

## Southern Shores Region Minutes

by Noreen James, Southern Shores Support Group Leader



For July's meeting, we had a wonderful treat. Chelsea Budde presented along with her service dog, Reagan. He is a black lab with special skills. He cares for Budde's son & daughter, Justus & Noelle, who are both Autistic. Reagan was trained through a non-profit organization called 4 PAWS.

Their mission is "to enrich the lives of people with disabilities by training and placing service animals to provide them with companionship and promote independent living". They place these service dogs with people who are often rejected by several other organizations.

Another goal of 4 PAWS is to reduce the number of unwanted animals who would otherwise be destroyed by obtaining the majority of their animals from shelters and rescue groups. The process of acquiring a service dog through 4 PAWS takes two main things: raise the funds to train the dog and then bond with the dog for up to 12 days. Once the funds are raised (between \$8,000 and \$14,000) intense training begins at a designated 4 PAWS location with the selected family or person in need of a service dog. The rewards have been great with Reagan. He has given the Budde family security and a safer environment for their children. And let's not forget that he gives great fun and tons of love.

Visit Chelsea Budde's 4 PAWS web site at <http://www.4pawsforjustusandnoelle.org> or call her at 262-896-0028. You can also visit the 4 PAWS main web site at <http://www.4pawsforability.org>

A total of 28 members gathered for July's meeting. Industry guests present were from Accredo, Coram, Baxter, and CSL Behring. Food and refreshments from Q'Doba was provided by Accredo, <http://www.accredotx.com>, the distributors of Aralast® and Zemaira®

## Northern Lights Region Mtg. Minutes

by Judy Parker, Northern Lights Region Support Group Leader

### National Conference Reunites Alpha Cousins After 50 Years

Judy Parker, Alpha Pack Support Group Leader in the Northern Lights Region attended the National Conference in Washington D.C. in June. While there, she met Marianne Mullen, Support Group Leader from Arizona, and they spent

some time getting to know each other. During the course of conversation, it came out that Marianne grew up in Wisconsin, not more than 15 miles from Judy. In continuing the conversation, it was questionable that Judy had a relative of Marianne's in her group. Judy received a card and photo from Marianne a short time after the conference. In the card were two pictures of Marianne, one for Judy and one for what might be Marianne's cousin and a question to ask Gerald (Jerry) Handlos in determining if he is indeed Marianne's cousin.

Judy was confident that Jerry was Marianne's cousin from the description. At the last Northern Lights Support Group Meeting on July 19th, Judy asked Jerry if he had a sister and he said yes, her name was Peggy. He answered the question correctly, and Judy presented him with the card, address, and picture of his long lost cousin. It had been 50 years since they had seen each other. They have since been in contact via e-mail and glad to be reunited!

### Noreen James Attends Northern Lights Region Support Group Meeting

During the Northern Lights Support Group meeting on July 19th, Judy had the pleasure and opportunity to introduce Noreen James, SSR SGL to her group. Judy explained to the group that Noreen was the heart and rock of The Alpha Pack and without Noreen the NLR would not exist. Judy thanked Noreen for coming and for all that she does for all Alpha's and that her hard and devoted work does not go unrecognized. The group was glad to have her and meet her.

### Karen Block Exceeds

Karen Block, Endeavor Therapy and Sleep Center Administrator ([www.endeavortherapy.com](http://www.endeavortherapy.com)), exceeded the time frame for speaking at the July 19th NLR support group meeting. The group was asked to leave the building as it was being shut down. The attendees at the meeting were so impressed and interested in what Karen had to say that time just ran out as they went over the time allowed for the meeting room. The NLRSG thought that Karen was a "fantastic speaker" and enjoyed having her in their "little north country". Many thanks to Karen for taking the time to come and speak to our group.

A total of 12 members gathered for July's meeting. Industry guests present were from Accredo and CSL Behring. Food and refreshments from The Experience was provided by Accredo, <http://www.accredotx.com>, the distributors of Aralast® and Zemaira®. Speaker hosted by CSL Behring makers of Zemaira®.

## We Need Your Help

Ten months out of the year, we publish The Alpha Pack News. Many of our subscribers receive this newsletter by postal mail. Because of the time and costs associated with printing and mailing the newsletter, we ask that you consider receiving the newsletter in your email if you are able. To sign up for the email edition of The Alpha Pack News, please contact [info@thealphapack.org](mailto:info@thealphapack.org).

## Meet Dawn, Alpha Pack Member



Hi, my name is Dawn. I live in Merrill, WI. My shortness of breath started back in 1995, but I put it down to being out of shape (I'm overweight). I kept thinking I would start to get back in shape soon but that never happened. Then in the summer of 2003, I was having lots of problems with S.O.B. and I told my husband if it didn't get better I would go in to see the doctor. I did have pneumonia a couple of times but that is all except for the S.O.B. I have 3 brothers and only one has been tested but we don't know his phenotype yet. One sister has been tested, and she is a SZ like me but has no problems at all. She did ask the doctor why since all our lives we did pretty much the same (started smoking around the same time and quit smoking around the same time). I did have two pregnancies and she had none. Anyway he said "maybe in a hundred years they will know why".

One daughter has been tested, and she is an MZ; the other daughter will be tested soon. Inhalers don't help me, and so far the insurance won't pay for other treatments so right now I am on O2 all the time. I attend The Alpha Pack, Central Fields Region in Marshfield, WI. I am interested in co-leading this group. Talking with another Alpha-1 near me would be wonderful. Please contact me anytime. I can be reached at (715) 536-8145 or email me at [Dawny1804@aol.com](mailto:Dawny1804@aol.com). I also have a blog listed on Spiderspun at [www.spiderspun.net](http://www.spiderspun.net).

## Alpha-1 Genetic Counseling Service

In July, the Alpha-1 Association launched its new Alpha-1 Genetic Counseling Call Center. The Call Center, under the supervision of Charlie Strange, M.D., Associate Professor of Medicine at the Medical University of South Carolina, offers information and resource to Alphas, family members, and medical professionals on the genetics of Alpha-1 and provides information on testing options.

**1-800-785-3177**

The Center can help Alpha-1 community members to understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. In addition, individuals can obtain information about inheritance, testing, management, prevention, resources, and research.

The Center helps individuals reach informed choices and adapt to their risk or condition. Supportive counseling and referral to community or state support services is available as well through the Center. To contact the Alpha-1 Association Genetic Counseling Call Center call: 1-800-785-3177.

## Hike for Lung Health 2007



Team Alpha-1 is forming at the Hike for Lung Health 2007 on Sunday, September 23<sup>rd</sup> at 10 a.m. It is a 3 mile walk to raise COPD Awareness created by the Respiratory Health Association of Metropolitan Chicago (formerly the ALA of Metro Chicago). No walking is necessary for those who prefer to sit. Registration can be found at two locations: Chicago-Montrose Harbor, 3700 North Lake Shore Drive or Palatine-Deer Grove Forest Preserve. The fee is \$10.00, and the Team Captain is Natalie Maihack. A total of 70% of Team Alpha's funds raised will go towards the Alpha-1 Foundation and research. To sign up to become a Team Alpha-1 walker, contact Jodi Roth (WI's AlphaNet coordinator) at [jroth@alphanet.org](mailto:jroth@alphanet.org) or (877) 662-4774. Visit the web site at [www.hikeforlunghealth2007.kintera.org](http://www.hikeforlunghealth2007.kintera.org).

## 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 West Port Hotel (314-878-1500) at \$109 + tax per night. For more information, contact [info@alpha1.org](mailto:info@alpha1.org) or call 1-800-521-3025.

## Picture This!



Alpha Pack Members Having Fun at the National Conference in Washington, D.C.

September 13, 2007

Dear Reader,

I am Elizabeth McPherson, a medical geneticist interested in many genetic conditions including alpha-1 antitrypsin deficiency. Some Alphas with flexible joints asked me if there is a correlation between AAT deficiency and connective tissue disorders. I had not thought much about that, but it does make sense since people with connective tissue disorders can be at risk for lung problems like emphysema or spontaneous pneumothorax. It is important to find out if connective tissue weakness can be part of AAT deficiency because that suggests that at least some Alphas might need to be watched for problems with heart valves, bruising and bleeding or wound healing. Furthermore, if some Alphas have connective tissue problems, they might benefit from treatments that help people with connective tissue disorders.

As a first step in finding out if AAT deficiency and connective tissue problems go together, I am enclosing a questionnaire in **The Alpha Pack News**. The more Alphas that fill it out, the more I can learn about connective tissue problems in Alphas. For comparison, I also would like some people who are not Alphas (like unaffected spouses, brothers and sisters or others receiving this newsletter) to fill out the same questionnaire so I can tell if connective tissue problems are really more common in Alphas. Because flexibility of joints does vary with age, I only want adults over 18 to complete the questionnaire. If you are over 40, please try to remember what your joints were like when you were younger as you complete the questions on flexibility.

This is considered a research study. Since it does not involve any treatment, the major risk of participating would be a risk to your privacy. I am not asking you to sign a research consent because then I would know your identity. You will note that the questionnaire does not ask your name or any identifying information. If you do not wish to send the completed questionnaires to me directly, you can send them to **The Alpha Pack's** main office address, who can forward them to me (with no identifying information). Assuming that I get enough replies to obtain useful information, I will summarize the results in a future issue of this newsletter. If you have questions or need additional questionnaires, you may contact me:

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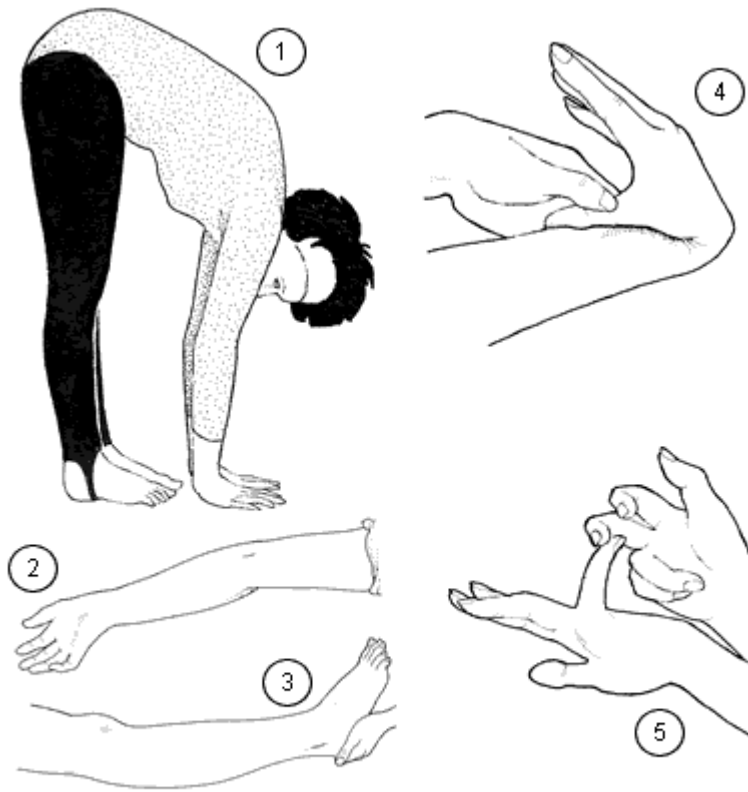
or

The Alpha Pack  
Connective Tissue Study  
2216 South 9<sup>th</sup> Street  
Sheboygan, WI 53081  
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920-803-2668

CONNECTIVE TISSUE QUESTIONNAIRE FOR ALPHAS, FAMILY & FRIENDS

Do you have alpha-1 antitrypsin deficiency?	Y	N
Level, if known _____		
PI type if known _____		
Do you have lung disease?		
Emphysema/COPD	Y	N
Other _____		
What treatment have you needed for your lungs?		
Hospitalized for exacerbations	Y	N
AAT augmentation	Y	N
Home Oxygen	Y	N
Surgery (volume reduction)	Y	N
Transplant	Y	N
Did you have liver disease as a child?	Y	N
Do you have chronic liver disease now?	Y	N
Do you think that you bruise more easily than average?	Y	N
Do you think you bleed more than the average person?	Y	N
Do you have any problem with poor healing or wide scars?	Y	N
Do you have stretch marks unrelated to childbirth?	Y	N
Do you know of any heart problems?		
Innocent murmur?	Y	N
Mitral valve prolapse?	Y	N
Problems with the aorta or aortic valve?	Y	N
Heart affected by lung disease (cor pulmonale)	Y	N
History of heart attack or coronary artery disease?	Y	N
Other _____		
Are you nearsighted (need glasses/contacts to see far away)?	Y	N
Do you need reading glasses?	Y	N
Any other eye problems? Please list _____		
Do you think you are very flexible or "double-jointed"?	Y	N
Have you ever dislocated any joints?	Y	N
Can you now (or could you ever): (see illustration A)		
Bend over (straight legs) and put you palms on the floor?	Y	N
Bend your little finger back more than 90 degrees?	Y	N
Bend your thumb down till it touches your forearm?	Y	N
Hyperextend your knee?	Y	N
Hyperextend your elbow?	Y	N
Put your thumb across your palm past base of 5 <sup>th</sup> finger	Y	N
Do you have scoliosis?	Y	N
Do you have sunken chest or pigeon chest?	Y	N
Gender	M	F
Height _____		
Shoe size _____		

# Illustration A



Beighton's modification of the Carter and Wilkinson scoring system. Give yourself one point for each of the manoeuvres you can do, up to a maximum of nine.