

## Northern Lights Region Minutes

by Judy Parker, Northern Lights Support Group Leader



At March's meeting, there was not a silent moment in three hours. Folks started to arrive at 6:00, and folks started to leave at 9:00. The room was buzzing the entire time, while we all enjoyed Joe Zuraw's presentation, Alpha-1 Overview. Joe is the

Senior Director of Pulmonary Operations for Talecris. It was like a little family, and it was absolutely wonderful!

A total of 8 members gathered for March's meeting. Industry guests included Gabriel Luster (Talecris), Joe Zuraw (Talecris), and Teri Frank (Accredo). Food and refreshments from Kris's Pheasant Inn were provided by Talecris ([www.talecris.com](http://www.talecris.com)) manufacturers of Prolastin® [www.prolastin.com](http://www.prolastin.com).

### Upcoming Northern Lights Meeting Agenda

All meetings are held, from 6:30-9:00 p.m. in the Burnette County Government Center. 7410 County Road K (2 miles north of Siren on Hwy 35) in Siren, WI.

Date	Details
May 17 <sup>th</sup>	Medical Discrimination Issues Speaker: Miriam O'Day, Senior Director of Public Policy for the Alpha-1 Foundation

is a wonderful read, and by all means, a positive reflection on how one family and one boy rose above all else to conquer the fears and joys of the transplant process due to Alpha-1. Holloway is an Associate Dean for Student Affairs Professor at the Medical College of WI. A copy of his book, *My Name is Joe*, is available at Amazon ([www.amazon.com](http://www.amazon.com)). Look for Dr. Holloway at the 16th Annual Alpha-1 Conference in Alexandria, VA as well!

A total of 28 members gathered for March's meeting. Industry guests included Nathan Spielman (Coram), Ryan Glor (Baxter), Gabrielle Luster (Talecris), and Jean Andre (Accredo). Food/refreshments were provided that evening by Coram [www.coramhc.com](http://www.coramhc.com) distributors of Aralast® [www.aralast.com](http://www.aralast.com).

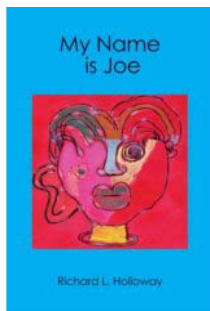
### Upcoming Southern Shores Meeting Agenda

All meetings are held the second Thursday of the month at 6:30 p.m. in the Community Conference Center, 8700 Watertown Plank Road in room #2, Milwaukee, WI 53226.

Date	Details
May 10 <sup>th</sup>	Pathogen Safety and Nucleic Testing Speaker: Doug Lee
June 14 <sup>th</sup>	TBD
July 12 <sup>th</sup>	4 Paws- Helper & Therapy Dogs Speaker: Chelsea Budde

## Southern Shores Region Minutes

by Noreen James, Southern Shores Support Group Leader



Outside, March roared in like a lion with drifting snow and howling winds, but inside, warmth enveloped us as Richard Holloway, PhD spoke candidly on the inspiration behind his book: *My Name is Joe*. The story developed as he and his family dealt with their 4-year old son's (Evan's) diagnosis of Alpha-1 and liver transplant.

Evan (now in his teens) is the basis for the fictional tale of a college youth named Joe, and the medical journey he took when he was four. We are placed at Joe's level where frustration and discomfort, as well as humor and joy, are openly expressed. Readers also get a glimpse of the family dynamics and the courage needed as one member is faced with an illness. So in truth, the fictional world of Joe is very much like the real world that Holloway experienced and tapped into. The story not only shows the depth of his creativity, but the strength it took to face Alpha-1. The book

## Get Educated!

Alpha-1 Association 16th Annual Education Conference  
 June 8 -10, 2007

Hilton Alexandria Mark Center  
 5000 Seminary Road, Alexandria, VA 22311  
 703-845-1010

Don't miss your opportunity to:

- Expand your knowledge and increase mind body strategies for managing Alpha-1.
- Hear about the latest research from the top researchers in the field.
- Learn legislative updates on federal and state initiatives and learn how you can be an advocate.
- Catch up with your local Alpha-1 support group members and meet members of other groups.
- Network with others and share ideas in a spirit of camaraderie.
- Know how you can get involved in the Alpha community and make a difference.

Download the registration form:

<http://alpha1.org/support/documents/NationalConference-RegistrationForm.pdf>

## Life after Medical Retirement

by Judy Parker

When I took medical retirement in 2003, I didn't really know where my life would go from there. My health had rapidly started to change. To date, the disease has progressed with my lungs and affected my heart. Affecting my heart was of no surprise as most people with chronic lung disease eventually end up with heart disease. I am grateful for every day I wake up and for the things I can do. Most of my friends are still in awe of what I can accomplish in my daily activities and in my life, but that doesn't come without help from my friends and close family members.



I now know what my life after medical retirement is: to promote Alpha-1 awareness and help other Alphas in need. I started an Alpha-1 support group for northern WI last fall. We are part of the WI support group called The Alpha Pack (no surprise there huh), my region is Northern Lights Region. The Alpha Pack has over 100 members, and has been in existence since 1990. There is a Southern Shores Region in Milwaukee, and a new region starting up in Green Bay, called the Green Bay Region.

My last support group meeting was this past week on March 15, and I was presented the latest Talecris brochure. I was surprised to see myself in it. I've accomplished a lot in my life, considering my limitations, but I think my biggest accomplishment and the one that brings the most joy and contentment within is to help others in need, especially those with Alpha-1.

In January 2007, Talecris sent a film crew up to interview me. The taped interview took about 2-3 hours. They took gobs of still shots and filmed me working out with weights and on the treadmill. They also interviewed a friend of mine. I am one of five people chosen to be in an educational DVD (three Primary Immunodeficiency patients and two Alpha-1 patients). The DVD will be distributed to medical facilities, doctors etc., in educating them and promoting awareness of Alpha-1. I am proud of what I am doing now.

## 6<sup>th</sup> Annual Scientific Conference



The Alpha-1 Foundation organized the 6<sup>th</sup> International Scientific Conference entitled *New Insights into the Biology of AAT: The Expanded Role of AAT in the Treatment of AAT Deficient Individuals and Other Diseases* in Miami, Florida February 8-10, 2007. Mark L. Brantly, M.D., Robert A. Stockley, M.D., and

Charlie Strange, M.D. co-chaired this innovative conference, which updated our understanding and expanded the scope of interest of the role of the alpha-1 antitrypsin protein (AAT) in both AAT deficient individuals and those with other diseases. This conference was very important because it showcased how our understanding of AAT is leading to new therapies for AAT deficient individuals and for potential application for other disease states. There was much interest and dialog among the group of over 100 presenters and investigators that came from Europe, the Middle East, US, and Canada representing state of the art biological expertise.

## Mother's & Father's Day Gifts to Benefit the Alpha-1 Foundation



Give a gift on Mother's Day and Father's Day that will benefit the Alpha-1 Foundation. Mother's Day scarves and Father's Day ties will be available for purchase benefiting the Alpha-1 Foundation. The new designs will be unveiled soon. Please contact Yiomara at [yperry@alphaone.org](mailto:yperry@alphaone.org) to give a special gift that will benefit the Alpha-1 Foundation.

## Upcoming Events

Upcoming events to possibly raise Alpha-1 Awareness are:

Date	Details
May 19 <sup>th</sup>	Rock 50/50, Janesville, WI <a href="http://www.rockoutdoorevents.com/rock_50.htm">www.rockoutdoorevents.com/rock_50.htm</a>
June 8-10 <sup>th</sup>	Alpha-1 Association National Education Conference, Alexandria, VA Hilton Alexandria Mark Center 5000 Seminary Road Alexandria, VA 22311 <a href="http://www.alpha1.org/home/index.asp">www.alpha1.org/home/index.asp</a>
June 16 <sup>th</sup>	Wisconsin Liver Walk, Waukesha, WI <a href="http://www.active.com/donate/wiliverwalk2007">www.active.com/donate/wiliverwalk2007</a>
June 16 <sup>th</sup>	Horribly Hilly Hundreds, Mt Horeb, WI <a href="http://www.horriblyhilly.com">www.horriblyhilly.com</a>