



The Flu is Coming

The influenza, also known as the flu, season is rapidly approaching here in Wisconsin. The best tool for preventing the flu is the flu vaccine, and the best time to get a flu vaccine is from early October to mid-November. The vaccine can also be given at any point during the flu season, even if the virus has already begun to spread in your community. Flu vaccines are given every year because the virus is constantly changing, and new vaccines are developed annually to protect against new strains.

You can obtain a flu shot from your doctor or from a flu shot clinic. To find a clinic, go to www.findaflushot.com for a location near you.

Meet GBR's Medical Liaison



Dr. Raul Mendoza is our Medical Liaison for The Alpha Pack, Green Bay Region (GBR) at the Aurora BayCare Hospital. He is a pulmonologist at BayCare Hospital in Green Bay, WI. His specialties include Pulmonary Medicine and Critical Care. He studied at Universidad Anahuac (Mexico) in 1991. His residency, internship, and fellowship were completed at University of Miami Jackson Memorial Hospital. He gave The Alpha Pack a well presented talk on *How to Catch an Alpha* at the GBR's very first meeting on June 19th. A turn out of 23 Alphas and their families attended that evening. Besides Alpha-1, Mendoza also supports awareness for the autoimmune condition called Sarcoidosis. His physician web page and published articles can be viewed at www.baycare.net

Welcome Home Morgan!



Welcome home! Johanna's son, Morgan, is safely back from Iraq. Thank you for your courage Morgan!

Breathtaking Quilt

Judy Golding created a quilt with a poem called Breathtaking by Amy Pearce Jackson sewn into the pattern. The poem is about Alpha-1. Judy donated the quilt to the [Caring Voice Coalition](#) Art Auction on September 14, 2007.



Breathtaking

by Amy Pearce Jackson, 2007

Mountains during a sunset
as day light seems to slowly fade
Outlining the natural wonder
that was so miraculously made
Breathtaking.....

An ocean in the winter time
as its icy surface seems to glow
As creatures wait for spring
in their homes far below
Breathtaking.....

Winding country roads
as fall colors have consumed the trees
As if driving through a tunnel
made out of beautiful leaves
Breathtaking.....

seem to dance with the wind
Making synchronized movements
with no beginning or end
Breathtaking.....

Standing near a waterfall
as the thunderous sound projects its place

Yet in awe when so close
Yet the sprinkles dance across your face
Breathtaking.....

Laid on a blanket
as stars gather to twinkle in the night
Although millions of miles away
they still lay in our sight
Breathtaking.....

Beautiful accents of nature, tend to make us stop and smile
Reminding us of the precious moment, if only for a short while
YOU too are a wonder, because in illness you persevere through

An Alpha-1 survivor, another
Breathtaking view.....

The Alpha Pack's Holiday Fundraiser

The Alpha Pack's holiday fundraiser with [Tastefully Simple](#) is on for 2007. 25% of all the proceeds will go towards The Alpha Pack. From main dishes to desserts, they offer a wide variety of gourmet foods and gifts for every day and every occasion. Order by Nov 8th, and items will be shipped directly to your home before Thanksgiving. Make all orders through diane_s_martin@yahoo.com or call Diane at 1-414-421-9322.

2008 National Conference

The next Alpha-1 Association National Education Conference will be June 20-22nd in St. Louis, MO. The hotel will be the Sheraton Westport Chalet (314-878-1500) at \$109 + tax per night. You can check it out at:

www.starwoodhotels.com/sheraton/property/overview/index.html?propertyID=795

Scholarships to the conference are available. For more information, contact info@alpha1.org or call 1-800-521-3025.

World COPD Day is November 14th



World COPD Day is an annual event organized by the [Global Initiative for Chronic Obstructive Lung Disease \(GOLD\)](#) to improve awareness and care of chronic obstructive pulmonary disease (COPD) around the world. World COPD Day 2007 will take place November 14.

Southern Shores Region Mtg. Minutes

by Noreen James, Southern Shores Support Group Leader

September's meeting was an open forum. It was an opportunity for members to give their personal feedback on Alpha-1. We shared personal insight on good books, healthy eating, health insurance, and the highs and lows that we face everyday. Most of our meetings usually start off with a speaker. This can leave little time left over for members to socialize and talk with others. The Alpha Pack wants to focus more of their meetings on having a social setting more often. Thus, in the future, we plan to focus on promoting more open settings to just talk and mingle. A total of 15 members gathered for September's meeting. Industry guests present were from Accredo, Baxter, and CSL Behring. Food and refreshments were provided by CSL Behring, the manufacturers of Zemaira® www.zemaira.com

Central Fields Region Mtg. Minutes

September's meeting welcomed Jerry Dzierlinga. He presented on Inogen One. "The Inogen One is one device designed to make life easier for patients. It is designed to be one solution for home, away and travel, for today and tomorrow." www.inogen.net The device is an all-in-one O2 pulse dose delivery system. It creates its own oxygen. There are no tanks to fill. The unit is portable and durable. It comes with rechargeable batteries that are good for up to 3 hours. It

weighs in under 10 lbs, and this device is allowed for travel on almost all airlines. To find out more, you can contact Jerry at (630) 688-1024 jdzierlinga@inogen.net. A total of 7 members gathered for September's meeting. Industry guests present were from AlphaNet, Baxter, and Coram. Food and refreshments was provided by Baxter, the manufacturers of Aralast® www.alpha1health.com.

Northern Lights Region Mtg. Minutes

by Judy Parker, Northern Lights Region Support Group Leader

Congrats on 1 year anniversary as a group!



September's meeting welcomed Bill Brechue. He presented on *Relaxation Therapy - Get your body in sink with your emotions*. Speaker Bill Brechue was wonderful. Our November meeting will also be our "Holiday Get Together". Date is Nov 29th. Place and times will be announced. Jodi Roth, WI Alpha Net Coordinator- will do a short presentation *What is Alpha Net?* at the November meeting. It was decided that we are going to cancel the January meeting as it is too cold here in the North Country and resume in March. A total of 9 members gathered for September's meeting. Industry guests present were from Accredo and CSL Behring. Speaker, food, and refreshments from Chattering Squirrel were provided by CSL Behring makers of Zemaira® www.zemaira.com

Green Bay Region Mtg. Minutes

Dr. Elizabeth McPherson presented on Genetics, Bench to Bedside, in which she discussed the history of Alpha-1 alongside the study of genetics. Understanding the role of DNA has led researchers to further discover the link to properly diagnosing hereditary conditions such as Alpha-1. McPherson is a Clinical Geneticist/ Dymorphologist at Marshfield Clinic in Wisconsin. She is also the Medical Liaison for The Alpha Pack, Central Fields Region. Her Physician web page and published articles can be viewed at the Marshfield Clinic web site www.marshfieldclinic.org. She is also currently conducting a research study on Connective Tissue and Alpha-1. To find out more about this study, contact her at (715) 221-7409 or mcperson.elizabeth@marshfieldclinic.org or The Alpha Pack at (920) 803-2668 or info@thealphapack.org. A total of 16 members gathered for September's meeting. Industry guests present were from Accredo, AlphaNet, Baxter, and CSL Behring. Food and refreshments were provided by CSL Behring, the manufacturers of Zemaira® www.zemaira.com

Research Study

Alpha-1 Genetic Testing of at Risk Children

The objective of this study is to investigate the ethical, legal, and social impact of testing at risk children for Alpha-1. The results will inform the development of recommendations for health care professionals on what constitutes disclosure of risks and benefits in informed consent or assent by children who are considering testing for Alpha-1.

As a pre-study, we will conduct 2 focus groups: one in Denver, Colorado on November 10, 2007 and one in Orlando, Florida on December 1, 2007. To participate in a focus group, you must be a parent who has made a decision to test or not to test your at risk child for Alpha-1 or an adult who was tested for Alpha-1 as a child. To enroll in the focus group or for more information please email marilyn.coors@uchsc.edu or call 1-303-315-0203. To participate in the study survey, please enroll in the Alpha-1 Research Registry. The study is funded by the Alpha-1 Foundation.

To enroll in the Alpha-1 Research Registry at the Medical University of South Carolina, read the following information:

The Alpha-1 Research Registry is a confidential database of individuals diagnosed with Alpha-1 Antitrypsin Deficiency (Alpha-1) and persons identified as Alpha-1 carriers. It serves as a resource for investigators seeking individuals with Alpha-1 to participate in clinical trials, surveys, and other scientific and medical data collection activities. The Registry's Family Linkage Program facilitates genetic research and other studies requiring family member participation while protecting the privacy and autonomy of each family member. The Registry is also a vital component to other Alpha-1 research endeavors such as the Alpha-1 Coded Testing (ACT) Study and Genetic Modifiers Study. The Registry is conducted under the direction of Charlie Strange, M.D. at the Medical University of South Carolina. For more information about the Registry Program, you may visit the website at www.alphaoneregistry.org, email at alphaone@musc.edu or call toll free at 1-877-886-2383.