

# ANNUAL REPORT



Annual Report  
FY 2013-2014

# YEAR IN REVIEW

To Our Supporters:

We are very proud of our accomplishments in 2014 and we couldn't have done it without your support. Each donor and volunteer is critical to our success as we strive to raise awareness, support patients and their families and encourage new research into the mystery of Sjögren's.

As you will see throughout this annual report, the SSF achieved many accomplishments again this year and made great strides in reaching our mission. As the only non-profit organization focused on conquering Sjögren's, we continue to be a patient oriented organization serving our members as well as industry leaders serving as the credible source for Sjögren's information.

If you would like more information about our accomplishments, we encourage you to contact the SSF at 301-530-4420 or by visiting our website at [www.sjogrens.org](http://www.sjogrens.org). You can find our Federal IRS 990 Tax Return online and/or request the Federal IRS 990 and/or our Audited Financial Report by calling the SSF office.

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

Sincerely,  
The SSF Board of Directors

# Board of Directors



**S. Lance Forstot, MD**  
*Chairman of the Board*

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*Chair-Elect*

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*Secretary*

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*Treasurer*

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**Jack Faricelli**

**Cathy Ingels**

**Theresa Lawrence Ford, MD**

**Mary McNeil**

**Shari Rood**

**Vidya Sankar DMD, MHS**

# SSF Leadership Staff



**Steven Taylor**  
*Chief Executive Officer*

**Kathy Ivory**  
*Vice President of Field Services*

**Sheriese DeFruscio**  
*Vice President Development*

**Kathy Hammitt**  
*Vice President of Research*

# 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 Breakthrough Goal

In January 2012, the SSF launched a new *5-Year Breakthrough Goal*:

**“To Shorten the Time to Diagnose Sjögren's by 50% in 5 years”**


# SSF 2014 Priorities

**The SSF's Board of Directors adopted three specific action items to achieve our *5-Year Breakthrough Goal*:**

- ◆ 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 for 2014 and how the SSF did against those goals.

We hope you will be as excited as we are about our successes this past year.



**The Sjögren's Syndrome  
Foundation increased  
awareness.**



# SSF 2014 Goals

## 💧 **Strengthen the Awareness Ambassador Program:**

- 💧 Hosted annual training for our 509 Awareness Ambassadors
- 💧 Awareness themes for 2014 included educating rheumatologists, dentists, primary care physicians, OBGYNs, and community health leaders
- 💧 Secured funding from Carroll Petrie Foundation to support Awareness Ambassador Program

# SSF 2014 Goals

- 💧 **Develop awareness and media outreach plan:**
  - 💧 April Sjogren's Awareness Campaign on Facebook received over 10 million impressions and SSF Facebook posts were shared over 389,000 times
  - 💧 SSF brought together 17 international organizations to participate in World Sjogren's Day
  - 💧 Partnered on media campaigns with companies such as Costco, Tearlab, and Nicox to increase awareness for Sjogren's
  - 💧 SSF was recognized by *PM360*, a leading healthcare publication, for their awareness & early diagnosis marketing campaign with Nicox Diagnostics

# SSF 2014 Goals

## 💧 **Expand fundraising efforts:**

- 💧 Raised over \$1.8 million through various fundraising avenues including individual giving, special events and corporate support
- 💧 SSF signature events (Walkabouts, Sip for Sjogren's, and Team Sjogren's) were held in 21 markets
- 💧 Held 30<sup>th</sup> Anniversary Dinner to honor SSF founder Elaine Harris
- 💧 Encouraged patients to host mini-events in their communities with over 35 events held

# SSF 2014 Goals

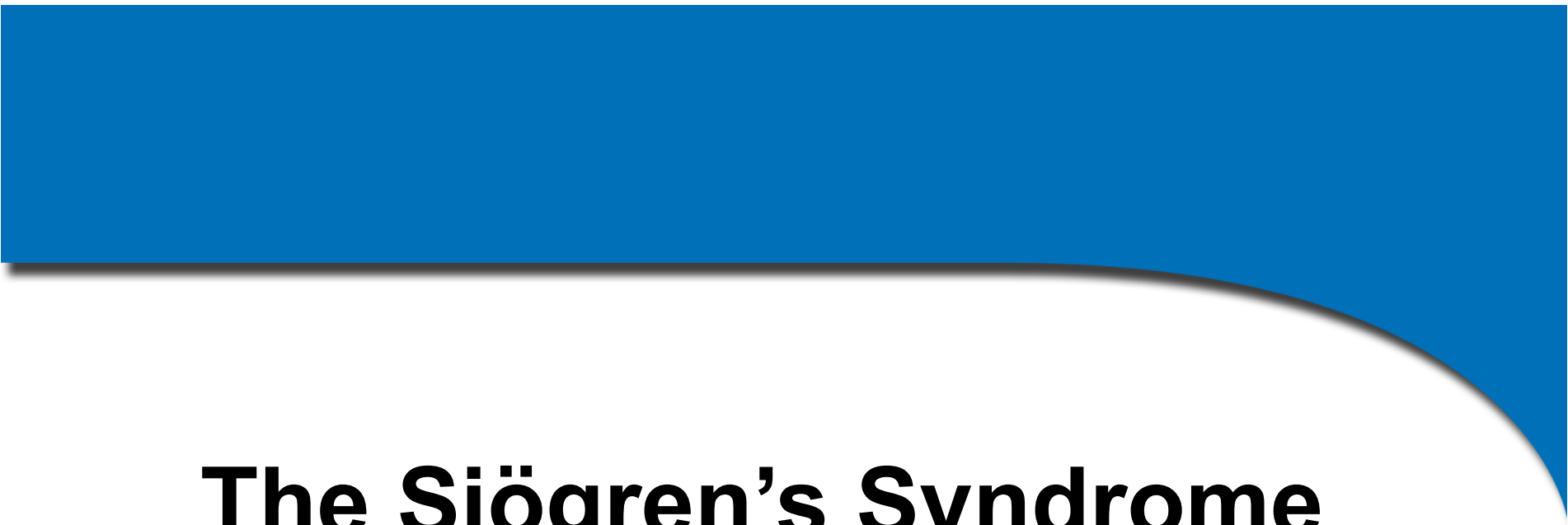
## 💧 **Utilize social media consistently:**

- 💧 Received over 271,000 views to our SSF blog
- 💧 Expanded website to include 20 Faces of Sjogren's, receiving 66,000 views
- 💧 Introduced new, non-branded blog focused on symptoms of Sjögren's for those searching internet for a diagnosis
- 💧 Increased Facebook followers from 9,643 to 19,722

# SSF 2014 Goals

## 💧 **Represent Sjogren's patients:**

- 💧 Hosted international meeting of researchers and clinicians to discuss new Sjogren's diagnostic criteria
- 💧 Staff of SSF served on NIH's Autoimmune Diseases coordinating committee
- 💧 SSF CEO presented to Senate Finance Committee and House & Ways Sub-Committee on Capitol Hill
- 💧 SSF served on numerous coalitions to ensure the voice of Sjögren's patients were considered.



**The Sjögren's Syndrome  
Foundation educated patients,  
their families and healthcare  
professionals.**

# SSF 2014 Goals

## • **Serve as the authoritative resource on Sjogren's:**

- Produced quarterly publication for healthcare professionals, the *Sjögren's Quarterly*, that has annual distribution of 25,000
- Hosted annual meeting for over 100 Rheumatologists on the development of new therapeutics for Sjögren's
- Distributed over 20,000 complimentary patient brochures to physicians' offices
- Produced monthly patient publication, *The Moisture Seekers*, with annual distribution of 120,000

# SSF 2014 Goals

## 💧 **Develop first-ever Clinical Practice Guidelines for how to treat, manage and monitor Sjögren's:**

- 💧 Finalized Rheumatologic Recommendations for Biologic Therapy
- 💧 Drafted Fatigue Recommendations and Inflammatory Musculoskeletal Pain Recommendations
- 💧 Finalized ocular guidelines and submitted to Peer Review Journal for publication
- 💧 Completed first oral topic area focused on Caries (dental decay) Prevention



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**The Sjögren's Syndrome  
Foundation encouraged  
research.**

# SSF 2014 Goals

## ▹ **Launch Clinical Trials Consortium:**

- Held first Steering Committee to determine priorities for SSF's Clinical Trial Consortium
- Developed list of targeted and potential therapies and diagnostics for Sjogren's

# SSF 2014 Goals

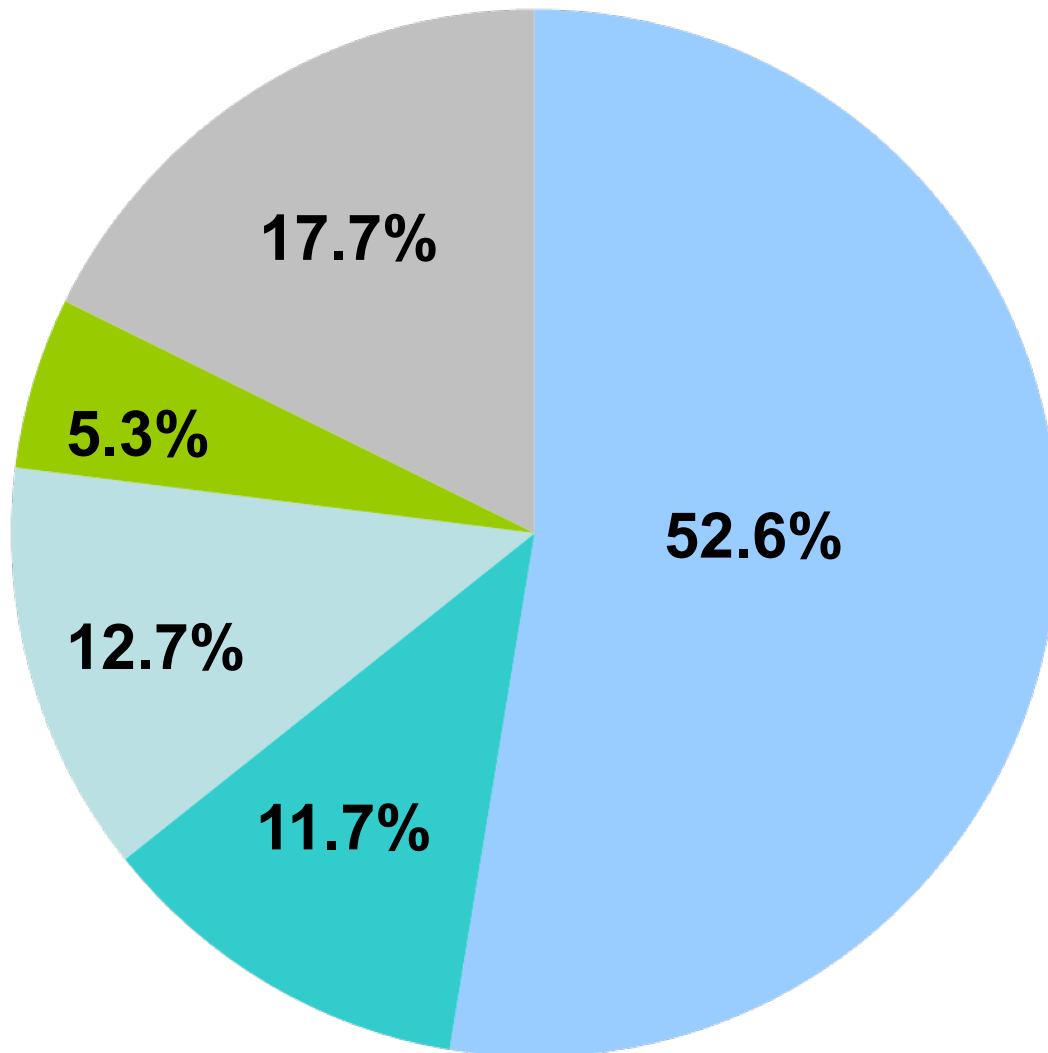
- 💧 **Fund innovative Sjogren's Research:**
  - 💧 Awarded fellowships to students working in Sjögren's labs
  - 💧 Awarded Sjogren's research grants placing high priority on research looking at the cause, detection, and treatment of Sjogren's
  - 💧 Grants awarded to researchers at institutions such as:
    - 💧 Oklahoma Medical Research Foundation
    - 💧 Rockefeller University
    - 💧 National Institute of Dental and Craniofacial Research

# FY 2013/2014 Financials

## *Income & Expenses*

# FY 2013/2014 FINANCIALS

INCOME TOTAL = \$1,843,086



■ **Contributions**  
\$968,887 – 52.6%

■ **Conferences & Products**  
\$215,367 – 11.7%

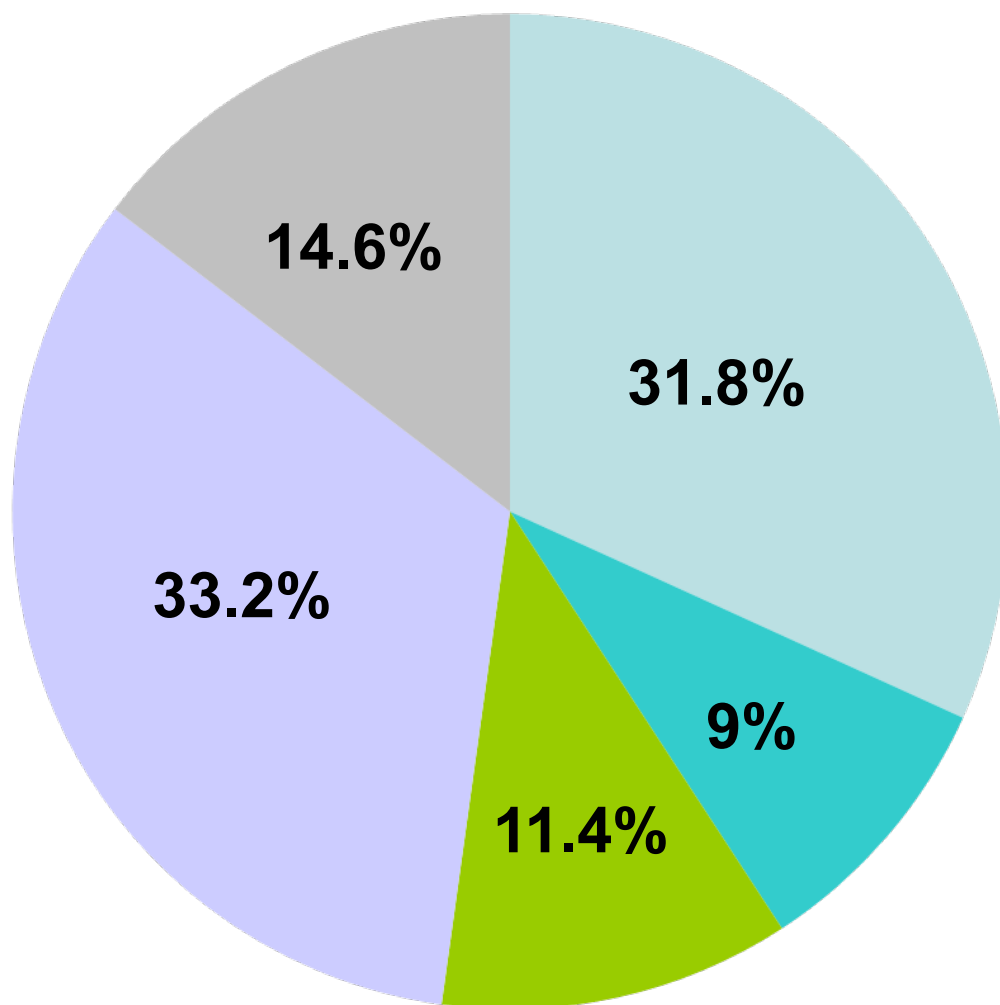
■ **Dues**  
\$233,865 – 12.7%

■ **Other**  
\$98,397 – 5.3%

■ **Special Events (net)**  
\$326,570 – 17.7%

# FY 2013/2014 FINANCIALS

EXPENSES TOTAL = \$1,762,960



■ **Patient Services**  
\$560,036 – 31.8%

■ **Administration**  
\$159,127 – 9%

■ **Fundraising**  
\$201,611 – 11.4%

■ **Awareness**  
\$585,322 – 33.2%

■ **Research**  
\$256,864 – 14.6%

# FY 2013/2014 Donors

*Donors & Supporters*

# FY 2013-2014 Donors

The generous support of the following individuals, families, corporations, businesses, foundations and organizations helps to ensure that the SSF's programs of research, education and awareness continue to expand.

## **\$50,000 +**

*Allergan USA  
Carroll Petrie Foundation  
Galewood Foundation  
Nicox Inc.*

## **\$10,000 - \$49,999**

*Akorn, Inc.  
Rochelle E. Bain Estate  
Bannon Humphery Foundation  
Bausch & Lomb Pharmaceuticals, Inc.  
Biogen Idec  
Sharon Bromberg  
Troy & Leslie Daniels, DDS  
Freddie Mac Foundation  
Mary Hammond  
Invado Pharmaceuticals  
Laclede Inc.  
Kathryn McCarren  
MedActive Oral Pharmaceuticals  
Mediacom US  
Mission Pharmacal*

## **\$5,000 - \$9,999**

*Andrea Cavitolo Foundation  
Alcon Laboratories, Inc.  
Allergan Foundation  
Jennifer Bromberg  
Gary Brown  
Eye Eco Inc.  
Kenneth Lay  
Kathleen Marble  
Newell Devalpine Foundation  
SBH Diagnostics  
Steven Taylor  
TearLab Corporation*



# FY 2013-2014 Donors

## **\$1,000 - \$4,999**

*Abbott Laboratories*

*Alvin & Fern Davis Foundation*

*Apothecary*

*Arthritis & Rheumatism*

*Associates, P.C.*

*Johnathan & Janet Axelrod*

*Barbara and Edward Netter*

*Foundation, Inc.*

*Debra Baxter*

*Ben & Jerry's*

*Leonard & Barbara Berenfield*

*David Berger*

*Peter Binkow*

*Amy Bloom*

*Blount Motors*

*Lindsey Criswell, MD*

*Charles Borchelt*

*Kimberly Brett-Ley*

*Bristol-Myers Squibb Foundation*

*Cancer Treatment Centers*

*of America*

*Nancy Carteron MD, FACR*

*Casale Rent-All*

*Colorado Center for Arthritis &*

*Osteoporosis*

*Comfortfit Labs*

*Community Foundations of the*

*Hudson Valley*

*Corneal Consultants of Colorado*

*Cotton Market & Risk*

*Management Consulting*

*Kate Cubitt*

*Herbert Cullis*

*Sheriese DeFruscio*

*Corinne Devereux*

*Anne & Kenneth Economou*

*Elizabeth Hekman Gordon Family*

*Foundation*

*Fagadau, Hawk & Swanson*

*Dr. S. Lance Forstot, MD*

*Fred R. Fernandez - Irma R. Rodriguez*

*Foundation*

*Dan Fuoco*

*Genentech*

*Adrienne & Robert Ginsberg*

*Elisabeth Giovine*

*Elizabeth Gordon*

# FY 2013-2014 Donors

## **\$1,000 - \$4,999 cont'd**

*Mike Grady*

*Ronald Hansman*

*Beth Harkavy*

*Ira Harkavy*

*William Hartman*

*Ruth Heyenbrock*

*Hospital for Special Surgery*

*Lauren Issembert*

*Jim & Marlene Greene*

*Foundation*

*John M. & Sally B. Thornton*

*Foundation*

*Joan Kahn*

*Troy Kaneaster*

*Holly Kent*

*Mary Kimball*

*Kinney Family Foundation*

*Kirkland & Ellis Foundation*

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*Jane Korman*

*Christina Kozich*

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*Lawrence & Sylvia Wong  
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*Leisure World Community*

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*Leventhal Sutton & Gornstein*

*Cynthia Lopynski*

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*Mary Martin*

*Bonnie McCabe*

*Denise & Peter McGuire*

*Laura McKenney*

*Marie McMahan*

*Metal Prep Company*

*Microsoft*

*Margaret Moore*

*Nathan P. Jacobs Foundation*

*National Cinemedia*

*Natural Ophthalmics*

*Kerry & Linda Neall*

*Kathleen Nichols*

*Keith & Marti Nicoll*

*Oasis Medical*

*Janet Oden*

*Mary Cay O'Malley*

# FY 2013-2014 Donors

## **\$1,000 - \$4,999 cont'd**

*Orahealth USA*

*Bonnie Orkow*

*Orr Family Foundation, Inc.*

*Susan Ostrow*

*Oxford University Press*

*Ann Pearson*

*Penn Medicine*

*Andrea Pines*

*Patricia Prout*

*Prudential Foundation*

*Don Reynolds*

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Sports*

*Penny Valentine*

*Venta Airwasher*

*Fred & Virginia Vivino*

*Walmart*

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*Paul Williams*

*Winthrop University Hospital*

*Monica Wischmeyer*

*Leonard Zaner*

*Judith Zarin*



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Special thanks to our volunteers and donors who made this past year such a great success!

# Contact Us



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