

Inspiration

Winter 2008

A newsletter for people with COPD and those who love them



2008 RHAMC COPD Initiative—A Year in Review



Lung health advocates show their support in Washington, DC at the first United for Lung Health Federal Advocacy Day.

2008 has been a monumental year for COPD at RHAMC and throughout Illinois! This year, COPD was a common theme throughout all of our RHAMC activities from special fund-raising events to state policy efforts.

February. At least 208 climbers and 5 volunteers at our *Hustle up the Hancock* event told us their lives were affected by COPD. The stories are powerful and everyone was climbing or volunteering to make a change.

April and May. People living with COPD were well represented at both state and federal advocacy days hosted

by RHAMC. In Springfield for *State Advocacy Day*, we sought ongoing support to keep Illinois Smoke-Free and to require that Illinois Department of Public Health establish dedicated staff to work on COPD issues. Local respiratory therapists and patients from their pulmonary rehabilitation groups advocated side by side. For *Federal Advocacy Day*, RHAMC brought together 75 advocates from 18 states to form *United for Lung Health* to advocate for lung health issues.

May. Illinois became only the second state to have developed a statewide *COPD Coalition* and

a resulting *COPD State Plan*. The coalition was convened by RHAMC to develop the comprehensive plan to raise COPD awareness and improve care and resources for people living with COPD and their families. Later in the month RHAMC and 3 people living with COPD along with their pulmonary rehabilitation leader delivered the COPD State Plan to legislators in Springfield.

Also in May, RHAMC, through its *Catch Your Breath: Women and Lung Health Initiative* honored Grace Anne Dorney Koppel for her efforts to increase COPD Awareness. Ms. Koppel is the national spokesperson for the National Heart, Lung, and Blood Institute's COPD Learn More Breath Better campaign.

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Inspirations

FROM THE EDITOR

Winter Health



Let's face it. Chicago winters are long. They seem to drag on forever and they test your motivation to get out and stay active. If you have COPD, cold weather can literally take your breath

away. There are, however, things you can do to feel your best even when the weather works against you.

You may not be able to go outdoors for a walk when it's especially cold or when there's snow on the ground, but it's important to stay active. Consider exercising at home with a video or handheld weights. Walk in a nearby mall or public building. Or sign up for a program through your local parks and recreations center. If you haven't already, talk to your doctor about starting a pulmonary rehab program.

In addition, I hope you got a flu shot this year—it's best practice for people with COPD. Try to be proactive about managing your COPD by preventing colds, flu and pneumonia. Stay out of crowds and away from people who are ill. When a sick person sneezes or coughs, virus-laden droplets fill the air and are then inhaled by others. Wash your

hands often with soap and water to limit your exposure to germs and viruses. Cold viruses can live for hours on tissues, telephones, and even pens. So, it's a good idea to wipe down objects, as well as bathrooms and kitchen countertops with anti-microbial agents such as Lysol to control the cold viruses in your home.

Finally, pay attention to how you're feeling emotionally. Living with COPD can be a challenge. Find ways to add social support during this winter season. If you find yourself feeling sad or hopeless, or losing interest in the things you enjoy, you may be depressed. Depression can get in the way of doing what you need to do to take care of yourself. However, it is treatable, so if you feel depressed or sad, reach out to someone you trust and talk to your doctor about what can be done to help with these symptoms.

Have a safe and happy new year!

Peter H.S. Sporn, MD

Associate Professor of Medicine

*Director, Pulmonary and Critical Care Medicine Fellowship Program
Feinberg School of Medicine, Northwestern University*



Why Can Cold Air Make COPD Feel Worse?

Cold air can irritate your bronchial tubes and cause the airways to constrict. When temperatures and humidity dip, wear a scarf to help warm the air as it enters your lungs. Breathing through your nose also helps to humidify air before it reaches your lungs. Also, to help with dryness in the air, try to keep humidity levels around 40% in your home.

A Year in Review (continued from page 1)



Team Pactivo, lead by Captain Joe Doyle, received an award for the largest team, with 17 members riding in The CowaLUNGa 2008 Bike Tour.



On September 21st walkers came out to Chicago and Palatine to raise funds for lung health programs and research.

June. On a gorgeous summer day in June, over 500 people living with COPD and their caregivers joined RHAMC for *Cruising with COPD* in Chicago. We cruised from Navy Pier on the Spirit of Chicago and Odyssey ships, shared a delightful lunch, played COPD Bingo and witnessed the Chicago skyline on a wonderful summer day.

August. *CowaLUNGa* is a 3-day bike tour held in August. More than 300 participants biked from Gurnee through Wisconsin to raise over \$170,000 to help promote healthy lungs and fight lung disease. Many of these riders support our mission because they have personally been affected by COPD.

September. The 2nd annual *Hike for Lung Health* was held in September at Chicago and Palatine. This year 65 participants from 9 different groups joined hikers as *virtual walkers*—walking during pulmonary rehab time or on their own. On the day of the event there were nearly 1000 hikers and volunteers who participated; we raised nearly \$140,000!



On November 5th participants came from cities throughout Illinois for a conference dedicated to people living with COPD.

November. Our eventful year for COPD ended with RHAMC's *5th Annual Respiratory Rally*. On this beautiful fall day, nearly 300 people living with COPD, their family members and caregivers came together for a conference in Arlington Heights to learn and discuss different ways to positively manage COPD. Participants enjoyed education sessions, resource exhibits and spending time with others living well with COPD.

Thank you all for showing your support in 2008!

Health Policy Update for Home Oxygen and Pulmonary Rehabilitation

HR 6331 *Medicare Improvements for Patient and Providers Act* passed in July 2008. This new law repealed the "rent to own" provision under which any Medicare beneficiary who had been receiving coverage for home oxygen equipment for 36 months would be considered the owner of the

equipment beginning January 1, 2009. This is very good news for those who



receive oxygen at home, as they will not own the equipment and Medicare will continue to reimburse the oxygen supplier. Medicare will still, however, cap reimbursement for home oxygen equipment at 36 months. If you use home oxygen equipment, please communicate with your oxygen provider about your equipment and services prior to January 1st.

National Coverage Determination for Pulmonary Rehabilitation also passed in July 2008. This new provision to HR 6331 makes pulmonary rehabilitation a covered Medicare benefit for those who qualify. Criteria for qualification will be dependent on the entity that administers the Medicare benefit. This national coverage is scheduled to begin on **January 1, 2010.**

Patient's Perspective

2008 Cruising with COPD

Perfect weather, low humidity and calm waters allowed participants of this year's *Cruising with COPD* event to enjoy themselves. On June 17, 2008 RHAMC hosted the 3rd annual summer classic at Navy Pier in Chicago aboard the



Gale Ruff posing with Anne State and RHAMC Board Member, Dr. Claudio.

Odyssey and Spirit of Chicago cruise ships. Over 500 people living with COPD, their families and caregivers boarded the cruise ships to delight in an afternoon on the lakefront. Anne State, co-anchor of Channel 2 News kicked off the event

by welcoming the guests. The event included the beautiful Chicago lakefront cruise, a buffet luncheon, COPD Bingo, entertainment and a raffle. Twenty pulmonary rehabilitation groups from across Illinois participated in this year's event, including groups from Arlington Heights, Chicago, Elgin, Elmhurst, Joliet, Naperville, Oak Lawn, Oak Park, Orland Park, Peoria, Rockford, Skokie and Tinley Park. Supplemental oxygen was available for the cruisers. Many cruisers strolled around the outside deck and soaked in the sun while posing for pictures, smiling, and admiring the Chicago skyline.

Gale Ruff joined us on the cruise and her positive attitude was contagious. She enjoyed getting out on the water and socializing with friendly doctors, nurses, RHAMC staff and

fellow individuals with COPD. Gale stays young by participating in various activities at Southeast Atlas Senior Center, directing her church choir, and generally loving life. She manages her COPD by attending the gym three times a week and

"I had a wonderful time on the cruise! I learned ways to manage my COPD, and the oxygen provided allowed me to truly enjoy myself."

—Gail Ruff

insists that her COPD does not hold her back, "I enjoy my life. Nothing can stop me from having a good time!" She advises all those living with COPD, to simply "get up and go—you have to keep moving to stay healthy!"

Save-The-Date!



We hope you can join us on June 16, 2009 for the annual cruise on Lake Michigan hosted by RHAMC's

COPD Initiative. Come enjoy good food, entertainment, and a chance to meet others living with COPD. Registration information will be available in March. For more information, contact Dyette Hernandez at (312) 628-0227.

Ask the Doctor

Avoiding Pneumonia this Winter

Today, Dr. Helena Wang answers our questions about pneumonia vaccinations for people with COPD.

Who needs a pneumonia vaccination?

Anyone with a chronic disease such as COPD should be vaccinated. Medicare covers the vaccine, so there's no reason not to have one.

Why is the vaccine important for people with COPD?

Pneumonia affects people with COPD more severely. So a lung infection that may not bother a healthy person much can be a bigger problem for someone with COPD. They can have more trouble breathing, and a harder time getting mucous out of their lungs.

Can the vaccine make me sick?

No. There's nothing infectious in the vaccine. There are no proven side effects either, but some people report feeling a little under the weather the next day, or discomfort around the injection site. If you already have some sort of infection, let your body finish fighting that illness first before you get the shot.

How often should I get a pneumonia shot?

Re-vaccination among healthy persons previously vaccinated is not recommended. However, re-vaccination is recommended for those who are considered by their doctor to be high-risk for serious infection. Only one re-vaccination



Pulmonologist Dr. Helena Wang with Loyola University Health System specializes in COPD, pulmonary hypertension and Sarcoidosis.

dose is recommended for high-risk persons. The second and final dose should be administered after age 65 and after 5 or more years has elapsed since the first dose.

What if I can't remember when I got my last shot?

Ask your doctor if it is documented in your medical records. If not, there is no danger in getting another vaccine within two or three years. Then be sure to have it documented in your records.

What are the symptoms of pneumonia?

The bacterial infection often causes a cough, mucous, fever, chest discomfort and/or shortness of breath. Any time you notice something different from your usual COPD symptoms, call your doctor.

Any other advice?

1. Join an exercise program.
2. Quit smoking. If you're still smoking, keep trying to quit. And don't be ashamed to ask for help. It's tough, but the benefits are endless. We won't judge—we just want to help.
3. Get your flu shot every year!

It's not too late to consider getting a flu shot!

October and November are the best months for people to receive vaccinations, but you can still get vaccinated in December and later. Flu season can begin as early as October and last as late as May. RHAMC is conducting its 13th annual campaign to immunize Chicagoland residents seeking to protect themselves against the seasonal flu. The annual flu immunization program is offered in conjunction with the Chicago Department of Public Health and the Cook County Department of Public Health at neighborhood sites across the entire Chicagoland area. Visit www.lungchicago.org to find more information about the flu. To find a flu clinic near you, call 311 for those in the City of Chicago. Or if you live in suburban Cook County call (708) 492-2000. For further questions, please call Doreen Minnice at (312) 628-0201. Special thanks to VNA Foundation and Blowitz-Ridgeway Foundation for their support of RHAMC's flu immunization program.

Chicago Alphas Information and Support Group

Alpha-1 Antitrypsin (AAT) deficiency is an inherited disorder that can cause lung disease (much like emphysema) and liver disease in adults and children. Cindy Wilson, a lung health advocate and recent lung transplant recipient living with Alpha-1, started a support group in order to share information and resources with other “alphas” and to learn information from others dealing with this genetic disorder.

Cindy wanted to provide a nurturing, helpful and caring place where other Chicagoans living with Alpha-1 and their family members, friends and caregivers could come together to share their knowledge and information with one another.

Leroy Fennewald, a member of the Chicago Alphas group feels that this support group helps him cope and live with Alpha-1. He finds the meetings very interesting and informative. “This group provides us with the opportunity to meet people. Cindy invites doctors to speak who are empathetic and

have the ability to relate to patients.” *For more information about this support group, please see the last page of this newsletter in the **Spotlight** area.*



Haven't Found a COPD Support Group in Your Community?

Forming a support group of your own is a great way to share your COPD experiences with others who understand what it means to have COPD and

how to meet the challenges of living with COPD. Here are some things to consider:

- Have an idea of how many people want the support group.
- Identify two or three people who share your interest in starting a support group.
- Decide how often your group will meet and who can attend.
- Location—quite a few places have meeting rooms available for non-profit community events and are very approachable for good causes (e.g. senior centers, churches, and schools).
- Decide what you will do in your meetings and how you will get the word out.

Support groups are about helping one another with emotional support, not about finding cures or debating medical procedures. Attending a support group can lift your spirits and make your condition seem a little easier to manage. RHAMC can help you launch your COPD support group. Call Dyette Hernandez at (312) 628-0227 for more information.



The Chicago Alphas Support Group meeting held on October 18, 2008.

Advances & Updates

Call for Cleaner CTA and Pace Buses

There's a reason breathing diesel exhaust is not good for your lungs. The fine particles in the smoke from diesel trucks and buses have been connected to asthma flare-ups, strokes and heart attacks as well as lung cancer, increased respiratory hospitalizations and premature deaths. Pollution controls today however, can eliminate over 90%



of this dangerous air pollution. Installing a device known as a particulate filter on the exhaust system incinerates those toxic particles before they get out into the air you breathe. Among the dirtiest diesel engines running today are those in construction equipment. One bulldozer can emit as much harmful pollution as 500 cars.

RHAMC is working with local governments to encourage the adoption of clean diesel construction practices, where contracts for government projects require that such equipment use the cleanest fuel possible and require the installation of tailpipe pollution controls. New York City and the states of Massachusetts and Connecticut now require government money to be spent this way to reduce the public's exposure to dangerous diesel pollution. To find out more, read about the Clean Diesel Campaign under Policy on www.lungchicago.org or call Ashley Collins at (312) 628-0202.

Patient Advocacy Events

This coming spring, RHAMC will host patient advocacy events in Springfield and Washington, DC.

State Advocacy Day in Springfield, IL is a 1-day event that provides an opportunity for you to join our staff and volunteers to meet with state senators and representatives to discuss important issues that affect your quality of life. State Advocacy Day will likely occur in March. We are waiting for the Legislative calendar to be set.

United for Lung Health Federal Advocacy Day is a 2-day event held in Washington, DC where you will have the opportunity to speak with elected officials about important lung health issues. United for Lung Health is tentatively scheduled for May 13th and 14th. Please consider joining us for one of these events.

If you cannot attend these advocacy events, there are other ways you can help in your community. Let us know if you are interested, we would be happy to discuss other ways you can get involved. Contact Dyette Hernandez at (312) 628-0227 or visit our website at www.lungchicago.org and click on "policy" for more information.



Lung health advocates at United for Lung Health Federal Advocacy Day 2008.

SPOTLIGHT

In each issue we spotlight four COPD pulmonary rehabilitation centers and/or support groups for those living with chronic lung conditions. For a detailed list of programs in your area, visit www.lungchicago.org or call Dyette Hernandez, Director of COPD Initiatives at (312) 628-0227.

CANTON

**Graham Hospital
Cardiac/Pulmonary Rehabilitation
and Better Breathers Support Group**
Graham Wellness Center
235 W. Walnut St.
Canton, IL 61520
Carla Bahr, RN
CBahr@grahamhospital.org
Phone: (309) 647-4087
Fax: (309) 649-5179

CHICAGO

**Chicago Alphas
Support Group**
1022 N. Rockwell Street
Chicago, IL 60622
Cindy Wilson, Coordinator
chicago.alphas@gmail.com
Phone: (773) 484-5163

NAPERVILLE

**Edward Hospital
Pulmonary Rehabilitation**
801 South Washington
Naperville, IL 60540
Donna Serlin
dserlin@edward.org
Phone: (630) 527-3390
Fax: (630) 527-3699

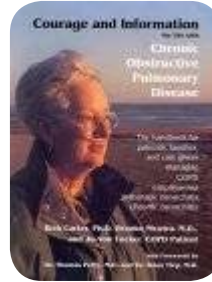
NAPERVILLE

**Edward Hospital
Pulmonary Fibrosis
Support Group**
Heart Hospital Conference Room
801 S. Washington
Naperville, IL 60540
Donna Serlin
dserlin@edward.org
Phone: (630) 527-3389

COPD Book Corner

Courage and Information for Life with Chronic Obstructive Pulmonary Disease

Written by Jo-Von Tucker



Jo-Von Tucker provides a compelling story of her first-hand account with COPD while pulmonary doctors Rick Carter and Brooke Nicotra explain the medical aspects of the illness in the book, *Courage and Information for Life with*

Chronic Obstructive Pulmonary Disease. By looking at COPD from a personal and medical perspective, readers are provided a unique, in-depth look at the disease and given tools on how to effectively manage it. Tucker's stories of isolation and fear are gripping, while her rise from despair inspires the reader to proactively deal with their illness. All three authors stress the importance of communication between patients and their doctors and how those with COPD can live quality lives long after their diagnosis.

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Board Chair	Joan Boomsa
President & Chief Executive Officer	Joel J. Africk
Director, COPD Initiative	Dyette Hernandez
Communications Director	Megan Vidis

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of Metropolitan Chicago

1440 W. Washington Blvd.
Chicago, IL 60607

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