



Thank You Governor Doyle



May is Alpha-1 Awareness Month in Wisconsin thanks to Governor Jim Doyle. He gave his official signature and seal on May 5, 2008. This will be the sixth year that Governor Doyle has signed a proclamation to raise awareness in Wisconsin. Due to his continued support through a proclamation, our efforts have been recognized across the state by the medical community (i.e. Wisconsin research), the media (i.e. local newspaper articles, TV stations, and radio), and the local community.

GINA Passes!

As of May 1, the Genetic Information Non-discrimination Act has passed both the House and the Senate. This legislation will deny employers and health insurers from discriminating against individuals on the basis of their genetic information. "GINA will be the first civil rights act passed by the Congress in almost 20 years," said Jeremy Gruber, Legal Director for the National Workrights Institute. "This marks the first time in the history of our country that legislation has been passed to protect against genetic discrimination before it becomes deeply ingrained in the very fabric of our society." Visit the www.geneticalliance.org

Alpha-1 Featured at WI ALF Event

by Jaime Freitag, Mother of Hunter and Mia

On April 27, our *Flavors of Milwaukee* evening was a once in a lifetime experience; an event we will never forget. It will always remain close to our hearts. We were so kindly invited by The American Liver Foundation- Milwaukee Chapter as the guest speakers for this annual culinary event. Our family was the focus for Families & Faces of Liver Disease.

As we arrived on the main elevator of the 7th floor- The Pfister's Grand Ballroom we were welcomed by a large easel with a 30x40 angelic picture of Hunter and Mia. Our eyes welled with tears and a knot was in our throats- "Wow", we thought- "those are our babies!" We've seen thousands of pictures of all our kids on our walls, in albums and at family and friends houses, however we were never touched so deeply.

We proceeded to the registration table and then made our way around the silent auction area while enjoying hors d'ovres- puff pastries with spinach, cream cheese & raspberries, salmon mousse in mini waffle cones (I scraped off the caviar- icks!) and vegetables wrapped in oriental beef. As the reception neared an end we made our way into

the ballroom and saw the angelic picture of our 2 young Alphas displayed on the large movie screen. Everyone entering the room saw this and we were so sorrowfully happy. We commented on how we wish our 2 would not have Alpha however we have been blessed with so many supportive and loving friendships- we wouldn't want it any other way. We were seated at the Heaven City table and that was just the beginning of taking our breath away. The owner and executive chef introduced themselves and the rest was taken care of by their talents. Five courses and we still can't decide to this day what the best course was. Was it the Chilean Bass with Risotto Patty, the Artichoke and Prawn Soup, Spinach Salad with Duck Pastry Puff, Lake Trout and Filet Mignon or the Whipped Chocolate Mousse in Waffle Cone with Fresh Raspberries?

As our desserts were being prepared, we were quickly whisked to the front of the room for all to see. We approached the stage nervously and I took a deep breath. Glancing at the pictures on the slide show, the knot in my throat reappeared. "Oh no", I quickly thought. My voice trembled as I began to speak but with each word I focused on the audience and refused to look at the pictures. I had practiced a couple times each day but no matter how much I rehearsed it just came out the way it did. Thanking everyone, I ended my speech and the room filled with applause. Inside I was yelling, "Yes I did it" and soon after, a splitting headache filled my head. My nerves, emotions and the array of wines served with each course had constricted every blood vessel in my head- ouch! As we stepped down from the spotlight we were given hugs and standing ovations. We sat down and dove into the chocolate raspberry delight and relaxed.



The night was coming to an end and ALF's most important part of the night had begun- fundraising for liver disease! A very special man and his wife gave a huge donation in honor of Hunter and Mia and continued his generosity with various auctions. The charity and gift-giving continued for awhile and we were so thrilled that Alpha will be given additional aid for research. We were approached by many and we thanked everyone graciously for their support, generosity and willingness to help fight liver disease. It was time to go home to our children and give them each an extra hug. We had the most wonderful evening and it was all because of a horrible genetic condition. Who would have ever thought that something so unfortunate would bring us such joy?

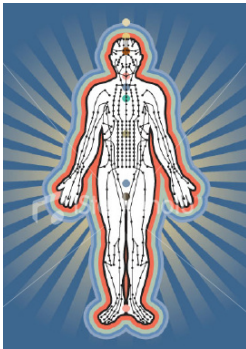
On the Air



To help promote Alpha-1 Awareness in 2008, Wisconsin's Alpha Pack support group is signaling the airwaves by submitting PSA's (Public Service Announcement) to state-wide radio stations. Radio is a wonderful medium to spread the word about Alpha-1, and anyone can participate. Simply go to our web site to download a PSA from our home page, then submit it to a radio station in Wisconsin willing to air it. The PSAs are also available in written form which can be perfect for faxing. Or use our sample to create your own. Go to www.thealphapack.org and click on either PSA1 or PSA2. To request a free copy, contact our office at (920) 803-2668 or info@thealphapack.org. Let's get Alpha-1 on the air!

Southern Shores Region Mtg. Minutes

by Noreen James



The April 10th, 2008 meeting welcomed Curry Chaudoir, a Certified Acupuncturist. He presented on the topic, *Eastern Influence on Health*. Acupuncture is a Chinese healing art that dates back thousands of years. The practice uses special needles to tap into Qi (pronounced *chee*) to create communication with the body's organs to promote harmony and health. Curry and his certified staff

can help with such conditions as; PMS, digestive disorders, sleep disorders, allergies, fatigue, and even headaches. It was a wonderful and highly informative presentation. Acupuncture & Holistic Health Association is located 5150 N. Port Washington Road, Suite #102, Milwaukee, WI 53217. To learn more, visit www.holisticacupuncture.net or call (414) 332-8888. A total of 12 members gathered for April's meeting. Food and refreshments from QDoba were provided by Baxter, the manufacturers of Aralast® www.alpha1health.com

Alpha-1 at Future Genetic Workshop

by Dr Elizabeth McPherson, Marshfield Clinic, WI

To all those who helped with my research questionnaire on Alpha-1 and Connective Tissue, my abstract entitled "AAT DEFICIENCY: AN INFLAMMATORY DISEASE OF CONNECTIVE TISSUE?" has been accepted as a poster presentation at the David W. Smith Workshop on Malformations and Morphogenesis. The workshop will be held at Mont Tremblant, Quebec in August 2008. This is a small meeting for medical geneticists established to honor Dr David Smith who is a pioneer in the study of birth defects.

You may wonder what AAT deficiency has to do with malformations and morphogenesis (the development of body structure). The results of the questionnaire suggest that AAT

deficiency, by increasing the inflammatory response throughout the body, can cause progressive damage not only to the lungs but to connective tissues in the skin and joints. Although this is different from genetic disorders in which the connective tissues are abnormal from birth (such as Marfan* syndrome) and harder to recognize because it is not associated with the physical signs like tall stature that occur when connective tissues are abnormal at birth, the end result may be the same. The suggestion is that some Alphas may be at greater than average risk for joint problems such as osteoarthritis or dislocations and for problems with small blood vessels in the skin leading to increased bleeding and bruising. This raises concern that there might be other hidden risks possibly involving the heart or blood vessels internally. It also suggests that medications being tested for genetic connective tissue disorders might eventually help people with AAT deficiency as well. Of course this was a small study and much more work is needed to be sure if these results apply to larger groups of Alphas. For this, I am working with Dr Charlie Strange to do a larger study through the AAT registry.

**Marfan syndrome is a genetic disorder which is much less common than AAT deficiency and inherited in a different way (a parent passes it on to half of his/her children). It is due to structural abnormalities of fibrillin which is part of the connective tissue scaffolding that holds the body together. Marfan syndrome affects bones and joints causing tall stature with long arms and legs, scoliosis, dislocation of the lens in the eye, and heart problems especially enlargement of the aorta (the big vessel leading away from the heart). Occasionally people with Marfan syndrome also get emphysema or spontaneous pneumothorax. It has recently been shown that the abnormal connective tissue in Marfan syndrome is related to chronic inflammation. A therapeutic trial using Losartan (a drug for high blood pressure which also reduces inflammatory response) to treat Marfan syndrome is underway.*

Check us out!



Hunter and Devon Freitag are all ready for Team Galaxy's soccer season! To find out their soccer schedule, along with Alpha Pack meetings, visit our web site. Or contact a meeting region by phone to find out the latest

dates. For *Northern Lights* (Siren), contact Judy Parker at (715) 653-2666. For *Southern Shores & Team Galaxy* (Milwaukee), contact the Freitags at (262) 797-0620. For *Green Bay* (Green Bay), contact Ron Bernard (920) 490-7811. For *Central Fields* (Marshfield), contact Dawn Smith (715) 536-8145. For our main office, contact Noreen James (920) 803-2668. Have a safe and happy Memorial Day!