

## three-fold mission



### research

To stimulate and support research designed to identify the cause and cure of scleroderma as well as improve methods of treatment.



### education

To enhance the public's awareness of this disease.



### support

To provide education and emotional support to people with scleroderma and their families.

## support groups

FINDING STRENGTH IN NUMBERS

### Connecticut

Greater Hartford  
(860) 741-5028  
hartford@scleroderma.org

Stamford  
(203) 357-1489  
stamford@scleroderma.org

### New Jersey

Northern NJ  
(973) 328-2627  
northernnj@scleroderma.org

Union County Area  
(908) 654-1427  
unioncounty@scleroderma.org

### New York

Albany Capital District  
(518) 360-9940  
albany@scleroderma.org

Binghamton  
(607) 723-1658  
binghamton@scleroderma.org

Buffalo  
(716) 998-1480  
buffalo@scleroderma.org

Central New York  
(315) 953-4011  
centralny@scleroderma.org

Cooperstown  
(607) 547-5099  
cooperstown@scleroderma.org

Greater Rochester  
(585) 723-1026  
rochester@scleroderma.org

Long Island  
(631) 940-7110  
longisland@scleroderma.org

Nassau/Queens  
(917) 572-8154  
nassauqueens@scleroderma.org

New York City  
(516) 384-1340  
nyc@scleroderma.org

Orange County  
(845) 986-4451  
orangecounty@scleroderma.org

Plattsburgh  
(518) 566-1280  
plattsburgh@scleroderma.org

Southwestern Albany County  
(518) 239-6907  
swalbany@scleroderma.org

Staten Island  
(917) 531-6564  
stateniland@scleroderma.org

Spanish  
(631) 940-7110 (longisland@scleroderma.org)



SCLERODERMA FOUNDATION, TRI-STATE CHAPTER

# you are not alone

ANNUAL REPORT | 2012

A beautiful sight for awareness!

Collaborating with the Scleroderma Society of Ontario, a joint education forum was held in October 2012. That night, Niagara Falls was lit in teal to help promote awareness of scleroderma.

## board of directors

### Founders

Mark Flapan, PhD (deceased)  
Helene Flapan, MA

### President

Jeff Mace

### Vice President

Bruce Cowan

### Secretary

June Bender

### Treasurer

Rosemary Markoff

### Members

Maryann Caliri  
Emily Chillino  
Andrea Goldstein  
Gerold Kirschner  
Marc Krieger  
Estelle Randolph  
Debra Signorelli  
Patricia Waszmer  
Joanie Weick

### Medical & Scientific

#### Advisory Board

#### Co-Chairpersons

Harry Spiera, M.D.  
*Mount Sinai,  
School of Medicine*  
Robert Spiera, M.D.  
*Hospital for Special Surgery*

### Members

Howard Blumstein, M.D.  
*Rheumatology Associates of Long Island*  
Avram Goldberg, MD  
*North Shore - LIJ Health Systems  
Scleroderma & Raynauds Treatment Center*  
Jessica Gordon, MD  
*Hospital for Special Surgery*  
Barry Gruber, MD  
*Long Island Regional  
Arthritis & Osteoporosis Care, PC*  
Charles P. Melone, Jr., MD  
*The Hand Surgery Center, Beth Israel  
Medical Center*  
Maria Luisa Padilla, MD  
*Mount Sinai, School of Medicine*  
Naomi Rothfield, MD  
*University of Connecticut, School of Medicine*  
Lee Shapiro, MD  
*Steffens Scleroderma Center*  
**Executive Director**  
Jay Peak



## you are not alone

WE ARE HERE TO HELP

By all accounts, 2012 can be qualified as a great success. The hard work of our dedicated volunteers and staff helped achieve fundraising goals despite economic concerns. They also made sure our patient education and support programs exceeded expectations by growing to meet needs in underserved areas of the Tri-State area.

The 2012 Stepping Out to Cure Scleroderma series of events was one of our most successful ever as \$433,000 was raised. Twelve events were organized by more than 300 volunteers and attended by 3,185 registered participants. More than ninety corporate sponsors provided an array of in-kind support as well as donations of \$66,000.

The success of our walks enabled us to take on a new vision. We committed to join the Scleroderma Foundation in its developing and nurturing of “the next generation of research leaders”, by providing sponsorship funding for the Scleroderma Foundation’s first New Investigator Conference. The conference – slated to be held just prior to the 2013 International Workshop on Scleroderma Research at Boston University– is being created to facilitate interaction between experienced researchers and new investigators allowing for feedback on current work. It should be an environment conducive to mentoring and encouraging the advancement of scleroderma research.

The Chapter also took a leadership role providing seed funding for a new MultiCenter Collaborative Research Grant program that allow groups of researchers to team up and build on a larger pool of knowledge and resources. The inaugural grant cycle will be in 2013 with the first funding released in 2014.

Central to our support efforts is the ongoing relationship with patients. In 2012 we started four new support groups – Plattsburgh, Staten Island, Nassau/Queens and Union County (NJ) – which gave us 17 active support groups at year’s end. To equip our support group leaders, a support group leader’s conference was held in Callicoon providing new and established leaders a chance to learn and network. Our ever popular 800 number as well as our presence on Facebook and Inspire.com enabled us to keep in contact and assist patients that prefer interacting with us virtually.

Our vibrant educational program also grew as we produced nine educational forums including one in partnership with neighboring chapter, Delaware Valley and another with the Scleroderma Society of Ontario (Canada). We rounded out our active program with three additional educational events plus participation in a half dozen larger community health fairs.

None of this would happen without the generosity of donors and the passion of volunteers. Their encouragement is the energy behind our work and our vision. Together we will battle to find hope. Together we will find a cure.

*Jeff Mace*

President

*Jay Peak*

Executive Director

## helping virtually

EXPANDING OUR SERVICE

The electronic delivery of educational and support information has allowed Tri-State to increase the number of people it reaches and serves.

- New SclerodermaTriState.org and Scleroderma.org Websites were unveiled in August. The sites serve as complementary source of assistance for patients, caregivers and health professionals seeking information about the disease our organization. Together the sites give us a platform to serve all who need us as well as raise funds and promote events.

- Our educational resource, sclerodermavideo.com video streaming Website, enables us to broaden the reach of our educational forums and serves as an excellent information source for scleroderma patients within the Tri-State area and beyond. This natural offshoot of our educational forums now hosts more than 50 presentations featuring leading scleroderma researchers and care professionals.

- Regular monitoring of the scleroderma support community on Inspire.com allows us to interact with patients that do not desire to be involved in a physical support group.

Use of these channels allows our impact to be felt throughout the Tri-State region even if there is not an active presence in a particular area.

## financial statements

STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

### Changes in Unrestricted Net Assets:

#### Revenue & Gains

Contributions, Gifts, Bequests and Dues	\$153,845
Special Fund Raising Events	426,031
Interest, Dividend and Other Income	<u>25,591</u>
Unrestricted Income	605,467
Net Assets Released from Restrictions Research	<u>0</u>
<b>Total Unrestricted Income</b>	<b>\$605,467</b>

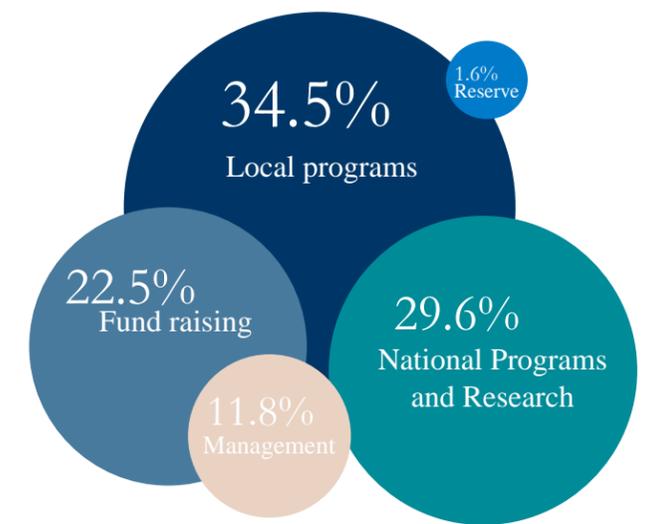
#### Expenses

Program Services	\$388,248
Management & General	71,304
Fund Raising	<u>136,215</u>
Total Expenses	<u>595,767</u>

**Total Increase (Decrease) in Net Assets** **\$9,700**

Net Assets Beginning of Year \$1,593,350

**Net Assets End of Year** **\$1,603,050**



Expenses 2012

All personal information provided is for the exclusive use of the Scleroderma Foundation and will not be sold or divulged to any third party. If you want your information removed, please contact the Tri-State, Inc. Chapter. Additional financial information is available by contacting the Tri-State, Inc. Chapter, visiting the website or going to [www.guidestar.org](http://www.guidestar.org) [IRS 13-3128296]