



# Scleroderma Michigan's Source

*There Is No Cure For Scleroderma.  
Together, We Can Change That!*

## BOARD OF DIRECTORS

### President

Ilene Ringle

### Vice President

Barbara Donohoe

### Treasurer

Richard A. Green, CPA

### Secretary

Mark Saidman, DDS

### DIRECTORS

Brian P. Donohoe

Jack A. Herberholz

Jason M. Knurek

Duane M. Maladecki

Sharon L. Noechel

Joan Provizer

Patricia Thomas, PhD, RN

Annie Q. Valle

### HONORARY BOARD

Peggy B. Graham

Carole Larson Wendzel

### STAFF

### Executive Director

Laura Dyas LSW, MA

### Patient Services Coordinator

Carol Hilf

### Executive Assistant

Janus Landrum

### MEDICAL ADVISORY BOARD

Henry W. Lim, M.D.

Richard W. Martin, M.D.

Vallerie V. McLaughlin, M.D.

Tammy Clark Ojo, M.D.

Melvyn Rubenfire, M.D.

Earl Rudner, M.D.

Mark Saidman, D.D.S.

Delfin Santos, M.D.

Elena Schioppa, M.D.

Lisa Zemens, D.D.S.

**WINTER 2010**

**WWW.SCLERODERMA.ORG/CHAPTER/MICHIGAN**

30301 Northwestern Highway, Suite 300 Farmington Hills, MI 48334

Tel: (248) 865-7259 Toll Free: (800)716-6554

MIchapter@scleroderma.org

## Change In Law Saves On Prescription Costs

Under a new law, more Medicare beneficiaries could qualify for Extra Help with their Medicare prescription drug plan costs because some things no longer count as income & resources.

### Who can get Extra Help?

Anyone who has Medicare can get Medicare Part D prescription drug coverage. Some people with limited income and resources are eligible for Extra Help to pay for the costs—monthly premiums, annual deductibles and prescription co-payments—related to a Medicare prescription drug plan. To qualify for Extra Help:

- You must reside in one of the 50 states or the District of Columbia.

Your resources must be limited to \$12,510 for an individual or \$25,010 for a married couple living together. Resources include such things as bank accounts, stocks, and bonds. Social Security **does not** count your house and car as resources; and your annual income must be limited to \$16,245 for an individual or \$21,855 for a married couple living together. **Even if your annual income is higher, you still may be able to get some help.** Some examples where your income may be higher are if you or your spouse:

- Support other family members who live with you;
- Have earnings from work;

### How does the new law change what is counted as income & resources?

Beginning January 1, 2010, when determining your eligibility for Extra Help:

- Social Security no longer counts as a resource any life insurance policy; and, they will no longer count as income the help you receive regularly from someone else to pay your household expenses—food, mortgage, rent, heating fuel or gas, electricity, water and property taxes.

For more information about getting Extra Help with your Medicare prescription drug plan costs, visit [www.socialsecurity.gov](http://www.socialsecurity.gov) or call Social Security at 1-800-772-1213

## \$1,050,000 Awarded in 2010 To Worthy Researchers

Most people donate to nonprofits never truly knowing where their dollars go. At the Michigan Chapter we strive to educate our donors on exactly where your contributions are being spent so you will be secure in the knowledge

that every dollar you give to us is being used to benefit our three-fold mission of education, support and research. In 2009, \$1,050,000 was awarded to seven worthy researchers that are working hard to find a cure for scleroderma. Their

specific research can be found by going to: [www.scleroderma.org](http://www.scleroderma.org). It is exciting to see the different areas that are being studied. Your hard earned dollars are going to fund these projects and we thank you all for your contributions.

## Patient Education Day's Expanded In The State

### St. John Macomb Hospital

April 10, 2010 -1:00-3:00 p.m.

#### "All About Pulmonary Hypertension"

Kelly Howard - PAH and how it effects scleroderma

Linda Kaminski- MS, RD, CDE

Nutrition and the role it plays in your health.

Janet Randolph- Moving Meditation and Tai Chi demonstration

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Center for Health Services

#### Henry Ford Health System

#### Brownstown

April 22, 2010 6:30 - 8:30 p.m.

#### "Keeping A Positive Attitude With A Chronic Illness"

Beverly M. Beltramo MA, BCC

Hatha Yoga- Southgate Yoga For Peace

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Borgess Health and Fitness

#### Center Kalamazoo

May 13, 2010 6:30-8:30 p.m.

#### "How to Deal With the Physical Aspects of Scleroderma"

Dr. James Taborn

Joyce Ross RD- a nutritional discussion

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Charles E. Anderson Building Allegiance Health Hospital Jackson

July 22, 2010 6:30 - 8:30 p.m.

#### "Hyperbaric Oxygen Therapy"

Dr. Bindesh Patel

Maria Galdeas RD- benefits of healthy eating for patients

Meditation Circle

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Mount Clemens Public Library

#### Mount Clemens

August 12, 2010 6:30 - 8:30 p.m.

#### "Striving To Live A Healthier Life With Scleroderma"

Dr. Iris Daniel

Hyperbaric Oxygen Therapy- benefits for scleroderma patients

Dr. Raymond McCracken Anchor Bay Dental

Dental care for scleroderma patients

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### McLaren Community Medical Center Flint

August 26, 2010 6:30 - 8:30 p.m.

#### Healthy Body, Healthy Spirit- Living With Scleroderma"

Dr. Kevin Gaffney

Skin care issues with hands, feet and the body of a scleroderma patient.

Linda Kaminski MS, RD,CDE - how to properly feed our bodies so we can live a healthy life.

Meditation Circle-group meditation

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Munson Community Health Center Traverse City

Sept. 23, 2010 7:00-9:00 p.m.

#### "Mind Over Matter-How Do I Deal With Scleroderma?"

Kristi Siemer OT,CHT

Margaret Magner- Yoga and Reiki demonstration

Judy Nichols-Scleroderma Patient to speak- Living With Scleroderma With A Smile

### MSU- Fee Hall Lansing

September 30, 2010 6:30-8:30

#### "Stressful Times Stressful Situations-Strategies to Help You Become Master of Your Emotional Well Being"

Dr. Jeffrey Frey

Marg Pestka RD-nutrition

Motivational DVD of Judy Nichols Scleroderma Patient "Living With Scleroderma With A Smile"

### Holy Spirit Church Grand Rapids

October 7, 2010 6:30-8:30 p.m.

#### "Hints, Tips and Gadgets: OT/PT Suggestions To Help You Thrive in Spite of Scleroderma"

Jeanine Biese, EdD,OTR,CHT

Kelly Howard RN, BSN

PAH Basics

Meditation Circle

Judy Nichols-Scleroderma Patient to speak- "Living With Scleroderma With A Smile"

## Phase One of Study Is Completed

The Scleroderma Registry has completed phase one of the Genome Wide Association study! They have identified a number of gene regions that have shown a strong association to scleroderma.

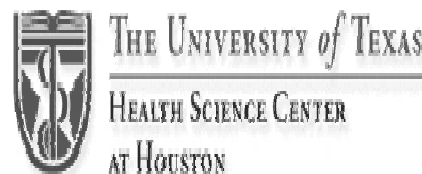
Phase two of the project is also under way with the establishment of 10 recruitment centers in the United States and Canada.

The University of Michigan is one of the participants along with the University of Minnesota, Medical University of South Carolina, and

the University of California Los Angeles. They will be adding Boston University in March. These samples will allow them to explore the gene regions from their first study as they try to determine what is going on.

If patients are already in the Registry your efforts are greatly appreciated and if you are not, you are invited to enroll. Please contact (713)-500-7196 or 1-(800)-736-6864 for more information.

By placing yourself in the Registry you will be assisting the research team in getting closer to finding more links to scleroderma.



## Tai Chi Is Beneficial For Your Mind, Body and Spirit

### Exercise Is An Important Component of Osteoporosis Prevention and Treatment

Tai Chi may be a safe alternative to conventional exercise for maintaining bone mineral density (BMD) in postmenopausal women. Bone mineral density is one of the key indicators of bone strength. Low BMD is associated with osteoporosis, a bone disease characterized by reduced bone strength that can lead to fractures, which are a significant cause of disability in older people.

Exercise is an important component of osteoporosis prevention and treatment. Tai Chi is a mind-body practice that originated in China as a martial art. It consists of slow and gentle body moves, while breathing deeply and meditating (Tai Chi is sometimes called "moving meditation").

Peter Wayne, Ph.D., and colleagues conducted a systematic review of research looking at the effect of tai chi on BMD. They found that tai chi may be an

effective, safe, and practical intervention for maintaining BMD in postmenopausal women. They note that the evidence is preliminary because the research they reviewed was of limited scope and quality, but enough evidence of effectiveness exists to warrant further research.

The authors further note that the benefits of Tai Chi appeared similar to those of conventional exercise. However, tai chi may also improve balance, reduce fall frequency, and increase musculoskeletal strength.

#### References

Peter M. Wayne, Douglas P. Kiel, and David E. Krebs, et al. The Effects of Tai Chi on Bone Mineral Density in Postmenopausal Women: A Systematic Review. *Archives of Physical Medicine and Rehabilitation*, May 2007.

In the state of Michigan, those who are interested in enrolling in a Tai Chi class can seek more information by looking at the following web sites:

[www.taotaichi.org](http://www.taotaichi.org)

[www.thetaichisite.org](http://www.thetaichisite.org)

[www.michigan.usa.taoist.org](http://www.michigan.usa.taoist.org)

[www.arthritis.org](http://www.arthritis.org)

Tai Chi is sometimes described as "meditation in motion" because it promotes serenity through gentle movements — connecting the mind and body. Originally developed in ancient China for self-defense, Tai Chi evolved into a graceful form of exercise that's now used for stress reduction and to help with a variety of other health conditions. Tai Chi, also called Tai Chi Chuan, is a noncompetitive, self-paced system of gentle physical exercise and stretching. To do Tai Chi, you perform a series of postures or movements in a slow, graceful manner. Each posture flows into the next without pause, ensuring that your body is in constant motion. Tai Chi has many different styles, such as yang and wu. Each style may have its own subtle emphasis on various Tai Chi principles and methods.

## How To Dance In the Rain

On October 23, 2010 the Scleroderma Foundation MI Chapter will be hosting a conference, **“How to Dance in the Rain: Rx's for Mind, Body and Spirit- A Full Day Seminar for the Autoimmune Community”**. This all day conference will be held in conjunction with the American Autoimmune Related Diseases Association, Lupus Foundation of America Inc, Sjogrens' Association, National Fibromyalgia Association and the National Rheumatology Nursing Society.

The conference will be held at the John Lewis Center of Macomb Community College, located on 14500 East 12 mile Road in Warren, MI 48088-3896.

The day will begin with registration and a breakfast of fresh fruit salad, granola, yogurt, fresh muffins and coffee and teas being served at 8:00 a.m.

The first speaker, Kathy Neumann, MSN, RN, HSMI will be presenting, **“Laughter: Just What the Doctor Ordered: Techniques In Managing Stress Including the Latest in Laughter Therapy”**.

Well renowned and respected author, Rita Baron-Faust will be speaking and presenting on, **“Women and the Autoimmune Connection.”** Her books are loved by all who read them. She has written books ranging from, **“Guide to Sleep”**, **“Being Female: What Every Woman Should Know About Gynecological Health”**, to **“Mental Wellness for Women”**.

Keynote speaker, Dr. Noel Rose is Chairman Emeritus of the Scientific Advisory Board of the American

Autoimmune Related Diseases Association (AARDA) on which he has served since 1992, first as a member and then as Chair. An immunologist, pathologist, and molecular microbiologist, Dr. Rose long has been associated with Johns Hopkins University, in Baltimore, Maryland, where he has served as professor and Chair of the Department of Immunology and Infectious Diseases. Today he is professor of pathology and of molecular microbiology and immunology and Director of the Johns Hopkins Center for Autoimmune Disease Research. Dr. Rose's pioneering research some 50 years ago was instrumental in establishing the concept of autoimmune disease and helped immunologists understand, for the first time, that the immune system was capable of directing a response to healthy tissues and organs of the body, not just to invading foreign viruses and bacteria. He is co-editor of the classic textbook *The Autoimmune Diseases*, now in its 4th edition. Dr. Rose has published more than 760 articles in peer-reviewed journals, has edited or co-edited some 22 books, and has served as an editorial board member of more than 27 journals.

A box lunch will be served after the morning presentations are completed.

Break out sessions will be occurring in the afternoon with various topics for participants to select from. Once participants have sent in their registration forms, additional information, including the topics of the break out sessions will be forwarded via standard mail.

In the afternoon, a Tai Chi demonstration showing the

benefits of this ancient art will be presented. Tai Chi is sometimes described as "meditation in motion" because it promotes serenity through gentle movements — connecting the mind and body. Originally developed in ancient China for self-defense, Tai Chi evolved into a graceful form of exercise that's now used for stress reduction and to help with a variety of other health conditions.

Virginia Ladd, President and Executive Director of the American Autoimmune Related Diseases Association, Inc. (AARDA), an organization that she founded in order to bring a national focus to autoimmunity and increase collaboration in research, education, awareness, and advocacy programs will be presenting in the afternoon. She has been involved in the nonprofit community for over 30 years as a patient advocate and educator. Mrs. Ladd served as president and executive director of the Lupus Foundation of America. She is one of the founders of the Michigan-based Chronic Illness Awareness Coalition (CIAC). Ms. Ladd will be speaking on **“Coping with a Chronic Illness”**.

In the afternoon participants will be treated to a sweet temptations break time snack. An assortment of miniature pick me-up sweets including specialty cookies, brownies, assorted dessert bars, mini French pastries and chocolate strawberries will be served.

The afternoon will finish up with a presentation by Cheryl Beshada, Reiki Master-Instructor. She will conduct a meditation for the group.

The conference will end at 4:00 p.m. It will cost \$30 for the conference and the fee includes all the food and materials. Register early to assure your space!

## Registration Form For Patient Education Days & Conference

### Personal Information:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

E-mail: \_\_\_\_\_

Telephone: ( \_\_\_\_\_ ) \_\_\_\_\_

### Credit Card Information:

Number: \_\_\_\_\_

Expiration date: \_\_\_\_\_ CVD Three Digit Code: \_\_\_\_\_

Signature: \_\_\_\_\_

### Patient Education Days:

- St. John Macomb Hospital– April 10
- Center for Health Services, Henry Ford Health Services-Brownstown-April 22
- Borgess Health and Fitness Center/ Kalamazoo– May 13
- Allegiance Health/Jackson– July 22
- Mount Clemens Public Library– August 12
- McClaren Community Medical Center/ Davison, Flint - August 26
- Munson Community Health Center/Traverse City - September 23
- Fee Hall MSU/Lansing - September 30
- Holy Spirit Catholic Church - Grand Rapids, October 7
- How To Dance In The Rain Joint Conference - October 23 (more information will be sent to you)



## 31st Annual Walk and Run



Mark your calendars for June 27th when the Scleroderma Foundation Michigan Chapter will be hosting their **31st Annual Stepping Out to Cure Scleroderma Walk and Run**. This fun filled event will be held at the Detroit Zoo in Royal Oak.

A 5K Chip-Timed Run will start off the fun-filled morning beginning with registration at 7:00 a.m. The run will start at 8:00 a.m. and go through Huntington Woods. All runners must be over the age of 16 years.

The 31st Walk will begin at 8:30 and consist of a two mile walk through the Detroit Zoo. The Scleroderma Store filled with scleroderma merchandise and educational information will be open from 8:00—10:00 a.m. and the Food Tent will also be open from 8:00—10:00 a.m.

This year the Michigan Chapter is excited to be partnering with Magic Radio 105.1 on the 31st Walk and Run. Live music will highlight the event and start off the walk inside the zoo. Listen to 105.1 for more information on the 31st Walk and Run.

Registration fees for the 31st Run will be \$25 before May 8th and \$30 after the 18th.

Registration fees for walkers will be \$15 for those who are 13 years and up, before May 18th and \$20 for those who are 13 years and up after May 18th. Ages 12 and under will have free admittance for the 31st walk.

In addition to the registration fees, walkers must agree to raise a minimum of \$50 in pledges per participant, ages 13 years and up for the 31st walk. Those who are

12 and under will not be required to raise pledges.

All participants must be registered and can do so by filling out the registration form in the newsletter, going on-line to [www.Firstgiving.com/31stwalk](http://www.Firstgiving.com/31stwalk) and following the instructions on the home page to make a secure payment with your credit card or by faxing the registration form to (248) 865-7523. On-line registration will be available until 9:00 a.m. on June 25, 2010.

**All participants must register no later than 8:30 a.m. on Sunday, June 27th at the walk to obtain your zoo entrance ticket for entry to our walk. If you are later, you will be charged a separate zoo fee. We regret any inconvenience this might have on you, but this is a rule of the Detroit Zoo and thus no exceptions can be made. We ask that you plan accordingly.**

T-shirts are only guaranteed to those who register prior to May 18th.

Securing pledges for the 31st Walk can be easy this year if you start NOW!!! Why not try and collect pop bottles, ask your co-workers to do a jeans day, bring in donuts or cookies to your office and leave a donation box, or even ask 10 neighbors/friends for \$5.00. While \$50 may seem like an overwhelming amount to raise, when you break it down into the amount of weeks you have before the walk, it amounts to a few dollars a week.

For those who collect a minimum of \$500 to \$999 in pledges, an appreciation bag valued at \$15 will be given the day of the event and for those who collect \$1,000 to \$1,499 in pledges an appreciation bag

valued at \$25 will be given the day of the event. This is the MI Chapter's way of saying, thank you for your dedication and support to our mission.

For those who are able to collect \$1,500 or more in pledges the MI Chapter will be hosting a private dinner after the 31st Walk and Run in your honor. You will receive a coupon for this dinner the day of the event.

The top fundraiser for 2010 will be treated to a private dinner for 6 at the home of Executive Director, Laura Dyas. This home cooked meal will be served to you and your five guests with candles, music and wine! Start collecting your pledges today so you won't miss out on these terrific opportunities.

The MI Chapter is asking for donations of the following items:

- Variety Pack Crackers (lunch sized) (1,000 needed)
- Special K Bars (500 needed)
- Nutri Grain Variety Pack Bars (500 needed)
- Nature Valley Chewy Trail Mix Bars (500 needed)
- Light Yogurt ( 1,000 needed) please watch for expiration dates
- Spoons (1,000 needed)
- Napkins (5,000 needed)
- Cheese sticks (1,000 needed)

Don't look at pledges as a negative, look at them as your way of helping the MI Chapter get one step closer to finding a cure. The goal of the 31st Walk and Run is to raise funds so that we can continue to meet our - mission of education, support and research. Without your dedication and support we cannot meet these goals. Come show your support at the 31st Walk and Run.

# Registration Form for 31st Walk and Run

**REGISTRATION FORM:**

I am walking in the 31<sup>st</sup> Annual Walk and Run       I am running in the 31<sup>st</sup> Annual Walk and Run

**Personal Information:**

1	First Name	Last Name
	Address	
	City	State
	Zip	
	Phone/Day	Cell Phone
	E-Mail	Age
	Male/Female	

**OTHER REGISTRANTS:**      (*Registrant from the same household*)

2	First Name	Last Name	Age	Male/Female
---	------------	-----------	-----	-------------

3	First Name	Last Name	Age	Male/Female
---	------------	-----------	-----	-------------

4	First Name	Last Name	Age	Male/Female
	(Participant from other household)			

5	First Name	Last Name	Age	Male/Female
---	------------	-----------	-----	-------------

Address				
City	State	Zip		
Phone/Day	Cell Phone			

**PAYMENT INFORMATION:**

\$ \_\_\_\_\_ is enclosed for the registration option that I selected made payable to: **Scleroderma Foundation**.  
**NOTE: If registering after May 18, 2010, please add \$10.00 per individual for registration fee.**

I am unable to attend but want to support this event through a tax deductible donation of \$ \_\_\_\_\_.

Please charge \$ \_\_\_\_\_ to my:     American Express     VISA     MasterCard     Discover

Card Number: \_\_\_\_\_

Name on the Card: \_\_\_\_\_

Expiration Date: \_\_\_\_\_ 3 Digit Code: \_\_\_\_\_

**In consideration of being permitted to participate in the 31<sup>st</sup> Annual Walk and Run, I hereby, for myself, my heirs and personal representatives assume any and all risks which might be associated with the event. I further waive, release, discharge and covenant not to sue the Scleroderma Foundation, any chapter, support group, officers, employees, sponsors, organizers, volunteers or other representatives or their successors, and assigns, for any and all injuries or damages of any kind whatsoever suffered as a result of taking part in the event and any related activities. I agree to the use of any photo, film, or videotape, of the event for any purpose. (Parent must agree to waiver if participant is under 18 years if age).**

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Parent: \_\_\_\_\_

Please mail this registration and your payment/donation to:  
 Scleroderma Foundation Michigan Chapter  
 30301 Northwestern Highway, Suite 300  
 Farmington Hills, MI 48334  
 Fax: (248) 865-7523  
 Additional forms can be obtained via the website or by calling the office  
 (248) 865-7259  
[www.Firstgiving.com/31stwalk](http://www.Firstgiving.com/31stwalk)

**SELECT T-SHIRT SIZES:**

Adult:  
 \_\_\_ S \_\_\_ M \_\_\_ L \_\_\_ XL \_\_\_ XXL \_\_\_ XXXL

**T-Shirts are not guaranteed after the May 18<sup>th</sup> registration date.**

## From the Desk of the Director...



Greetings!

It seems so hard to believe we are already so far into 2010. The

days just seem to be going by so quickly. Before long, the 31st Walk and Run will be here. We are very excited about our partnership with Magic Radio this year and we look forward to their participation in our largest fund raiser. I am also looking forward to hosting the top fund raiser at my home. This private dinner is something new we are doing and just our way of saying thank you to the person who raises the most pledges. We will also be offering a private dinner to those who raise a \$1,500 or more in pledges. The funds that we raise directly support our Patient Education Days, the joint conference that we hosting in October this year with four other nonprofits, our outreach to the medical community, the 800 line and the day to day operations of the MI Chapter.

I am so excited about the fact that in 2010 we are able to provide scleroderma patients, family members and friends with a total of nine educational opportunities, being offered all over the state of Michigan. Never before in the history of this Chapter have we been able to do this. We are already working on the plan for 2011, reaching out into even more of your communities so that we can provide education to more individuals. No two speakers are alike and the topics have all been selected per area to meet your needs.

The 2010 joint conference will be hosted at the Macomb Community College John Lewis Center on October 23rd. This all day conference will bring to you not only a chance to hear speakers such as Dr. Noel Rose, from the Center for Autoimmune Diseases at John Hopkins but also, break out sessions will be offered allowing you the chance to select which ones you attend. Space is limited so sign up early to assure you do not miss out on this wonderful experience.

In 2010, the Michigan Chapter will be working to increase our support groups for patients and our Caring Core groups for family members and friends. You will see articles on each of these areas in the newsletter and I encourage you to join one of these groups or to contact Carol our Patient Services Coordinator to discuss your specific needs. Carol is available now five days a week. She can assist you with referrals or if you just need someone to listen.

As you can see we are dedicated to meeting your needs. I ask that you contact me if there is anything I can personally do to assist you or your family. The Michigan Chapter is here for YOU so please reach out and become a member today! Your \$25 makes a real difference to keep our programs and services going. We currently have a database of over 3,700 with a membership of only 166. Help us to increase that number by sending in your check for \$25.00.

Hope to see you all at the 31st Walk and Run! *Laura Dyas*

## Night Hawks Scleroderma Charity Ride

On August 1, 2010 the Huron Valley Night Hawks M/C Ypsilanti will be sponsoring their Second Annual Charity Ride benefitting the Scleroderma Foundation MI Chapter.

The ride will begin at their clubhouse in Ypsilanti with registration starting at 11:00 a.m. The clubhouse is located at 10250 Geddes Road in Ypsilanti, MI. Kickstands will be up promptly at noon when bikers will travel to Hell, MI for the first stop of the day and a visit to

Smitty's Damn Site Inn. Arrival time will be approximately 12:45-1:00 p.m. 4045 Patterson Lake Road, Pinckney, MI. 48169

After a short visit to Hell, bikers will travel the roads to Historical South Lyon Hotel in South Lyon, MI. 201 South Lafayette Street, South Lyon, MI. This Hotel has outstanding food and bikers will definitely want to stop and enjoy a burger or even the pizza before heading back to the clubhouse.

The last bike will be in by 4:00

p.m. The day's activities will include food, refreshments and plaques for the Best Bike, Top Rider and Top Passenger.

Cost for the ride will be \$25.00 for single riders and \$30 for double riders. More information can be found at [www.HVNHMC.com](http://www.HVNHMC.com) or by calling the MI Chapter at (800)- 716-6554.



## Michigan Chapter Support Groups

### Flint

**7 p.m. Fourth Monday of Every Month**

Flint Area Support Group  
McLaren Community Medical Center, 10090 E. Lippincott Blvd., Davison, Michigan.

**Support Group Leader:** Kathy Hartner, 810-655-8762, [kahart6@comcast.net](mailto:kahart6@comcast.net)

### Lansing

**12:30-2:00 p.m.**

**Third Saturday of Month**

Lansing Area Support Group  
**Support Group Leaders:** Celia B. Guro, Ph.D., M.S.U. Director, Personal Counseling and Professional Development at 517-432-2734; or Doris Soliz-Hill, 517-316-4849

### Livonia

**Second Thursday of each month except July and August. Call for time.**

Livonia Support Group  
Livonia Civic Park Senior Center-15218 Farmington, Livonia, MI 48154

**Support Group Leader:** Barbara Case, (734) 464-3644, [bcase04@mi.rr.com](mailto:bcase04@mi.rr.com)

### Taylor

**10 a.m.-noon.**

**3/20, 4/17, 5/22, 7/17, 8/21, 9/15, 10/16, 11/20**

Downriver Support Group  
Our Lady of Angels, 6442 Pelham Road, Taylor, Mich. 48180  
**Support Group Leader:** Annie Valle, 313-291-2055, [avalle1930@hotmail.com](mailto:avalle1930@hotmail.com)

### Grand Rapids

**6:30 – 8:00 Third Wednesday of each month**

Holy Spirit Church-lounge area- 2230 Lake Michigan Drive NW, Grand Rapids, MI 49504-5999. Church is wheelchair accessible. **Support Group Leader:** Jean Hehrer, (616) 791-9384

### Warren

**2nd Saturday of the month from 11:00 a.m. to 1:00 p.m.**

Warren Support Group  
St. John's Macomb Hospital, Auditorium A, Physical Rehabilitation Services Bldg., 12000 E. 12 Mile Road, Warren, Michigan.

**Support Group Leader:** Sharon Noechel, 586-573-7749, [noech@comcast.net](mailto:noech@comcast.net)

The Michigan Chapter is currently looking to add support groups to the following areas:

- Alpena
- Bay City
- Detroit
- Flint
- Holland
- Jackson
- Kalamazoo
- Marquette

- Monroe
- Mount Pleasant
- Muskegon
- Port Huron
- Rochester Hills
- Traverse City

If you reside in these areas and you would like to be in a support group, please contact the Michigan Chapter and place your name on a list. As soon as we obtain enough names for a group to begin, we will open the group up. If we are unable to secure a leader for these areas we will locate a social worker who can run the group.

**The Michigan Chapter is committed to meeting YOUR needs!**

248-865-7259, 800-716-6554



## 2010 National Conference Heads To Boston

The Scleroderma Foundation recently released the dates for its upcoming 2010 National Conference: **July 30th-August 1st, 2010** at the Sheraton Boston Hotel located in downtown



Boston! Discounted hotel rooms are already being set aside at the Sheraton for conference attendees and you can start making reservations within the "Scleroderma Foundation" room block now. Just call (617) 236-2000 and ask for reservations. Mention the Scleroderma Foundation and you will receive the \$149/night rate.

Room rate is not guaranteed after July 7, 2010. Room rate is available only for July 24 to August 4.

Further information regarding conference registration can be found on the Foundation's Web site. [www.scleroderma.org](http://www.scleroderma.org)

So don't wait – book your flight today. Visit Boston and attend the conference while enjoying all historical and cultural sights the city has to offer! For more information about Boston's many attractions, or to begin planning your trip, visit: <http://www.10best.com/Boston,MA/>.

## Become A Partner In Finding A Cure

The MI Chapter is looking for individuals and businesses who want to partner in finding a cure for scleroderma. There are four levels of partnership, each coming with donor benefits.

**Advocate of the Michigan Chapter**  
**\$ 5,000 or more**

**Patron of the Michigan Chapter**  
**\$3,500**

**Benefactor of the Michigan Chapter**  
**\$2,500**

**Friend of the Michigan Chapter**  
**\$1,500**

At the Advocate level, the benefits

include: a dinner for Advocate members, 8 tickets to the 31st Walk, membership for 1 year, entrance to all the Patient Education Days for self and all members of the your household and entrance to the medical conference for two. At the Patron level, benefits include a dinner for Patron members, 6 tickets to the 31st Walk, membership for 1 year, entrance to all the Patient Education Days for self and all members of the your household and entrance to the medical conference for two. At the Benefactor level, benefits include, a special dessert and coffee for Benefactors, 4 tickets to the 31st Walk, membership for 1 year, entrance

to all the Patient Education Days for self and all members of the your household and entrance to the medical conference for two. At the friend level, benefits include, an ice cream social evening, 2 tickets to the 31st Walk, membership for one year, entrance to all the Patient Education Days for self and all members of the your household and entrance to the medical conference for two. At all levels, participants will receive a sponsorship pin and recognition in the Chapter newsletter and on the MI Chapter website. Sign up on the on-line store or complete the form on the back page of this newsletter.

## Caring Core MI Support Group

Scleroderma effects not only patients but family members and friends. Members of the Farmington Hills Caring Core Support Group have found that by talking openly about their experiences and their feelings it has helped them better cope with the day to day ups and downs.

The MI Chapter is offering to

branch out with the Caring Core Support Group to other areas in the state in an effort to offer support to those in need. If you are desiring to meet with other scleroderma families and friends and to have the opportunity to share your personal story in a safe and nurturing environment than please contact the MI

Chapter at (248) 865-7259. Our goal is to have groups in every large city in MI. Calling is the first step toward getting the support and networking you need to have less stress, more education and feel more confident about the situation you are in. You are not alone, the MI Chapter is here for you!

## Membership News

The Michigan Chapter is now accepting membership dues for 2010. Dues are \$25.00 and come with many benefits. As a member you receive the National publication of the *Voice*. This magazine is packed full of articles that keep patients, family members and the medical community up to date on the latest activities and research regarding scleroderma. It is filled with interesting and uplifting stories of scleroderma patients

that are living proof that scleroderma does not mean a death sentence. As a member you also receive the MI Chapter's newsletter and e-mails with educational information and you and members that reside in your household are entitled to entrance to all of the Patient Education Days. Without membership there is a \$10 per session charge.

Membership dues enable the MI Chapter to offer quality

educational experiences for patients, maintain a Patient Service Coordinator, and keep our doors open.

Fill out the form on the back page of the newsletter today and let's increase the MI Chapter's membership beginning with YOU! You can also ask your family and friends to become members. They will be happy to support you and to learn more about the disease that effects your life.



## A Scleroderma Family Speaks Out

Hi!

My name is David Warchuck and my daughter Tricia has scleroderma. My family supports everything about Scleroderma; the Michigan Chapter, the members and most of all, the events the Michigan Chapter sponsors. Our family has found that these events have not only helped raise funds for the Chapter but they have been equally beneficial for our family by educating us and helping us to create awareness for our family members that did not know about scleroderma.

In October of 2009 my family sponsored the food & decorations for the MI Chapter Halloween party. We enjoyed ourselves so much that we have chose to sponsor the 2010 Halloween party completely, and to make this an annual Warchuck family event. We are so excited about undertaking this project!

Our family wants you to know that anyone can put on an

event- whether its within your church, school or community. All it takes is a little planning and help from your family and friends. Events can be fun-filled and a wonderful way to create awareness for this disease that has touched all of us.

The Warchuck family has found that the staff at the MI Chapter office are so willing to assist us in anyway possible. Laura & Janus will help advertise throughout the Chapter. A small event you start in 2010, could one day be huge if held annually.

Some ideas for events are: a bake sale, a car wash, church dinner (spaghetti/hot dogs/pizza), or a garage sale. If you have a high school student in your family that is active in school, they can have their group sponsor an event. Bowling can be a great way to raise funds or even a run can be a fun way for a group to create awareness and funds easily. Whatever your hobby or passion is, think outside the box

and turn it into a fund raiser for the Chapter that does so much for us.

It doesn't matter what the event is or how big it is, anything is a step in the right direction to help out.

"WE ARE ALL IN THIS TOGETHER, SO LET'S MAKE 2010 THE YEAR WE ALL PITCH IN AND MAKE A REAL DIFFERENCE."

DAVID WARCHUCK

The Warhuck family is looking forward to seeing everyone at the walk!! Our daughter is the 31st Walk and Run Chair and we are so proud of her hard work and dedication. Please come out and support her hard work and the efforts of the MI Chapter. We are all in this together so let's make 2010 the year we all pitch in and make a REAL difference. It begins with us, NOW! If we can do it, so can YOU!

David Warchuck



**SCLERODERMA  
FOUNDATION**  
SUPPORT · EDUCATION · RESEARCH  
MICHIGAN CHAPTER

**We're On the Web! Check Our On-Line Store**  
[www.scleroderma.org/chapter/michigan](http://www.scleroderma.org/chapter/michigan)

**OUR MISSION**

The mission of the Scleroderma Foundation is threefold: To provide educational and emotional support to people with scleroderma and their families; to stimulate and support research designed to identify the cause and cure scleroderma as well as improve methods of treatment; to enhance the public's awareness of this disease.



**WHAT IS SCLERODERMA?**

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. There is also much variability among patients.

**What Scleroderma Is Not**

Scleroderma is not contagious, it is not infectious, it is not cancerous or malignant.

**THERE IS NO CURE FOR SCLERODERMA. TOGETHER WE CAN CHANGE THAT!**

Scleroderma Foundation Michigan Chapter  
30301 Northwestern Highway Suite 300  
Farmington Hill, MI 48334

**Partners In Finding A Cure**

- Advocate.....\$5,000     Patron.....\$ 3,500     Benefactor..... \$2,500  
 Friend..... \$1,500     Donor..... \$1,000     Contributor.....\$500     Other.....

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

E-mail: \_\_\_\_\_ Phone: \_\_\_\_\_

- Please renew my membership dues, \$25.00 for 2010.     Please enroll me as a new member, for \$25.00.

This gift is made in honor of or in memory of \_\_\_\_\_.

I would like to contribute on a monthly basis. Please send me envelopes. I will contribute \$\_\_\_\_\_ per month for 2010 to further the Michigan Chapter's mission.

**Credit Card Information:**

Number: \_\_\_\_\_

Expiration date: \_\_\_\_\_ CVD Three Digit Code: \_\_\_\_\_

NON-PROFIT PRESORT

U.S. POSTAGE

**PAID**

PERMIT #3

SOUTHFIELD, MI

Address Correction Requested