



Toledo Area

Scleroderma and PH Newsletter

March 2010

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Support Group Meeting is March 18, 2010

7:00pm-9:00 pm in Room 2

St. Luke's Hospital

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Welcome to the Toledo Area Scleroderma and PH Support Newsletter

We will have a Speaker Sharon Loukx, RN, BS, CCRC, and Clinical Research Coordinator Jacobson Center for Clinical & Translation Research at the University of Toledo Health Science Campus, Sharon will be discussing the Raynauds Study regarding using nitroglycerine gel and DTech study regarding Scleroderma and PH.

We will also discuss if we are going to have meetings in December 2010, January and February 2011, Also we will be discussing an Educational Day for June 19, 2010, I will be asking for some help planning this so please if you are interested in helping let me know.

### **The Sclero News11**

The Ohio Chapter of the Scleroderma Foundation has teamed with NE Ohio Candy maker Malley's for a two month campaign to raise money to fund

the fight against this disfiguring, disabling and life-threatening disease that attacks over 300,000 patients in America and for which there is no known cure or specific treatment.

Please email your family and friends asking them to go online and order some candy for the Easter or Passover holidays or just for the delicious treat of Malley's chocolates.

There's plenty to choose from so go directly to the Malley's Campaign site at [malleys.sfohio.org](http://malleys.sfohio.org) <<<==== click here for Malley's online! And choose from some great Malley's candy selections. Your order will be delivered wherever you choose.

**Newly Diagnosed** doesn't have to be overwhelming, even though the disease is complex. The symptoms of scleroderma vary greatly from individual to individual, and the effects of scleroderma can range

from very mild to severe. The seriousness will depend on what parts of the body are affected and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

Scleroderma is not contagious; it is not infectious; it is not cancerous or malignant. There are an estimated 300,000 people in the United States who have scleroderma, and one third of whom have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult and there may be many misdiagnosed or undiagnosed cases as well.

There are two major classifications of scleroderma: [localized scleroderma](#) and [systemic sclerosis \(SSc\)](#).

- [Frequently asked questions](#)
- [Scleroderma overview](#)
- [Scleroderma fact sheet](#)
- [Types of Scleroderma Chart](#)
- ["Understand & Managing" booklet](#)
- [What scleroderma is not](#)

Becoming better informed and more organized will help you be a more effective partner in your healthcare. Knowledge is power, and we certainly want you to be as empowered as possible.

- [Articles](#)
- [Medications](#)
- [Scleroderma registries](#)

Listed below are resources we have compiled in an effort to assist patients and their families, many of whom have expressed a need for these types of services.

- [Find a doctor](#)
- [Research & Treatment Centers](#)
- [Join the Scleroderma Foundation](#)
- [Suggested books to read](#)
- [Weekly eLetter](#)
- [Additional resources](#)

You are not alone! Others who know how you feel can offer support.

- [Find a chapter](#)
- [Find a support group](#)
- [Use our message board](#)
- [Find an event near you](#)
- [Come to our National Conference](#)
- [Contact us](#)
- [About Us](#)

## The PH News11

Toledo/Northwest Ohio PH group site:  
<http://www.phassociation.org/ToledoGroup>

## Newly Diagnosed

"Take a deep breath and hang in there. PAH is not a death sentence. With each passing year, there are more ways to manage symptoms. You have to accept a different state of normal, but that doesn't mean you can't have a great quality of life."  
- *Patty Farrow, PH patient (diagnosed 2001)*

## You were just diagnosed with PH. What's next?

Learning that you have pulmonary hypertension can be overwhelming, but you're not alone. Like the tens of thousands of people diagnosed with PH before you, you have a compassionate and inspiring community of people ready to help. We are

here to provide you with information and support as you adjust to your new life with PH.

While there's currently no cure for PH, there are PH-specific therapies available to manage your symptoms and improve your quality of life. We know patients on treatment who have been living with PH for more than 20 years and counting.

### **Taking the First Steps**

#### **Request your Envelope of Hope**

- [Order a free information kit for recently diagnosed patients](#)

#### **Get the facts**

- [Learn more about PH](#)
- [Order A Patient's Survival Guide](#)

#### **Seek treatment**

- [Find a doctor who treats PH](#)
- [Get ready for your first appointment](#)

#### **Meet people who understand**

- [Call the Patient-to-Patient Helpline](#)
- [Find your local support group](#)
- [Connect online](#)
- [Join our community of hope](#)



Have you renewed your membership with Scleroderma Foundation or with Pulmonary Hypertension Association?

PHA

<http://www.phassociation.org/Page.aspx?pid=797&chid=99>

Scleroderma Foundation

<http://www.scleroderma.org/development/ember.shtm>

If you would like to renew your membership at the next meeting just let Jerri know.

#### *Note from Jerri*

*I am so excited about the up coming months, the educational day for the Toledo Area June 19th, not only that the The PHA is Conference June 25<sup>th</sup> through June 27<sup>th</sup>.*

*Scleroderma Foundation Conference is July 30 through Aug 1<sup>st</sup>. Scholarships are available from The Scleroderma Foundation and the PHAssociation.*

*The Ohio Chapter Scleroderma Will be hosting a conference in October. More information as it comes in. Take care and see you soon.*

*Jerri Sue DeTray  
Support group leader for scleroderma and Ph*

