



Welcome to March!



Genetic Nondiscrimination (GINA) Action Alert



Call on Senator Reid to bring GINA to the floor! We must push GINA to success in the Senate for it to become law. With Senator Coburn's hold on the bill, our best alternative is to get GINA on the Senate floor for a vote. Senator Reid, the Senate Majority Leader can make this happen, but only if he hears about how important GINA is to all Americans. Help to make

GINA one of Senator Reid's priorities. Call his office in Washington, DC at 202-224-3542 and tell his staff that you want GINA (S.358) to come to the floor for a vote. Or contact your own senators and ask them to contact Senator Reid and ask him to bring GINA to the floor.

Herbert Kohl (D) WI (202) 224-5653 FAX: (202) 224-9787

Russ Feingold (D) WI (202) 224-5323 FAX: (202) 224-2725

Source: http://www.geneticfairness.org/action_alert5.html

Could WI Be Vitamin D Deficient?

Your ability to fight disease, build muscle and prevent broken bones may all hinge on how much vitamin D your body receives and produces. But new research published in the Wisconsin Medical Journal (Volume 106, No. 8) finds residents of the dairy state are vitamin D deficient. "As a result of low dietary intake and sun avoidance, low vitamin D status is endemic in Wisconsin," say the authors, from the University of Wisconsin Osteoporosis Clinical Center and Research Program in Madison.

Vitamin D is produced in the skin when we're exposed to sunlight. But the risk of skin cancer has scared many of us out of the sun and has increased the popularity of using sunscreen, even though sunscreen "effectively blocks cutaneous vitamin D production." While preventing skin cancer is important, so is preventing falls, especially since as of 2002, Wisconsin had the highest "crude death rate from falls in the United States," according to the Journal article. "Since low vitamin D status increases falls risk, and supplementation reduces falling, it is likely that vitamin D supplementation is an inexpensive way to reduce falls and fractures in Wisconsin and elsewhere," the authors conclude. They estimate the cost at as little as \$1 per month. Milk, salmon and other fatty fish are good sources of vitamin D, but spending a little time in sunshine is probably necessary too, unless you take supplements.

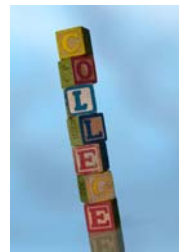
Source: <http://www.wisconsinmedicalsociety.org/public>

Research Opportunities

The Cholestatic Liver Disease Consortium (CLiC), whose purpose is to define the natural history of Alpha-1 liver disease, will follow for five years up to 250 children and young adults to the age of 25 years with Alpha-1 and liver problems. For more information please visit: <http://rarediseasesnetwork.org/clic>.

Jeffrey Teckman, M.D. is studying the *Contribution of Genetic Modulators of Disease Severity in Alpha-1 and Cystic Fibrosis*. He is recruiting individuals with Alpha-1 liver disease to look for the CF gene and other genes that may be part of what causes the liver problems. The project goal is to get a better understanding of the genetic mechanisms affecting Alpha-1 that will ultimately result in better ways of predicting disease severity; and new treatments for Alpha-1. He will recruit and draw blood during the Alpha-1 Association National Education Conference in Saint Louis, MO for this study. For more information, contact Dr. Teckman at 314-577-5647 or teckmanj@slu.edu.

Peter Smith Scholarship: Applications Due April 1st



The Alpha-1 Association Peter Smith Scholarship Fund is available for post high-school education to individuals with Alpha-1 Antitrypsin deficiency, their spouses, and their children. This scholarship honors the memory of Peter Smith, who believed that knowledge is power. The intent of the Peter Smith Scholarship is to continue the tradition of inspiring and assisting by helping those with Alpha-1 and their families learn and achieve. The scholarship is open to Alphas or children of Alphas who demonstrate financial need and who have been accepted for study at an approved institution, i.e., an accredited university, community college or technical institute. Funds may be used for

- Tuition
- Registration and other fees
- Books and related materials

Three scholarships are awarded annually in the amount of \$500 (2) and \$1,000 (1) based on eligibility. Applications are due by April 1, 2008.

Download an application from the Alpha-1 Association web site: <http://www.alpha1.org/education/peterSmith.php>

DrConnection



Developed by the Wisconsin Medical Society, DRconnection is a central repository of physician demographic information. The Society is committed to providing and maintaining accurate, complete physician data through one convenient resource. Go here for link:

http://www.dataloomsolutions.com/wms_drconn/SearchWMS.aspx

National Education Conference

Plan now to attend the Alpha-1 Association's 17th Annual National Education Conference on June 20-22, 2008 in St. Louis, MO. The conference theme is *Building a Better Future* and features keynote speaker, Frank Deford, who is a noted author and sports commentator for Sports Illustrated. In addition, Jeffrey Teckman, M.D., Asst. Professor of Pediatrics at St. Louis Children's Hospital will speak on *Potential Breakthroughs in Alpha-1 Liver Research* and Research David Lomas, M.D. Deputy Chair, University Chair, Cambridge University in England will speak on *Potential Breakthroughs in Alpha-1 Lung Research*.

- Learn about the latest Advances in Research from some of the top researchers in Alpha-1
- Hear the latest "State of the Cure"
- Have an opportunity to meet the experts in Alpha-1 related liver and lung disease and lung transplantation
- Expand your knowledge of Alpha-1
- Learn current legislative issues that affect you
- Connect with the Alpha-1 Community and see how you can make a difference.

Registration Deadline: Thursday, June 5, 2008

Location: Sheraton Westport Plaza Lakeside Chalet 191 Westport Plaza Lakeside Chalet, St. Louis, MO 63146

Room Rates: \$109 per night plus tax

Reservations: 1-800-822-3535, 314-434-5010, or online:

www.starwoodmeeting.com/book/alpha18

Discounted Room Rate Deadline: May 18, 2008

Alpha-1 Education Day in Chicago

On Saturday, April 26, 2008, the Alpha-1 Association will host a Chicago education day. Members of the Alpha-1 Association as well as individuals who are on the Alpha-1 Foundation mailing list will receive invitations 4-6 weeks prior to the event. Stay tuned for more information here:

http://www.alpha1.org/education/nat_education_days.php

Want a Personal AAT Web Page?

The Alpha-1 Association partnered with CaringBridge to offer Alpha families and friends the ability to stay connected and share their experiences online. Through CaringBridge, you can create your own free web page so your loved ones can keep track of your progress. To create a page, go to: <http://www.caringbridge.org/alpha1>.

Southern Shores Region Mtg. Minutes

by Jen Bauernfeind

The **February 14th, 2008** meeting welcomed Ryan McCumber and Jim from Oxygen One, Inc., who presented on different types of oxygen and home medical equipment. Members were shown several different kinds of portable oxygen concentrators, oxygen tanks, and pulse oximeters. They both discussed how it is important to work with a trained respiratory therapist, who will ensure your equipment matches your specific health needs. They also stressed the need to adhere to the suggested use of your equipment and not to defy your doctor's orders in regard to your equipment. Overall, they said it was important to investigate all of your options so you can have the "best fit" for your needs. Oxygen One, Inc. is located at 1900 Pewaukee Road, Suite F, in Waukesha, WI 53188. Their telephone number is (262) 521-2202. Their web site is www.oxygenone.com. A total of 6 members gathered for February's meeting. Food and refreshments were provided by CSL Behring, the manufacturers of Zemaira® www.zemaira.com

Green Bay Region Mtg. Minutes

The next Green Bay meeting on Medicare Reimbursement Updates for the Alpha-1 Patient is planned for **March 18, 2008**. For details, contact Ron Bernard at (920) 490-7811 or schnitzle4@new.rr.com.

Central Fields Region Mtg. Minutes

The next Marshfield meeting is planned for **May 1, 2008**. For details, contact CFR Co-Leader, Dawn Smith, at (715) 536-8145 or dawny1804@aol.com.

Northern Lights Region Mtg. Minutes

The next Siren meeting on Lung Volume Reduction Surgery & Lung Transplant: Who is a Candidate. & A1AD and Liver Disease is planned for **May 15, 2008**. For details, contact Judy Parker at (715) 653-2666 or siparker@centurytel.net