

ANNUAL REPORT



Annual Report
FY 2012-2013

YEAR IN REVIEW

To Our Supporters:

2013 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 disease.

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 for all stakeholders – including patients, their families and healthcare providers.

We are very proud of our accomplishments this past year that 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 those additional documents.

Thank you to all those that supported us this past year. Your support is the reason we are able to continue our great programs and services that help Sjögren's patients and their loved ones.

Sincerely,
The SSF Board of Directors.

Board of Directors



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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 2013 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 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...

- 💧 **Launching National Awareness Campaigns**

- 💧 April Sjögren's Awareness Month
- 💧 World Sjögren's Day

- 💧 **Increasing Social Media Presence**

- 💧 Facebook, Twitter & Blogs
- 💧 April 2013 Facebook Campaign reached 3,189,577
- 💧 Introduced 2 Sjögren's Blogs

- 💧 **Expanding our Awareness Ambassador Program**

The SSF is increasing awareness by...

💧 **Building partnerships:**

- 💧 Launched a national partnership with Tupperware
- 💧 American College of Rheumatology Simple Tasks Campaign
- 💧 Partnered with celebrities – Shannon Boxx and Venus Williams

💧 **Telling the Sjögren's Story**

- 💧 Utilizing patients stories through Sjögren's Webpage, social media, traditional media & other publications
- 💧 Was chosen by The Giving Library to create two information videos about the SSF

The SSF is educating by...

- ◆ **Serving as the most credible resource through our...**
 - ◆ 65 patient support groups in the United States
 - ◆ 503 Awareness Ambassadors
 - ◆ Annual National Patient Conference
 - ◆ www.sjogrens.org
 - ◆ Moisture Seekers Newsletters
 - ◆ Resource Sheets & Brochures
 - ◆ Books and CDs
- ◆ **Expanding relationships with associations that represent healthcare professionals that treat Sjögren's.**

The SSF is educating by...

- 💧 **Developing the first-ever Clinical Practice Guidelines for how to treat, manage and monitor Sjögren's**
 - 💧 Currently over 150 healthcare professionals volunteering on three sub-groups
 - 💧 Oral Manifestations
 - 💧 Ocular Issues
 - 💧 Systemic Manifestations
 - 💧 Final product will give physicians and dentists data and options on how to treat Sjögren's as well as monitor patient's risk of developing serious complications
 - 💧 Project is currently being supported by American College of Rheumatology and American Dental Association

The SSF is encouraging research by...

- **Launching a Clinical Trials Consortium to:**
 - Facilitate more Sjögren's clinical trials in the US by:
 - Increase education among pharmaceutical industry
 - Recruiting physicians that are interested in conducting clinical trials in Sjögren's (76 so far)
 - Connecting companies with potential patients
 - Engage in dialogue with FDA to speed approval of new therapies

The SSF is encouraging research by...

- 💧 **Continuing to fund innovative research**
 - 💧 SSF Awarded 6 research grants in 2013
 - 💧 Recent Awardees included research into:
 - 💧 Genetics/Epigenetics
 - 💧 Mechanisms in Dry Eye
 - 💧 Novel Diagnostics
 - 💧 Novel Molecular Mechanisms
 - 💧 Immunology
- 💧 **Advocating for more federal funding for research**

Fundraising & Events

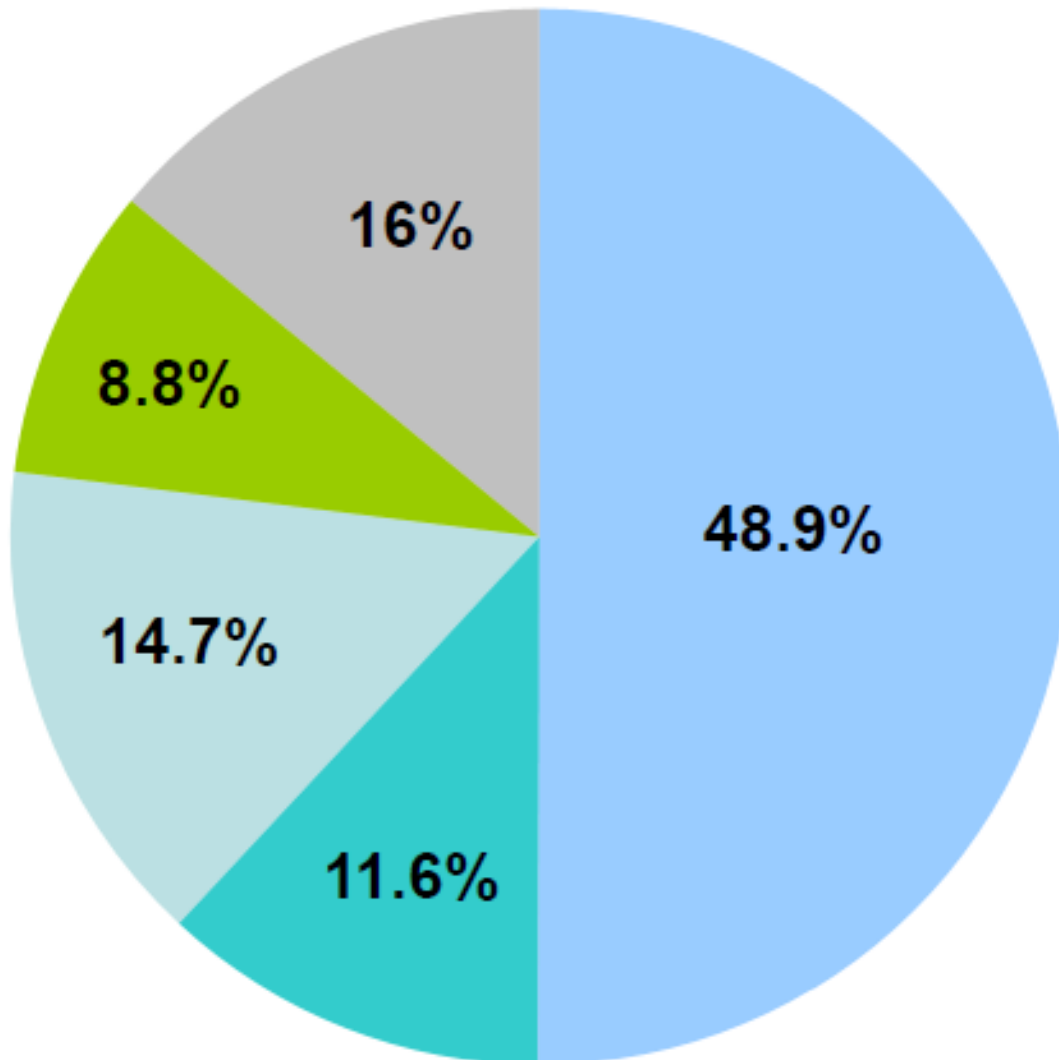
- 💧 **The SSF holds fundraising and awareness events in various states throughout the year**
 - 💧 **Sjögren's Walkabouts take place in 13 states; 5 of them incorporate a Health Fair which includes non-profits, healthcare professionals, government agencies, and other health-related companies in the community.**
 - 💧 **Sip for Sjögren's *Fine Water Tasting* takes place in 3 states.**
 - 💧 **Team Sjögren's participates in 2 marathons each year including numerous individuals that participate in their local Turkey Trot or events in support of the SSF.**
 - 💧 **SSF works with individuals throughout the country to organize third-party fundraisers in their local community.**

FY 2012/2013 Financials

Income & Expenses

FY 2012/2013 FINANCIALS

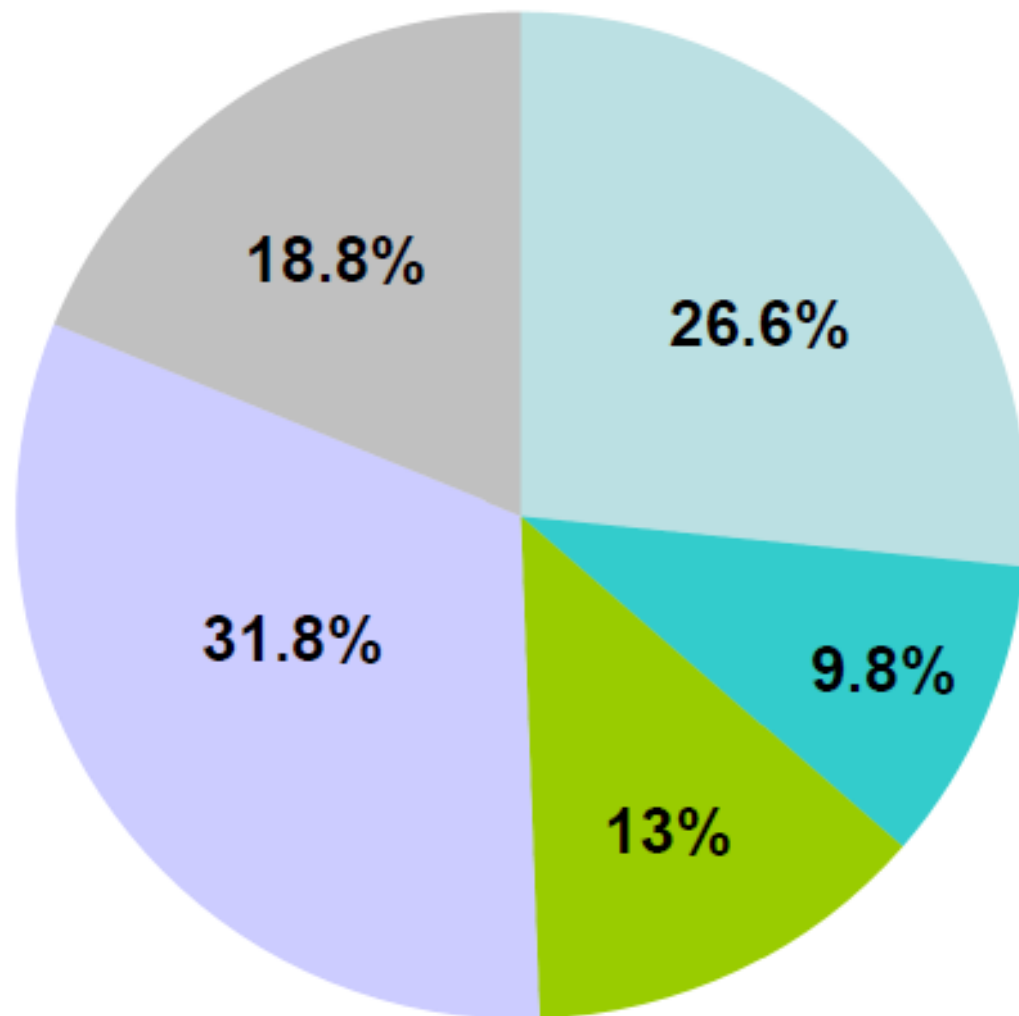
INCOME TOTAL = \$1,677,327








- Contributions**
\$820,439 – 48.9%
- Conferences & Products**
\$195,404 – 11.6%
- Dues**
\$246,441 – 14.7%
- Other**
\$146,895 – 8.8%
- Special Events (net)**
\$268,148 – 16%

FY 2012/2013 FINANCIALS

EXPENSES TOTAL = \$1,850,798



 Patient Services	\$492,949 – 26.6%
 Administration	\$180,932 – 9.8%
 Fundraising	\$240,078 – 13%
 Awareness	\$587,839 – 31.8%
 Research	\$349,000 – 18.8%

FY 2012/2013 Donors

Donors & Supporters

FY 2012-2013 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, Inc.
Carroll Petrie Foundation
Galewood Foundation
Sheila Leach*

\$10,000 - \$49,999

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FY 2012-2013 Donors

\$1,000 - \$4,999

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Acculens

Apothecary

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FY 2012-2013 Donors

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

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FY 2012-2013 Donors

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

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Greens, Inc.*



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

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