

Northern Lights Region Minutes

by Judy Parker, Northern Lights Support Group Leader



January's meeting began with introductions, and then Patty Riley spoke about the basics of Alpha-1 Antitrypsin Deficiency:

- Lungs
- Liver
- Skin
- Genetics

A total of 14 members gathered for January's meeting. Industry guests included Jean Andre (Accredo) and Susan Mayhew (CSL Behring). Food and refreshments from the Chattering Squirrel were provided by CSL Behring www.cslobehring.com, manufacturers of Zemaira@ www.zemaira.com.

Upcoming Northern Lights Meeting Agenda

All meetings are held, from 6:30-9:00 p.m. in the Burnette County Government Center, Room 165. 7410 County Road K (2 miles north of Siren on Hwy 35) in Siren, WI.

Date	Details
March 15 th	Alpha-1 and Prolastin Overview Speaker: Todd Weber
May 17 th	Medical Discrimination Issues Speaker: Miriam O'Day, Senior Director of Public Policy for the Alpha-1 Foundation

the fee-for-service program, and Medicare Advantage prescription drug (MA-PD) plans, such as HMOs or PPOs, that cover drugs and other Medicare benefits. In 2007, there are 1,875 PDPs nationally. In Wisconsin alone, there are 54 PDPs to choose from. At this time approximately 22.5 million patients are enrolled in Part D and 16.2 million have elected to stay with employer sponsored or federal plans. Beneficiaries need to make sure the PDP they choose covers the drugs they are on. Medicare provides formularies to find a PDP within a state at <http://formularyfinder.medicare.gov> or call 1(800) 633-4227. Another avenue for medical help is contacting a state's Insurance Commissioner. For Wisconsin, it is Sean Dilweg at <http://oci.wi.gov> or 1(800) 236-8517.



Southern Shores Region Minutes

by Noreen James, Southern Shores Support Group Leader



Our February meeting welcomed less snow, but colder temperatures. However, we had two presentations to keep us warm that evening!

Our first speaker was Ashok Chainani from Talecris with a presentation on a *Medicare Update, The New Part D Program*. Our second speaker was Barb O'Leary from Medical Equipment Specialists with a talk on *Medicare Updates on O2 Therapy*.

Chainani explained that, since January 2006, Medicare Part D has been available to 43 million elderly and disabled beneficiaries. It is offered through private payer plans. Medicare replaces Medicaid as the primary source of drug coverage for low-income (LI) and disabled people. LI/Disabled people have coverage from both Medicare and Medicaid ("dual eligibles"). Assistance with drug benefit premiums and cost sharing is available to beneficiaries with low incomes. There are stand-alone prescription drug plans (PDPs) for people getting other Medicare benefits through

Chainani also suggested visiting the Plasma Protein Therapeutics Assoc (PPTA) at www.pptaglobal.org or (410) 263-8296. As the global representative for the plasma therapeutics industry, PPTA works cooperatively with patient groups, legislators, regulatory agencies and others to address critical issues that impact the industry and those people who depend on plasma protein therapeutics. For example, PPTA alerts us that as of August 23, 2006, CMS published its proposed rule for the *Calendar Year 2007 Hospital Outpatient Prospective Payment System (PPS)*. The proposed rule has a number of policies that further erode access to quality care for patients who need IVIG, a life-maintaining therapy. The proposed rule seeks to eliminate the preadministration-related services payment for IVIG and also seeks to further reduce payment to ASP plus 5% (currently, it is reimbursed at ASP plus 6%). Encourage your Senators and Representatives to take immediate action to ensure that Medicare beneficiaries with primary immune deficiency diseases regain access to all brands of IVIG in all sites of care.

Next, after a very short “speaker” breather, O’Leary presented on the *Deficit Reduction Act (S.1932)* that now affects both O2 therapy patients & supplies. In the past, patients rented their oxygen concentrators for as long as they needed it. However, now oxygen will be paid as a rental for the first 36 months. After that time, if the patient still needs the equipment, Medicare will no longer make rental payments on the equipment. If insurance deductible and copays are met, the equipment title will transfer to the patient. Medicare will then pay for refilling a patient’s oxygen cylinders and for repairs and service of your equipment. Medicare will also separately pay for oxygen accessories such as tubing, masks and cannulas after the purchase price has been met. The problem arises in that Medicare reimburses only so much for repairs, thus the both the patient and supplier suffer in the long run. What can we do? O’Leary urges us to contact our member of the House of Representatives and request that he/she co-sponsor HR 621, the *Home Oxygen Patient Protection Act of 2007*. Call our two WI Senators Russ Feingold (D) (202) 224-5323 and/or Herb Kohl (D) (202) 224-5653 to support similar legislation in the Senate.

A total of 17 members gathered for February’s meeting. Industry guests included Gabrielle Luster (Talecris) and Jean Andre (Accredo). Medical Equipment Specialists <http://www.medicalequipmentspecialists.com> or (414) 282-5451, serves Metro-Milwaukee and SE WI. Food/refreshments from QDoba were provided by Talecris (www.talecris.com) manufacturers of Prolastin@ (www.prolastin.com). Chainani offers his WI Medicare presentation on CD, if interested, please contact him at ashok.chainani@talecris.com.

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.

Date	Details
April 12 th	LVRS-Who is a Candidate? Speaker: George B. Haasler MD
May 10 th	Pathogen Safety and Nucleic Testing Speaker: Doug Lee

Promising Lung Research



Molecular scientists at the Brown Foundation Institute of Molecular Medicine for the Prevention of Human Diseases (IMM), which is part of the University of Texas Health Science Center at Houston, have developed a new procedure for the differentiation of human embryonic stem cells, with which they have created a transplantable source of lung epithelial cells. The cells were derived from a human embryonic stem cell line approved by the National Institutes of Health (NIH). The cells are alveolar epithelial type II cells, which produce proteins including surfactant that inflates lungs. They also make other cells lining the inner lung, and they

regulate lung fluids and oxygen levels. Transplantable alveolar epithelial type II cells can be explored as treatments for pulmonary genetic diseases. Hereditary lung disorders most likely to benefit from transplantation of alveolar epithelial type II cells include respiratory distress syndrome of the newborn, Alpha-1 related emphysema, and cystic fibrosis. Still years away from their use in regenerative medicine, the next step involves research trials with mice.

Source: <http://www.physorg.com/news91879247.html>

Tax Deductions for Oxygen Users

If you are an oxygen user you may be able to deduct the cost of the electricity used to operate your concentrator as a medical deduction. Check with whoever prepares your annual income tax return if you can, or would benefit from taking this deduction. This hidden cost of oxygen is very real to users. Get the details at the web page mentioned below:

Source: <http://www.pulmonarypaper.org/main.asp?CatID=33&ArticleID=1>

Picture This!



Johanna’s son, Morgan, is currently serving in Iraq.

Upcoming Events

Upcoming events to 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