

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





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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 (**NE**w **C**linical **E**ndpoints in primary Sjögren's **S**ndrome: an **I**nterventional **T**rial based on stratify**Y**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.



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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



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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

