



## Happy New Year!



## Heaven Gains an Alpha-1 Angel



Irene Lang (Sept 12, 1946 – November 16, 2008). It is with great sorrow that we say good-bye to Alpha Pack member, Irene Lang. She passed away on Sunday, November 16, 2008 at St Luke's Hospital in Milwaukee. She leaves behind no kin. A memorial service was attended by friends, Alpha Pack members, and nurses who cared for her. Irene had a double lung transplant on January 2, 2008 due to Alpha-1 and Bronchiectasis.

Since her transplant she enjoyed breathing well for the first time in her life. She loved dogs, and her favorite kind was the Pomeranian. She also belonged to the Wisconsin Wolf Society. Irene waitressed all her life and loved it until she could no longer do so due to her lungs. She was very independent and resourceful despite her limitations. She had a caring and compassionate heart. And always asked how you were doing no matter how sick she became. We will miss you, Irene. Rest in peace.

There is a collection being made through the Wisconsin's Alpha Pack to help purchase a tombstone for Irene's resting place at Arlington Cemetery. Our hope is to have enough funds by spring to order one. If you are interested in donating towards Irene's headstone, please request our donation form or send a check to Irene's Memorial c/o Wisconsin's Alpha Pack, 2216 S 9th Street, Sheboygan, WI 53081. Any funds in excess will go towards our organization. For questions, contact our office at (920) 803-2668 or [info@thealphapack.org](mailto:info@thealphapack.org).

## Television Show Features Alpha-1

Healthy Body, Healthy Mind (HBHM) takes a look at Alpha-1 Antitrypsin Deficiency and helps viewers to understand Alpha-1. The show is currently running on the Public Television Network, so contact your local Public TV Station for listings. The Alpha-1 Foundation is currently hosting the TV show online here: <http://www.alphaone.org/news/health-and-wellness-series-features-alpha-1>

## Ron's Emergency LVRS

As many of you know, Green Bay's Support Group Leader, Ron Bernard, doesn't let any of his meeting go by without some of his antics. Thus, you learn quickly not to take him seriously. However, the November 18th meeting was an exception to his rule. He sent his wife Sher over to run the show that night because his doctor (Dr Mendoza, who was the guest speaker) decided his blown lung needed emergency attention. Thus, Ron got a free pass to skip the meeting; he had to go to Aurora BayCare's I.C.U. instead. Most of the members asked, "Are you kidding?" No, this time it wasn't a joke. Ron was seriously ill. His left lung had collapsed from advanced emphysema due to Alpha-1. Doctors made several attempts to fix the lungs, but surgery was the last resort. Thus after a few weeks in I.C.U., cardiothoracic surgeon, Dr Alexander Roitstein preformed a LVRS (Lung Volume Reduction Surgery) on Ron's left lobe. And due to the emergency situation, it was the first LVRS ever done at Aurora BayCare in Green Bay, WI. As of January 5th, Ron is finally back home healing. His wife Sher said it's a miracle as to how well he is doing. Ron will be back to his funny business in no time. If you wish to send Ron a get well wish, contact him or Sher at [Schnitzle4@new.rr.com](mailto:Schnitzle4@new.rr.com) or (920) 490-7811.

## Alpha-1 Families Teleconference

*by Jaime Freitag, Liver Aide*

The first Alpha-1 Families teleconference sponsored by Alpha-1 Kids and the Alpha-1 Association was held on December 2, 2008 with guest speaker Dr. Jeffrey Teckman. There were 27 parents on the call throughout the USA and Canada. Dr. Teckman is an Associate Professor of Pediatrics, and Biochemistry and Molecular Biology at the St. Louis University School of Medicine, Cardinal Glennon Children's Medical Center. In the Alpha-1 community, he is a known researcher and clinician. His worldwide research involvement includes studying liver damage in Alpha-1 and how to treat and prevent damage from occurring.

Dr. Teckman began the teleconference by giving a background on Alpha-1 in children and current research findings. An open forum followed, opening up the phones to parents with personal experiences and questions. From preemies with Alpha-1 to successful liver transplants, many topics were discussed, and numerous questions were answered. Dr. Teckman gave some advice such as what to watch for with Alpha-1 and liver disease, diet/intake tips, and keeping on top of your health to prolong life. Dr. Teckman has research opportunities currently available. He is presently studying the Contribution of Genetic Modulators of Disease Severity in Alpha-1 and Cystic Fibrosis. He is currently recruiting individuals with Alpha-1 liver disease to see if the CF gene and other genes may partially cause liver problems.

The goal of the project is to better understand the genetic mechanisms that affect Alpha-1. This will better predict the severity of Alpha-1 and new treatments for Alpha-1. For more information, contact Dr. Teckman at 314-577-5647 or [teckmanj@slu.edu](mailto:teckmanj@slu.edu). You can listen to this teleconference at any time. Please go to <https://www.spiderphone.com/2392120780> and follow the directions.

## Central Fields Region Mtg. Minutes

by Dawn Smith, Support Group Co-Leader

The next Central Fields Region meeting will be May 7, 2009 at 3:00 p.m. For details, contact CFR Co-Leader, Dawn Smith, at (715) 536-8145 or [CFRcoleader@thealphapack.org](mailto:CFRcoleader@thealphapack.org).

## Green Bay Region Mtg. Minutes

by Noreen James, President and Director of Operations



Green Bay's November meeting was an open forum along with a special guest, Dr Raul Mendoza, Pulmonologist, Aurora Bay Care. Mendoza took time out his busy schedule that evening to take questions and answers on Alpha-1. He is the medical liaison for the Alpha Pack's Green Bay Region and has years of experience with caring for Alpha-1 patients. He truly believes in educating as well as caring for the patient. He also encourages that a family of a patient look into testing (if not already done) so that preventative steps can be taken to ensure the best quality of life and health for all involved. It was enlightening session to hear Mendoza's review on the topic of therapy for MZ phenotypes. He also described his first experience with Alpha-1 years ago when he practiced at a VA in Florida. This meeting welcomed 11 people in attendance. Coram, an infusion and nursing service for Aralast® [www.coramhc.com](http://www.coramhc.com) hosted food. Accredo, an infusion service for Zemaira® & Aralast® [www.accredotx.com](http://www.accredotx.com) hosted the refreshments. Next meeting will be on Thursday, March 17th, OPEN FORUM, weather pending. For details, contact Ron Bernard at (920) 490-7811 or [GBRleader@thealphapack.org](mailto:GBRleader@thealphapack.org).

## Northern Lights Region Mtg. Minutes

by Judy Parker, Support Group Leader



Siren's November meeting featured Darrell Nall, double lung transplant recipient, and he spoke about his experience with

transplant. Darrell will be 6 years out in February, 2009. The Holiday Bash was simply wonderful and filled with laughter and smiles! The party started about 6 p.m. and ended sometime after midnight. A GREAT time was had by all! The meeting welcomed 13 people, in attendance. Talecris, the manufacturers of Prolastin® [www.prolastin.com](http://www.prolastin.com) hosted food and refreshments that evening. The next Siren meeting will be "Latest lung medications and oxygen equipment" and is planned for May 21, 2009. For details, contact Judy Parker at (715) 653-2666 or [NLRleader@thealphapack.org](mailto:NLRleader@thealphapack.org).

## Southern Shores Region Mtg. Minutes

by Noreen James, President and Director of Operations



Milwaukee's November meeting was an open forum along with a special guest, Mary Pierce, Alpha-1 Advocate, Centric Health Resources. Mary is an Alpha-1 patient that went through a double lung transplant back on April 3, 1993. She is an inspiration not only for having gone 15+ years post transplant, but also for her involvement in life. She bikes, walks, kayaks, and works full time. And in her spare time, she travels across the U.S. to present on her personal experience regarding Alpha-1. Her journey was not an easy road. In the days before being diagnosed, she struggled with every step. Routine tasks became mountains to climb. Her weight dropped as she battled to maintain nutrition in competition with her body's needs. Many doctor visits came up empty as to why she was becoming so short of breath. Thus, she was truly grateful for the day she was properly diagnosed in 1987. Six years later she had her lung transplant and was given the gift of life. And with this, Alphas too are given a gift, for without Mary's story of strength and courage, there would be less inspiration and hope for those faced with these odds. Mary is an Alpha-1 Advocate for Centric Health Resources, a pharmacy [www.centrichealthresources.com](http://www.centrichealthresources.com) for Prolastin®. At this meeting, we welcomed 13 people in attendance. Talecris, the manufacturers of Prolastin® [www.prolastin.com](http://www.prolastin.com) hosted food and refreshments that evening. Thank you Mary and to everyone who could attend! Next meeting will be on Thursday, February 12th, OPEN FORUM, weather pending.

*Holiday Thanks:* A big thank you goes out to the many that made the Southern Shores Region Christmas Party a wonderful event! Jaime- for reserving the New Berlin Center, Cleveland Room (it was fantastic!) and for arranging the gift baskets for the raffle table. Johanna-for arriving really early for table setup and decorations. Bob- for the smoked fish! Jake- for his booming raffle voice. Lois-for taking photos. Lynnette- for arranging the children's prizes. Don and Lorretta-for donating hand-crafted art & jewelry for the raffle. Thanks also to Accredo, Baxter, Coram, CSL Behring, and Talecris for sponsoring the room costs, the catered food from Maggiano's, Little Italy, and the refreshments. And to all those who brought holiday cheer and sweets,...thank you, thank you, thank you. Everyone had an enjoyable time and it was great to see you all. Happy New Year!