

CONQUERING Sjögren's

January/February 2024

40 Years

 **Sjögren's**
FOUNDATION



www.sjogrens.org



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The History of the Sjögren's Foundation– Built on a Strong Doctor-Patient Relationship



Solid foundations are built on strong relationships. The Foundation has told the history behind its establishment from the viewpoint of our Founder Elaine Harris. We wanted to share a key part of the story that started when she was first diagnosed. In 1982, Elaine was searching for answers to her ever-present symptoms. That is when she saw James “Jim” Sciubba, DMD, PhD, where he performed several laboratory tests and evaluations. His conclusion: Type 1 Sjögren’s Syndrome.

“Is there a medication or a surgery?” Dr. Sciubba recalls Elaine asking with his answer containing the unfortunate news that there was no specific treatment, only preventative measures. “Can I get in touch with an expert?” she insisted. Dr. Sciubba contacted Norman Talal, MD, a rheumatologist, and told him that Elaine would be coming to see him. Elaine, eager to see the expert Dr. Sciubba suggested, got on a plane in New York and went to the University of Texas in San Antonio to see Dr. Talal.

Upon her return trip, Elaine saw Dr. Sciubba again and said, “Ok, it’s Sjögren’s Syndrome— what next?”

Elaine had shared with Dr. Sciubba that she felt gathering patients to learn more about this disease would be beneficial. Dr. Sciubba and Elaine collaborated to organize a first-of-its-kind meeting about Sjögren’s. They rounded up Sjögren’s patients from Dr. Sciubba’s practice and other physicians, including Robert “Bob” Greenwald, MD, Steve Carsons, MD, and Ira Udell, MD. Dr. Sciubba was working at the Long Island Jewish Medical Center, where he was the chair the Dental Medicine Department, and reserved a conference room for the meeting. In the meeting of about 15-18 patients, he discussed the disease, what treatments were available, and preventative mea-

asures patients could take. This group started small, but little did they know how much larger the group and their message would grow in the future.

Dr. Sciubba had access to departmental funds to create a mailing list of Sjögren’s patients from contacts through rheumatology and ophthalmology practices on Long Island, NY. Elaine, her husband Herb, Dr. Sciubba, and his wife Dolores worked diligently to start a newsletter containing information for Sjögren’s patients called *The Moisture Seekers*— named after the support group— to send to the mailing list. This newsletter would eventually become the Sjögren’s Syndrome Foundation (SSF) newsletter, which is now titled- *Conquering Sjögren’s*. The goal of the newsletter was to highlight symptom management and to share stories about the fierce strength and determination patients have while living with Sjögren’s.

The tenacity and networking strengths of Elaine helped create several chapters in New York and beyond. With a talented team of doctors—Dr. Sciubba (oral), Dr. Carsons (rheumatology), Dr. Greenwald (rheumatology), and Dr. Udell (ophthalmology)— and a supportive husband, Elaine helped grow the small chapters of Sjögren’s patients into a nationally and now, internationally known organization.

Dr. Sciubba has dedicated his oral-maxillofacial medicine expertise and time to helping Sjögren’s and other patients of salivary gland diseases, among others. He continues to be actively involved with the Foundation as part of the Foundation’s Medical and Scientific Advisory Council. The Foundation is indebted to Dr. Sciubba for his willingness to go above and beyond for his patients as well as his longstanding support of Elaine and her mission to help other

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“Sjögren's History” *continued from page 7* ▼

Sjögren's patients. The Foundation is truly an example of the remarkable things that can come out of a strong doctor-patient relationship.

During our interview with Dr. Sciubba, we asked him questions about his experience with Sjögren's in the 1980's as well as the impact of recent medical research and the Foundation on Sjögren's.

Q *With many of our patients describing their difficulty in getting diagnosed currently, how did you know that Elaine had Sjögren's?*

A I learned about Sjögren's in my graduate training and my PhD research was focused on the pathology of rheumatic diseases, among others—so Sjögren's was part of my postdoctoral training. Sjögren's is not cryptic and it's not rare. There is just no magic pill for it, though Pharma has made steady strides in addressing treatment. Doctors know what Sjögren's is, they just need to be reminded that it is a prevalent and systemic disease.

Q *With the increase in research information and medical management of Sjögren's, where do you think the biggest change has occurred for Sjögren's?*

A The preventative strategies—oral, ocular, gynecology, etc.—have helped reduce the morbidity that follows Sjögren's. There has been an overall moderate improvement of symptoms that are attended to now

compared to the 1980s. Hopefully, the strategy to treat autoimmune dysfunction will help reduce the damage done to the exocrine glands by the autoimmune process which drives this disease.

Q *What advice would you like to share with Sjögren's patients?*

A Get into the right hands! Make sure your internists know what Sjögren's is and be confident that they are willing to get you into the right hands—dental, gynecology, primary care, rheumatology, pulmonology, ophthalmology, etc. The doctor-patient relationship is the key to getting things done and Sjögren's requires a team approach in prevention and treatment.

Q *Can you describe the impact of the Sjögren's Foundation?*

A One small group—that was started in one small department in a once small hospital on Long Island—grew into a nationally known organization. Dr. Steve Carsons, Elaine, and I pushed the organization—later the Foundation—forward. The determination of Elaine and the people she brought on board really drove the Foundation and was integral in how Sjögren's was established as a condition in the public media. Elaine never took “No” for an answer, as anyone who knew her could attest.

Thank you, Dr. Sciubba, Elaine, and the many others that were integral in the creation and continued success of the Sjögren's Foundation! ■



Highlights from Sjögren's Programs at ACR Convergence 2023



In November, the Foundation attended the American College of Rheumatology (ACR) Convergence 2023 in San Diego, CA. This is the largest meeting for the rheumatology community with more than 13,000 attendees joining this year. This event is a premier opportunity for healthcare providers, pharmaceutical companies, patient advocacy groups, and researchers to meet and discuss important and timely topics in rheumatology, including prevention, diagnosis, and therapies for all rheumatic diseases. This was quite a year for Sjögren's as there were 64 Sjögren's-related scientific abstracts and three Sjögren's-related scientific sessions.



The Foundation booth within the ACR Convergence 2023 Exhibit Hall.

Scientific Sessions of Sjögren's

The oral sessions provided information on important topics and new insights into Sjögren's research and medical management. Each session had a full

audience of providers and researchers eager to learn and share information about Sjögren's.

Session: De-"mystifying" Sjögren's Dryness: Molecular Interactions and Genetics Explained

The session focused on identifying Sjögren's disease-associated cell types that explain the heterogeneity of Sjögren's. The session was moderated by Darise Farris, PhD and Teresa Tarrant, MD. Christopher Lesnard, PhD, led the session by providing an update on how genetic associations point to involvement of specific cell types in Sjögren's glandular tissue and blood. Following this, Blake Warner, DDS, PhD, MPH, shared how genetic data from tissue can help identify disease pathophysiology in Sjögren's. Lastly, Cintia S. de Paiva, MD, PhD, discussed gene pathways in the conjunctiva (mucous membrane of the eye) of Sjögren's patients.

Session: Childhood Sjögren's

Moderated by Scott Lieberman, MD, PhD, and Akaluck "Ben" Thatayatikom, MD, this session focused on bringing awareness to childhood Sjögren's as an underdiagnosed disorder with unique clinical manifestations, which makes childhood Sjögren's difficult to diagnose. Sara Stern, MD, discussed the physical manifestations in children with Sjögren's, which include less prominent dryness and greater frequency of inflammation in the parotid gland. She also provided information for how to manage salivary gland inflammation in childhood Sjögren's. Cuoghi Edens, MD, offered her perspective as both a rheumatologist and adolescent/young adult women's reproductive health specialist on the unique challenges facing young women with Sjögren's as they mature.

“ACR Convergence” *continued from page 5* ▼

Session: Oral Abstracts in Sjögren’s Basic and Clinical Research

There were two Sjögren’s poster sessions for basic and clinical science that included a combined 36 abstracts. Non-Sjögren’s-specific sessions also contained a combined 28 more abstracts on Sjögren’s-related work. Of the submitted abstracts, the ACR chose six for oral presentations:

- Dose Dependent Modulation of a B Cell Protein Signature by Ianalumab in Patients with Sjögren’s Disease by Stephanie Finzel, MD, University Medical Center Freiburg
- Iscalimab (CFZ533) in Patients with Sjögren’s Disease: Week 24 Efficacy and Safety Results of a Randomized, Placebo-controlled, Phase 2b Dose-ranging Study by Benjamin A. Fisher, MD, MBBS, University of Birmingham
- Deep Learning Accurately Predicts Focus Score and Diagnosis of Primary Sjögren’s Syndrome Using Labial Salivary Gland Biopsies by Vincent Bouget, MSc, Scientia Lab
- Dazodalibep, a CD40L Antagonist, in Subjects with Sjögren’s Having Moderate-to-Severe Systemic Disease Activity: Full Crossover Results from a Phase 2, Randomized, Double-Blind, Placebo-Controlled, Proof of Concept Study by Eugene St. Clair, MD, Duke University Medical Center
- IgG-Fc-N-Sialylation and -Galactosylation in Primary Sjögren’s Syndrome (pSS) and its Potential as Marker of Disease State and Activity by Helena Achten, MD, Ghent University
- CD40L Inhibition with Dazodalibep Rapidly Reduces Blood Biomarkers of T and B Cell Costimulation in Subjects with Sjögren’s Having High Disease Activity or High Symptom Burden by Tuyet-Hang Pham, MS Horizon Therapeutics plc

Session: Challenging Complications of the Nervous System in Sjögren’s

The final Sjögren’s oral session was Monday evening and discussed the nervous system manifestations in Sjögren’s and how to create a management strategy for Sjögren’s patients with neurological complications. This session was moderated by Sara McCoy, MD, PhD, and Thomas Grader-Beck, MD, PhD. Brent Goodman, MD, discussed orthostatic intolerance (the inability to remain upright without symptoms) and the increasing association of dysautonomia (disorder of autonomic nervous system) with Sjögren’s. He also gave insights into the evaluation of dysautonomia in these patients.

Next, Arun Varadhachary, MD, PhD, gave a talk on the development of migraines in Sjögren’s and how the immune system may impact neurological manifestations. Lastly, Julius Birnbaum, MD, a doctor that specializes in both rheumatology and neurology, discussed practical management strategies for Sjögren’s patients presenting with neurological complications.

Overall, the Foundation was excited to see so many providers present on and learn about the systemic nature of Sjögren’s.

Foundation Luncheon

Every year, the Foundation hosts our annual ACR Convergence luncheon to discuss updates on Foundation news, research advancements, and partnerships with research-funding organizations and coalitions. More than 100 healthcare professionals, researchers, and industry partners attended this invite-only event.

This year’s theme was “Collaborations Moving Sjögren’s Forward,” which emphasized the amount of work that the Foundation and our research partners have been able to do through medical and scientific collaboration. This event was moderated by Kathy Hammitt, MA, VP of Medical and Scientific Affairs at the Sjögren’s Foundation. The luncheon began with important updates from the Foundation, including our new research grant policies and offerings and their availability through Proposal Central (an online hub for researchers to search for funding opportunities). Furthermore, it was announced that the Foundation’s State of Sjögren’s professional virtual event— which will address the topic of the difficult-to-diagnose patient— will be accredited for continuing medical education (CME) this year.

NIH Leadership Scholars Program

The Foundation also recognized Sara McCoy, MD, PhD, for her selection to the NIH Leadership Scholars Program for her project titled “Sjögren’s Disease Salivary Gland Mesenchymal Stromal Cells: Defining the Transcriptional and Epigenetic Landscape Changes in Health and Disease” to further Sjögren’s research. You can read more about this in the past November/December issue of *Conquering Sjögren’s*.

Foundation of the National Institutes of Health (FNIH) Biomarkers Consortium

As part of the scientific program, Darise Farris, PhD, provided updates on the FNIH Biomarkers Consortium, a longtime collaborator with the Sjögren’s Foundation. Over the past 16 years, the Biomarkers Consortium has provided tools that helped advance 14 therapeutics, nine clinical tools for drug development, five FDA guidance documents, one clinical safety biomarker,

and the Biomarker Evidence Criteria and Framework Guidance. The Biomarkers Consortium has more than 50 publications with 800+ citations. They are working on determining diagnostic biomarkers of Sjögren's disease to improve how patients are placed into subgroups for more effective disease management and advances in therapeutic development. The goals of this project are to help understand the heterogeneity of Sjögren's and provide data to update classification criteria and improve patient identification. The project is planned for three years. The approval for funding and launch of this project is scheduled for mid-2024.

Sjögren's Team for Accelerating Medicines Partnership (STAMP) and Accelerating Medicines Partnership® for Autoimmune and Immune-mediated Diseases (AMP®AIM)

Judith James, MD, PhD, and Caroline Shiboski, DDS, PhD, MPH, provided an update on the AMP®AIM and STAMP. The overarching goal of AMP®AIM and STAMP is to transform the model for developing new diagnostics and treatments by identifying and validating promising biological targets. STAMP has completed its planning and pilot phase and has started recruiting Sjögren's patients for testing. The next phase is to scale up and begin standardized clinical research protocols across sites and tease out the molecular mechanisms behind Sjögren's in hopes to better understand the disease to improve Sjögren's diagnosis and treatment for all Sjögren's patients. Once these data are collected and generated, they will be publicly accessible to scientists and medical professionals.

NEW Clinical Endpoints in primary Sjögren's Syndrome: an Interventional Trial based on stratifying patients (NECESSITY)

Gaétane Nocturne, MD, PhD, discussed the NECESSITY project. The goals of NECESSITY are to develop and assess clinical endpoints (or the outcome(s) by which clinical trials measure the effectiveness of the intervention) and to identify and evaluate biomarkers used to distinguish Sjögren's patients. The clinical endpoint developed by the NECESSITY project is called the Sjögren's Tool for Assessing Response (STAR). STAR was developed based on analysis of nine clinical trials using international experts and patients. Currently, STAR is undergoing external validation (testing of the original method on new sets of patients) in the NECESSITY trial and plans to be done with recruitment for this trial by January 2025. You can learn more about NECESSITY by visiting <https://sjogrens.org/researchers-providers/scientific-initiatives/necessity>.

Outcome Measures in Rheumatology (OMERACT) Sjögren's Working Group

Dr. Sara McCoy presented an update on the OMERACT Sjögren's Working Group. The goal of OMERACT is to develop core outcomes for clinical trials in Sjögren's and provide guidelines for the development and validation of outcome instruments. Phase 1 of this effort was to assemble a working group for Sjögren's and create domains which include health and disease aspects that are important for patients/healthcare providers/researchers for clinical trial outcomes. A scoping literature review was used to create a preliminary set of core domains. Once agreed upon, the domains will undergo a group consensus and a vote for the final core domain set. To learn more about the OMERACT Sjögren's Working Group, you can find information by visiting <https://sjogrens.org/researchers-providers/scientific-initiatives/omeract-sjogrens-working-group>.

Foundation's Outstanding Abstract Awards for ACR Convergence 2023

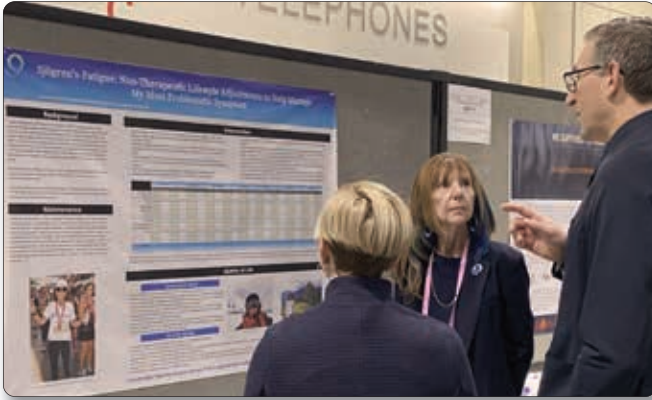
Our luncheon ended with Scott Lieberman, MD, PhD, announcing the Foundation's Outstanding Abstract Awards for ACR Convergence 2023. Our Outstanding Abstract Award winner was Maxwell Parker from the University of Wisconsin School of Medicine and Public Health. We also had two honorable mention awards—Dr. José Miguel Sequí-Sabater and Dr. Andreas Goules. Please visit <https://sjogrens.org/news/2023/sjogrens-foundations-outstanding-abstract-award-winners-at-acr-convergence-2023> to learn more about the winning abstracts.

Poster Sessions

This was the first year that the Foundation participated in the Patient Perspectives poster session at ACR Convergence. The Foundation collaborated with two patients, Susan Barajas and Lisa Rubenstein, to present their posters titled “Sjögren's-Fatigue: Non-Therapeutic Lifestyle Adjustments to Help Manage my Most Problematic Symptom” and “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”, respectively. It was important to show providers and researchers what patients experience and how they manage their symptoms. To view the abstract for Lisa Rubenstein's Patient Perspectives poster, please visit <https://acrabstracts.org/abstract/my-four-pillars-of-wellness-how-sleep-diet-exercise-and-stress-reduction-enable-me-to-define-my-life-and-not-let-sjogrens-define-me/>.



“ACR Convergence” *continued from page 7* ▼

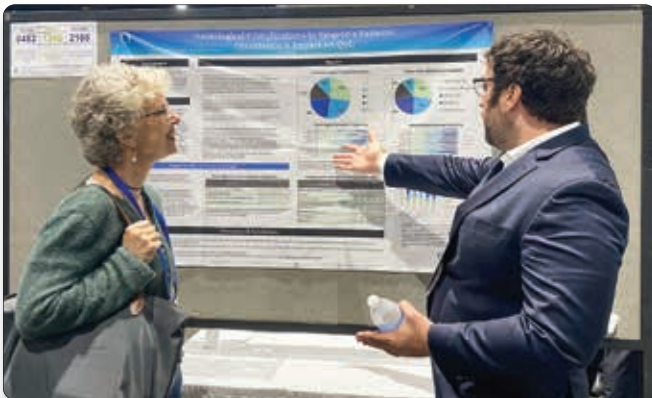


Susan Barajas presenting her Patient Perspectives poster at ACR Convergence 2023

To view Susan’s abstract, please visit <https://acrabstracts.org/abstract/sjogrens-fatigue-non-therapeutic-lifestyle-adjustments-to-help-manage-my-most-problematic-symptom/>.



The Foundation presented a poster titled, “Neurological Complications in Sjögren’s: Occurrence and Impact on Quality of Life (QoL),” which was well-received by those in attendance. Additionally, Foundation staff collaborated on three posters related to patient-reported outcomes in Sjögren’s for clinical trials that were presented during the conference.



Matt Makara, Sr. Director of Research and Scientific Affairs for the Foundation, discussing the Foundation’s poster on Neurological complications in Sjögren’s with Caroline Shiboski, DDS, MPH, PhD.

Foundation Booth and Professional Awareness

As in years past, the Foundation hosted and staffed a booth as part of the exhibit hall and enjoyed meeting the many healthcare professionals and researchers that stopped by to learn more about Sjögren’s and the Foundation. Foundation staff discussed key items with attendees, including the availability of

“It’s critical for doctors and medical personnel to understand the patient perspective when developing a treatment plan. Fatigue is one of the most challenging symptoms to treat and occurs with many rheumatic diseases, not just Sjögren’s. Through my Patient Poster, I was able to share the significant impact fatigue has on my everyday life and the non-therapeutic ways I lessen its impact. I’m hopeful that my perspective can help ACR attendees better understand the impact of fatigue on patients, and perhaps suggest some of my techniques for fatigue management, thus helping improve patients’ quality of life.”

— *Susan Barajas,*
Chair, Sjögren’s Foundation Board of Directors

both patient and professional resources, the development of clinical practice guidelines, the Foundation’s new grant mechanisms, and the upcoming *State of Sjögren’s* event taking place in January.

Additionally, Matt Makara, MPH, Sr. Director of Research and Scientific Affairs for the Foundation, participated in two ACR-led events to further promote how the Foundation can support professionals. First, in what have been branded as Lightning Talks, Matt provided a 5-minute run-through on an exhibit hall stage about the professional aspects of the Foundation’s Mission and specific ways for professionals to get involved and stay informed on Sjögren’s. This presentation included mention of *Sjögren’s Quarterly*, grant funding, the availability and ongoing development of new clinical practice guidelines, CME courses, clinical trial resources and training through the Sjögren’s Training and Education Platform (STEP), and, lastly, the *State of Sjögren’s* event. To further discuss grants, Matt participated in the “Meet the Funders” session, where he discussed the Foundation’s new grant mechanisms and answered questions for interested investigators.

In addition to the above, Foundation staff had many meaningful and productive conversations with many individuals, industry partners, and fellow advocacy and education organizations, the results of which will help the Foundation continue to expand our professional networks and improve our offerings.

The Foundation looks forward to next year at ACR Convergence 2024, which will be held in our hometown of Washington, DC! ■

40 Years 1983–2023 of Sjögren's Progress

KEY

- Major Milestones
- Foundation Created/Led
- NIH RESEARCH GRANTS

1983

- The Sjögren's Syndrome Foundation was founded by Elaine K. Harris who was diagnosed with Sjögren's Syndrome in 1982, along with Drs. James Scuibba and Ira Udell
- First Patient Support Group held in New York

1984

- *The Moisture Seekers* newsletter first published



1985

- Sjögren's Syndrome Foundation was incorporated

1986

- First International Symposium on Sjögren's Syndrome (ISSS) (Copenhagen, Denmark)

2003

- Restasis is approved by the FDA
- Sjögren's Syndrome Outcome Measures Workshop held by the Foundation
- Foundation helped secure \$11.9 million NIH grant for an international alliance and registry based at University of California at San Francisco (UCSF) to gather data, serum, and tissue samples from Sjögren's patients
- Foundation drives first Capitol Hill Day for Sjögren's community

2002

- American European Consensus Criteria published

2001

- Foundation provides oral testimony to U.S. House of Representatives Committee on Appropriations successfully getting Sjögren's included in Congressional Appropriations language
- First Foundation *National Patient Conference* (Los Angeles, CA)

2000

- Cevimeline approved for dry mouth by the FDA

NIH RESEARCH GRANTS

- 1 NIH research grant in Sjögren's
- 2 NIH research grants in dry eye

1998

- April declared Sjögren's Syndrome Awareness Month by Congress
- Pilocarpine approved by the FDA for dry mouth



1995

- First Foundation Student Fellowship awarded

1991

- First Foundation testimony before a Congressional Committee
- First Foundation Research Grant awarded

1989

- NIH held "The Many of Faces of Sjögren's Syndrome" conference
- First *Sjögren's Syndrome Handbook* released



40 Years of Sjögren's Progress

2004

- NIH International Sjögren's Syndrome Registry begins accepting patients
- First Sjögren's Walkabout



2005

- Foundation Lymphoma Workshop held at John Hopkins University
- July declared Dry Eye Month by Congress

NIH RESEARCH GRANTS

33 NIH research grants in Sjögren's

6 NIH research grants in dry eye

2006

- Foundation hosts International Symposium on Sjögren's Syndrome (ISSS)
- First issue of the *Sjögren's Quarterly* published for clinicians and researchers

2007

- First Sip for Sjögren's event

2008

- Foundation holds Research Reception at the University of Southern California
- Social Security Disability Guidelines include Sjögren's for the first time



2009

- Team Sjögren's Marathon & Half-Marathon Training program is created

2010

- First World Sjögren's Day
- Foundation partners with the American College of Rheumatology (ACR), American Association for Dental Research (AADR), and Contact Lens Association (CLAO) for Student Fellowship Award Programs
- First outcome measures in Sjögren's (ESSDAI) published



NIH RESEARCH GRANTS

76 NIH research grants in Sjögren's

70 NIH research grants in dry eye

28 NIH research grants in oral manifestations of Sjögren's/ salivary glands

2014

- Foundation creates Clinical Trials Consortium (CTC) to ensure new therapies for treating Sjögren's
- The Foundation supports 17 international Sjögren's patient groups as part of the International Sjögren's Network
- Foundation co-hosts Sjögren's criteria meeting at ISSS in Japan
- EULAR Big Data International Sjögren's Cohort

eular

2013

- Foundation partners with the LAM/Rare Lung Disease clinics to include treatment for Sjögren's patients
- Venus Williams steps up as the Honorary Chairperson of Foundation Sjögren's Awareness Ambassador Program
- Foundation launches annual Pilot and High Impact grant awards

2012

- Foundation Funds \$1.5 Million in Sjögren's Research
- Foundation welcomes Shannon Boxx, member of the U.S. National Women's Soccer Team & Olympic gold medalist, as the Honorary Walk Chairperson
- Foundation testifies before the Subcommittee on Oversight of the House Committee on Ways and Means

2011

- Foundation Medical & Scientific Advisory Committee launches *Clinical Practice Guidelines* initiative
- Foundation wins *Telly Award* for patient education video "Sjögren's Syndrome: A Place to Begin"
- Foundation launches *5-Year Breakthrough Goal*: "To shorten the time to diagnose Sjögren's by 50% in five years!"
- Foundation Blog *Conquering Sjögren's* is first published





KEY

- Major Milestones
- Foundation Created/Led

NIH RESEARCH GRANTS

2017

- Foundation publishes the *Living with Sjögren's: Summary of Major Findings*, which examined the variety and severity of symptoms Sjögren's patients experience living with the disease
- Foundation launches (STEP) to train clinical trial investigators in Sjögren's
- Foundation launches an online community through Smart Patients platform
- Tear Film Ocular Society (TFOS) Dry Eye Workshop (Dews) II is published, which included findings by 150 international clinicians to increase understanding of dry eyes and create a path forward for dry eye clinical trials

2016

- New ACR EULAR classification criteria for Sjögren's are published
- Foundation publishes *Clinical Practice Guidelines for Systemic Manifestations in Sjögren's Patients*
- Foundation publishes *Clinical Practice Guidelines for Oral Management: Caries Prevention in Sjögren's*
- Foundation welcomes Carrie Ann Inaba from ABC's "Dancing with the Stars" as its National Awareness Ambassador
- Foundation launches "This is Sjögren's" Campaign to bring awareness to the systemic nature of the disease
- HarmonicSS is launched in a major international effort to improve stratification and treatment of Sjögren's
- First *Living with Sjögren's* patient survey conducted

2015

- Foundation publishes the first ever *Clinical Practice Guidelines for Sjögren's Ocular Management*
- Pediatric rheumatologists from around the world form the Childhood Sjögren's Workgroup
- First major clinical trial completed for systemic therapy (rituximab) in the U.K. with others entering phase 2 for 1st time

NIH RESEARCH GRANTS

65	NIH research grants in Sjögren's
79	NIH research grants in dry eye
35	NIH research grants in oral manifestations of Sjögren's/ salivary glands

2018

- The Foundation surpasses 5-Year Breakthrough Goal and reports the average diagnosis is 2.8 years
- Foundation launches the redesigned Foundation's Walk program to "Walk for Sjögren's – Celebrating our Strength"
- Foundation leads, mentors, and supports 25 international Sjögren's groups as part of the International Sjögren's Network
- The Foundation expanded the Clinical Trials Consortium, which dramatically increased enthusiasm for the development of a systemic therapy for Sjögren's (25 therapies evaluated)
- Foundation for the NIH Biomarkers Consortium Sjögren's Working Group established



2019

- NECESSITY (**NEw Clinical Endpoints** in primary Sjögren's **Syndrom**e: an **I**nterventional **T**rial based on stratify**ING** patients) launched; funded by the European Innovative Medicines Initiative

2020

- Renamed the Foundation to the **Sjögren's Foundation** and redesigned all materials to drop the words "syndrome", "secondary", and "primary" to more accurately reflect the seriousness of the disease

NIH RESEARCH GRANTS

92	NIH research grants in Sjögren's
152	NIH research grants in dry eye
41	NIH research grants in oral manifestations of Sjögren's/salivary glands

Sjögren's ("SHOW-grins") is a systemic autoimmune disease that affects the entire body.



40 Years of Sjögren's Progress

KEY

- Major Milestones
- Foundation Created/Led

NIH RESEARCH GRANTS

2022

- New Office of Autoimmune Disease Research is created under the NIH Office of Research on Women's Health
- New research grant awarded by the Foundation to study dysautonomia in Sjögren's
- *State of Sjögren's*, professional conference highlighting multidisciplinary care is launched
- First Pri-Med CME course on Sjögren's for primary care professionals facilitated
- Foundation successfully leads an international nomenclature initiative with clinicians and patients to rename Sjögren's syndrome to Sjögren's disease

2021

- New *Living with Sjögren's* national survey launched by Foundation with Harris Poll has over 3,600 respondents
- First partnership for major research grant with another non-profit (on dysautonomia in Sjögren's)
- ICD-10 Coding for Sjögren's expanded to include 7 new categories and no longer identified as "sicca syndrome"
- FNIH Accelerating Medicines Partnership® Autoimmune & Immune-Mediated Diseases (AMP® AIM) research program includes Sjögren's. The Foundation commits funds to be on the Steering Committee
- *Pulmonary Clinical Practice Guidelines* published by the Foundation in CHEST Journal



2023

- FNIH AMP® AIM research program enrolls first patient
- Clinicians and researchers adopt the use of Sjögren's disease in projects and articles
- Foundation increases funding for annual grants and adds two new grant mechanisms, Dynamic and Partner grants, to attract researchers
- Second Pri-Med CME course on Sjögren's for primary care professionals facilitated
- First PRIME CME course on Sjögren's for Rheumatologists facilitated
- First Foundation Dynamic Grant awarded to Oklahoma Medical Research Foundation to expand the genome project
- 19 companies with 22 potential systemic therapies for Sjögren's are in clinical trial
- Additional systemic therapies launched for Phase 3 clinical trials in Sjögren's



NIH RESEARCH GRANTS

103	NIH research grants in Sjögren's
139	NIH research grants in dry eye
43	NIH research grants in oral manifestations of Sjögren's/salivary glands



(301) 530-4420

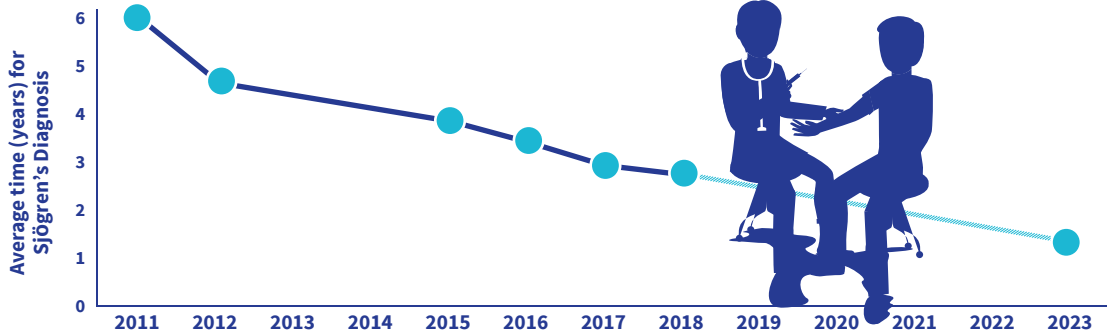
10701 Parkridge Blvd., Suite 170
Reston, VA 20191

www.sjogrens.org

5-Year Breakthrough Goal – Reduce time to diagnosis by 50%.

AVERAGE TIME FOR SJÖGREN'S DIAGNOSIS

2011	6 years
2012	4.7 years
2015	3.9 years
2016	3.5 years
2017	3 years
2018	2.8 years





Sjögren's Foundation *In Action!*

Coverage of Over-the-Counter Preventive Services

The Foundation is proud to continuously advocate for our patients and raise awareness for Sjögren's, so when opportunities arise to improve healthcare for our patients— we take action! We had an opportunity to answer an information request from the Administration (the Department of the Treasury, the Department of Labor, and the Department of Health and Human Services) that would demonstrate the need for a prescription to over-the-counter (OTC) switch for several products as well as coverage of OTC preventive services.

The Foundation emphasized the impact that expanding the list of OTC preventive products would have on the health equity, cost, and overcoming of barriers for women as well as racial and ethnic minorities. By declaring current prescription preventive products as OTC, this would increase access to much needed preventive care and avoid the high cost and delay of care caused by needing a prescription.

We took this opportunity to educate the Administration on the needs of Sjögren's patients and their dependency on a combination of prescription and OTC products to manage disease symptoms and improve their quality of life. In many instances, OTC products are key to preventing and slowing the progression of clinical manifestations, including dry mouth and dry eye, in Sjögren's.

A list of current prescription dry mouth and dry eye products with proven clinical safety as well as other products that are similar to currently approved OTC

products was included in our letter to the Administration. Since access is not the only barrier, we made the Administration aware that high cost of OTC products as well as their lack of insurance coverage also provide a barrier for Sjögren's patients. These barriers can prohibit patients from frequent use of preventive products, which can lead to poorer quality of life and significant consequences.

Overall, we hope this support will improve access and reduce the cost of OTC products and services that are necessary for preventive care in Sjögren's.

Excerpt from the "Request for Information; Coverage of Over-the-Counter Preventive Services" sent to the Administration:

"Even though this letter is to support prescription drugs coming to OTC for greater access, we would be remiss if we did not highlight that access to OTC products, due to the expense of so many needed products, is still incredibly expensive for Sjögren's and many reduce their use and opt for a poorer quality of life due to cost. Additionally, many office procedures that help ameliorate dry eye and dry mouth are not covered by insurance. Sjögren's patients face serious consequences to their health when they cannot access all the tools available on the market. We hope that all these aspects of disease management will be discussed as the opportunity arise so patients can afford their medications, whether prescription or OTC, to increase their quality of life and slow progression of the disease (which then becomes debilitating and more expensive)." ■

Clinician's Corner: Dry Eye and Sjögren's



*Esen K. Akpek, MD
Bendann Professor of Ophthalmology
Director, Ocular Surface Clinic
The Wilmer Eye Institute*

Dry eye is arguably the most common clinical feature of Sjögren's and likely the most underappreciated. Sjögren's-related dry eye (Sjögren's-DE) is a progressive form of inflammatory ocular surface disease, not just lack of moisture. If not addressed timely and adequately, dry eye can lead to permanent damage to the tear secreting glands that produce the three components of tear film: mucin, aqueous layer and meibum. Once destroyed, these glands cannot be restored. The result could be loss of vision due to corneal complications. Worsening of Sjögren's-DE in the winter is common due to a decrease in relative humidity of the air. Forced-air heating is especially drying.

Unfortunately, the patient may not always recognize the worsening of dry eye, due to frequent association of decreased corneal sensitivity to pain. Particularly the individuals with worse dry eye may only notice fluctuation or blurring of vision due to corneal epithelial erosions which represent tiny, microscopic scratches. Therefore, it is important to see a qualified eye care provider to have a detailed ocular surface evaluation, particularly staining using vital dyes even in the absence of symptoms.

In order to cope with dry eye in the winter, the best approach is to regulate the indoor humidity and keep humidity at around 60%. In addition, the below tips can be helpful:

- Warm compresses with lid scrubs using baby shampoo or commercially available scrubs can improve meibum quality. Meibum is the tear film layer that traps the moisture on the corneal surface by restricting the evaporation of tears.
- Remain well-hydrated by drinking adequate amounts of water daily. Limit the intake of natural diuretics, such as alcohol or caffeine.
- Do not use too many drops of over-the-counter artificial tears to compensate for the worsening dryness. Overuse of eye drops will only wash off the good ingredients from the tear film. Switch to gels or ointments if the symptoms are not improved after applying eye drops four times daily. Newly approved intranasal tear stimulant bypasses the ocular surface and will not disrupt the homeostasis of the tears.
- Take frequent breaks to rest your eyes when doing prolonged visual activities such as reading, driving, working on the computer, or watching TV.
- Limit contact lens usage and take proper care of your contacts. Do not sleep in contacts.
- Wear protective, tightly fitting goggles when doing outdoor activities to limit eye exposure to dry air.
- If your eyes feel dry and uncomfortable, or if you have excessive tearing, blurred vision, or light sensitivity— schedule a visit with a qualified eye care provider. ■



Navigating Dental Coverage: A Guide for Sjögren's Patients to Demonstrate Medical Necessity

Danielle Brown, My Smile Insured

Sandy Buechler, ImpleMed Dental Resources

Living with Sjögren's disease brings a unique set of challenges, and your dental health requires special attention. Dental treatments for Sjögren's patients can be extensive and expensive, making it essential to explore avenues for financial support, including leveraging medical insurance coverage. This article aims to provide steps for Sjögren's patients to demonstrate medical necessity and increase the likelihood of having their dental treatments covered by medical insurance.

Document Your Symptoms

Begin by keeping a detailed record of your Sjögren's symptoms, especially those affecting your oral health. Note instances of dry mouth, difficulty swallowing, oral infections, and any other symptoms that impact your dental well-being. This documentation will serve as crucial evidence when explaining the medical necessity of specific dental treatments.

Consult with Your Rheumatologist

Your rheumatologist plays a pivotal role in establishing the connection between your Sjögren's and dental issues. Schedule an appointment to discuss your symptoms and the impact on your oral health. Request a written statement from your rheumatologist, outlining the medical necessity of certain dental procedures in managing your Sjögren's symptoms.

Collaborate with Your Dentist

Work closely with your dentist to establish a treatment plan tailored to your specific needs. Ensure that your dentist is aware of the medical intricacies associated with Sjögren's. Request a written treatment plan that highlights the necessity of each procedure in managing your oral health within the context of your autoimmune condition.

Obtain Supporting Documentation

Gather all relevant medical records, test results, and imaging related to your Sjögren's. This documentation will provide a comprehensive overview of your condi-

tion and reinforce the medical necessity of your dental treatments. Include any reports that showcase the impact of your symptoms on your oral health.

Submit Preauthorization Request

Contact your medical insurance provider to inquire about their preauthorization process for dental treatments related to Sjögren's. Submit a preauthorization request that includes all the documentation gathered, emphasizing the medical necessity of the proposed dental procedures. This step can significantly increase the chances of insurance coverage.

Appeal if Necessary

In the event of a denial, don't be discouraged. Insurance companies may initially deny coverage, but you have the right to appeal their decision. Gather additional supporting documents and work with your healthcare providers to strengthen your case. Clearly articulate how the dental treatments are integral to managing your Sjögren's symptoms and maintaining overall health.

Seek Assistance from Patient Advocacy Groups

Reach out to patient advocacy groups, such as the Sjögren's Foundation, for support and guidance. They may have resources and information on navigating insurance challenges specific to Sjögren's patients. Their expertise can be invaluable in helping you present a compelling case to your insurance provider.

Conclusion

Successfully navigating the complexities of obtaining medical insurance coverage for dental treatments related to Sjögren's requires diligence, collaboration with healthcare professionals, and a strong emphasis on demonstrating medical necessity. By following these steps and advocating for yourself, you can increase the likelihood of receiving the financial support needed to obtain comprehensive dental treatment and optimal oral health in the face of Sjögren's challenges. ■



Conquering Sjögren's One Step at A Time! Join us in a Spring Walk as we celebrate 40 years of Progress!

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

Spring 2024 – Walk for Sjögren's Calendar

March

Virtual Southwest Walk for Sjögren's

Saturday, March 16, 2024

Virtual Southeast Walk for Sjögren's

Saturday, March 16, 2024

April

Virtual Mid-Atlantic & National Walk for Sjögren's

Saturday, April 13, 2024

May

LIVE Tri-State Walk for Sjögren's in Philadelphia, PA

Saturday, May 11, 2024

June

NEW LIVE Midwest Walk for Sjögren's in Madison, WI

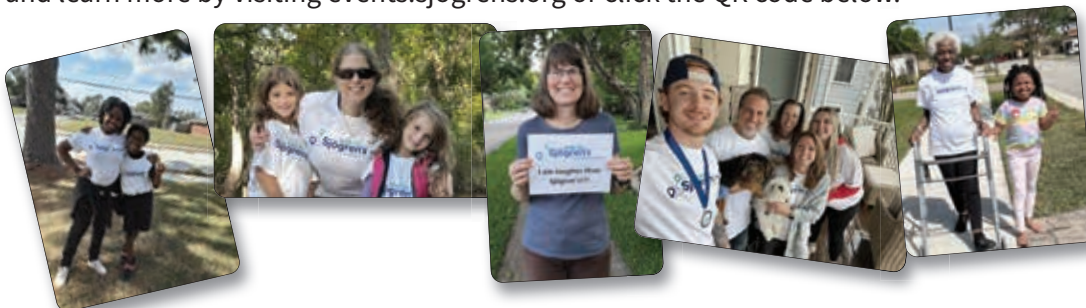
Saturday, June 1, 2024

Virtual Colorado Walk for Sjögren's

Saturday, June 22, 2024

events.sjogrens.org

Congratulations and thank you to our Walk for Sjögren's Stars in 2023! They contributed to the success of a Walk for Sjögren's with their outstanding outreach and by raising more than \$1,000 each. View our 2023 Stars and learn more by visiting events.sjogrens.org or click the QR code below.



You Stood Up!

My Cause My Cleats

Cleats 2021



Cleats 2022



Every year, the National Football League (NFL) players and coaches participate in a fund-raising campaign called My Cause My Cleats. Players and coaches choose a cause that is close to their heart and attributes to their passion on the field. Players and coaches wear their causes on their feet in cleats and shoes, respectively.

Lunda Wells, the tight-end coach for the Dallas Cowboys, chose to represent the Sjögren's Foundation for the third year in a row. He wore shoes supporting the Sjögren's Foundation in honor of his wife, Tiffany, and all other Sjögren's patients. This year, Ari Solomon designed Coach Wells shoes along with over 300 cleats for the campaign. The My Cause My Cleats gameday for the Dallas Cowboys was on November 30th, 2023, where they won against the Seattle Seahawks. Check out Coach Lunda Wells with his current and past designed shoes for My Cause My Cleats. ■



Cleats 2023





IN MEMORIAM

In Memory of Betty Adams

Laura Boycourt

In Memory of Carmen Eva Ayala

Marilyn Cristoff-Gonzalez

In Memory of Lois Berenato

Ann and Lisa Hall

In Memory of Elizabeth "Lee" Boebel

Jeffrey Apple

Sandra Derbin

Kathy Fleshman

Panos and Debi Kalaritis

Ekatarene Lawrence

Jesse Palmer

Charles Roberts

Karen Santolupo

Dominick Summa

Mary Tatum

In Memory of Jean Buckley

Deborah Waters

In Memory of Heidi Ann Burke

John Burke

In Memory of Patricia Burns

Patricia Brown

In Memory of Louise Calaway

Laura Calaway

In Memory of

Karen Elizabeth Cannon

Mary Dykeman

Anne Flannery

In Memory of Mary Ellen Cantabene

James Seils

In Memory of

Dennis Ming-Hong Chen

Dennis Ming-Hong Chen Foundation

In Memory of

Cynthia Cristabel Conliffe

Patricia Engel

In Memory of Geraldine C. Courcy

Joseph and Genevieve Magliari

In Memory of Karen Desberg

Mary Crawford

Nancy Hellner

Sarah Simon

In Memory of Grace DeSilvio

Antoinette Schielein

In Memory of Janet M Doyle

Denise Cotton

In Memory of Sharon Dutcher

Jessica Levy

Carole Pierie

In Memory of Florence Fox

Janis Fox

In Memory of Marilyn Fusco

Kathleen Schneider

In Memory of Carol Ann Gergel

James Gergel

In Memory of Jan Gordon

Kevin McCaffrey

In Memory of Alice Glupe

Karin Blaney

Margaret WrenGlupe

In Memory of John Greenspan

Caroline Shiboski

In Memory of Ray Grimes

Margaret Bailey

In Memory of Carolyn Hall

Edna Sutton

In Memory of Betty Hardgrave

Kathy Sivils

In Memory of Nancy Hargrave

Elizabeth D'Angelo

In Memory of Linda Kay Harrell

Janette Martin

In Memory of Martha C. Hernandez

Maria Eugenia Hernandez

In Memory of Mildred Higa

Shannon Brown

Mildred Higa

In Memory of Susan Kilgore Hill

Frank Hill

In Memory of My Mom Ida

Mercedes Dombi

In Memory of Shirley Kaplan

Rochel Kaplan

In Memory of Bonnie Litton

Linda Phillips

In Memory of Phyllis McCardle

William Locke

Brian Locke

In Memory of Charlene McCuistion

Pamela Mitchell

In Memory of Betty McMinn

Julie McMinn

In Memory of Waneta Mehaffey

William and Kathleen Balcom

In Memory of Maria Robles Mijangos

Christine Judd

In Memory of Brenda Mills

Jose Gomez

In Memory of Marie Olson

Debbie Appleton

In Memory of Jeannine Pappous

Carol Ann Ormes

In Memory of Jennifer Paragano

Gerald Miller

Katie Tarasov

In Memory of Ron Parker Jr.

Kathy Hosea

In Memory of Patsy Patricelli

Vincent Patricelli

In Memory of Norma Jean Peevler

Kathy Cowart

In Memory of Joan Polcari

Elizabeth and Matthew Renz

In Memory of

Carol Jean Mason Richards

Richelle Becker

In Memory of Ruth Rotenberg

Steve and Lisa Shapiro

In Memory of Vivian Sangil

Amy Semanscin

In Memory of Liesbeth Schoen

Marty Ehrlich

In Memory of Ella Whitten Sisler

Darla Rae

Joe Sisler

In Memory of

Linda Patterson Slappey

Tony Patterson

In Memory of

Sabrina Jean Spector Smith

Steve and Lisa Shapiro

In Memory of Betsy Jester Squaires

Connie Holmes

In Memory of Jennifer L. Stark

Nancy Visocki

In Memory of Vivian Stark-Curry

Marifran Mazza

In Memory of Nita Sudbury

Veronica Bird

In Memory of Freida VanMeter

Brenda Brocksmith

Marilyn Hannah

In Memory of Barbara Wallin

Kathleen Malone

In Memory of Douglas West

Susan West

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Ann Chipman

Warren Harless

Janice Moore

Steven Myers

Sean Rife

Jackson Salvant

John Speegle

Paul Springman

Linda White

In Memory of Jeri Jo Wischmann

Camille Johnson

In Memory of Kellie Young

Yoko Imamura

In Memory of Joan M. Zaleta

Penny Zaleta

In Memory of Shirley Ziff

Catherine Ziff

In Memory of Vijayamma

Manoj Pillai

IN HONOR

- In Honor of Sharon K. Adley**
Lyle Adley-Warrick
- In Honor of Grace Aquilino**
JeanMarie Panagakos
- In Honor of AnnMarie Beaulieu**
Lynn Beaulieu
- In Honor of Ina Jean Begoun**
Richard Begoun
- In Honor of Nancy Beja**
Nancy Kaufmann
- In Honor of Patricia Benolkin**
Barbara Trebisovsky
- In Honor of Janine Bensman**
John Bensman
- In Honor of Sue Bockelman**
Barbie Cole
- In Honor of Martha R. Bragdon**
Martha Bragdon
- In Honor of Jennifer Bromberg**
Robert Wald
- In Honor of Wendy Budd**
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Christopher Campbell
- In Honor of Stefanie Campbell**
Ellen Campbell
- In Honor of Heather Chamberlain**
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- In Honor of Linda Champion**
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- In Honor of Dorothy Cleary**
John Cleary
- In Honor of Nancy Crabbe**
Pete Giacopelli
- In Honor of Lisa Crum**
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- In Honor of Maurine Daniels**
John Daniels
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Heather Donovan
- In Honor of Deborah Dudley**
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- In Honor of Anne Economou**
Gretchen Shelton
- In Honor of Bonnie Flagg**
Frances Gamble
- In Honor of Yolanda Gales**
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- In Honor of Robert I. Fox, MD, Ph.D**
Charles and Teresa Grenier
Henry J Fox Charitable Trust
- In Honor of Teresa and Charlie Grenier**
Janet Enger
- In Honor of Wendy and Dave Grube**
Pamela McNamara
- In Honor of Cecile Haley**
Alvin Haley
- In Honor of Heida Harris**
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- In Honor of MaryAnne Hines**
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Maryellen Kebbel
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- In Honor of Jessica Levy**
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- In Honor of Lari Lopp**
Isabelle DesFontaines
- In Honor of Chris, Teri, and Dakota Makulec**
David Makulec
- In Honor of Lucy March**
Judy Rabinovitz
- In Honor of Paula Markowitz**
Theresa and Lee Markowitz
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Charles and Teresa Grenier
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- In Honor of Marge Yetman**
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- In Honor of Rose Young**
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- In Honor of Ashley Young**
Brenda Brocksmith
- In Honor of Alexandra and Charlene**
Liz Hamel
- In Honor of Behnaz**
Kathleen Kelley-Hoppe
- In Honor of Kristi**
Laurette Payette
- In Honor of My Daughter**
Kathleen Kinzeler
- In Honor of Our Lord And Savior, Jesus Christ!**
Elizabeth Panico-Garrison
- In Honor of Williams-Marshall Family**
Jacqueline Baptiste
- In Honor of The Hermans**
Edythe McPherson



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



Sjögren's Foundation
National Patient Conference 2024

Join us for the 2024 Sjögren's Foundation National Patient Conference!

Friday, April 5, 2024 12:30-5pm (Eastern Time)

Saturday, April 6, 2024 12:30-5:30pm (Eastern Time)

Mark your calendars for the Sjögren's Foundation's premier patient education event! This year's National Patient Conference will be a two-day virtual event, once again allowing for worldwide access to credible Sjögren's experts.

We are excited to share that we will be moving to a NEW and UPGRADED virtual platform for this year's conference! While you can expect to learn from Sjögren's experts who will share content rich presentations with time for Q & A, you can also enjoy more patient-to-patient interaction and direct exhibitor contact during dedicated conference time. Our all-new Sjögren's patient communities, each with a different focus area, will allow patients to choose the communities in which they want to come together to connect, share, and learn from each other. In addition, our new virtual exhibitor booths will allow you access to company resources and/or product literature as well as the ability to interact with company representatives via chat. You have come to count on the Sjögren's Foundation as your credible Sjögren's resource and we look forward to bringing you the same high-quality conference, now with even more pathways to help you become educated and empowered to manage your Sjögren's!



Check our website for more updates as we work on finalizing our agenda <https://sjogrens.org/get-involved/find-an-event/national-patient-conference>

