



Hotline for Oxygen Complaints



The COPD Foundation has created a hotline to take oxygen complaints to assist consumers with issues regarding home oxygen and home oxygen equipment. Please register your complaint first directly with Centers

for Medicare and Medicaid Services (CMS) by calling 1-800-Medicare (1-800-633-4227) or, for users of TTY, 1-877-486-2048. Then call the COPD Foundation to register your complaints with the COPD Foundation by calling 1-866-316-2673, and they will follow up with CMS regarding your complaint.

Panniculitis Particulars

Panniculitis is an inflammation of the panniculus, the layer of fatty and fibrous tissue just beneath the outer layers of our skin. This layer of the skin looks like a honeycomb, with globules of fat separated by walls, or septae. Like most medical conditions, panniculitis can have many underlying causes. Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of those causes. Panniculitis in Alpha-1 is found in different phenotypes, some with severe deficiency of serum levels of alpha-1 antitrypsin (typically PI*ZZ), and others with only mild deficiency (typically PI*MZ).

Various therapies have been tried for panniculitis, including panniculitis due to Alpha-1, among them corticosteroids, antibiotics (including doxycycline and dapsone), the complete exchange of the body's blood plasma, and augmentation therapy – intravenous infusions of donated alpha-1 protein. In panniculitis due to Alpha-1, augmentation therapy has been the most dramatically successful of these therapies. Several reports describe resolution of panniculitis after as few as three doses of augmentation therapy. The dose of augmentation therapy for panniculitis is the same as that for established emphysema, 60 mg/kg once weekly. Unfortunately, no treatment for panniculitis is 100 percent effective. Undoubtedly, treatment choices for panniculitis will grow as research continues on new therapies for Alpha-1.

Source: *Alpha-1 Foundation web site:*
<http://www.alphaone.org/alphas/?c=12-Alpha-1-Panniculitis>

Have GINA Questions? Try this Q&A!

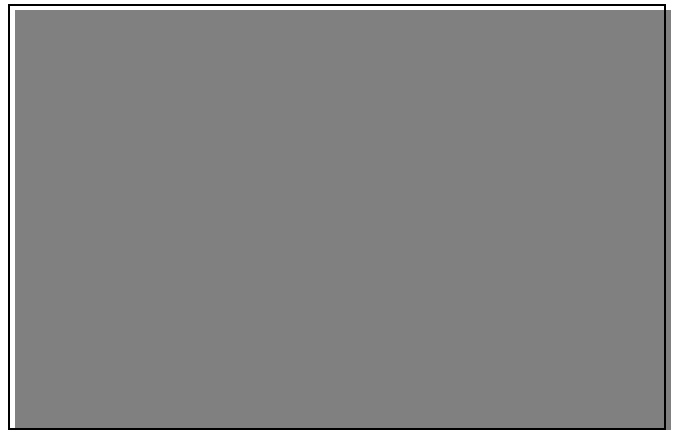
The Coalition for Genetic Fairness has put together a questions and answers document about the implementation of the Genetic Nondiscrimination Information (GINA) Act. The questions and answers cover aspects of the law, including its protections in relation to direct-to-consumer genetic services, diagnosed conditions, and GINA enforcement, among other topics. You can obtain the document at this URL: <http://www.dnapolicy.org/resources/MoreQandAforGINAwebsite01.09.pdf>

ADMAPP Improves Outcomes

AlphaNet's Alpha-1 Disease Management and Prevention Program (ADMAPP) improved health outcomes in a study of patients with Alpha-1-related COPD, according to a study reported in the medical journal COPD: Journal of Chronic Obstructive Pulmonary Disease. The two-year study, usually referred to as the "Outcome Study," evaluated patients across the United States enrolled in AlphaNet's ADMAPP program. A total of 878 patients completed the study. During the intervention year (the second year of the study) significant improvements were reported in total exacerbation rates, unscheduled physician visits, and emergency room visits. Significant improvements in general health were also reported. Source: *Alpha-1 Foundation Web Site:* http://www.alphaone.org/file_download/763

Alpha-1 Get Tested Video Available

The Alpha-1 Foundation's new video, "Short of Breath? Get Tested," focuses on the symptoms of Alpha-1 as well as the problems Alphas face in getting the right diagnosis. You can help spread awareness about getting tested for Alpha-1 by sharing this video with your friends.

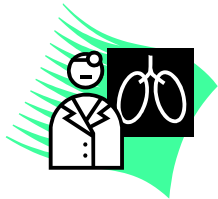


URL: <http://www.youtube.com/watch?v=prMk1SGn1Hs>

Condolences

Judy Golding's father, Earl J. Teunissen, passed away on Wednesday, February 25, 2009. Earl was born September 11, 1924 in Cedar Grove, WI to Henry and Gertrude (Prinsen) Teunissen. On October 19, 1945 Earl was united in marriage to Dorothy (Kaat) Teunissen. Dorothy preceded him in death on July 8, 2005. He is survived by six children, twenty-four grandchildren; thirty-one great-grandchildren; brother; nieces, nephews, other family members, and friends. Earl will be missed greatly by all those who knew and loved him.

Scientists Create Portable Lung



Lung Researchers say their device, which oxygenates blood outside the body before it goes through the lungs, could be an alternative to transplants. The Swansea University scientists say it could take many years before the device, the size of a spectacles case, is available.

Lung patients, who have seen how it would work, have welcomed the research. According to the British Lung Foundation, there are more than 40 conditions which affect the lungs and airways and impact on a person's ability to breathe. They include lung cancer, tuberculosis, asthma, chronic obstructive pulmonary disease (COPD), cystic fibrosis, sleep apnoea, avian flu, bronchiolitis and many others. Its research suggests that one person in every seven in the UK is affected by lung disease - this equates to approximately 8m people. As of 6 March 2009, 217 people were on the waiting list for a lung transplant according to figures by NHS Blood and Transplant. Now scientists in Swansea are developing a portable artificial lung which could transform the lives of patients. Researchers claim that in the long term the device could offer an alternative to lung transplants, giving hope to those who suffer from conditions such as emphysema and cystic fibrosis. The device mimics the function of a lung - by getting oxygen into and carbon dioxide out of the blood stream. Professor Bill Johns came up with the idea after his son died of Cystic Fibrosis. "It is important that we make something that will help people, who instead of being confined to a wheelchair with an oxygen bottle, can actually walk around and do things for themselves, he said. Although the research has been welcomed by leading charities, caution has also been voiced over the length of time it will take before a portable lung will become available. "We have to stress that this is several years away from being used, even in a trial stage," said Chris Mulholland, head of the British Lung Foundation. "While we welcome the advances, we have to be realistic and know that one in five people could do with that help now." Patient Elizabeth Spence from Swansea has been refused the double lung transplant she needs but remains hopeful that one day the new device could help her. "My body will reject the lungs, so this possibly could be an answer - another way of getting new lungs without actually having the transplant," she said. Source: BBC NEWS; http://news.bbc.co.uk/go/pr/fr/-/2/hi/uk_news/wales/7931243.stm

Central Fields Region Mtg. Minutes

by Dawn Smith, Support Group Co-Leader

The next Central Fields Region meeting will be May 7, 2009 at 3:00 p.m. For details, contact CFR Co-Leader, Dawn Smith, at (715) 536-8145 or CFRcoleader@thealphapack.org.

Green Bay Region Mtg. Minutes

by Noreen James, President and Director of Operations

The next meeting will be "Understanding the Stimulus Package" by Scott Weir held on Tuesday, March 17th. For details, contact Chelsea Krueger (414) 265-3058, cmkrueger@wisc.edu

Northern Lights Region Mtg. Minutes

by Judy Parker, Support Group Leader

The next Siren meeting will be "Latest COPD medications and oxygen equipment" and is planned for May 21, 2009. For details, contact Judy Parker at (715) 653-2666 or NLRleader@thealphapack.org.

Southern Shores Region Mtg. Minutes

by Noreen James, President and Director of Operations

Milwaukee's February meeting invited Duane Aimers, Radio Entertainment Disc Jockey. Duane spoke about the radio show he hosts from 7pm-10pm on WGEZ 1490 AM in Beloit, WI on Sundays. The program begins with oldies music and then switches to a talk show format (8:30-9:30pm) devoted to health topics such as COPD and Alpha-1. Each Sunday, listeners can hear a new guest interview and are encouraged to call the studio line at (608) 368-1490 with questions or comments. Duane is a passionate advocate for Alpha-1, and with his gift of voice and love for radio, awareness is easily spread to listeners throughout the area. Thoughts, ideas, and sponsors for his program are welcome. So if interested, please contact Duane personally at (608) 346-2144 or duaneaimers1814@hotmail.com.



Our February meeting welcomed 20 people. Accredo, (www.accredotx.com) the pharmacy service for Aralast® and Zemaira® hosted food and refreshments. Thank you to everyone who could attend that evening. The next meeting (weather pending) will be on Thursday, April 9th, with the topic Optimizing Sexual Health (for mature audience).