

ANNUAL REPORT

Sjögren's Syndrome Foundation 2018 – 2019 Annual Report



Year in Review

To Our Supporters:

For the past 35 years, the Sjögren's Syndrome Foundation (SSF) has been humbled and honored to support Sjögren's patients. The mantra of our founder, Elaine Harris — “founded by a patient, for patients” — remains the center of what we do by ensuring that the patient voice is never lost in our efforts.

The SSF saw great results in 2018/2019 from our efforts to help Sjögren's patients. This includes surpassing our Breakthrough Goal to reduce the time of diagnosis by 50% in 5 years; writing and publishing the first-ever clinical practice guidelines on how to treat and manage Sjögren's patients with Phase 2 currently underway; our work in getting closer to developing a drug to treat all Sjögren's symptoms; and efforts to increase awareness and educate healthcare professionals to ensure Sjögren's is not forgotten in the research, pharmaceutical or physician communities.

As the only national non-profit focused on conquering Sjögren's, we continue to be a patient oriented organization focused on serving our members as well as the source for Sjögren's information for all stakeholders – including patients, families and healthcare providers.

We are very proud of our accomplishments which you will see below. You will also find our Federal 990 Tax Return and Audited Financial Report available online at www.sjogrens.org or you can contact us at (800) 475-6473 to be mailed a copy of the documents.

On behalf of the SSF, we want to thank you for investing in us, for volunteering with us, and for sharing our passion and vision for strengthening OUR Sjögren's community.

The SSF Board of Directors

Board of Directors



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Vice President of Scientific & Medical Affairs

Kathy Ivory

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SSF Mission

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

SSF Vision

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

SSF 2018/2019 Priorities

The SSF's Board of Directors adopted the following priorities for the past year:

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

On the following pages, you will see our goals under each priority and how the SSF did against those goals as well as our financials for both income and expenses. We hope you will be as excited as we are about our successes this past year.

**The SSF supported
patients and their
loved ones by...**

The SSF supported patients and their loved ones by...

💧 Expanded our communication with our constituents

- Continued to develop a quality patient newsletter with up-to-date information on pressing topics and patient tips.
 - 2018/2019 newsletter distribution was more than 100,000
- Continued to send the “*Sjögren’s Snapshot*”, a regular quarterly e-mail communication to ALL non-members about the impact the SSF is making
 - Delivered quarterly to more than 40,000 non-members
- Continued to update our “*Conquering Sjögren’s*” blog
 - Two (2) blog posts published monthly on various topics
 - Most popular blog posts included “What is a Sjögren’s flare?” (28,030 views) and “15 Types of Sjögren’s Fatigue” (19,963 views)

The SSF supported patients and their loves ones by...

- **Expanded our communication with our constituents (cont.)**
 - Continued providing quarterly talking points for Support Group Leaders
 - Talking points were sent to Support Group Leaders covering various topics which included research, SSF news and/or product promotion to then share with the attendees of the support group
 - Expanded the use of our “Town Hall” meetings with various constituent bases including new members and donors
 - Hosted two (2) town hall meetings for new members with each having more than 100 RSVPs to attend
 - Held a town hall meeting for major donors to discuss the impact of their gift
 - Held three (3) “face-to-face” town hall meetings during the year

The SSF supported patients and their loves ones by...

💧 Launched a new Sjögren's Care Community (SCC) pilot program in one city / community

- Officially launched SCC in Boston, Massachusetts
- Kickoff was held in Fall 2018 at Research Reception in Boston
- Continue to recruit physicians and phone support volunteers

💧 Ensured our online patient experience is helpful

- Developed guidelines for Facebook pages for local support groups
- Continued to offer clinical trial information on website
 - Information on open clinical trials in Sjögren's is on www.sjogrens.org
- Researched new and modern virtue-mart for product sales

The SSF supported patients and their loved ones by...

💧 Continued to offer patient services

- Conducted two-day National Patient Conference
 - National Patient Conference was held in Boston, MA area on April 5th & 6th
 - There were over 500 attendees (*first time ever conference was sold out*)
 - There were 11 exhibitors, 12 speakers and 4 patient speakers
- Continued to manage 64 support groups in the United States
 - New groups were started in Houston, ST. Clair, MI and San Antonio
 - SSF offered three virtual support groups for:
 - » Women in their 20s & 30s
 - » Men with Sjögren's
 - » Pediatric Sjögren's (children 19 & under and their parents)
 - Annual Support Group Leader training was held in May 2019

The SSF supported patients and their loved ones by...

💧 Continued to offer patient services (cont.)

- Continued to serve as the lead organization for the International Sjögren's Network of Sjögren's patient groups
 - SSF led, mentored and supported 28 international Sjögren's groups
 - International Sjögren's Directory is housed on www.sjogrens.org
 - Steven Taylor, SSF CEO and Kathy Hammitt, SSF Vice President of Medical & Scientific Affairs, regularly meet with these groups at meetings such as:
 - » The European League Against Rheumatism (EULAR)
 - » The International Symposium on Sjögren's (ISSS)
 - » The NECESSITY project
 - » HarmonicSS

(to learn more about these international groups/coalitions/projects, contact the SSF offices)

**The SSF educated
healthcare
professionals by...**

The SSF supported healthcare professionals by...

💧 Led and facilitated discussions and presentations on changing ICD coding for Sjögren's

This initiative was undertaken with the recognition that the existing ICD-10 (*International Statistical Classification of Diseases and Related Health Problems, 10th revision*) code for Sjögren's (M35.0, Sicca syndrome [Sjögren]) does not represent the disease and contributes to misinformation and confusion. Changes to the code will benefit providers, investigators, researchers, insurers, and, of course, patients, and address key complications of Sjögren's that were not included in the current code.

The current ICD-10 code creates confusion, contributes to misinformation and is potentially detrimental to patients, whose diagnosis carries an incorrect label, which can influence subsequent difficulty with insurance reimbursement, clinicians, who may be unsure of how to best code the disease, study investigators and researchers, who may have trouble accurately identifying Sjögren's patients for clinical trials and data acquisition, and insurers, who grapple with inaccuracy, which can influence reimbursement to both patients and providers.

The SSF supported healthcare professionals by...

💧 Led and facilitated discussions and presentations on changing ICD coding for Sjögren's (cont.)

- The SSF assembled an advisory team of 14 multi-disciplinary experts (represented by a non-profit, a professional society, academia, industry, rheumatology, pediatric rheumatology, primary care, neurology, gastroenterology, pulmonology, nephrology, oncology, ophthalmology & oral medicine) to convene and collaborate on the best course forward. It was also co-sponsored by American College of Rheumatology (ACR).
- A proposal was submitted with suggestions for modifications to the code for Sjögren's (including 7 additional complications under listing)
- SSF staff and members of the advisory team presented twice before the Centers for Medicare & Medicaid Services (CMS) in Baltimore, MD in September of 2018 and again in April of 2019

The SSF supported healthcare professionals by...

💧 Led and facilitated discussions and presentations on changing ICD coding for Sjögren's (cont.)

- In partnership with ACR, the SSF was excited to announce that it had led a successful effort to revise the U.S. ICD-10 code for Sjögren's – a major victory for the Sjögren's community. These changes are expected to be folded into the ICD-11 Code for international use and slated to take effect in October 2020.

TABULAR MODIFICATIONS

M35 Other systemic involvement of connective tissue

Revise	M35.0	Sicca syndrome [Sjögren] <u>Sjögren syndrome</u>	New code	M35.05	Sjögren syndrome with inflammatory arthritis
Add		Sicca syndrome	New code	M35.06	Sjögren syndrome with peripheral nervous system involvement
Add		Excludes1: Dry mouth, unspecified (R68.2)	New code	M35.07	Sjögren syndrome with central nervous system involvement
Revise	M35.00	Sicca <u>Sjögren</u> syndrome, unspecified	New code	M35.08	Sjögren syndrome with gastrointestinal involvement
Revise	M35.01	Sicca <u>Sjögren</u> syndrome with keratoconjunctivitis	New code	M35.0A	Sjögren syndrome with glomerular disease
Revise	M35.02	Sicca <u>Sjögren</u> syndrome with lung involvement	New code	M35.0B	Sjögren syndrome with vasculitis
Revise	M35.03	Sicca <u>Sjögren</u> syndrome with myopathy	New code	M35.0C	Sjögren syndrome with dental involvement
Revise	M35.04	Sicca <u>Sjögren</u> syndrome with tubulointerstitial nephropathy	Revise	M35.09	Sicca <u>Sjögren</u> syndrome with other organ involvement

The SSF supported healthcare professionals by...

- 💧 **Continued to look for ways to expand our relationship with ACR through the annual ACR Annual Meeting and other potential collaborations**
 - As previously mentioned, invited ACR to join SSF's ICD-10 Code initiative as co-sponsor
 - Participated in ACR initiative to develop reproductive health guidelines in rheumatic disease (*publication under review*)
 - Continued dialogue with ACR on SSF Clinical Practice Guidelines

The SSF supported healthcare professionals by...

- 💧 **Launched process for writing of the 5th Edition Sjögren's Book**
 - New book layout was developed by SSF staff and Dr. Dan Wallace, Editor
 - Working with nearly 60 experts/authors to complete new book
 - Final draft being presented to Oxford University Press in late Spring 2020
- 💧 **Continued to deliver a quality publication for healthcare professions (*Sjögren's Quarterly*)**
 - Conducted a reader survey with over 200 responses that found:
 - 99% of respondents find SQ somewhat or very useful
 - 64% said SQ is their primary source for information on Sjögren's
 - Produced 4x a year with a distribution in FY18/19 of nearly 30,000

The SSF supported healthcare professionals by...

💧 **Launched our Sjögren's Training & Educational Platform (STEP)**

- STEP officially launched in winter 2019
- One pharmaceutical company using it for their clinical trial and extremely pleased with the training
- The SSF is actively recruiting additional partnerships with numerous companies interested in STEP

💧 **Expanded the SSF “referral” program in rheumatologists offices through the Sjögren's Care Community**

- Continued to distribute our “referral” poster and tear-off sheets
 - Distributed over 2,500 in past two years
- Continued to receive phone calls as a result of this program

The SSF supported healthcare professionals by...

💧 Expanded outreach to additional specialists that treat Sjögren's utilizing Awareness Ambassadors

- A general packet was developed for Awareness Ambassadors to distribute to any specialists

💧 Continued work on phase 2 of SSF's Clinical Practice Guidelines

- Drafted clinical recommendations for first rheumatology / systemic topic (Pulmonary)
- Developed outline for two additional rheumatology/systemic topics (PNS and CNS) and executed literature search for one topic (PNS)
- Formed Topic Review Groups for final two additional rheumatology / systemic topics (Vasculitis & Lymphoma)
- Formed Topic Review Groups for three oral topics (Mucosal Management & Treatment, Use of Secretagogues, and Caries Restoration & Management)

The SSF supported healthcare professionals by...

💧 The SSF CEO, staff and board members attended numerous professional conferences which included:

- Food & Drug Administration (FDA) Center for Biologics Evaluation and Research (CBER) Science Symposium
- 9th American Association for Dental Research (AADR) Fall Symposium
- HarmonicSS international meetings
- National Health Council Meetings:
 - Health Leadership Conference
 - Chief Medical & Scientific Officers Conference
 - Washington Representatives Conference
- The International Association for Dental Research (IADR) / AADR Annual Conference
- EULAR Annual Conference

**The SSF served as the
voice for all Sjögren's
patients by...**

The SSF served as the voice for all Sjögren's patients by...

💧 Recruited committee to revamp and rewrite mission statement and new vision statement for SSF

- New mission and vision were developed and approved by SSF Board
 - **Updated Mission of the SSF:**
 - Support Sjögren's patients and their loved ones through education, resources and services
 - Provide credible resources and education for healthcare professionals
 - Serve as the voice for all Sjögren's patients through advocacy and awareness initiatives
 - Lead, encourage and fund innovative research projects to better understand, diagnose and treat Sjögren's
 - **New Vision Statement for the SSF:**
 - "To create a community where patients, healthcare professionals and researchers come together to conquer the complexities of Sjögren's"

The SSF served as the voice for all Sjögren's patients by...

💧 Engaged in consistent use of social media outlets

- Increased Facebook to over 49,000 likes; adding nearly 6,000 likes
 - 49,103 followers as of 7/1/2019 (43,546 in 7/1/2018)
- Increased Twitter followers to over 7,000
 - 7,032 followers as of 5/8/2019 (6,408 as of 6/2018)
- Increased Smart Patients subscribers to over 3,500
 - 3,108 subscribers as of 5/1/19 (2,862 as of 6/2018)
- Expanded use of LinkedIn and increase our following to nearly 500
 - 490 followers as of 7/1/2019 (314 as of 6/2018)
- Increased following on Pinterest to over 1,250
 - 1,323 followers as of 5/8/2019 with over 27,600 monthly views
- Increased following on Instagram to over 1,600
 - 3,706 followers as of 5/8/2019 with increase of 700+ just in April 2019

The SSF served as the voice for all Sjögren's patients by...


💧 **Formally changed the organization's name by dropping the word "syndrome"; Name changed from "Sjögren's Syndrome Foundation" to "Sjögren's Foundation"**

- Designed new logo for Sjögren's Foundation along with style guide to accompany changes
- All existing materials are being reviewed and updated to include the name change and style guide
 - All materials will be completed and available in the middle of FY20
- Began extensive redesign of www.sjogrens.org to enhance patient and visitor experience
 - Website will be completed and launched in the middle of FY20



The SSF served as the voice for all Sjögren's patients by...

💧 **Launched a new online media experience for patients and others called “*Exploring Sjögren's*”**

- A new  **YouTube** series that explores Sjögren's and the lives of Sjögren's patients
- Episodes were created to discuss Sjögren's as a disease and treatments and research for the disease as well as help increase awareness of the complexities of Sjögren's, knowing that each patient experiences the disease uniquely
- Episodes are hosted by SSF CEO Steven Taylor and feature Sjögren's patients and Sjögren's experts from around the country



<https://www.youtube.com/exploringsjogrens>

The SSF served as the voice for all Sjögren's patients by...

💧 Launched a new online media experience for patients and others called “*Exploring Sjögren's*” (cont.)

- Officially launched with first episode on April 30, 2019
 - The *Exploring Sjögren's* YouTube channel has over 1,650 subscribers
 - Episode 1 was titled “*What is Sjögren's*” and has over 20,000 views
- There were six episodes uploaded over a six week period
 - Episode 1: What is Sjögren's
 - Episode 2: Living with Sjögren's
 - Episode 3: Pregnancy & Sjögren's
 - Episode 4: Research & Sjögren's
 - Episode 5: Tips for Living with Sjögren's
 - Episode 6: Clinical Trials & Sjögren's



The SSF served as the voice for all Sjögren's patients by...

💧 Evaluated Awareness Ambassador program and made necessary changes for 2019/2020

- Awareness Ambassadors are now encouraged to visit any specialist in their area at any time
 - New general professional packet was developed to educate any specialist

💧 Relaunched Patient Support Volunteer (PSV) program and increased number of PSVs

- There are over 140 PSVs (including support group leaders) who volunteer to take calls from patients and be sources of information for Sjögren's
- Promoted program with ads in monthly newsletter and on SSF website to recruit new volunteers
- Piloted new ways to utilize PSVs through our Boston Sjögren's Care Community

The SSF served as the voice for all Sjögren's patients by...

- 💧 **Served on at least five (5) coalitions that help advance the SSF's mission and goals**
 - **SSF staff selectively chose numerous task forces and coalitions to work with which included:**
 - **Various National Health Council Initiatives/Coalitions:**
 - » Planning Committee for 2020 Health Leadership Conference
 - » Planning Committee for NHC Science of Patient Engagement
 - » NHC Medical Innovation Action Team
 - » NHC Policy Action Team
 - » SSF CEO Steven Taylor also serves as NHC Board of Director Chairperson
 - **National Coalition of Autoimmune Patient Groups**
 - **American College of Rheumatology's Coalition for Accessible Treatments**
 - **AADR's Friends of the NIDCR Patient Advocacy Council**
 - **Interagency Pain Research Coordinating Committee (IPRCC)**
 - **Surgeon General's Oral Health Report**
 - **National Institute of Arthritis & Musculoskeletal and Skin Diseases (NAMS) / NIH coalition**
 - **Childhood Arthritis & Rheumatology Research Alliance (CARRA)**

The SSF served as the voice for all Sjögren's patients by...

💧 Expanded April Awareness Month promotions

- Campaign was entitled *“Conquering the Complexities of Sjögren's”* and featured patients' stories promoted on all social media platforms
 - SSF chose 30 stories to share (one each day)
 - April 1st Facebook post announcing campaign received 148,900 impressions and first patient story post had 137,200 impressions
 - Nearly 7,000 followers updated their social media picture using the April Awareness Facebook Frame



The SSF served as the voice for all Sjögren's patients by...

💧 Expanded April Awareness Month promotions (cont.)

- Posted three blog posts in the month of April that had more than 52,000 views and more than 8,200 call to action links clicked

💧 Expanded World Sjögren's Day (July 23rd) promotions

- World Sjögren's Day was promoted on the SSF website, all social media outlets and on the SSF Blog
 - More than 2,300 people updated their Facebook & Instagram profile pictures with the World Sjögren's Day frame

💧 Promoted SSF's 35th Anniversary through all channels & social media

- SSF newsletter featured a cover story, history of SSF, 35 year timeline and interview with founder, Elaine Harris



SSF's 35th Anniversary

Sjögren's Syndrome Foundation Timeline 1983 – 2018



1983
■ Foundation was founded by Elaine K. Harris

1985
■ Foundation was incorporated

1989
■ First *Sjögren's Handbook* released
■ NIH held "The Many Faces of Sjögren's Syndrome" conference

1995
■ First SSF Student Fellowship awarded

1998
■ April declared Sjögren's Awareness Month by Congress

1999
■ Fire destroys SSF office (Jericho, NY)

2001
■ First SSF National Patient Conference (Los Angeles)
■ SSF headquarters moved to Bethesda, Maryland
■ First time Sjögren's was included in Congressional Appropriations language

2005
■ July declared Dry Eye Month by Congress
■ SSF officially raised over \$1 million
■ SSF Lymphoma Workshop held

2006
■ SSF hosts ISSS
■ *Sjögren's Quarterly* first published

1991
■ First SSF testimony before a Congressional Committee
■ First SSF Research Grant made

1986
■ First International Symposium on Sjögren's Syndrome (ISSS) (Copenhagen, Denmark)

2002
■ American European Diagnostic Criteria published

1984
■ *The Moisture Seekers* newsletter first published

■ Restasis® approved by the FDA
■ Sjögren's Syndrome Outcome Measures Workshop held by the SSF
■ SSF helped secure NIH funding for to get funding for an international clinical alliance and registry based at UCSF to gather data and serum and tissue samples from Sjögren's patients.
■ Steven Taylor started as SSF CEO

2004
■ First Sjögren's Walkabout
■ NIH International Sjögren's Syndrome Registry begins accepting patients launched at University of California at San Francisco (UCSF) with the award of a five-year \$11.9 million grant

2010
■ First World Sjögren's Day
■ SSF first partnership with American College of Rheumatology (ACR) for Student Fellowship Award Program

2009
■ SSF unveiled newly designed website
■ Team Sjögren's Marathon & Half-Marathon Training program created

2008
■ SSF holds Research Reception at USC
■ Social Security Disability includes Sjögren's
■ SSF officially raises over \$2 million

2007
■ First Sip for Sjögren's event
■ NIH Funded Research Project: Identification of Biomarkers in Sjögren's

2011
■ "Bold Blue Day" Program first started
■ SSF Launches Awareness Ambassador program
■ SSF Medical & Scientific Advisory Board launch Clinical Practice Guidelines
■ SSF wins Telly Award for patient education video "Sjögren's Syndrome: A Place to Begin"
■ SSF launched 5-Year Breakthrough Goal: "To shorten the time to diagnose Sjögren's by 50% in five years!"
■ SSF Blog Conquering Sjögren's is first published
■ 4th edition of the Sjögren's Syndrome Handbook released
■ The average time to diagnosis Sjögren's is over 6 years

2012
■ SSF Funds \$1.5 Million in Sjögren's Research
■ SSF welcomed Shannon Box, member of the U.S. National Women's Soccer Team & Olympic gold medalist, as the Honorary Walkabout Chairperson
■ Steven Taylor, SSF CEO, testified before the Subcommittee on Oversight of the House Committee on Ways and Means
■ New research showed that it takes an average of 4.7 years to diagnose Sjögren's

2014
■ SSF creates Clinical Trials Consortium (CTC) to increase the availability and accessibility of therapies for treating Sjögren's
■ The SSF supports 17 international Sjögren's groups as part of the International Sjögren's Network
■ SSF co-hosts Sjögren's criteria meeting at ISSS in Japan
■ 26 Patient Education Resource Sheets are published on the SSF website

2013
■ SSF partners with LAM/RLDC clinics to include treatment of Sjögren's pulmonary patients
■ SSF reaches 10,000 Facebook "Likes"
■ Team Sjögren's California officially raises \$100,000 for the SSF
■ "Faces of Sjögren's" website launched for patients
■ Venus Williams steps up as the SSF Honorary Chairperson of our Sjögren's Awareness Ambassador Program

2015
■ SSF publishes the first ever *Clinical Practice Guidelines for Sjögren's Ocular Management*
■ The average time to diagnosis Sjögren's is reduced to 3.9 years
■ Pediatric rheumatologists from around the world begin to form the Childhood Sjögren's Workgroup

2016
■ New classification criteria for Sjögren's is published
■ SSF publishes *Clinical Practice Guidelines for Systemic Manifestations in Sjögren's Patients*
■ SSF publishes *Clinical Practice Guidelines for Oral Management: Caries Prevention in Sjögren's*
■ SSF welcomes Carrie Ann Inaba from ABC's "Dancing with the Stars" as our National Awareness Ambassador and Spokesperson
■ SSF launches "This is Sjögren's" Campaign
■ Wake Up, Koala!, a puzzle game/App for iOS and Android devices, is developed by students at Bradley University
■ HarmonicSS is launched in a major international effort to improve stratification and treatment of Sjögren's
■ The average time to diagnosis Sjögren's is reduced to 3.5 years

2017
■ The average time to diagnosis Sjögren's is reduced to 3 years
■ The SSF leadership and volunteer physicians started phase 2 on Rheumatology and Oral Clinical Practice Guidelines
■ SSF publishes the *Living with Sjögren's: Summary of Major Findings*. Conducted by Harris Poll on behalf of the SSF it examined the variety and severity of experiences patients have with Sjögren's and the impact it has on their quality of life
■ Launches the first-ever online platform (STEP) to train clinical trial investigators in Sjögren's
■ SSF launches *Smart Patients*, an online Sjögren's community
■ SSF reaches over 40,000 Facebook "Likes"

2018
■ The SSF surpasses 5-Year Breakthrough Goal and reports the average diagnosis is 2.8 years
■ SSF office moves to Reston, VA
■ Over 35 Patient Education Resource Sheets are published on the SSF website
■ SSF launches the redesigned SSF's Walk program to "Walk for Sjögren's - Celebrating our Strength"
■ SSF leads, mentors and supports 25 international Sjögren's groups as part of the International Sjögren's Network
■ The SSF expanded our Clinical Trials Consortium, which dramatically increased enthusiasm for the development of a systemic therapy for Sjögren's (25 therapies currently being evaluated for potential)

35
Years
Strong

**The SSF led,
encouraged and
funded research by...**

The SSF led, encouraged and funded research by...

💧 Continued efforts with the SSF's Clinical Trial Consortium

The Clinical Trial Consortium (CTC) is the international initiative of the SSF whose mission is to increase the availability and accessibility of therapies for treating Sjögren's. Since its inception, the CTC has focused on supporting and promoting objectives that facilitate successful design of clinical trials; increasing industry partnerships with the SSF; and engaging in dialogue with government agencies that oversee drug approval.

The SSF continues to expand our efforts and is working with 11 pharmaceutical companies looking to develop potential therapies for Sjögren's. The SSF works alongside these companies that have compounds/molecules currently under review for clinical trials in Sjögren's, or active clinical trials, so they can better understand the disease and our patient community and we can ensure that the patient voice is included in clinical trial design.

In addition, in 2019, the SSF designed and launched the first ever online Sjögren's Training and Education Platform (STEP) to be used to train clinical trial investigators.

The SSF led, encouraged and funded research by...

💧 Continued efforts with the SSF's Clinical Trial Consortium (cont.)

- Held a teleconference call and hosted two (2) face-to-face meetings with CTC committee and corporate members
 - First face-to-face meeting held in October 2018 in Chicago, IL
 - Second face-to-face meeting held in April 2019 in Boston, MA
- Developed next steps and 2019/2020 action plan for CTC which includes:
 - Launching and expanding the STEP online training program
 - Continuing our meetings with the FDA to determine next steps
 - Focusing on development of better outcome measures in Sjögren's which involves continued participation with international initiatives NECESSITY (new clinical endpoints in primary Sjögren's syndrome: an interventional trial based on stratifying patients) and OMERACT (Outcome Measures in Rheumatology)
 - Focusing on the discovery of diagnostic and prognostic biomarkers.
Biomarkers can more precisely diagnose a disease, help predict a patient's risk factors for complications, and help determine which treatment will work best for each individual patient. This will include expanding relationship/efforts with the Foundation for the National Institutes of Health Biomarkers Consortium

The SSF led, encouraged and funded research by...

💧 Led and expanded our relationship with the FDA

- Investigated new avenues for interaction with the FDA (externally led patient-focused drug development (PFDD), listening sessions, white paper, patient engagement collaborative)
- Attended FDA learning and engagement opportunities through the Center for Biologics Evaluation and Research (CBER) and the Center for Drug Evaluation and Research (CDER) which included the CBER Scientific Symposium and CDER meetings on patient engagement and the PFDD Meeting on Chronic Pain.
- Connected with Professional Affairs & Stakeholder Engagement (PASE) to further engagement to enhance drug development and safety.
- Continued our relationship/contacts with key FDA staff

The SSF led, encouraged and funded research by...

- **Coordinated meetings with key stakeholders, corporate partners and those developing therapeutics to advance clinical trials**
 - Expanded our relationship with current and potential corporate members
 - o Met with nine (9) companies during the ACR Annual Meeting to expand relationships and secure corporate memberships
 - o Held numerous touch-base teleconferences throughout the year with several different companies
 - Led special projects for companies including focus groups, clinical trial recruitment programs and expert advice meetings
 - Attended company-led events including Boehringer-Ingelheim's round table; Celgene's ACR Reception and BMS Advocacy Forum

The SSF led, encouraged and funded research by...

- **Continued participation in numerous international Sjögren's efforts**
 - **SSF CEO Steven Taylor and SSF Board Member & Sjögren's researcher, Kathy Sivils, PhD, serve on HarmonicSS as well as co-lead the Patient Advisory Group**
 - o HarmonicSS is an international network and alliance of partners and cohorts, entrusted with the mission of addressing the unmet needs in Sjögren's and semantically interlink and harmonize them into an integrative Sjögren's cohort structure in the clouds.
 - **Kathy Hammitt, SSF Vice President of Scientific & Medical Affairs, has a role on two committees for Europe's Innovative Medicines Initiative (IMI) outcome measure project – NECESSITY**
 - **Theresa Lawrence Ford, MD, SSF Medical & Scientific Advisory Board Chair, leads the OMERACT initiative on outcome measures.**

The SSF led, encouraged and funded research by...

Restructured the SSF's Research Program

The SSF is dedicated to advancing Sjögren's research and fostering change for the benefit of the entire Sjögren's community. During the past 10 years, the SSF has provided nearly \$4 million to fund a broad range of scientific initiatives, including the support of clinical and scientific studies through Foundation research grants. We are extremely proud of the leadership role that we have taken to move Sjögren's research forward and are even more excited about what is yet to come.

One of the cornerstones of the Foundation's research efforts is our Research Grants Program. This program is focused on supporting innovative research projects that will have the greatest impact on the lives of those living with this devastating disease. These grants help encourage the scientific community to generate creative ideas that will bring novel approaches to Sjögren's research while placing a high priority on both clinical and scientific research into the cause, prevention, detection, treatment and, ultimately, conquering Sjögren's.

The SSF led, encouraged and funded research by...

💧 Restructured the SSF's Research Program (cont.)

- The SSF announced a new funding opportunity for researchers, called the **SSF High Impact Research Grant** offered at \$75,000.
 - o This grant significantly increases past funding for a single grant from the SSF, and has already attracted a wider range of experience levels, including more senior investigators.
 - o This new award encourages more fully developed research proposals, which already have the necessary preliminary data and methodology in place to move into the next phase of research.
- The Foundation will also continue to award numerous **SSF Pilot Research Awards** at \$25,000.
 - o These grants assist investigators in conducting feasibility studies, collecting preliminary data and performing other research assistance necessary to advance their project, while ultimately helping them prepare to pursue larger grant funding in the future.

The Sjögren's Syndrome Foundation is proud of our accomplishments

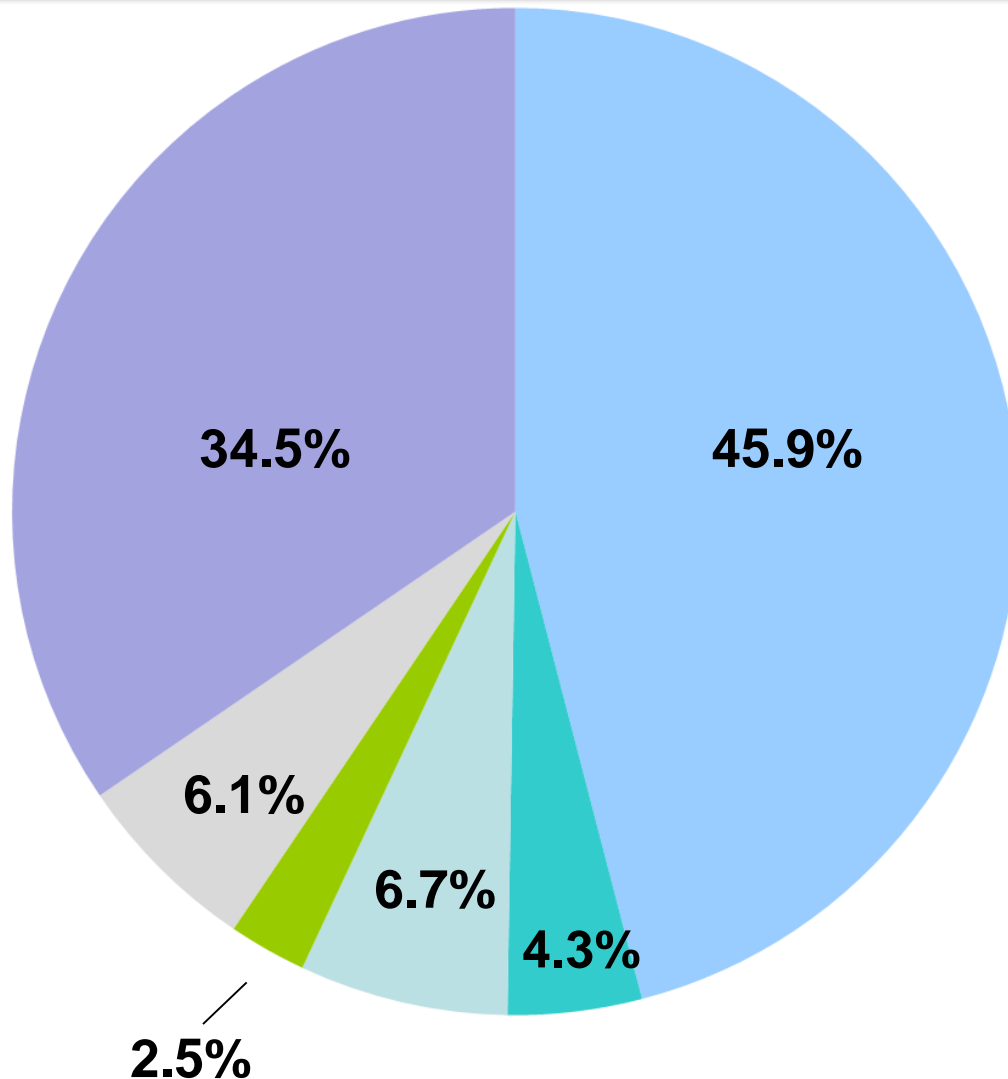
- 💧 Our website, www.sjogrens.org was viewed by 1,200,356 unique visitors between July 2018 and May 2019
- 💧 Awarded 5 Sjögren's research grants in FY19, including new High Impact Research Award
- 💧 Managed 64 active support groups in the United States
- 💧 Continued to fight for the development of a systemic therapy for Sjögren's by expanding our Clinical Trials Consortium and launching the STEP Platform
- 💧 Served as international mentor to 28 international Sjögren's Patient Groups
- 💧 Increased our social media presence through Facebook, Twitter, LinkedIn and Instagram
- 💧 Launched our new YouTube Talk Show – “Exploring Sjögren's”
- 💧 Attended numerous professional conferences to represent the voice of Sjögren's patients
- 💧 Expanded our “Walk for Sjögren's” program to three new cities
- 💧 Staff managed over 750 volunteers who give their time each year to the SSF
- 💧 Updated the SSF's mission statement while developing a new vision for the SSF to:
**“Create a community where patients, healthcare professionals, and researchers
come together to CONQUER THE COMPLEXITIES of Sjögren's”**

FY 2018/2019 Financials

Income & Expenses

FY 2018/2019 Financials

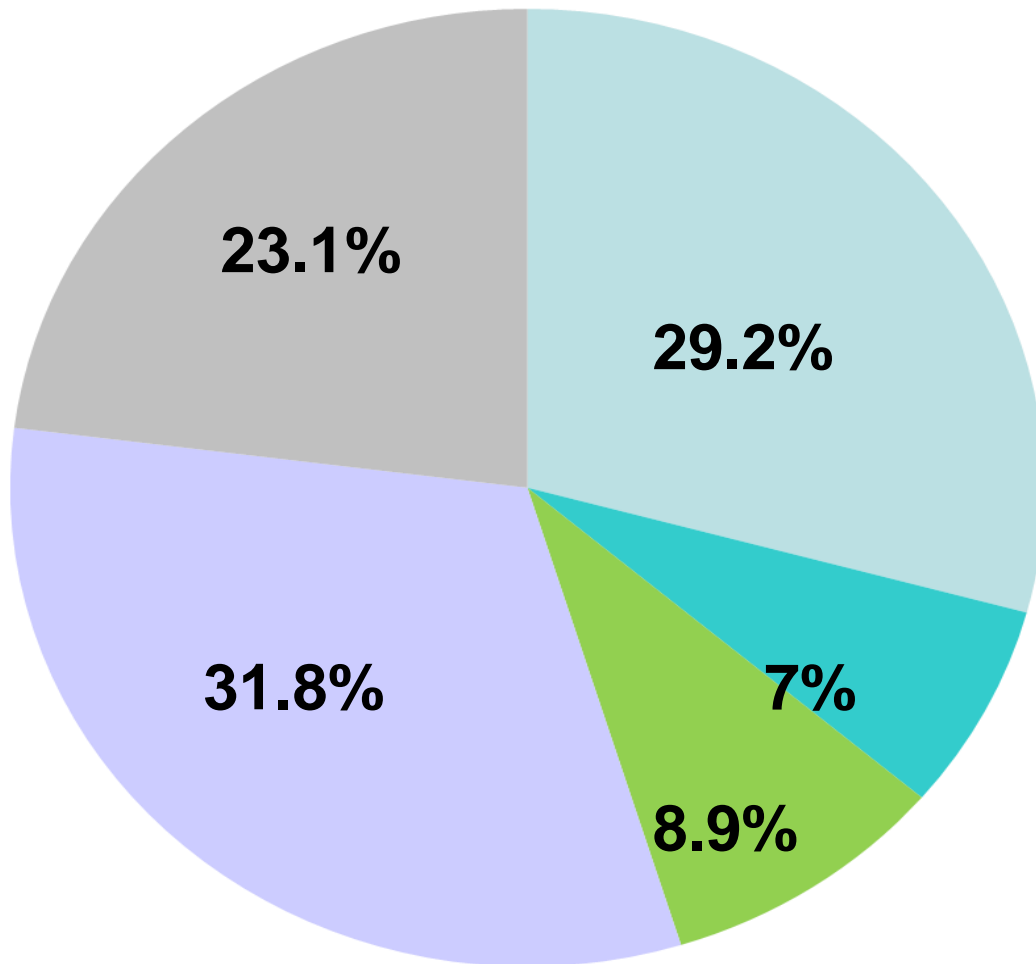
INCOME TOTAL = \$3,422,076



Contributions	\$1,569,931 – 45.9%
Conferences & Products	\$146,685 – 4.3%
Dues	\$227,237 – 6.7%
Other	\$86,630 – 2.5%
Special Events (net)	\$209,746 – 6.1%
Planned Giving	\$1,181,847 – 34.5%

FY 2018/2019 Financials

EXPENSES TOTAL = \$2,347,370



■ Patient Services

\$685,312 – 29.2%

■ Administration

\$164,131 – 7%

■ Fundraising

\$210,174 – 8.9%

■ Awareness

\$746,831 – 31.8%

■ Research

\$540,922 – 23.1%

About our financials...

The SSF is supported by contributions from individuals, corporations, small businesses and foundation grants. We actively seek tax deductible contributions for programs that help us advance our mission. Our major sources of funding include the following:

- **Individual Donations**

We are very proud that many individuals trust the SSF with their donations. The SSF is proud of our success in achieving our mission and helping those that suffer from Sjogren's Individual donations constitute 23% of our overall income.

- **Special Events**

We hold many events throughout the year to raise awareness of Sjögren's and raise critical funds to support our mission. Special event income represented 6% of our total income.

- **Private, Family and Corporate Foundations**

Our Foundation receives support from a number of Foundations through restricted and unrestricted gifts. These gifts represent 12% of our total income.

- **Corporate Support**

Corporations support the Foundation's mission through sponsorship of special events, corporate gifts, employee matching programs, workplace programs, grants, in-kind contributions, and more. Approximately 16% of the Foundation's total annual revenue was raised through pharmaceutical/biotechnology company support.

The SSF thanks all our donors as well as those that support the SSF in other ways!

FY 2018/2019 Donors

The SSF is grateful for the individuals, companies, foundations and organizations that choose to contribute financially and support our efforts.

\$50,000 +

Bristol Myers Squibb
Estate of Alice Kozel
European Commission
Galewood Foundation
Gilead Sciences
HarmonicSS
Servier Pharmaceuticals
Shire US
Kim Spiro
William H. Donner Foundation

\$10,000 - \$49,999

Akorn, Inc.
Anna B Milburn Charitable
Lead Annuity Trust
Blue Chip
Jennifer Bromberg
Sharon & Henri Bromberg
Carroll Petrie Foundation
Nan Clifford
Estage of Joan Hunt
F. Hoffman-La Roche, Ltd
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Novartis Pharmaceuticals
Andrea Pines
RHMM
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Viela Bio Inc.

FY 2018/2019 Donors

\$5,000 - \$9,999

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Foundation
Troy & Leslie Daniels
Eye Eco Inc.
Frank & Linda Morse
Family Foundation
Ronald Hansman
Incyte Corporation
Carolyn Kennedy
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Cheryl Lugenbill

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Paragano Family Foundation
Jan Sogge
Spinato's Pizzeria
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\$1,000 - \$4,999

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Frederic Bogart

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Nick Casale
Casale Rent-All, LLC
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FemmePharma
Wade & Bev Fetzer
Fred R. Fernandez-Irma R.
Rodriguez Foundation
GEICO Philanthropic Foundation

FY 2018/2019 Donors

\$1,000 - \$4,999 cont.

Damien Graeff	Mayo Clinic	Reams Foundation
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Robert Hale	Charles McManus	Salesforce.org
Lisa Hettinger	Linda Morgan	SC Johnson
Susan Horst	Mutual of America	Scheie Eye Institute
Lauren Issembert	NOVA Perio Specialists	Science Based Health
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Joan Kahn	John & Joan Polcari	Valassis Direct Mail Inc
Toni Kaplan	William & Patricia Prout	Fred & Virginia Vivino
Sheila Manischewitz	Quest	Jim & Joan Walsh
	Ravenal Foundation	Irith & Seth Weiner
		Ziena Eyewear

Thank You!

**The Sjögren's Syndrome
Foundation would like to thank
all of our volunteers and donors
who helped make this past year
such a great success!**

Contact Us



**10701 Parkridge Blvd
Suite 170**

Reston, VA 20191

(301) 530-4420 / (301) 530-4415 (fax)

www.sjogrens.org

info@sjogrens.org