

ANNUAL REPORT



Annual Report FY 2010-2011

YEAR IN REVIEW

To our supporters:

July 1, 2010 - June 30, 2011 was another great year for the Sjögren's Syndrome Foundation. The Foundation continued on its path of supporting Sjögren's research, adding to our educational programs as well as working on raising awareness about this debilitating disease.

We continue to provide our members and patients with excellent customer service and hope to serve as the credible source for Sjögren's information for all stakeholders – including patients, their families as well as healthcare providers.

We are very proud of our accomplishments this past year as you will see below. We also have available online or via US mail – our Federal 990 Tax Return as well as audited financial report. Please visit www.sjogrens.org or contact us at 1-800-475-6473 for those additional documents.

A special thank you to all those that supported us this past year. Your support is greatly appreciated and it is because of you – we are able to continue our great programs and services that help Sjögren's patients and their loved ones

Sincerely,

SSF Board of Directors

Board of Directors



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Kathy Hammitt

Vice President of Research

Our 2010-2011 Priorities

The SSF's Board of Directors adopted three priorities for fiscal year 2010-2011. They were as follows:

- *Increase Awareness of Sjögren's and the Sjögren's Syndrome Foundation*
- *Improve services, support and resources for patients and professionals*
- *Strengthen the Sjögren's Syndrome Foundation*

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

PRIORITY #1

***Increase Awareness of
Sjögren's and the Sjögren's
Syndrome Foundation***

Increase awareness of Sjögren's and the Sjögren's Syndrome Foundation

Developed and delivered plan to increase visibility of SSF online.

• Created a Social Media and Internet Plan:

- Created SSF Facebook Fan Page
- Started “MoistureSeekers” Twitter Page in April 2010
- Partnered with various organizations to utilize their social media pages. (ie Grapevine Mills Mall, Ben & Jerry's, Roosevelt Field Mall, Reston Town Center)
- Assisted with launch of www.livingwithdryness.com and www.defythedry.com websites to expand Sjögren's web presence.
- Expanded use of www.firstgiving.com fundraising website
- Regularly updated www.sjogrens.org

Increase awareness of Sjögren's and the Sjögren's Syndrome Foundation

Forged relationships with professional and community organizations to expand SSF outreach.

- 💧 **Forged stronger relationships with ACR, CLAO & AADR through SSF Student Fellowship program**
- 💧 **Partnered with Dental Hygiene Programs around the United States**
- 💧 **Expanded outreach to professional societies including statewide dental associations.**
- 💧 **Continued involvement with National Health Council**
- 💧 **Partnered with community groups to expand involvement in our Sjögren's Walkabouts**

Increase awareness of Sjögren's and the Sjögren's Syndrome Foundation

Expanded awareness and educational opportunities outside the Sjögren's Community

- 💧 Partnered with Ora Clinical Research Labs to host our 2011 National Dry Eye Patient Conference**
- 💧 Presented at 2011 California Dental Association's Annual Scientific Meeting**
- 💧 Increased community awareness activities by launching our Awareness Ambassador program**

Increase awareness of Sjögren's and the Sjögren's Syndrome Foundation

Launched innovative awareness programs including:

- 💧 Educational DVD on Sjögren's
- 💧 Assisted with development of www.livingwithdryness.com website and testimonial videos
- 💧 Launched 2011 Awareness Ambassador Program – “Defy the Dry.”

PRIORITY #2

Improve services, support and resources for patients and professionals

Improve services, support and resources for patients and professionals

Continued to serve as the organization that offers credible information on Sjogrens' through our:

- 💧 **4th Edition of the Sjögren's Book published September 2011**

- 💧 **Patient educational materials and conferences including:**
 - Our new Product Directory
 - Our re-designed Dry mouth, Dry eye and What is Sjögren's brochures
 - Our 3 patient conferences
 - Our national dry eye patient conference

- 💧 **Moisture Seekers & Sjögren's Quarterly Newsletters**

Improve services, support and resources for patients and professionals

Served as lead voice and resource to encourage the expansion of Sjögren's research.

- 💧 **Served on coalitions to encourage more funding for NIH**
- 💧 **Received more funding from major donors to support Sjögren's Research**
- 💧 **Supported CAMBRA Meeting with California Dental Association**
- 💧 **Provided oral and written testimony for SSA Compassionate Hearing Allowances**

Improve services, support and resources for patients and professionals

Ensured a leadership role for SSF in improving patient treatment through development of Clinical Practice Guidelines and encouraging the investigation into new therapeutics.

- 💧 **Continued to move forward with development of CPG**
- 💧 **Created alliance with American College of Rheumatology on CPG including:**
 - **Recruiting ACR Representative to assist SSF with guidelines**
 - **Following ACR protocol for development of guidelines**
 - **Increasing recruitment of physicians/dentists for working groups**
- 💧 **Enhanced relationships with companies that have an interest in launching new products for Sjögren's**

Improve services, support and resources for patients and professionals

**Awarded over \$270,000 in Sjögren's research grants
to the following institutions:**

- 💧 Allegheny-Singer Research Institute
- 💧 Schepens Eye Research Institute
- 💧 University of California, San Francisco
- 💧 UCLA School of Dentistry
- 💧 The Research Foundation of SUNY, University at Albany
- 💧 Oklahoma Medical Research Foundation
- 💧 University of Florida, Gainesville

PRIORITY #3

***Strengthen the
Sjögren's Syndrome
Foundation***

Strengthen the Sjögren's Syndrome Foundation

Evaluated SSF programs and events to ensure long term growth and viability for SSF. (e.g. events, support groups, publications, etc.)

- 💧 **Evaluated all support groups and surveyed leaders**
- 💧 **Evaluated all special events for potential**
- 💧 **Continued Editorial Committee for TMS to ensure quality newsletter each month**

Strengthen the Sjögren's Syndrome Foundation

Investigated and evaluated additional revenue streams

Continued to streamline internal processes to best utilize limited staff resources.

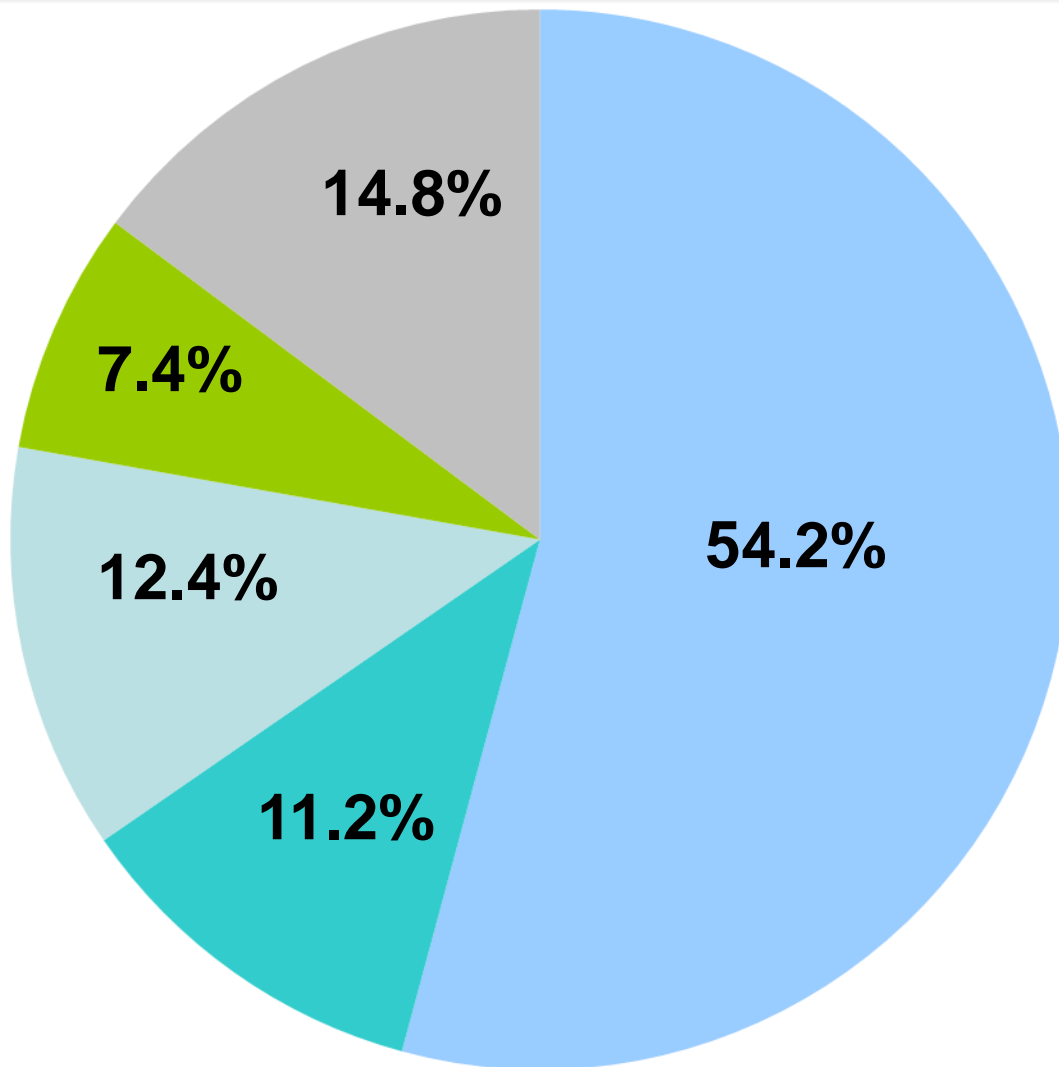
Cultivated relationships with potential/future board members, MSAB members and national volunteers.

FY 2010/2011 Financials

Income & Expenses

FY 2010/2011 FINANCIALS

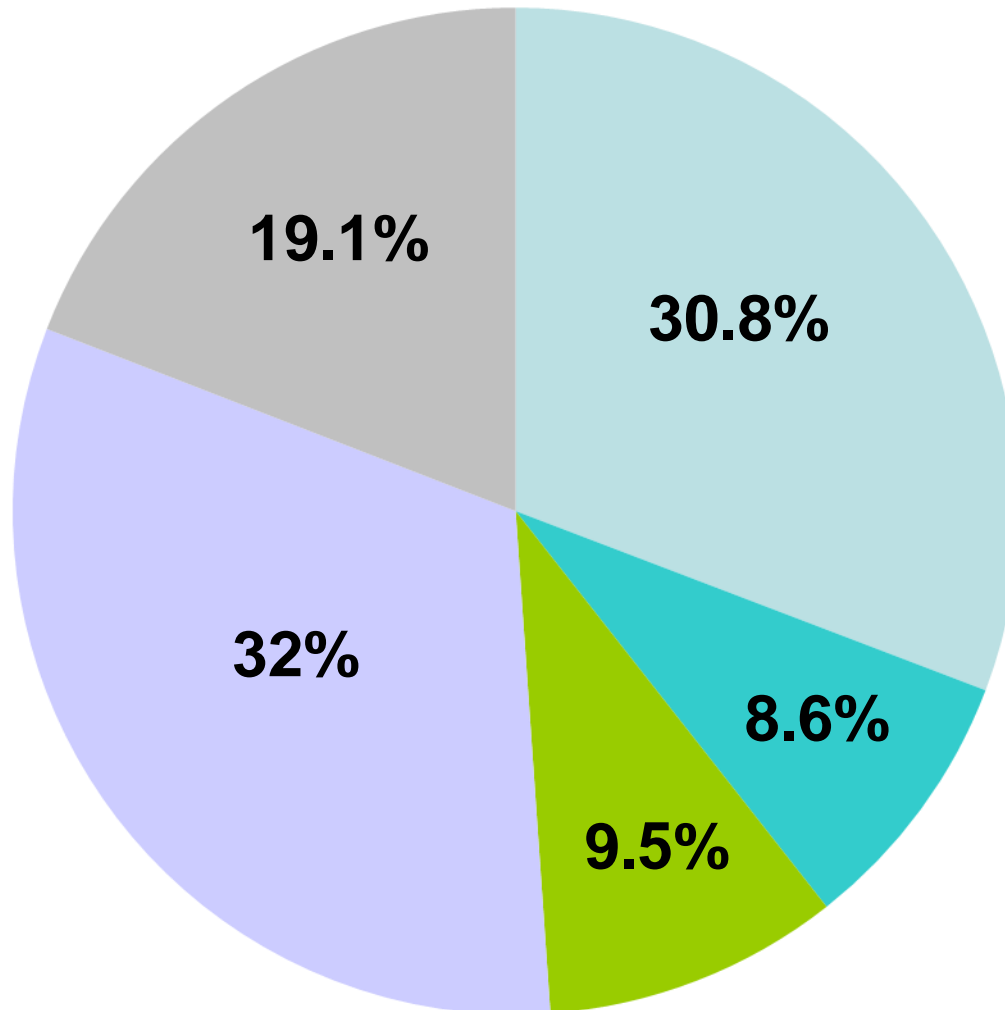
INCOME TOTAL = \$2,059,419



- Contributions**
\$1,116,925 – 54.2%
- Conferences & Products**
\$230,508 – 11.2%
- Dues**
\$254,345 – 12.4%
- Other**
\$152,601 – 7.4%
- Special Events (net)**
\$305,040 – 14.8%

FY 2010/2011 FINANCIALS

EXPENSES TOTAL = \$2,055,957



■ Patient Services

\$632,118 – 30.8%

■ Administration

\$177,261 – 8.6%

■ Fundraising

\$196,081 – 9.5%

■ Awareness

\$658,288 – 32%

■ Research

\$392,209 – 19.1%

FY 2010/2011 Donors

Donors & Supporters

FY 2010-2011 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 +

Advanced Vision Research

Allergan

Daiichi-Sankyo

Galewood Foundation

Sheila Leach

Adele Smith

\$10,000 - \$49,999

Align Pharmaceuticals

Troy & Leslie Daniels

Mary Fidler

GlaxoSmithKline

Mary Hammond

LaCleda

MediaCom

The Newell Foundation

\$5,000 - \$9,999

Alcon Laboratories

Amplimmune

Andrea Cavitolo Foundation

Anonymous

Sophia & Bruce Beckley

Fred Fernandez & Irma Rodriguez Foundation

Susan Gatto

Humphery Bannon Foundation

Kathleen Marble

Quantum Health

SLCM, LLC

Steven Taylor

Hannah Yu

FY 2010-2011 Donors

\$1,000 - \$4,999

7eye

Mou-Lan Abbott

Hector Alcalde

Elaine Alexander

Arizona Community Foundation

Arthritis & Rheumatism Associates, P.C.

John Barrette

Ben & Jerry's

Estrella Bibbey

Peter Binkow

Charles Borchelt

Tracey & James Bottiglia

Johnathon Brandau

Susan Bridges

Jennifer Bromberg

Sharon Bromberg

Chad Brown

Gianna Casale

Corneal Consultants of Colorado

Cotton Market & Risk Management

Fern & Al Davis

Cliff & Roberta Detz

Deutsche Bank Americas Foundation

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Ken & Anne Economou

Eye Eco Inc.

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G J Murch, Inc.

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Donna Gotshall

Rondald Hansman

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Andrew Hixon

Nancy Huerter

Integrity Metals & Slitting

Jewish Communal Fund

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Lawrence & Sylvia Wong Foundation

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Madison Street Holding Company Inc.

Kathryn McCarren

MedActive Oral Pharmaceuticals, LLC

Metal Prep Company, Inc.

Mills Family Charitable Foundation

FY 2010-2011 Donors

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

Margaret Moore

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OcuSoft

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Lynn-Anne & Stuart Spitzer

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The Harvey Hubbell Foundation

The Jim and Marlene Greene Foundation

The National Football League

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Valentine

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Wischmeyer Benefit Partners

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