NECANews

National Emphysema/COPD Association Summer 2004

2425 Ridgecrest Drive, SE
Albuquerque, NM 87108
www.NECACommunity.org

NECA is a patient-centered, member-driven, and member-governed organization. Our mission is to empower people with emphysema/COPD and their families and caregivers to improve the quality of patient care and the quality of their lives.

Nothing About Us Without Us

Barbara Rogers, President

We need your help! The National Emphysema/COPD Association Your International COPD Resource Network is committed to involving people with COPD and their families in all that we do. We need more people with COPD to help us implement and improve our exciting programs to empower people with COPD.

More patients are needed in the initial "cores" we have developed for COPD Grassroots Networks (CGNs) in Alaska, Colorado, Florida, Hawaii, Illinois, Indiana, Minnesota, New Mexico, New York, and Washington State. Carolyn Hull and Don Soderstrom, NECA and COPD-ALERT members who have COPD, are spearheading network development in West Palm Beach, Florida, and Albuquerque, New Mexico. They and the institutions sponsoring their efforts, ALA Southeast Florida and Lovelace Respiratory Research Institute, respectively, are available to help patients in other areas gain confidence to form networks. Suggestions for starting a COPD Grassroots Network in your area are given in this issue.

In addition to NECA board and council members (left, p. 19), leaders in the National Lung Health Education Program are helping us across the country. Tom Petty and Louise Nett urge members of all patient groups also to join NECA now and work together to find ANSWERS (Advocacy, Networking, Support, Wellness, Education, Research, Service) for living with COPD.

In this issue you also will find articles on self-care and peer support programs. Just as we need more patients to participate in and develop new CGNs, we are looking for patients to learn and teach our Self-Care Peer Support Program. Your help is vital in expanding this exciting stretching and breathing program developed especially for NECA by Dr. Vijai Sharma, an internationally recognized yoga authority. Field testing of Dr. Sharma's program has begun across the country and soon we will be ready to offer this program to individuals and groups.

Board Member Carl Wiezalis is leading the effort to help develop links between respiratory therapy schools and COPD peer support groups but needs COPD patients to help him launch this new venture. As a team

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The National Emphysema/COPD Association is a public, non-profit, member-based advocacy, networking support, wellness, education, research, and service organization. EIN # 14-183-6126

Please send all corrections, suggestions, and comments to Editor, Hannah Hedrick, Box 298, Mountain View, HI; 808-968-7013; *HHedrick@NECA Community.org*, or Assistant Editor, Vlady Rozenbaum, PhD. *Vlady.rita@verizon.net*

PFAC Members Lead Networks

The National Emphysema/COPD Association is working with the National Lung Health Education Program to form collaborative COPD Grassroots Networks in 10 pilot sites during 2004. Members of the Patient/Family Advisory Council (PFAC) are assuming leadership roles in every phase of this activity. They participate in local grassroots "cores" and ANSWERS (Advocacy, Networking, Support, Wellness, Education, Research, and Service) Working Groups. PFAC members keep networks focused on mobilizing and facilitating patient and family participation in all programs and activities to help them become "activist advocates."

Patient/Family Advisory Council Members

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Dr. Smita Shaw, MBChB, Wentworthville, Australia
Don and Jackie Soderstrom, Albuquerque, NM (COPD)
Janet Taylor, Nova Scotia, Canada
Eileen Zacharias, JD, Northbrook, IL (ARDS survivor)

Help Us Establish COPD Grassroots Networks

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Meetings organized by NECA during the past three years have identified patients and others enthusiastic about working collaboratively to empower people with COPD and their families. NECA is now working with the National Lung Health Education Program (NHLEP) to establish a foundation for forming collaborative COPD Grassroots Networks (CGNs) in the pilot locations indicated on page 4. We hope these meetings will result in local working groups developing and mobilizing specific projects in the ANSWERS (Advocacy, Networking, Support, Wellness, Education, Research, and Service) areas.

Use the following suggestions to initiate a COPD Grassroots Network in your area. Or participate in either a pilot network or regional COPD summit by contacting the individuals listed on page 4.

Setting Up Meetings, Initiating Networks

1. Identify two or more people willing to lead collaborative efforts as members of an initial "core" team.
2. Contact members via e-mail, phone, or face-to-face communications and negotiate core team roles and responsibilities such as who will serve as contact person, coordinate activities, and maintain a record of plans, actions, and outcomes.
3. Identify a local host organization and develop a list of potential invitees: patient groups or patients, respiratory therapists, physicians, social workers, discharge planners, cultural competency experts, oxygen providers, etc.
4. Poll several individuals about their interest in attending a meeting by focusing on: their needs and contributions; national and local resources; and establishing a foundation for forming CGNs.
5. Establish a date, place, and time for the initial planning/organizational meeting, with space provided by the host.
6. Develop a draft agenda (see below) and solicit input from individuals who responded positively to earlier inquiries.
7. Develop and e-mail (regular mail only if necessary) the invitation with the agenda topics.
8. Ask all invitees to send the agenda and other information to their local media sources.
9. Focus throughout the meeting on identifying participants in specific ANSWERS working groups.
10. Identify roles and resources, and establish a support structure or committee for laying a foundation to develop CGNs.

Formatting and Arranging Meetings

- Plan a late morning working group of 7-10 people committed to collaborative efforts to empower patients.
- Hold an afternoon general meeting, including other potential network leaders and participants.
- Have local sponsor provide complimentary space and meeting materials.
- Contact NECA to provide box lunches for the morning working group and refreshments for the general meeting.
- Let attendees at initial meetings pay their own transportation costs, including parking.

Suggested Agenda, Topics, Outcomes

- Use presentations by NECA and NLHEP.
- Give presentations by or about patient and professional organizations such as COPD-ALERT; Better Breathers Clubs; sleep disorder and tobacco cessation groups; National Emphysema Foundation; Lovelace Respiratory Research Institute; National Heart, Lung, and Blood Institute; lung associations, and U.S. COPD Coalition.
- Include presentations by or about state and local tobacco prevention/cessation programs, especially those involving youth.
- Use processes and outcomes of NECA's National COPD Community Needs Assessment to develop local surveys to guide development of relevant programs. (See page 2.)

Nothing About Us Without Us, continued

member, you will be working directly with Mr. Wiezalis, past president of the American Association of Respiratory Care and Professor of Respiratory Care, SUNY Upstate Medical Center, Syracuse, New York. Please contact him at *weizalic@upstate.edu.*

And because of generous technical help, we are now able to incorporate your feedback on our website. Visit us at *www.NECA Community.org* and let us know what attracts you, or what you would like to see added or deleted.

Participate in 2004 Pilot Networks

Contact the following individuals if you would like to participate in meetings in their area during 2004:

Alaska, Hawaii – Hannah Hedrick *(hedrickhneca@aol.com)*
Lorna Higgs *(lorna1@gci.net)*
Colorado – Greater Denver area:
Patrick Koff *(patdkoff@hotmail.com)*
Kristin McFall *(kmcfall@thevest.com)*
National Jewish Medical and Research Center:
Barry Make *(makeb@njc.org)*
Florida – West Palm Beach: Carolyn Hull *(hullhaus@bellsouth.net)*
Illinois – Donna Frownfelter *(frownfed@finchcms.edu)*
Daryl Isenberg *(dipeace@aol.com)*
Indiana – Terre Haute: Michele Pantle *(m-pantle@indstate.edu)*
Indianapolis: Deborah Cullen *(dcullen@iupui.edu)*
Minnesota – Mayo Clinic and Minneapolis:
Ashok Patel *(patel.ashok@mayo.edu)*
New Mexico – Albuquerque:
Don Soderstrom *(avoidcourt@aol.com)*
New York – Syracuse: Carl Wiezalis *(wiezalic@upstate.edu)*
Washington State – Hannah Hedrick *(hedrichhneca@aol.com)*
Seattle area: David Au *(dau@u.washington.edu)*
Okanogan County: Nancy Nash *(nnash@mvhealth.org)*
National Lung Health Education Program
Ashok Patel *(patel.ashok@mayo.edu)*
Physical Therapists – Donna Frownfelter *(frownfed@finchcms.edu)*
Respiratory Therapists – Carl Wiezalis *(wiezalic@upstate.edu)*

PARTICIPATE IN REGIONAL COPD SUMMITS

Regions establishing COPD Grassroots Networks are considering hosting regional COPD Summits in fall 2004. If you are interested in participating, contact the pilot network coordinators above or Hannah Hedrick at *hedrickhneca@aol.com*. The regional COPD Summits will continue efforts to:

- Establish Strategic Partnerships
- Develop Common COPD Awareness, Education, and Action Agendas
- Form Collaborative COPD Grassroots Networks
- Organize Conferences in 2005 on *Bridging Patient and Professional Approaches to Coping with COPD*

Empowered Patient and Advocate Stories

Don Soderstrom: Ultimate Commitment

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This past March was a very heralding one to say the least. I was very weak and in constant pain ever since I was rushed to the ICU. Because I was about to pass out from lack of oxygen – my O_2 SATS when I first arrived in the chest clinic were 64 at 4.0 L – they increased the O_2 intake to 5.0 L; but the SATS only increased to 75. When I was rushed into the ICU, the medical team originally thought they would put a ventilator in me. Instead, thank goodness, they put me on a Bi-Pap machine and in about 30 minutes they had my breathing stabilized.

But when a nurse inserted a catheter in spite of my frantic objections (I told her this procedure had failed about two and a half years ago) all hell broke loose. She did not use a probe light, and I have two urethra tubes: one that goes into the bladder and a false one. She pushed the catheter up through the false one and I bled very profusely for about 30 minutes. Although it looked like I was going to be rushed to surgery, fortunately I stopped bleeding. Finally a urologist did the procedure, but it still took him two tries. I still have the cather in and can barely walk or sit because of extreme pain.

When I saw my primary care physician again, I talked with the Patient Advocate about what happened. Then my wife, Jackie, and I went over to Lovelace (right next to the VA hospital) to pick up copies of the Fall/Winter newsletter. By the way, while I was in ICU, I managed to talk again with Drs. Brian Kersch and Dona Upson about NECA and helping us form a COPD Grassroots Network.

Caro Hull Connects COPD "Lights" in Florida

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Caro, as Carolyn Hull prefers to be called, exemplifies the model "empowered patient" – a modest team player who leads from within the group. Caro was diagnosed with emphysema in May 1993. After a bout with pneumonia in January 1999, she began to use oxygen 24/7. Her advocacy and support efforts began in 1995, when she helped Lil Stone revive the *Breathe Easy Newsletter*.

Caro attended NECA's first COPD Education Day. Fewer than four months later, she had activated current and former lung association contacts, COPD patients and professionals, and tobacco awareness networks to conduct the first inclusive, broad-based network meeting in the state. She is now working with the "core" team formed at the February 19, 2003, meeting to form ANSWERS Working Groups, which include patients and family members.

Caro's outreach includes writing an item for the local lung association newsletter to inform readers of

Carolyn Hull with Jim Sugarman, Executive Director, American Lung Association of Florida; Southeast Area

Empowered Patient and Advocate Stories, continued

NECA's mission and activities. She praised the October COPD Education Day near Orlando, where she "met old friends and new ones alike." Caro encourages people to contact her for more information about NECA and the Florida COPD Grassroots Network and networks with COPD-ALERT members in other states. Above all, she generously offers guidance and support to people with COPD in other areas who wish to assume leadership roles in establishing networks.

COPD Conference in Thailand

Our very first COPD conference, May the World Be Aware of COPD, took place here in our small town of Chiang Mai on November 19, 2003. It was organized by our university hospital and sponsored by Spiriva, Advair, Fluimucil and Symbicort. Approximately 100 participants registered, then 300 people showed up! Hasty adjustments were made to provide a seat and enough free food for everyone. My assigned duty as a person with COPD was to be seen wearing my nose hose and carrying my portable oxygen on my shoulder to encourage Thai people with COPD people to get out and about. It worked, because dozens of people asked lots of questions and took my picture (stardom at last!).

The conference was a phenomenal success, well orchestrated and animated by a team of six pulmos, two therapists, an oxygen advisor, and two very pretty girls who did a respiratory aerobic session that had everyone on their feet. Afterwards, one of the doctors collapsed back onto his chair and gasped, "Now I know how they feel!" The success of the conference was its simplicity, the vast amount of basic knowledge that was given out, the compassion, and the fun. A booklet crammed with information and suggestions was handed out. A COPD club was founded and will meet weekly in a room at the hospital that will also offer free weekly rehab sessions. All-in-all it was a wonderful day, and I am grateful to have been a part of it.

Best wishes to everyone,
Helen in Chiang Mai
(From COPD-ALERT)

Quality of Life for People with COPD in France

Philippe Joud, Lyons, France
COPD Grassroots Network
Coordinator, France

Quality of life has become a priority for people with COPD in France, where programs of pulmonary rehabilitation and patient education have been under development for several years. A person with emphysema or COPD having an exacerbation is hospitalized in a pulmonary or an intensive care department. Upon discharge, patients can spend some time in a rehabilitation center in the Alps or Pyrenees or another place with an appropriate climate and altitude. There they can participate in a program led by a multidisciplinary team, including a physician, physiotherapist, nurse, counselor, and dietician. The program includes exercise training, breathing exercises, bronchial drainage, and an education program including smoking cessation, adherence to recommended treatments, inhalation therapy, gymnastics, and walking.

After returning home, patients can participate in an ambulatory pulmonary rehabilitation program three times a week in a pulmonology center or a respiratory physiotherapy center. For people with severe COPD who are on oxygen therapy or mechanical ventilation, the rehabilitation program is provided in the home. A physiotherapist or nurse checks the training program once a month. Patient associations for people with asthma, COPD, or cystic fibrosis work with health professionals or gymnastics teachers to organize group physical activities (walking in the country, cycling, swimming, etc).

Sisters Appeal to Family, Friends, Professionals

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Sisters Lorna Higgs and Linda Goff, both recovering smokers, have developed some unique methods for promoting membership in NECA. Motivated by the death of a beloved relative and by other family members and friends with COPD, Lorna and Linda simply take the word wherever

Empowered Patient and Advocate Stories, continued

they go. They use humor and examples of their own tobacco wars to break through the denial of smokers or others with COPD symptoms. Whether at church or "chunky dunking" (swimming in Hawaiian warm pools), they make new friends through their desire to help others.

Lorna's Tips

1. Begin by talking with family and friends about COPD. I used my 2003 Christmas letter to let people know how good I feel about increasing COPD awareness. Maybe something in our newsletter or on our website will help someone with COPD, someone who wants to stop smoking, or someone who wants to keep their kids from smoking.

2. Hand out the newsletter or ANSWERS flyer. Sit down at your computer and help people with COPD join free. Encourage others to join at the $15 (fixed income) or $25 rates.

3. Make sure NECA materials give us what we need. Ordinary people like me, as well as people with COPD, need the basics repeated over and over again.

4. Ask NECA Board and Council members in your area to help you connect with others. Their names are on the website and on the back pages of NECANews because they want to help.

5. Ask others in your area to identify people who could be helped by learning more about treating and living with COPD. Invite people to meet in your home, community center, or church, to form a support group or organize a COPD Grassroots Network. The national office will help you.

Linda's Tips

1. Ask NECA to identify professionals and others to contact. Don't waste time going through the phone book!

2. Take NECA materials with you wherever you go. I take newsletters to the grocery store, doctor's appointments, local hospitals and clinics, van companies that provide transportation to people with oxygen tanks, weatherization agencies providing service to people with limited income, fire stations, etc.

3. Focus on the most isolated populations and organizations serving them, such as the Alaska Native Medical Association. Lung diseases, including COPD and TB, are tremendous problems with native populations.

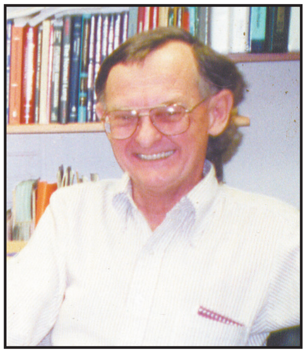
4. Ask friends and family to get involved. My daughter, who has a young son, is working with NECA's Tobacco Awareness campaign on tobacco prevention and cessation in schools in Homer, Alaska.

5. Use humor to break down denial and guilt, especially with smokers. I have a blast saying, "I'm an ex-smoker, and it doesn't make any difference if you are a sinner who still smokes!" That usually gets a laugh.

Pathfinder Jo-Von Tucker's "Living Legacy"

With the death of Jo-Von Tucker on December 17, 2003, at age 66, the COPD world lost one of its most well-known and effective voices for empowering people with COPD. This tragedy came as a great shock to those of us who interacted with her at the first National COPD Conference in November. Appearing to be in radiant health, Jo-Von was her usual outspoken, "pathfinder" self. Jo-Von tells her own story in *Courage and Information for Life with Chronic Obstructive Pulmonary Disease* (1999, 264 pages), co-authored with Rick Carter, PhD, and Brooke Nicotra, MD. This book, her newsletters, and other writings serve as a living legacy, taking her voice to those not fortunate enough to meet her in person. Copies are available from New Technology Publishing, Inc., 6 West Blvd., POB 1737, Onset, MA 02558-1737. Or by calling 888-706-COPD. Elaine Shinberg used Jo-Von's words in "What Caregivers Need to Know" in her *Coping with Chronic Obstructive Pulmonary Disease* (2003). For information about Jo-Von's impressive accomplishments, go to *www.healthyresources.com/copd/courage/devastation.html* or *www.coloradohealthsite.org/COPD/tucker-bio.html*.

Fifteen Million Potential Volunteers, Votes



Ron Peterson, Adult Co-chair
Tobacco Awareness Campaign
Ron@preventionvido.com

Fifteen million people diagnosed with COPD equal 15 million potential volunteers and 15 million potential voters to create social policy to decrease tobacco use. NECA's Tobacco Action Plan emphasizes enlisting tobacco's victims in our "tobacco wars." We encourage smokers and former smokers to help us promote higher tobacco taxes, clean indoor air, and gain easy access to aids to quit smoking.

You can help us reach our goal by instituting the ideas presented below.

- Work in both smoking prevention and smoking cessation programs across the age spectrum.
- Use individual and collective advocacy efforts to promote local and national tobacco control policies.
- Be proactive in forming alliances with others, including countries outside the United States.
- Use all appropriate forms of motivational communication materials.
- Emphasize highly motivational and culturally appropriate materials.
- Develop a COPD Peer Support Group Directory and Resource Guide that includes smoking cessation groups as well as encouraging development of support groups where none exist, including buddy systems.
- Assist organizations (excluding tobacco companies) and individuals attempting to establish tobacco prevention and cessation programs; network with producers of motivational materials.
- Develop a state Tobacco-Free Advocates Coalition to help identify and empower advocates in states where legislation is being considered.
- Develop a Student/Teacher Tobacco-Free Advocates Coalition (elementary, middle, high school, postsecondary – both public and private)

For information about youth smoking prevention and cessation resources and activities, including how to order Arthur Pitchenik's *They're Rich, You're Dead*, go to *www.NECAcommunity.org*.

Please Send References for Website

We are currently developing a Tobacco Awareness section on our website, beginning with the hundreds of resources listed in previous issues of the newsletter. We are especially interested in:

State-specific resources, such as Steps to Help you Quit Smoking: How Other Moms Have Quit, Washington State Department of Health

Professional association programs and educational materials, such as Tar Wars, American Academy of Family Physicians, and Tobacco Cessation Tool Kit, American College of Chest Physicians

Web-based medical education programs, such as Treating Tobacco Use and Dependence, University of Wisconsin Medical School of Health

Collaborative documents and programs, such as Teen Tobacco Use: Prevention and Treatment, Illinois Academy of Family Physicians, Family Practice Education Network, American Academy of Pediatrics, Illinois Chapter of AAP, and Illinois Department of Public Health

If you are willing to help us get the youth-focused resources described below into the hands of teachers and others who will share them with students, please e-mail me at *ron@preventionvideo.org.*

Test Your Lungs, Know Your Numbers

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If you can blow out candles, you can take this test. It's that simple and painless to test your lung function! The test is called spirometry (spy-ROM-uh-tree). You simply take in the deepest breath possible and then blow out as hard and as fast as you can into a spirometer (spy-ROM-uh-ter). The key measurements we make are the *amount* of air you breathe out and how *fast* you can push the air out. People with normal lung function can exhale all the air in about six seconds – about 80 percent of that amount in the first second. Then, we compare how much you exhaled with a database of thousands of results, based on your age, height, and gender.

While spirometry does not necessarily diagnose a specific disease, we can learn much about many diseases from your lung function. We look for two key abnormalities: The most common is called obstructive disease. We use this term when the person taking the test blows out as fast as possible, but may only be able to blow out 50 percent (instead of the normal 80 percent) of the total amount of air in the first second. The air is slowed down because of a blockage – or obstruction – to airflow. This obstruction may be caused by mucus in the breathing passages, called airways, that typically causes a partial obstruction. The inability to get air out may also be caused by collapse of the tiniest airways, which blocks air movement altogether. Several diseases and combinations of diseases that cause this kind of obstruction, such as emphysema and chronic bronchitis, are now grouped together under one name, *chronic obstructive pulmonary disease, or COPD.*

Spirometers, Spirometry Testing

The Test Your Lungs, Know Your Numbers campaign of the National Lung Health Education Program (NLHEP) has increased awareness of the value of early detection of COPD. Recent national and regional meetings have focused on and even offered spirometry testing. At the American Thoracic Society 2003 annual meeting, President Homer Boushey, MD, announced development of the ATS Spirometry Project. The American Association for Respiratory Care has posted a list of free screenings at *www.aarc.org/headlines/lung*.

To support this increased interest, NLHEP is stimulating design and development of simple, accurate handheld spirometers suitable for use in the office and clinic. The NLHEP Spirometry Validation Process is developing acceptable parameters for these instruments.

Information about currently available spirometers appears in *RT, The Journal for Respiratory Care Practitioners,* October 2003, page 54 (*www.rtmagazine.com*). Summaries and websites are provided for Koko spirometer and DigiDoser; Eaglet computer-based spirometer; MicroLab portable spirometer; Children's SpiroFlow; Spirotrac 6800; KoKoMate Personal Diary (designed to meet NLHEP parameters); Pony FX desktop spirometer; and Satellite/Base Station 3 handheld system.

Simple Office Spirometry for Primary Care Practitioners

Thomas L. Petty, MD, and Paul L. Enright, MD, have produced a 30-page document intended for primary care practitioners but largely written in language understandable by the general public. Beautifully designed and illustrated, the document includes sections on “How to Perform a Spirometry Test,” “Post-Bronchodilator Spirometry,” “How to Interpret Spirometry Results,” “Spirometry in the Diagnosis and Management of Lung Disease,” glossary of spirometry terms, bibliography, and sample patient handouts. NLHEP and AlphaMedica, Inc., encourage you to download the PDF file from *www.nlhep.org/resources.html,* and duplicate and distribute it.

Evaluating and Improving Breathing Capacity

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The following paragraphs delineate how a physical or respiratory therapist evaluates and teaches a person with COPD to alleviate breathlessness.

Evaluating Breathing Capacity

To help people with COPD improve their breathing, physical therapists look for the proper spinal curves, the position of the head and neck, and the pelvic position. We also evaluate rib cage and spine mobility in various planes of movement. The head and neck of many people with COPD are in a forward position, which limits upper chest wall mobility. The shoulders rotate forward, making the middle (thoracic) spine look rounded, or “khyphotic.” Physical therapists also look at the position of the pelvis. When the top of the pelvis is tipped back further than the bottom of the pelvis, the person tends to slump forward, which limits breathing. When the top of the pelvis is pushed forward, the chest tends to lift and open, which usually makes it easier to breathe. We encourage people who slump to place a roll at the lower (lumbar) spine when seated to tilt the top of the pelvis forward so they can breathe better without having to focus on it.

Inhale Against Gravity, Exhale with Gravity

A physical therapy evaluation includes teaching people with COPD techniques for coordinating breathing and movement. We encourage them to exhale when bending forward (as in putting on pantyhose) and inhale when straightening their torso or arching backward. We also help them match muscle contraction (movements that shorten the muscles) with inhaling and muscle expansion (movements that lengthen the muscle) with exhaling. For example, a man rolling over in bed would breathe in while lying on his back and exhale as he rolls over. This breathing pattern would facilitate the trunk going into flexion. A woman extending her arm to get something from a shelf would be encouraged to breathe in, as the movement requires more trunk extension. Sitting down would be accompanied by an exhalation, as lowering the body involves a lengthening or release contraction of the quads and of the diaphragm. A simple rule-of-thumb is to inhale when moving against gravity and exhale when moving with gravity.

Techniques to Relieve Breathlessness

I suggest a three-step process that has helped hundreds of people who are breathing rapidly and shallowly because they can't get enough air.

1. Do a very relaxed pursed (whistle-shaped) lip exhalation. I ask them to think of blowing a bubble from a wand and often actually have them do this to emphasize how gentle the breath is. Another visual is to have a candle about a foot in front of them; then they gently exhale to see the candle flicker, but not go out. This helps decrease respiratory rate.

2. Take in a slow, easy (rather than deep) breath through the mouth, then pause briefly at the end of the in breath before exhaling through relaxed pursed lips. The inhalation and brief pause are similar to a yawn maneuver; the brief pause is not forced and does not harden the abdomen and throat. The pause helps people feel they have taken in more air.

3. Take in a slower breath, pause briefly again, then exhale through relaxed pursed lips.

Effects of Medicare Reform on Oxygen Patients

Peter M. Wilson, PhD, oxygen patient and patient advocate
Author of *Portable Oxygen: A User’s Perspective*, at
http://www.portableoxygen.org/petewilson@
portableoxygen.org

In November 2003, the new Medicare bill passed both the Senate and the House. Because of the media focus, oxygen patients may have no forewarning about the changes that will affect them. Starting in 2005, expect a reduction in Medicare reimbursements for oxygen and oxygen equipment. This means the company that serves you will receive less for the same level of service and your co-pay will be smaller. If you live in one of the 100 largest metropolitan areas in 2007, then the company that provides you with oxygen will be chosen by competitive bidding. This process will ensure that you will be served by a lowest bidder.

What can you expect? I have been following the demonstrations Medicare has been conducting on competitive bidding in Polk County, Florida. The demonstrations, intended to set aside any fear that oxygen companies or patients might have about competitive bidding, compared services of participating Polk County patients with those received by non-participating patients in nearby Brevard County. The good news from the demonstrations is that patients’ co-pays were 20 percent lower in Polk County. The bad news is that Polk County patients did not receive as many home service calls and were less likely to be issued portable oxygen equipment. What troubled me the most was that none of the companies from the first demonstration participated in the second one. Prepare for having a company with fewer, less trained employees. Prepare yourself by fully understanding your medical condition and learning enough to take responsibility for managing your oxygen and the equipment that delivers it.

New Home Product Available

Deane Hillsman, MD, has developed a simple version of his visual biofeedback tool, Breathing Trainer v1.0, which may be seen at *www.sierrabiotech.com*; pictures of the more advanced biofeedback version may also be viewed. The difference between the two versions is the removal of the real-time patient breathing signal, a function that required $2500 for the hardware. People with COPD should find the home system useful, although not as good as the true biofeedback device. Patients using the system should ideally have initial training in an office or clinic, where trained medical personnel can generate the various breathing parameters. General instructions are provided. Patients can then practice with the parameters at home. Deane, a pioneer since the 1970s in trying to get breathing training technology into the home, feels this is the first step. For a preview, go to *www.sierrabiotech.com/prompter.htm*. Deane will provide a free license to local facilities that refurbish free computers for schools and those who cannot afford computers. If your doctor or therapist does not have the program, you are permitted to allow him or her to copy your program. He also intends the product for use in classes on yoga, meditation, relaxation, etc.

National Meetings Call for Grassroots COPD Networks,Caucus

COPD Education Day Leads to Grassroots Networks

COPD-ALERT Education Day Attendees Marylin Lashin, Carolyn Hull and Vlady Rozenbaum

The October 16, 2003, COPD Education Day organized by the National Emphysema/COPD Association resulted in February and May meetings to organize 10 pilot COPD Grassroots Networks (CGNs). The grassroots approach arose from interactions of COPD patients with leading respiratory disease experts involved in current treatment, research, and public policy issues.

Tom Petty, first recipient of the Thomas L. Petty Distinguished Achievement Award established in his honor, encouraged NECA to work with the National Lung Health Education Program and others "to create a large, forceful, and well-organized patient advocacy group to deal with all sorts of issues facing COPD patients and their families." Although he claims to be retired, Tom continues to function as "social architect, master builder, and universal solvent" to help people with COPD and their families speak with one voice. The 10 CGN pilot sites include isolated areas with few or no COPD resources, as well as populous areas with health care and research facilities.

Presentations, Theme Tables, Interactive Round Tables

Individual talks, panels, and roundtables at the COPD Education Day were supplemented with hands-on opportunities. Attendees tried innovative medical equipment and participated in breathing, stretching, and t'ai chi chih sessions. Speakers and roundtable panelists included over two dozen distinguished names in respiratory medicine and research, many of whom serve on the NECA Board or Medical Advisory Council. For additional information about topics and individual presenters, see the Fall/Winter 2003 newsletter (*www.NECACommunity.org*).

Join the COPD Caucus

The First National COPD Conference, conducted November 14-15, 2003, in Arlington, Virginia, by the U.S. COPD Coalition, was attended by more than 500 patients, well-known health care professionals, and representatives of patient, professional and government organizations. Well-represented patient organizations included NECA, COPD-ALERT, and EFFORTS.

Sessions relevant to people with COPD included the report of NECA's COPD Community Needs Assessment, presented by John Walsh, CEO and president of the Alpha-1 Foundation. The primary outcome of interest to people with COPD and their families was agreement that collaborative action is immediately required to form a COPD caucus to make COPD a household word.

Senator Mike Crapo (R-ID), younger brother of two well-known pulmonary medicine physicians also presenting at the conference, reported on the amazing lack of knowledge about COPD. Senator Crapo has proposed a COPD caucus aimed at increasing awareness and attacking and treating COPD. To join in making this caucus a force for change, e-mail or send a succinct letter to your senators and congressmen. Mary Burns, Pulmonary Education and Research Foundation, will print in *Second Wind* an honor roll of those who join this effort. For detailed information of interest to people with COPD, including a summary of this landmark COPD conference and illustrations, go to *Second Wind* online at *www.perf2ndwind.org/html/news/2003/December/index.html*.

Patients, Families Suffer from Poor Communication

E-mails to the editor emphasize how poor communication of health care providers with patients and other health care providers may compromise patient care. Pam DeNardo, who has COPD, identified inadequate communication related to her mother's health care experiences.

"I have been visiting my mother first at the hospital for three weeks, and then the nursing home for the last five weeks. I have witnessed first hand the difficulties of my mother and her roommate in using prescribed Combivent inhalers. Neither can plunge the canister down (arthritic fingers), nor do they know when to inhale, even with spacers. I can actually see the medicine come out the sides of their mouths. The nurse enters, sticks the inhaler in their mouths, tells them to inhale, and plunges the canister. What a waste. I have asked why they do not use nebulizers like the hospitals do and they just shrug their shoulders. I have asked the doctor to prescribe a nebulizer for when my mother goes home. She finds this to be much easier. As she says, 'you just breathe.'"

Dawn Brennan, PT, related a recent situation in which lack of agreement about appropriate treatment compromised optimum patient care.

"I see many lobecotomies, esophagotomies – in essence, all thoracotomy patients. Based on recent physical therapy education programs, I have been encouraging my patients to spend more time in side-lying. However, on the floor on which I currently work, the nurses are very proactive in getting these patients to sit in a chair for ong periods of time, even all day. When I advise my patients to spend time in bed, even just to do postural drainage, they are skeptical because I am suggesting that they go against what the doctors and nurses are telling them. Right now, two of my patients who have extremely diminished lung sounds on one side, especially at the bases, are sitting in chairs literally for 10 hours a day. When they are in bed, they are lying on their backs."

Communication Resources

- **"Making Asthma Education More Effective to Enhance Patient Outcomes":** *RT, The Journal for Respiratory Care Practitioners*, October 2003. In this article, Patricia Carroll emphasizes the importance of partnering with patients by listening and improving understanding. Although the case studies feature people with asthma, the advice applies to using active participation to improve outcomes in all chronic diseases. Pat, a member of NECA's Medical Advisory Council, provides excellent advice for achieving patient-centered care. Steps include assessing patient readiness, willingness, and ability to learn about the disease; focusing on the patient's learning style as an adult (andragogy); addressing literacy as a barrier; and primary methods for overcoming cultural barriers.

- **Chronic Condition Self-Management Guidelines:** *Summary for General Practitioners* similarly emphasizes the importance of communication in a patient-centered approach and informed decision-making as a framework for self-management. Available at *www.racgp.au/downloads/pdf/20020703gp.pdf*, this outstanding document emphasizes the importance of modification by local primary care providers to "reflect their community's unique needs." The categories of intervention include Peer Support and Motivation, Self-management Programs Led by Lay People, and Community-based Skill Groups.

- **Keeping It Alive! Addresses Patient Issues:** Keeping it Alive! was the theme of the annual meeting of the California Society for Pulmonary Rehabilitation (CSPR), in conjunction with the American Lung Association of Los Angeles. The April 22-23, 2004, meeting in Long Beach included numerous sessions of vital interest to people with COPD. Topics included the latest information on advances, new challenges facing pulmonary rehabilitation, ambulatory oxygen, financial concerns, clinical applications, and research results.

Providing culturally-appropriate care was the focus of several sessions including: "Patient Education: Sexuality" (Brian Tiep, MD), "Pulmonary Medicine in Other Countries," working with Asian patients, and improving communication with patients who don't speak English. You can contact the CSPR at the address below to learn more about this valuable resource or visit their website at www.cspr.org.

California Society for Pulmonary
Rehabilitation
4455 Torrance Blvd. #500
Torrance, CA 90503-4398
Phone: 877-280-CSPR (2777)
E-mail: info@cspr.org

End of Life Issues

End of Life Terribly Mishandled

Tom Petty's December letter, *End of Life Matters (www.perf2ndwind.org/html/news/)*, was prompted by the Terri Schiavo case in Florida. Tom states that end-of-life care is “terribly mishandled.” He emphasizes maintaining dignity while postponing death only as long as is “reasonable and possible.” Let physicians know what you want done when facing a catastrophic situation via a living will or durable power of attorney. Tom feels very strongly that lawyers, the legal system, and courts should not be involved.

Patients Don't Discuss End-of-Life Plans

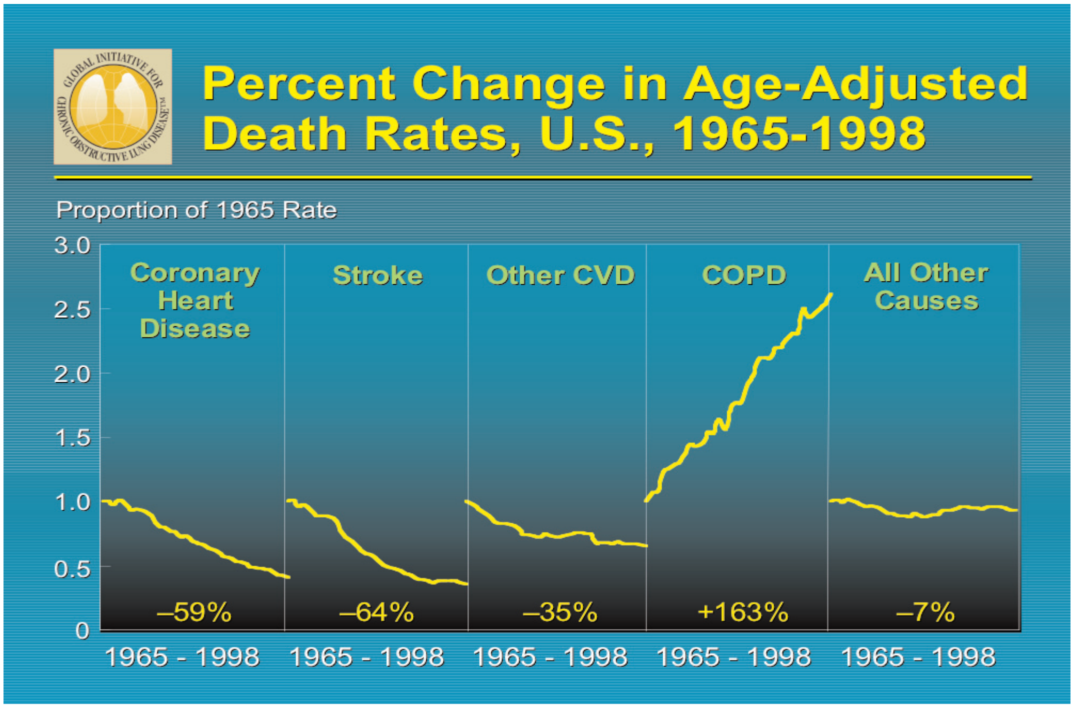
The five-year mortality rate for patients with severe COPD, usually around 50 percent, is upward of 60 percent if intensive care and mechanical ventilation were required in the previous year. On October 27, 2003, Michel Chalhoub, MD, reported the reluctance of physicians to discuss end-of-life plans with people with end-stage lung disease. Dr. Chalhoub and others reviewed the pulmonary function tests of all patients admitted to their institution between 2000 and 2002, selecting for study those with a forced expiratory volume at one second (FEV1) that was 50 percent less than predicted. Of the 83 patients with advanced COPD, all of whom were regularly seeing physicians, 78 percent expressed a desire to discuss end-of-life issues. Unfortunately, 83 percent had not been able to do so. **Moreover, 26 percent were unaware of their diagnosis and what it meant!**

Deaths From COPD May Be Underestimated

Patricia Reaney (London, Reuters, October 27, 2003) reports that the London COPD death toll could be much higher than estimated. According to Dr. Anna Hansell, Imperial College of Medicine, “It is contributing to a whole host of other deaths.” Dr. Hansell and colleagues studied death certificates to find that in addition to the 27,000 people in England and Wales who die annually from COPD, COPD was linked to 18,000 more deaths annually from 1993-1999 – a total of 45,000 per year. For example, COPD was likely the underlying cause of many deaths related to pneumonia. Results were reported in *European Respiratory Journal*.

The Quiet Killer

For information about COPD and end-of-life issues, see *The Quiet Killer: Emphysema/Chronic Obstructive Pulmonary Disease*; eds. Hannah Hedrick, PhD, and Dr. Austin Kutscher, 2002, 224 pages. ISBN 0-8108-4173. $39.50, cloth. Scarecrow Press, 800-462-6420. Reviewed in September 2003 *Hispanic Outlook*.

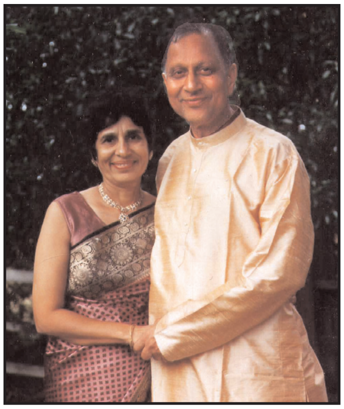


SELF-CARE RESOURCES

Creating an "Upward Spiral" via Yoga

Vijai Sharma, PhD, Chair, Self-Care/Peer Support Program
Dr.sharma@mindpub.com

Vijai Sharma has maintained lung function at the same level as when he was tested and diagnosed 10 years ago. Because daily practice of yoga has contributed to this "upward spiral," he has developed a yoga-based breathing and stretching DVD and program. Also available from Vijai is his *Yoga and COPD*, which describes in personal terms how to use yoga to combat symptoms and maintain lung function.



Sudha and Vijai Sharma

Major sections include very clear descriptions of COPD; how to use specific breathing muscles to alleviate symptoms; symptoms that may go unnoticed or undiagnosed; lack of proper assessment or specific diagnosis; preparing teachers to help people with COPD learn to breathe appropriately; and belly, pursed lip, and diaphragmatic breathing techniques. The Guidelines for Practice of Yoga Poses section suggests specific poses.

AARP: Acupuncture, T'ai Chi, Yoga Relieve Arthritis

In the March/April 2003 issue of *AARP*, Melissa Gotthardt summarizes the recommendations of "many experts" to "mix" Eastern and Western remedies. Best options include:

- **Acupuncture:** Endorsed in 1980 by the World Health Organization for treating osteoarthritis and rheumatoid arthritis and by the National Institutes of Health in 1997 for fibromyalgia and postoperative pain.
- **T'ai chi:** Numerous studies lead the Arthritis Foundation to include t'ai chi among its accepted forms of movement and to offer T'ai Chi from the Arthritis Foundation via a toll-free number, 800-283-7800.
- **Yoga:** University of Pennsylvania rheumatologist Sharon Kolasinski, MD, reports on research showing that yoga can help people with rheumatoid arthritis and osteoarthritis. Her own study found that two months of yoga cut pain by 50 percent among patients with knee osteoarthritis. A free guide on yoga and arthritis is available at *www.raacademy.com*.

Needed: Professionals to Work with Self-Care/Peer Support Program

Vijai Sharma, PhD, Chair, Self-Care/Peer Support Program
Dr.sharma@mindpub.com

We continue to hear that patients trying to talk with physicians are interrupted within 14 seconds. When questions are answered, it may be in technical jargon patients don't understand. But many health care professionals really listen to their patients and use clear language to help with real-life issues. If you were not one of those people you would not have read this far.

I personally invite you to help us promote the common goal of patient/caregiver collaboration in managing symptoms and improving the quality of life. By creating collaborative COPD Grassroots Networks across the nation and around the world, we can help persons with COPD figure out what they can do for their own health. We can model programs after the one Carl Wiezalis has started in New York, in which respiratory therapy schools partner with patients to develop peer support groups. Educators, researchers, and clinicians serve as resources to help with practical needs. Members of these COPD support groups help one another manage symptoms, use medications and devices as they are supposed to, increase physical activity, and perform activities of daily living.

Please contact me if you are willing to work with patients, patient groups, and others to develop specific ANSWERS (Advocacy, Networking, Support, Wellness, Education, Research, and Service) programs for coping with COPD.

Peer Support Resources

Self-Help Group Sourcebook

Seventh edition, 448 pages, $15.00 each plus $3.00 postage/handling (bulk rates available)
Credit card orders at 973-326-6789 or send checks to:
Saint Clare's Health Services
American Self-Help Clearinghouse
100 E. Hanover Ave., Suite 202
Cedar Knolls, NJ 07927-2020
www.selfhelpgroups.org
Ed Madara, Director, *ashc@cybernex.net*

The *Self-Help Group Sourcebook*, available at cost to COPD Grassroots Networks, lists more than 1,100 national, model, and on-line mutual help groups. Information on self-help groups, including how to start a community or online group and local self-help group clearinghouses worldwide, is available at *www.selfhelpgroups.org*. Chapters include: "Understanding the Value and Dynamics of Self-Help Groups," "How to Start a Community Group (to Include Professional Roles)," "Finding and Forming Online Groups," "Local Self-Help Group Clearinghouses Worldwide," and an additional 300 specialty toll-free help lines. Chapter 4 includes reviews by Stanford School of Medicine staff of 45 empirical research studies done of self-help groups. A variety of groups in the *Sourcebook* are of interest to those involved in groups related to lung impairments, sleep disorders, smoking cessation, and diseases frequently co-existing with COPD.

How to Start a Pulmonary Peer Support Group

Mary Burns
Pulmonary Education and Research Foundation
Box 1122
Lomita, CA 90717-5133
310-539-8390
www.perf2ndwind.org

In addition to all of her work with the Pulmonary Education and Research Foundation and its website and newsletter, Mary Burns has written several articles and chapters in different books, detailing how to start a patient support group. "Social and Recreational Support of the Pulmonary Patient" is in Hodgkin's book on *Pulmonary Rehabilitation – Guidelines to Success.* "Continuing Care Programs" is in Casaburi's and Petty's *Principles and Practices of Pulmonary Rehabilitation*. NECA hopes to work with Mary Burns and Ed Madara, American Self-Help Clearinghouse, to develop a document for the COPD Grassroots Network Tool Kit.

COPD-ALERT

Vlady Rozenbaum, Founder and Moderator
http://www.NECACommunity.org

COPD-ALERT-subscribe@yahoogroups.com
Go to *www.COPDResourceNetwork.org* for information about COPD-ALERT and about Vlady Rozenbaum.

"TransAction" Increases Oxygen Acceptance

Linda Neiswender
2297 Blake Way
Ocoee, FL 34761
407-296-6878
lin52@bellsouth.net

Linda Neiswender and other members of a Better Breathers Club have formed an informal support group, TransAction, for lung transplant candidates. The core members were put in touch with one another through their doctor's staff. Now they meet monthly to swap information and offer support and practical advice. When they wear their oxygen apparel of choice to their brunch restaurant meeting, they educate the public while relieving the isolation that can be such a devastating part of lung disease.

Tips for Improving Patient/Professional Communication

A recent article in the *Annals of Internal Medicine* describes the communication gap between the knowledge and information physicians intend to convey during an office visit and what patients understand. As a person with COPD, a family member, or a health and human service professional, do you have special tips for communicating with professionals or patients? Please send suggestions for companion documents on patient/professional communication, part of which will be published in the next issue of *NECANews*. We are also requesting annotated references to communication resources relevant to people with COPD.

COPD CLINICAL TRIALS

COPD clinical trials, currently are being held in the states and cities listed below. For more detailed information or to participate in one of these studies near you, please call the number listed or visit our website at *www.NECACommunity.org*. Some sites may be running more than one trial.

ALABAMA

- **Birmingham**
  Research Site: 1-877-CTLILLY
  (1-877-285-4559)
  Reference #6484

ARIZONA

- **Phoenix**
  Lovelace Scientific Resources, Inc.
  602-636-1880; Fax: 602-636-1883

  Radiant Research - Phoenix North
  877-70-STUDY

- **Tucson**
  Research Site: 877-285-4559

  ACRC/Arizona Clinical Research
  Center, Inc.
  520-290-9896; Fax: 520-290-2508

ARKANSAS

- **Searcy**
  Research Solutions: 877-457-8839
  Fax: 501-223-4717

CALIFORNIA

- **Beverly Hills**
  Lovelace Scientific Resources, Inc.
  310-432-1492

- **Irvine**
  Radiant Research: 1-877-STUDY-39

- **Loma Linda**
  Research Site: 877-CTLILLY
  (1-877-285-4559)
  Reference #6484

- **Long Beach**
  West Coast Clinical Trials
  Thompson/Centerwatch
  www.centerwatch.com
  562-997-8850

- **Los Angeles**
  UCLA Medical Center
  310-794-9107

  California Allergy and Asthma
  Medical Group, Inc.
  310-966-905
  Fax: 310-966-9042

- **Norwalk**
  Center for Clinical Trials, LLC
  562-868-7978; Fax: 562-868-6797

- **Palo Alto**
  Research Site: 877-285-4559

- **San Diego**
  Damluji Research Center
  760-599-4832

  Wetlin Research Association, Inc.
  619-583-1954 ext. 17

  Institute of HealthCare
  Assessment, Inc.
  619-582-5564; Fax: 619-582-5126

  Encompass Clinical Research
  619-660-9068; Fax: 619-593-2545

- **San Francisco**
  Research Site: 877-285-4559

- **San Luis Obispo**
  Coastal Medical Research
  Group, Inc.
  805-549-7570

- **Spring Valley**
  Encompass Clinical Research
  619-660-9068 or
  1-800-NEW-STUDY
  Fax: 619-593-2545

COLORADO

- **Aurora**
  Research Site: 877-285-4559

CONNECTICUT

- **Hartford**
  Physicians Research Center, Inc.
  860-251-6666

FLORIDA

- **Clearwater**
  Clinical Research of West Florida
  727-466-0078; Fax: 727-461-7793

- **Hollywood**
  Research Site: 877-285-4559

- **Miami**
  Lovelace Scientific Resources, Inc.
  305-670-3901; Fax: 305-670-3905

- **Panama City**
  Emerald Coast Research
  Associates
  850-785-6550; Fax: 850-785-6804

- **Sarasota**
  CNS Clinical Trials: 941-342-8288
  Fax: 941-378-8320

- **Tampa**
  University of South Florida Asthma,
  Allergy and Immunology Clinical
  Research Unit
  813-631-4024, ext. 204

- **West Palm Beach**
  Palm Beach Research Center
  561-689-0606

GEORGIA

- **Atlanta**
  Clinical Research Atlanta
  678-432-3013; Fax: 770-507-1539

- **Marietta**
  Radiant Research - Atlanta West
  770-424-4233

- **Stockbridge**
  Clinical Research Atlanta
  678-432-3013; Fax: 770-507-1539

ILLINOIS

- **Elk Grove Village**
  Alexian Brothers’ Center for Clinical
  Research: 847-640-6240

- **Maywood**
  Research Site: 877-285-4559

- **Peoria**
  Research Site: 877-285-4559

INDIANA

- **Indianapolis**
  Research Site: 877-285-4559

- **Muncie**
  Research Site: 877-285-4559

IOWA

- **Des Moines**
  Research Site: 877-285-4559

KENTUCKY

- **Lexington**
  University of Kentucky Chandler
  Medical Center: 859-323-6176

- **Louisville**
  Family Allergy and Asthma Research
  Institute: 502-368-0732
  Fax: 502-363-1165

LOUISIANA

- **New Orleans**
  Research Site: 877-285-4559

MARYLAND

- **Cumberland**
  Research Site: 877-285-4559

- **Hagerstown**
  Research Site: 877-285-4559

MICHIGAN

- **Ann Arbor**
  ClinSite®, Inc.: 734-930-3700
  Fax: 734-996-3330

MINNESOTA

- **Minneapolis**
  Research Site: 877-285-4559

  Clinical Research Institute
  612-333-2200

MISSOURI

- **St. Charles**
  Midwest Chest Consultants, PC
  636-946-1650; Fax: 636-757-1900

- **St. Louis**
  The Clinical Research Center, LLC
  314-514-8509 or 1-866-75-TRIAL

NEBRASKA

- **Omaha**
  Endocrine Studies Clinic
  314-514-8509 or 1-866-75-TRIAL

NEVADA

- **Las Vegas**
  Lovelace Scientific Resources, Inc.
  702-878-8428

NEW JERSEY

- **Berlin**
  Comprehensive Clinical Research
  856-753-7335, ext. 37

- **Voorhees**
  Research Site
  877-285-4559

NEW MEXICO

- **Albuquerque**
  Lovelace Scientific Resources, Inc.
  505-348-9500

NEW YORK

- **Albany**
  Research Site: 877-285-4559
  Pulmonary and Critical Care
  Services, P.C.
  518-438-4496; Fax: 518-438-5803

- **Bay Shore**
  Pulmonary Medical Research of
  New York, PLL
  631-665-7392; Fax: 631-665-8172

- **Endwell**
  Regional Clinical Research, Inc.
  607-754-6247; Fax: 607-748-0413

- **New Hyde Park**
  Biomedical Research Alliance of
  New York
  718-470-7369 or 718-470-7251
  Fax: 516-488-7162

- **New York**
  Research Site: 877-285-4559

- **Stony Brook**
  Research Site: 877-285-4559

NORTH CAROLINA

- **Chapel Hill**
  UNC Pulmonary Research
  919-966-4675; Fax: 919-843-8870

- **Raleigh**
  North Carolina Clinical Researc:
  919-881-0309; Fax: 919-783-9406

OKLAHOMA

- **Oklahoma City**
  Research Site: 877-285-4559

OREGON

- **Portland**
  Research Site: 877-285-4559

PENNSYLVANIA

- **West Reading**
  Research Site: 877-285-4559

SOUTH CAROLINA

- **Greer**
  Radiant Research: 864-848-1002

- **Spartanburg**
  Spartanburg Pharmaceutical
  Research: 864-583-155
  Fax: 864-583-2292

TENNESSEE

- **Nashville**
  Research Site: 877-285-4559
  Clinical Research Associates, Inc.
  615-329-2222; Fax: 615-320-7883

TEXAS

- **Dallas**
  Research Site: 877-285-4559

- **San Antonio**
  Research Site: 877-285-4559
  Lung Diagnostics: 210-692-715
  Fax: 210-692-1999

- **Temple**
  Research Site: 877-285-4559