

Southern Shores Region Minutes

by Noreen James, Southern Shores Support Group Leader



Welcome April, and a warm welcome was provided to our April speaker, George B Haasler, MD. He took the reigns on the topic of *Lung Volume Reduction Surgery (LVRS)-Who is a candidate?* This is a surgery about choice and quality of life. It involves a thoracic surgeon removing the less-than-functioning space from a lung area that has seen better days. Having a bad breathing day? Alpha-1 is a condition that can cause this through lung damage, and the effect on a patient diagnosed in their 30s and 40s (or at any age) with advanced emphysema due to Alpha-1 can be devastating news.

It could mean the loss of a job. It could mean the loss of caring for a family. It could mean the loss of breath every minute of every day. The choices are simple. Choose to act or not to act. Selection will, more than likely, be due to increasing quality of life. The patient wants to get on with



life again...preferably soon, if possible. And these are the choices Haasler taught to us that evening through his presentation and his experience. LVRS is a choice. Lung transplant is a choice. None of the above is even a choice. Do all have risks? Yes, even choosing to cross the street is a risk. A well-informed patient is the main key. To cross that street, we learn through question and answer on

how to make the wisest decision. Haasler is not only the surgeon, but the teacher. The patient is the student. He wants the patient to get an A+ (even on effort!). Listen and learn. Is it worth the risk? What will increase quality of life? We all have the choice.

Haasler is the *Director of Thoracic Surgery & Lung Transplantation* at the Medical College of Wisconsin. His office at Froedert can be reached by calling 414-456-6902 or 800-272-3666. A total of 25 members gathered for April's meeting. Industry guests included Ryan Glor (Baxter) and Jack Pearce (CSL Behring). Food/refreshments were provided that evening by Accredo <http://www.accredotx.com>.

Thank you Governor Jim Doyle!

May is Alpha-1 Awareness Month across the nation. The goal is to receive a signed proclamation from each Governor

each year. It is with great gratitude and appreciation that The Alpha Pack and Alpha-1 community says "Thank you" to Governor Jim Doyle for signing the proclamation for May 2007. This will be The Alpha Pack's 7th year running in bringing about Alpha-1 education and awareness in Wisconsin through our Governor. Go Pack Go!

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. To attend a meeting, please **RSVP** Noreen James (920) 803-2668 or spiderspun@charter.net

Date	Details
June 14 th	Financial Assistance – HELP! Speaker: Karen Ellenbecker
July 12 th	4 Paws- Helper & Therapy Dogs Speaker: Chelsea Budde
August 5 th	Southern Shores Region Picnic in Wauwatosa, WI

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. To attend a meeting, please **RSVP** Judy Parker (715) 653-2666 or sjparker@centurytel.net

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

www.alphapack.org

So, have you seen the beautifully designed brand new web site for The Alpha Pack? You can find meeting agendas, locations, Wisconsin events, Alpha-1 community news, and so much more. Go ahead! Check it out!



Get Educated!



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>

Genetic Information Nondiscrimination Act



April 25, 2007 – In the 110th Congress the Genetic Information Nondiscrimination Act passed the U.S. House of Representatives by a vote of 420-3. The bill was placed on the Senate Legislative calendar in March and therefore should come to the floor for a vote. The President has indicated that if this legislation is presented to him he will sign it into law. This is phenomenal progress in light of the legislative history of this initiative.

In 1995, legislation on genetic nondiscrimination was first introduced in the 104th Congress. Neither the House or Senate version passed. Similar legislation was introduced in both chambers of Congress in the 105th and 106th Congresses. None of these bills made it to the President. The Genetic Information Nondiscrimination Act (GINA) was introduced in 2002 during the 107th Congress by Senator Olympia Snowe (R-ME) and addressed discrimination in both health insurance and employment decisions. The bill did not pass. Similar legislation was introduced in the 108th Congress, in the House again by Congresswoman Louise Slaughter (D-NY) and in the Senate by Senator Snowe. The Senate bill passed 95-0. The House bill did not.

In the 109th Congress, advocates for the legislation switched to House Republican leadership and had the bill introduced by Congresswoman Judy Biggert (R-IL). It gained 244 cosponsors, but did not pass. In the Senate, Sen. Olympia Snowe (R-ME) introduced the bill and it passed 98-0. This legislation has traveled a long hard road but now stands a significant chance of becoming law. In the next few weeks, the Alpha-1 Association/Alpha-1 Foundation will issue a new Action Alert requesting the Alpha-1 community to contact Senate members for positive action on this legislation.

Join Team Alpha-1 in the Liver Walk

Jen and Charlie Bauernfeind have formed Team Alpha-1 in the American Liver Foundation's Liver Walk on June 16th at Frame Park in Waukesha, WI. If you'd like to walk with us or just come to support us while you relax in the park, please contact Jen Bauernfeind using the contact information in the footer of this newsletter. We'll be raising funds for the American Liver Foundation, Alpha-1 Foundation, and the Alpha Pack this year.

Spotlight on Alpha-1 Organizations

Organization	Details
Alpha-1 Association	http://www.alpha1.org/home/index.asp The Alpha-1 Association is a member-based, nonprofit organization founded to identify those affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improve the quality of their lives through support, education, advocacy, and research.
Alpha-1 Foundation	http://www.alphaone.org The Alpha-1 Foundation is a not-for-profit organization dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1.

Upcoming Events

Upcoming events to possibly raise Alpha-1 Awareness are:

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

The Alpha Pack

COOKBOOK FUNDRAISER

Favorites From Our Table: The Alpha Pack Collection 1st Edition Cookbook 2007



Softcover Cookbook.....\$10.00 Donation
Cookbook on CD-Rom.....\$5.00 Donation

*For shipment, please add \$2.00 s/h charge for the cookbook and
\$1.00 s/h charge for the CD-Rom

CD-Roms
are now
available!

Cookbooks
will be
available
mid-June!

All funds donated to The Alpha Pack **benefit** local Wisconsinites affected by AATD, our awareness activities, and national research studies to find a cure. All monetary donations are tax deductible.

Please submit a donation for an **Alpha Pack Cookbook** by either:
U.S. Mail.....2216 S 9th St, Sheboygan, WI 53081 (use attached form)
Online.....www.thealphapack.org

If you have any questions, please contact
Noreen James, President
spiderspun@charter.net or 920-803-2668

or

Jaime JS Freitag, Liver Aide and Fundraising Assistant
jskier77@yahoo.com or 262-797-0620

Attention Everyone! The Alpha Pack will be releasing a 2nd Edition cookbook in the future. We will be looking for more recipes and if interested, we invite you to contact us and submit your recipe!

The Alpha Pack Fundraiser/Donation Form

For All

I am donating towards an Alpha Pack (check one):

- Cookbook, please indicate which version and how many (___) softcover \$10 ea. (___) CD-ROM \$5 ea.
- Other item _____ with a suggested donation of \$ _____ ea.
- Pledger who is in a ground event air event water event
- Name of Pledger _____
- General group activity, please indicate use: () unrestricted () restricted for _____

Please provide us with the following *information (please print):

Enclosed is my contribution of: \$5 \$10 \$25 \$50 \$100 \$250 Other _____

Today's Date _____ Name _____

Address _____

City _____ State _____ Zip _____

Email (optional) _____

* your information will be kept private and confidential

- My check *payable* to **The Alpha Pack** is enclosed
- Cash donation (in-person only). I received a receipt for this amount on _____ from _____
- Please charge the above amount to: VISA MasterCard

**Credit Card # _____ Exp. Date _____

Name on Card _____ Tel.# _____

** your information will be kept private and confidential

I would like to make this gift in honor memory of: _____

Please send a card acknowledging this gift to: _____

Address _____ City _____ State _____ Zip _____

- Please keep my name **anonymous** in terms of a gift and/or in Alpha Pack publications
- Please mail me an *acknowledgment letter* of this amount for my tax records
- Please **add** me to your mailing list for future Alpha Pack publications

Please mail this form to:

The Alpha Pack
2216 S. 9th Street
Sheboygan, WI 53081-6024