

ANNUAL REPORT

Annual Report 2016-2017



YEAR IN REVIEW

To Our Supporters:

2016/2017 was another great year for the Sjögren's Syndrome Foundation. The Foundation continues to support Sjögren's research, provide educational programs and work towards raising awareness about this debilitating and life altering disease.

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 being the credible source for Sjögren's information for all stakeholders – including patients, families and healthcare providers.

We are very proud of our accomplishments this past year 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 1-800-475-6473 to be mailed a copy of the documents.

Thank you to all those that supported us this past year.

Sincerely,
The SSF Board of Directors.

Board of Directors



Stephen Cohen, OD
Chairman of the Board

Janet Church
Chair-Elect

Tricia Gooding
Secretary

Kathy Sivils, PhD
Treasurer

Nancy Carteron, MD
Medical & Scientific Advisory Board Chairman

Esen Akpek, MD

Herb Baraf, MD

Ken Economou

Jack Faricelli

Patricia Hurley

Cathy Ingels

Cynthia Lopynski

Monica McGill

Timothy Niewold, MD

Tom Sutton

Michelle Wallace

Ava Wu, DDS

SSF Leadership Staff



Steven Taylor
Chief Executive Officer

Ben Basloe
VP of Philanthropy

Kathy Hammitt
VP of Scientific & Medical Affairs

Kathy Ivory
VP of Field Services

Sheriese DeFruscio
VP of Marketing & Corporate Relations

Sjögren's Syndrome Foundation Mission

- 💧 To increase public and professional awareness of Sjögren's
- 💧 To educate patients and their families
- 💧 To encourage research for new treatments and ultimately a cure for Sjögren's


SSF 2016/2017 Priorities

The SSF's Board of Directors adopted three specific action items to achieve our mission:

- ♠ Increasing public awareness
- ♠ Increasing involvement from our friends and partners
- ♠ Increasing education and awareness among healthcare professionals

On the following pages, you will see our goals under each priority and how the SSF did against those goals and 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 is increasing
awareness by...***

The SSF is increasing awareness by...

- **Expanded the SSF Blog & Use of Social Media**

- Monthly SSF blog posts used to promote early diagnosis and awareness to help patients get a prompt diagnosis and correct treatment
- Increased Facebook followers to **39,234** from **31,793**
- Launched SSF LinkedIn page in April 2017
- Increased twitter followers to **5,562** from **4,506**

- **Produced our monthly patient newsletter “The Moisture Seekers” (TMS)**

- Over 120,000 copies were printed in 2016/2017

- **Website**

- BTG is updated on our website and through our Blog

The SSF is increasing awareness by...

- **Strengthened our Sjögren's Ambassador program by:**
 - **Expanding our Patient to Provider Ambassadors (Awareness Ambassadors)**
 - SSF has 210 active AAs who focus on visiting local healthcare providers with Sjögren's information.
 - SSF continues to recruit new awareness ambassadors year-round
 - **2016/2017 Calendar for Awareness Ambassadors included:**
 - » Summer 2016 – Eye Care Providers - (Clinical Practice Guidelines)
 - » Fall 2016 – Dermatologists – (Dry Skin Fact Sheet)
 - » Spring 2017- Dentists – (Clinical Practice Guidelines)
 - **Launching our new program of Patient Support Volunteers (PSVs)**
 - These new PSV's are agreeing to be trained and take phone calls from patients
 - Currently have over 56 PSVs
 - **Developed new training modules for both ambassador programs**
 - Volunteers receive a training module to review and complete once they agree to serve

The SSF is increasing awareness by...

💧 **Expanded our April Awareness Month promotions**

- o Developed comprehensive Sjögren's Awareness Month plan to include social media, consumer media & trade journals/associations
- o Used 2016 Patient Survey results as our cornerstone of the project
- o Networked with corporate partners, bloggers, non-profit organizations and trade associations

💧 **Expanded our outreach to traditional marketing avenues:**

- o Created media ready materials and updated media tab on sjogrens.org for easy download of materials
- o Through our April campaign, SSF created relationships with print, television and radio contacts to further awareness of Sjögren's which included stories or interviews in/on such media as:
 - » US News & World Reports
 - » Philadelphia Inquirer
 - » Local Fox News - Philadelphia
 - » Sirius XM Satellite Radio

The SSF is increasing awareness by...

- **Expand our communications with our constituents by:**
 - **Continued our “Sjögren’s Snapshot”**
 - **Sjögren’s snapshot is sent quarterly to non-members of SSF**
 - » i.e. April 2017 Snapshot was received by 62,937 non-members, with a 20% open rate and 4.1% click rate
 - **Snapshot allows SSF to highlight SSF projects and programs**
 - **Continued our quarterly talking points for Support Group Leaders**
 - **SSF continues to send the “Sjögren’s Connection” to our SGLs to share with their attendees/members**
 - **Launched Town Hall Meetings with various constituent bases**
 - **Held quarterly “new member” town hall meetings (conference calls)**

The SSF is increasing awareness by...

• **Serving on coalitions to represent Sjögren's patients**

- Joining organizations like the Arthritis Foundation and the American Cancer Society by serving on the National Health Council's Board of Directors
- NIH Coalitions: NIAMS Coalition and Friends of the NIDCR (Kathy Hammitt is co-chair)
- Autoimmune Diseases Coordinating Committee
- ACR's Coalition for Accessible Treatment
- Health Choices Coalition – by Consumer Health Product Alliance
- Rare Lung Disease Consortium

• **Serving in lead roles in the advocacy arena**

- Kathy Hammitt (Vice President, SSF) was keynote speaker for *“Research & Hope Awards”* hosted by PhRMA
- SSF was featured in AARDA Ad promoting PDUFA in Politico Newspaper
- Steven Taylor (CEO) served as Master of Ceremonies for AARDA & NCAPG's National Summit entitled *“Autoimmunity: Yesterday, Today & Tomorrow”* at the National Press Club in DC.
- Steven Taylor (CEO) chaired National Health Council's Annual Leadership Conference

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***The SSF is
educating by...***

The SSF is educating by...

- 💧 **Managing and supporting over 63 active Sjögren's support groups in the United States**
- 💧 **Conducting a two-day National Patient Conference**
 - 2017 NPC was held in Cherry Hill, NJ (Philadelphia area) on March 31st and April 1st
 - Nearly 500 attendees with new topics included pediatric Sjögren's and men with Sjögren's
- 💧 **Serving as the lead organization for the International Sjögren's Network - a network of 25 international Sjögren's patient groups.**
 - ISN collaborated on a joint flyer/poster/promotions in multiple languages for World Sjögren's Day (July 23rd)

The SSF is educating by...

💧 **Reaching out to specialists that treat Sjögren's**

- Utilized our new partner, "Outcome Health", to help educate healthcare providers and/or patients by utilizing their marketing system in waiting and exam rooms
- Distributed SSF Clinical Practice Guidelines to all specialists
- Expanded SSF relationships into new treatment areas due to the phase 2 our Clinical Practice Guidelines – neurologists, pulmonologists, oncologists and new rheumatologists

💧 **Participating in American College of Rheumatology's Annual Meeting**

- Organized our annual SSF Luncheon for rheumatologists during ACR
- Distributed SSF educational packets during "Meet the Professors" Session
- Attended ACR's 3 poster sessions on Sjögren's, 2 oral abstract sessions, 2 major Sjögren's presentations and 2 Sjögren's study groups. This marking the most ever Sjögren's focused agenda ever during ACR!

💧 **Launch partnership with pediatric rheumatologists who treat Sjögren's!**

- Supported Pediatric Rheumatologists study group on Sjögren's and launched SSF pediatric Sjögren's support group for children and their families



***The SSF is leading the
fight for more treatment
options and research by...***

The SSF is leading the fight for more treatment options & research by...

• **Coordinating the SSF's Clinical Trials Consortium**

- Consortium consists of key opinion leaders (rheumatologists and researchers), pharmaceutical company representatives and SSF staff.
- Meetings held to discuss held to engage our partners on potential initiatives that will help encourage clinical trials and overcome barriers to success
- Continued to partner with companies on patient recruitment for trials
- Assisted with clinical trial design, outcome measures and site selection
- Met with FDA ey staff to discuss Sjögren's Clinical Trials and find out how the SSF could assist in ensuring successful trials

The SSF is leading the fight for more treatment options & research by...

💧 **Leading the development of the first-ever Sjögren's Clinical Practice Guidelines**

- **Rheumatology**

- **Published the first three topic areas in rheumatology (Biological Therapy, Fatigue, and Inflammatory Musculoskeletal Pain)**

- **Published in ACR journal, *Arthritis Care & Research* – 2016/2017**

- » “Carsons SE, Vivino FB, Parke A, Carteron N, Sankar V, Brasington R, Brennan MT, Ehlers W, Fox R, Scofield H, Hammitt KM, Birnbaum J, Kassan S, Mandel S. Treatment Guidelines for Rheumatologic Manifestations of Sjögren's Syndrome: Use of Biologic Agents, Management of Fatigue, and Inflammatory Musculoskeletal Pain. *Arthritis Care Res (Hoboken)*. 2017 Apr;69(4):517-527.”

- **Also published all 3 guidelines together in additional publication:**

- » “Vivino FB, Carsons SE, Foulks G, Daniels TE, Parke A, Brennan MT, Forstot SL, Scofield RH, Hammitt KM. New Treatment Guidelines for Sjögren's Disease. *Rheum Dis Clin North Am*. 2016 Aug;42(3):531-51”

The SSF is leading the fight for more treatment options & research by...

💧 Ocular

- New Working Group formed – Peter Donshik and Michael Goldstein, Chairs;
- Initiative will start following publication of TFOS DEWSII report

💧 Oral

- New Working Group formed – Domenick Zero and Caroline Shiboski, Chairs;
- 3 topics and members of each topic group set:
 - Caries Management & Restoration
 - Mucosal Management & Treatment
 - Use of Secretagogues
- 4th topic group designated that overlaps rheumatology, oral and ocular:
 - Parotid & Lacrimal Gland Swelling (led by Ava)

The Sjögren's Syndrome Foundation is proud of our accomplishments. Here are a few more highlights from the year:

- ◆ Our website, www.sjogrens.org was viewed by 1,108,927 unique visitors between July 2016 and May 2017
- ◆ Awarded 6 Sjögren's research grants in FY17
- ◆ Managed 63 active support groups in the United States
- ◆ Launched our largest awareness campaign for Sjögren's Awareness Month in history of SSF
- ◆ Served as international mentor to 25 international Sjögren's Patient Groups
- ◆ Started phase 2 on Rheumatology and Oral Clinical Practice Guidelines
- ◆ Launched, Smart Patients, a new online community for Sjögren's patients
- ◆ Began the development of the first-ever online platform (STEP) to train clinical trial investigators in Sjögren's
- ◆ Attended numerous professional conferences to represent the voice of Sjögren's patients
- ◆ Nearly 500 patients attended our 2017 National Patient Conference in Philadelphia
- ◆ Staff manage over 700 volunteers who give their time each year to the SSF
- ◆ And time to diagnose Sjögren's has now dropped from nearly 6 years to 3 years

And we do this all for the Sjögren's patient!

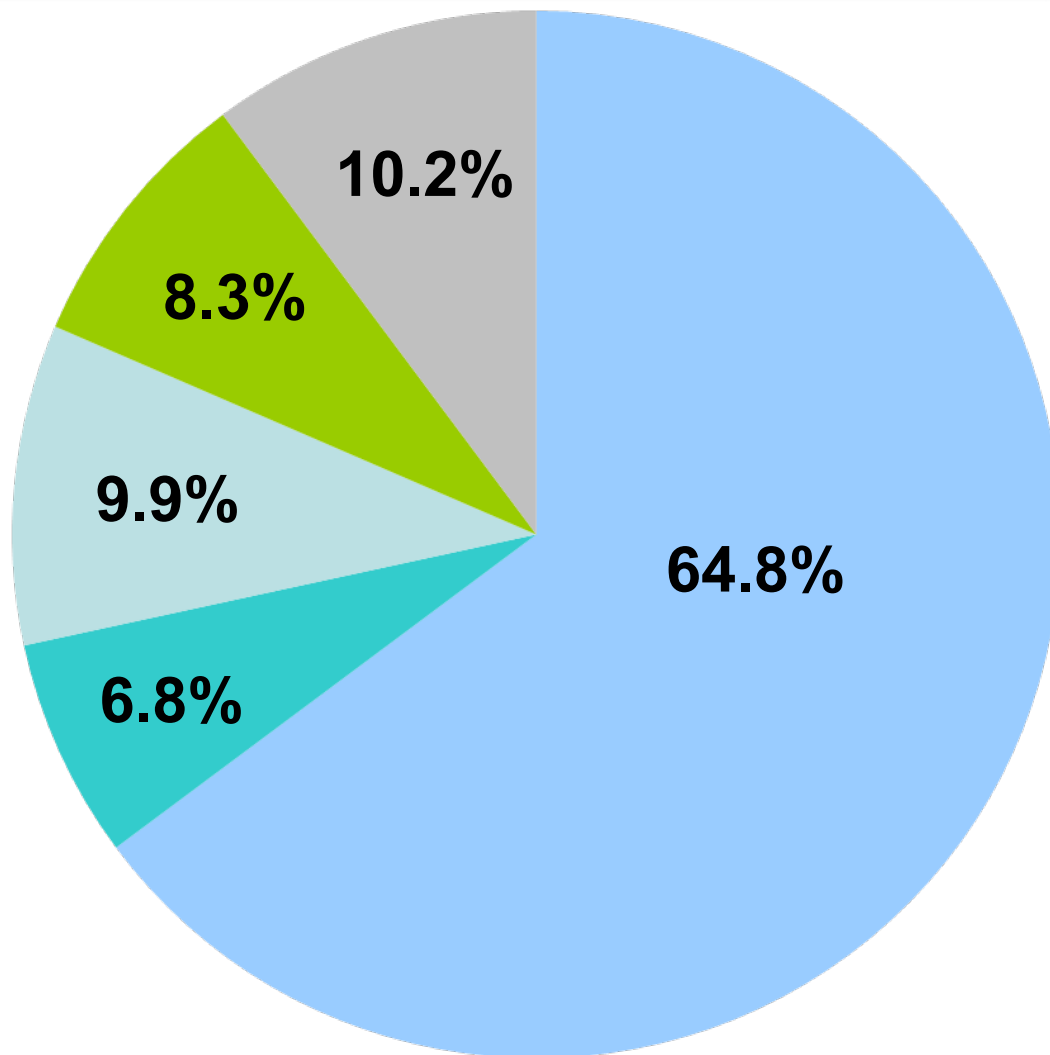
Together, we will conquer this serious autoimmune disease!

FY 2016/2017 Financials

Income & Expenses

FY 2016/2017 FINANCIALS

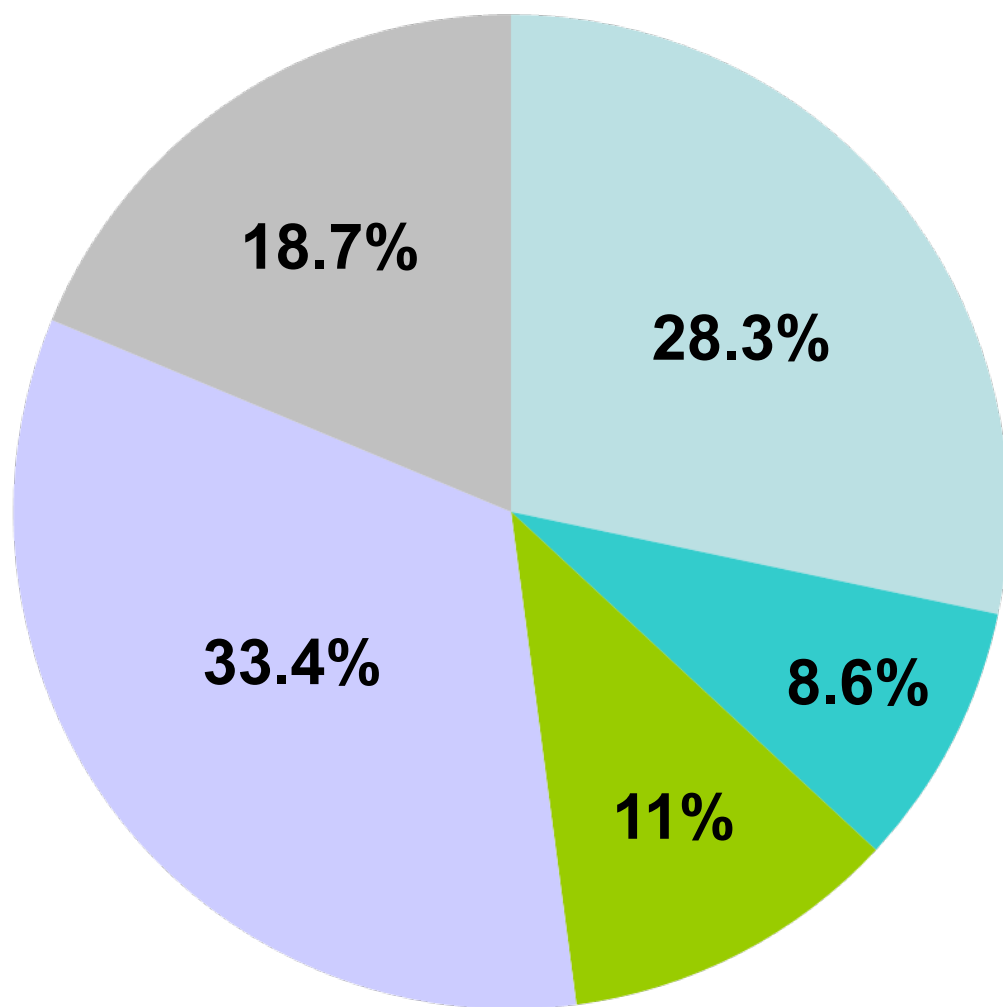
INCOME TOTAL = \$2,293,840








■ Contributions	\$1,486,745 – 64.8%
■ Conferences & Products	\$154,916 – 6.8%
■ Dues	\$227,317 – 9.9%
■ Other	\$189,711 – 8.3%
■ Special Events (net)	\$235,151 – 10.2%

FY 2016/2017 FINANCIALS

EXPENSES TOTAL = \$2,174,716



 Patient Services	\$616,450 – 28.3%
 Administration	\$187,264 – 8.6%
 Fundraising	\$239,596 – 11%
 Awareness	\$725,550 – 33.4%
 Research	\$405,856 – 18.7%

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 13% 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 14% 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 18% 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 !

Thank You...

**Thanks to all of you and our hard-working volunteers
for the countless hours as well as generous donations
that helped us to achieve these great milestones!**