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

S. Lance Fortsot, MD
Chairman of the Board

Ken Economou
Chair-Elect

Pamela S. Brown
Secretary

Kathryn P. McCarren
Treasurer

Denise Faustman, MD, PhD
Medical & Scientific Advisory Board Chairman

Estrella Bibbey
Michael Brennan, DDS
Nancy L. Carteron, MD, FACR
Janet E. Church
Stephen Cohen, OD
Jack Faricelli
Theresa Lawrence Ford, MD
Mary McNeil
Lynn M. Petruzzi, RN, MSN
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
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
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”
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
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
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.
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
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.
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
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

$5,000 - $9,999

- Allergan Foundation
- Andrea Cavitolo Foundation
- Leonard & Barbara Berenfield
- Sharon Bromberg
- Kate Cubitt
- Troy & Leslie Daniels, DDS
- Kathleen Marble
- The Newell Devalpine Foundation
- Steven Taylor
- TearLab Corporation

$10,000 - $49,999

- Akorn, Inc.
- Bannon Humphery Foundation
- Daiichi-Sankyo, Inc.
- Eye Eco, Inc.
- Mary Hammond
- Human Genome Sciences
- Invado Pharmaceutical
- MedActive Oral Pharmaceuticals
- Mediacom US
- Pfizer Pharmaceuticals
- SLCM, LLC
FY 2012-2013 Donors

$1,000 - $4,999

Mou-Lan Abbott
Acculens
Apothecary
Arthritis & Rheumatism Associates, P.C.
David Berger
Charles Borchelt
Joyce Branch
Bristol Myers Squibb
Jennifer Bromberg
Carol Carrochi
Nancy Carteron, MD
Casale Rent-All, LLC
The Chicago Community Foundation
Janet Church

Cinemedia
Lindsey Criswell, MD
Paul Clifford
Betty Collier
Colorado Center for Arthritis and Osteoporosis
Community Foundation for Northeast Georgia
Corneal Consultants of Colorado
Cotton Market & Risk Management Consulting, Inc.
D&D Custom Construction
Desert Harvest
Sheriese & Chris DeFruscio
Corrine Devereux
Kenneth & Anne Economou
Elizabeth Hekman Gordon Family Foundation

Fallien Cosmecueticals
Jack & Lisa Faricelli
S. Lance Forstot, MD
The Fred R. Fernandez - Irma R. Rodríguez Foundation
Freddie Mac Foundation
Stacey Gallant
Patrick and Julia Garvey
Genalyte, Inc.
Genex
Robert & Adrienne Ginsberg
Elisabeth Giovine
GlaxoSmithKline
JoAnn Graham
Teresa Grenier
Janet Haley
FY 2012-2013 Donors

$1,000 - $4,999 cont’d

Ronald Hansman
William Hartman
The Harvey Hubbell Foundation
AI & Debbie Herman
Richard Hurd
Immco Diagnostics, Inc.
Integrity Metals & Slitting
Kathy Ivory
Jewish Communal Fund
Jim & Joan Walsh Foundation
Jim & Marlene Greene Foundation
Peter Joseph
JVR Communications
Jean Kahan
Joan Kahn

Japji Khalsa
Mary Kimball
Kirkland & Ellis Foundation
Jane Korman
KPMG
Laclede, Inc.
Eric & Wendy Leon
Lawrence & Sylvia Wong Foundation
Levanthan Sutton & Gornstein
Lil’ Drug Store
Theresa Lee Markowitz, PhD
Audrey Mattos
Bonnie McCabe
Kathryn McCarren
Marie McMahon
Merck Employee Giving Campaign

Metal Prep Company, Inc.
Sherree Meyers
Microsoft
Margaret Moore
MSL- New York
The Nathan P. Jacobs Foundation
Linda & Kerry Neall
Lori Neely
Kathleen Nichols
Patricia Nicholson
Oasis Medical, Inc.
Old Republic Title
Charles O’ Niell III
Orahealth USA
Ann Pearson
Ashley Pease
FY 2012-2013 Donors

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

Penn Medicine
Andrea Pines
Prudential Foundation
Quantum Health, Inc.
Revere Control Systems
Lourdes & Paul Ruh
Sylvia Scheinfeld
Nancy Schoofs, RN
Linda Schurman
Ida Shachar
Gary Skidmore
Charles Smith III
Marc & Bonnie Sosin
Jack Sperco

Anne & Frederick Stemp
Sally Thornton
Greg Tiemeier
UPS Foundation, Inc.
Venta Airwasher, Inc.
Fred & Virginia Vivino
Norman & Marilyn Weizenbaum
Irmtraud Carey Wettjen
Winthrop University Hospital
Monica Wischmeyer
The Women’s Group of the Greens, Inc.
Special thanks to our volunteers, staff and donors who made this past year such a great success!
Contact Us

6707 Democracy Blvd
Suite 325
Bethesda, MD 20817
(301) 530-4420 / (301) 530-4415 (fax)
www.sjogrens.org
info@sjogrens.org