NECA News

National Emphysema/COPD Association Fall/Winter 2003

NECA
ADVOCACY
NETWORKING
SUPPORT
WELLNESS
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National Emphysema/COPD Association

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 or patient care and the quality of their lives.

Come Celebrate the First COPD Education Day!

Barbara Rogers, President

Dear Members and Friends,

NECA's exciting summer started with a well-attended reception at the American Thoracic Society International Conference in Seattle, WA. Many thanks to sponsor Dey LP; attendees raved about the terrific buffet! The "full house" included physicians, other healthcare professionals, and patients from NECA's Board and Councils, as well as other leaders in COPD from around the country and the world. Thanks largely to Byron Thomashow, Medical Advisory Council Co-Chair, and Carl Wiezalis, International Affairs Liaison, NECA's Medical Advisory Council's (MAC's) international component now includes world-renowned COPD leaders from Belgium, Brazil, Canada, India, Italy, the Philippines, Poland, and Spain. The eight NECA Board members at the ATS meeting also participated in the Public Advisory Roundtable's Poster Session, the organizational meeting of the International COPD Coalition, and packed COPD sessions.

From Seattle, WA, Hannah Hedrick, Patient/Family Advisory Council Coordinator, and I went to Chicago for a meeting with Torre-Lazur–McCann Healthcare Worldwide (voted the #1 agency in 2000 by Med Ed News). Torre-Lazur is providing pro bono PR services to NECA, so watch for a NECA "makeover" and coverage of upcoming events described below. John Walsh (Alpha-1 Foundation President and NECA Special Advisor) and I met again with our primary Torre-Lazur contacts, Skip Thurnauer (President/General Manager) and Amy Maggio (senior Vice President/Managing Director), on July 10, followed by a meeting on August 18–19 with additional NECA Board members to initiate our campaign.

NECA's first COPD Education Day will be October 26 at the Orlando Hyatt. Nationally known professional and patient leaders from all over the country are providing a day of fun, education, and hands-on opportunities to see and try some equipment and participate in NECA's two premiere

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

NECA Establishes Thomas L. Petty, MD, Award

Thomas L. Petty, MD, has done more than any individual on the planet to promote improved quality of care and of life for people with COPD. The National Emphysema/COPD Association is dedicated to helping the National Lung Health Education Program and Tom realize his dream of creating a large, forceful, and well-organized patient advocacy group to deal with all sorts of issues facing COPD patients and their families. Through the COPD networks and other collaborative initiatives reported throughout this issue of *NECANews*, NECA and NLHEP promote patient empowerment. To draw national attention to these collaborative efforts, NECA is establishing an award in Tom's name, to be presented annually to an individual who has made significant progress in involving people with COPD in Advocacy, Networking, Support, Wellness, Education, Research and Service (ANSWERS) activities. Tom himself will be the first recipient of this award, which will be presented at the COPD Education Day in Orlando, FL, October 26. ■

NECA, NLHEP, Alpha-1 Foundation, National Emphysema Foundation, and Lovelace Respiratory Research Institute Form COPD Networks

The National Emphysema/COPD Association (NECA), National Lung Health Education Program (NLHEP), Alpha-1 Foundation, National Emphysema Foundation, and Lovelace Respiratory Research Institute are working together to form COPD networks throughout the U.S. and the world. Their combined effort will complement other national and local initiatives, many of which are reported via *NECANews* and *www.NECACommunity.org*.

The first joint activity, a meeting on August 18 in Chicago at the headquarters of the American Medical Association, promoted networking and collaborative activities. It brought together COPD patient and professional leaders and organizations to identify common COPD agendas. Presentations were provided by NECA officers, NLHEP Executive Board members, Alpha-1 Foundation officers, Smokeless States National Tobacco Policy Initiative Program staff, and Walgreens Spirometry Pilot Program coordinators. ■

If You Can't Breathe, Nothing Else Matters

Ambulatory Oxygen and Reimbursement: Most Important Issue

Thomas L. Petty, MD

Oxygen is the only proven treatment for advanced stages of COPD that has been shown by first-rate studies to increase both the length and quality of life and to reduce hospitalizations. Today a million Americans, most of whom have COPD, receive long-term oxygen therapy (LTOT) in the home.

The specter of "competitive bidding" looms large and has already passed the House of Representatives. I hope it can be thwarted in the Senate. If competitive bidding remains "modality neutral," this will be a disaster, because the new advances in ambulatory technology, which are naturally more expensive, will be threatened.

The reason is simple. Providing a stationery concentrator and an E-cylinder on wheels is cheaper. But this system inhibits movement and daily living activities. The Nocturnal Oxygen Therapy Trial (NOTT) showed an improvement in survival and a reduction in hospitalizations for groups with an ambulatory system. These groups could do more exercise than groups limited by a stationary system.

Ambulatory oxygen has become the standard of care, as indicated in "Recommendations of the Fifth Oxygen Consensus Conference" (*Respiratory Care*, 2000, 45:957-961). This is undoubtedly the most important issue facing any COPD group, and NECA should be the standard bearer for this issue. It is an important part of the efforts of NECA, NLHEP, and others to promote public awareness that COPD is a long-standing and progressive chronic disease. We need to work together not only on early identification and intervention, but on the entire continuum, from asymptomatic to late-stage disease.

(Dr. Petty's regular letter in Mary Burns' *Second Wind Newsletter* (now online) is accompanied by a picture of Tom, with a flashing "Test Your Lungs, Know Your Numbers." the URL *www.perf2ndwind.org/html/tompetty/2003/June-2003.html* includes all of Tom's monthly letters for recent years. Tom's July letter, "On the Receiving End," describes his "lessons learned" as an oxygen user. His June 2003 letter discusses portable oxygen concentrators providing supplemental oxygen, including a battery-powered concentrator that may be approved for use in airplanes because it does not use either liquid or pressurized oxygen.)

Please Go To www.aahomecare.org and Sign Letter

The House has passed a bill **with a competitive bidding provision** that will severely damage providers' ability to provide higher-cost, higher tech supplemental oxygen systems. The Senate has also passed a bill, with a seven-year freeze on homecare durable medical equipment (DME) reimbursement **but without competitive bidding.** If competitive bidding is to be avoided, we must all support Senator Grassley and the Senate version of the bill.

The American Association for Homecare web site (*www.aahomecare.org*) contains an open letter that all of us, especially COPD patients, are encouraged to sign and send to our Senators and Congressmen. The letter points out that competitive bidding will eliminate smaller providers and actually reduce competition in the homecare market. According to Bob Fary, National Director of Respiratory/HME Services for Apria Healthcare, "in the two counties where competitive bidding has been piloted, oxygen users do not have access to the most modern equipment, such as lightweight portable tanks and liquid systems. Customers receive less service, and some do not have the ability to contact their providers after hours." Reduced reimbursement in the pilot areas made it too expensive for oxygen users to access the most beneficial devices and

If You Can't Breathe, Nothing Else Matters (Cont'd)

services. Bob believes that oxygen users in particular can impact the proposed legislation and encourages all oxygen users and their providers, caregivers, and families to use the www.aahomecare.org web site to contact their legislators immediately and support the seven-year freeze provided in the Senate bill, while strongly opposing the competitive bidding requirement in the House bill. For additional information, contact Bob at *robert_fary@apria.com,* 949-639-2420.

COPD-ALERT on Portable Oxygen Supplies

COPD-ALERT founder and moderator, Vlady Rozenbaum, echoes the message NECA has received at dozens of meetings throughout the country: mobility and independence are at the top of patients' priority lists. "Portable oxygen supplies for travel are of major interest to COPD patients, whose mobility is dependent on light equipment that offers oxygen for substantial lengths of time." The American Thoracic Society reports that AirSep's LifeStyle Portable Oxygen Concentrator "is in the process of getting FAA and Transportation Security Administration (TSA) approval for air travel. Because the device is battery operated and does not have any concentrated gases, it does not qualify as a hazardous material (which is the problem for liquid oxygen and compressed oxygen. The TSA will be drafting a memo to airport security people discussing rules and proper procedure for people using supplemental oxygen." Vlady points out that "We do not have much information about consumer satisfaction with the AirSep Concentrator." (For specifications, see *trimed.freeservers.com/TM/page31.htm*). "With a price tag of $5000, a 50-minute charge, and a 2-hour charge time, we suspect that it may not resolve enough travel issues to appeal to large numbers of patients at this time."

The TSA solicited input from the U.S. Department of Transportation (DOT), Federal Aviation Administration (FAA), Air Transport Association (ATA), National Home Oxygen Patients Association (NHOPA), National Council on Disabilities (NCD), American Thoracic Society, and Apria Healthcare, as well as representatives from Puritan-Bennett, AirSep, and Airline Oxygen Systems. According to Bob Fary (see above), who attended these meetings, the manufacturers' representatives brought in products proposed for use on aircraft. Puritan-Bennett showed Helios; AirSep showed its LifeStyle portable concentrator; and Airline Oxygen Systems displayed an M-6 tank encased in a sealed lexan box, to prevent tampering. Discussion issues included the possibility of tampering with the devices, how to properly scan the devices and users, safety of the devices in flight, etc.

Breathing/Travel/Oxygen: Indispensable Resources

Better Breathers Traveler: How to Travel Easily If You Have Breathing Challenges

American Lung Association of San Diego and Imperial Counties
2750 Fourth Avenue
San Diego, CA 92103
Fax Credit Card orders to 619-297-8402.
Discounts for bulk purchases: Kathy Sullivan, 619-297-3901.

Reviewed by medical experts and people with lung disease, Better Breathers Traveler ($10 each, plus $2.00 shipping and handling; 60 pages) helps travelers on a 2-hour drive or a cruise around the world deal with shortness of breath and fatigue, oxygen use issues while in flight or at high altitudes, and continuous oxygen use. The guide includes a review of breathing techniques and practical information on:

- How to plan for specific conditions, such as climate, air pollution, altitude changes, and allergies
- Tips for sticking to your self-care routine
- Reducing stress and fatigue
- Oxygen and smoking policies and other pros and cons of various forms of travel (cars, buses, trains, planes, and ships)
- International travel issues

Practical Information from Mary Burns

"The Importance of Proper Breathing Techniques" (June 20, 2003)
www.perf2ndwind.org/html/breathing.html
"Altitude, Oxygen Levels, and Oximetry" (July 23, 2003)
www.perf2ndwind.org/html/news/2003/July/Page2.html
Mary Burns
Second Wind Newsletter
Pulmonary Education and Research Foundation
Box 1133 Lomita, CA 90717-5133
Tel/Fax: 310-539-8390

Don't miss the two indispensable articles listed above! Mary Burns always "blows me away" with her conversational style, specific information, detailed instructions, and practical advice. She paints clear "word pictures" of the effect of COPD on the structure and function of the lungs and on the mechanics of breathing. The first article focuses on

If You Can't Breathe, Nothing Else Matters (Cont'd)

the techniques and effects of "pursed lip breathing," which is covered in hundreds of publications and rehabilitation programs. Mary emphasizes points based on mistakes she sees patients make, such as blowing out too forcefully (which can lower the oxygen level of the blood) or of taking in "a little gulp of air through the mouth" after breathing in through the nose! The second article provides a "crash course" on oximeters, including the difference between using an oximeter and having an arterial blood gas test performed, things that affect the accuracy of finger oximetry (including smoking!), when to report oximetry readings to a physician, how to use PLB to increase oxygen saturation numbers, and information about different small oximeters and where to purchase them. The article also includes information on how to identify oxygen needs via a nomogram or a high-altitude simulation test (HAST).

I've spent 25 years affiliated with various peer support groups, including 5 years with lung disease groups, and Mary's materials and communications with people with COPD and other lung disease are among the best I have ever seen. She asks people to write or e-mail if they have questions, and she promises to answer all letters.

Cape Cod COPD Support Group Newsletter Reprints "Not Breathing Easier"

The June 2003 issue of Jo-Von Tucker's "Cape Cod COPD Support Group Newsletter" reprinted "Not Breathing Easier," an information-packed article by Judy Foreman, *Boston Globe*, May 20, 2003. Foreman quotes COPD stalwarts Gail Weinmann, MD (National Heart, Lung, and Blood Institute), Bartolome Celli, MD (St. Elizabeth's Medical Center, Boston), Sonia Buist, MD (Oregon Health and Sciences University), and others in presenting numbers, symptoms, etc. Useful information is given on various treatment options (some of which can be used together): inhaled bronchodilators (beta-agonists, anticholinergics, and theophylline-based bronchodilators), anti-inflammatory drugs and antioxidants, and portable oxygen and rehabilitation. Lung-volume reduction surgery and transplants are mentioned also.

Respiratory News and Views Reviews Schachter's Life and Breath

John Leaman included an informative review of *Life and Breath: Preventing, Treating, and Reversing Chronic Obstructive Pulmonary Disease* (Neil Schachter, MD, Broadway Books, Random House, New York, 2003; 336 pages, $24.95) in the April 2003 issue of *Respiratory News and Views* (172 East 4th St, #11-F, New York, NY 10009; 212 7777-0486). "Unusual strengths" John found in this "gold mine of a book" include the sections related to improving nutrition to improve breathing, the "healthy home," treatments currently in use and those "on the horizon," overcoming obstacles to smoking cessation, and the complete chest examination.

The January 2004 issue of *NECANews* will include an interview with Dr. Schachter, Co-chair (with Vijai Sharma) of NECA's Self-Care/Peer Support Program, with more information about the wellness/"empowerment" program he is developing at Sinai.

Mental Benefits from Pursed Lip Breathing

In addition to helping you cope with COPD symptoms, pursed lip breathing may help you remember names! According to Marie Riley, director of the Acupressure Center of Hawaii, slow breathing techniques help relax the body and revitalize the mind. "When you're feeling stressed, … place one hand over the upper rib cage beneath your collarbone, thus covering a pressure point. Now slowly inhale through the nose, then exhale through the mouth as if blowing into a soda straw." (*Island Scene*, Hawaii Medical Service Association, Winter 2002; *www.islandscene.com*)

"Breathing Backwards"

Dear Hannah, I would like to get some materials about COPD, but what I really need is information detailing the physical limitations that the condition causes. When I see my friend take a breath, it's short and shallow, and he seems to be pushing his diaphragm down as he exhales and up on the inhale. I don't know if he does this because of COPD, or because he is breathing backwards. Thank you. Dan Murphy, yogidanny@yahoo.com.

Dear Dan, Please see the articles here related to breathing, including Vijai Sharma's "story" and his web site, www.mindpub.com. Many people without lung disease also "breathe backward," lifting the shoulders and drawing the belly in, diaphragm up, when they inhale. Vijai's forthcoming video and other NECA resources are intended to provide self-care/peer support information so that people like you can help their friends with lung disease. See the resources cited above for additional information. *Hannah* ■

COPD Networks, Education Days, and Support Groups

National/International COPD Networks

As indicated on page 2, the National Lung Health Education Program, Alpha-1 Foundation, National Emphysema Foundation, and Lovelace Respiratory Research Institute are working with NECA to form national/international COPD networks. The five organizations will invite other groups to identify common agendas in this country and around the world. In this country, discussions have already been initiated with leadership of the American Association for Respiratory Care; American College of Chest Physicians; American Lung Association; American Physical Therapy Association; American Thoracic Society; National Heart, Lung, and Blood Institute; Pulmonary Education and Research Foundation; International COPD Coalition; and US COPD Coalition.

During the past few months, communications also have been exchanged with patient and professional associations and healthcare and educational institutions in other nations. Several contacts have offered to translate portions of *NECANews* for patient organizations and to write items for *NECANews* and *NECACommunity.org*.

First COPD Education Day

The first major event organized by the National COPD Network is the COPD Education Day, October 26, 2003, 11:00 AM to 4:00 PM, Renaissance Worldgate (near the Convention Center), in Orlando, FL. Registration is being handled by Brenda Buenaventura, 888-825-7421, ext 242, or *brendab@alphaone.org.*

The program is geared toward people with emphysema/COPD and their families, but professionals, educators, researchers, and corporations across the country are invited to attend.

Program Co-Chairs: Byron Thomashow, MD, Director of the Jo-Ann LeBuhn Center for Chest Disease and Respiratory Failure, New York City, who co-chairs NECA's Medical Advisory Council with Tom Petty, MD, Co-Chair, National Lung Health Education Program.

The Education Day will include 10 THEMED TABLE DISCUSSIONS staffed at 10:00–11:00 AM, 12:50–1:30 PM, and 4:00–5:00 PM:

- Research opportunities (Gerard Turino/John Walsh)
- Smoking cessation (Ron Peterson)
- Self-care techniques: breathing and stretching (Vijai Sharma), t'ai chi chih® (Hannah Hedrick)
- Physical therapy (Donna Frownfelter)
- Oxygen therapy and quality of life (Debbie Cullen)
- Airway-clearance modes/devices (Judy Whitman)
- Invasive options: lung volume reduction surgery, lung transplantation (Pat Jellen, Lori Tartell)
- Home care (Tim Buckley)
- Peer support resources (Vlady Rozenbaum)
- Spirometry testing (Vicky Shrader)

The central program will consist of five presentations in the morning on current topics of interest to patients and their families:

- COPD Now in the Public Eye (public figure)
- COPD Symptoms and Therapies (Steve Rennard, MD)
- Exacerbations and COPD: Getting Over the Hump (Fernando Martinez, MD)
- COPD and the NHLBI (Jim Kiley, MD)
- Living with COPD (patient)

The afternoon session includes four interactive roundtable discussions, with patient Co-Chairs (discussion will be presented twice):

- Travel with COPD (Barbara Rogers, Angela King, and Judy Whitman)
- COPD Around the Country and Around the World (Carl Wiezalis, MS, RRT, Robert Wise, MD, Roger Goldstein, MD [Canada], Sreedhar Nair, MD, and Dr. Jan Zielinski [Poland])
- Rehabilitation, Noninvasive Ventilation, and Oxygen (Andy Ries, MD, Gerry Criner, MD, and Frank Sciurba, MD, and Ashok Patel, MD)
- Continuum of COPD Care: Home, Intensive Care Unit, Transplant Unit, End of Life (Norma Braun, MD, David Shelledy, PhD, RRT, and John Reilly, MD)

The program will conclude with two presentations and a panel:

- Adventures of an Oxy-Phile (Tom Petty, MD, and Ron Peterson)
- Moving Toward Hope in COPD Care (Bart Celli, MD)
- Reality Check: Patient Resources and Perspectives (John Walsh, Vlady Rozenbaum, PhD, Vijai Sharma, PhD)

Regional COPD Networks

August 18 Chicago Meeting of COPD Leaders, Organizations, Patients

On August 18, the Smokeless States National Tobacco Policy Initiative, coordinated by Thomas Houston, MD, hosted the first COPD Network meeting. More than 30 patient and professional leaders in COPD addressed collaborative "patient empowerment" activities. Tom, an international expert in tobacco prevention/cessation programs, co-chairs (with Ron Peterson) NECA's Tobacco Awareness Campaign. Presentations included:

- Ashok Patel, MD: "Approaches to COPD and Asthma Program Development/Implementation in Minnesota" (in the context of the National Lung Health Education Program and ALA-MN and Minnesota Department of Health Perspectives)
- Hannah Hedrick, PhD, Coordinator, Patient/Family Advisory Council: "NECA's Premier Patient Programs"
- Barbara Rogers: "COPD Networks and Education Days"
- John Walsh, President and Founder, Alpha-1 Foundation: "COPD Patient Group Needs Assessment Survey"
- Thomas P. Houston, MD, Director, Science and Community Health Advocacy, AMA: "Smokeless States National Tobacco Policy Initiative"
- Tim Buckley, RRT, FAARC, Director, Respiratory Services, Walgreens Health Initiative: "Spirometry Testing Pilot Program"
- Janet Boehm, President-elect, American Association for Respiratory Care, "Your Lung Health Website"

Information also was provided about the AMA's Health Literacy program (Joanne Schwartzberg, MD) and the AMA's a fall media event on COPD (Brian Pace). Representatives of the Indiana Area Health Education Center, Indiana University, and Indiana State University attended to get ideas about organizing COPD networks in Indiana. Dates were set for meetings in Indianapolis and Terre Haute to identify participants in the networks.

Alaska Family Members Initiate Statewide COPD Network

Lorna Higgs
112 S Alaska St, Apt. 112, Palmer, AK 99645
907 746-2788; *lorna1@gci.net*

Carol Abbe
1580 Firth St, Wasilla, AK 99687
907 376-8540; *abbe@mtaonline.net*

Lorna and Carol are initiating a COPD network–Alaska and "Midnight Sun COPD Support Group." Based on information in *NECANews* and *www.NECACommunity.org*, co-leaders Lorna and Carol are both COPD family members. Carol's husband, Tom, was diagnosed in 2002, and Lorna's cousin, Omar Smith, died in early 2003 from smoking-related emphysema. As long-time Alaska residents who have lived and worked throughout the states, Lorna and Carol are using their contacts with a variety of physicians, respiratory care practitioners, and other health professionals to help identify people affected by COPD. They are structuring the COPD Network–Alaska after the NECA structure, with a central board and professional and patient advisory councils.

Phoenix COPD Patient Seminar

William Grimm, RRT, NECA Board
bgrimm@thevest.com

Nancy Cangemi, RRT, BS, Vice President of Programs,
ALA of Arizona/New Mexico
ncangemi@lungaz.org

Rhonda K. Follman, Director of Lung Health Programs,
ALA of Arizona
rfollman@lungaz.org

Bill, Nancy, and Rhonda are coordinating a free 1-day patient/community seminar that will focus on three to four topics. For each topic, a physician will give a mini-presentation followed by a person with COPD discussing issues pertinent to that topic. Possible topics include flying with oxygen, exercise, and medication use. Support will be sought from product manufacturers, who will have a unique opportunity of having face-to-face contact with patients, and from pharmacies and other businesses that interact with patients. A seminar planning committee is being formed, to consist of a patient and five or six individuals from organizations such as home healthcare companies, pulmonary rehabilitation facilities, Arizona Cardiac/Pulmonary Rehabilitation Group, Geriatric Services of America, and the Foundation for Senior Living. The first meeting of the planning committee was held in mid July.

Big Island: Smoke-Free Partnership Leads to COPD Network–Hawaii, "Aloha COPD Support Group"

Hannah Hedrick is working with more than two-dozen organizations participating in partnership and coalitions to promote a smoke-free Hawaii. NECA and NLHEP issues identified by Hannah have been included in the group's mission and strategic plan. She has also brought the COPD "patient empowerment" issue to the forefront of efforts to pass a comprehensive smoke-free workplace ordinance. As part of its public education campaign, the group is considering collaborating with NECA and NLHEP to sponsor a fall Lung Health Event, including a major segment on COPD. Kaiwi Perkins (Fern Forest) and Betty Jo Power (Hilo) are empowered women with emphysema helping to organize "Aloha COPD Support Groups" in their areas. They are working with community leaders, healthcare professionals, volunteer firefighters, churches, youth groups, and senior citizens to develop a variety of tobacco and COPD-related programs. ■

Alpha-1 Foundation and AlphaNet

Alpha-1 Foundation Model Recognized by National Health Council

2937 SW 27th Avenue, Suite 302, Miami, FL 33133
Toll-Free: 1 877 228-7321; Fax: 305 567-1317
www.alphaone.org

The Alpha-1 Foundation, founded in 1995 as a not-for-profit organization by individuals diagnosed with Alpha-1 Antitrypsin Deficiency (Alpha-1), provides leadership and resources to increase research, improve the health of people with Alpha-1, encourage worldwide detection, and promote a cure for Alpha-1. A common genetic disorder that can result in life-threatening lung and liver disease, Alpha-1 affects not only the estimated 200,000 individuals with Alpha-1 worldwide, but also the 25 million Americans who can pass the defective gene on to their children and who may be at risk for lung or liver disease. The Foundation has provided more than $12 million in funding for research since 1995.

The Foundation is being increasingly recognized as a template for developing a successful organization. The powerful National Health Council has invited the Foundation to present its model as a "case study" at the NHC leadership conference. The Institute of Medicine has requested a presentation of the organizational model at an FDA Office of Orphan Drug Development workshop.

The Foundation works with medical experts, the Alpha-1 community, government, industry, and other organizations to jointly resolve critical issues in the field of Alpha-1 research and treatment via an infrastructure that promotes research and the development of new therapies via the following programs and activities:

- The **Grants Award Program** funds a broad range of research related to the AAT protein and AAT deficiency, including projects to: 1) promote basic science and clinical research; 2) attract and train clinical researchers; 3) support and encourage established scientists to work on medical problems and ethical, legal, and social issues; and 4) develop effective therapies for clinical manifestations.
- The **Alpha-1 Detection Program** promotes worldwide awareness and the identification of AAT-deficient individuals in populations at risk for Alpha-1, such as individuals with COPD, adults and adolescents with asthma and/or chronic liver disease, and individuals with a family history of Alpha-1. Diagnostic testing is offered free of charge through the University of Florida College of Medicine Alpha-1 Genetics Laboratory (see contact information above).
- The **Alpha-1 Research Network** represents expertise in North America and Europe of Alpha-1 research and clinical care and includes more than 50 clinical resource centers throughout North America with a focus on Alpha-1 patient care, including pulmonary and liver centers.
- The **Alpha-1 Research Registry** is a confidential database of individuals diagnosed with Alpha-1 (the largest in the world) that provides a population base eligible for clinical trials and research studies.
- The **Alpha-1 DNA and Tissue Bank**, housed at the University of Florida, provides the world's largest researcher-accessible repository of disorder-specific tissue from individuals with Alpha-1.
- The **Alpha-1 Research Program** was established at the University of Florida College of Medicine and is an academic research program (the first exclusively devoted to the study of Alpha-1) that includes: an endowed Alpha-1 Chair, a Clinical Research Unit, a Translational Research Laboratory, and an Alpha-1 Genetics Laboratory.
- **Scientific Meetings, Conferences, Workshops, Working Groups, and Symposia** address critical issues in the areas of improved treatments, education, detection, and ethics.
- **A Reference and Reprint Service** offers over 10,000 titles related to Alpha-1, organized by topic, author, or title.
- **Publications** include a bi-annual newsletter for patients,

fact sheets on Alpha-1 and research activities, and educational materials for patients, their families, and healthcare providers (also available at www.alphaone.org).

AlphaNet: Peer Support/Mutual Aid in Action

Mary Walsh
800-577-2638
www.alphanet.org

AlphaNet, a not-for-profit health management company, was founded in 1995 by John Walsh, Susan Stanley, and Sandy Lindsey, three individuals diagnosed with Alpha-1 Antitrypsin Deficiency (Alpha-1), to provide comprehensive services exclusively to the Alpha-1 community. Most of AlphaNet's Board Members and all 22 Patient Services Coordinators have a diagnosis of Alpha-1. Coordinators may have had lung transplants, and some are on waiting lists for transplant. Coordinators may lead Alpha-1 support groups, through which they offer support, encouragement, and inspiration. When they tell their members, "I understand," they really do.

AlphaNet is committed to:

- Developing greater independence and control of healthcare for Alphas
- Promoting optimal health of Alphas
- Funding compassionate care
- Employing Alphas to serve Alphas
- Supporting and participating in scientific research
- Supporting awareness and detection

AlphaNet's unique business model may be of interest to other patient groups who want to help members manage their lives and futures and gain some control over their medical care. AlphaNet provides enrollment assistance to Alphas receiving Prolastin through the Bayer Direct program, and helps coordinate patient care. AlphaNet Coordinators are the point of contact for Alphas to get information on insurance and nursing care, ordering necessary supplies for infusions, and finding the answers to questions members may have. It also provides free test kits and information about testing through the Alpha-1 Antitrypsin Deficiency Program at the University of Florida.

New members of AlphaNet are assigned one of the 22 Coordinators, who call immediately following diagnosis and send information packets to the patient (and offered to physicians who may be inexperienced in treating Alphas). A training video, developed by Nursing Coordinator Kathy McKay is made available to all Alpha-1 infusion nurses who may earn CEUs from using it.

AlphaNet also conducts research, under its Medical Director, Dr. Robert Sandhaus, on ongoing health issues of Alphas. Completed and ongoing studies include the Exacerbation Study (completed 2002) and the Outcome Study (ongoing) related to AlphaNet's Disease Management Program, to be rolled out in 2004.■

National Lung Health Education Program

Thomas L. Petty, MD
NLHEP@aol.com, www.nlhep.org

A planning conference in 1994 and a comprehensive workshop in 1995, sponsored by the Lung Division of the National Heart, Lung, and Blood Institute, preceded the launch of a new initiative, described in "Building a National Strategy for the Prevention and Management and Research in COPD" (Petty TL, Weinman GG: *JAMA* 1997; 277:246-253). With Tom Petty as the founding chairman, NLHEP was incorporated in 1997 as a not-for-profit entity. In 2000, Dennis Doherty, MD, chief of pulmonary and critical care medicine at the University of Kentucky, became Co-Chair. The executive committee, which now includes representatives from all collaborating and supporting professional, patient, and government groups, generally meets at the times of the annual ATS and ACCP meetings. Financial support is provided by pharmaceutical and medical equipment companies.

NLHEP Enthusiastically Supports NECA Goals and Objectives

NECA is honored to have Thomas L. Petty, MD, as co-chair of its Medical Advisory Council. Tom was among the first COPD leaders to recognize the need for and potential of a national membership organization devoted to COPD. He and colleague Louise Nett helped NECA founders focus on the areas that eventually led to the ANSWERS categories: Advocacy, Networking, Support, Wellness, Education, Research, and Service.

Collaborative Model

NLHEP collaborations with the American College of Chest Physicians (ACCP), American Thoracic Society (ATS), American College of Physicians (ACP), American Association of Cardiovascular and Pulmonary Rehabilitation (AACPR), and American Association for Respiratory Care (AARC) followed shortly after incorporation. The list now includes the American College of Allergy, Asthma, and Immunology, American Society of Internal Medicine, and Society of General Internal Medicine. Other organizations, including the National Emphysema Foundation; National Cancer Institute; National Emphysema/COPD Association; National Heart, Lung, and Blood Institute; and National Institute of Occupational Safety and Health have since been included in the NHLEP collaboration.

NLHEP interfaces with numerous segments of the primary care and specialty care communities, other health professions involved in COPD, various government agencies, and educational and healthcare institutions, including HMOs. NLHEP is supportive of and complementary to the Global Initiative for Chronic Obstructive Lung Disease (GOLD), US COPD Coalition, and International COPD Coalition (currently being formed). NLHEP enthusiastically supports the goals and objectives of NECA and plans to be an active partner with NECA activities, now and in the future.

Promotes Spirometry Testing, Simple Device

NLHEP's mission is to create awareness about COPD as a major health problem. We emphasize the fact that 50% (12 to 15 million) of the people with COPD are not diagnosed or treated, even though they may be symptomatic. Using the motto "Test Your Lungs, Know Your Numbers," NLHEP promotes the widespread use of spirometry for diagnosis and monitoring of disease, including responses to therapy. NLHEP advises spirometry in all current and former smokers 45 years of age or older and in anyone of any age with chronic cough or wheeze, dyspnea on exertion, or mucus hypersecretion. For more detail, see "Office Spirometry for Lung Health Assessment in Adults: A Consensus Statement from the National Lung Health Education Program" (Ferguson GT, et al., *Chest* 2000; 117:1146-1161). To promote implementation of the recommendations in the consensus statement, NLHEP has stimulated the design and development of simple, accurate hand-held spirometers suitable for use in the office and clinic (Schoh RJ et al., Performance of a new screening spirometer at a community health fair, *Resp Care* 2002; 47:1150-1157).

Partnering with AARC in CME Seminars for Primary Care Practitioners

In 2000, NLHEP and AARC developed a strategic partnership designed to implement NLHEP goals and objectives at the grassroots level. During the past three years, the AARC has been instrumental in helping to promote regional half-day CME seminars for primary care practitioners. These seminars can now draw on additional physicians, from more than 25 different schools of medicine and of osteopathic medicine, who attended the June 26 seminar in Dallas, TX. These "Physician Champions for COPD and Respiratory Health" now have the educational materials and instruments necessary to regularly provide half-day "Saturday A.M. Seminars" throughout the USA, sponsored by any of the many COPD stakeholders.

November 30 Deadline for Personal Vignettes for New Petty Book

Since 1965, Tom Petty has written hundreds of books, articles, and items on the science and benefits of long-term oxygen therapy (LTOT). Tom, now an oxygen patient himself, is getting another perspective on oxygen from "the other end of the stethoscope." Thus the book he is now writing, *Adventures of an Oxy-Phile*, will be a mixture of science and experiences as a user. He wants other oxygen users to participate by sending him one- to two-page personal vignettes on a wide variety of experiences, from funny or frustrating to successes and failures. He is especially interested in vignettes related to work, travel, and adventure. How has oxygen facilitated mobility? When have problems with access to oxygen prevented or hindered mobility? Please send your experience by November 30 via e-mail, fax, or regular mail: NLHEP@aol.com; 303 996-0870; 899 Logan St, Ste 203, Denver, CO 80203.

NLHEP Liaison with NECA, AARC, and Other Lung Disease Organizations

Gretchen Lawrence, BA, RRT, FAARC, serves as the liaison from the National Lung Health Education Program to the National Emphysema/COPD Association, American Association for Respiratory Care, and other organizations working with people with lung disease. Prior to assuming this responsibility in 2002, Gretchen spent 18 years as manager of the Baylor Asthma & Pulmonary Rehabilitation Center and the pulmonary labs at Baylor Medical Center in Dallas, TX. Current NLHEP projects for Gretchen include developing a network of respiratory therapist "experts" within NLHEP so that these experts can assist primary care practitioners as they learn more about COPD, especially early identification, smoking cessation, and treatment options. And these same "experts" can be called upon by their state societies to present on COPD and NLHEP and its programs.

Gretchen is also coordinating the Spirometry Validation Process (SVP) as part of NLHEP's mission to increase awareness of COPD. The SVP is intended to assist spirometer manufacturers in knowing what parameters to include in the simple spirometers they make. It will let primary care practitioners know that devices marketed as "NLHEP Compliant" will be appropriate for use in their office. The spirometer used in the PCP office should be less complicated than those used in a pulmonary lab, while providing just the data needed to diagnose COPD. A group of pulmonary function technology experts is helping NLHEP develop this document. NLHEP is seeking input from the device manufacturers prior to publication of the process and checklist documents. Coming in 2004 is a "How To" list to help healthcare providers use NLHEP criteria to develop programs in their communities. Check out the NLHEP Web Site (*www.nlhep.org/*) to find out more about NLHEP and the various activities and educational materials available. ■

Research!America

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Research!America was founded in 1989 as a national, not-for-profit, membership-supported public education and advocacy alliance to make medical and health research a much higher national priority. The Research!America agenda includes advocacy for research to prevent disease, disability, and injury and to promote health via its Prevention Research Initiative, which raises awareness of the importance of public health research. With the support of its 460+ member institutions representing 40 million voices, Research!America played a major role in the successful efforts to double the National Institutes of Health budget over a five-year period. The alliance is now leading the effort to ensure that future medical and health research funding will have much greater support than the potentially devastating amounts currently proposed by Congress and the Bush administration.

The organization is also working for growth in research investment of other agencies, such as the Centers for Disease Control and Prevention, National Science Foundation, Agency for Healthcare Research and Quality, and Veteran's Administration. The alliance also coordinates outreach programs to bring business and industry together with academia, government, and the media. Working together, these sectors can collectively advocate for a legislative and regulatory climate that stimulates growth in research and development.

Grassroots Connections

Research!America conducts public opinion polling and provides a unified link between the voices of citizens who strongly support research and the influence of local, state, and national opinion leaders and decision makers. Its Board of Directors, chaired by former U.S. Representative Paul Rogers (former chair of the House Subcommittee on Health and Environment), includes distinguished leaders in business, medical and health research, and academia. Members include academic institutions, hospitals and research institutes, professional societies, business and industry, voluntary health organizations, foundations, and individuals.

NECA members may be familiar with Research!America via Mary Woolley, President and CEO, who is a frequent presenter at patient-centered meetings. Patient groups attending the February 2002 meeting of the NHLBI Public Interest Organization meeting benefited greatly from her featured presentation detailing how to develop a successful advocacy agenda. Mary's guest editorials and letters to the editor help other grassroots organizations promote their causes, as do Research!America advocacy resource materials prepared for member organizations and public service announcement campaigns. Mary also serves on the Board of NECA's COPD Network Partner, the Lovelace Respiratory Research Institute. ■

COLD Comparative Table and Overview

Robert Fallat, MD

The comparative table below provides a simplified depiction of the various manifestations of chronic obstructive lung disease (COLD), also known as COPD. Because definitions and methods for ascertaining the presence of COLD vary, prevalence numbers are hard to pin down. Most physicians and researchers agree that the lower numbers underestimate the prevalence.

	Asthma		Chronic Bronchitis	Emphysema		
	"Pure"	Part of COLD		Panacinar	Centrolobular	Bullous
Defining Characteristic	Fully reversible	Responds to bronchodilator	Chronic cough with sputum	Diffuse loss of small air sacs (pea size)	Loss of air sacs behind obstructed airway (apple size)	Huge empty air-space (melon size)
Prevalence in U.S.	4 to 8% 2 of 30 children under 18	30 to 90% of COLD patients	5 to 10% 10 to 30 M	10% of COLD 1 to 3 M	Some in most with chronic bronchitis	Unusual Less than 1 M
How to Measure	**Spirometry**			**Chest X-ray or CT Scan**		
	FEV1 returns to normal > 80%	Increases with bronchodilator > 200 ml & 12%	Sputum > 3 tbsp/day > 3 mos/year	Lower lobes darker	Scattered dark areas, mostly upper lobes & thickened airways	Huge dark area, often compressing lung
Monitor						
O_2 Pressure	Low to normal > 80 mmHg		Low, < 60%	Low only with exercise or severe disease (pink puffer)	Low	When all are low, may be helped with LVRS
O_2 Saturation	Low to normal > 95%		Low, < 89% ("blue bloater")		Low	
CO_2 Pressure	Low to normal 36 to 40		High, > 50 mmHg	Low	Normal to high	
DLCO	Normal		Low to normal	Very low	Low (LVRS?)	

LVRS = lung volume reduction surgery; DLCO = diffusing capacity; M = Million

The numbers for asthma are the most confusing. About one-third of children with asthma will "outgrow" it and never develop COLD. Another one-third will have asthma all their lives, but only when exposed to whatever they are susceptible to. They may not have permanent damage to the lung, so the amount of air they can blow out in the first second (forced expiratory volume, or FEV1) returns to normal with treatment or time. The other one-third of children with asthma are susceptible to develop a chronic asthma with the defining characteristic of COLD: the FEV1does not return to normal with treatment or time.

When COLD develops in adults, most commonly from cigarettes, there is usually a component of "asthma," even in people who did not have asthma as children. This asthma component of COLD is defined by the American Thoracic Society as "reactive airways." This means that in response to an inhalation of a bronchodilator, the amount of air you can blow out in the first second (FEV1) will increase by 12% and 0.2 liters (which is close to one-fifth of a quart).

Chronic Bronchitis

Some smokers of cigarettes and workers in dusty or irritating environments will have irritation and damage to the airways. This irritation and damage leads to a cough and production of sputum, the typical "smoker's cough." When this cough persists for more than 3 months of the year and is associated with a declining FEV1, the condition is called "chronic bronchitis."

Panacinar Emphysema and Alpha-1 Antitrypsin Deficiency

Smokers who do not develop a persistent cough can still experience lung damage due to a breakdown of the small, fine air spaces known as alveoli. Normal elasticity of the lung is reduced as these sacs break down into larger airspaces; this loss of lung tissue is called "emphysema." One form of emphysema is called "panacinar," which means the breakdown of the airspaces spreads through the entire lung. This diffuse breakdown can occur slowly over the years with no cough or bronchitis, and people can continue to do normal daily activity even with diminished lung capacity. Eventually, however, the lung impairment affects their ability to do things that require exertion, such as walking up a hill, running, or being at a high altitude. This type of "pure emphysema" is unusual, but is the common way that lung disease develops in people with a deficiency of alpha-1 antitrypsin, a genetic disorder that occurs in 1 of 2,000 to 5,000 Caucasians.

The other, more common, type of emphysema occurs because of the damage done to the lung behind a bronchitic airway that is obstructed and irritated. This obstruction and irritation cause inflammation behind the bronchitic airway, with a larger localized breakdown of the lung. This type, called "centrolobular emphysema," is associated with the larger central airways. When these large empty spaces grow to a very large size, they are called "bullae," and the type of emphysema is identified as "bullous emphysema." These large bullae sometimes compress the normal lung. A person with this kind of emphysema can be helped a lot with a "bullectomy" to remove bullae. The smaller bullae can also be removed via lung volume reduction surgery (LVRS), which may help in some cases. A recently completed study suggests that LVRS is useful if the bullae are in the upper lobes and there is marked decrease in exercise capacity.

"Gas Exchange" To Evaluate Severity of COLD

Evaluating the FEV1, a simple test that can be done in any doctor's office, is very useful in determining the severity of COLD. However, it does not detect the emphysema that can be clearly seen on chest X-rays or even better on CT scans. But these static pictures don't tell you about how much lung function is impaired. For that you need to look at "gas exchange." The diffusing lung capacity of the lung (DLCO, a test done in a pulmonary laboratory) is well correlated with the degree of emphysema and measures how big a surface area there is for gas exchange. All forms of COLD cause some reduction in the ability of the lungs to get oxygen into the blood. This reduced ability can be measured with an arterial blood sample to measure the paO_2 and $paCO_2$, the pressure produced by O_2 or CO_2 in the blood.

Oximetry, a simple, non-invasive method for determining oxygen saturation, uses an infrared beam to "look" at the finger and measure oxygen saturation continuously, even during sleep or exercise. By monitoring DLCO and O_2 saturation (rest or with exercise or during sleep), the degree of lung function and impairment can be more accurately assessed, particularly when the disease has progressed to the point that gas exchange is affected. ■

"Quiet Killer" Facts

- Nearly 119,000 adults died in the U.S. of COPD in 2000, making COPD the fourth leading cause of death.
- More than 10,000,000 adults in the U.S. have been diagnosed with COPD by a physician with COPD; an additional 15,000,000 have symptoms of impaired lung function, indicating that COPD is under-diagnosed.
- Risk factors for COPD include long-term smoking, a family history of COPD, exposure to air pollution or secondhand smoke, and a history of frequent childhood respiratory infections.
- COPD is progressive and is not fully reversible, even with smoking cessation, rehabilitation, and medication.
- As COPD progresses, the airways and alveoli in the lungs lose elasticity and the airway walls collapse, closing off smaller airways and narrowing larger ones, causing chronic coughing, shortness of breath, increased effort to breathe, and increased mucus production.
- More than half of all adults who suffer from COPD report that their condition limits their ability to work, sleep, and participate in social and physical activities; they feel they are not in control of their breathing, panic when they cannot catch their breath, and expect their condition to worsen.
- COPD accounted for 8,000,000 office visits to doctors, 1,500,000 emergency department visits, and 726,000 hospitalizations by adults in the U.S. in 2000.
- COPD cost the economy of the U.S. an estimated $32,100,000,000 in 2002.

(Adapted from "Supporting the Goals and Ideals of COPD Awareness Month," House of Representatives, July 16, 2003; Congressional Record article 28 of 96)

Living with an "Invisible" Disability

Mary Lincoln

Until people with COPD go on supplemental oxygen, their illness is fairly "invisible." This can lead to false judgments, even attacks, from others who underestimate the severity of the person's limitations. Once, after I'd just picked up my inhalers in a pharmacy, a woman accosted me and told me I didn't look sick enough to need disabled parking. When I responded that I had COPD, she continued her tirade, saying that her sister-in-law who had died of COPD "looked a lot worse than you do." The irony of the situation was that with only 16% of normal lung function, I actually needed the disabled parking space then more than I do now, when no one questions my use of parking or other accommodations for people with disabilities!

On another occasion, I was seeking help with a public agency by phone. When I explained to the clerk that one of the reasons I needed the help was because of my lung disability, she replied, "You don't sound disabled."

More distressing to me than the unkindness of strangers is the attitude of the managers and some of the people in the apartment complex where I live, who think I'm a malingerer. I may not "look disabled" when I walk to the dumpster or to my car, but they don't see me when I'm too breathless to walk to the door, much less to the dumpster. They think I should get a desk job or other stationery job, not realizing that any work environment could expose me to a respiratory virus that could very well be my last.

They see my dirty windows, my carpets that need shampooing, my unwashed floors, my baskets of laundry, and they think I'm some sort of slob. They can't believe I am physically unable to clean or take loads of clothes to a laundromat. My neighbors are more accepting of residents with more visible disabilities, but my need for in-home supportive services is just as severe as someone with cerebral palsy. As the American Lung Association says, "If you can't breathe, nothing else matters."

When my body needs more oxygen than my lungs can supply, my mind is affected as much as my body. For example, once when I feared my cat had gotten outside, I finally found him in a basket in the bedroom. When I went into another room, I immediately began looking for him all over again! It wasn't until he came trotting out that I remembered having found him moments earlier.

What bothers me most about the "vigilantes" is that they think they can tell more by looking at me than the doctors learned from thousands of dollars worth of diagnostic tests. Do they really think I am clever enough to scam the doctors and public agencies that have given me disability benefits and disabled parking placards? If so, how can they possibly think someone so clever would be content to live on disability income well below the poverty level?

Friends advise me not to care what these misguided people think. But it still bothers me to be around angry people who feel I caused my own disease and think I am getting undeserved benefits paid for with "their" tax money. The vigilantes who prejudge people with impaired lung function may not be aware that genetics plays a role in the 27% smokers who eventually get COPD. While smoke is a contributing factor, people with COPD deserve just as much care and support for their illnesses than those with certain genetically pre-disposed cancers or heart ailments who over-eat or under-exercise.

The vigilantes who believe smokers should "Just Say No!" are not aware of the complexity of tobacco addiction. I started smoking when I was 13 years old, long before the dangers of smoking were well known. Once I was addicted to tobacco, quitting was complicated by my use of nicotine to self-medicate my chronic depression. Stopping was also difficult because I could not "feel" or "see" the damage being caused by the drug and other substances.

In defense of the vigilantes, I admit that COPD in its early stages is invisible even to the person developing the disease. By the time the symptoms can no longer be ignored, lung function is already significantly reduced. Resources such as COPD-ALERT and Dr. Tom Petty's "National Lung Health Education Program" draw attention to the seriousness of COPD and the importance of early detection and treatment. People with COPD need all the help they can get in informing the vigilantes and others that COPD is a serious disease that disables people and robs them of their quality of life long before it eventually kills them. ■

From Smoker to Anti-Tobacco Advocate

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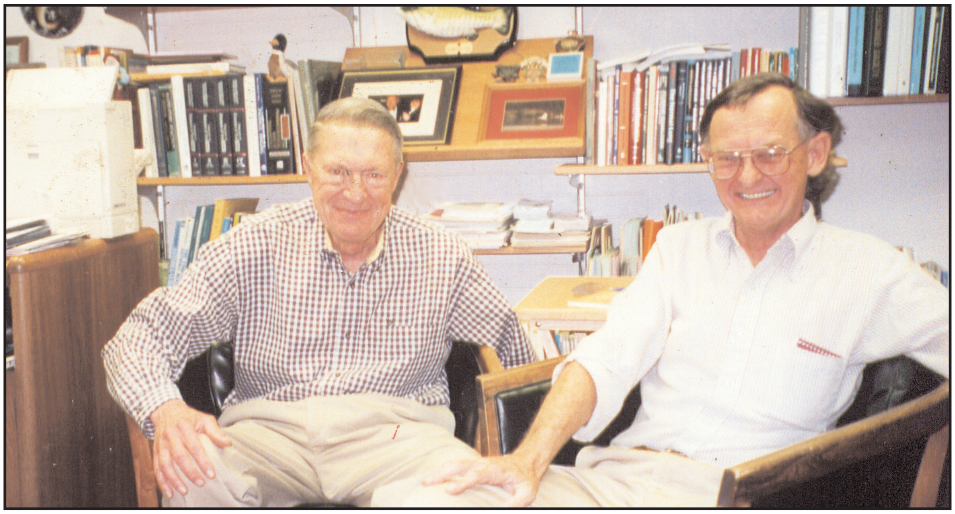
(Adapted from personal communications and "Walden Pond on High," by Thomas L. Petty, MD, and Ron Peterson; available at COPD-ALERT, www.geocities.com/wrozenba/COPD.html.)



Thomas L. Petty, MD, and Ron Peterson

Ron Peterson, Co-Chair of NECA's Tobacco Awareness Campaign, is using his own experiences to help teens avoid the almost fatal mistake he made to start smoking when he was only 13. Two years later, when a Surgeon's General report clearly identified cigarette smoking as a cause of lung disease, Ron was already strongly addicted. Every day thereafter for 38 years, he tried to quit, using every known method and some he developed himself ("My Battle Against Smoking," P.M. Ronson and R.M. Peterson, *Psychology for Living*, July-August, 1995).

Still unable to stop when he was diagnosed with emphysema at age 44, Ron had to leave the small cabin he and engineer friends had built at 9,000 feet in the Rocky Mountains. Rapidly debilitating emphysema made him unable to work and by age 50, he was dependent on Social Security disability. A year later, when a single puff from a cigarette caused such severe coughing spasms that he blacked out, he was finally able to replace the negative habit of smoking with the positive habit of exercising. Because his other organs were relatively healthy, Ron received a lung transplant at the end of 2000, rare good fortune considering that approximately 1,999 people also needing a transplant did not receive one.

In 1997, Ron created the non-profit Prevention Video Corporation (PVC), involving primarily lung disease patients and families of those who have contracted their disease from smoking cigarettes. PVC has created four videos designed to prevent youth smoking initiation. The third video, "Teen Smokers Speak Out," described by Vijai Sharma elsewhere in this issue, is being used by state tobacco prevention programs and prevention groups in several countries. Ron is also working with smoke-free advocates worldwide to counteract campaigns by tobacco companies. ■

PLEASE VOLUNTEER FOR "BUDDY SYSTEM"
Please provide Ron with the names of adults with lung disease willing to "connect teens who have a burning desire to help their peers never to start smoking or assist those who have started to quit." Ron's approach consists of a "buddy system" pairing a youth with an adult, with the youth member "calling the shots." For information, see the fourth video, which attempts to motivate youth to help their peers not to start smoking or to quit smoking.

Networking Creates "Activist Advocate"

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Networking can provide the support to create "activist advocates," as exemplified by the story of how Betty Jo "BJ" Power came to testify at the July 23 hearing on smoke-free workplace legislation for the Big Island of Hawaii. The first meeting of the Tobacco-Free Hawaii Partnership–East Hawaii, coordinated by Tracie Yoshimoto, was attended by representatives from heart, lung, and cancer groups; educational and healthcare institutions; physicians, nurses, and public health experts; and the Hilo police. At my suggestion, we reached out to respiratory therapists, and Dan Gonzalez, RRT, North Hawaii Community Hospital, and Keith Kanetani, RRT, Apria Healthcare, now attend partnership meetings and trainings. Dan was the first RRT to testify at a smoke-free workplace hearing, and Keith was the first to get a patient, BJ, to testify. Tiffany Edwards' interview with BJ in *West Hawaii Today*

("Woman Speaks Out About Emphysema Experience") begins with the sentence "Her oxygen provider suggested she testify on the smoking ban," the first time she had spoken publicly about her disease.

BJ's story sounds familiar to NECA members. Raised in a tobacco state, Georgia, she rolled cigarettes for her father at age 10 and started smoking at age 16, practicing, as my mother did, in front of a mirror to see how glamorous she looked. In 1948, there were no Surgeon General warnings, and smoking in movies and public places was not questioned. As a Marine captain's wife, BJ frequently socialized with her husband at officer's clubs. ''It was like smoking and drinking went together," she said. By the time she was diagnosed with emphysema, she had the "classic" symptoms: constant cough, several bouts of bronchitis, and a hard time breathing when going upstairs.

Diagnosed at age 51 in 1983, BJ was able to quit shortly thereafter, aided by making a pledge with the American Lung Association (she still carries a pledge card in her purse). In the early stages of emphysema, she continued to go to places where smoking was allowed. Thirty years ago, it was difficult to find smoke-free restaurants, theatres, etc. BJ's emphysema is now classified as "severe," and she avoids secondhand smoke.

BJ credited ambulatory oxygen with allowing her to remain independent, introducing her oxygen tanks as her "best friend." Since each tank last only 3 hours, BJ takes a spare in her car when she takes her daily outing on the days when her illness allows her to do so. Her portable tank allows her to do water exercises and take showers, and her driver's license was recently renewed until 2009. BJ lives alone (with a "lot of help" from friends), and unless she is using her portable, she is hooked up to a compressor 24 hours per day, which increases her electric bill to more than $100 per month.

Thanks to her oxygen tanks, BJ was able to speak eloquently in favor of a comprehensive smoking ban including bars and nightclubs. But Mayor Kim and at least three Council members valued the testimony of bar owners more highly than that of the thousands of responses favoring comprehensive legislation. When it appeared that comprehensive legislation might achieve a majority vote, one council member moved to derail the ordinance by calling for a public hearing. He withdrew that motion when other Council members, fearful that no legislation would be passed, agreed to amendments exempting bars. With confidence gained during her advocacy "debut," BJ will continue to help them see the error of their ways. Her patient support efforts include helping create the "Aloha COPD Support Group–Hilo." ■

From Self-Pity to Positive Action

Vijai Sharma, PhD
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Co-chair, NECA Self-Care/Peer Support Program

If you have emphysema, as I do, you know a day is going to be crummy as soon you open your eyes in the morning. Perhaps the pollen lays a thick coating on your driveway (and your lungs), or the humidity is so high it's ready to turn into droplets any time. Perhaps the temperature has suddenly turned too cold or too warm without enough time for your lungs to adjust, or it feels as if your lungs are drowning in mucus.

I awoke to one such day recently. The day my wife and I expected two couples for a delicious lunch at our home and a slightly uphill hike to a nearby beautiful waterfall started off as one of the crummiest! Hot and humid! How could I go hiking when just walking a few steps made my heart race and my legs and hands tremble? Thinking about our guests' disappointment made my heart and breath race even more.

"How ridiculous," I thought to myself, "I won't be letting anybody down. We'll have a delightful lunch and they can go to the waterfall on their own. I need to respect whatever is going on in my body and do what I can right now to make myself feel better." In spite of my positive self-talk, I felt a surge of self-pity. Surely there had to be more to life than lying down all day to try to control the breathlessness and the nausea! The nausea was caused by excessive mucous, nasal congestion, and sinus headache. Fortunately, I noticed the self-pity almost immediately and used it to remind myself to be grateful for the whole bag of tricks I could still use to improve my symptoms!

I rolled a small blanket to a thickness of about 2-inches and put it under me along my spine from waist to head. With my spinal column on the rolled up blanket, I let my shoulders relax toward the floor and allowed my chest to open while I focused on softening my breath. I then did pursed-lip breathing until I noticed that my diaphragm was moving and I felt less breathless. With each inhalation, my ribcage moved up and down and my chest expanded; my exhalation was becoming longer and fuller.

Encouraged by the results, I placed a rectangular bolster about 4" high and 10" wide under me from my lower back to my head, with my head supported with another pillow. Since I didn't feel breathless at this point, I replaced the pursed-lip breathing with diaphragm breathing while opening my chest and activating the breathing muscles. Within the next 15–20 minutes, I was breathing more rhythmically and deeper and fuller, without a pause or jerk. My chest and back felt stronger and more flexible, so I placed a 9" high round bolster crosswise (horizontally) under my mid back, which enabled my diaphragm to move more freely and vigorously. Every few minutes I moved it to a different part of my back and chest until the congestion in my sinuses and throat was partly dissolved.

After less than 2 hours, I felt strong enough to get up and join the hikers, although I was still a little apprehensive that my frequent stops to catch my breath would slow the others down. I soon realized that due to being overweight or having back or knee problems, our friends moved at about the same rate as I did, and we all ended up helping one another over the rough spots!

This experience deepened my understanding of how helpful and "healthful" it is to let go of expectations of myself and others. By accepting my health status and "listening" respectfully to my body on that "crummy" day, I was able to use each moment as a starting point or building block to the next moment. And perhaps I will move more quickly from self-pity to positive action on crummy days in the future! ■

From Patient to Patient Advocate

Eileen Rubin Zacharias, JD
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NECA Patient/Family Advisory Council

After graduating from the University of Illinois College of Law, I worked as a criminal prosecutor in Chicago, IL, until I established my own practice. At almost the same exact time, I experienced a severe lower backache, unlike anything I had ever felt before. Within days, the pain moved to my lungs, and only days later, I was hospitalized, on a respirator, and diagnosed with acute respiratory distress syndrome (ARDS). At age 33, I had a life-threatening illness I had never even heard of.

I was lucky to survive a 4-week coma, 8 weeks on a ventilator, a 9-week hospital stay, and a drop in weight to 82 pounds! I was even luckier to get pregnant twice after my ordeal, with my first pregnancy occurring only 6 months later. But even as my life returned to "normal," I felt in the back of my mind that I needed to use my devastating experience to help others. I had learned that in spite of the number of people who are affected by ARDS each year, including many deaths, most people were like me–they didn't hear about ARDS until they had it! So in December 2000, I co-founded the ARDS Foundation, both to create and distribute written information and to offer personal information and support.

It is gratifying but somewhat amazing to realize that our web site provides information 100,000 times a month! In the process of what is frequently two-way communication, I have learned that those who survive ARDS suffer from many other lung ailments post ARDS. By serving on NECA's Patient/Family Advisory Council and working with other lung organizations, I am able to expand my ability to receive and share information of benefit to those within the ARDS community. I try to reciprocate to these organizations by including their web sites and other contact information in the online ARDS newsletter.

Through NECA's community-building meetings, as well as the public interest organizations hosted by the National Heart, Lung, and Blood Institute and the Public Advisory Roundtable of the American Thoracic Society, I have received another unimagined benefit: the opportunity to interact with a variety of lung health professionals, educators, and advocates. I am learning to use these relationships to improve the care and quality of life of people with ARDS and related diseases.

I encourage all relatively healthy people with lung disease to become involved in similar efforts. I love my roles as wife, mother, and attorney, but I am also proud of the difference I make as a "patient advocate." ■

Tobacco Awareness Campaign

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The structure of the Tobacco Awareness Campaign (TAC), developed in part to get the word out about Tom Petty's National Lung Health Education Program *(www.NLHEP.com*), reflects NECA's empowerment mission and peer support approach. Most of NECA's current programs include plans to identify partners in mobilizing local, national, and international tobacco awareness activities and campaigns. NECA's strong international network provides an excellent opportunity to share resources; the incidence of smoking in some countries is twice as high as in the U.S. because tobacco companies target countries that do not limit smoking in public places. Two pairs of co-chairs lead the campaign: adult co-chairs Ron Peterson and Tom Houston, MD, and youth co-chairs Jaime Snider and another youth to be selected. Please let the co-chairs know if you are interested in being considered to serve on the TAC Adult or Youth Coordinating Committees.

Jaime, 17, whose grandmother has emphysema, was selected because of her commitment to accomplishing her "dream of a continuing line of smoke-free generations," starting with her own. Jaime's activities include letters about smoking prevention sent to the director of a chamber of commerce in a town in each of the 50 states and to President Bush. Ron and Jaime have communicated with youth around the world. In India, 200 youths who saw Teen Smokers Speak Out indicated they would not start smoking.

TAC Activities, Fall 2003/Spring 2004

- Identify other organizations and groups interested in a collective approach to mobilizing local, national, and international tobacco awareness activities and campaigns
- Disseminate information about resources, activities, etc., via *NECANews* and www.NECACommunity.org
- Promote NLHEP activities
- Promote development and distribution of materials and events involving youth
- Conduct smoking prevention/cessation activities in the COPD Network pilot sites
- Organize smoking cessation support groups for youths, adults, and youths/adults/seniors (mentor program)

Teens Helping Children and Teens Say "No"

Vijai P. Sharma, PhD

I recently had the privilege of viewing *Teen Smokers Speak Out,* a free, public service video intended to discourage a child from smoking that FIRST cigarette. Remember the first puff of a cigarette or a sip of alcoholic drink you tried? It was awful, wasn't it? But we went on to take another puff or another sip because it was "cool" and because the older kids were doing it. Some of us stopped "experimenting" with smoking, either because it didn't taste good or we were alarmed by strong health warnings. But others became so physically and psychologically dependent on nicotine they could not quit.

Ron Peterson and the Prevention Video Corporation (PVC), the makers of *Teen Smokers Speak Out,* want to prevent this addiction by helping children and youth say "no" to that first cigarette—all it took to hook Ron! He actually tried to quit at age 15! But it took him 36 more years (9 years after being diagnosed with emphysema) before he finally succeeded at age 51, when smoking even a "mild" cigarette caused him to black out.

Ron replaced his passion for cigarettes with a passion to prevent smoking, focusing on 8- to 12-year-olds because those are the years when a majority of children try their first cigarette. The 13- to 15-year-olds in the video share their personal stories of the damage caused by smoking. These youth, who appear to be the picture of health, are shown experiencing breathlessness or other negative effects. One can hardly breathe after carrying a laundry basket up just two flights of stairs, another has to drop out of a sports team, and a third can't run a mile without coughing and having to stop to catch his breath. Other youths in the video have excessive sputum, experience anxiety attacks, or use food money to buy cigarettes. Others reported feeling "less than human"—one teen was told by a classmate that she would not go out with him because he is a smoker.

Current scientific knowledge indicates that the age at which a person starts smoking is more related to the risk of DNA damage and the ability to repair that damage than the duration of smoking. For example, youths who start smoking at age 8 and smoke for 10 years are more at risk for disease than adults who smoke for the same length of time. Adults appear to have a better capacity to repair the DNA damage if they stop smoking before being diagnosed with a life-threatening illness.

PVC has asked major corporations and local merchants to participate in incentive programs that reward youth for not smoking. The PVC Web Site includes an affidavit that can be used to obtain rewards from participating merchants. Kids can print out the affidavit, get an adult to witness their signature, then take it to participating merchants for free food or discounts. They can also request a personalized Smoke-Free Youth (SFY) identification tag from PVC.

Teachers, counselors, church youth leaders, scout leaders, and others who work with elementary and middle school children are invited to download the free video from www.preventionvideo.com or request a copy by mail. Ron encourages us all to distribute as many copies as possible to help children resist that first puff!

"We've Got the Power Now!"

Available Soon

Prevention Video Corporation's new video, "We've Got the Power NOW!," soon will be available for viewing and downloading at www.preventionvideo.com.

Contacts for Youth Programs

National Peer Helper Association, Missouri: publishes *Peer Facilitator Quarterly*; www.peerhelping.org, 877-314-7337.

General Peer Resources in Canada: www.peer.ca,

managed by Ray Carr, carr@islandnet.com.

International Association of Laryngectomees: 100 local groups, some of which have been involved in local stop-smoking campaigns in schools because most of their members have cancer from smoking. For local groups, dial the California headquarters at 866-425-3678, www.larynxlink.com.

Students Against Destructive Decisions:
National group focusing on alcohol and drug use prevention; some regional contact people are well versed in, and include, smoking prevention. For local groups, dial the headquarters in Maine, 877-SADD-INC; www.saddonline.com.

Kids Konnected:
More of a peer-support group than a prevention program, Kids Konnected was started in 1993 by Jon Wagner-Holtz after his mother was treated for breast cancer and he could not find a program where he could talk to other kids who knew what it was like to have a sick parent. Local groups are headed by youth leaders and co-facilitated by professionals. Services include a hotline, Youth Leadership program, monthly meetings, information and referrals, newsletter, and summer camps. 800-899-2866 or 949-582-5443 (24 hrs); www.kidskonnected.org.

REAL, the Hawaii Youth Movement Against Tobacco Use

Cancer Research Center of Hawaii
1960 East-West Rd., Biomedical Bldg. C-105
University of Hawaii
Honolulu, HI 96822
808-441-8195
www.therealmessaage.net

REAL, housed in the Cancer Research Center, is funded by Master Settlement dollars. Activities include an activist role in Big Island efforts to adopt a comprehensive smoke-free workplace ordinance, an analysis of smoking in today's films, a survey of tobacco marketing in Hawaii, and four Summer Island Summits. The summits, called The REAL Experience, feature REAL teen trainers. Training includes information on how tobacco companies target youth, guerilla marketing tactics youth can use to fight back, developing a message that fits a specific community, and how to get anti-tobacco action going at the community level. Information about REAL is available on its web site (above) or from Mary Jane Ahrendes, REAL Project Director, 808-441-8194, fax 808-586-3077; mahrende@crch.hawaii.edu.

Smokeless Joe Provides Information, Advocacy Platform

www.SmokefreeAir.org.

Joe Cherner provides up-to-the-minute information on smoke-free legislation via e-mail alerts to people who request them via his web site. On July 8, he informed subscribers about the report released at the 12th World Conference on Tobacco in Helsinki (compiled by the Centers for Disease Control and the World Health Organization) that 17.8% of girls in the U.S. are smokers, compared with 17.7% of boys. Big tobacco ads relate smoking to being slim and feminine for girls, tough and macho for boys. We know from a number of sources that women are more susceptible to tobacco-caused diseases than men, yet women who smoke are in denial about their health risks.

Joe's web site also provides numerous opportunities to contact local and national key decision makers via his smoke-free EZ-letter service. Joe provides statistics and "sound bites," such as calling tobacco addiction "the world's most lethal weapon of mass destruction." He cites World Health Organization estimates that tobacco addiction kills 5 million people worldwide each year. Advocates can place their local activities in a worldwide context by accessing Joe's information, such as the fact that the World Health Organization, made up of 192 member countries, voted unanimously to adopt the Framework Convention on Tobacco Control (FCTC). The Convention urges countries to eliminate tobacco advertising, establish bigger/stronger warning labels, raise cigarette prices, and adopt smoke-free workplace laws. He keeps a running tally of progress in states and cities in the U.S. that have gone totally smoke-free, those that have gone partially smoke-free, and those that are considering legislation. With the click of an icon, you can add your support to these efforts. To search the Joe Cherner announce archives, go to *http://smokefree.net/JoeCherner-announce/messages/*. Currently, more than 36,000 people subscribe to this service.

Joe Cherner

www.SmokefreeAir.org/whosupports.pdf

provides information on union leaders, including the United Federation of Teachers, who support smoke-free workplaces and public school campuses.

NECA Promotes Smoke-Free Hawaii

NECA is an active participant in Hawaii's smoke-free partnerships and coalitions to promote comprehensive smoke-free workplace legislation and to convince union leaders to stop using collective bargaining to justify smoking on public school campuses. On the "Big Island," the UPW prevailed against an attempt by the Department of Education "to shove down our throats a smoking-ban policy, without mutual consent, in violation of existing law and the UPW Unit 1 and 10 contracts." Peter Liholiho Trask, UPW/AFSCME administrator, claims that current UPW policy, allowing smoking in designated areas with the door closed and in the absence of a non-smoker, ". . . makes more sense, is less intrusive, does not trample the rights of public employees and is not hypocritical." *(Posted on http://the.honoluluadvertiser.com/current/op/letters, Tuesday, July 1, 2003, Letters to the Editor)*

Women in Denial about Smoking-Related Health Risks

"Going Up in Smoke: What Smokers Need to Know"
Michelle Bridenbaker, CPhT
Medscape Cardiology, Vol. 7, No. 1, 2003 (Posted 06/24/03)

Michelle Bridenbaker covers the "smokefront" in this concise article, which provides ammunition for people involved in NECA's Tobacco Awareness Campaign and similar activities. Particularly disturbing is her finding that women are in denial about the health risks related to smoking. "An analysis published in the *Journal of Women's Health* reported that the majority (60%) of female smokers in the study rated their lifetime risk for developing heart disease or lung cancer as average or below average."

To balance her article, Michelle also provides information about the "economic and crowding tolls" that smoke-free ordinances have produced in larger cities. In New York City, people have taken to the streets with "noise, litter, and clouds of smoke." People lingering outside to smoke have reduced business by 30% in some cases. She also describes the often-quoted tobacco-funded study reported in the *British Medical Journal*, which suggested that "the long-term clinical consequences may not be as severe as once thought." Critics pointed out that the study was "flawed and inadequate to measure the impact of passive smoking." Another study, related to Helena, Montana's Smoke-Free Ordinance, reported that reduced exposure to tobacco smoke produced a "substantial and rapid reduction in hospital admissions for acute myocardial infarction (AMI)."

Call for Information about Smoking Cessation Programs

We would like to include references to specific smoking cessation programs in the Winter 2004 *NECANews*. We are especially interested in programs that include behavioral interventions, support groups, and non-pharmacologic approaches.

Smoking Cessation and Revitalization Programs

ESOCEN®
Del Pe, President (mdp@esocen.com)
Box 7947, The Woodlands, TX 77387
800-325-6014
www.mdpglobal.com/

The ESOCEN® program approaches smoking cessation by helping participants examine the origins of their addiction and use drug-free approaches to stop smoking. The program includes opportunities to learn what Del Pe describes as "Inner Powers" development to prevent relapse, individualized stress management techniques; and lifestyle changes. Program information is available at *www.esocen.com/*; products, book, video, and CD information is available from the web site. ■

RESEARCH

Encouraging Signs in Clinical Research in COPD

Robert A. Wise, MD, Professor of Medicine
Johns Hopkins University School of Medicine
NECA Medical Advisory Council

Chronic obstructive pulmonary disease (COPD), one of the most common and disabling disorders in the U.S., is projected to become one of the leading causes of disease burden internationally over the next two decades. Early detection of disease, smoking cessation, and medical treatment can do quite a bit to prevent complications and improve the quality of life of people with COPD, but they do not significantly modify the course of the disease. This is in stark contrast to mortality for other diseases, such as coronary artery disease, which fell by 35% between 1965 and 1998, while mortality from COPD increased by 163%. Yet COPD is ranked as the fourth leading cause of death in the U.S. in 1999 and as 27th in government research funding. The situation has improved somewhat in recent years, during which the National Institutes of Health conducted a series of workshops to define the clinical and basic research priorities for COPD. COPD research is now supported by the government, pharmaceutical companies, and non-profit organizations, all of which have to comply with strict ethical and patient-safety requirements.

Terms Used in Clinical Research

- Clinical trials: Trials compare different forms of treatment, such as two different drugs, to see which treatment has better health outcomes and fewer side effects.
- Placebo: Trials may also compare a new form of treatment to an inactive medication, a “placebo” such as a sugar pill that looks identical to the active treatment.
- Blinding or masking: In order to allow a fair evaluation of the effect of the active drug, the identity of the drug is hidden from the patient who is participating in the trial.
- Double-blinding or double-masking: The doctors and nurses who examine the participating research volunteers also do not know what treatment is given to each patient.
- Unmasking: If a patient has an unexplained reaction to a research treatment that could, for example, be a side effect of a new drug, the actual treatment assignment can be found out by opening a sealed envelope (or similar system).
- Informed consent and other protections: Researchers are required to provide prospective participants with information necessary for them to freely decide whether to participate in research and to follow protections to ensure that volunteers are not subjected to pressure to participate or unnecessary risks.
- Review boards: Research proposals must be evaluated by an independent “Institutional Review Board” (IRB) for safety, scientific value, and compliance with consent procedures. When several different research institutions participate, a central expert “Data and Safety Monitoring Board” usually reviews the data from the trial several times per year and determines if the trial should be stopped early, either because the treatment is not proven to be significantly beneficial or if it has unacceptable side effects.

Research Supported by the Government

Government-sponsored COPD trials test available treatments of unproven effectiveness or support studies in areas in which there is no commercial incentive for drug or medical device manufacturers to fund research. Large clinical trials in COPD sponsored by the National Institutes of Health (NIH) have included research on positive pressure breathing machines (not found to be effective), continuous oxygen for people with low oxygen blood levels (found to be very effective), smoking cessation programs (found to be very effective), and inhaled corticosteroids (found to help some, but not all, participants). At present, the NIH is sponsoring research on the use of lung volume reduction surgery and retinoic acid in emphysema treatment.

Clinical trials may be originated by a request for researchers, usually from universities or nonprofit research centers, to submit a proposal to study a specific topic; suggestions for trials may also originate with researchers. Proposals undergo a competitive process (only 15% receive funding) involving rigorous review. The application process (intense effort over several months) and low funding rates are discouraging to researchers. In the past two decades only two investigator-initiated multi-center clinical trials for COPD have been funded, one on methods to rest fatigued respiratory muscles, and the other on the use of inhaled corticosteroids. The NIH research network is being developed to encourage more applications by permitting a consortium of five or six centers to conduct a series of clinical trials, without having to submit applications for separate funding.

Research Funded by the Pharmaceutical Industry

In the past five years, the pharmaceutical industry has recognized that COPD is a common disease and that new drugs can improve the quality of life for patients. Using private research companies or private medical practitioners, major pharmaceutical manufacturers are testing targeted treatments that inhibit many of the cells and substances that cause deterioration of lung function in COPD. Because of the appropriately strict standards for effectiveness and safety a drug must pass before it can be approved, the process can take 5 to 10 years and cost $50 million or more, with no guarantee of success. Approval by the Food and Drug Administration is necessary to make a particular claim about the drug's effectiveness in treating COPD in general or a particular symptom, such as shortness of breath.

Research Funded by Non-profit Organizations

Non-profit organizations such as the Alpha-1 Foundation, Cystic Fibrosis Foundation, and American Lung Association provide funding for unmet research needs. Support includes sponsoring young investigators, pilot projects that serve as a platform for obtaining larger research grants from NIH, and organizing workshops and meetings to enhance communications among investigators, particularly to identify important research topics and opportunities for collaboration.

Epidemiology, Basic Research Needed

Good clinical research draws upon both epidemiological studies and basic research to determine which people with COPD would be good candidates for inclusion in research studies, what measures provide good information about the progress of the disease, and what treatments are most promising to improve disease outcomes. Epidemiology (the study of populations) is essential to describe the natural course of COPD, to identify which people are at greatest risk for complications, and to reach agreement on measurements to assess disease severity. Basic research is essential to find out how and why COPD is caused and to evaluate methods of reversing factors that cause the changes in the lung.

With all of these working together, perhaps the next decade we will see not only an increase in the quality of life of people with COPD, but also a significant decrease in mortality.

Live Satellite Videoconference Addresses Asthma/COPD Interface

Vlady Rozenbaum, PhD, Founder and Moderator,
COPD-ALERT

On June 12, 2003, the American Thoracic Society presented a live satellite videoconference, "A Close Look at the Cutting Edge of Obstructive Lung Disease," beamed simultaneously to several dozen U.S. cities. A panel of COPD experts presented an overview of the latest research, as well as their own clinical perspectives. William Calhoun, MD, University of Pittsburgh, noted in "Airway Inflammation in Asthma and Disease Severity" that "despite the recognized central role of inflammation in asthma, no consensus exists" on the proper techniques, measurement of outcomes, or interpretations of the data that shed light on the intensity of airway inflammation. Dr. Calhoun presented information about genetic mapping, "the advent of technology for high-throughput gene expression profiling," and "important insights into the kinetics and degrees of gene activation or suppression." He also reported on recent information that "sheds light on the mechanisms by which asthma and chronic obstructive lung disease develop."

Stephen Rennard, MD, University of Nebraska, tackled the provocative question, "Differentiating Between Asthma and COPD: Is It Possible?" Dr. Rennard believes that asthma may not only overlap with COPD but, in some cases, can progress to become COPD. He outlined the degrees of similarity/difference in smooth muscle contraction/tone, mucous hypersecretion, narrowing of the small airways, destruction of lung tissue with loss of lung elastic recoil (with and without lung tissue destruction), presence of eosinophil cells (more prominent in asthma) and neutrophil cells (more common in COPD), and CD4 lymphocyte cells (relatively prominent in asthma) and CD8 lymphocyte cells (more prominent in COPD). In the absence of consensus guidelines, Dr. Rennard urged his colleagues to make the most accurate diagnosis possible based on historical features, clinical findings, laboratory measures, and response to treatment. Diagnosis of either asthma or COPD, or both, is important, because the therapeutic strategies for common medications and the therapeutic goals, including those for non-pharmacologic interventions, differ greatly.

The satellite videoconference also included presentations by Theresa Guilbert, MD (Asthma Therapy: Lessons from Clinical Trials), Douglas Mapel, MD (COPD: From Nihilism to Justified Optimism), and Barry Make, MD (Effects of Pharmacologic Intervention, Pulmonary Rehabilitation, and Surgery in COPD).

NETT/LVRS Articles Summarized in "Patient" Language

Patricia Carroll, RN, BC, CEN, RRT, MS
NECA-Medical Advisory Council

For a simplified report on the 1999–2003 articles in *Chest* and the *New England Journal of Medicine* on the National Emphysema Treatment Trial (NETT), set up to study the outcomes of lung volume reduction surgery (LVRS), go to *www.nursesnotebook.com* and read "Does Lung Volume Reduction Surgery Work? Initial Results of the National Emphysema Treatment Trial," under "Current Topics." Originally written for the *Atrium Medical Corporation's Clinical Update for the Professional Nurse* (June 2003), the article summarizes the purpose of the NETT, the results of primary and secondary analyses, and "lessons learned." While it's too soon to tell if the subgroups appearing to benefit from LVRS will sustain those benefits over time, it appears that the thoughtful combination of patient selection and state-of-the-art technology will make LVRS an important part of COPD treatment in years to come.

Self-Care/Peer Support Program

NECA's unique Self-Care/Peer Support (SCPS) Program has been described in previous issues of *NECANews* (*www.NECACommunity.org*). As indicated in the May 2003 issue, we are seeking

- Teachers and participants for pilot activities in the areas in which COPD Networks are currently being formed: Alaska, Arizona/Colorado/New Mexico, Chicago, Florida, Hawaii (Big Island), Indiana, New York City, and Washington State
- Materials to reproduce in the COPD Peer Support Group Tool Kit and to include in the *COPD Peer Support Group Directory and Resource Guide*
- Patient and professional volunteers to serve on the SCPS Coordinating Committee

The SCPS Program is currently focusing on

- Breathing techniques (rehabilitative, therapeutic, and meditative)
- Adequate hydration, nutrition, and rest
- Appropriate activity, including *t'ai chi chih®* movements, mindful walking, yoga-based stretching (land, water, chair, bed versions), dancing
- Meditation and relaxation techniques
- Healing touch techniques that can be adapted for group participation and that patients and their families can learn and use on each other
- Importance of service, intimacy, and spiritual practices

Self-Care/Peer Support Resources

This issue of *NECANews* contains several items related to self-care and peer support, focusing primarily on breathing and healthy movement. Breath-related items appear in "If You Can't Breathe, Nothing Else Matters," an ongoing *NECANews* section. Information on t'ai chi chih® and yoga appear below, indicating the increased attention to these body/mind/spirit approaches. Both *Respiratory News and Views* and the *Cape Cod COPD Support Group Newsletter* have described the benefits of yoga and t'ai chi and have identified local classes and resources. The July 2003 issue of *RNV*, edited by John Leaman, announced "Free Chair Yoga Relaxation Classes" offered by the Center for Cardiac and Pulmonary Health, Beth Israel Medical Center. John described t'ai chi benefits reported by a member of the homebound support group and referred readers to the *Living Arts Catalog* (800-254-8464), which includes information about books, videos, equipment, and other resources.

T'ai Chi Chih® Benefits to the Emphysema/COPD Community

For 25 years I have been in peer support groups and energy balancing classes with people in the final stages of life-threatening illnesses, such as cancer and AIDS. In 1986, I learned Justin Stone's 19 t'ai chi chih® (TCC) movements and one pose to provide students and friends with the profound benefits of this easy-to-learn "Moving Meditation." My experiences indicate that doing even a few t'ai chi chih® movements regularly would also help people with COPD cope with their increasing physical, emotional, and spiritual challenges. COPD can make vigorous movement uncomfortable or even impossible, but the gentle TCC movements can be done in a very small space and require no special clothing or equipment. Even people who must rest during a class benefit from the peaceful, gentle movements being performed around them.

We are therefore identifying appropriate t'ai chi chih movements, print and electronic materials, and accredited teachers to include in NECA's Self-Care/Peer Support Program. *As with all segments of the Self-Care/Peer Support Program, we will consult with patients, practicing physicians, and researchers to identify TCC movements appropriate for various stages of lung impairment and other health considerations.*

T'ai Chi Chih® Resources

Tai Chi Chih®—Joy Through Movement: illustrated text and video, by originator Justin Stone, of 19 safe, easy-to-learn movements and one pose designed to circulate and balance "vital energy" ("chi" or "qi")

Catalog of books, tapes, videos, and other resources available from Good Karma Publishing, Box 511, Fort Yates, ND 58538 or 888-540-7459

Teacher referrals or information: Kathy Albers, *thevitalforce@yhaoo.com*, or 314-727-1983.

Essential Self-Care Methods Guide

The Healer Within (book and video)
Roger Jahnke, OMD, Director
Health Action and Institute for Self-Initiated Healing
243 Pebble Beach, Santa Barbara, CA 93117
800 824-4325

Roger Jahnke's *The Healer Within: The Four Essential Self-Care Methods for Creating Optimal Health* presents a clear, simple system of gentle movement, self-massage, meditation, and breathing exercises. Techniques are tailored to various degrees of health and ability, including suggestions for general populations, for people who are sitting or lying down (including in wheelchairs and hospital beds), and for people so frail or weak they can only visualize the techniques. Techniques also vary with the purpose: health maintenance, health improvement, disease intervention, and getting started.

What I like best about the book is that it includes examples of specific routines practiced by people with various health challenges, which allows readers to "match" their situation and pick up helpful hints. It also contains personal stories demonstrating that "average people can teach each other to do self-healing." This is the philosophy behind NECA's Self-Care/Peer Support Program, which goes one step farther in teaching that people with an illness can learn simple healing techniques to exchange with one another.

The clear descriptions of the physiological benefits from suggested techniques should help people with impaired lung function determine if particular movements would be appropriate for them. Several breathing practices are built on the natural abdominal breathing pattern of babies, "belly" or "diaphragmatic" breathing. The "sigh of relief," which slows down the exhalation and is therefore "calming," may be of special interest to people with COPD. Roger recommends practicing for a few minutes several times a day if 20 minutes at a time is too much, pointing out that even "10-second momentary relaxations" can make you feel better.

Roger demystifies "Oriental medicine" concepts in his descriptions of the body's incredible self-healing abilities. He obviously prefers "natural" healing to aggressive interventions of Western medicine, and some of the stories of remarkable health improvements may create skepticism. But the benefits of gentle movement, self-massage, meditation, and breathing exercises in general have been reported in numerous scientific, peer-review publications in this country. Moreover, Roger is very conscientious about recommending that people with health problems work closely with their physicians. I believe that people with COPD who want to focus on total health and well-being may find this book and its programs of interest.

COPD Self-Management Education Review

The bi-monthly e-mail briefing sponsored by Boehringer Ingelheim–Europe includes the latest news and articles on COPD. *NECANews* readers may be particularly interested in "Self-Management Education for Patients with Chronic Obstructive Pulmonary Disease: A Systematic Review," by E. Monninkhof, P. van der Valk, and J. van der Palen, et al., from the Netherlands (in *G. Thorax* 2003; 58: 394-398). The summary of this article, by Health Media Group (© HMG Worldwide 2003) writers, points out that the value of self-management programs to improve the quality of life (QOL) and lung function of COPD patients has only recently become the subject of research.

"Self-Management Education . . . " reports the findings of a systematic review of trials evaluating the impact of COPD education and self-management programs on both health outcomes and healthcare use. The authors found that participants in these programs experienced some benefits. The review reported that the eight randomized controlled trials they identified on COPD conducted after 1985 were generally of good quality. The studies, which included 1,295 patients, assessed various outcomes on health-related QOL, symptom scores, number and severity of exacerbations, need for oral steroids or antibiotics, use of rescue medication, hospital admissions, emergency department visits, use of other healthcare facilities, days lost from work, lung function, or exercise capacity.

The interventions studied are outlined in the Health Media Group review. There were no significant differences between the two groups in the number of hospital admissions (four studies), emergency department visits (one study), doctor/nurse visits (three studies), days lost from work (two studies), or lung function (four studies).

Yoga Information from Lung Transplantee

Access information about Janet Kolish and the 1998 "transplant games" on the Ron Peterson's Prevention Video Site, *preventionvideo.com/ronaldpeterson.geo*, by clicking on "exercise information" and then on "Janet Kolish's home page."

Please Review Yoga-Based Breathing and Stretching Materials

Patients, support group leaders, professional and family caregivers, educators, researchers, and others are invited to review the yoga-based breathing and stretching materials under development for the first self-instructional video for NECA's Self-Care/Peer Support Program. "COPD Yoga Program in the Works" (Jill Winkler, in YogaChicago, editor Sharon Steffensen, May-June, 2003; www.yogachicago.com) describes the program being developed by NECA Board member, Vijai Sharma, PhD. Jill's article contains an excellent description of NECA's Self-Care/Peer Support Program, which Vijai co-chairs. His breathing/stretching video, developed to support the program, will be the first in a series of videos intended for use in peer-support settings, such as autonomous self-help groups, groups at rehabilitation centers, etc. If you are willing to review Vijai Sharma's preliminary materials, please contact him at Dr.Sharma@mindpub.com.

Yoga and Emphysema

Trisha Feuerstein, Director of Research
Yoga Research and Education Center and
International Association of Yoga Therapists
mail@yrec.org
www.iayt.org/biblio.html
www.yrec.org

In my capacity as Director of Research for the Yoga Research and Education Center (YREC) and the International Association of Yoga Therapists (IAYT), I collect and track information on completed and ongoing yoga research on dozens of health disorders, on various populations (seniors, children, etc.), and on yoga's general psychophysiological effects. Through the IAYT, we provide referrals to member yoga professionals who specialize in working with various health disorders and populations. If you would like to inquire about a yoga professional in your area, please e-mail your request (include your zip code), to *mail@yrec.org* or call us at 530-474-5700.

Interest in yoga and yoga research has grown significantly over the past decade. Several studies are currently being funded by the National Institutes of Health and the Centers for Disease Control. These studies include research on the effect of yoga on asthma, conducted by Prem Kumar, MD, at Tulane University; research on yoga and peak air flow rates in pregnant asthmatics, conducted by Judith L. Balk, MD, at Magee-Women's Hospital; and research on asthma comparing Iyengar-style yoga with a stretching "control group," conducted by David L. Katz, MD.

To date, I have compiled information on yoga research into 75 bibliographies, 40 of which (including one on "Yoga and Asthma") may be downloaded from our IAYT web site: *www.iayt.org/biblio.html*. The following "Yoga and Emphysema Bibliography" is not yet available at the web site.

Yoga and Emphysema Bibliography

Compiled by Yoga Research and Education Center
Box 426, Manton, CA 96059, USA
530 474-5700

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Ongoing Research

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Conducting NIH-funded research on the efficacy of yoga for self-management of dyspnea in COPD.

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Planning research on the effect of yoga on the respiratory system.

Huong Nguyen, RN, MS
Dyspnea Research Group
UCSF School of Medicine and Nursing
Hqnguy@itsa.ucsf.edu
Writing a grant proposal to the National Institutes of Health to conduct a study on alternative forms of exercise such as yoga for decreasing shortness of breath in people with bronchitis and emphysema.

Vijai Sharma, PhD, Director
Behavioral Medicine Center
Cleveland, TN
Dr.Sharma@mindpub.com
As reported in the May-June 2003 issue of *YOGAChicago*, Dr. Sharma is working with the National Emphysema/COPD Association to design a yoga-based breathing and stretching video specifically for people with COPD. Sharma, who was diagnosed with COPD in 1994 and has 30% reduced lung capacity, attributes the fact that he is able to function almost as well as people with normal lung capacity to his yoga practice and teachings. The video will emphasize specific deep breathing, in coordination with the movement of the spine, to effectively strengthen the muscles used to breath.

P. K. Vedanthan, MD
Northern Colorado Allergy & Asthma Clinic
1124 East Elizabeth
Fort Collins, CO 80524
PKV1947@yahoo.com
Ongoing research on yoga and asthma and yoga and COPD. ■

Self-Care Tips From the Trenches

Be breath conscious and start pursed lip breathing early in the game. Some people keep ignoring the shortness of breath until it starts getting severe, and then they start pursed lip breathing. It is better to start early and keep doing it until you get back to your own version of normal breathing. (Vijai Sharma)

Put a book or box of Kleenex on your belly to check your diaphragm breathing. (Vijai Sharma and Ron Peterson)

Do diaphragm breathing all the time, especially when walking, although it takes a bit of practice to "belly breathe" while standing. (Doris Bozarth, COPD-ALERT)

Optimally treat all of your conditions, as each of them may affect your breathing. If you have a few extra pounds, try losing them. Short a few? Try gaining some. If you have allergies, get optimal treatment to control them. If you have heartburn or acid reflux (GERD), be sure to get it evaluated and controlled as well. Treat those heart conditions, because they can worsen our lung function! (Valerie Chang, COPD-ALERT)

One thing that saves me a lot of time is not to make the bed. I just use a bottom sheet and throw cotton comforters over the top. It looks neat, but it's almost effortless. In the summer I sleep on the couch in the living room to be near the air conditioner. Just throw a sheet over the cushions and leave it there. Keep a folded cotton blanket nearby. What could be easier? (Mary Lincoln, COPD-ALERT)

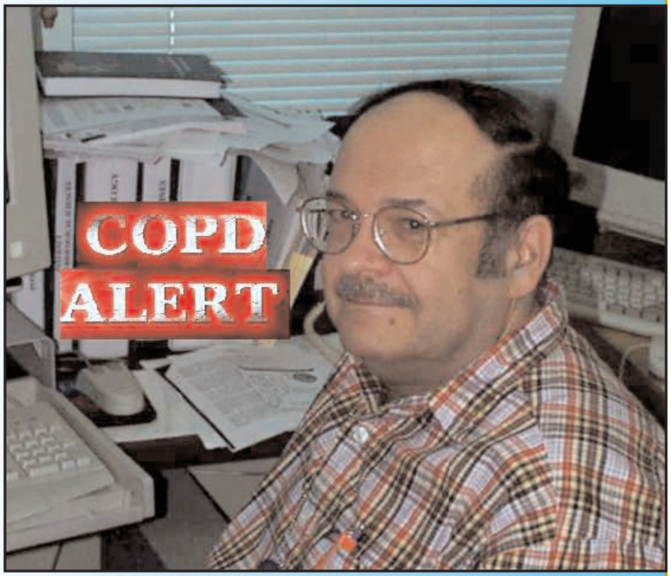
Use a wheeled serving cart to carry things from room to room. It comes in handy when doing laundry, cleaning, picking up, or even eating dinner in front of the TV. I bought mine at a yard sale of for $10.00. It has three different shelves and the top one is actually a tray that lifts off as needed. (Mary Lincoln, COPD-ALERT)

Safeway and Albertson's both deliver to my area for a $10.00 fee. It really helps if I'm getting a lot of heavy items, like bottled water, 10 lb sacks of potatoes, flour, or sugar, and large containers of cat litter or food. Well worth the fee considering that I'd have to spend something to drive there myself anyway. All I have to do is order online and like magic, groceries appear at my door. (Mary Lincoln, COPD-ALERT)

Eat small meals, four, five or six times a day. Yes, even on special occasions like birthdays, anniversaries, Christmas, Thanksgiving, etc. (Vijai Sharma)

Take your time. Your activities now require more effort and time–use them very wisely. Even if you use supplementary oxygen (or, perhaps, especially, when you use it), pace yourself and anticipate requirements for effort and its duration. Whenever possible, try to perform your activities in increments, so your breath/oxygen regeneration time will make it possible to continue your activity without a major problem. (Vlady Rozenbaum)

First thing in the morning, drink a concoction of a teaspoon of honey and a teaspoon of apple cider vinegar mixed in 8 ounces hot water. I've used this Kentucky concoction for 6 years. When considering if you want to take this, remember that we are instructed to disinfect our nebulizers daily to kill the germs with a vinegar water solution. Also remember that our bronchial tubes are susceptible to infection from germs and that "A spoonful of honey makes the medicine go down"! None of the hundreds of peers with lung disease to whom I have recommended this drink has ever come back with a bad report, and I have received many positive reports of its effectiveness. (Ron Peterson)



Vlady Rozenbaum

Events

COPD Conference for Patients and Health Care Providers

October 17–18, 8:00 am to 5:00 pm
Roosevelt Hospital Center
1000 Tenth Avenue (between 58th and 59th Streets)
New York City
Contact: 212-523-5471

On Friday and Saturday, October 17 and 18, the James P. Mara Center for Lung Disease, the Alpha-1 Foundation, and the National Emphysema/COPD Association are sponsoring a COPD Conference for Patients and Health Care Providers. Several members of NECA's Medical Advisory Council, including Byron Thomashow, are featured presenters. The Conference covers some of the "hottest topics" in COPD research, treatment, and care:

- Current research issues
- Impact of gender on research and treatment
- Lung volume reduction surgery (National EmphysemaTreatment Trial)
- Lung transplantation
- Importance of screening for Alpha-1 antitrypsin deficiency
- Exacerbations caused by anxiety and panic disorder

CHEST 2003

The 69th Annual Scientific Assembly of the American College of Chest Physicians will take place on October 24-October 30, 2003, at the Gaylord Palms Resort & Convention Centre, Orlando, FL, USA. COPD is high on the list of subjects in the comprehensive program on lung health and disease. COPD-related presentations and activities are highlighted in the conference preview, along with information about accommodations and other useful tips; go to *www.chestnet.org/* and click on CHEST 2003.

Lung Health Day, October 22, 2003

Kris Williams, Communications Manager
American Association for Respiratory Care
11030 Ables Lane
Dallas, TX 75229
972-243-2272, 972-484-2720 (Fax)
williams@aarc.org

Lung Health Day (October 22) is a major public awareness campaign, sponsored by the American Association for Respiratory Care, to promote the importance of lung health and build awareness about diseases and conditions that adversely affect the lungs. This campaign coincides with National Respiratory Care Week (October 19–23), a celebration of the work of respiratory therapists in all care settings, including advocacy, public education, research, and day-to-day professionalism. Each day will "celebrate" a different topic: Monday, "Staff Appreciation"; Tuesday, "School Visit" (including coverage of COPD and asthma); Wednesday, "Lung Health" (promoting screenings); Thursday, "Staff Education"; and Friday, "Information Day for Vendors and Community Groups." Visit *www.aarc.org* for specific information closer to Respiratory Care Week.

Spirometry Testing at African American Male Health Event

On June 14, 2003, the American Lung Association of Metropolitan Chicago participated in the 1st Annual African American Male Health and Fitness Experience organized by the Thapelo Institute, Inc., at Malcolm X College. The ALAMC collaborated with Boehringer Ingelheim to provide spirometry testing to all interested participants. In just 5 hours, BI tested 125 participants, many of whom went to the ALAMC table for more information on COPD, asthma management, smoking cessation tools, and programs in schools for raising tobacco awareness. Twenty individuals signed a petition showing support for the Smoke-Free Chicago Ordinance, which is pending in City Council.

Resources

The Culture of Emotions: A Cultural Competence and Diversity Training Program

Harriet Koskoff
415 Noe Street #5
San Francisco, CA 94114-2064
415-864-0927; 415-621-8969 (Fax)

Emotional ups and downs are part of every life-threatening illness, and perhaps even more so when the breath is at stake. Concepts of "breath" vary greatly among racial and ethnic groups, as well as among other "cultural" units.
The video "The Culture of Emotions: A Cultural Competence and Diversity Training Program"is directed primarily to mental health professionals, but its concepts align with NECA's mission of ensuring that people with COPD receive cultural-

ly appropriate care. The concepts in The Culture of Emotions are especially relevant for peer support groups, which develop a "culture" of their own.

The video introduces the DMS-IV Outline for Cultural Formulation (OCF), with presentations by 23 professionals from varied racial, ethnic, and professional backgrounds. Psychopharmacological information would be helpful to pulmonologists and others wishing to acknowledge mental health needs, as well as those related to COPD and concurrent illnesses. The five sections cover

- Cultural identity
- Cultural expression and explanations of illness
- Cultural stressors and supports
- Cultural elements of the clinician-patient relationship
- Cultural assessment for differential diagnosis and treatment planning

Free Internet COPD Decision-Support Tool

www.lungusa.org, click on COPD Lung Profiler icon

The American Lung Association offers a free Internet-based lung health decision-support tool for people with COPD. The COPD Lung Profiler is a user-friendly interactive web-based tool that confidentially matches an individual's clinical information to a carefully selected group of peer-reviewed clinical studies. Profiler users receive personalized information about treatment options and side effects relevant to their disease stage, along with helpful questions to discuss with their doctors. The Profiler is also intended for use by people with a constant nagging cough, excess mucus production, or shortness of breath after mild exertion who have not yet been diagnosed with COPD.

www.DisABILITIESBOOKS.com

Online "bookstore" of classic and new titles related to disabling conditions, including lung impairment. Has a "Nonprofit Partner Program" that might be of interest to patient organizations.

Participatory Research/Patient Empowerment

Chapter by Daryl Isenberg (NECA Patient/Family Advisory Council) in *Participatory Community Research: Theories and Methods in Action* on how "participatory community research" addresses the gap between scientific knowledge and community-based research methods. Participatory research techniques empower community populations to shape the research agenda. Their participation often results in generating greater awareness and change in the community. Case studies illustrate how these participatory approaches have led to high-quality collaborations, interventions, and prevention projects. Self-help groups interested in working as full partners with community researchers in examining the group may contact Daryl at *dipeace@aol.com*.

COPD Patient Rights Under HIPAA

- You have the right to review your records upon request.
- You have the right to obtain a copy of your records with or without fee. In most cases, the fee should not be more than $10 for the copying of the records. In fact we recommend that you always request a copy of the office note your doctor writes upon your visit. Such a request builds in some accountability on the part of a medical office. If you do not agree with something written in your records or you think that the information is false or inaccurate, you can request that your medical records be amended accordingly. Your health professional may or may not amend the records as requested, but he or she is obligated to include the amendment provided by you.
- Your health professional must keep a log of all releases and disclosures of your medical records.
- You have the right to inspect that log to know who all received a copy of your medical records.

Publications

Outpatient Oral Prednisone after Emergency Treatment of COPD

The article in the June 26, 2003 issue of the *New England Journal of Medicine* (pages 2618-2625; by S.D. Aaron, K.L. Vandemheen, P. Hebert, et al.) reports outcomes of a randomized, double-blind, placebo-controlled trial studying the effectiveness of prednisone in reducing relapse risk after outpatient exacerbations of COPD. The scientists randomly assigned 147 volunteer patients being discharged from the emergency department after an exacerbation of COPD to 10 days of treatment with 40 mg of oral prednisone once daily or identical-appearing placebo. All patients received oral antibiotics for 10 days, plus inhaled bronchodilators. The primary end point was an unscheduled visit to a physician's office or a return to the emergency department because of worsening dyspnea, within 30 days after randomization. Outpatient treatment with oral prednisone was

Pulications continued

found to offer a small advantage over placebo patients in the trial. The same issue includes "Systemic Corticosteroids for Acute Exacerbations of Chronic Obstructive Pulmonary Disease" (pages 2679-2681; by R. S. Irwin and J. M. Madison), along with related editorials.

Six-Minute Walk Test

"The 6-minute Walk Test: A Quick Measure of Functional Status in Elderly Adults–A Review, " by P. L. Enright, M. A. Mcburnie, V. Bitner, et al., for the Cardiovascular Health Study (*Chest* 2003: 123: 387-398)
Reviewed by Health Media Group writers. © HMG Worldwide 2003

Researchers from several centers reported the results of a study that investigated what factors were associated with the distance walked during a six-minute walk test in a population sample of adults over the age of 68 years. The researchers found a direct relationship between the distance walked and FEV1 in women, but not in men. They concluded that the 6-minute walk test was a simple and safe method to measure the impact of lung and other diseases on exercise capacity in the elderly.

Noninvasive Ventilation in Subset of People with Acute Exacerbations of COPD

Judith R. Fischer, Editor, *IVUN News*
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www.post-polio.org/ivun

Several studies in *Chest* and other pulmonary journals have reported on the use of noninvasive ventilation in a small subset of people who have acute exacerbations of COPD. Information about the use of noninvasive ventilation with a variety of masks is available via the web site, quarterly newsletter, and resource directory of the International Ventilator Users Network (IVUN) Web Site (*www.post-polio.org/ivun*) and quarterly newsletter *(IVUN News.)* *IVUN Resource Directory* includes information on respiratory health professionals with expertise in home care and assisted ventilation, long-term ventilator users, manufacturers of ventilator equipment and related aids, and organizations related to homecare and assisted ventilation. ■

"Patient-Friendly" Web Sites with COPD Content

Vlady Rozenbaum, PhD, COPD-ALERT
Co-editor, *NECANews*
Vlady.rita@verizon.net

This issue of *NECANews* introduces a new ongoing section: a list of "patient-friendly" web sites with COPD content. We hope to cut down the surfing time needed to find exactly what you need. The newsletter sections will be compiled into a section of the *COPD Peer Support Group Directory and Resource Guide* and as components of the Tool Kit.

At least one study has indicated that "Among web sites providing information on COPD, commercial sites were much more likely to be of poorer quality compared to sites of non-commercial organizations." This conclusion appears in an abstract of "Quality of Web-based Medical Information on Stable COPD: Comparison of Non-commercial and Commercial Web Sites." Authors H. Kunst and K. S. Kahn (Department of Respiratory Medicine, St. Mary's Hospital, London, UK; *hkunst@doctors.org.uk*) used a metasearch engine to locate 11 relevant commercial and 12 relevant non-commercial web sites that included medical information on the management of COPD. They then rated the sites for credibility and accuracy on a scale of 0 to 10. Non-commercial web sites more often provided information about cessation of smoking (100% vs. 64%), preventive influenza vaccinations (42% vs. 9%), and use of long-term oxygen therapy (92% vs. 45%). (The original article was published in *Health Information Library Journal*, March 2002, pages 42-48; the abstract was located using PubMed, indexed for MEDLINE–PMID: 12075849).

While the study was conducted more than two years ago, the situation has not improved much. A number of "flagship" COPD sites continue to list "patient" links that primarily promote fee-for-service programs. Please contact me if you know of a professional publication evaluating a host of medical sites or if you wish to suggest web sites for review.

(In alphabetical order according to organizational or institutional host)

www.chestnet.org/
American College of Chest Physicians
Invaluable resources divided into several categories: Physician Resources; Patient Resources; Online Education; Annual Meeting; CHEST Journal; CHEST Foundation; Guidelines; and Advocacy Resources.
Special feature: Tobacco Cessation Tool Kit with materials oriented to patients

Language: Geared more toward professionals than for patients, but understandable
Navigation: Excellent, including a very good links section

www.lungusa.org/diseases/
American Lung Association
Includes lots of information about lung disease, from current medical news to descriptions and treatments. Patient Lung Profilers (including one for COPD) protect privacy while allowing patients to get a closer look at their condition and offering steps to be taken. Information divided into several major components, including Diseases A-Z, Asthma, Tobacco Control, Air Quality, Occupational Health, School Programs, Data and Statistics, and Publications, among others. Many invaluable links are grouped in several categories: Advocacy & Information, Federal Resources, Healthcare Associations, Health Insurance, Patient Information, Social Services, Special Health Issues, and others.
Language: Easy to understand
Navigation: Fairly simple

lung.ca/copd/
Canadian Lung Association
Contents and organization similar to the ALA site, but not as crowded. "Breathe Easy—A Guide to Living with COPD" provides helpful basic information.
Special feature: "BreathWorks™" focuses on community programs and resources available across Canada, including supports groups (via the BreathWorks Helpline, 866-717-2673), respiratory rehabilitation programs, community centers, help lines, home care resources, and public health units
Language: Very basic and direct
Navigation: Easy

www.lib.uiowa.edu/hardin/md/resp.html
Hardin Library for the Health Sciences, University of Iowa
A very good list of links to Respiratory System and Lung Diseases, including very helpful pictures and illustrations.
Language: Fairly technical, but pictures and illustrations help with understanding
Navigation: Easy

www.intellihealth.com
Harvard University Medical School
Includes extensive information about COPD and pulmonary diseases.
Language: Somewhat technical but clearly written
Navigation: Very user-friendly, with an effective search feature to access specific information

www.howstuffworks.com/lung.htm
"How Your Lungs Work," from HowStuffWorks, Inc., provides a good description of how breathing and lungs work, with easy-to-understand illustrations.

www.mic.ki.se/Diseases/C08.html
Karolinska Institutet University Library (top medical center in Sweden)
Diseases and Disorders section includes links pertaining to respiratory tract diseases. Excellent collection of articles and images from and links to the most reputable resources around the world. Although geared to medical professionals, patients familiar with medical language and literature may benefit greatly from visiting this site.
Language: Requires knowledge of basic medical language and literature
Navigation: Easy, with links to world-wide resources

www.mdlinx.com/pulmonologylinx/index.cfm
MDLinx Network provides links to important pulmonology articles from leading medical journals.
Language: Technical but understandable
Navigation: Clear links

www.medicinenet.com/lungs/focus.htm
MedicineNet.com, a health and medical information site produced by doctors but geared toward patients, provides basic information on COPD and respiratory diseases, procedures and tests, and smoking risks.
Not elaborate, but covers the basics.
Language: Directed to general public
Navigation: Basic

http://content.health.msn.com/content/healthwise/193/61841.htm?printing=true
MSN Medical Encyclopedia, produced in cooperation with WebMD, provides a fairly comprehensive presentation of COPD topics, ranging from causes and symptoms to exams, tests, and treatment. The section on inhalers is particularly helpful.
Language: Easy
Navigation: Very simple

www.nhlbi.nih.gov/health/public/lung/index.htm
National Heart, Lung, and Blood Institute
The site helps the NHLBI provide "leadership for a national program in diseases of the heart, blood vessels, lung, and blood; blood resources; and sleep disorders." It provides information for medical professionals and patients, as well as insight into government-sponsored programs and policies.
Language: Relatively technical
Navigation: Extensive search feature allows users to find specific, useful information about COPD and respiratory diseases

www.njc.org
National Jewish Center for Immunology and Respiratory Medicine
Intended for people with lung, allergic, and immune diseases who need competent diagnosis and care. This site promotes NJC patient services, free publications, and "Lung Line." It contains a wealth of information on COPD medical facts (COPD MedFacts) and other respiratory diseases, from smoking cessation programs to treatment, medications, and explanations of tests and procedures. The site also offers medical news and information on current research.
Language: Presents scientific information in patient terms
Navigation: Easy

www.nlhep.org/
National Lung Health Education Program
Established by NLHEP Co-Chair and Founder, Dr. Thomas L. Petty, world-renowned COPD expert and patient advocate. This site focuses on "the prevention of lung disease and the promotion of lung health." It explains spirometry and provides guidance on smoking cessation. Patients will value the Resources page, which offers articles, slide presentations, and information for downloading.
Language: Plain
Navigation: Easy

www.pulmonologychannel.com/
Pulmonology Channel by HealthCommunities.com is a comprehensive site with clear links to major topics of interest to COPD patients.
Special features: Online videos on lung conditions and patient-to-patient forum.
Language: Clear with lots of visual aids
Navigation: Very easy

portableoxygen.org/
"Portable Oxygen: A User's Perspective," is an outstanding site for information on oxygen systems.

www.perf2ndwind.org
Pulmonary Education & Research Foundation
Offers valuable information, grouped in several categories: Education (breathing, oxygen therapy); 21st Century Therapies (a review by Dr. Casaburi; new research); news; scientific articles; and an online edition of *Second Wind* (including a regular column by Dr. Tom Petty). *Second Wind* itself is packed with useful information, including articles covering various aspects related to travel, breathing, self-care, equipment, resources, research, etc.
Language: Geared to patients
Navigation: Straightforward; includes a helpful search feature

www.radiologyinfo.org/content/chest_radiography.htm
Radiography-Chest (Chest X-Ray), by Radiology Information of the Radiological Society of North America, provides comprehensive information about chest X-rays that patients will find very useful.

www2.jeffersonhospital.org/e3front.dll?durki=5226&site=616&return=9555
Thomas Jefferson University Hospital
Provides general yet quite comprehensive information on respiratory disorders, including specific diseases, diagnoses, and treatments, as well as descriptions of tests and procedures.
Language: Understandable by patients
Navigation: Very easy ■

Reader Response Sought

We are looking for suggestions for making the listings as helpful as possible. Ed Madara, American Self-Help Clearinghouse (*ashc@cybernex.net*), feels that the "bottom line" is "how useful and helpful the sites really are to meeting patients' needs." Because this information does not yet appear to be available, we are asking *NECANews* readers to submit the names and descriptions of web sites they recommend and the reasons for the recommendations. Based on the list we develop from your responses, we could develop a COPD web site message board and ask you to use a one to five "star" system to rate the value of sites, as well as to suggest new sites.

- Recommended sites and why:
- Information you would like to see but were not able to find:

Please email to Vlady at *vlady.rita@verizon.net*. If you have web site expertise and experience and are interested in serving on NECA's Web Site Development Committee, please contact Vlady.

Need funds for developing a web site? Get on the waiting list for free web site consultation proved by *www.charityfocus.org*.

International Surge of Interest in COPD

Carl Wiezalis, MS, RRT
International Affairs Liaison

NECA is honored to have numerous contacts with international COPD leaders, enabling us to draw on their expertise, to build strong relationships among respiratory experts (physicians, respiratory and rehabilitation therapists, etc.), and to learn from relationships between patients and professionals. We are gratified by reports that these experts have found *NECANews* and *www.NECAcommunity.org* of assistance in their efforts to establish COPD patient groups. Our international friends also have commented positively about the information and resources available via COPD-ALERT (founded and moderated by NECA Board member, Vlady Rozenbaum, PhD) and the National Lung Health Education Program (featured prominently in each issue of *NECANews*).

1st Alpha-1 International Patient Congress

On June 11, 2003, the Alpha-1 Foundation hosted the first Alpha-1 International Patient Congress in Barcelona, Spain, for patient leaders from around the globe. These leaders had communicated via the Internet for years; the International Patient Congress provided them with an opportunity to interact face-to-face to discuss key issues that impact people diagnosed with Alpha-1 and their families. The Congress was co-chaired by Sarah E. Everett, Alpha-1 Foundation Board of Directors (United States), and Shane Fitch, Asociacion Espanola Para El Deficit de Alfa-1-Antitripsina (Spain). Congress participants included representatives of patient support groups from 14 countries, of government agencies from Spain, and from industry. For more information please visit *www.alphaone.org* or call toll free 877-2-CURE A1 (877-228-7321).

Brazilian COPD Patients' Organization

www.dpoc.org.br

Maria Christina Lombardi O. Machado, MD
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Rua Botucatu 740 - 3o andar
0402.3062 San Paulo SP Brazil

The Brazilian COPD Patients' Organization, established and coordinated by Christina Machado, MD, is the largest patient group identified during the American Thoracic Society meeting in Seattle, WA, in May 2003. Dr. Machado exemplifies the ideal patient-centered physician with the passionate commitment necessary to inspire patients to work together to improve the quality of care and of their lives. In 2000, the patients themselves invited Christina to be their "official medical director," a gratifying culmination of her 20 years of treating people with severe COPD. Those who experienced her warmth, compassion, and sincerity at the ATS meeting would understand immediately why the patients selected Christina to champion their cause.

Her first-hand experience of the complications and challenges accompanying the various stages of COPD have equipped Christina to help the Patients' Organization accomplish its goals. These accomplishments include increasing the number of people associated with the Patients' Organization in order to impact on the political system. Patients and professionals will work together to establish a National COPD Program that will contribute to a global approach to treating COPD and supporting patients.

Canada Developing Online COPD Patient Module

Roger Goldstein, MD
rgoldste@westpark.org

Dr. Roger Goldstein and his Canadian colleagues are nearing completion of an online COPD patient module, to be available to anyone in Canada at no cost (sponsored by an unrestricted educational grant from Boehringer-Ingelheim). The module has been extensively peer reviewed and used by about 50 patients. Plans include customizing the module for use in the United States, including modifying drug names, spelling, etc. Watch *www.NECACommunity.org* for availability of this important patient resource. An early reviewer of the site, Vlady Rozenbaum thinks it will provide a great service to people with COPD.

Canadian Thoracic Society COPD Guidelines for Family Doctors

The Canadian Thoracic Society has published *COPD Guidelines for Family Doctors*, developed by a committee chaired by Denis O'Donnell, MD (*odonnell@post.queensu.ca)*
The Executive Summary was published in the May/June 2003 issue of the *Canadian Respiratory Journal*.

NECA Medical Advisory Council Adds Eight International Members

NECA recently added the following COPD leaders committed to patient empowerment to its Medical Advisory Council:

Dr. Rohini Chowgule–India
Dr. Jose Jardim–Brazil
Dr. Josep Roca–Spain
Dr. Marc DeCramer–Belgium
Dr. Tan Wan Cheng–Phillipines
Dr. Jan Zielinski–Poland
Dr. Roger Goldstein–Canada
Dr. Claudio Donner–Italy

Patient/Family Advisory Council Encourages Advocacy, Activism

The Patient/Family Advisory Council (PFAC) is dedicated to making patient-centered care a reality by mobilizing and facilitating patient/family participation in Advocacy, Networking, Service, Wellness, Education, Research, and Service

(ANSWERS) activities. Through the newsletter and web site, seminars, workshops, and presentations at patient and professional meetings, the PFAC encourages people with COPD to become "activist advocates."

2003 Priorities

During 2003, we encouraged members and others to join local support or advocacy groups, be identifed with COPD causes, attend congressional and other public hearings, and participate in appropriate clinical trials. We also asked for input to the Self-Care/Peer Support Program designed to support patient efforts to actively manage their own care and make healthier life choices. We made progress in developing a yoga-based breathing and stretching video and in organizing the Tobacco Awareness Campaign.

2004 Priorities

During 2004, the PFAC will support the efforts of people with COPD and their families to participate in developing COPD networks and COPD events to encourage early identification and treatment, prevention, and improved treatement and care. Patients and patient groups will be asked to provide information for the *COPD Peer Support Group Directory and Reseource Guide* and to develop support groups to address unmet needs. The PFAC will also address obstacles to patient/family participation by recommending mechanisms to permit participation of patients with severe symptoms or cultural barriers (including health literacy and language barriers).

Please contact Hannah Hedrick (information below) if you are interested inserving on the (PFAC).

Patient/Family Advisory Council Members

Hannah L. Hedrick, PhD, Coordinator
Box 298, Mountain View, HI 96771
808-968-7013
hedrickhneca@aol.com

Tim Buckley, RRT, FAARC, Director
Respiratory Services, Walgreens Health Initiatives
Chicago, IL

Nancy Cangemi, Vice President of Programs
American Lung Association/Arizona-New Mexico
Phoenix, AZ

Daryl Isenberg, PhD, President, Illinois Self-Help Coalition
Chicago, IL

Philippe Joud, COPD Network Coordinator, Lyons, France

Amy Maggio, Senior Vice President
Torre Lazur PR, Chicago, IL

Linda Marshall, CTC, ACC, Group Travel
Network, Ticonderoga, NY

Kitty McAndrews, Deputy Executive Director
Professional Services & Research, ALA of Metropolitan
Chicago, Chicago, IL

Kristen McFall, Cystic Fibrosis Foundation, Denver, CO

Ronald Peterson, Prevention Video Corp., Kerrville, TX

Vlady Rozenbaum, PhD (see Board)

Vijai Sharma, PhD (see Board)

Don Soderstrom, Albuquerque, NM

Janet Taylor, Nova Scotia, Canada, International Section

Diane Walsh, Alpha-1 Foundation, Miami, FL

Eileen Zacharias, JD, ARDS Foundation, Northbrook, IL ■

Come Celebrate, continued from page 1

self-care activities: yoga-based breathing and stretching and t'ai chi chih®. Professional speakers include Tom Petty, MD, Co-chair of the National Lung Health Education Program, and James Kiley, MD, Director, Division of Lung Diseases, National Heart, Lung, and Blood Institute. Patient leaders include John Walsh and NECA Board members, Vlady Rozenbaum and Vijai Sharma. Registration is free, so bring your friends and relatives!

October (National Respiratory Care Week, Lung Health Day) and November (National COPD Month, World COPD Day) provide many opportunities for collaborative COPD events. NECA, the National Lung Health Education Program, and other national and local professional and patient groups will be conducting COPD Education Days and COPD/Lung Health Events at many locations around the country. These events can range from simply handing out literature to a full day of screenings and educational programs. Be sure to contact me if you would like to help plan or coordinate an event.

Finally, I encourage all of you to contact your congressional representatives about COPD issues via the new advocacy page at *www.NECACommunity.org*! Register for the Orlando COPD Education Day today by calling Brenda Buenaventura at 888-825-7421 X 242 or by e-mail at *brendab@alphaone.org*. ■

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