

CONQUERING Sjögren's

September/October 2024

October is Dysautonomia Month

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A Letter from your CEO, Janet E. Church



Hello Sjögren's Foundation members and fellow patients! I'm excited for you to read this edition of Conquering Sjögren's! In this issue, we pay homage to Dysautonomia Month (October) share an overview of how we continue to push for dental coverage with the Centers for Medicare and Medicaid Services (CMS), and we share information about our 2024 Research Grant recipients. We are also introducing you to our newest member of the Board of Directors, Lisa Rubenstein.

Dysautonomia and Sjögren's

Dr. Brent Goodman is a well-known neurologist specializing in the neurological manifestations of autoimmune disease (especially dysautonomia). Last April, in Amsterdam at the International Sjögren's Disease Symposium, I spent some time with Dr. Goodman where he shared his new focus and passion – the Glymphatic System. I was fascinated by our discussion about this fairly new discovery and how it might contribute to symptoms such as fatigue and brain fog. He has generously written an article for us that I know you will find interesting. In the coming year, I am sure we will learn more about how this system plays a role in patient symptoms. Our second nod to Dysautonomia Month is an article by Dr. Sezen Karakus helping us understand the dysautonomia and Sjögren's ocular connection.

Research Grant Recipients

We know so little about this disease! That is why research is critical and why we have been expanding our research program the past three years. For our 2024 grant cycle, we saw more proposals than ever

before, and proposals with important hypotheses to move forward! In this issue, we highlight our five 2024 Foundation Research Grant recipients. This year, we awarded three Pilot Grants, one High Impact Grant, and one Dynamic Grant. Take a look at their exciting projects and get to know these researchers. All of them are committed to Sjögren's and to making a difference in patients' lives.

Advocacy and CMS

This past year, we have invested in advocacy efforts and have great achievements. One of these is our new House Resolution 1094 declaring April as Sjögren's Awareness month, updating facts about the disease, and officially changing the disease name. In fact, this document has already helped to change the disease name on NIH agency communications (NIAMS and NIDCR). But another important advocacy effort this year has been a focus on CMS. This is our second year working on efforts for dental coverage with CMS and unfortunately, we did not achieve success this year. It is incredibly difficult to get new services added due to the tight budgeting around the program and the longevity of service that is required once approved. What we did get is key CMS people now understand Sjögren's and the debilitating impact that Sjögren's has on oral health. Read about the history of our efforts and know that we will persist!

Fall Activities at the Foundation

Our Fall Walk for Sjögren's season is in full swing! This year, we moved our Texas Walk from the June time-frame to September 28th. We are seeing an increase in

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The Glymphatic System



*Brent P. Goodman, M.D.
Chief Medical Officer
Metrodora Institute*

Did you know that the brain has its own waste management system called the glymphatic system? This recently described system may play a critical role in brain health and various nervous system diseases and injuries.

Overview

Most people are aware of the lymphatic system, which has important roles in immune function and in the transport of extracellular fluids from the body's different tissues. The glymphatic system is a recently described system, hypothesized to function as the waste management system for the brain. Interest in this system has exploded in recent years, as investigators have explored its role in brain health, aging, and in various pathological conditions, including neurodegenerative diseases, vascular and traumatic brain injuries, headache disorders, and autoimmune central nervous system conditions.

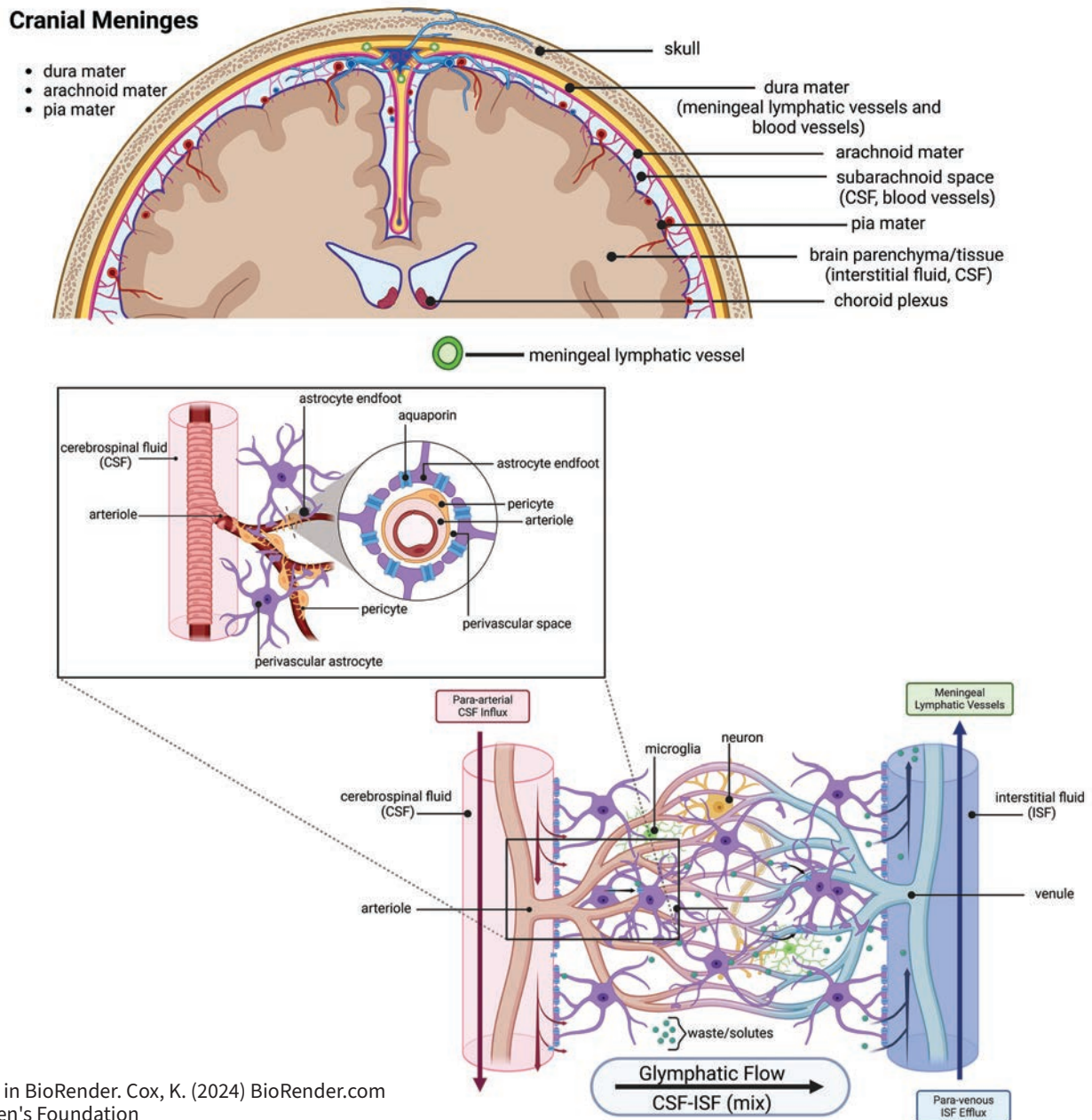
Up until recently, it has been believed that the lymphatic system did not exist within the brain, and that clearance of debris and metabolites from the brain occurred through other mechanisms. In 2012, a multi-center investigator group reported that cerebrospinal fluid (CSF) entered brain tissue (parenchyma) and mixed with another type of fluid—interstitial fluid—and subsequently drained out of the brain, carrying with it important substances (Iliff 2012). This “waste” fluid ultimately drains into the peripheral lymphatic system. Precise mechanisms responsible for fluid movement through this system are still being elucidated. It has been proposed that the mechanics of respiration, arterial pulsations, and other independent, spontaneous oscillations of blood vessels drives CSF into and through brain tissue, towards the venous system. In 2015 another landmark observation, identified the presence of lymphatic vessels in

the meninges (membranes) surrounding the brain (Aspelund 2015; Louveau 2015), and it is now thought that multiple substances drain into these vessels or possibly through cranial or spinal nerves.

Important Components of the Glymphatic System

In order to understand the glymphatic system, it is helpful to understand the fluid components of the brain, brain barriers, and the important structural components of this system. There are four fluid components in the brain, including: cerebrospinal fluid, interstitial fluid, intracellular fluid, and blood. As noted above, glymphatic system function relies on cerebrospinal fluid entering brain tissue and mixing with interstitial fluid, prior to exiting the brain into the external lymphatics. Interstitial fluid is produced via filtration of plasma in cerebrovascular endothelial cells, while cerebrospinal fluid is continuously produced by choroid plexus lining the ventricles of the brain. In addition to playing a critical role in glymphatic function, cerebrospinal fluid provides protective cushioning for the brain, buffers pH (acidity), maintains important chemical gradients, and distributes neurotrophic growth factors (small proteins that support the growth, survival, and differentiation of neurons). The transport of cerebrospinal fluid into brain parenchyma relies on aquaporin 4 water channels that are attached to astrocytic end feet (see **Figure 1**).

A number of different substances have been demonstrated to be cleared by the glymphatic system. These substances include potassium and lactate, peptides

Figure 1: The Glymphatic System

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and proteins that cause disease such as amyloid beta and tau, and proteins from damaged neurons. It has also been suggested that the glymphatic system may play a role in the transmission of neuromodulators and diffusion of growth factor through the central nervous system. The glymphatic system may also play a key role in the removal of inflammatory cytokines, which play an important role in immune function. There is increasing interest in the role of the glymphatic system in central nervous system immune surveillance and potential interactions with immune cells and other immune system functioning outside of the nervous system.

Regulation of the Glymphatic System

Glymphatic system function is carefully regulated, with the sleep-wake cycle playing a critical role in glymphatic system processes. Movement of cerebrospinal fluid and clearance of substances through the glymphatic system is significantly increased during sleep. Glymphatic function appears to be most rapid and efficient during slow wave sleep. Mechanisms responsible for differences of glymphatic functioning related to sleep and wakefulness have not yet been fully elucidated, but the sympathetic component of the autonomic nervous

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“Glymphatic System” *continued from page 5* ▼

system appears to play an important role. Activation of the sympathetic or “fight or flight” component of the autonomic nervous system is thought to reduce glymphatic function, and less sympathetic nervous system activation during sleep appears to facilitate glymphatic functioning. Additionally, it has been hypothesized that less synchronous neuronal activity characteristic of wakefulness results in a less porous brain that has greater resistance to fluid flow and ultimately, reduced clearance of substances via the glymphatic system. Conversely, synchronous neuronal activity during sleep may be associated with a more porous brain that may be more conducive to fluid movement and clearance of substances from the brain during sleep. Mouse models have demonstrated that extracellular space expands during sleep, facilitating fluid movement through the glymphatic system, while cellular expansion and reduction of the volume of extracellular space during wakefulness is thought to reduce glymphatic function.

Role of the Glymphatic System in Neurological Diseases, Aging, and Brain Injury

The role of the glymphatic system in various neurological diseases is an area of active investigation. Neurodegenerative disorders such as Alzheimer’s Disease, Parkinson’s Disease, and Dementia with Lewy bodies are characterized pathologically by the accumulation of waste proteins within the brain. Amyloid beta plaques and tau protein aggregate (clump together) and accumulate in Alzheimer’s disease, and alpha-synuclein aggregates in Parkinson’s Disease and Dementia with Lewy Bodies, leading to progressive neurological deterioration. The glymphatic system appears to play an important role in the clearance of these waste proteins, preventing or limiting their aggregation and accumulation. Not surprisingly, potential mechanisms for enhancing glymphatic function to minimize accumulation of these waste proteins and decrease the likelihood of developing these neurodegenerative diseases is an area of active research. Age, for reasons not currently understood, is associated with reduced glymphatic functioning. Mouse models have demonstrated that glymphatic function is reduced 80-90% in old versus young mice. Several factors have hypothesized to account for the reduction of glymphatic function with aging such as, decreased cerebrospinal fluid production with aging, increased arterial stiffness, reduced cerebrospinal fluid pressure, reactive astrocytes, and structural changes to aquaporin 4. Neuroimaging studies have demonstrated a larger amyloid beta burden in individuals with longstanding sleep disruption and shorter sleep duration.

Furthermore, cerebrospinal fluid amyloid beta concentration has been demonstrated to be lowest during sleep, and higher during wakefulness. Other studies have also demonstrated higher levels of amyloid beta and tau in individuals with longstanding histories of shorter sleep duration. Mouse models of Parkinson’s disease have demonstrated reduced accumulation of pathogenic alpha-synuclein in animals with pharmacologically-enhanced slow wave sleep (Morawska 2021). There is evidence of disrupted glymphatic function following traumatic brain injury. Traumatic brain injury results in damage to the blood brain barrier, activation of an inflammatory response, activation of excitatory neurotransmitters, accumulation of astrocytes and microglia around the site of injury, and accumulation of the waste proteins amyloid beta and tau. Mouse models of mild traumatic brain injury have demonstrated reduced uptake of gadolinium (a contrast used during an MRI) into the glymphatic system and brain parenchyma and prolonged glymphatic clearance times. Mouse traumatic brain injury models have demonstrated decreased expression of aquaporin-4 along with structural changes to astrocytes. Sleep disruption, known to be common in traumatic brain injury, might also play a role in reduced glymphatic function.

Glymphatic System and Dysautonomia in Sjögren’s

The autonomic nervous system plays a key role in glymphatic system regulation. Sympathetic nervous system activation reduces glymphatic clearance, while parasympathetic activation enhances glymphatic function. Mouse models have demonstrated that blockage of adrenergic (sympathetic) receptors enhances cerebrospinal fluid flow into brain parenchyma, thereby increasing glymphatic function. Vagal nerve stimulator implantation, which activates parasympathetic function, has been shown in mouse models to improve glymphatic function. It is reasonable to hypothesize that various autonomic nervous system disorders or dysautonomia, may result in abnormal glymphatic function. Sjögren’s disease, which has a predilection for causing dysautonomia of varying severity and type, presumably could result in disrupted glymphatic function either through over-activation of sympathetic pathways (hyperadrenergic form of dysautonomia), or impairment of parasympathetic function. Further research is necessary to determine whether these mechanisms have relevance to cognitive symptoms (i.e. “brain fog”) reported by many individuals with Sjögren’s disease.

It is at this point unclear whether or how systemic autoimmune conditions affect the glymphatic system

directly, or whether the glymphatic system plays a significant role in the development of systemic autoimmune disorders or their manifestations. The presence of enlarged perivascular spaces (small fluid-filled structures that surround blood vessels in the brain) has been reported to correlate with inflammatory activity in patients with Lupus (Miyata 2017). It has also been demonstrated that peripheral systemic disease can activate inflammatory processes in the brain through activation of neurons in the medulla and hypothalamus via the vagus nerve, and peripheral inflammatory cells may reach the brain directly through a damaged blood brain barrier. It is not known whether disordered (or enhanced) glymphatic function influences peripheral, systemic, autoimmune diseases. ■

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To summarize, the glymphatic system is a recently described system that:

1. Is hypothesized to be responsible for clearance of waste substances from the brain; similar to the lymphatic system elsewhere in the body.
2. Primarily functions during sleep.
3. Declines in function with age.
4. Is suppressed by sympathetic nervous system activation.
5. Is likely responsible for limiting the aggregation and accumulation of proteins that are responsible for the development of neurodegenerative diseases such as Alzheimer's disease.
6. Is modulated by autonomic nervous system function.

"Letter from CEO" continued from page 3 ▼

participation and fundraising by our volunteers and walkers so I'm glad Texas is enjoying the new date. We are holding our West Coast and Northeast Walks on the same day, which is October 19th. To get involved as a walker, or to come to the virtual Walk meeting and ask our experts questions, you need to register. Information on how to register is on the back page of this issue. Join us as we conquer Sjögren's One Step at a Time!

Fall Focus

On November 9th, we are hosting our Fall Focus conference which will be a deep dive into how to care for our Sjögren's eyes at every stage and learn about new research to help us with our dry eye in the future. I have learned so much this past year from my personal journey with severe dry eye and eye surgeries, and I wanted to bring this information to all of you (as well as other information). Take a look at the Fall Focus ad in this issue and get ready to register!

Dry eye affects 95% of Sjögren's patients, so this education program will be helpful to everyone!

Closing a Year of Celebration!

On October 19th, with the completion of our West Coast and Northeast Walk for Sjögren's, we close our 40th anniversary year of celebration. It has been an amazing year, and I will give a full recap of our 40th year later. But in November, we will replace our 40th anniversary logo with our corporate logo. So, enjoy the 40th anniversary branding in this issue of Conquering Sjögren's!

So much is happening with the Sjögren's Foundation and our work is all possible because of our donors, our passionate volunteers, and our dedicated staff and Board of Directors. We are growing and making a greater impact than ever before, and it is all with your help! Thank you all for making the Sjögren's Foundation what it is today. Together, we will conquer the complexities of this disease! ■

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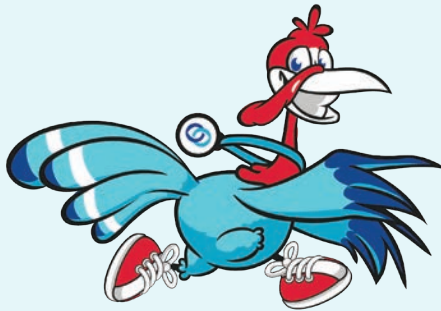
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Turkey Trot 40th Anniversary Redux

*Commemorative Shirts to spread awareness at a low price!
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Instead of creating a new Turkey Trot design for 2024, we are selling the remaining 2023 shirts at cost. It is still a great shirt to spread Sjögren's awareness and to share that the Sjögren's Foundation is moving into our 41st year!

Order by November 4th to be received before Thanksgiving!

Kit 1 Includes: \$15 plus S&H

- Sjögren's 40th Short Sleeve Cotton T-shirt
- "Stronger than my Sjögren's" wristband
- Sjögren's "Turkey Trot" Medal

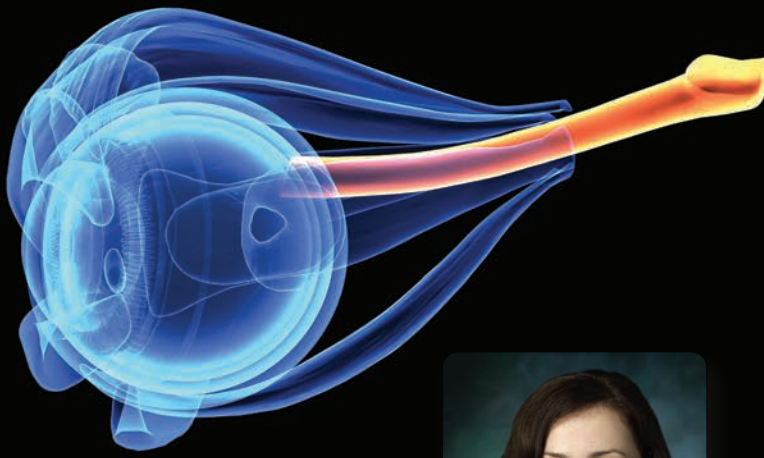
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- Sjögren's "Turkey Trot" Medal



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Understanding the Ocular Health Implications of Dysautonomia in Sjögren's Disease



Sezen Karakus, MD; Jane Huang, BS.
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Sezen Karakus, MD

For Dry Eye Awareness Month in July, we published this article by Dr. Sezen Karakus on understanding the link between ocular health and dysautonomia. Since October is Dysautonomia Awareness Month, we wanted to be sure that you had the opportunity to read this article. Below is the introduction of the article that was first published in our blog on July 18th, 2024. You can read more at www.sjogrens.org/blog or see below to scan the QR code or follow the URL to be directly linked to the article.

Introduction

Dry eye and dry mouth are hallmarks of Sjögren's disease, originally described by Dr. Henrik Sjögren, an ophthalmologist who noticed a pattern in a group of patients with severe dry eye.¹ These patients also experienced dry mouth, as well as generalized joint and muscle pain. The proposed pathogenesis was that inflammatory infiltration of the lacrimal and salivary glands would eventually destroy these glands, causing dry eye and dry mouth.¹ Over the years, we have learned that Sjögren's is a systemic disease that can affect multiple other organs and systems, including the central, peripheral, and autonomic nervous systems, with recent attention given to its impact on the autonomic nervous system.²⁻⁴ Dysautonomia is a condition where the autonomic nervous system does

not function properly. Given the role of the autonomic nervous system in controlling various bodily functions, autonomic dysfunction may have a more significant impact on someone with Sjögren's than we currently understand. Recognizing the possible role of dysautonomia in Sjögren's can help us better understand some of the symptoms patients experience and consider different ways to address them. Here, we discuss the possible role of dysautonomia in ocular health in patients with Sjögren's and how the presentation may differ from patients manifesting with classical keratoconjunctivitis sicca. ■

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Learn more about ocular health and dysautonomia:
<https://sjogrens.org/blog/2024/understanding-the-ocular-health-implications-of-dysautonomia-in-sjogrens-disease>

Insights:

Sjögren's Foundation Leads Medicare Dental Coverage Advocacy for Autoimmune Disease Patients



The Sjögren's Foundation has led the charge for Medicare coverage of medically necessary dental treatment for Sjögren's and other autoimmune disease patients ever since Medicare opened the door to potential coverage two years ago. We have submitted two nominations so far, met with officials from the Centers for Medicare and Medicaid Services (CMS), and engaged lawmakers on Capitol Hill to highlight this Medicare coverage pathway and increase awareness for Sjögren's disease.

Following our first nomination and feedback from CMS, after which CMS ruled that dental coverage could not be provided for oral manifestations caused by a systemic disease, we refined the nomination in 2024 to target autoimmune disease patients undergoing immunosuppressive therapy. Since CMS approved the coverage of certain dental services for cancer patients undergoing chemotherapy, we argued there is a similar need for autoimmune disease patients undergoing immunosuppressive therapy. We worked with medical experts who presented on the risks to Sjögren's patients' oral health when initiating immunosuppressive therapies.

Unfortunately, despite two years of fighting for Sjögren's and autoimmune disease patients to obtain access to dental coverage under Medicare, CMS did not move forward with our nomination. While CMS acknowledged the negative oral health consequences individuals with autoimmune diseases face when undergoing immunosuppressive therapy, they requested further information and data on the inextricable link between dental care and immunosuppressive therapy for autoimmune disease patients.

This setback is certainly disappointing, but we have made enormous progress raising awareness for this Medicare coverage pathway and for Sjögren's disease. We feel we have opened new opportunities to advance issues important to the Sjögren's community and will continue to explore those opportunities. We

also feel that CMS has provided feedback so that we can continue our pursuit for Medicare dental coverage for Sjögren's patients.

This work is not possible without our dedicated team advocating to improve access and outcomes for individuals with Sjögren's disease. Below we provide additional information on how we got here, what next steps look like, and how you can support these efforts in your community.

Background

In 2022, CMS clarified its interpretation of Section 1862(a)(12) of the Social Security Act (the statutory exclusion for dental services in Medicare), which resulted in CMS identifying certain scenarios where payment could be permitted under Medicare Part A and B for dental services that are inextricably linked to, and substantially related to the clinical success of, certain other covered services.

Those scenarios included dental or oral examinations prior to any organ transplant surgery, cardiac valve replacement, and dental or oral examinations prior to treatment for head and neck cancer. CMS said this was a modest expansion and would result in an increase in spending in the range of \$230,000 to \$3 million. CMS also established a pathway to annually collect and review recommendations for other clinical scenarios where payment could be permitted under Medicare for certain dental services.

The Sjögren's Foundation leapt at the opportunity to chair the Autoimmune Diseases Working Group in partnership with the Oral Health Consortium to ensure that the voice of Sjögren's patients was heard. Our initial nomination and subsequent presentation to CMS highlighted data, clinical evidence, and compelling patient stories, which drove home the urgent need to expand dental coverage to Medicare beneficiaries with an autoimmune disease. We also met with Capitol Hill offices to highlight this opportunity

to encourage CMS to thoroughly evaluate all nominations to improve access to dental services.

In its decision, CMS stated that its current view of the restrictions around Medicare coverage for dental services means stakeholders must establish an inextricable link between dental services and the success of an already covered Medicare service. An example of eligible coverage under this view would be for dental care before undergoing joint replacement surgery, as there is an inextricable link between oral health and potential infection and the success of the joint replacement surgery. CMS did not advance several proposals, including ours for systemic autoimmune diseases and a proposal for diabetes, and instead requested additional comments and evidence on the covered service.

While CMS set a high threshold for stakeholders to meet, they have demonstrated a commitment to work with stakeholders and highlight the impact poor oral health access has on other health outcomes. CMS signaled to interested parties to remain engaged in this process but to consider circumstances for which dental services are inextricably linked to a specific covered service, such as chemotherapy, and not a diagnosis, such as Sjögren's disease or diabetes.

Second Nomination Submitted to CMS for Dental Coverage

The Sjögren's Foundation led the nomination process again in 2024, modifying the nomination to focus on coverage of dental services for autoimmune disease patients on immunosuppressive therapy. Prior to meeting with CMS, we engaged Capitol Hill to build awareness and support for Sjögren's disease and this dental coverage pathway.

This resulted in the first congressional resolution in over 20 years in the House of Representatives, led by Rep. Joe Morelle of New York, which highlighted the disease burden for individuals with Sjögren's and the need for more research and funding to improve access and outcomes for individuals with Sjögren's disease. Rep. Morelle also led a congressional sign-on letter to CMS with eight co-signors highlighting our nomination and the implications for improving access to dental coverage for this population. These were major developments on the Capitol Hill side to increase awareness for Sjögren's disease and opportunities to improve access to dental coverage.

Our hard work throughout 2024 also resulted in another meeting with CMS to present on clinical evidence for the nomination. We presented on the oral health consequences for autoimmune disease patients on immunosuppressive therapy, how routine dental coverage would enhance the success of

such treatment, and walked through several studies demonstrating this link. While we are disappointed CMS did not accept this nomination, we believe their feedback recognizes this link but does not satisfy the high threshold to overcome the statutory restrictions in place around Medicare dental coverage.

CMS agrees that research should continue into whether there is a connection between dental and oral evaluations and treatment prior to immunosuppressive therapy and outcomes for such therapies. CMS also seeks comment on whether the level of immunosuppression utilized in the treatment of autoimmune diseases is similar to the immunosuppression levels employed in the treatment of cancer. As noted above, CMS previously finalized payment for dental exams for certain cancers and chemotherapy.

CMS is also seeking information on the connection between immunosuppressive therapy in the treatment of autoimmune disease and the likelihood of systemic infection and sepsis. In our nomination, we noted that CMS stated that proceeding without a dental or oral exam of the mouth prior to chemotherapy could lead to systemic infection or sepsis, among other complications, and similar outcomes can follow for those receiving immunosuppressive therapy to treat autoimmune diseases.

Lastly, CMS is seeking information regarding standards of care or clinical guidelines that recommend that a dental infection be addressed before proceeding with the immunosuppressive treatment. We are investigating a potential approach of demonstrating that specific immunosuppressive therapies used by Sjögren's patients pose relatively higher risks to patients, but further research is necessary. We also are moving up development of the foundation's clinical practice guidelines for managing and treating oral manifestations of Sjögren's in the hope that this will provide evidence required by CMS. And, we are exploring additional avenues for gathering data needed to convince CMS to provide dental coverage for Sjögren's patients.

What Comes Next

The Sjögren's Foundation will provide comments on CMS' decision and regroup this fall to consider a nomination that is targeted at Sjögren's disease patients on Medicare. We encourage you to not just reach out to the Foundation with your experiences, thoughts, and questions, but to also consider outreach to your lawmakers. The Foundation is committed to increasing awareness for Sjögren's disease and unlocking new opportunities for funding that will make it easier for new therapies to come to market in the future. This is an all hands-on-deck effort, and we appreciate your support and willingness to engage on these important issues. ■



Meet Lisa Rubenstein, Newest Member of the Sjögren's Foundation Board of Directors

The Sjögren's Foundation would like you to meet our newest member of the Board of Directors, Lisa Rubenstein! Welcome!

First, how is a Board of Directors member selected?

The Sjögren's Foundation is governed by a Board of Directors made up of patients, healthcare providers, caregivers, and people who may perform a role that is beneficial to the Board. To be considered for a Board seat, an individual must meet specific criteria including a level of knowledge about Sjögren's disease and the Foundation, what it is like to live with the disease, and how their specific background can enrich the Board and therefore the guidance of the Foundation. Each Board seat term is for three years, and the seat can be renewed for another three-year term.

A potential board member is vetted by the Governance Committee (comprised of current Board members) and then presented at the May Board of Directors' meeting to be voted in. Each new Board member term begins on July 1st, which is the first day of the Foundation's fiscal year. The Board of Directors for the Foundation meets three times per year to review the goals and priorities of the Foundation, and to set long term strategy and plans that will most benefit patients.

Meet Lisa Rubenstein, patient advocate

Lisa was diagnosed with Sjögren's in 2013 at the age of 47. After spending years seeing doctors for various odd ailments that seemed unrelated, Lisa received a Sjögren's diagnosis. Despite having an autoimmune disease, she finally got answers for her ailments under one diagnosis. Her most prominent symptoms were—and still are—neuropathy, fatigue, muscle and joint pain, gastrointestinal issues, and persistent interstitial cystitis. After diagnosis, she immediately turned to the Foundation for information and support.

Hailing from the Dallas-Fort Worth (DFW) area, Lisa joined the DFW Support Group after diagnosis. She also became an active volunteer for the Foundation by chairing the Dallas Walk for Sjögren's, speaking at Walk kick-offs, and generously sponsoring the Texas Walk.

Last year, Lisa agreed to be a subject patient for a presentation poster entitled, "My Four Pillars of Wellness: How Sleep, Diet, Exercise and Stress Reduction Enable Me to Define My Life and not let Sjögren's Define Me," which was displayed at the American College of Rheumatology Convergence conference. Her ab-

stract for this poster was also subsequently published in a special online supplement of the journal, *Arthritis & Rheumatology*. To view the abstract for Lisa Rubenstein's Patient Perspectives poster, please visit [here](#).

Don't quit your day job!

Lisa brings her business experience to the Board as well as her patient experience. Lisa was the managing director of a technology consulting firm in Dallas, Texas before Sjögren's required her to alter her career. She is now an ICF (International Coaching Federation) Professional Certified Coach with a focus on working with executive and senior leaders of Fortune 500 companies. In this role, she serves as a guide and strategic business partner to equip leaders to thrive in today's rapidly evolving business landscape. Lisa's business, coaching, and executive leadership skillset will be an asset to the Board as will her patient-lived experience.

Why Lisa joined the Sjögren's Foundation Board of Directors

"I am grateful to have been asked to join the Sjögren's Foundation Board of Directors. Each of my reasons for saying yes to the nomination are just as important as the next, so they are not in any particular order. This is an opportunity for me to be of service which is a very significant value held by me and my family. It is important to be a patient advocate on the Board and be the voice of those on our Sjögren's battlefield. It's personal for me, as a Sjögren's patient myself, and I have a dear friend's daughter, who at 30, has had significant Sjögren's related health issues, including cancer. I would like to do all I can to raise awareness and funds to bring new and better therapies to the forefront and make it easier for all of us and those who are yet to be diagnosed. I am in awe of the work I've seen over the years by the Board, President/CEO, and staff at the Foundation, and it's both a privilege and responsibility to be a part of what's next!" – Lisa Rubenstein, member of the Sjögren's Foundation Board of Directors

Welcome to the Foundation's Board of Directors, Lisa! We know you will be a great asset to both the Foundation and the Sjögren's community! ■

Sjögren's Foundation Announces 2024 Research Grant Recipients

The Sjögren's Foundation is excited to announce the selection of five new research grant recipients for the Foundation's High Impact Grant, Dynamic Grant, and Pilot Grants.

Types of Foundation Grants and their Impact

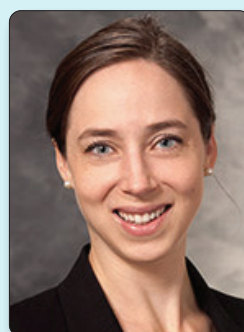
The Sjögren's Foundation High Impact Grants are given to more fully developed research proposals to help a project that has preliminary data and good scientific methodology in place to move forward into the next phase of their project. We are fully committed to awarding one High Impact Grant each year.

The Pilot Research Grant assists investigators in obtaining resources, like preliminary data or feasibility studies, necessary to advance their project to help them pursue larger funding from other resources like the National Institutes of Health (NIH), or a High Impact Grant with the Foundation. We are also committed to awarding one Pilot Grant each year. In 2024, we awarded three Pilot Grants.

The Foundation's Dynamic Grant is given to investigators that have time-sensitive, but critical work that may fall outside the scope of the Foundation's other funding opportunities. Proposals for this grant are considered based on their scientific strength, needs for the patient, and available funding.

These Foundation grants not only support research that will benefit patients with Sjögren's, but they are also an investment in the researchers who receive the grants. To demonstrate the importance of this, two past grant recipients, who are internationally recognized Sjögren's researchers share their gratitude.

Sara McCoy, MD, PhD is a rheumatologist who established the Sjögren's Clinic at the University of Wisconsin, where she also has a Sjögren's research lab. Dr. McCoy credits the Foundation.



My grant from the Sjögren's Foundation served as my first steppingstone toward independent research, building my research program momentum. Without this first extramural grant from the Foundation—investing not only in an idea, but also in an early stage

Sjögren's investigator—I would not be in the position to help patients that I find myself now. Since my grant, I've been an investigator or collaborator on four NIH-funded grants, including as an AMP® AIM Leadership Scholar Program recipient. I am thankful for the opportunity the Foundation provided and I hope that I can return the favor by improving Sjögren's patients' lives.

Christopher Lessard, PhD, a scientist at the Oklahoma Medical Research Foundation, leads the international Sjögren's Genetics Network. He received his very first research grant from the Foundation in 2013 and shared the immense value of that grant.



Sjögren's Foundation grants provide vital support for researchers focused on advancing our knowledge about Sjögren's. A Foundation Pilot Grant was the first grant I received as an early-career investigator. It was instrumental in the early progression of my

career, and I know several other investigators that

“Grant Recipients” *continued from page 9* ▼

have had similar experiences. Nearly a decade later, my research program was honored as the first recipient of the Foundation’s Dynamic Grant, which is aiding in our ongoing efforts to improve genetic understanding of the disease. Foundation grants go a long way towards building the Sjögren’s research community and providing pilot or bridge funding to projects that may otherwise not have happened.

As the only non-profit organization for Sjögren’s patients, we have a key mission to fund innovative research, we are proud of the research we have funded and honored to have impacted so many amazing investigators.

Grant Recipients

We are thrilled to see where these projects lead our investigators and how it will impact Sjögren’s patients in the future. Please continue to read about this exciting research funded by the Foundation’s research grants below.

High Impact Grant Recipient

R. Hal Scofield, MD
Professor
Oklahoma Medical Research Foundation

Project Title
Mechanisms of Fatigue in Sjögren’s

Abstract

Sjögren’s disease (SjD) is chronic autoimmune disease in which the deleterious immune response is directed primarily towards the exocrine glands, including the lacrimal and salivary glands. Severe fatigue is common in SjD. There is only a limited understanding of the pathophysiology of fatigue in SjD. Overall, there are large areas of unmet medical needs in SjD, including understanding the pathophysiological mechanisms of the clinical manifestations. Our preliminary data demonstrate mitochondrial dysfunction in SjD patients, a novel finding. Also, fatigue is highly correlated with mitochondrial dysfunction. We find increased free radical damage and abnormal expression of mitophagy-related genes. These findings provide a powerful premise for the proposed work. The PI hypothesizes that mitochondrial dysfunction is associated with fatigue and is caused by abnormal mitophagy, with increased free radical generation by

defective mitochondria. We propose the following specific aims to address our hypothesis: In Aim 1, we will determine the clinical associations and correlates of mitochondrial dysfunction among a large group of SjD patients, testing the hypothesis that mitochondrial dysfunction is correlated with fatigue. We further hypothesize that kynurenine levels, lowered by chronic, low-level inflammation, will be associated with mitochondrial dysfunction and fatigue in SjD. For Aim 2, we hypothesize that worsened free radical damage will be strongly associated with worsened mitochondrial function. Here, we will determine the role of free radicals in SjD mitochondrial dysfunction. In Aim 3, we will determine the role of mitophagy in SjD mitochondrial dysfunction, testing the hypothesis that not only will one of the two central pathways for mitophagy be abnormal within lymphocytes in the peripheral blood, but that this abnormal expression will be found among those patients with mitochondrial dysfunction and fatigue.

What does Dr. Scofield’s research mean for Sjögren’s patients?

According to the *Living with Sjögren’s* patient survey results, 88% of respondents experienced fatigue and 79% said that fatigue had a major or moderate impact on their life. Approximately 25% of patient respondents said that fatigue had the greatest negative impact on their life. Dr. Scofield’s research aims to determine the underlying mechanism of fatigue in Sjögren’s, which can help develop future management and treatment options for patients with Sjögren’s and fatigue.

Pilot Grant Recipients

Jennifer King, MD, PhD
Associate Clinical Professor in Medicine
University of California, Los Angeles

Project Title
Molecular Phenotyping of Treatment Responsive Sjögren’s Patients

Abstract

There are no FDA-approved treatments for Sjögren’s disease (SjD). The reasons for failures of immune modulating medications are multi-factorial, including diversity of clinical disease and challenges of selecting primary endpoints to define treatment response. This proposal will examine SjD patients considered treatment responsive (defined here as changes in 1 or more validated Sjögren’s outcome measures) to define objective cellular and molecular markers of

change. We will compare these patients to treatment non-responsive and no treatment. We will use single-cell sequencing to examine individual's pre- and post-treatment samples, looking at global signatures in all immune cells, but also specifically in monocyte subsets. We hypothesize that treatment responsive SjD patients have distinct cellular and molecular characteristics that correlate with changes in disease activity. The goal is to define objective signatures that may be used in conjunction with current disease outcome measures to assess treatment response.

What does Dr. King's research mean for Sjögren's patients?

Since Sjögren's is a heterogeneous disease, there are many unknown factors that play a role in the effectiveness of a treatment. Dr. King's work will determine cellular and molecular signatures of individual SjD patients and how that affects their response to treatment. This work has huge implications on patient stratification- or separating them into groups- to provide better treatments and will likely impact future drug discovery and clinical research.



Abigail Koppes, PhD

*Associate Professor, Chemical Engineering
Northeastern University*

Project Title

Parsing Dysautonomia in a Dish: Neural Exposure to Exogenous Sjögren's Patient Derived Serum

Abstract

The complexity of nervous system interactions and cause-effect of glandular involvement in organ health in Sjögren's patients creates a difficult disease to treat and identify. Dysautonomia and gastrointestinal disorders are correlated with the presence of autoantibodies and interferon and interleukin cascade activation, but the cause is not known. In this proposal, my lab will apply a new in vitro microphysiological system (MPS), or organ-on-a-chip, that combines human autonomic, central, and enteric neurons to systematically examine morphology and excitability in response to Sjögren's derived serum and autoantibody insults. Our MPS will be used for effluent collection, electrophysiology, imaging, and transcriptomics with a systems biology approach to identify the molecular regulators and reveal if there are Sjögren's-based differences in neuron responses to inflammatory cues. Through this proposal, a new MPS will be engineered to controllably study and disrupt the nervous system in the gut-brain axis environment typically inaccessible in vivo.

What does Dr. Koppes' research mean for Sjögren's patients?

Dr. Koppes' research utilizes a newer technique to create a local nervous system microenvironment, also called a "nervous system on a chip", to study the effect of various disease states. This research will look at how autoantibodies and other factors found in the serum of Sjögren's patients affect developing neurological conditions associated with the gut-brain axis. We hope this will give us clues to the cause of gastrointestinal disorders and dysautonomia in Sjögren's patients and allow us to examine the mechanisms of neuro-Sjögren's.



Eiko Yamada, DDS, PhD

*Research Fellow
National Institute of Dental and Craniofacial Research*

Project Title

Exploring Target Cells Contributing Higher Interferon Status Through cGAS-STING Pathway in Sjögren's Disease

Abstract

Sjögren's disease (SjD) is a common systemic autoimmune disease with heterogeneous clinical presentation involving multiple biological pathways. The primary clinical symptoms include characteristic dry eyes, dry mouth, and profound fatigue. Currently, there are no approved and efficacious medications that can reverse disease progression or improve the main clinical complaints of SjD. One pathway that is classically involved in SjD is the Type-I interferon (IFN) signaling. However, the upstream mechanisms driving the increase in expression, or lack of feedback inhibition, of Type-I IFN is not elucidated deeply. The cGAS-STING pathway is a recently discovered intracellular pathogen sensing pathway that primarily responds to cytosolic double-stranded DNA. The cGAS-STING pathway has become a hot topic in immune and inflammatory diseases due to its ability to potentially mediate the inflammatory response. Although a recent study offered the first direct evidence that cGAS-STING pathway is activated in systemic lupus erythematosus patients and modulates Type-I IFNs, the role of this pathway in SjD pathogenesis is unknown. Our preliminary bulk RNAseq data demonstrate enrichment of DNA Sensing Pathway and increased Type-I IFN-stimulated gene score in the blood and gland correlate with specific disease features in SjD. We discovered the novel findings that cGAS-STING proteins are activated in SjD and that correlates with Type-I IFN bioassay in

“Grant Recipients” *continued from page 15* ▼

sera. Based on these findings, we hypothesize that cGAS-STING pathway is chronically activated in SjD and contributes both local (glandular) and systemic (peripheral blood) symptoms via upregulated and persistent expression of IFNs. This study proposal aims to identify the specific cell types contributing cGAS-STING pathway in SjD-affected patient samples. This work will produce a deeper understanding of what happened as immune cell subset in SjD and support the future development of cGAS-STING proteins as targets for therapy.

What does Dr. Yamada’s research mean for Sjögren’s patients?

For autoimmune diseases, the prevention of inflammatory responses is a well-known therapeutic pathway. This work will determine deep immune phenotyping (characteristics) and the activation level of cGAS-STING pathway in Sjögren’s patients. Investigation of the cGAS-STING pathway may produce a deeper understanding of its role in Sjögren’s patients and provide another therapeutic option for Sjögren’s treatment.

Dynamic Grant Recipient



Dana DiRenzo, MD, MHS
Assistant Professor in Medicine
University of Pennsylvania

Project Title

Development of a Core Outcomes Set of Domains for Sjögren’s Disease

Abstract

Sjögren’s disease (SjD) has limited precise and reliable patient-reported outcome measures (PROs) to understand health related quality of life (HRQoL) from the patient perspective. SjD highly impacts HRQoL because of symptoms such as pain and fatigue, which drive patient disability, loss of work productivity, and healthcare utilization. The overall objectives are to

identify SjD domains that are important to all relevant SjD stakeholders and generate a core outcome domain set. The rationale is that through the rigorous methodologic OMERACT framework, we will define key disease domains and core set measures to generate optimal measurement tools for clinical trials. The central hypothesis will be tested by three specific aims: 1) Generate a comprehensive list of important domains in SjD for each key aspect of disease (oral, ocular, biological, extra glandular, life impact) via literature reviews and focus groups; and 2) Conduct a Delphi exercise of generated domains in SjD to gain consensus agreement and inform a core domain set; and 3) Generate a core domain set and seek approval from the OMERACT community. The research proposed is innovative because for the first time, it engages all stakeholders from at least three continents from the start of the process for generation and selection of instruments to measure response in SjD clinical trials.

What does Dr. DiRenzo’s research mean for Sjögren’s patients?

Dr. DiRenzo’s research is an extension of the work done by OMERACT (Outcome Measures in Rheumatology) to produce reliable patient-reported outcome measures to be used for clinical trials. This work will identify Sjögren’s domains that are important and relevant to generate optimal measurement tools, and ultimately, provide critical new outcome measurements for clinical trials. The international Sjögren’s community will be involved to ensure that instruments used to measure response in Sjögren’s clinical trials are best practice and globally accepted.

Congratulations to our Foundation Research Grantees! Good luck with your research this year and we look forward to the impact your research will have on the Sjögren’s community!

If you would like to learn more about the Foundation’s research opportunities or current and past grant recipients, please visit <https://sjogrens.org/researchers-providers/research-grants>. ■



You Stood Up! Thank you Donors and Amgen!

The Sjögren's Foundation wants to recognize our donors for helping us achieve our match goal of \$40,000 for World Sjögren's Day during our 40th year celebration! The Sjögren's Foundation thanks you, and we are truly grateful for your generosity!

In addition, we would like to thank our sponsor, AMGEN, for pledging a dollar-for-dollar match up to \$40,000 in honor of the Sjögren's Foundation celebrating 40 years.

Our overall donation total for World Sjögren's Day was more than \$80,000!

Your donations will have a great impact at the Foundation and will help fund initiatives like those below:

- Sjögren's Research including grants awarded by the Foundation into the cause, prevention, detection, treatment, and cure for Sjögren's
- Professional Education such as CME courses for healthcare physicians to increase their education of Sjögren's and Clinical Practice Guidelines for Sjögren's to improve the quality of care for patients
- Advocacy to further improve the lives of all Sjögren's patients and make sure the patient

voice is heard. Efforts such as continuing to advocate for Medicare to include coverage for medically necessary dental care.

World Sjögren's Day was a huge success because of YOU!

Although World Sjögren's Day has now passed, the fight against Sjögren's continues. While it certainly made an impact, one day alone is not enough to conquer the complexities of Sjögren's. We must continue to work together and maintain our momentum. We hope you will stay engaged with the Foundation while continuing to increase awareness about Sjögren's.

Please don't hesitate to contact the Foundation if you have any questions on how your donations impact our efforts. Most importantly, we are here to assist you or your loved ones to find knowledge and support to help fight the burden of this disease. Let us know how we can help.

On behalf of the Sjögren's Foundation and the 4 million Americans living with Sjögren's, we thank you again for helping to make a difference on World Sjögren's Day. ■





Sjögren's Foundation 2024 Fall Focus Conference

Looking Deeper into Ocular Manifestations of Sjögren's Disease

November 9, 2024 • 12-5pm (ET)

Join us on Saturday, November 9th for the 2024 Sjögren's Foundation Fall Focus Conference. This year we will take a comprehensive look at ocular complications and management in Sjögren's.

Sjögren's patients know all too well about that dry, gritty, sand-in-your-eyes feeling. Dry eyes affect 95% of Sjögren's patients and is stated to be one of the greatest daily challenges of living with this disease. Without healthy tear production and lubrication, eye damage can occur, affecting comfort and sight. Whether your dry eye symptoms are mild or severe, understanding proper care and management is critical. This virtual conference will give you the information you need to care for your eyes at every stage.

Each conference session will be delivered live in a virtual format by Sjögren's experts in ocular medicine, who are committed to researching and understanding the complexities of Ocular Surface Disease in Sjögren's

patients. After each clinical presentation, you will be able to present your questions at a live Q&A!

At this year's fall conference, you will hear from experts on these key ocular health topics:

- Foundational Overview of Sjögren's Effect on the Eye
- What to Expect in a Comprehensive Eye Examination
- An Explanation of Medications Available for Dry Eyes in Sjögren's
- Understanding how Sjögren's patients may experience eye pain differently
- Ocular Interventions available for Sjögren's Patients
- Surgical Considerations for Sjögren's Eyes
- Exciting Research Currently Happening for Sjögren's Dry Eye!

Join us on November 9th and get the credible information needed to give your eyes the best chance of battling the ocular effects of Sjögren's!

Watch for more exciting conference details on the Foundation's website – www.sjogrens.org or by scanning the QR code.

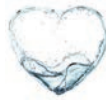


Sjögren's
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Thank you to our presenting sponsor, Amgen, for supporting the 2024 Fall Focus Conference!

AMGEN



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Conquering Sjögren's

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CONQUERING SJÖGREN'S ONE STEP AT A TIME

Walk for Sjögren's is an amazing series of events where patients build community together, interact with Sjögren's experts, educate family and friends, and raise funds for important initiatives and research.

Join us at one of our fall events! We will start with an educational and celebratory virtual ceremony on Zoom. Afterwards, you can walk from where you are located, host an in-person meetup, or find a group to join. For more information, please contact Jessica Levy at jlevy@sjogrens.org, visit events.sjogrens.org, or scan the QR code.

Fall 2024 – Walk for Sjögren's Calendar

September

Virtual Texas Walk for Sjögren's
Saturday, September 28, 2024 (10:00 am CT)

October

Virtual Northeast Walk for Sjögren's
Saturday, October 19, 2024 (10:00 am ET)

Virtual West Coast Walk for Sjögren's
Saturday, October 19, 2024 (10:00 am PT)

events.sjogrens.org

We would like to thank our National Sponsors for their support!

