

Learn More About Your ANA

Scleroderma Dramatically Under-Diagnosed With Commercial Screening Method

Washington, DC – New research from <http://gumc.georgetown.edu/> Georgetown University Medical Center (GUMC) suggests that up to 40 percent of scleroderma patients will not be correctly diagnosed with the disorder using a new automated commercial screening test. The findings of the study will be presented Wednesday, November 10th at the Annual Scientific Meeting of the American College of Rheumatology in Atlanta, Georgia.

The American College of Rheumatology recommends immunofluorescence antinuclear antibody (IF-ANA) testing to help detect the presence of scleroderma specific antinuclear antibodies. Finding the antibodies is a helpful predictor of disease manifestations, clinical course and outcome in scleroderma. However, many commercial labs have recently adopted a newer, automated method that use non-immunofluorescence antinuclear antibody testing. This test is known as NEW ANA.

To test the accuracy of the commercial method for detecting scleroderma antibodies, GUMC researchers evaluated all the test results performed through commercial laboratories of more than 200 scleroderma patients treated in the Georgetown scleroderma clinic between June 2008 and June 2009.

Test results using NEW ANA were available in 58 scleroderma patients. Twenty-eight patients (48 percent) tested negative. Of these 28 patients, 22 had

either positive results using IF-ANA or one of the scleroderma specific antibodies. “The NEW ANA testing, that is the ANA test without immunofluorescence, failed to identify patients with a particular subset of scleroderma specific antinuclear antibodies and other patterns that are picked up with IF ANA testing. This finding was significant,” says Victoria K. Shanmugam, MBBS, MRCP, assistant professor in the Division of Rheumatology, Immunology and Allergy who presented the findings.

NEW ANA test results were not available for the remaining 183 scleroderma patients. IF ANA testing was conducted in these patients and the positive antibody results were divided by subtypes.

“Given what we know about the subsets that are not detected by the NEW ANA testing, it appears that as many as 40 percent of the scleroderma patients would have tested negative using the new commercial testing method,” Shanmugam says. “If a clinician has clinical suspicion for scleroderma, they should order the immunofluorescent ANA.”

Shanmugam’s research is funded by the American College of Rheumatology, Research and Education Foundation, Physician Scientist Development Award and from the National Center for Research Resources.

The authors report no potential financial interests.

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DID YOU KNOW?????

You don’t have to be a Facebook member to look at our facebook page. Just type in www.facebook.com/SFDeVal to see what our chapter is up to.

SFDV FUNDRAISING NEWS

Your Fundraising Matters

What We Do

The National Scleroderma Foundation helps people affected by scleroderma by funding cutting edge research, driving change through advocacy, facilitating professional education and providing programs and services to assist people with scleroderma and their families maintain the quality of life they so deserve.

Since its charter in 1988, the **Delaware Valley Chapter** has been in the forefront of providing programs and services for people with scleroderma and those who care for them. We serve clients and their families in eastern Pennsylvania, central and southern New Jersey and the state of Delaware. Clients turn to us for educational programs, news in the scleroderma community from the Pursuit, our newsletter and connection to other clients via our network of support groups. Furthermore, we campaign to bring awareness into the community and advocate for increased scleroderma research funding at the NIH. Most important we support the research grant program at the National Scleroderma Foundation with restricted research donations.

The Delaware Valley Chapter appreciates the generosity of our donors and takes every step possible to ensure that funds are used responsibly and effectively as we work to achieve a world free of scleroderma.

With lower than average administrative and fundraising costs, the National Scleroderma Foundation is committed to ensuring that the maximum amount of money raised funds innovative research and provides direct services for local people living with scleroderma. The Scleroderma Foundation rates 4 stars with Charity Navigator, an independent organization evaluating the financial health and transparency of more than 1000 nonprofit organizations.

New in 2013

Over the last year many of you have commented that you would like us to have more educational seminars throughout the year to include educating doctors and other

Mission Accomplished!

As anyone with scleroderma knows educating the public about scleroderma is a primary goal of the Scleroderma Foundation, especially to young healthcare professionals including medical students and nurses. We were afforded a unique opportunity on January 29th to present scleroderma to a large group of medical students at the Philadelphia College of Osteopathic Medicine. We were fortunate to have Dr. Chris Derk from the Hospital of the University of Pennsylvania present a lecture on scleroderma basics focusing on how to recognize scleroderma and make a diagnosis. Along with Dr. Derk we had two of our Board members, Susan Pierce and Joyce Roby-Washington, and a newly-diagnosed patient speak from a patient's point of view. A question and answer session followed the lecture where students had a

healthcare professionals about scleroderma. As always we want to increase our support of research programs awarded through the National Scleroderma Foundation. In 2013 the SFDV would like to expand its educational programs directed at both patients and their families and healthcare providers on the frontline of recognizing and treating scleroderma. Furthermore, we would like to increase our direct donation to research at the National level.

The more successful we are at fundraising the more we are able to contribute to our ultimate mission – funding research and finding a cure for scleroderma.

At our upcoming 2013 “Stepping Out To Cure Scleroderma” Walks you will see a few changes that include:

1. A dedicated event webpage with an easy-to-remember and distribute web address such as scleroderma.org/shorewalk which you can send out to your network of contacts.
2. Registration on line and adult fee of \$25. Your T-shirt size can be selected and extra shirts ordered.
3. Team building guidelines both individual and corporate – an easy step-by-step feature to build your own fundraising team including tips and guidelines
4. Incentives/prizes. All teams captains and individual donors not part of a team who raise at least \$500 will receive a pair of Scleroderma Spirit Socks.

Those who raise:

\$1000 to \$1999 will receive a Scleroderma Tote Bag

\$2000 to \$2999 will receive a Scleroderma Beach Bag

\$3000 to \$3999 will receive a long sleeved Scleroderma Hoodie

\$4000 and over will receive a \$100 Joy of Spa or Best Buy Gift Certificate

We are anxious to use our new website and fundraising features to reach more people and reach our 2013 goals.

chance to speak one-on-one with our presenters and gain a greater understanding of the challenges scleroderma patients face. At the conclusion of the seminar a young student approached our scleroderma representative and stated that when she is in practice she will never see a patient with Raynaud's and fatigue and not think of scleroderma – Mission Accomplished!

Special thanks to Richard Ngo and the Philadelphia College of Osteopathic Medicine Internal Medicine Club for inviting us to speak, Dr. Chris Derk for being our guest lecturer, Susan Pierce and Joyce Roby-Washington for sharing their scleroderma insights, and to Eric Larson for initiating this opportunity after overhearing a conversation about scleroderma at a local Starbucks!!



CRUISE FOR A CURE
A Scleroderma Fundraiser
Help Us Find a Cure for Scleroderma



Mt. Pleasant High School, Wilmington, DE
April 21, 2013 (Rain Date April 28)

The 2nd Annual “Cruise For A Cure” Car Show will be held in Wilmington, Delaware, on April 21, 2013 (rain date April 28). All proceeds will support the SFDV and scleroderma research. 1st and 2nd place will be awarded in 20 categories. Goodie bags will be provided to the first 100 entrants. The day will feature music, refreshments, 50/50, raffle, and prizes and trophies.

******You don’t have to enter a car to participate in this event. Support the SFDV and scleroderma patients by becoming a virtual car enthusiast and receive a car show T-shirt.*******

Go to scleroderma.org/cruiseforcure to for more information and to register or contact the SFDV at 1-866-675-5545.

2012 Philadelphia Thanksgiving Parade

Volunteer scleroderma patients, caregivers, and supporters pulled the Bugs Bunny float at the 2012 Philadelphia Thanksgiving Parade on November 22, 2012. Members of the Cimini, Batzel, Crawl, and Cowan families participated in the parade passing along Benjamin Franklin Parkway and finally in front of the Art Museum. Philadelphia is home to two Scleroderma Centers at Thomas Jefferson University Hospital and the Hospital of the University of

Pennsylvania, as well as home to “Stepping Out To Cure” Scleroderma, an annual walk along Kelly Drive every October. We want to say thank you to Team Scleroderma for taking part in the parade on behalf of the Scleroderma Foundation Delaware Valley Chapter and especially our newest Board member, Bill Cowan, for organizing and leading the team.



For more information about scleroderma or the SFDV go to www.scleroderma.org/Delawarevalley.

Joint Chapter Educational Forum
October 27, 2012



The annual Joint Chapter Education Forum supported by the Tri-State and Delaware Valley Chapters of the Scleroderma Foundation was held last October at Robert Wood Johnson University Hospital in New Brunswick, NJ. Dr. Vivien Hsu, Director of the Scleroderma Program at the University Hospital spoke about “Therapies That Make a Difference,” and Dr. Elliot Rosenstein from the Institute of Rheumatic and Autoimmune Diseases in Summit, NJ, spoke about “What Makes Scleroderma Different from Other Autoimmune Diseases.” The seminars were videotaped and are available to borrow from either chapter. They are also available for viewing at www.sclerodermavideo.com, courtesy of Starlight Productions who have supported the Scleroderma Foundation for many years. Thank you to Colleen Ferara at the SFDV who organizes our educational seminars and does a great job.

Upcoming Shore Walk 2013 – We've Grown!!

What: Stepping Out To Cure Scleroderma

Where: Historic Allaire Village, Farmingdale, NJ

When: Saturday June 8, 2013

Time: Registration: 9:30 AM

Walk: 10:30 AM

Our Shore Walk has moved a few miles from the actual shore. Over the years we've walked in Manasquan our turnout has exceeded the space available – that's actually good news. This year we have arranged to hold our "Stepping Out To Cure" Walk in Historic Allaire Village inside Allaire State Park in Farmingdale, NJ. The State Park is accessible by both the Garden State Parkway and Route 195. Allaire Village has many walk-friendly features including a large parking lot close to the village walk path, admission to the village shops after 12 noon, a scenic train ride, hiking trails, and yes, it is pet friendly and kid friendly. The Allaire community building will allow us to have registration in a warm, dry, wind-free environment. In addition we will have the opportunity to participate in opening day festivities with an information table.

New this year we are offering incentives for successful team builders. We are also looking for individuals who would like to

get their workplace involved by forming a corporate team. There will be fundraising prizes for team captains. All teams captains and individual donors not part of a team who raise at least \$500 will receive a pair of Scleroderma Spirit Socks. Those who raise:

\$1000 to \$1999 will receive a Scleroderma Tote Bag

\$2000 to \$2999 will receive a Scleroderma Beach Bag

\$3000 to \$3999 will receive a long sleeved Scleroderma Hoodie

\$4000 and over will receive a \$100 Joy of Spa or Best Buy Gift Certificate

Check out our team building guide online to get ideas for building your team.

Information about registration, team building, and donations can be found at www.scleroderma.org/shorewalk, or by calling 856-779-7225.

NEXT YEAR

Tentative Date for 2014 is Sunday, June 9th (2nd week after Memorial Day). Start building your team now!

Philadelphia Walk OCT. 14, 2012

The 23rd annual Philadelphia "Stepping Out To Cure" Scleroderma walk was held last October 14, 2012. 600 walkers raised over \$60,000 in a day which featured great weather and a stroll along beautiful Kelly Drive in Philadelphia. Top teams with the most walkers were Team Joey (67 walkers), Team Bhagat (38 walkers), and Team Dottie (37 walkers). We were honored to award the top fundraiser award from 2012 to Team Cimini who raised over \$16,000. Team Joey and Team Bhagat followed Team Cimini with 2nd and 3rd place fundraising awards for 2012.

We have many people to thank as an event this size does not happen without a lot of planning. We had several generous sponsors including Actelion Pharmaceuticals, Genentech,

Healthmark Foot and Ankle, and Penn Medicine – home of our newest Scleroderma Center in Philadelphia. We must also give thanks to Bernies's Pretzels of Aldan, PA, who never let us down with their hot pretzel delivery, to Charlie Danelutt who emceed our walk and supplies all the audio equipment required – a big savings to our chapter and most generous, to Scott Ritchie from Ocean Trophies who donates the beautiful trophies each year, and to Pradeep Bhagat and Navneet Verma who take our team photos year after year.

Thank you volunteers. We rely on our volunteers to make this walk happen. Set up, donations, food, entertainment, photos – you name it – a volunteer takes care of it. We are in debt to these generous people and again, thank you.



Stepping Out To Cure Scleroderma Walk



Thank You

Thank you Stonebridge Women's Club

The Stonebridge Women's Club located in Monroe, NJ, is an active group of women who fundraise throughout the year for causes affecting their community. In 2012 they raised over \$27,000 for various organizations and on December 13, 2012, held a dinner to celebrate their success and to recognize the charities they support. The Scleroderma Foundation received a check for \$2100 supporting research directed at finding a cause, better treatments, and eventually a cure for scleroderma. In 2012 the Scleroderma Foundation granted 1.2 million dollars to researchers studying scleroderma. The 30 chapters throughout the United States are active in fundraising for not only research, but also for programs that support scleroderma patients and their families including educational seminars, support groups, and public awareness campaigns. The Scleroderma Foundation is grateful for the support of organizations like the Stonebridge Women's Club and was thankful to accept their donation.

Nishi Bhagat Shares Her 16th Birthday!

Nishi turned 16 on December 8, 2012, with a happy celebration on January 5, 2013. In lieu of gifts to celebrate this milestone she requested that donations be made to the Scleroderma Foundation Delaware Valley Chapter in honor of her mother and chapter Board member, Neerja Bhagat. Nishi is an excellent student at The Agnes Irwin School in Rosemont, PA and an accomplished athlete participating in competitive soccer and swimming, but more importantly Nishi is a compassionate person who is a wonderful example to her family and friends by supporting a cause she is passionate about. We thank Nishi and applaud her generosity and support of the scleroderma community. We also congratulate her parents, Neerja and Pradeep, who are very proud of Nishi.



Thank You Alpha Delta Sorority of Ocean View

On June 7, 2012, the Alpha Delta Sorority of Ocean View in Delaware held a dinner-dance fundraiser at the Turquoise Room at Sea Colony. To date the Alpha Delta sorority has raised over \$19,000 to help local charities and people in need. This year they contributed \$800 to the SFDV to help support scleroderma patients and their families through education and research. We want to thank Sandy Fehre who was instrumental in obtaining this gift and all the members of Alpha Delta for their generosity.

Scleroderma Support Group Learns About Journaling



The act of journaling can be an important method in reducing pain and stress for people dealing with chronic illness. Local writer/poet/actress Pheralyn Dove presented a seminar about journaling to the Scleroderma Philadelphia Support Group last November at the Presbyterian Medical Center in Philadelphia, PA. The participants learned about the process of writing and the various ways to express their thoughts in an effort to meet the challenges that scleroderma patients face every day. Support Group leader Joyce Roby Washington holds bi-monthly meetings for scleroderma patients and their caregivers often inviting guest speakers to provide new insights into their illness. For more information about scleroderma you can contact the local chapter at scleroderma.org/delawarevalley.

New Resources!!!

Thanks to two of our very talented volunteers, Michelle Bielko and Yoojin Lee, as well as our anchor graphic artist, Wendy Faggart, we have three new items to share. All are available on-line at <http://www.scleroderma.org/delawarevalley> (click the resources button) or by contacting the office directly.

1. **Updated Chapter Brochure.** Look for our brochure online at scleroderma.org/delawarevalley and click resources, or contact us and request some

- copies to take to your doctors' offices and anywhere else to spread the word.
2. **Support Group Information Cards.** These information cards are available to distribute to your doctors' office also.
3. **Social Services Guide.** Michelle and Yoojin have created an in-depth compilation of social services available in our three states, what they provide, and how to contact them. A colossal undertaking and well done.

Support Group Meeting Locations

DELAWARE

Wilmington, Delaware (North Delaware)

Angie Crowl, 302-425-5054,
anglcrowl@aol.com
Every other month on Wednesdays
at 6:00 pm
Woodlawn Library
2020 West 9th Street
Wilmington, DE 19805
302-571-7425

NEW JERSEY

Cherry Hill, New Jersey (Burl-Cam)

John Keegan, 856-767-4783,
johnkeegan@comcast.net
2nd Thursday of every other month at 1:30
pm – meetings resume in March
385 Kings Highway North, Cherry
Professional Building
Cherry Hill, NJ 08034
856-779-7225

New Brunswick, New Jersey **new**

Ronnie Keppler, 732-598-2612,
ronniekep@gmail.com
1st Tuesday of every other month at 1:00 pm
– next meeting March 6
Robert Wood Johnson University Hospital
180 Somerset Street
Acute Care Building, 3rd floor
Clinical Research Center Day Room 105
New Brunswick, NJ 08901
732-828-3000

PENNSYLVANIA

Allentown, Pennsylvania **new**

Michael Szczepkowski, 215-350-8126,
maszpe@pobox.com
2nd Thursday of each month at 6:00-8:00 pm
Harry C. Trexler Center for Assistive
Technology
Good Shepherd Health & Technology Center
Good Shepherd Plaza, Main level
conference room
850 South 5th St.
Allentown, PA 18103
610-776-3100

Doylestown, Pennsylvania

Desiree Bleam, 215-249-1132,
desireealan@verizon.net
4th Monday of the month, quarterly at 6:30
pm – March 25, June 24, Sept 30, Nov 25 –
speaker at March 25 meeting - Dr. Miguel
Madariaga, Medical Director of the Wound
Care Center at Doylestown Hospital,
to speak about wound care needs of
scleroderma patients especially as it
relates to their hands and feet.
Doylestown Hospital
Conference Room G (main entrance eleva-
tors to ground floor, go right off elevator)
595 West State Street
Doylestown, PA 18901
215-345-2200

Langhorne, Pennsylvania (Bucks County)

Telephone contacts for support:
Ilene Nusblatt, 215-321-1670,
inusblatt@comcast.net
Sharon Durham, 215-638-2771

Philadelphia, Pennsylvania

Joyce Roby-Washington, 215-474-0259 or
267-516-6987, joycerw757@msn.com
2nd Wednesday of every other month at 1:30
pm – next meeting April 11
Presbyterian Medical Center, University of
Pennsylvania Health System
39th and Market Streets,
Wright Saunders Building
Gardner Conference Room 128-C
Philadelphia, PA 19104
215-662-8000

Reading, Pennsylvania

Dawn Batzel, 610-310-2566,
happy81070@verizon.net
2nd Saturday of every other month at
10:00 am – starting in January
Reading Pediatrics office
40 Berkshire Court, Wyomissing, PA 19610
610-374-7400

Williamsport, Pennsylvania

Jayne Young, 570-323-4228,
weyclu@sunlink.net
Gayle Bullock, 570-398-0551 (co-leader)
1st Wednesday of the month at 1:00 pm
(except January, February, July & August)
Life Center in the Lycoming Mall
300 Lycoming Mall Cir #3021,
Muncy, PA 17756 570-546-6879
June and December meetings held at 1:15 pm
at local restaurant Grace Buffet, 811 N.
Loyalsock Ave., Montoursville, PA 368-8666

York, Pennsylvania

Telephone/email contact for support:
Kathleen Gaskell-Blankenship,
717-428-1464, karlkathleen@earthlink.net



E-mail Support Group

We have started an e-mail support group for those patients and families that are not close to one of our existing support groups or those who would like to participate in addition to attending a support group. There is a weekly topic of discussion by email and everyone is free to comment or ask a question at any time. You can participate as little or as much as you like. If you are interested in being part of an email support group, please contact the office at 856-779-7225 or via e-mail at cferara@scleroderma.org.

Support Group Leaders Needed

We are always looking to expand our support groups into new areas. Please contact our office if you are interested in becoming a Support Group Leader.

Delaware

Southern DE Area

New Jersey

Cape May Area
Monmouth County Area
Co-leader for New Brunswick
Co-leader for Ocean County/ Toms River Area

Pennsylvania

Carlisle/Harrisburg Area
Delaware County Area
Norristown Area
York/Lancaster Area

Disclaimer: The Scleroderma Foundation in no way endorses any drugs or treatments reported in this newsletter or at SFDV sponsored meetings. Information is provided as a resource to be used with discretion. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with one's physician to assure proper evaluation and treatment.

NEWSLETTER OF THE SCLERODERMA FOUNDATION
DELAWARE VALLEY CHAPTER
385 KINGS HIGHWAY NORTH
CHERRY PROFESSIONAL BUILDING
CHERRY HILL, NJ 08034

UPCOMING EVENTS

March 25 – Educational Seminar, Doylestown, PA
April 21 – Cruise for a Cure Car Show, Wilmington, DE
(rain date April 28)
June 10 – Lacy/MacCutcheon Golf Outing, Monroe, NJ
July 26-28 – National Conference, Atlanta, GA
August 10 – Stepping Out to Cure Scleroderma Walk,
York, PA

September – Teri's Run, Downingtown, PA
September/October – Stepping Out to Cure Scleroderma
Walk, Philadelphia, PA
October – Educational seminar, New Brunswick, NJ
November 28 – Thanksgiving Parade, Philadelphia, PA

Check our website at www.scleroderma.org/delawarevalley for news and information. Check out our Facebook page for frequent postings at www.facebook.com/SFDeVal

MISSION STATEMENT

-  To help patients and their families cope with Scleroderma through mutual support programs, peer counseling, physician referrals and educational information.
-  To promote public awareness and education through patient and health professional seminars, literature and publicity campaigns.
-  To stimulate and support research to improve treatment and ultimately find the cause and cure of Scleroderma and related diseases.

SFDV Office

Scleroderma Foundation
Delaware Valley Chapter
385 Kings Highway North
Cherry Professional Building
Cherry Hill, NJ 08034
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866-675-5545
DVchapter@scleroderma.org
www.scleroderma.org/delawarevalley

