SCLERODERMA EXCHANGE

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Scleroderma Foundation Tri-State, Inc. Chapter
Binghamton, New York

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MISSION

To provide educational and emotional support to people with scleroderma and their families

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

To enhance the public's awareness of this disease

STEPPING OUT TO CURE SCLERODERMA 2017

We did it! Thank you to everyone who helped support the 2017 "Stepping Out to Cure Scleroderma" walks. With the backing from all of our volunteers, walkers, and media coverage, we are able to further our mission of support, education, and research.

This year, more than 2,500 volunteers and walkers in the Tri-State region came together to raise over $350,000 to fund the Tri-State Chapter's mission. As announced at the walks, our chapter has pledged more money in 2017 than ever before towards research! We hope to continue to provide additional support, generate more awareness, and fund even more research in the years to come.

We are incredibly thankful for all of our sponsors, and would like to give special recognition to our Diamond Sponsor: Bethpage Federal Credit Union; our Platinum Sponsors: Crane Foundation, Inc., Valentine Fenti (I Love Kay), Jarden Foundation; and Gold Sponsor: Arizona Beverages. Additionally, we were fortunate to receive funding for all of our walks from our National Level Sponsors: Actelion Pharmaceuticals, Bayer Pharmaceuticals, and Reata Pharmaceuticals. We are so very grateful for all of the donations received throughout this walk season. No matter how large or small, every single gift is helpful and important!

We can't thank you enough for everything you have accomplished, and for choosing to contribute to the Tri-State Chapter. The goal with these walks is to get all of us - with a common goal - bolstering each other up as a strong show of force for the cause; not as victims, but as fighters! Your support means so much to us, and to all of those affected by this disease.

Kyle Mills
Fundraising Manager

2017 Stepping Out to Cure Scleroderma Major Sponsors

Bethpage Federal Credit Union — Built to give you more.
CRANE Foundation, Inc.
I Love Kay
AriZona
ACTELION
BAYER
REATA PHARMACEUTICALS

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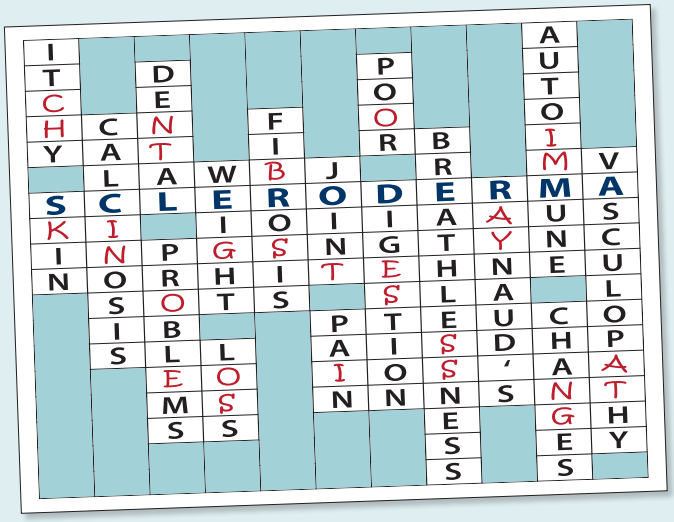
www.SclerodermaTriState.org

Walk, Learn & Win! Challenge

We hope that you participated in our 2017 Challenge!



There were 3 winners of Amazon gift cards drawn randomly from completed game cards at each 2017 Stepping Out To Cure Scleroderma walk, which added excitement to participation. The game, now in its 3rd year was developed to add a bit of education to our fundraisers.

This year our educational game focused on the challenges faced by someone with scleroderma. Above is the completed puzzle and below the clues that helped players to Walk, Learn & Win!

S Scleroderma skin can be very tight. The disease can destroy important glands leaving many with tight and IT__ __Y S__IN.

C Deposits of a hard and white substance are quite common. These lumps are referred to as CALC__ __OSIS and their cause is unknown.

L DE__ __AL PR__BL__MS are common and occur due to factors such as small mouth opening, dry mouth and poor hygiene leading to tooth loss, gum disease and cavities.

E As scleroderma progresses, it changes the body's ability to absorb nutrients leading to WEI__HT L__ __S.

R The process of FI__RO__IS changes connective tissue damage into scarring. This can occur in the skin, heart, lungs and kidneys – almost anywhere in the body.

O JOIN__ PA__N is a very common issue – including the fingers, elbows, hips, feet, knees and spine.

D The disease is usually accompanied by P__OR DIG__ __TION often the entire digestive tract is targeted by scleroderma.

E Changes in the lungs may include high blood pressure, scarring and fibrosis. One of the signs that patients notice first is BREATHLE__ __NESS.

R 95% of all scleroderma patients also have R__ __NAUD'S Phenomenon making it the most common overlapping disease.

M Scleroderma is an autoimmune disease. Researchers think AUTO__ __MUNE CHA__ __ES are triggered by environmental factors that put the process into motion.

A Widespread changes to the veins and arteries is referred to as VASCULOP__ __HY.

Have you moved? Changed your phone number or address?
Keep our records up-to-date by contacting us with your new information:
sdtristate@scleroderma.org or (800) 867-0885.

2017 Patient Education Forums

We're planning many educational opportunities for patients and families - free of charge!

August 19, Saturday
Daemen College
Amherst, NY
Mary Margaret O'Neil, MD
Jennifer Frustino, DDS, PhD

September 16, Saturday
The Bone & Joint Center
Albany, NY
Aixa Toledo-Garcia, MD
Vivek R. Mehta, MBBS

September 30, Saturday
UConn Medical Center
Farmington, CT
Santhanam Lakshminarayanan, MD
William E. Traverse, MD

October 14, Saturday
Rochester Educational Opportunity Center
Rochester, NY
R. James White, MD, PhD
Additional Speaker to be announced

October 22, Sunday
Rutgers University, Graduate Student Lounge
New Brunswick, NY
Presented in partnership with the Delaware Valley Chapter
Fabian Mendoza-Ballesteros, MD *and* Ira Merkel, MD

November 19, Sunday
Annual Research Forum - Hospital for Special Surgery
New York, NY
Theresa Lu, MD, PhD
Additional speaker to be announced

December 9, Saturday
Mt. Sinai Beth Israel
New York, NY
Margrit Wiesendanger, MD
Ioannis Tassiulas, MD *and* Maria L. Padilla, MD

Visit sclerodermavideo.com for recordings from previous events.

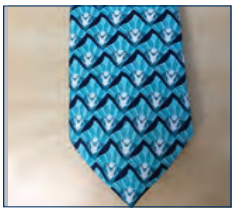
Tri-State Scleroderma Awareness items – prices include shipping

Purchase #UNTEALTHERESACURE awareness apparel items today! Tell the world you support finding a cure for scleroderma!

If you post a pict and tag us you'll be entered to win a prize! #UNTEALTHERESACURE

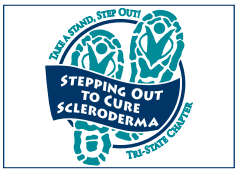
Order online at ***Scleroderma.org/sftsawareness***

36" x 36" Ladies SF Damask Pattern Scarf **$28** each


Adult SF Shell Pattern Neck Tie **$25** each

Adult SF Shell Pattern Self-tie Bow Tie **$25** each

Call us to purchase these Tri-State awareness items **800-867-0885**



2017 Walk T-Shirt **$10** each

Touchscreen Gloves **$8** each

Navy Hoodie **$25** each

Teal Car Magnet **$5** each

Embroidered Blanket **$25** each

Power Bank Charger **$5** each

SCLERODERMA FOUNDATION
SUPPORT · EDUCATION · RESEARCH
TRI-STATE, INC. CHAPTER
59 Front Street
Binghamton, NY 13905

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No longer want to receive our newsletter? Or receive it by email only? Please call 800-867-0885 to help us Go Green!

The Scleroderma Foundation in no way endorses any of the drugs or treatments in this newsletter; the information is provided to keep readers informed. Because the manifestations and severity of scleroderma vary, individualized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.

You can make a Difference with a Donation.

Donations of $25 or more include membership to the Tri-State Chapter and the Scleroderma Foundation on a national level.

Name_____

Email *(save postage)*_____Phone_____

Address _____

City_____State _____ Zip _____

Amount_____

Checks payable to SF Tri-State *(email required)* **or Donate online www.SclerodermaTriState.org**

Credit Card *(all information required)*

❑ Visa ❑ Master Card ❑ American Express ❑ Discover

Card Number _____Security Code *(CVV)*_____

Expiration Date _____Zip_____E-mail_____

Contribution is made: ❑ In honor of ❑ In memory of ❑ Dues ❑ Donation
(No Membership)

Name _____

❑ No acknowledgement needed ❑ Send acknowledgement to:

Name_____

Email *(save postage)* _____

Address _____

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City_____State_____Zip_____

Mail to: Scleroderma Foundation Tri-State Chapter, 59 Front Street, Binghamton, NY 13905

Thank You for Your Support!

2017 Stepping Out To Cure Scleroderma Tri-State Chapter

Stepping Out To Cure Scleroderma 2017 walk season has been a success! The outstanding support of volunteers, participants and donors made it possible to achieve 12 Tri-State walks. Thank You for your devotion, dedication and most of all the warmth of your hope. Our work truly begins with you!

Albany, NY

June 4, 2017 | Crossgates Mall, Albany, NY
Amount Raised: $30,700 **Walkers:** 196
Primary Volunteers: Lori Presley, Louis & Gerri Renni, Ray Littlejohn, Carla Gage, June Bender, Nancy & Mike Sokil
Individual raising the most: Nancy Sokil
Team raising the most: Nancy Jean's Team
Largest Team: Nancy Jean's Team

Teams:
Anna's Angels
Courtney's Crusaders
In Memory of Viola Zinzow
Lana's Crew
Meaney
Nancy Jean's Team
Rafferty
Shannon Place
Suzy's Supporters
Team Gage
Team Kristin
Team Mary
Team Mayville & Renna Corporate

Corporate Sponsors:
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Hannay Reels
Piller TSC Blower Corp
Price Chopper
RJ McNamara Financial Consultant
The Center for Rheumatology, LLP
Ulster Federal Credit Union
Westmere Fire Dept

Binghamton, NY

June 4, 2017 | Otsiningo Park, Binghamton, NY
Amount Raised: $28,000 **Walkers:** 248
Primary Volunteers: Terri-Jo Ramia, Rosemary Markoff, Carol Porcino, Jessica Remza, Kate Chura-Lynch, Bob Truman
Individual raising the most: Rosemary Markoff
Team raising the most: Connie's Crew-Saders
Largest Team: Connie's Crew-Saders

Teams:
Bob's Babes
Connie's Crew-Saders
Crystal's Crew
Jill's Jewels
Kaddy's Klassics
Porcino's Pals
Rosy's Buds
Sue's Steppers
Team Costello
Team Elie

Corporate Sponsors:
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HP Hood, LLC
M&T Charitable Foundation
NBT Bank
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Piaker & Lyons, P.C.
Progressive Tool Company, Inc.
Regional Rheumatology Associates, LLP
Tall Pines Farm, Inc.
The George Group, Merrill Lynch
Visions Federal Credit Union
Wegmans Food Markets, Inc.

Buffalo, NY

June 3, 2017 | Eastern Hills Mall, Williamsville, NY
Amount Raised: $26,500 **Walkers:** 230
Primary Volunteers: Tom Fazio, Mandy Hebert, Deborah Golinski, Kathy Leutze, Lisa Fazio-Beeson, Annette Federio
Individual raising the most: Kathy Leutze
Team raising the most: Kathy's Krew
Largest Team: Team Tony

Teams:
Gietzen's Scleroderma Squad
Karen's Golfers
Kathy's Krew
Kent's Knights
Mandy's Sclero Slayers
Merna Mays Marchers
Nonna's Donors
Peters for a Cure
Sherry's Fighting Scleroderma Warriors
Stacey's Strollers
Steps 4 Sandie
Team Doris
Team Heer
Team Tony

Corporate Sponsors:
Eastern Hills Mall
George & Shelly Adams
Praxair, Inc.

Long Island, NY

June 4, 2017 | Wantagh Park, Wantagh, NY
Amount Raised: $51,700 **Walkers:** 323
Primary Volunteers: Melissa Coppola, Amanda Davi, Barbara Geller, Sheila Brayman Borgese
Individual raising the most: Barbara Musco
Team raising the most: Team Musco
Largest Team: Josephine's Dancing Angels

Teams: Bina's Scleroderminators
Cleary4ACure
Dina's Walking Warriors
DOOTS
East Coast Walkers
Elaine Levy
Infinity
Josephine's Dancing Angels
Liz's team
Raindrop
Rochielle's Belles
SUZIEQ
Team Bunker
Team Cole
Team Courtney
Team Dott
Team Elaine
Team Grutts
Team Jean O'Sullivan
Team Kennedy
Team Musco
Team Robert Coppola
Team Strong
The Brutus Group

Corporate Sponsors:
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Hellma USA
Justine M. Metz Fund
Land Baron Abstract Company, Inc.
Northwell Health, Division of Rheumatology
Turan Family Foundation
Woodmere Medical Associates, P.C

Manhattan, NY

June 11, 2017 | Riverside Park, New York City, NY
Amount Raised: $50,500 **Walkers:** 336
Primary Volunteers: Lindsay Cowan, Olga Casarella, John Cowan, Jeffrey Toromoreno **Individual raising the most:** Jeffrey Toromoreno
Team raising the most: Team Cowan **Largest Team:** For Digna

Teams:
#Team Shirley
Alice cooper
Amy Nakano
Arcuri Hoopsters
Bruce's Angels
Columbia Rheumatology
For Digna
Hope for Prasha
In Memory of Eithne Hughes
In Memory of Susan Costello
Lori's Angels
Madeline Cortes
Nassau Queens Support Group
Painter
Sattyn & Her Angels
Scleroderma WalkStars
Shirley Alvarez
Team Barckow
Team Buckley
Team Connie O.
Team Cowan
Team HSS
Team Jazzy
Team Jim
Team Josiah Pinckney
Team Meka
Team Yolanda
The Bernsteins

Corporate Sponsors:
Charles P. Melone / HSC, Beth Israel
Columbia University Medical Center
Hospital for Special Surgery
NYU School of Medicine
Republic Capital Group, LLC

Hartford, CT

June 10, 2017 | U of St. Joseph, West Hartford, CT
Amount Raised: $16,500 **Walkers:** 223
Primary Volunteers: Julie Albrecht, Christine Cassidy, Wendi Jamison, Cheryl Argiros, Karen Legault
Individual raising the most: Robin Wojeck
Team raising the most: Wendi's Warriors
Largest Team: Quags

Teams:
Brenda's Beautiful Butterflies
Cheryl's Angels
Cheryl's Crusaders
Coastal Cruisers
Covalli's Cruisers
Junebug
Michelle's Marchers
Mimi's Marchers
Neen
Quags
Raising Hope
Shirley's Steppers
Team Doreen
Team Valentin
Think Teal Warriors
Wendi's Warriors
Zayas

Corporate Sponsors:
New England Rheumatology
PoliceApp.com
Stateline Senior Services

Poughkeepsie, NY

June 17, 2017 | Vassar College, Poughkeepsie, NY
Amount Raised: $25,800 **Walkers:** 126
Primary Volunteers: Scott Cornell, Carolyn Fisher
Individual raising the most: Antonietta Chiocchi
Team raising the most: Sclerovivors
Largest Team: Molly's Angels

Teams:
4 BEA
Annie's Team
Molly's Angels
Nichtern
Sclerovivors
Sis's Survival Squad
Smith
Team Carmen
Team Piaquadio
Team Val
Walkin For Fish

Corporate Sponsors:
Kingston Nissan
Salute Restaurant

Ridgefield Park, NJ

June 11, 2017 | Overpeck Park, Ridgefield Park, NJ
Amount Raised: $29,400 **Walkers:** 225
Primary Volunteers: Marc Krieger, Natalie Puccio-Murdolo
Individual raising the most: Marc Krieger
Team raising the most: Team Krieger
Largest Team: Team Larkin

Teams:
Amy's Army
Avison Young
CARLSON4
Ellen's Angels
Fernando
For Carol
For María Elena
Jumping Judy
Linda's Warriors
McLaughlin 2017
Natalie2017
Notorious C.U.R.E.
Otto's Army
Scleroderma Squashers
Team Kirsten
Team Krieger
Team Larkin
Team Mary Ann
Team Peggy
Team Precious
Team Roe
Team Rosie
Team Shana
Team Stacey

Corporate Sponsors:
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Care One
Cushman & Wakefield Metropolitan, Area Capital Markets Group
FreshPro Food Distributor
Kearny Federal Savings
Poskanzer Skott Architects
Red Pine Capital Partners, LLC
Scerbo Sanitation Service

Rochester, NY

June 3, 2017 | Seneca Park, Rochester, NY
Amount Raised: $27,100 **Walkers:** 244
Primary Volunteers: Greater Rochester Scleroderma Support Group Committees
Individual raising the most: Valentine Fenti
Team raising the most: I Love Kay
Largest Team: Walkers 4 Wanda, Forever Friends

Teams:
#TeamKya
Better Together
Forever Friends
Garland's Gallops
I Love Kay
Lisa's Hope
Melba's Journey Warriors
Pullano & Farrow
Roxie's Rascals
Sindoni Posse
Soleful Strutters
Suzi's Supporters
Team Florence
Team Gabby
Team Patty
Team Shonta
Team Wigley
Walkers 4 Wanda

Corporate Sponsors:
Celebrating Life & Love with Rosa Johnson
I Love Kay
The Purple Hippo

Staten Island, NY

June 25, 2017 | FDR Boardwalk & Beach, Staten Island, NY
Amount Raised: $5,700 **Walkers:** 61
Primary Volunteers: Jeanne & Jim Ryan, Amey Primiano, Jo Ann & Joe Anastasi, Lisa Pagano, Rosanne Burrell
Individual raising the most: Lisa Pagano
Team raising the most: Joann's Jewels
Largest Team: Team Rageen

Teams:
Fossils
IMO Susan Costello
JoAnn's Jewels
Ryan's Dream Team
Team Rageen

Corporate Sponsors:
Northfield Bank Foundation

Syracuse, NY

June 11, 2017 | Onondaga Lake Park, Liverpool, NY
Amount Raised: $13,700 **Walkers:** 134
Primary Volunteers: Kara Peck, Suzanne Craft, Linda & Bob Jackson, Crystal Vitale, Dallas & Nancy Sumner
Individual raising the most: Linda & Bob Jackson
Team raising the most: Nancy's Nomads
Largest Team: Team Meave

Teams:
Carole's Crusaders
Janine
Johnson & Johnson
Nancy's Nomads
Pamtastics
Team Christine
Team Lee
Team Maeve
Team Nina

Corporate Sponsors:
Haun Welding Supply

Westchester, NY / Stamford

June 11, 2017 | Irvington HS, Westchester County, NY
Amount Raised: $44,500 **Walkers:** 195
Primary Volunteers: Filomena LoRusso, Joy Mandel, Sara Bauer, Donna O'Gorman, Anna Morgan, Angelina & Mary Contadino
Individual raising the most: Adriane Schorr
Team raising the most: Italian Stallions
Largest Team: Cazzy's Crew

Teams:
Adriane's Network
Cazzy's Crew
Filo
Heavenly Daffodils
Italian Stallions
John Tatti
Kimmie
Patty Cakes
Peggy's Healing Hands
Team Nonna
Team Terri
Tom's Foggy Dew Crew

Corporate Sponsors:
Adriane's Network
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Crane Foundation, Inc.
Daniele's Auto Body Shop, Inc.
Irvington Union Free School District
Jarden
Riko's Pizza
Source Contracting Corp.
Wells Fargo Bank

STEPPING OUT TO CURE SCLERODERMA 2017

THANK YOU FOR YOUR PARTICIPATION AND SUPPORT, OUR WORK BEGINS WITH YOU!

ALBANY
JUNE 4
2017

BINGHAMTON
JUNE 4
2017

BUFFALO
JUNE 3
2017

HARTFORD
JUNE 10
2017

LONG
ISLAND
JUNE 4
2017

MANHATTAN
JUNE 11
2017

RIDGEFIELD
PARK
JUNE 11
2017

POUGHKEEPSIE
JUNE 17
2017

ROCHESTER
JUNE 3
2017

STATEN
ISLAND
JUNE 25
2017

SYRACUSE
JUNE 11
2017

WESTCHESTER
& STAMFORD
JUNE 11
2017

SCLERODERMA FOUNDATION
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