Thanks to you, in 2012 the Scleroderma Foundation has...

- Chartered the Foundation’s 24th chapter to serve those living in Iowa, Nebraska, and eastern South Dakota
- Unveiled the Foundation’s newest research initiative, the “Multi-Center Collaborative Research Grant”
- Funded eight promising research projects
- Increased patient support through new support groups in Georgia, North Carolina, Ohio, New Jersey, Pennsylvania, Colorado, California, New York and New Mexico
- Designated three new Scleroderma Centers of Excellence
- Increased outreach to patients through social media with more than 10,000 following the Foundation
- Launched the Foundation’s largest and most comprehensive multichannel media campaign to spread awareness
- “Scleroderma Voice” recognized as most improved magazine or journal by the APEX Awards For Publication Excellence

- Raised revenues to support an increase in 2012 research funding to $1.2 million
- Hosted one of our largest National Patient Education conferences with over 500 in attendance
- Provided 33 scholarships to many first-time attendees to the Conference
- Sponsored the Second World Congress on Systemic Sclerosis held in Madrid, Spain
- Began efforts on a newly-designed website to provide a more valuable resource for those living with scleroderma
- Hosted Capitol Hill Day and National Congressional Call-In Day to continue advocacy for the “Scleroderma Research and Awareness Act
- Outreach efforts helped the U.S. Department of Defense fund three important scleroderma research projects

- Unveiled the Foundation’s first ever Continuing Medical Education Program for physicians and nurses.
- Provided direct support to thousands of those living with scleroderma through our weekly eLetter, the “Scleroderma Voice” quarterly magazine, our toll-free helpline, and over 60 patient education events hosted by our chapters
- Attracted over 13,000 participants to our “Stepping Out to Cure Scleroderma” walk-a-thons through the country
- Awarded Charity Navigator’s highest four-star charity rating for the 4th year in a row
- Increased outreach to the medical community through exhibits at major medical meetings, through publication of our third “Scleroderma Spectrum,” a publication specifically for medical professionals.
- Unveiled the new scleroderma.org website

- Exhibited strong fiscal responsibility spending 34 percent on patient support and advocacy, 49 percent on research and education, while keeping administrative costs to 13 percent and fundraising Costs to 4 percent.
A Message from the Board Chair, Joseph P. Camerino, Ph.D.

Dear Friends,

On behalf of the entire Scleroderma Foundation membership, I offer my most sincere thanks for your generous support of our organization’s mission. Whether you made a gift to the Annual Fund, to our research program, through one of the Foundation’s 24 chapters, in memory of someone whose battle with scleroderma has been lost, or as a volunteer of your time and talent, your commitment to the work of the Foundation sustains it.

During my tenure as Chair of the national Board of Directors, it has often struck me how diverse the scleroderma community is. Scleroderma does not discriminate, and our community is bound together by the common bonds that make up our mission: to support individuals and families impacted with this disease by providing education on how to live as fully as possible in spite of its challenges; and to foster the best research so that better treatments and, eventually, a cure can be found.

In this Annual Report, you will have the opportunity to look back at the activities and achievements that took place in 2012 that bind our community together. You’ll also see the financial report that encompasses our fiscal year (July 1, 2012 – June 30, 2013). From this report, you’ll see that the Scleroderma Foundation is financially strong, much thanks to the generosity of our members and friends. In challenging economic times, we’ve been able to sustain and even grow programs, including such things as our commitment to research funding, scholarships for patients to attend our National Patient Education Conference, and the development and rollout of a new Web site at www.scleroderma.org.

2012 also saw a breakthrough in fibrosis research from our own Dr. Carol Feghali-Bostwick, which you can read more about in this report on page 11. We also achieved the highest recognition from the independent nonprofit watchdog group, Charity Navigator, which awarded the Foundation its highest four-Star rating for a fourth consecutive year, demonstrating the organization’s commitment to strong financial management and programming.

I look forward to the day when the Chair’s message in the Scleroderma Foundation’s Annual Report will announce that the organization is going out of business because our goal of finding the cure for this disease will have become a reality. Until that time, however, all of us are bound together by our commitment to conquer scleroderma. Your continued support of our mission of support, education, and research can make that hope become a reality.

Sincerely,

Joseph P. Camerino, Ph.D.
Chair, Board of Directors

Only Those Who See the Invisible Can Do the Impossible!
The Scleroderma Foundation was established on January 1, 1998, through a merger between the West coast-based United Scleroderma Foundation and the East coast-based Scleroderma Federation, both organizations have histories dating back to the early 1970s. The merger united two groups sharing similar missions, goals and programs to collaborate and support the scleroderma community by funding important education and research initiatives.

Today, the Foundation has grown to include a network of 24 chapters and 160 support groups throughout the United States. Under the guidance of a 10-person Board of Directors, a three-fold mission of support, education and research drives the organization. A full-time staff in the National Office, based in metro Boston, manages daily operations.

**SUPPORT**

With the help of its chapters and support groups across the country, the Foundation connects people living with scleroderma. These groups host patient education seminars to inform those affected by the disease, including patients, caregivers, family members and friends. Thanks to the work of the chapters and support groups, individuals living with scleroderma are welcomed into a safe, positive and inspiring environment to learn more about the disease and hope for a better future. Additionally, the Foundation offers a toll-free support line with a dedicated staff to answer telephone inquiries and provide instructive materials and resources.

**EDUCATION**

Education has always been a vital piece of the Foundation's mission and we remain committed to offering high quality resources to patients, family members and the public to foster a better understanding of scleroderma and the tools available to help manage the disease. Each year, our chapters and support groups host a number of patient education events, fundraisers, galas, walk-a-thons and seminars to raise awareness about the disease. In addition, the National Patient Education Conference serves as an annual retreat for scleroderma community members, health care professionals and others to collect the latest information about scleroderma. The annual conference provides a unique opportunity for people living with scleroderma to connect with others and share their experiences in a supportive environment. Publications, such as the Scleroderma Voice and the weekly online eLetter, keep members informed about the most recent scleroderma-related news.

**RESEARCH**

Since its beginning, the Scleroderma Foundation has been a leading provider of scleroderma research funding. This remains the organization’s largest budgeted expense, as we allocate at least $1 million for scleroderma research to new and established scientists. Our research program works to foster and support education among scleroderma research programs around the world. The program has provided vital funding to investigators to help advance their work and help unlock the clues to the scleroderma mystery. An independent Peer Review Committee, comprised of leading medical experts, reviews, evaluates and scores research grant applications, based on National Institutes of Health guidelines, to ensure that funding is used to support the most promising research initiatives currently taking place.
Thanks to your support, people find a safe and welcoming environment to share stories, information, and most of all, inspiration and hope through the Scleroderma Foundation. When dealing with an unpredictable and often deleterious disease such as scleroderma, support is essential to survival - support your contributions make possible.
The Scleroderma Foundation's nationwide network of 24 chapters and 165 support groups provides invaluable support to people living with scleroderma, family members and friends. The organization offers peer counseling, medical referrals and reliable educational information.

In 2012, the Foundation chartered its 24th chapter in the United States. The Heartland Chapter assists people living in Iowa, Nebraska and parts of South Dakota. Additionally, we formed new support groups in several states, including groups based in Georgia, North Carolina, Ohio, New Jersey, Pennsylvania, Colorado, California, New York and New Mexico. Support groups offer a safe and open environment to share feelings, concerns and information. They also are a place for much-needed hope, inspiration and encouragement to assist with coping. Regularly, meetings feature special guests, such as scleroderma experts, who are available to answer questions and concerns in an intimate setting.

For many individuals who are unable to attend a support group due to physical limitations or because one doesn't exist nearby, the Foundation offers support and information that can be readily accessed by phone or online. Our discussion board, hosted by Inspire (www.inspire.com/groups/scleroderma-foundation), has more than 10,000 members from around the world. The website is an excellent place for advice, collaboration and encouragement. Several of the Foundation's chapters also host support groups and education seminars via telephone or webinar so that people living with scleroderma can easily connect with others from the comfort of their own home.

The Foundation's dedicated staff and volunteers at chapters also answers patient questions via our tollfree helpline (800-722-HOPE) as well as through email (sfinfo@scleroderma.org). In 2012, an estimated 20,000 calls and 3000 email inquiries were received for information and resources about scleroderma.

In addition to providing beneficial material to help improve quality of life, the helpline staff shares local resources that are available. Nearly 700 of our free “Scleroderma Information Packets” were mailed to people interested in learning more about the disease. This collection of the organization's most popular printed materials covers topics, such as coping with scleroderma, gastrointestinal problems and lung involvement. In addition, 1,100 of the packets were downloaded from the Foundation's newly redesigned website (www.scleroderma.org).

The Foundation's Medical Advisory Board designated three new Scleroderma Centers of Excellence. Newly added centers are located in Colorado, Pennsylvania and Florida. These recognized research and treatment facilities must demonstrate their commitment to provide people living with scleroderma reliable resources, support and care, in addition to performing important disease research.

Finally, the annual National Patient Education Conference is one of the greatest support resources that the Scleroderma Foundation offers. This annual event provides a unique and inspiring opportunity for people affected by the disease. Frequently, the connections made at the Conference are some of the strongest bonds and support networks that can be created for a person living with scleroderma.

Chapters, support groups, Scleroderma Centers of Excellence and others resources are vital elements that the Scleroderma Foundation offers to the community.

The organization remains strongly committed to empowering people living with scleroderma to access the tools they so desperately need to improve their quality of life.
Children with scleroderma hope for the same things that healthy children hope for – they dream of being princesses or pirates, being a superstar, getting married and having children. Thanks to your support, the Scleroderma Foundation is trying not to let scleroderma get in their way.

Cheyenne Cogswell, now eight years old, is a ball of energy. From the moment she wakes until her head gently rests on the pillow, she's nonstop motion – laughing, singing, asking inquisitive questions, and alternately playing and fighting with her younger sister, Cadie. In other words, she's a lot like any other third grader.

But only on the good days. Cheyenne lives with a severe case of systemic sclerosis – very big words for such a young lady, and yet she has had that word attached to her since before she was six.

“That Cheyenne is alive at all is miraculous,” shared her mother, Bonnie. “Doctors warned us that she might not be with us by last Christmas.”

On Valentine’s Day in 2009, Cheyenne required emergency, life-threatening kidney surgery. Two years later, again on Valentine’s Day, Cheyenne developed a throat condition needing surgery that left her in critical condition. “It was only after the second surgery that doctors diagnosed her with scleroderma,” shared Bonnie. “My reaction was shock. Hearing the words scleroderma and your child’s name in the same sentence was unimaginable. I immediately went on the Internet and began researching scleroderma, its outcomes and its treatment. I kept praying the diagnosis was wrong.”

Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. To this day, she continues with daily chemo through injections, but now given by her mother. As a single mom of a critically ill child, Bonnie has faced extreme consequences from the financial burden. “It has been very difficult. I lost everything – my house, my job;” Bonnie said. “But we have hope, and if you keep saying this is going to get better, instead of being scared, life gives you hope, and with hope comes happiness.”

Cheyenne is a magnificent beacon of that hope. She rarely complains, never feels sorry for herself, and always has faith that she will have good days. “I believe her destiny is to inspire and enlighten others about the privilege of life,” said Bonnie. “Throughout her illness, we have experienced support from a large circle of family and friends but the greatest support has come through our already strong faith. I honestly don’t know how people without a faith survive this. We won't ever take things for granted, ever.”

The Cogswells live in a small poverty-stricken community in Kentucky, which was ravaged by a flood in 1997, leaving 80 percent of the town under water. There are no support groups within hundreds of miles. So, Bonnie reaches out through the Foundation’s online community at Inspire.com. I was feeling so alone but, between my friends on Inspire and the Foundation’s Facebook page, I always have somewhere to turn on the dark days. It is a huge comfort to know that there are people working to find a cure and who care about Cheyenne even though they don’t know her.”

“I learned about the juvenile program being held at the National Patient Education Conference,” Bonnie shared. “I applied for a scholarship to attend with Cheyenne. When we learned we were the recipients of a full scholarship, Cheyenne did her first happy dance in a while. Cheyenne asked, ‘Am I going to meet other kids that look like me?’”

She did make many new friends. “It is difficult to put our feelings into words since coming home from the Conference,” said Bonnie. Relief, gratitude, joy, hope. All of these are true, yet none of them fully encompasses the journey the family has traveled, or the road ahead. They know that the journey ahead is a marathon, not a sprint.

Cheyenne’s attitude about having scleroderma is, “Some people get it and others don’t, so it makes me special.” And, she truly is special. Cheyenne spends as much time as she can coloring, painting, dancing and working with clay. She aspires to become a famous actress, so she can have all the money in the world to help others. “Cheyenne is a giver,” beamed Bonnie. “Even though she is fighting a horrific battle, she is always thinking of others.”

“The first thing Cheyenne did when we returned from Atlanta was to take all of her change and put it in a piggy bank,” said Bonnie. “I am saving all of my money so that I can see all of my new friends next year, Mommy,” said Cheyenne, as she dreams of attending the 2014 Conference in Anaheim, Calif.
Thanks to your support, we were able to achieve several important advances in educating the public further about scleroderma in 2012.

The Foundation remains dedicated to sharing as much information as possible with its community via innovative tools and technologies, and continued to make strides in 2012. In August, we unveiled a redesigned website that made it much easier for people wanting to access information about scleroderma to navigate and find the resources they need online. Our website is key way that the organization educates the public about scleroderma. Additionally, many of our chapters and support groups began to leverage online tools so that they could provide education on a community-level about the disease. At the national level, the Foundation’s official Facebook page experienced a 41 percent increase in followers. We also became more active on Twitter, YouTube and Pinterest. Our online discussion board, through a partnership with Inspire, also continued to see measurable growth and discussion. The weekly “eLetter,” sent to more than 9,500 subscribers, continues to provide reliable information and resources for scleroderma patients, caregivers and family members and friends.

The Scleroderma Foundation was a proud sponsor of the patient education program during the Second World Congress on Systemic Sclerosis, which was held in Madrid, Spain, in Feb. 2012. More than 1,100 health care professionals and 261 patients attended the joint congress that focused on educating patients and presenting information about advances in scleroderma research and treatments.

Also in February, scleroderma advocates traveled to the nation’s capital to urge their elected leaders to co-sponsor important scleroderma-related legislation. These individuals shared their personal scleroderma stories with Congressional leaders and urged them to cosponsor the “Scleroderma Research and Awareness Act.” Supporters who were unable to visit in-person with their representatives were invited to take part in an innovated online awareness campaign. The proposed legislation (H.R. 1672 and S.649) would help increase scleroderma funding and create the first federal-funded public awareness program about the disease.
Our youngest conference attendees enjoyed fun games and activities that were geared just for them. But, they also could attend specialized workshops and panel discussions to learn more specifically about the unique experience of living with scleroderma as a child or young adult.

Each year, the Foundation offers scholarships to attend the Conference to individuals who otherwise would not be able to attend. In 2012, thanks to the generous support of donors like you, we were able to offer 34 scholarships to attendees. The weekend concluded with the annual Awards Banquet, where the Scleroderma Foundation honored its dedicated chapters, support groups, volunteers and donors for their triumphs in the past year. More than $10,000 was raised through a raffle for the Conference Scholarship Fund to help send people to the next year’s conference in Atlanta.

Back by popular demand, Dr. Jim G. Lemons, a medical psychologist and director of The Lemons Center for Behavioral Pain Management in Kansas, presented the opening keynote address, “How to Live with a Chronic Illness.” In his address, Dr. Lemons discussed ways to help patients focus more on effective coping strategies using techniques such as relaxation and humor. Seth D. Ginsberg, a patient advocate, concluded the weekend with a closing keynote. He is co-founder and president of Creaky Joints, an arthritis advocacy organization, and part of the Global Healthy Living Foundation, which campaigns for improved health care across the country.

This year’s conference also included new and improved programming for kids and teens affected by scleroderma. The Foundation teamed up with child life experts, including CoachArt, a nonprofit organization that works to improve the lives of children living with chronic illnesses.
The Scleroderma Foundation’s commitment to both local and national advocacy initiatives continued to move forward in 2012.


Thanks to the collaborative effort of the Foundation’s Advocacy Committee, Health and Medicine Counsel of Washington (HMCW) staff, and grassroots advocates, the Foundation also hosted National Congressional Call-in Day. Supporters who were unable to visit in-person with their Congressional representatives were invited to take part in an innovative online awareness campaign. The Foundation developed a dedicated virtual space to mobilize the scleroderma community and create a buzz about the proposed legislation.

The Foundation’s ambitious project, which included live Facebook and Twitter chats with Scleroderma Foundation leaders about the bill, was a huge success with a record number of scleroderma advocates joining the effort.

The scleroderma community rallied together and their message resonated on Capitol Hill. Their message was loud and clear: more funds should go to find the cause and cure of scleroderma. “Together, we have the power to make things happen and to drastically increase the resources for people living with scleroderma,” said Robert J. Riggs, the Foundation’s CEO.

Please visits the Foundation’s Advocacy Page at www.scleroderma.org/advocacy to learn more about how you can join the fight to facilitate awareness across the nation.
Serendipity and Perseverance. A Winning Combination.

You may have heard of Dr. Carol Feghali-Bostwick, a champion of the Foundation and of scleroderma research as she is vice chair of the Foundation's Board of Directors and chair of the Research Committee. What you may not know is that Dr. Feghali-Bostwick's inner motivation for scleroderma research came from her own diagnosis with systemic sclerosis early in her graduate career. “My diagnosis was confirmed by the chief of the division of rheumatology, Dr. Dennis Boulware, at Tulane University where I was studying microbiology and immunology,” said Dr. Feghali-Bostwick. “He and my mentor, Dr. Laura Levy, enabled me to pursue my new, rather serendipitous, research interest in scleroderma by offering resources, guidance and support.”

“Shortly after my diagnosis, the Scleroderma Foundation funded me as a new investigator to conduct a study about twins with scleroderma,” shared Dr. Feghali-Bostwick. The logic behind her study is that if inheritance is important in the development of a disease, then one would expect identical twins to both develop the disease, since they both inherit the same sets of genes from their parents. If only one twin of an identical twin pair develops the disease, then the disease is not primarily due to inherited genes and is more likely due to environmental factors and/or genetic changes that occur after birth. “Thanks to the Foundation’s support, I transitioned from fellowship to a junior faculty position and was able to complete the only twin study of scleroderma in the world,” she said.

Ironically, or perhaps serendipitously, Dr. Feghali-Bostwick and her husband Chris welcomed their own twins, Serena and James, in November of 2010. In addition to the twin study, Dr. Feghali-Bostwick’s lab has been researching the fibrotic process, which affects virtually all organ systems in scleroderma. Just last year, it was published that Dr. Feghali-Bostwick and her team identified an essential peptide (E4) that can block fibrosis in skin and lungs. “Fibrosis is an excessive formation of the fibrous connective tissues,” Dr. Feghali-Bostwick shared. “This finding is significant, not only to the scleroderma community, but to several other diseases as well, as tissue fibrosis contributes to 45 percent of all deaths in developed countries. Any insights we gain in fibrosis in scleroderma will ultimately benefit a much broader patient population than just those with scleroderma.” “We made this discovery serendipitously,” she went on to say. Serendipity is when one stumbles upon something fortunate, especially while looking for something else. But it takes a scientific perspective and perseverance to look beyond and see it as something worth following, which Dr. Feghali-Bostwick’s team accomplished. Thanks to their efforts, the discovery could have enormous impact on mortality and quality of life.

“Discoveries such as that of the E4 peptide begin at the bench in laboratories of scientists,” said Dr. Feghali-Bostwick. “Scientists in all disciplines are currently struggling for funding, and the lack of funding hinders research progress and delays the identification of the cause and cure for scleroderma. It also discourages young investigators and jeopardizes the future of research on scleroderma and other diseases. Thus, it is critical to support research via organizations that promote peer-reviewed research, such as the Scleroderma Foundation.”

“We know a lot more than we did 20 years ago and have better tools that allow us to advance research at a faster pace but we need the funding to do so,” she continued. “It may not be a major breakthrough but rather small serendipitous discoveries that provide us with the pieces to solve the scleroderma puzzle. You never know when a discovery will happen and where, which is why it is critical we continue to fund scleroderma researchers, both new and established.”

Dr. Feghali-Bostwick’s deserved awards are too numerous to mention. However, a recent accolade is worthy of sharing. As of October 2103, Dr. Feghali-Bostwick accepted a prestigious endowed chair at the Medical University of South Carolina in Charleston, South Carolina, where she is co-director of its Scleroderma Center.

“Through both serendipity and perseverance, there is little doubt that Dr. Feghali-Bostwick will continue to make her mark on the puzzle that is scleroderma,” said Tracey O. Sperry, the Foundation's Director of Development and Research.
In 2012, the Foundation continued to actively support vital initiatives to identify potential new treatments and strategies to help people living with scleroderma better manage the symptoms of the disease and improve their health.

Administered by the Scleroderma Foundation’s Board of Directors and staff, the program is guided by the advice of world-renowned experts in scleroderma research. The program has four hallmarks, according to Tracey O. Sperry, the Foundation’s Director of Development and Research. “We cast a wide net by soliciting proposals from a large pool of scientific talent. We provide seed grants for researchers to establish preliminary data in the hope that a meritorious project may lead to much larger and longer-term grants from the National Institutes of Health (NIH). We use the NIH Peer Review Model and fund only proposals that have scientific merit. Our researchers often publish their results in leading medical journals and at major medical conferences.”

The Scleroderma Foundation’s commitment to research funding continues despite the difficult economic climate. In 2012, the Foundation increased its research funding from the budgeted $1 million to $1.2 million. At a time when many organizations and government agencies are cutting back on vital research funding, the Foundation continues to fortify its role as the leading private funder of scleroderma research. Funding quality research projects is our top priority, and in 2013, we will continue the long-standing tradition of making research our single, largest budgeted expense.

An example of that commitment is the announcement by the Foundation that a new research funding initiative is in development for 2014. The Scleroderma Multi-Center Collaboration Grant will fund collaborative basic or clinical research projects involving two or more Scleroderma Centers at different institutions. The Scleroderma Foundation’s Board of Directors has committed $500,000 to this program in addition to its current research grant program.

Additionally, the Foundation has created a research mentorship forum, the New Investigator Conference, that brings together established investigators and new investigators designed to keep new investigators interested in scleroderma research.

Although the cure remains elusive, research funded by the Foundation and government agencies has increased understanding of many aspects of scleroderma and has enabled the development of new therapies.
**2012 Research Grant Awards**

**“Marta Marx Fund for the Eradication of Scleroderma” Award**

*Elena Tourkina, Ph.D.*
*Medical University of South Carolina*

*Caveolin-1 Deficiency Predisposes African Americans in SSc ILD*

**Mark Flapan Award**

*Ai (Anna) P. Lam, M.D.*
*Northwestern Feinberg School of Medicine*

*Selective Inhibition of Wnt/β-catenin Signaling as Novel Therapeutic Target for Systemic Sclerosis-related Pulmonary Fibrosis*

**The Walter A. Coyle Memorial Grant Research Grant**

*Flavia V. Castelino, M.D.*
*Massachusetts General Hospital*

*Role of Lysophosphatidic Acid and its Receptor LPA1 in Scleroderma Dermal Fibrosis Mechanisms of Macrophage Activation and Function in Scleroderma*

**Barbara D. Smith, B.S., M.A., Ph.D.**
*Boston University School of Medicine*

*Collagen Regulation in Systemic Sclerosis*

**Heidi Jacobe, M.D.**
*University of Texas at Dallas*

*Something New Under the Sun: A Randomized, Double Blinded, Controlled Trial of UVA1 Phototherapy in Localized Raynaud Phenomenon*

**Eric Lorne Greidinger, M.D.**
*Miller School of Medicine University of Miami*

*Antigenic Targets of Autoimmunity-associated Raynaud Phenomenon Inflammasome Regulation of miR-155 During Fibrosis*

**Thomas M. Ruenger, M.D., Ph.D., Boston University**

*Intracellular Degradation of Collagen in Scleroderma*

**Richard M. Silver, M.D.**
*Medical University of South Carolina*

*Molecular Basis for Therapeutic Interventions in SSc-ILD by Inhibition of Thrombin*

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Dr. Jessica Gordon, a grant recipient from 2010, shares, “This grant has enabled me to initiate my career with dedicated time and focus on research with the overarching aim to improve the lives of scleroderma patients.”

The Foundation is proud and honored to continue to fund stellar researchers who have both scientific and clinical expertise needed to conduct groundbreaking studies – for it is our hope that our funds will make a significant difference to researchers whose investigations may lead to a cure.

The Foundation extends its appreciation to the many researchers and clinicians who have made the research program possible and to the many individuals, corporations, and Foundation chapters who have contributed to raising funds for the research grant program.
The work of the Foundation would not be possible without our farsighted donors like you. Your philanthropy allows the Foundation to create programs that affect the lives of those living with scleroderma.

From individual gifts to corporate sponsors, from major chapter events to national initiatives, 2012 was a year rich in philanthropic support. It is very heartening to see that the work we do to fight scleroderma is still something in which many are willing to invest. Without our donors, sponsors and members, the work of the Scleroderma Foundation could not continue, nor could we have grown into the world’s largest nonprofit organization dedicated to serving the needs of the scleroderma community.

The Foundation continued to actively support vital initiatives to identify potential new treatments and strategies to help people living with scleroderma better manage the symptoms of the disease and improve their health.

Adding more hope and longevity to the lives of people living with scleroderma was the united mission of thousands who came together in 2012 to help the Scleroderma Foundation achieve its ultimate goal: finding a cure. Families affected by the disease, dedicated volunteers, corporate sponsors and other friends contributed to and participated in hundreds of events nationwide, raising millions of dollars to help support scleroderma research, education, care and other Foundation programs.

From walking, cycling, and climbing to dancing the night away at fundraising galas, volunteers once again used their collective talents to help the Foundation continue to make progress in the quest to find a cure.

Support to the Foundation comes in many shapes and sizes – from a walk of 1,000 people to a children’s birthday party, from a marathon run to an elegant gala. Whether it’s a donation of water for an event, a memorial gift, or corporate grant; workplace giving donation, direct mail response, or membership, each and every donation sets the Foundation to benefit millions of people with scleroderma for years to come.

Although all the efforts made by so many to support the Foundation are too numerous to mention, below are some philanthropic highlights of 2012:

**“Stepping Out to Cure Scleroderma”**

“Stepping Out to Cure Scleroderma” walkathon, the Foundation’s largest fundraising event, continued to expand its reach, generating an outstanding $1.3 million. Moved by the tremendous difference the Foundation is making in the lives of those with the disease, thousands of walkers and runners participated at 53 sites across the country in 2012. Each year, these events provide a great way for supporters of the Scleroderma Foundation to come together and help advocate for a great cause. Beyond the financial success of the events, “Stepping Out to Cure Scleroderma” events raise an inestimable amount of awareness and generate significant media coverage in cities small and large throughout the country.

**Collaborative Efforts**

Longtime corporate friendships and valuable new collaborations were instrumental in supporting the work and mission of the Foundation in 2012.
For more than 5 years, Actelion Pharmaceuticals US, Inc. has supported the Scleroderma Foundation cause and community through its national sponsorship. Through this important partnership, the Foundation received an unrestricted educational grant that provided significant underwriting to support key programs and services, both at the national and chapter levels. Among the programs that benefited from the support of Actelion in 2012 were:

- The National Patient Education Conference in Grapevine, Texas
- The Chapter and Support Group Leadership Conference, also in Grapevine, Texas
- Stepping Out to Cure Scleroderma walk-a-thons
- Over 60 Chapter patient educational events
- National patient support activities, including the Foundation’s website, patient information packs, new patient education literature and the national toll-free Helpline.
- Support of the Foundation’s Echo Campaign

The Scleroderma Foundation leadership is profoundly grateful to Actelion for their continued and significant support of the work and mission of the organization. Their corporate philanthropy has had a profoundly positive impact on the Foundation’s ability to grow and improve services to the scleroderma community.

**Beta Sigma Phi**

For 30 years, the sisters of Beta Sigma Phi have supported the work and the mission of the Scleroderma Foundation. Since 1980, the California Councils and the Beta Sigma Phi international endowment have raised awareness and contributed over a half a million dollars to support the Scleroderma Foundation. This year, the philanthropic chairs donated close to $50,000 for the various California councils and the national organization.

**Chapter Support of National Initiatives and Programs**

In 2012 there was a significant increase in the chapters of the Scleroderma Foundation giving dollars from their local treasuries to support initiatives and programs at the national level, thus advancing the true synergistic partnership between the national office and 24 chapters that are critical to advancing the mission of the Foundation at the local level. As in years past, the chapters of the Foundation generously supported scleroderma research and in 2012 collectively provided more than $400,000 through voluntary research contributions. These voluntary research contributions are given out of chapters’ budgetary surpluses or cash reserves. The level of such support is a true testament to the common hope that everyone within the Foundation shares – the hope of a cure.

We are committed to excellence in each aspect of our mission of support, education and research, and thank you for collaborating with us on this important work. Through our partnerships with you, we touch lives to bring hope and compassion. We also provide much needed research funding to bring us a step closer to a cure. Together, we make a difference in the scleroderma community and beyond.

Each gift, no matter the size, is important. Every donor plays a critical role in the fight to eliminate this disease and support those whose lives have been affected by scleroderma until a cure is found. On the following pages, you will find a list of donors who supported the Foundation’s work in 2012 with gifts of $1000 and greater. To those listed, and to those not listed (to conserve both financial and natural resources), we extend our deepest gratitude for your generosity and gracious support.
In 2012, for the fourth year in a row, Charity Navigator, the independent organization that rates the financial health and efficiency of charities, gave its top rating of four stars to the Scleroderma Foundation. This “exceptional” rating indicates that the Scleroderma Foundation “consistently executes its mission in a fiscally responsible way, and outperforms most other charities in America.” Charity Navigator’s rating system examines two broad areas of a charity’s financial health: 1) how responsibly it functions day to day and 2) how well positioned it is to sustain its programs over time. According to Charity Navigator, this four-star designation reflects the commitment of the Scleroderma Foundation’s leadership to strengthening its overall operation, effectiveness and cost reduction practices.

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$50,000+. 
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$25,000 – $49,999
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Crane Foundation, Inc. 
Crane Foundation, Inc. 
Crane Foundation, Inc. 
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Nurse On Call 
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$1,000 – $4,999

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Beta Sigma Phi/Central CA Council
Beta Sigma Phi/Far Northern California Council
Beta Sigma Phi/Mission CA Council
Beta Sigma Phi/Orange Coast CA
Beta Sigma Phi/Southern CA Council
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Bloomingdale Properties, Inc.
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The Goetz Family
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Goldstein Enterprises, Inc.
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H. Lowell Hall
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The Harrick Family
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Patrick Hayes
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Wendell N. Jarrard Foundation, Inc.
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Heather Johnson
Rosa Johnson
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MaryEllen Jones Trust
Robert Kacick
Sally & William Kahn
Dan Katcher
Stanley Kaufman
Helen Kay Charitable Trust
Dan, Matt & Lucas Keating
Cynthia Keats
Doris Ann Kennedy
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Eileen Kimbell-Meaney
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Terrance P. Kinsella
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Noelle Piotrowski
Noreen & Albert Platten
Frank R. Postma
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We gratefully acknowledge our generous donors and thank you for your support. Please accept our apology if we have made any errors or omissions with your name or gift. If your listing requires correction, please contact Tracey O. Sperry, Director of Development and Research, at (800) 722-4673 or tsperry@scleroderma.org. We will correct our records immediately.
### Revenue and Other Support

<table>
<thead>
<tr>
<th>Description</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>2013 Total</th>
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<td>Contributions</td>
<td>1,817,104</td>
<td>165,259</td>
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<td>1,982,363</td>
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<td>Special Events, net</td>
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<td>14,264</td>
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<td>772,481</td>
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<td>Bequests</td>
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<td>200,000</td>
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<td>Affiliate Dues</td>
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<td>Net Unrealized Gain on Investments</td>
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<td>Voluntary Research Revenue</td>
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<td>Interest and Dividends</td>
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<td>(1,157,019)</td>
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**Total Revenue and Other Support**

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<th>2013 Total</th>
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### Expenses - Program Services:

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<td>Support and Advocacy</td>
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**Total Program Services**

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<td>3,374,697</td>
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### Expenses - Supporting Services:

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<td>General and Administrative</td>
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<td>Fundraising</td>
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**Total Supporting Services**

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**Total Expenses**

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**Increase (Decrease) in Net Assets**

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<td>834,593</td>
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**Net Assets at Beginning of Year**

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<th>2013 Total</th>
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<td>9,182,832</td>
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**Net Assets at End of Year**

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<th>2013 Total</th>
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<td>10,017,425</td>
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National Chapter Manager

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The work of the Scleroderma Foundation could not reach the people who need our assistance most without the tireless efforts of our volunteers and staff in chapters across the country.

<table>
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<th>California</th>
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Chapters by State
On October 20, 2012, the Scleroderma Foundation’s Tri-State Chapter and the Buffalo New York Support Group held a free educational forum at the Niagara Falls Memorial Medical Center. As part of the event, organizers worked with U.S. and Canadian officials to illuminate Niagara Falls with teal in honor of scleroderma awareness.