products for dry mouth, please visit [www.sjogrens.org](http://www.sjogrens.org) to view the Sjögren’s Foundation Product Directory.
- Hydration is as important as any other treatment modalities. Keeping the body hydrated will flush toxins and keep tissues moisturized.
- Regular dentist visits cannot be overstressed. Keeping oral health in check and preventing any issues is the best approach a person suffering with Sjögren’s and Xerostomia can benefit from.

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# You Stood Up!

## *Stylish Bracelets for a Great Cause*

Erin knows that Sjögren's patients deserve better treatment options and decided to help!

From watching her mother, Kim, live with Sjögren's, Erin decided to create a fundraiser by selling home-made bracelets to raise money for the Foundation.

Erin's stylish bracelets have a big meaning behind them. "I don't want to see my mom be in pain anymore from Sjögren's. Some of her friends also have it, and it worries me that there still isn't a cure for it. I'll sometimes help my mom get all her medicines ready for the week, and it just seems like there are too many. If we were able to lower the number, or better, her not need any, that would be great. I also really like making band creations, so I might as well do both," said Erin.

When Erin told Kim about her fundraising idea, she was shocked! "I had told Erin about the Foundation a while ago, but one day she came to me and told me about her plan to sell her bracelets and donate all the money to the Sjögren's Foundation to 'help them find a cure.' I honestly wasn't sure how it all would work and if people would even buy the bracelets," said Kim.

The mother-daughter duo decided to go door-to-door (wearing masks of course) to sell the bracelets. To Kim's surprise, almost everyone she talked with were interested and learning about the disease and either bought a bracelet or gave a donation, encouraging Erin to keep up the good work.

The Sjögren's Foundation agrees with Erin that there needs to be better treatment options! We are committed to accelerating the development of therapeutics that will have the greatest potential impact on improving the quality of life for patients. And with supporters like her strengthening our community, we know that together we will conquer Sjögren's!

To date, Erin and Kim have raised \$330 and plan to continue selling bracelets this spring. If you are interested in learning more about hosting your own fundraiser to support the Foundation, please email [info@sjogrens.org](mailto:info@sjogrens.org). ■





**“Clinician’s Corner”** *continued from page 10* ▼**“My teeth are falling out because of my Sjögren’s. What is the difference between implants v. crowns?”**

Xerostomia is one of the major signs of Sjögren’s that in turn causes difficulty in swallowing, widespread decay, periodontal conditions and oral infections. Dentists are usually the first clinicians to detect the early signs in the oral cavity because of the higher frequency of dental exams. Patients with Sjögren’s have an increased risk of six most common oral conditions including dental caries, pulpitis, gingivitis, periodontitis, oral ulceration and stomatitis. Due to the widespread effects on teeth and gums, sometimes severe damage or loss of tooth or teeth is inevitable, if proper management is not planned out at the initial stages.

There are multiple treatment options for teeth that have been damaged due to Xerostomia associated with Sjögren’s depending on the condition of teeth. Teeth could be moderately decayed or damaged, which may be restorable using dental crowns. If the damage is irreparable and teeth are non-restorable, they will be planned for single or multiple extractions and replacement with dental implants.

**Dental Crowns**

Dental decay causes structural damage to a tooth. When caught and treated early, decay is eliminated and the small damage on the tooth structure is replaced/filled with a filling material, a composite resin material is used most commonly nowadays.

In some instances where the damage is deeper and larger due to decay or fracture, dental crowns (also commonly known as caps) have to be placed to protect the weakened tooth structure, to improve the function and shape of the tooth structure and to restore chewing ability. Crowns are placed on an existing restorable tooth to preserve the natural tooth structure. Patients are placed under local anesthesia and due to the advancement in modern technology, crowns can sometimes be placed on the same day of prepping the tooth (Cerec/one day crowns). Crowns are also used to replace teeth if placed over dental implants. (See below, Dental Implants).

There are different materials that have been used by dentists. Previously, different casted alloys, gold and porcelain fused to metal material has been used to preserve the tooth structure. Due to extensive innovation in dental materials, the most commonly used crown materials nowadays are metal-free and can be customized for strength, durability and esthetics depending on the location of the teeth. Some examples of most commonly used materials are IPS Emax (Lithium Disilicate) and Zirconia (monolithic or high translucent).

**Dental Implants**

Severe xerostomia can induce widespread decay, which may cause induce severe damage to the tooth structure. If the deterioration of a tooth structure is so extensive that there is not enough solid tooth structure left to provide a healthy foundation for a crown, the tooth will need to be extracted to prevent infection and pain. When extracted, a tooth needs to be replaced to prevent shifting and drifting of the existing teeth and to restore healthy chewing function.

Dental implants have been successfully used in the last 30 years to replace missing and extracted teeth. They are the strongest devices available to support replacement teeth – and even better, they allow these new teeth to feel, look and function naturally. Think of dental implants as artificial tooth roots, similar in shape to screws. When dental implants are placed in jawbone, they bond with the natural bone. They become a sturdy base for supporting one or more artificial teeth, called crowns.

A connector known as an abutment is placed on top of the dental implant to hold and support the crowns.

*continued page 14* ▼

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**In Memory of Marleen Gall**  
Roxanne Yates

**In Memory of Mazelle Baird**  
Emily Borden

**In Memory of Pat**  
Laurence Brown

**In Memory of Phyllis June Mace Taylor**  
Sherri Taylor

**In Memory of Phyllis McCordle**  
Will Locke

**In Memory of Sandra Staley**  
Anonymous

**In Memory of Sharon Meyer**  
Susan Papenbrok  
Illeana Jensen  
Suzanne Anderson  
Naji Azzam  
Patrick Holleran  
Bernard Jensen  
Karen and Joe O'Brien  
Lenore Peters  
Ken Napolitano  
Catherine Carone  
Rosalie Terrano  
Connie Nelson  
Florence Krych

**In Memory of Sharon Rogers**  
Thomas and Gail Dibble  
Nanette Shoemaker

**In Memory of Phyllis Karola Foster**  
Susanne Reary

**In Memory of Sheri Williams**  
Marion Hasbrouck

**In Memory of Sheryl Clum**  
Jennifer Brennan

**In Memory of Shirley Kaplan**  
Rochel Kaplan

**In Memory of Shirley Ziff**  
Catherine Ziff

**In Memory of Stephan Feller**  
Elaine and Larry Levin

**In Memory of Sue Flaherty**  
Beth and Art Soderfelt

**In Memory of Susan Hansen**  
Bruce Hansen

**In Memory of Susan Prowant**  
Paula Berghoff Martin

**In Memory of Teresa Vitale**  
Tom Vitale

**In Memory of Timothy Hurteau**  
Flora Hurteau

**In Memory of Tina Farris**  
Elaine and Larry Levin

**In Memory of Vera Rottenberg**  
Judith Rottenberg

## IN HONOR

**In Honor of Adrienne Jones**  
Ariel Weber

**In Honor of Angela Anderson**  
Bridget Kirkpatrick

**In Honor of Barbara Cook**  
Sherrie Markman

**In Honor of Betty McMinn**  
Billy McMinn

**In Honor of Brigitte Hall**  
Brigitte Hall

**In Honor of Charlene Thayer & Alexandra Arcidy**  
Liz Hamel

**In Honor of Christina Kantzavelos**  
Christina Kantzavelos

**In Honor of Diane Doyle**  
Thomas Doyle

**In Honor of Dr. Gerald Falasca**  
Susan Rawlston

**In Honor of Elaine Levin**  
Barbara Bernheim

**In Honor of Elizabeth Ward**  
Doris Markham

**In Honor of Gordon Lockman**  
Mary Anne Redick  
Vanetta Lockman  
Jullia Joret  
Tasha Steward  
Sandra Twaddell

**In Honor of Jane Nelson**  
Ann Franke

**In Honor of Janine Bensman**  
Anonymous

**In Honor of Kathryn Donnelly**  
Elvira Albert

**In Honor of Kay Sheehan**  
Charlie Allinson

**In Honor of Linda & Dennis Howard**  
Martha Costa

**In Honor of Lindsey Hatfield**  
Joseph & Francine Vido

**In Honor of Liz Perry**  
Don Perry

**In Honor of Margaret Mondlak**  
C.D. Spangler Foundation

**In Honor of Margaret Voshell**  
Marcia Wood

**In Honor of Martha Bragdon**  
Martha Bragdon

**In Honor of Mary Kendall**  
Kimberly Kendall

**In Honor of Mary Winning**  
Melinda & James Rae

**In Honor of Nancy Lewis**  
Christopher Lewis

**In Honor of Noah Syndergaard**  
Thorne Research

**In Honor of Sam Wiseman**  
Mary Wiseman

**In Honor of Samantha Trainor**  
Karen Becker

**In Honor of Scott Postell**  
Anonymous

**In Honor of Shauna Hansen**  
Kacie McManus

**In Honor of Shirley Temple**  
Karri Brackett

**In Honor of Stefanie Campbell**  
Ellen Campbell

**In Honor of Steven Taylor**  
Jeanine Balsis  
Gary Foulks

**In Honor of Steven Taylor & Janet Church**  
Carole Bekken

**In Honor of Susan Barajas**  
Arlene Inglis

**In Honor of Vanetta Lockman**  
Bernard Kelley

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





## April is Sjögren's Awareness Month

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

In our 2021 theme, we are highlighting you, the many Faces of Sjögren's, to expand our #ThisIsSjögrens online campaign. You are the voice and the face of the Foundation and it is the collection of your experiences that truly portrays this complex disease. During this past year apart, we not only want to raise awareness of Sjögren's, but also share how patients are effectively coping with the disease and offer advice for others.

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

We hope you will join us in educating the public about Sjögren's and use April Awareness Month as a way to talk about the disease and follow our online campaign. Every day is an opportunity to start a conversation about living with Sjögren's and how it affects you. Remember, the more others understand, the more support you can find.

Visit [www.sjogrens.org](http://www.sjogrens.org) to learn more about our April #ThisIsSjögrens campaign and how you can submit your story to be one of our highlighted Faces of Sjögren's. ■

### "Clinician's Corner" continued from page 12 ▼

The crowns are custom made to match natural teeth and fit mouth as discussed above under dental crowns. 3 million people in the United States have implants, a number that is growing by 500,000 annually.

Dental implants placement requires extensive planning to make sure they are being placed in a suitable area where it is away from other structures like maxillary sinuses and nerves in the jaws. A cone beam computed tomography (CBCT) scan is required to plan an implant placement in 3D. Implants are placed under local anesthesia (sometimes requires sedation as well) and is an outpatient surgical procedure done in a dental practice. Once placed implants need time for the bone integration and once completely integrated are restored with crowns. Implant number can vary depending on the number of teeth needed to be placed. Single implants are needed for a single extracted tooth while 4-6 implants can be used for a full arch restoration.

### Conclusion

Dental crown and dental implants are highly successful treatments with different indication. Because of innovation in dental materials, dental care and protocol, both the treatments have excellent prognosis as long as oral hygiene is maintained at the highest level possible. People who suffer from Sjögren's have to take extra measures to stay away from periodontitis, peri-implant infection (peri-implantitis) and recurrent decay of restored tooth structure. ■

### References

- <https://www.ada.org/en/member-center/oral-health-topics/sjogren-disease>
- [https://www.jstage.jst.go.jp/article/tdcpublish/59/3/59\\_2017-0036/\\_pdf/-char/en](https://www.jstage.jst.go.jp/article/tdcpublish/59/3/59_2017-0036/_pdf/-char/en)
- Chuang CJ, Hsu CW, Lu MC, Koo M. Increased risk of developing dental diseases in patients with primary Sjögren's syndrome-A secondary cohort analysis of population-based claims data. *PLoS One*. 2020 Sep 18;15(9):e0239442. doi: 10.1371/journal.pone.0239442. PMID: 32946501; PMCID: PMC7500664.
- <https://www.aaid-implant.org/dental-implants/what-are-dental-implants/>



# Awareness never looked so good!

## Limited Edition April Awareness Kit



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

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

	Qty.	Size: S-2XL	Total
<b>April 2021 Awareness Kit</b> \$38 ea.			
New Sjögren's Foundation Cotton T-shirt			
New Sjögren's Foundation Icon Pin			
New Sjögren's Foundation Hat with Logo			
"This is Sjögren's" Flier			
Sjögren's Foundation Referral Tear-Off Sheets			
(3) "What is Sjögren's?" Brochures			
<b>Shipping and Handling:</b>			
U.S. Mail: \$7 for first item + \$2 for each additional item			
<b>Total Amount Due</b>			

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_

E-Mail \_\_\_\_\_

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

☐ MasterCard ☐ VISA ☐ Discover ☐ American Express

Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Security Code \_\_\_\_\_

Signature \_\_\_\_\_





# Patient Education Sheet

## Pulmonary Involvement

*The Foundation thanks Teng Moua, MD, for authoring this Patient Education Sheet.  
Dr. Moua is affiliated with the Mayo Clinic, Division of  
Pulmonary/Critical Care Medicine, Rochester, Minnesota*

**One feature defining Sjögren's is the inappropriate infiltration of certain white blood cells into glandular tissues known as 'exocrine' glands. This infiltration contributes to reduced tear and saliva production, causing the classic symptoms of dry eyes and dry mouth associated with Sjögren's. Because the airway and lungs are lined with exocrine glands, the lung is commonly involved in Sjögren's, with respiratory symptoms occurring in up to two-thirds or more of patients. Some key facts:**

- Parts of the lung that may be involved in Sjögren's include the upper and lower airways, the small or microscopic airways, and the lung tissue or air sacs and their supportive structures.
- The most common respiratory symptom is a dry cough or airway irritation referred to as 'xerotrachea' or 'dry airway.'
- Other symptoms include cough productive of sputum, wheezing, and shortness of breath both at rest and with exertion. Patients with these symptoms should be investigated for disease in both airway and lung tissue or interstitial lung disease (ILD).
- Doctors may perform breathing tests (pulmonary function tests [PFT]) to assess for abnormalities and order chest x-ray and special radiologic testing such as high-resolution computed tomography [HRCT] to help characterize the extent of lung involvement.
- Findings on radiology may include patchy infiltrates or locally consolidated lung, suggesting inflammation or infection. Cysts, or small thin-walled air pockets in the lung, and thickened or elongated airways are other findings seen in Sjögren's.
- Other dryness symptoms and blood inflammatory markers for Sjögren's often do not correlate with the likelihood or severity of respiratory symptoms.
- Occasionally, Sjögren's may be associated with another autoimmune or inflammatory disease that can affect the lung. In this case, lung disease may be worse in terms of severity and progress more rapidly over time.
- Many medications used to treat Sjögren's may cause unintended side effects that injure the lung. A careful review is warranted, particularly if symptoms develop after starting a new medication.
- Medications that suppress the immune system may also increase the likelihood of lung infection. A careful assessment for possible infection is often the first step in managing new respiratory symptoms.
- Finally, if infection and medication side effects are ruled out, therapy directed at treating the underlying Sjögren's may need to be adjusted in an attempt to treat respiratory symptoms.
- Supportive treatments such as inhalers or oxygen, in severe disease, can be helpful for managing symptoms.
- The Sjögren's Foundation has published clinical practice guidelines for pulmonary disease in Sjögren's patients. Check the Foundation website for these and other guidelines.

**For more information on Sjögren's, contact the Sjögren's Foundation at:  
10701 Parkridge Blvd., Suite 170, Reston, VA 20191 • 800-475-6473 • [www.sjogrens.org](http://www.sjogrens.org).**

Clinicians: Please make multiple copies of this Patient Education Sheet and distribute to your patients.



Putting the health and safety of everyone first, our National Patient Conference will be a virtual event. You will experience the same valuable educational topics from leading Sjögren's experts from the comfort of your own home and computer.

**Join us for this two-day event on**  
**Friday, June 11<sup>th</sup> – 1:00 pm - 5:00 pm (EDT)**  
**Saturday, June 12<sup>th</sup> – 1:00 pm - 5:30 pm (EDT)**

This two-day online educational experience will help you take control of your health while you learn how to manage and understand your Sjögren's symptoms and complications from leading Sjögren's experts.

## ***PLEASE NOTE***

*Registrants must have a device with internet access to join the conference.*

*Recorded videos of each lecture will be available to registrants for 30 days after the conference.*

*You can also register online at <https://www.sjogrens.org/npc-registration>*



**QUESTIONS?** Call 301-530-4420 or visit [www.sjogrens.org](http://www.sjogrens.org)



# “Conquering Sjögren’s Together”

## Sjögren’s: An Overview

**Donald E. Thomas, Jr., MD**, a rheumatologist and Chair of the Sjögren’s Foundation Board of Directors, has a special interest in systemic autoimmune diseases, especially Sjögren’s. He is in private practice in Maryland, but also enjoys teaching health care providers about Sjögren’s in his capacity as an Associate Professor of Medicine at the Uniformed Services University of the Health Sciences in Bethesda, Maryland. Dr. Thomas will present a comprehensive explanation of the range of symptoms that Sjögren’s patients experience, explain their causes, and offer treatment options and practical tips for managing them.

## Clinical Practice Guidelines for Pulmonary Complications

**Augustine S. Lee, MD, MS**, is a pulmonologist and Associate Professor of Medicine at the Mayo Clinic College of Medicine and Science in Jacksonville, Florida. Here, Dr. Lee also serves as Chair of the Division of Pulmonary, Allergy/Immunology and Sleep Medicine, Director of the Chronic Cough Clinic and co-Director of the LAM Clinic. Dr. Lee co-lead the Foundation’s initiative to develop the first-ever U.S. clinical practice guidelines for pulmonary disease in Sjögren’s. Pulmonary manifestations occur much more frequently in Sjögren’s than is often recognized by healthcare providers and are a potentially serious complication of the disease. As part of the Foundation’s ongoing effort to develop clinical practice guidelines for Sjögren’s, Dr. Lee will share information from these newly published guidelines focused on identifying, evaluating, managing and treating pulmonary disease in Sjögren’s – an effort that is the culmination of many years of work and a major step forward for our community.

## Conquering Sjögren’s: What’s Next?

**Janet Church**

*Sjögren’s Foundation President & CEO*

The Sjögren’s Foundation continues to launch new patient, healthcare and research focused initiatives that are changing the direction of Sjögren’s. Join Janet Church, CEO of the Foundation, as she shares exciting updates about clinical trials, clinical practice guidelines as well as other projects that are on the horizon for Sjögren’s patients!

## Ocular Manifestations of Sjögren’s

**Esen K. Akpek, MD**, is the Bendann Professor of Ophthalmology and Rheumatology and Director of the Ocular Surface Diseases and Dry Eye Clinic at the Wilmer Eye Institute, Johns Hopkins University School of Medicine, Baltimore, Maryland. Dr. Akpek is also the Associate Director of the Jerome L. Greene Sjögren’s Syndrome Center at Johns Hopkins and a member of the Sjögren’s Foundation Medical and Scientific Advisory Council, the Foundation’s Clinical Trials Consortium and past national board member. Dr. Akpek is a world-renowned leader in the fields of inflammatory ocular disease and dry eye and will describe the latest dry eye therapies, covering the extensive range of options.

## Product Showcase

**Kimberly Kelley, PharmD**

Sjögren’s patients use a number of over-the-counter and prescription products to treat their various complications. Kimberly Kelley, a Doctor of Pharmacy in Arizona for 35 years with an expansive career, a Sjögren’s Foundation Board Member, and a Sjögren’s patient, will highlight the vast array of products that are available for Sjögren’s patients.

## Oral Manifestations of Sjögren’s

**Vidya Sankar, DMD, MHS**, is Associate Professor and Division Director for Oral Medicine, Department of Diagnostic Sciences, Tufts University, School of Dental Medicine in Boston, Massachusetts. She is also a current member of the Sjögren’s Foundation Medical and Scientific Advisory Council and a past national board member. Dr. Sankar will provide insights into how Sjögren’s impacts your oral health including tooth decay as well as share with us information to help manage and minimize the effects of dry mouth issues.

## Social Security Disability for Sjögren’s

**Stacy M. Tucker** is a partner with Kantor & Kantor, LLP, a law firm specializing in representing individuals whose health, disability, and life insurance claims have been denied. Ms. Tucker will bring her wealth of knowledge of the inner workings of disability insurance and healthcare to help attendees understand and navigate the often complex workings of the Social Security Disability system.

## Sjögren’s and Joint Pain

**Rochelle Rosian, MD**, is a rheumatologist and Staff Member, Department of Rheumatic and Immunologic Diseases at the Cleveland Clinic in Solon, Ohio, where she also serves as Director of Regional Rheumatology. Dr. Rosian has a general rheumatology practice, with special interest in rheumatoid arthritis, Sjögren’s, psoriatic arthritis and lupus. During her career at Cleveland Clinic, Dr. Rosian has been involved with medical division committees, World Class Service, resident and medical student education and the Center for Patient Experience and Healthcare Communication. Dr. Rosian will add to your understanding of the many causes of joint pain and Sjögren’s and will offer tips to help you cope as well as possible treatment regimens.

## COVID-19 and Sjögren’s Update

**Alan Baer, MD**, is a rheumatologist and Professor of Medicine at the Johns Hopkins School of Medicine in Baltimore, Maryland, where he is also Director of the Jerome L. Greene Sjögren’s Syndrome Center. Additionally, Dr. Baer is engaged in clinical research studies focused on Sjögren’s, both at Johns Hopkins and the National Institutes of Health (NIH). Currently, he is Chair of the Foundation’s Medical & Scientific Advisory Council and the Foundation’s Sjögren’s-COVID-19 Vaccination Committee, a member of the Foundation’s Clinical Trial’s Consortium Steering Committee and a member of the Board of Directors. Dr. Baer will provide the latest information on COVID-19, the vaccine and what Sjögren’s patients should know.

## Genetics and Sjögren’s Research

**Christopher J. Lessard, PhD**, is an Associate Member of the Genes and Human Disease Research Program at the Oklahoma Medical Research Foundation (OMRF) in Oklahoma City, Oklahoma, and an Adjunct Associate Professor in the Department of Pathology at the University of Oklahoma Health Sciences Center. Dr. Lessard is a former Sjögren’s Foundation research grant recipient and he and his team at the OMRF have recently been awarded a five-year, \$3.7 million-dollar grant from the National Institutes of Health to continue his ongoing efforts to understand how genetic variations lead to Sjögren’s disease. Dr. Lessard will share an overview of this exciting research with us!

## “Exploring Sjögren’s Spotlight” explained...

This year’s Conference will include breaks – entitled “Exploring Sjögren’s Spotlight” – to hear brief interviews with product company representatives, Sjögren’s patients, and medical experts.



*“Conquering Sjögren’s Together”*

# 2021 VIRTUAL National Patient Conference

## Registration Form

# 1

**Registrant**

Name \_\_\_\_\_

Street Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

# 2

**FEES** – please check appropriate fee**Member****\$80.00**☐**Non-Member****\$100.00**☐

# 3

**PAYMENT** – Mail to Sjögren’s Foundation, 10701 Parkridge Blvd., Suite 170, Reston, VA 20191☐ Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to Sjögren’s Foundation.☐ MasterCard ☐ VISA ☐ Discover ☐ AmEx

Card Number \_\_\_\_\_ Exp. Date \_\_\_\_\_ CC Security Code \_\_\_\_\_

Signature \_\_\_\_\_

Refunds must be made in writing. Registrants whose written requests are received by May 14<sup>th</sup> will receive a 75% refund. After that time, we are sorry that no refunds can be made.



**QUESTIONS?** Call 301-530-4420 or visit [www.sjogrens.org](http://www.sjogrens.org)



## Conquering Sjögren's

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

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

# Sjögren's Foundation Virtual Event Calendar

Register and learn more about how to fundraise to receive your 2021 Walk for Sjögren's T-shirt and other prizes!



April

**Mid-Atlantic Virtual Walk for Sjögren's**  
(DC, Maryland, Virginia, and West Virginia)  
**Saturday, April 17, 2021**

May

**Philadelphia Tri-State Virtual Walk for Sjögren's**  
(Pennsylvania, New Jersey, and Delaware)  
**Saturday, May 1, 2021**

**Colorado Virtual Walk for Sjögren's**  
**Saturday, May 22, 2021**

June

**Texas Virtual Walk for Sjögren's**  
**Saturday, June 26, 2021**

[events.sjogrens.org](https://events.sjogrens.org)

