

CONQUERING Sjögren's

March/April 2020



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Ask the Sjögren's Foundation Board of Directors



The Sjögren's Foundation Board of Directors is comprised of healthcare professionals, patients/family members of patients and pertinent professionals in the field, who volunteer their time to help lead the Foundation so we can fulfill our mission.

These dedicated individuals are responsible for setting our goals and priorities, overseeing policies, implementing our strategic plan, while also ensuring we raise the crucial funds we need to accomplish our mission. Together, the Foundation's staff and Board work to make the biggest impact and help all patients.

In this special part one installment of "Ask the Board," we want you to get to know these devoted volunteers by having them answer your questions. ■

The Foundation's mission is to:

- Support Sjögren's patients and their loved ones through education, resources and services
- Provide credible resources and education for healthcare professionals
- Serve as the voice for all Sjögren's patients through advocacy and awareness initiatives
- Lead, encourage and fund innovative research projects to better understand, diagnose and treat Sjögren's

The Foundation's vision is to:

"To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's."

Q *I'm having a hard time accepting my disease, have you experienced this as a patient and how did you handle it?*

Janet Church

Sjögren's Foundation Board Chair, Sjögren's patient

A I personally had a difficult time accepting the impact Sjögren's had on my life, although I didn't recognize it at the time. We talk a lot about accepting our disease and finding our "new normal," but this process is different for everyone. It is very important to recognize that there is a difference between processing grief and then coming to the end of the initial grief cycle to land on acceptance. It is also important to recognize that chronic illness can sometimes throw us back into grief, even after we think we've reached acceptance. I believe the key to true acceptance is in understanding yourself, understanding your disease, and learning how to objectively assess situations. After

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years of working on acceptance myself and talking with many patients, I believe true acceptance depends on several factors:

- Your disease activity level and how it impacts your quality of life.
- Time since diagnosis. Has it been a year or ten years?
- Your personality and how you approach challenges in life.
- Your emotional health. Depression is a common side-dish to Sjögren’s (and other chronic illnesses). Disease layered on top of past traumas can also make the grief cycle especially challenging.

The most important thing to address before you can truly accept your disease is the grief from losing your old life. If you are newly diagnosed, allow time to grieve and know that acceptance is in your future. Recognize that denial is definitely part of the grief cycle, but to get to acceptance, you do need to move through denial. If you believe you have been in grief for a long period of time and are not moving through it on your own, do seek help with a therapist (I did).

A therapist that has trauma experience can be especially helpful with our kind of grief. Our grief process is unique because only part of us has died... not our spirit, not our capacity for love and compassion, nor our intelligence. Our grief is also different because we may revisit grief phases after a Sjögren’s flare (also called a relapse), and then rise again to acceptance and reinvention.

If you believe you have processed through grief but are still having a difficult time with acceptance, try objectively investigating some other areas of your life or personality for clues and be OK asking for help. This objective thinking can be quite beneficial and especially if you leave self-judgement out of the process! Talk with yourself like you would talk with a good friend who needs a new and wise perspective. Or even talk to other patients with chronic illness.

Also, remember that our brain becomes accustomed to the story we tell it! If we have told it to deny the disease for a long period of time, it can take new training (and ongoing practice) to break this mental habit and create a new story. There are easy tools to support you like a gratitude journal, positive affirmations, and meditation, which are all proven to help re-pattern your brain away from stories that no longer serve you and towards what best serves you NOW.

Finally, at some point, you will decide that you want to be more fully engaged with your life on hon-

est terms and that acceptance may be the path to a happier life. Even if our bodies cannot be healed (at this time), there are no limits for our spirit!

One of my favorite quotes:

“And then the day came when the risk to remain tight in a bud was more painful than the risk it took to blossom...”

– *Attributed to Anais Nin (written by Elizabeth Appell).*

Q **What medications are used to treat Sjögren’s?**

Donald Thomas, MD
Sjögren’s Foundation Chairman-Elect

A There are many over-the-counter and prescription drugs that can help Sjögren’s patients feel better. I will not discuss the numerous over the counter medications used for pain and moisture nor the prescription pain medications but will concentrate on the prescription drugs used to increase moisture and to calm down the immune system. The following descriptions are brief. For complete information, ask your doctor or pharmacist.

Salagen (pilocarpine) and Evoxac (cevimeline):

These two drugs are approved by the U.S. Food and Drug Administration (FDA) to increase saliva in the treatment of dry mouth. They are prescribed when other dry mouth treatments (such as xylitol gum, xylitol lozenges, and artificial saliva) do not provide enough mouth moisture. Although FDA-approved to treat dry mouth, some people find that they also help other dry areas such as the eyes, nasal passages, and skin. They can help reduce cough when it is due to a dry windpipe from Sjögren’s, and they can improve heartburn (gastroesophageal reflux) by improving the flow of saliva down the esophagus. The most common side effect is excessive sweating. A downside of these drugs is that they need to be taken three to four times a day for full effectiveness.

Plaquenil (hydroxychloroquine, HCQ):

Since Sjögren’s is an autoimmune disease where the immune system is overactive, medications that calm down the immune system are sometimes needed. Plaquenil is one of the safest drugs used to treat Sjögren’s. It can especially be helpful for Sjögren’s arthritis, fatigue, and rashes. It is important to get two eye tests done every year to make sure that it

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doesn't cause any eye problems. It is best to get both a visual field 10-2 and an SD-OCT test done yearly. If you are of Asian ancestry, you need three tests yearly (the preceding two tests plus a VF 24-2 or a VF 30-2). If your doctor cannot do an SD-OCT or VF 10-2 it is OK to substitute one of these with an FAF or a mfERG test.¹ Make sure to show your eye doctor this paragraph to ensure you are getting the correct tests performed (you should be your own best health advocate to ensure you are getting the proper exams).

Immunosuppressant drugs:

These are stronger than Plaquenil and actually decrease (or suppress) immune system activity rather than just calm it down. These medicines are called immunosuppressants. They include methotrexate, mycophenolate mofetil, azathioprine, and cyclophosphamide. These are the most common immunosuppressants used for Sjögren's. Since they suppress the immune system, they can increase the risk of developing infections, so they should not be used during any periods of active infection. They also require blood counts and liver enzymes to be measured regularly to ensure that they are not causing any problems in the bone marrow (that is where blood cells are made) and liver.

Corticosteroids (steroids):

Steroids such as prednisone and Medrol (methylprednisolone) also suppress the immune system. Steroids work much faster than the preceding drugs. Unfortunately, most people get side effects from them. We like to use the lowest doses possible and to get our patients off steroids as soon as possible. Common side effects include weight gain, broken bones from osteoporosis, making diabetes worse, moodiness, cataracts and insomnia.

Did you know that cortisone is a broad term for steroids? A cortisone injection is an injection of steroids, usually into an inflamed joint to help arthritis, or into a large muscle to help decrease inflammation throughout the whole body.

B-cell depletors:

A type of white blood cell called B-cells is overactive in Sjögren's. Some patients may benefit by using medications that calm down these B-cells. You may see this referred to as “B-cell depletion” when reading the Sjögren's medical literature. The two drugs used are RITUXAN® (rituximab) and Benlysta (belimumab).

They are both liquids requiring infusion into a vein (IV), or by self-injection under the skin (SQ).

References:

- 1 Marmor MF, et al. Recommendations on screening for chloroquine and hydroxychloroquine retinopathy (2016 revision). *Ophthalmology* 2016;123(6):1386.

Q *I'm having a hard time getting my dry eye under control and my vision is becoming worse. What treatment options should I talk to my doctor about?*

Esen K. Akpek, MD

Sjögren's Foundation Board Member

A The pre-corneal tear film is the first structure having a direct and significant influence on the visual function. When dry eye is present, the tear film is degraded often due to insufficient tear secretion (quantity) and/or poor tear film stability (quality) leading to early decay of the tear film measured as tear break-up time. Poor tear quality can be due to meibomian gland dysfunction-related lipid deficiency or inflammation-related mucin deficiency. Poor tear quantity is due to inflammation-related changes in the tear secreting glands leading to reduced production. When dry eye becomes clinically significant, such as in patients with Sjögren's, both the quality and quantity of the tear film are reduced. Management of clinically significant dry eye is complex and should incorporate various strategies: make more tears, conserve tears, and replace tears.

Make more tears:

In patients with Sjögren's related dry eye, the first line of treatment should be topical anti-inflammatory medications to improve the aqueous tear secretion. Currently, available topical anti-inflammatory medications include cyclosporine, lifitegrast and various steroids. Although effective, use of topical steroids should be restricted to intermittent, short term only, due to considerable side effects. Topical non-steroidal anti-inflammatory medications should be avoided due to significant corneal toxicity. Recently approved regenerative treatments, such as electroceuticals, should be employed early on in order to stimulate main and accessory lacrimal glands as well as Meibomian glands. Improving meibum secretion is essential in the care of significant combined mechanism dry eye. Warm compresses and lid scrubs should be incorporated into the patients' everyday self-care. Office based therapies for meibomian gland dysfunction with or without anterior blepharitis (mechanical heat based or light-based therapies and microblepharofoliation) are available. These therapies are effec-

tive, albeit for a period of time, hence their required repeating and are costly. Oral and topical antibiotics and oral fatty acids might also be useful in improving significant combined mechanism dry eye.

Conserve tears:

Various types of tear duct plugs made of various materials are available to conserve tears in patients with significant aqueous deficient dry eye. However, those should never be the first line treatment for patients with chronic inflammatory dry eye, such as patients with Sjögren's. In cases where duct plugs are uncomfortable due to lid issues or when patients lose duct plugs several times, permanent sealing using thermal cautery, or suturing can also be employed. Tarsorrhaphy to decrease the interpalpebral fissure opening and reduce evaporation of tear film should be saved for severe dry eye usually with corneal complications such as non-healing epithelial defects or ulcerations. Use of large diameter scleral contact lenses can be very helpful to improve the corneal surface and vision but only appropriate for patients with adequate dexterity. Also, they are costly.

Replace tears:

In patients without an underlying systemic or local inflammatory condition, using over the counter tear

substitutes would be appropriate as first line treatment in the absence of significant ocular surface and tear film parameters. However, in patients with Sjögren's related dry eye, preservative free tears should never be a substitute for other/above treatments. Using these drops excessively/frequently can bother the homeostasis of the existing tear film and should not be recommended. Using human tissues such as amniotic membrane or fluids such as autologous serum tears, platelet rich plasma or amniotic fluid have been used with good results. Patients who cannot have successful blood draw, might be able to use allogeneic serum tears from known donors.

There are also several controversial strategies. Patients who have severe corneal punctate erosions, even in the absence of frank ulcerations, tend to have reduced corneal sensation. This could be attributed to inflammation leading to decrease in corneal subepithelial nerve plexus density as imaged with confocal biomicroscopy. Recently approved topical nerve growth factor treatment can effectively reverse the process and improve tear secretion as well as corneal epithelial regeneration. In patients with severe ocular surface inflammation due to Sjögren's who have tried the above treatments, successful results

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of systemic anti-inflammatories including corticosteroids, non-steroidal immunomodulators or biologics have been reported in the published literature.

In summary, Sjögren’s related dry eye can be severe, even in the absence of severe patient reported symptoms due to reduction in corneal sensation. Addressing both the aqueous and meibum layers of the tear film, improving the regeneration of corneal nerves and ocular surface epithelium are essential components of the management.

Q *I’m missing a lot of work because of my Sjögren’s. How do I begin to consider going on disability as an option?*

Thomas Sutton
Sjögren’s Foundation Board Member, Attorney

A 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. You will have to prove that your Sjögren’s (in combination with any other physical or mental impairments you may have) prevents you from working at any of your past jobs, or in any other job on a full-time basis (or, if you are 50 or older, that you are unable to perform physically demanding jobs). You may also apply for benefits through a private long-term disability policy that you may have through your employer (or may have purchased individually).

In any event, you should discuss your situation with your physicians so that they are aware of your application and will cooperate when requested; you should also consider obtaining representation by an attorney experienced in disability claims, which can be complex and may require appeals if your application is denied at first (and if that happens, do not become discouraged as many claims initially denied are later awarded through appeals). It is a good idea to keep a daily journal to record your difficulties with activities of daily living in your home, as an indication of the problem you would have functioning in a workplace 40 hours a week.

Q *Do I need a lawyer to help me through the disability process?*

Michelle Wallace
*Sjögren’s Foundation Board Member,
Attorney, Sjögren’s patient*

A Not everyone will need an attorney in order to apply for Social Security Disability benefits. Some claims are easy enough that claimants can complete an application and win approval of benefits all on their own. However, having an attorney could make the process easier and less stressful.

An attorney can provide you with valuable guidance on how to gather the appropriate medical documentation needed to prove your disability case and advise how you should submit your application in order to increase your chances of being approved at the initial application stage.

If, for some reason, your initial application is denied, an attorney can help you through the Social Security Disability appeals process. While no attorney can guarantee that you will receive the disability benefits you are applying for, a qualified Social Security attorney can greatly increase your chances of being approved for Social Security Disability benefits. If you do not have an attorney representing you, you may waste years of time, effort and money trying to represent yourself. In the end, you may have to turn to the services of a qualified attorney when you are forced to file a second (or even third or fourth) claim for Social Security Disability benefits.

Q *As a patient, how do you successfully manage the various doctors’ appointments and medical team?*

Tricia Gooding
Sjögren’s Foundation Board Secretary, Sjögren’s patient

A As a person living with a chronic illness such as Sjögren’s and someone who is also dealing with a cancer diagnosis, managing my medical appointments and medical team is somewhat of a juggling act.

I am actually guided by the principal of SMART (Specific, Measurable Goals, Achievable, Relevant and Time-bound) so that I am able to make the most of my appointments and medical team.

Specific – As a result of my specific medical diagnosis of Sjögren’s and breast cancer, I have a team of medical doctors who are fully aware of my specific medical needs and concerns. With that knowledge intact it is easy to reduce any barriers such as communication among the doctors because each of them

is aware of what is happening in my medical file. There is no confusion as to what “next steps” are in managing my health.

Measurable Goals – When going into multiple doctor appointments I need to have measurable goals in place, which for me, means that I will identify exactly why I am seeing a specific doctor. For example, a general goal would be to make an appointment to see my rheumatologist. A measurable goal would be to make an appointment to see rheumatologist for treatment options to better manage dry eye symptoms.

Achievable – Medical appointments can be difficult at times, leaving you with more questions than answers. Before I head off to an appointment, I plan what I want to ask and discuss so that my goal of care is achievable. Writing down what you want to ask and discuss is absolutely mandatory. Brain fog is real!

Relevant – Often times, with so many things going on in my medical life, I really need to remind myself that when I go and see my medical team that my issues are relevant and up to date. My past and present medical history may have significant relevant information that may have a bearing on my future. This is an important tool in the management of my medical needs.

Time-bound – As a result of being time-bound at appointments, I need to be completely organized. Whether that means having a calendar, a notebook or having my phone to record my appointments, it is to keep me on track and organized. Medical appointments can go by very quickly and organization is key to be efficient and productive. I will also bring along with me summaries of what each medical specialist said to make communication easier.

Using the SMART principal has allowed me to successfully manage my doctors’ appointments and medical team with confidence and understanding.

Q *What is the difference between Restasis® and Xiidra®?*

*Stephen Cohen, OD
Sjögren’s Foundation Immediate Past Chair*

A Until early 2003, there were no FDA-approved medications for dry eye. Dry eye “treatment” was often comprised of being given several brands of lubricating drops and being told to keep using the one that worked best. Restasis® (Cyclosporine 0.05%) changed that. It then took over 13 years for a second medication to be approved. Xiidra® (Lifitegrast 5%) has the same dosing as Restasis® (one drop in each eye twice a day), but there are differences between the two.

Artificial tears only provide temporary relief of dry eye symptoms, but these medications help to treat the underlying causes of dry eye. Restasis® increases production of tears, which is a major deficiency with Sjögren’s. Restasis® is not a steroid but does have anti-inflammatory qualities that impact the cycle of normal tear production. It is known as an “immunomodulator,” which helps to control the auto-immune response so common in Sjögren’s patients. The drops are safe to use over an extended period of time and needs to be regularly used to either slow down the progression (the first critical step) of dry eye disease in Sjögren’s patients, and hopefully to provide actual improvement in the condition over time. Results are not immediate and can take four-six weeks for any improvement to be noted, and up to six months before a determination of its efficacy can be established. However, studies have shown that even in year or two of treatment, there is continued improvement. The predominant side-effect is some stinging and burning upon instillation. This happens in about one of every five-six Restasis® users and could be more common in Sjögren’s patients. The vials or bottle can be refrigerated so that the cooling may lessen any stinging, or a lubricating drop can be instilled about ten minutes prior to using Restasis®. In any case, these side-effects are typically brief, and the benefits far outweigh the temporary discomfort that might be experienced. There are no major systemic side-effects from the use of Restasis®.

Xiidra® was approved in 2016 and was the first FDA-approved eye drop that improves both signs (what your eye looks like) and symptoms (what your eye feels like). It started a new class of treatment methodology by blocking particular steps in the ongoing cycle of inflammation. There are two side-effects that are most common, but like Restasis®, only occur in a minority of users. One is stinging upon instillation of the drop (similar to Restasis®), and the other is “dysgeusia,” which is a bad taste in the mouth. One advantage of Xiidra® is that some relief can be experienced in as little as two-three weeks of use, however, like Restasis®, this is a long-term treatment plan.

The most recent addition is Cequa™ (twice a day drops), which like Restasis® is a “cyclosporine-based” medication. It is a higher dose than Restasis® and uses “nanomicellular” technology that can increase absorption.

For Sjögren’s patients, one of these three medications are typically part of a treatment plan. Some doctors have a preference of one medication over

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another and for some patients, one may be more effective. If you are doing well on one of these medications, there is no need to stop or change, but certainly ask your eye doctor about their experience with the alternatives. If you are not currently on one of these medications, ask your doctor about adding it to your treatment plan. Remember, the best treatment can be attained when there is a partnership between you and your doctor. He or she may be the expert on eyes, but you are the expert on you!

Q *I feel like I have a lot of the symptoms of Sjögren’s but my blood tests came back normal. What should my next steps be?*

*Chadwick R. Johr, MD
Sjögren’s Foundation Board Member*

A As a physician, my first step in this situation would be to look for other causes of dryness aside from Sjögren’s. I would review your medication list to see if you are on any medications that may be causing dryness, fatigue, etc. Ask your rheumatologist what they think might be causing your symptoms if not Sjögren’s and if they feel any further testing would be helpful (such as blood testing for hypothyroidism).

Next, based on an overall suspicion for Sjögren’s consider looking for objective evidence of Sjögren’s in a stepwise fashion starting with easier tests. Ask your rheumatologist if they are able to do testing in their office to look for objective evidence of dry mouth (sialometry, a measurement of saliva production) and dry eye (Schirmer test, a measurement of tear production).

I would then see an eye care professional, who is familiar with performing an ocular staining score using both fluorescein and lissamine green, to look for objective evidence of dry eye. They can typically do the Schirmer test if your rheumatologist cannot.

I would also consider going for an ultrasound of the parotid glands to look for abnormalities typically found in Sjögren’s.

If any of those tests are suggestive of Sjögren’s, then I would consider going for a minor salivary gland biopsy. If none of those tests are suggestive of Sjögren’s, consider going for a nuclear salivary scan to look for other evidence of salivary gland dysfunction. If normal, then I would stop with the Sjögren’s evaluation. If abnormal, then I would go for a minor salivary gland biopsy.

Q *What is the most exciting thing you’ve learned by being on the Sjögren’s Foundation Board?*

*Susan Barajas
Sjögren’s Foundation Board Member, Sjögren’s patient*

A As you know, too many patients struggle to find doctors who are knowledgeable about Sjögren’s. Diagnosis can take years. Patients also struggle with the lack of drug(s) to treat the complexities of the disease.

What is the Sjögren’s Foundation doing to help this?

While I’m confident you are aware of many Foundation activities, you may be unaware of how Foundation activities impact your life as a patient. I learned of the Foundation shortly after my own Sjögren’s diagnosis in 2015. I quickly decided I wanted to become involved and help other patients. I have since started a support group, run with Team Sjögren’s, and chaired the Los Angeles Area Walk for Sjögren’s.

In 2018, I was honored to join the Board of Directors of the Foundation. As a Board member, I learned the full extent of the Foundation’s patient advocacy with the broader health community, both private

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April is Sjögren's Awareness Month

Sjögren's Awareness Month was first established in 1998 when New York Congresswoman, Louise Slaughter, read it into the Congressional Record. Today, the Foundation works to keep the spirit of national awareness alive every April. And now, during a time of increased stress and anxiety because of the coronavirus/COVID-19, it is even more important that we come together as a virtual community to raise awareness of Sjögren's.

In our new 2020 theme, we are going to be highlighting the many Faces of Sjögren's to expand our #ThisIsSjögrens online campaign and share your stories! You are the voice and the face of the Foundation and it is the collection of your experiences that truly portrays this complex disease.

Sjögren's is one of the most prevalent but still lesser known autoimmune diseases, affecting an estimated four million Americans, both men and women of different ages and ethnicities. One of the difficulties with awareness is that Sjögren's isn't a "cookie-cutter" disease and symptoms can manifest in various ways from patient to patient. Many symptoms are also referred to as invisible because you cannot see someone's profound fatigue or when the disease has advanced to his/her internal organs.

This leads to a misunderstanding about the serious-

ness of the disease, which can be extremely isolating for those living with it. The Foundation wants to help close the gap between the reality of living with the disease and the perception that many non-patients may have by showing the faces of real patients, talking about how the disease affects them and how we are working together to conquer Sjögren's.

Every day in April, the Foundation 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 encourage you to use April Awareness Month as a way to talk about the disease. Every day is an opportunity to start a conversation about living with Sjögren's and how it affects you. Help educate the world that this is a serious disease and remember, the more others understand, the more support you can find.

Visit 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. ■

#ThisIsSjögrens

Join Team Sjögren's in Chicago!

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We're looking for runners or walkers to join our Team Sjögren's Training Program for the Rock 'n' Roll series Chicago Half Marathon (13.1 miles) or 12K (7.4 miles) race on July 19th. Follow our program and we will prepare you to WALK or RUN in either race, where each turn is filled with the sights and sounds of Chicagoland.

Our Team is always full of walkers and runners – so don't fret if you aren't a runner!

The Team Sjögren's program takes people from the couch to the course. The Sjögren's Foundation staff and our Team trainer will help guide you through the entire process and ensure you are ready to participate in July! In addition, you will be increasing awareness for Sjögren's, as well as, helping raise crucial funds for Sjögren's research and education.

Voted one of the BibRave Top 20 Half Marathons, the Rock 'n' Roll Chicago Half Marathon is a must-do in 2020! The course takes you on a perfect tour of the Windy City where you will run/walk the Magnificent Mile, through downtown and along Lake Michigan. Whether you choose the Half Marathon or 12K, you will be cheered on by bands, cheerleaders and supportive spectators throughout the route!

The Foundation has a limited number of spots for this epic summer event and we hope you'll be one of them! If you don't feel you can walk or run in this event, do what so many other patients have done and recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them walk or run in your honor.

If you want to receive information about training and joining Team Sjögren's Chicago, please contact Steven Taylor at staylor@sjogrens.org!



As a Team Sjögren's member, you will receive:

- World-class training from our Team Trainer
- Leadership and mentorship from past runners and Sjögren's Foundation staff
- Hotel room accommodations in Chicago
- Airfare reimbursement
- An opportunity to join a Team of those wanting to make a difference
- And much much more

**“We Run in Honor of the 4 Million Americans with Sjögren's...
We Are Team Sjögren's”**

If you want to receive information about training and joining Team Sjögren's Chicago, please contact Steven Taylor at staylor@sjogrens.org!

You Stood Up!

Running for Mom

The Run Disney World® Marathon weekend had added magic this year as Steven Taylor, Sjögren's Foundation CEO, our Team Sjögren's Trainer Kalla Ford, and Sara Caron, proudly wore their jerseys and ran in honor of their mothers.

Sara's mother Karen, 51, passed away in December 2018 after a brief illness caused by pneumonia complicated from her Sjögren's. Karen was an active Foundation member who repeatedly stepped up to run as a part of the Team Sjögren's marathon training program with Sara. The mother-daughter duo ran in the Team Sjögren's Disney World®, Team Sjögren's Disneyland® and Team Sjögren's Nashville races, raising thousands of dollars for the Foundation and increasing awareness along the way. Karen, always with a smile on her face, was an inspirational member of Team Sjögren's.

Sara said, "My mom was my initial catalyst for running for Team Sjögren's. She was my best friend and a huge inspiration: never letting her diagnosis, brain fog, migraines, fatigue, or joint pain bring her down. She was the strongest person I will ever know. Since her passing, it's even more important to me to run. It's a part of carrying on her legacy and carrying her with me."

In addition to running the Half Marathon with Sara, Kalla and Steven also completed the Dopey Challenge, running 48.6 miles (a 5K, 10K, Half Marathon and Full Marathon) over the four-day race weekend.

Kalla explained her motivation, "I decided to run this weekend in honor of my mother because she has been through so much with her symptoms from Sjögren's and going through breast cancer. I thought if she can live each day with a positive outlook and smile on her face while dealing with the discomfort, brain fog and fatigue from Sjögren's, then I can endure the 48.6 miles of the Dopey Challenge. It is important for me to raise funds and awareness for people who suffer from this disease."

Steven started the Team Sjögren's training program twelve years ago in honor of his mother, who lives with the disease, and all Sjögren's patients. "When Sara and Kalla talked to me about participating in



Sara Caron crossing Half Marathon finishline



Steven Taylor, Sjögren's Foundation CEO, and Kalla Ford, Team Sjögren's Trainer

Run Disney World® weekend, I knew I wanted to be by their side," he said. "It was a hot and humid race weekend, but with each step, I thought about Karen Caron along with my mother, Kalla's mother and all the patients I have met during my time at the Foundation. Sjögren's patients inspire me every day and I am honored to work for them and run in their honor."

Congratulations Sara, Kalla and Steven on a very magical race weekend! ■

"We Run in Honor of the 4 Million Americans with Sjögren's... We Are Team Sjögren's"

Coronavirus/COVID-19 Precautions for Sjögren's Patients



Take cautionary steps in your everyday activities:

As the number of cases keep rising in the United States, the Foundation is encouraging all patients to consider taking necessary precautions as outlined by the Centers for Disease Control and Prevention (CDC) to reduce your exposure.

These precautions include:

- Wash your hands often with soap and water for at least 20 seconds
- Cover your cough/sneeze with a tissue or your elbow. Throw used tissues in trash
- Avoid touching your eyes, nose, and mouth with unwashed hands
- Wash hands each time before applying eye drops, dry mouth or dry skin products
- Avoid touching public surfaces
- Clean and disinfect frequently touched objects and surfaces
- Stay home when you are sick
- Practice Social Distancing – Keep 6 feet between yourself and other people and stay home whenever possible

If the COVID-19 is active in your community, consider avoiding crowded places or situations. If there isn't an active virus near you, please consider your personal health condition as you decide whether to go to where there are a lot of people.

As a Sjögren's patient, your risk is not necessarily higher for getting the coronavirus than others, but if you do get diagnosed, you should let your physician know that you suffer from Sjögren's and that you may be at higher risk of complications from COVID-19.

As a note – not all Sjögren's patients have compromised immune systems. This specific risk factor is for those who regularly take drugs to suppress the immune system. Examples include prednisone, methylprednisolone, Imuran, azathioprine, methotrexate, leflunomide, Arava, CellCept, mycophenolate, RITUXAN® (rituximab), cyclophosphamide.

Please note that hydroxychloroquine (Plaquenil) does NOT suppress your immune system and does not increase any risk for a more serious illness from COVID-19. However, all Sjögren's patients should still be diligent and be tested if symptoms become present.

The Sjögren's Foundation, in concert with our medical advisors, is closely monitoring the coronavirus/COVID-19 and what our patients should be doing. We know that the coming weeks will include times of stress and anxiety, as we are all chartering this unknown territory. Rest assured, that the Foundation will be alongside you as we continue to offer support and advice to Sjögren's patients on COVID-19.

Please check the Centers for Disease Control and Prevention and the Foundation's website for any updates. ■

Sjögren's Foundation Canceled Events

The Foundation has been monitoring the coronavirus 19 (COVID-19), outbreak and due to the unpredictable progression of the virus, we have come to the difficult decision to cancel all of our events through April 30th.

The health and safety of our patients, their families and our volunteers will always come first.

We will continue to evaluate future events as needed. Please visit www.sjogrens.org to learn more about event cancelations and COVID-19 precautions for Sjögren's patients.



Sjögren's Foundation Event Calendar

To learn more about Foundation events, please visit events.sjogrens.org or contact Jessica Levy at (301) 530-4420 ext. 218 or email jlevy@sjogrens.org.

May

Philadelphia Tri-State Walk for Sjögren's

Saturday, May 2, 2020

Philadelphia Zoo

Washington Region Walk for Sjögren's

Saturday, May 16, 2020

Sjögren's Foundation Headquarters, Reston Virginia

Denver Walk for Sjögren's

Saturday, May 30, 2020

The Hudson Gardens

June

Dallas Walk for Sjögren's

Saturday, June 20, 2020

The Parks Mall at Arlington



July

Team Sjögren's - Chicago

Sunday, July 19, 2020

events.sjogrens.org

Do we have your current e-mail address?

If you want to receive all the latest updates from the Sjögren's Foundation, then you should make sure we have your most up-to-date e-mail address! The Foundation is starting to share more information via e-mail, from news about the Foundation and Sjögren's, to information about the latest treatments and medicines, to local Support Group updates and more. So contact us at info@sjogrens.org to be certain we have your latest e-mail address in our database, and then keep an eye out in your Inbox for Sjögren's news.

Just like all information you give the Foundation, your e-mail address will remain private and will never be given or sold to an outside organization.

“Ask the Board” *continued from page 10* ▼

and governmental, even on an international level. It is amazing! Here are some of the organizations with whom the Foundation meets and to which it presents on a regular basis:

- National Institutes of Health
- U.S. Food and Drug Administration (FDA)
- American College of Rheumatology (ACR)
- National Health Council
- American Association for Dental Research
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- Childhood Arthritis & Rheumatology Research Alliance
- National Coalition of Autoimmune Patient Groups
- European League Against Rheumatism European Congress of Rheumatology – The European counterpart to the ACR*
- HarmonicSS – A European Union-led project for research institutions to come together to share and harmonize their data on Sjögren’s*
- OMERACT – Working to identify biomarkers *
- Sjögren’s Europe – A European Federation of Sjögren’s patient associations*
- International Association for Dental Research*

* Denotes an international group

Why does the Foundation’s involvement with these organizations excite me and what does this mean to you and me as patients?

- Every conference or convention the Foundation attends spreads the word that Sjögren’s is “out there” and important.
- Every study group in which the Foundation participates includes the perspective of Sjögren’s patients in the group’s outcome.

- Every meeting that discusses clinical trials helps ensure trials are held in a manner so that results are usable and ultimately accepted by the FDA.
- Every meeting with a governmental organization educates other attendees on the complexities of Sjögren’s and the importance of developing treatment options.
- Every meeting with pharmaceutical companies’ promotes the understanding of the need for new treatments.
- Every doctor who listens to a presentation or views the Foundation’s information booths at events becomes more knowledgeable about Sjögren’s.

As an example of this last point, the January/February 2020 issue of *Conquering Sjögren’s* discussed a recent presentation made to about 800 primary care doctors at Pri-Med, a continuing medical education session for primary care doctors. Feedback from the session described great enthusiasm with learning about Sjögren’s. Can you imagine – 800 doctors who now have a greater awareness of Sjögren’s, of methods used for diagnosis, and of treatment options! This can’t help but result in earlier diagnoses of Sjögren’s patients since primary care doctors are often the first doctors that patients see about their symptoms.

The efforts of the Foundation described above are paying off! The average time for diagnosis decreased from 6 years to 2.8 years over a recent five-year period. Patient care is improving as more doctors learn about the disease. And drug development has come so far that I’m confident we’ll finally have medications available to us in the near future that treat the disease itself. The future is full of hope! ■

Thank you to all of the Board members who answered questions above and shared their passion for helping Sjögren’s patients. Learn from more of the Foundation’s Board members in part two of “Ask the Sjögren’s Foundation Board of Directors” that will be in the May/June issue of Conquering Sjögren’s.



Sjögren's Foundation In Action!



National Health Council 99th Annual Membership Meeting & Luncheon

The Sjögren's Foundation CEO, Steven Taylor, chaired the National Health Council (NHC) 99th Annual Membership Meeting and Luncheon on December 10, 2019. This Meeting ended Steven's term as Chair of the 2019 NHC Board of Directors, a position he held previously in 2013. As Steven stepped down from his role of Chair, he passed the baton to Ann Palmer, CEO of the Arthritis Foundation, to lead the organization in 2020.

The NHC brings together all segments of the health community to provide a united voice for the more than 160 million people with chronic diseases and disabilities, and their family caregivers. Its members include 125 national health-related organizations, including the Arthritis Foundation, the American Heart Association, American Cancer Society, Lupus Foundation and the Hydrocephalus Association.

The Sjögren's Foundation will continue to be an active member of the NHC. Our involvement with them and their many member organizations helps to further bring recognition to Sjögren's, while elevating our voice and ensuring we have a seat at the proverbial table to participate in important discussions and decisions.



Celebrating the National Institute of Dental and Craniofacial Research Clinic's 35th Anniversary

Steven Taylor, Sjögren's Foundation CEO, and Kathy Hammitt, Sjögren's Foundation Vice President of Medical and Scientific Affairs, had the honor of speaking at the grand rounds to celebrate at the National Institute of Dental and Craniofacial Research (NIDCR) Clinic's 35th anniversary.

The event showcased the past, present and future of Sjögren's research, highlighting collaborations that have made the current progress in understanding the disease possible. As Jancie Lee, NIDCR Clinical Director, said at the end of the program, "These partnerships will be critical as we look forward in coming years to the goal of better treatments and a cure." ■





IN MEMORIAM

In Memory of Carol Schenkel

Joan Hetzler
Eric Smith
Andrea Zava
William Hetzler
Rebecca Piper
Bob and Linda Harris

In Memory of Grayce Swenson

Goldie Anderson

In Memory of Irene Belling

Kim and Wayne Sorenson

In Memory of Jacqueline Danielson

Diane Thomas

In Memory of James Santimaw

Nancy Faucher

In Memory of Jerry Bradley

Jessie Grace

In Memory of Patricia and Elfrida Frank

Diane Stadtmiller

In Memory of Shirley White

Karla O'Connor

In Memory of Virginia Kelly

Sheila and Gary Bigel

In Memory of Bonnie Tarnoff Litton

Naomi and Neil Arnold

In Memory of Joseph Bouchard

Josette Dufour

Betty Bouchard

IN HONOR

In Honor of Linda Vogel

Danielle Korn

In Honor of Cheryl Levin

Donna Epstein

In Honor of Diane Shurm

Christmas for Children Inc.

In Honor of Elaine and Larry Levin

Hannah and David Kaplan

In Honor of

Hannah and David Kaplan

Elaine and Larry Levin

In Honor of Irma and Fred Fernandez

Anna Miller

In Honor of Janis Rosenlund

Liane Leahy

In Honor of Jessica Levy

Eleanor Goldman

In Honor of Judy Frisone

Nina Carbone

In Honor of

Julian and Heather Orenstein

Lee Fanwick

In Honor of Linda and Dennis Howard

Martha Costa

In Honor of Lindsey Hatfield

Beth Ann Hatfield

In Honor of Margaret Mondlak

CD Spangler Foundation, Inc

In Honor of Marty and Sarah McEvoy

Kaye Beals

In Honor of Nora McLean

Janet Denton

In Honor of Shelli Culley

Betsy Burnham and Mark Stern

In Honor of Xiomara Arango

Omaira Arango

4 issues for just
\$20
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Stay informed. Stay aware.

Be your own best medical advocate.

To increase professional awareness about Sjögren's, the Foundation publishes the *Sjögren's Quarterly* – a professional resource geared toward medical and dental professionals, clinicians, researchers, and anyone interested in the latest in Sjögren's research findings and treatments.

Although the content is primarily written for a professional audience, *Sjögren's Quarterly* is not just for doctors and researchers. Patients may benefit from the information, too.

If you are interested in subscribing to *Sjögren's Quarterly*, we are offering a special introductory rate of just \$20 for Foundation members. Take charge of your healthcare by keeping on top of all the best medical information available.

Subscribe to *Sjögren's Quarterly* today, and you might just teach your doctor a thing or two about Sjögren's.

**Order by calling the Foundation office at
(301) 530-4420**

Summary of article written by Christiana Logan Dietetic Intern, Tufts University, Author of "Nutrition to Improve Symptoms of Sjögren's," Conquering Sjögren's, Volume 1, Issue 1

Sjögren's can cause digestive system difficulties such as difficulty eating (dysphagia), GERD (Gastro-Esophageal Reflux Disease), acid stomach (dyspepsia), and dysfunction of the pancreas and the liver which are essential for digestion and absorption of nutrients. Although these symptoms have the potential to affect nutritional status, the good news is that specific nutrition and diet changes can greatly improve Sjögren's symptoms.

How a decreased salivary flow (xerostomia) can impact the dietary choices of Sjögren's patients:

- Individuals who experience severe xerostomia tend to avoid crunchy foods such as raw vegetables, dry or tough foods such as meats and breads, and sticky foods such as peanut butter.
- In the absence of saliva, sugars stick to the teeth and increase bacterial proliferation and dental decay.
- Poor oral health in the form of missing or highly diseased teeth can cause patients to choose softer, more carbohydrate-rich foods that are easier to chew.
- While it can be difficult given the rough textures of vegetables and other nutritious foods, try having a variety of fruits and vegetables, lean meats and/or vegetable proteins, whole grains, healthy fats, and avoiding saturated fat, added sugars, and excess sodium as much as possible.
- In an effort to relieve symptoms of dry mouth, many people find themselves constantly sipping on beverages throughout the day, but here are some things to keep in mind:
 - Sugar-containing beverages like soda, juice, sweetened iced tea, coffee and any acidic beverages can promote tooth decay and dental enamel erosion, so it is best to avoid these.
 - Sipping on water washes away any saliva produced and diminishes its protective effect.
 - Try to use alternatives to drinking fluids like xylitol gums and salivary stimulants to relieve dry mouth symptoms.

How to improve the palatability of nutritious foods:

- Increase protein intake by cooking using moist cooking methods like baking in liquid, boiling, and slow cooking or pressure cooking.
- Incorporate meats into soups or sauces, add Greek yogurt to smoothies or dips, and try seafoods like fish and shellfish, as they tend to be softer.
- Increase vegetable intake by adding a variety of them to soups, stews, and smoothies, cooking them well and consuming them mashed, or juicing them.
- Try to increase Vitamin E and omega-3 fatty acid intake by having fatty fish like salmon several times per week and incorporating healthy oils like olive and flaxseed oils.

Adapting to Sjögren's often means limited dietary choices, however, this can lead to malnutrition and weight loss. Be sure to talk to your doctor if you are experiencing symptoms of GERD or other gastrointestinal complications. For further help, ask your doctor to refer you to a Registered Dietitian who can give you guidelines specifically tailored to your needs.



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

Are you looking for a meaningful volunteer experience?

Interested in making a difference in the lives of other Sjögren's patients?

Join us as a Patient Support Volunteer!

Patient Support Volunteers are seasoned Sjögren's patients who are willing to receive calls from newly diagnosed Sjögren's patients. You will provide them with support and Sjögren's information, especially about day-to-day living, coping strategies and available resources. The Foundation is looking for qualified volunteers throughout the country to be part of our growing network of support!

If you are someone who:

- Has been diagnosed with Sjögren's for 1 year or more
- Has been a Foundation member for at least 6 months
- Is knowledgeable about Sjögren's and the resources available to newly diagnosed patients
- Is known for being a great listener and having a positive outlook

This could be the perfect volunteer opportunity for you!

If you are interested in learning more about how to become part of our team of volunteers, contact Kathy Ivory at kivory@sjogrens.org for more information.

