Young attendees at the 2015 National Patient Conference in Nashville, Tenn.
The 2015 Annual Report is a publication of the Scleroderma Foundation, Robert J. Riggs, Chief Executive Officer. Thanks to those who submitted photos. The book was printed by LaPlume & Sons Printing Co., Inc. of Lawrence, Mass.
Dear Friends,

On behalf of all of us at the Scleroderma Foundation, please accept our most sincere appreciation for your support of our mission. We are honored to provide support, education and research for all those affected by scleroderma.

In FY 2015-16, we maintained our staunch commitment to research, funding more than $2 million in grants that were awarded to stimulate improved treatments while in search of the cure of scleroderma. We are honored to have an outstanding independent Peer Review Committee to guide our grant making. Dr. Carol Feghali-Bostwick, the National Board Vice-Chair and Chair of the Research Committee is a true point of pride, as she continues her study of lung fibrosis. Her findings are not only helpful to those with scleroderma but cross over seamlessly to a multitude of other lung illnesses.

The foundation held its 17th Annual National Patient Education Conference in Nashville in July, 2015. More than 600 patients, including many first time attendees and caregivers benefited from the 67 workshops conducted over three days. Expanded programming for children and teens was well received. Education is a key part of our mission, and this conference was the keynote of this effort.

Support for our patients and their families is part of every day’s work at the national office and in the chapters. The foundation is usually the first call made by the newly diagnosed in search of answers and resources. We strive to provide our callers with the most recent information and to connect them with a support group in proximity to their location.

Another endeavor deeply engrained in the foundation’s culture is our Stepping Out for Scleroderma Walks. This past walk season saw 66 events held from coast to coast while raising $1 million, significantly increasing visibility and awareness in the process.

However, none of this would be possible without generous donations from people like you! We strive to be worthy of your support and we have been earned the highest rating from Charity Navigator. Further, we conduct independent audits annually to ensure that we observe best practices of management with complete transparency.

Thank you for joining my family and me in supporting Scleroderma Foundation so that we may continue to serve the needs of the scleroderma community.

Sincerely,

Cos Mallozzi
Chair Board of Directors
What is SCLERODERMA?

Scleroderma is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. It is also known as systemic sclerosis. Hardening of the skin is one of the most visible manifestations of the disease, but symptoms vary from patient to patient. The effects of scleroderma can range from mild to life-threatening.

Currently, there is no cure for the disease, but there are many treatments for particular symptoms.
What is the SCLERODERMA FOUNDATION?

The Scleroderma Foundation is committed to its mission of Support, Education and Research for the benefit of all who have been affected by scleroderma. There is no known cause and no known cure. Our vision is to support our patients while funding research to find the cure.

The foundation has 20 active chapters and 160 support groups across the country.

To fulfill our mission, we fundraise to support research and patient support. We are pleased to provide you with this Annual Report.

Now, more than ever, we ask for your support! We can’t do it without you.
How we rank

Why INVEST in us?

Charity Navigator has awarded the Scleroderma Foundation a FOUR STAR rating.

According to its website, Charity Navigator has become the nation’s largest and most-utilized evaluator of charities.

The foundation annually incorporates best practices and principles to operate effectively and efficiently. As such, its performance ranks favorably in key factors utilized by Charity Navigator. Below are some of the foundation’s key metrics and figures that led to its achieving the highest available four-star rating.

Program Expenses: 84.6%

The percentage of total expenses spent on programs and services.

Fundraising Expenses: 4.2%

The percentage of total expenses spent to raise money that may include campaign printing, publicity, mailing and staffing costs incurred in soliciting donations, grants and memberships.

Fundraising Efficiency: $.04

The amount spent to raise every $1 in donations.

Administrative Expenses: 10%

The percentage of total budget spent on overhead, administrative staff and associated costs.

Program Expenses Growth: 9.5%

The percentage of growth from one year to the next.
a glance at our chapters

As of June 30, 2016, the foundation has 20 active chapters from coast to coast and 160 support groups to help patients, their families and friends. The map below illustrates the 20 chapter locations.
facts and figures

- **1.7m** Dollars awarded to research grant recipients
- **3,118** Discussion threads on Inspire web community
- **643** National conference attendees
- **59** National conference scholarships awarded
- **7,191** Scleroderma Info Packets shared
- **1,921** Total patient contacts by phone and email
- **75** Advocates at Capitol Hill Day in Washington, D.C.
- **42** Parents and Youth at national conference
The mission of the Scleroderma Foundation is SUPPORT, education and research.

We are fully committed to SUPPORTING patients and their families through mutual support programs, peer counseling, physician referrals and information. This important work is not possible without the generous SUPPORT of our donors.

Our 20 active chapters and 160 support groups provide safe settings for patients and their families to share feelings and concerns. Many of the chapters host patient education seminars. For those unable to join a support group, the foundation website offers comprehensive and current information. We also furnished more than 1,000 Scleroderma Information Packets to people who call our helpline at 800-722-HOPE.

The foundation hosts an online discussion community which grew by more than 18 percent in this fiscal year. The online community provides support, education and encouragement to patients and their families.

The foundation continually engages in new and innovative methods to SUPPORT our patients and their families.
education

The mission of the Scleroderma Foundation is support, **EDUCATION** and research.

In FY 2015-16, the foundation hosted its Annual Patient Education Conference in Nashville Tennessee from July 17-19. The conference was a major success, and we acknowledge the tremendous support and southern hospitality from the Tennessee Chapter.

Attended by over 600 patients, caregivers and medical professionals, the primary focus of the conference was education. Topics ranged from Pulmonary Arterial Hypertension, Classifications of Medications Used for Scleroderma to Emerging Therapies. Dr. Carol Feghali-Bostwick presented the key note address of S.C.I.E.N.C.E. ---So Cool It’s Everything Nature Can’t Explain. Dr. Feghali-Bostwick articulated how research is done and relevant to patients with scleroderma.

This year, we concurrently hosted a special program for 70 children and teens. The program is focused on pediatric patients and the children of patients. The goal of the program was to reinforce individuality and resilience.

The national conference is a highlight of our **EDUCATION** mission but not its only compment as we strive on a daily basis to deliver relevant and updated content across our platforms. Every week, the foundation publishes an e-newsletter with information for the scleroderma community. We frequently update our website with the latest news on new research and other exciting advances.
conference metrics on the rise

Scholarship Recipients

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Youth (5-17) Attendees and Parents

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Total Attendees

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<td>548</td>
<td>606</td>
<td>619</td>
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research

The mission of the Scleroderma Foundation is support, education and RESEARCH.

Our goal is to stimulate and support research to improve treatment and ultimately, find the cause and the cure of scleroderma and related disease.

The foundation’s Research Grant Funding Program has earned a unique place in the field of scleroderma research. It is respected by medical researchers and by government health agencies such as National Institutes of Health (NIH) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The program is administered by the Scleroderma Foundation’s Board of Directors and staff, and guided by the foundation’s Peer Research Review Committee. This committee, composed of scleroderma medical experts from around the world, helps determine which proposals will be funded each year by reading, critiquing and ranking all applications based on a scoring system utilized by the NIH.

We are proud to make available $2 million for new research projects, making the foundation the largest nonprofit funder of peer reviewed scleroderma-related research in the United States. On the following pages, you will learn more about the researchers and investigations funded in the 2016 grant cycle.
meet our grant recipients

During 2016, the foundation funded seven proposals through its regular grant funding program as well as a Multi-Center Research Grant (SCORE). A number of the grants are named in honor or in memory of significant figures and pioneers in the fight against scleroderma. The Marta Marx Fund for the Eradication of Scleroderma is funded by bequests from its namesake who had scleroderma as well as by her brother Rudolph Juhl. The Mark Flapan Award pays homage to the late psychologist and scleroderma patient. The Marie A. Coyle Award pays tribute to one of the foundation’s founders.

The research program has four hallmarks:

- Casting a wide net by soliciting proposals from a large pool of scientific talent.
- Providing seed grants for researchers to establish preliminary data in hopes that a larger project may result in a significant and long-term grants from the National Institutes of Health (NIH).
- Using the NIH peer review model to only fund proposals with scientific merit.
- Cultivating the next generation of researchers through its Early Career Investigator Workshop.

All of the gifted and talented researchers went through a rigorous and thorough approval process by the foundation’s Peer Review Committee. Each chose to study different aspects of the disease and hail from universities throughout the country. The grant recipients’ work is integral in achieving the ultimate goal of curing the disease.
meet our 2016 grant recipients

Marie A. Coyle Research Grant
Functional Analysis of the Contribution of Adipocytes to Scleroderma’s Skin Fibrosis
Valerie Horsley, Ph.D. -- Yale University

Mark Flapan Award
Function and Antifibrotic Mechanism of M10 in Scleroderma
Galina Bogatkevich, M.D., Ph.D. -- Medical University of South Carolina

Kao Family Foundation Score Grant
Identifying Juvenile Scleroderma Immunophenotype Subsets
Kathryn Torok, M.D. – Children’s Hospital of Pittsburgh and University of Pittsburgh Scleroderma Center

Marta Marx Fund for the Eradication of Scleroderma
Histone Deacetylases in Scleroderma: Investigation of Their Roles in Dysregulated Angiogenesis
Pei-Suen (Eliza) Tsou, Ph.D. – University of Michigan

Targeting Stat3 in Systematic Sclerosis and Dermal Fibrosis
Sandeep Agarwal, M.D., Ph.D. – Baylor College of Medicine

Profibrotic Role of TLR4 in Scleroderma: A Novel Target for Therapy
Swati Bhattacharyya, Ph.D. – Northwestern University, Feinburg School of Medicine

Adiponectin Drives Fibrosis in Systematic Sclerosis
Roberta Marangoni Goncalves, M.D., Ph.D. – Northwestern University, Feinburg School of Medicine

Regulation of Leukocyte: Matrix Interactions by Netrin-1 in Scleroderma ILD
Huanxing Sun, Ph.D. – Yale University
advancing our mission

Why your SUPPORT matters!

Your contribution supports the foundation’s efforts to empower individuals with resources and information about living with scleroderma. Your gift delivers education and support to caregivers and patients’ loved ones.

Every day, we receive calls from newly diagnosed patients. We are able to connect them with necessary resources as they come to terms with their diagnosis. Your generous contribution makes the time devoted to each caller possible. Our donors’ generosity enables us to provide no-cost educational materials and other pertinent resources upon request. This year more than 7,500 packets were downloaded from our website or mailed.

As a national foundation with 20 active chapters and 160 support groups across the U.S., our work is not possible without you.

Anyime you contribute to the Scleroderma Foundation, you’re helping us move towards an eventual cure. In addition to straight donations, other options including appreciated securities, charitable trusts and gifts directly from your IRA, if you’re 70½ and over are appreciated.
advancing our mission

• The Scleroderma Foundation website details current educational information about coping with the disease.

• The foundation’s YouTube videos provide insight for patients and caregivers.

• The online discussion community hosted by Inspire offers patients the opportunity to seek counsel and advice.

• Support groups provide in-person education and thoughtful encouragement.

• The Toll Free Hotline, 800-722-HOPE, handles thousands of information and help requests.

• Chapters host patient education seminars in their communities.

• The foundation advises on third party event fundraisers to support their events to raise funds for research.

• The Annual Capitol Hill Day brings patient advocates to legislators’ offices to underscore the need for increased research funding.
advocating our message

The Scleroderma Foundation takes its mission of advocacy to Capitol Hill every year. FY 2015-16 was certainly no exception.

On October 6, 2015, Robert Riggs led a group of 34 patients, caregivers and board members to Capitol Hill. Advocating with legislators is a critical part of our mission to ensure that federal funding for research continues to grow. The National Institute of Health is the primary federal funder, and funding critical research for all diseases continues to fall behind. In the rare disease space, a lack of resources results in fewer clinical and basic scientific research.

The Scleroderma Foundation was pleased to announce that on September 25, 2015, a bi-partisan bill was introduced into the U.S. House of Representatives. The Scleroderma and Fibrosis Research Enactment Act of 2015 (H.R. 3666) sought to improve health outcomes for scleroderma and fibrotic disease patients. The goal of the bill was to establish a national commission to develop a long-range research plan to study scleroderma as a prototypical condition for fibrotic disease.

Support and advocacy for this bill was the primary focus of the Scleroderma Foundation’s Capitol Hill Day efforts. Congressional response to the scleroderma advocates resulted in a recommended increase in research funding of $600 million.
advocating our message

Also, the foundation is pleased to report that more than 1,000 members responded to our call to action by contacting elected officials to request that scleroderma be included in the list of “approved conditions for research” under the Department of Defense’s Peer Review Medical Research Program.

From Capitol Hill to communities throughout the country, advocacy-related efforts of our members, patients, board members and staff make a meaningful difference every year. It is critical that we continue to ADVOCATE with determination and will.
recapping our walks

Stepping out to Cure Scleroderma events are a true point of pride as well as successful endeavors that have been ingrained in the foundation’s culture for years. Annually, chapters from coast to coast engage their constituencies in peer-to-peer fundraising to spread an inestimable amount of awareness and raise funds that go towards an eventual cure of scleroderma. The foundation provides direct guidance and support by custom designing websites geared towards donations. These websites create a sense of team-building and participant coaching. Chapter leaders and a loyal corps of volunteers handle event logistics prior to and on each walk day. Often, pre-event publicity and promotion performed at the grassroots level results in more walk participants and an uptick of overall awareness of the disease.

During walk season 2016, nearly 70 events were held raising $1 million. These metrics marked a significant increase from prior years. In all, a steady rise was seen in event registration, registration fees collected, total gifts as well as total donors.

What follows are joyful moments captured from walks across the country.
recapping our walks
hope
noun

a feeling of expectation and desire for a certain thing to happen.

synonyms: aspiration, desire, wish, expectation, ambition, aim, goal, plan, design, dream
appreciating our sponsors

The foundation is extremely grateful to its calendar year 2016 corporate sponsors. The generous support of these corporations and their staunch commitment to scleroderma research is necessary and appreciated.

Corporate sponsors attaching themselves to the foundation’s brand enjoy numerous opportunities for visibility and exposure across the country. The sponsors’ branding displayed prominently on the foundation’s website and the sites of all 20 active chapters which receive hundreds of thousands of visitors annually. In addition, event signage and logoed apparel bear their service mark as well.

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Bayer HealthCare

Boehringer Ingelheim

Genentech

Gilead Sciences

REATA Pharmaceuticals

United Therapeutics
Tennessee Chapter members and national conference volunteers show their exuberance.
saluting our donors

The Scleroderma Foundation is committed to each aspect of its mission of support, education and research. Thank you for collaborating with us on this work. Through our partnerships with you, we touch lives, bringing hope and compassion. We also deliver much needed research funding to bring us closer to a cure. Together, we make a difference in the scleroderma community and beyond.

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Combined Federal Campaign
Gilead Sciences, Inc.

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Martha Pierson
Kathleen Dean Prep
Lori Presley
Progressive Casualty Insurance
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Jim Snyder
Nancy Sokil
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Viant, Inc.

We gratefully acknowledge our donors and thank you for your support. Please accept our sincerest apologies if we have made any errors with your name or gift. Please note that the date range for the acknowledgment of the gifts above is July 1, 2015-June 30, 2016.
## FY 2015-16 financials

### Scleroderma Foundation Fiscal Year Ended June 30, 2016

<table>
<thead>
<tr>
<th>Revenue and Other Support</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>2015-16 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>2,284,888</td>
<td>305,233</td>
<td>0</td>
<td>2,590,121</td>
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<tr>
<td>Special Events, net</td>
<td>633,726</td>
<td>0</td>
<td>0</td>
<td>633,726</td>
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<tr>
<td>Contributions from Affiliates</td>
<td>504,858</td>
<td>0</td>
<td>0</td>
<td>504,858</td>
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<tr>
<td>Voluntary Research Contributions</td>
<td>0</td>
<td>191,256</td>
<td>0</td>
<td>191,256</td>
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<tr>
<td>Interest and Dividends</td>
<td>128,879</td>
<td>43,859</td>
<td>0</td>
<td>172,568</td>
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<tr>
<td>Net Unrealized Losses on Investments</td>
<td>(160,155)</td>
<td>(8,909)</td>
<td>0</td>
<td>(169,064)</td>
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<tr>
<td>Returned Grant Awards</td>
<td>99,206</td>
<td>0</td>
<td>0</td>
<td>99,206</td>
</tr>
<tr>
<td>Registration Fees</td>
<td>91,105</td>
<td>0</td>
<td>0</td>
<td>91,105</td>
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<tr>
<td>Bequests</td>
<td>17,680</td>
<td>0</td>
<td>0</td>
<td>17,680</td>
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<tr>
<td>Other Income</td>
<td>2,000</td>
<td>0</td>
<td>0</td>
<td>2,000</td>
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<tr>
<td>Net Assets Released from Restrictions</td>
<td>844,054</td>
<td>(844,054)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total Revenue and Other Support</strong></td>
<td>4,471,907</td>
<td>(302,627)</td>
<td>0</td>
<td>$4,169,280</td>
</tr>
<tr>
<td>Expenses - Program Services:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education and Support</td>
<td>2,565,604</td>
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<td>0</td>
<td>2,565,604</td>
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<tr>
<td>Research</td>
<td>1,633,995</td>
<td>0</td>
<td>0</td>
<td>1,633,995</td>
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<tr>
<td><strong>Total Program Services</strong></td>
<td>4,199,599</td>
<td>0</td>
<td>0</td>
<td>4,199,599</td>
</tr>
<tr>
<td>Expenses - Supporting Services:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General and Administrative</td>
<td>514,872</td>
<td>0</td>
<td>0</td>
<td>514,872</td>
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<tr>
<td>Fundraising</td>
<td>221,285</td>
<td>0</td>
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<td>221,285</td>
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<tr>
<td><strong>Total Supporting Services</strong></td>
<td>736,157</td>
<td>0</td>
<td>0</td>
<td>736,157</td>
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<tr>
<td><strong>Total Expenses</strong></td>
<td>4,935,756</td>
<td>0</td>
<td>0</td>
<td>4,935,756</td>
</tr>
<tr>
<td>Increase (Decrease) in Net Assets</td>
<td>(463,849)</td>
<td>(302,627)</td>
<td>0</td>
<td>(766,476)</td>
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<tr>
<td>Net Assets at Beginning of Year</td>
<td>8,298,303</td>
<td>577,295</td>
<td>1,542,375</td>
<td>10,417,973</td>
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<tr>
<td>Net Assets at End of Year</td>
<td>7,834,454</td>
<td>274,668</td>
<td>1,542,375</td>
<td>9,651,497</td>
</tr>
</tbody>
</table>

Audit performed by MFA – Moody, Famiglietti & Andronico, LLP, Tewksbury, Mass.
Full copies of the foundation’s FY 2015-16 audited financials are available at the national headquarters.
Inside the Numbers

Revenue

- Contributions: 50%
- Special Events: 13%
- Fundraising: 4%
- Registration: 19%
- Affiliate Dues: 10%
- General & Admin: 10%
- Research: 34%

Expenses

- Education and Support: 52%
- Research: 34%
- Fundraising: 4%
- General & Admin: 10%
- Bequests: 1%
- Net Unrealized Gain on Investments: 1%
- Voluntary Research Revenue: 3%
- Contributions: 50%
- Special Events: 13%
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Listing effective as of February, 2017.