



In Remembrance of 9/11/2001: Never Forget Patriot Day



World Stem Cell Summit September 22-23 in Madison, WI



Governor Jim Doyle will kick off the World Stem Cell Summit with a free public forum and festival called Lab on the Lake at the University of Wisconsin-Madison Pyle Center. The festival will take place Sept. 21, and the World Stem Cell Summit will be held Sept 22-23.

The event will also include Lunch with the Experts, where leading specialists in stem cell research will answer questions. Some of the planned topics of discussion include the morality of embryo use in research, religious positions on stem cell research, and advances in stem cell research in other countries.

The event is presented by the Genetics Policy Institute, WiCell Research Institute and the University of Wisconsin-Madison Stem Cell and Regenerative Medicine Center. The Alpha-1 Foundation is one of 150 sponsors of the summit.

Newborn Screening for Alpha-1 Critical Issues Workshop

R. Rodney Howell, MD, Special Assistant to the Director, National Institute of Child Health and Human Development, National Institutes of Health, will outline the current guidelines for newborn screening of genetic conditions at the Alpha-1 Foundation's Gordon L. Snider Critical Issues Workshop entitled "The Promise and Challenge of GINA: Is it Time for Newborn Screening for Alpha-1?" in Arlington, VA, Sept. 18-19.

Dr. Howell is a professor of pediatrics at the University of Miami Medical School and immediate past chair of the Muscular Dystrophy Association.

Participants will discuss the pros and cons of newborn screening for Alpha-1 Antitrypsin Deficiency (Alpha-1) after the Genetic Information Nondiscrimination Act (GINA) becomes law on Jan. 1, 2010. The workshop objective is to produce a report to the Foundation with recommendations on how to proceed on the issue of newborn screening.

Brad Zelk and Jen Bauernfeind will give perspectives of Alpha-1 caregivers on newborn screening, too.

Source: <http://www.alphaone.org>

Study Concludes Alpha-1 Testing Needed in Fibromyalgia Patients

A critical review of medical studies reported in the *Journal of Musculoskeletal Pain* concluded that patients diagnosed with Fibromyalgia should be tested for Alpha-1 Antitrypsin Deficiency. Fibromyalgia syndrome is a condition characterized by pain widespread in the body and often by fatigue and sleep disturbances.

Studies from 10 countries—Canada, the United States, Denmark, Finland, Germany, Italy, the Netherlands, Spain, Sweden, and Pakistan—were reviewed. The reviewers concluded that Alpha-1 testing should be recommended in Fibromyalgia patients and "the possible efficacy of AAT replacement therapy in severe deficiency FMS patients should warrant further studies."

Source: <http://www.alphaone.org/news/study-concludes-alpha-1-testing-needed-in-fibromyalgia-patients>

Support the Alpha Pack Using eBay



eBay buyers can now support the Alpha Pack through eBay Giving Works. Powered by Missionfish, a percentage of proceeds from listed items can now be designated to our charity through either Community Sellers or NonProfit Direct Sellers. Since we are now listed through Missionfish, eBay buyers, who purchase an item designated to the Alpha Pack, will automatically receive a tax receipt through eBay Giving Works. Shop now: http://donations.ebay.com/charity/charity.jsp?NP_ID=24057

Central Fields Region Mtg. Minutes

by Dawn Smith, Support Group Co-Leader

The last Marshfield meeting was September 4, 2008. Watch for meeting minutes in the next issue. The next Central Fields Region meeting will be November 6, 2008. For details, contact CFR Co-Leader, Dawn Smith, at (715) 536-8145 or CFRleader@thealphapack.org.

Green Bay Region Mtg. Minutes

by Chelsea Krueger, Support Group Co-Leader

July's meeting welcomed Lynn from Aging and Disability Resources of Brown County at 300 S. Adams St.. They serve clients 18 and older with disability or clients 60 and older without disability. The services they provide are:

- Nutrition such as home bound meals or meal centers
- Care giving such as support groups, tools classes
- Prevention services such as fall prevention, proper exercise and nutrition
- Benefits counselors who offer advice on power of attorney, benefits checkups, explanation of insurance/benefits, information and assistance

The next Green Bay Region will be meeting on Tuesday, November 18, 2008. For details, contact Ron Bernard at (920) 490-7811 or GBRleader@thealphapack.org.

Northern Lights Region Mtg. Minutes

by Judy Parker, Support Group Leader

July's meeting welcomed Dr. Gary Steven, MD, PHD from Milwaukee. He presented to us about Allergies, Asthma and Sinus issues. He answered many, many questions and had everyone interested the whole night. Dr. Steven was a wonderful speaker, and the NLR feels fortunate to have had someone of his caliber come to the North Country to speak to our little group. It was a great meeting with friends getting together sharing stories, laughing, and just having fun. After all, life is what you make it! Food and refreshments from were hosted by Talecris, the manufacturers of Prolastin@ <http://www.prolastin.com>.

The next Siren meeting will be an open forum hosted by Accredo and is planned for September 18, 2008. For details, contact Judy Parker at (715) 653-2666 or sjparker@centurytel.net

Southern Shores Region Mtg. Minutes

by Noreen James, President of The Alpha Pack

Our July meeting welcomed Ryan McCumber of Oxygen One. They are a home care company that places the needs of the respiratory patients as #1. They offer the latest in medical devices such as: Oxygen therapy for both home and travel, nebulizers, Pulse oximeters, and CPAP machines. Their staff includes licensed health care professionals and trained medical technicians, who take pride in improving the quality of life for their patients.

OxygenOne is a Wisconsin company located at 1900 Pewaukee Road, Suite F, Waukesha, WI 53188. Phone (262)521-2202. Web site www.oxygenone.com Food and refreshments that evening were hosted by CSL Behring, manufacturers of Zemaira, www.zemaira.com The next meeting will be October 9, 2008.

Back to School Time for Hunter and Devon

