NECA News

National Emphysema/COPD Association May 2003

NECA
ADVOCACY
NETWORKING
SUPPORT
WELLNESS
EDUCATION
RESEARCH
SERVICE
National Emphysema/COPD Association

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

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

Help NECA Develop “ANSWERS”

Barbara Rogers, *President*

Dear Members and Friends,

Thanks to your support and encouragement, the National Emphysema/COPD Association (NECA) has had a very rewarding “organizational” year! The many administrative services provided by Lovelace Respiratory Research Institute and financial support from Dey LP and the National Emphysema Foundation have enabled us to launch major patient programs.

NECA has established numerous supportive relationships with patient groups and national programs focusing on emphysema/COPD. The Patient/Family Advisory Board (PFAB), coordinated by Hannah Hedrick, PhD, mobilizes and facilitates patient/family participation in all aspects of NECA. The Medical Advisory Board (MAB), co-chaired by Byron Thomashow, MD, and Tom Petty, MD, promotes collaborative projects in the professional community to support empowerment of patients and their families, including participation in national meetings.

The PFAB and MAB are developing NECA Networks to organize collaborative “Lung Health Events” in locations around the country during October and November 2003. Events will reflect local priorities, but we hope to include spirometry testing, tobacco prevention and cessation materials, “ Tool Kits,” and group directory/resource guides at all locations. Already on board for these events are groups for people with emphysema/COPD and their families, lung associations, respiratory care organizations, the National Lung Health Education Program, rehabilitation and research centers, educational and healthcare institutions, public relations agencies, and corporations.

We are committed to giving people with emphysema/COPD and their families a voice! By uniting our advocacy efforts, we can make great strides forward in increasing access to information, providing resources for support, and having our needs heard. Please join NECA and help us develop “ANSWERS” related to living with and preventing lung diseases.

To show our commitment to persons living with emphysema/COPD, we offer **FREE membership to all COPD patients** via www.NECACommunity.org or the form on the back. The first 100 support group leaders who pay the $25 group fee will receive a free copy of *Frontline Advice for COPD Patients* (see page 5).

I would love to hear from all of you, especially if you wish to participate in developing collaborative Lung Health Events or if your contributions are not reflected in the following pages. Above all, let us know what issues you would like NECA to address to improve the lives of people with emphysema/COPD!

Register now for the National COPD Conference, November 13-15, 2003 (www.uscopd.com).

Overview of COPD

***Douglas W. Mapel**, MD, MPH*

Chronic obstructive pulmonary disease (COPD) is the clinical term physicians use to describe the two most common non-cancerous lung diseases: chronic bronchitis and emphysema. Most persons who smoke develop some degree of both disorders. Because the symptoms and effects of both diseases are similar, physicians tend to use the term COPD instead of the two more specific terms. Currently the fourth leading cause of death in the United States, COPD is the only disease among the top leading causes of death projected to increase over the next decade.

Chronic bronchitis

Chronic bronchitis is a disease of the lung airways. Symptoms usually include a chronic productive cough, shortness of breath with exertion, and frequent respiratory infections. People with chronic bronchitis may also experience episodes of wheezing and chest tightness associated with exercise or exposure to cold air. The symptoms and pathologic findings of chronic bronchitis share many features with asthma, and treatments are similar.

Emphysema

Emphysema is a disease of the lung acini, the fleshy part of the lung that contains the millions of tiny air sacs where oxygen and carbon dioxide exchange takes place. In emphysema, the walls of the air sacs are gradually destroyed, resulting in a lung full of holes in a pattern similar to Swiss cheese. Because emphysema progresses very slowly, people may not be aware of any problem until more than half of the lung tissue is destroyed.

Lung tissue cannot regenerate itself, so these holes are permanent, as is the chronic shortness of breath experienced by people with emphysema. The lung destruction may slow down if an individual quits smoking.

NECANews
National Emphysema/COPD Association

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

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

Complementary Health Practices and Lung Diseases

Complementary Health Practice Review, an international, peer-reviewed journal, requests manuscripts on topics related to complementary health practices in the treatment and care of people with lung disease. *Complementary Health Practice Review*'s mission is to foster communication across disciplinary, organizational, and specialty boundaries and promote critical thinking. How is complementary medicine integrating with or changing conventional models of health? Research results on cultural, sociological, demographic, political, philosophical, economic, and legal aspects of complementary practices are invited. For manuscript guidelines or information, contact Jonathan Zuess, MD, Editor, Arizona State University East, 7001 E. Williams Field Rd., CLRB Building, Mesa, AZ 85212; 480 727-1060, fax 480 727-1051; jonathan.zuess@asu.edu or go to www.sagepub.com/journal.aspx?pid=356.

US COPD Coalition Consumer Committee

On February 4, members of the US COPD Coalition Consumer Advisory Committee agreed that a survey should be conducted to identify the needs and contributions of patient groups. John Walsh, President of Alpha-1 Foundation, will develop a planning and funding process for the survey. Information: jwwalsh@alphaone.org.

NHLBI Public Interest Organization Meeting

On February 5, 2003, NECA participated in the National Heart, Lung, and Blood Institute's fourth annual Public Interest Organization meeting (www.nhlbi.nih.gov/public/pio2003/index/htm). *FYI from the NHLBI* (www.nhlbi.nih.govFYIfront.htm) will include items on the outcomes of the meeting, including one on how NHLBI PIO meetings have promoted collaborative initiatives to empower people with lung disease. The momentum initiated at the PIO meetings is sustained by Jim Kiley, MD, Director of the Division of Lung Diseases. Dr. Kiley's availability for advice and information, as well as his attendance at NECA-sponsored meetings, have been instrumental in achieving professional support of empowerment approaches.

NECA Networks Looking for "ANSWERS"

HHedrick@NECACommunity.org.

Local NECA Networks are being formed to fulfill NECA's mission of "empowering people with emphysema/COPD and their families and caregivers to improve the quality of patient care and the quality of their lives." NECA Network Coordinating Committees will bring NECA members together to form "ANSWERS" to living with emphysema/COPD:
A: Promote patient and professional Advocacy efforts
N: Provide Networking information and opportunities
S: Offer Support programs for patients and caregivers
W: NECA Self-Care/Peer Support "Wellness" Program
E: Sponsor and conduct Educational programs
R: Support local and national Research efforts
S: Provide Service to members, patients, and families

The primary focus in 2003 is to organize collaborative Fall "Lung Health Events," with special efforts to include people isolated due to age, incarceration, or advanced disease states.

Networks and planning committees are being formed in **Arizona/New Mexico** (Nancy Cangemi, ALA Arizona/New Mexico); **Boston** and **New York** (Barbara Rogers); **Chicago** (see below); **Hawaii** (Hannah Hedrick); **Indianapolis** (Debbie Cullen, Indiana University); and **Orlando** (John Walsh, Alpha-1 Foundation, and Byron Thomashow, Jo-Ann LeBuhn Center for Chest Disease & Respiratory Failure).

Chicago: First "NECA Network"

Members of Chicago's NECA Network Coordinating Committee, organized in February 2003, host meetings to organize NECA participation in collaborative events, such as the October 18, 2003, Chicago Lung Health Day. For information contact Lisa Zaenger (Lisa@pulmonaryexchange.com) or Daryl Isenberg (dipeace@aol.com). To participate in the above sites or organize events in additional locations, contact Barbara Rogers, BRogers@NECACommunity.org, 212 666-2210, or Hannah Hedrick, HHedrick@NECACommunity.org, 808 968-7013.

"It's Never Too Late to Quit!"

Carol Southard, *RN, MSN, Smoking Cessation Specialist*
Northwestern Memorial Hospital Wellness Institute
Chicago, Illinois

Tobacco use causes one in five deaths in the US, 33% of deaths from cancer, 30% from coronary heart disease, and 80-90% from COPD! It is the leading preventable source of illness and premature death.

Smoking prevalence has decreased over the past 25 years, but the number of current and new smokers is alarming; 50,000,00 adult Americans now smoke. Most troubling is the fact that the smoking incidence among adolescents is rising: **more than 3000 children and adolescents become regular users of tobacco each day**.

Nearly 35 million people in the US attempt to quit each year. But no addictive substance is more powerful than nicotine, so 90% of smokers **who try to quit without treatment assistance** start smoking again, most within a week.

The good news is that there are effective treatments, including participation in support programs. Unless contraindicated, six "first-line" medications are available. Repeated sessions with a health care provider or smoking cessation specialist are also effective in preventing relapse.

And it's never too late to benefit from quitting! Even older, long-term smokers already suffering from smoking-related lung disease, such as COPD, can enhance the quality of their lives.

"Teen Tobacco Prevention"

Thomas Petty, MD, and Ron Peterson have collaborated on "Walden Pond on High," an inspirational account of Ron's transformation into an "activist advocate" after receiving a lung transplant in 2000 for tobacco-acquired emphysema. Three videos designed to convince teens not to start smoking are available through Prevention Video Corporation. For information and Ron's "Teen Smokers Speak Out," see www.geocities.com/ronaldpeterson.geo.

Self-Care/Peer Support Program

Hannah Hedrick (**HHedrick@NECACommunity.org**)

I invite you to tell me your experiences/expertise related to NECA's Self-Care/Peer Support Program:

- Activities/materials that would help you develop healthier habits
- Your skills in developing self-care materials
- How you find people with similar challenges to support you
- Your experiences in lung disease stages and care settings that could help others

Self-care basics will be included in the *Lung Peer Support Program Directory and Resource Guide*, including

1. Breathing techniques (meditative and medical)
2. Achieving adequate hydration, nutrition, and rest
3. *T'ai chi chih* movements, mindful walking, yoga-based stretching (land, water, chair, bed versions), dancing
4. Meditation and relaxation techniques
5. Healing touch techniques
6. Importance of service, intimacy, and spiritual practices

Self-Care Resources

The relevance of the following self-care resources to people with COPD will be described at greater length in the October *NECANews*. The resources are being considered for inclusion in NECA's Self-Care/Peer Support Program.

Qigong: cultivates “vital energy” by integrating physical postures and breathing techniques with focused intention.

- “Discovering Qigong” video, featuring the “Five Treasures,” includes safe, basic Qigong movements. National Qigong (Chi Kung) Association, USA www.nqa.org; info@nqa.org, 218 365-6330.
- *The Way of Qigong: The Art and Science of Chinese Energy Healing* (Kenneth S. Cohen, Ballantine Books, 1997) includes easy-to-understand practical movements, benefits, and cautions, along with interesting history.

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, Ft. Yates, ND 58538 or 888 540-7459.
For teacher referrals or information, contact Kathy Albers, www.thevitalforce@yhaoo.com, 314 727-1983.

Yoga: Kripalu Yoga Teachers Association Website

To inquire about teachers experienced in working with people with impaired lung function, email kyta@kripalu.org.

Journey to Empowerment

Linda Marshal, CTC/ACC, Grouptvl@aol.com

During the early months of my experience with COPD, I felt I had been sentenced to death. Estimated survival times varied from 24 to 48 months. Health care professionals seemed as hopeless and helpless as I was about stopping, slowing down, or coping with my disease. I underwent all the tests from Alpha 1 to X-rays! Diagnosis: severe emphysema!

Now “Hopeful and Helpful”

But I no longer feel helpless or hopeless. I'm taking an active role, including participating in the FORTE study, doing pulmonary rehabilitation, and enrolling in the last stage of the Spiriva drug trials. I joined five COPD support groups in the New York City area, which led to my role as a media figure for the American Legacy Foundation's smoking cessation campaign for women (www.AmericanLegacy.org).

As chair of NECA's Patient/Family Advisory Board, I served on the NECA Board during the past year. From this national platform I shared my “empowerment” message: assume as much responsibility as possible in achieving the highest possible quality of life. This means having FUN! Get out there, visit with family and friends, live your “Wish List,” laugh, and love.

Currently, I am working on networking the COPD groups in Upstate New York and Vermont. I am also helping Interlakes Hospital create a pulmonary rehabilitation program, COPD support group, and caregivers group. Other activities include hospice volunteer training, an exercise program for people with chronic illnesses, and a health fair.

“Respectful Communication,” Hope, and Support

At dozens of presentations, I have worked with physicians and patients to encourage them to listen to each other. Only then can we work together to improve the whole process of diagnosis, treatment, and care. Through NECA, the American Legacy Foundation, and the Society for Accessible Travel with Hospitality, plus presentations at support groups and rehabilitation centers, we deliver the message of hope through research and support for an improved quality of life.

Linda is a member of NECA's Patient/Family Advisory Board (PFAB). She served in the PFAB Chair position on the NECA Board during the past year. She is currently organizing NECA Networks in Upstate New York and Vermont. She speaks publicly on travel for persons with disabilities, smoking cessation benefits, “Quality of Life with COPD,” and addictions.

Respiratory Therapists in the Home

The American Association for Respiratory Care (AARC) is working to gain recognition of respiratory therapists (RTs) under the Medicare home health services benefit. Under current federal regulations, homebound Medicare patients with emphysema/COPD and those who depend on ventilators do not have access to RTs. The AARC proposal would give home health agencies, under a physician's care plan, the flexibility of using RTs as another provider option to render this care.

Benefits of RT Home Health Visits

Patient: Access to care in the home from professionals with academic preparation, clinical training, and competency testing in respiratory therapy, resulting in appropriate transfer from acute care facilities to home settings and decreased emergency room visits and readmission after discharge.
Home health agencies: Greater flexibility in resource utilization, resulting in the ability to meet patient needs and control costs.
Physicians: Ability to tailor treatment regimens based on patient needs, resulting in improved continuity of care.
Medicare: Ability to offer choices to home health agencies, physicians, and patients without additional expense, resulting in improved quality of care and of life.

Working with the Centers for Medicare and Medicaid Services (CMMS), the AARC developed legislative language to recognize RTs under this benefit in a budget-neutral manner. The use of RTs would not be mandatory, and RTs would deliver care within their scope of practice.

If you support patient access to respiratory therapists in the home, contact Jill Eicher, AARC Director of Government Affairs, at 703 548-8538 or eicher@aarc.org for information.

National Respiratory Care Week

Many people still don't know that COPD is the fourth-leading cause of death in the US and the only major cause of death on the rise. National Respiratory Care Week is designed to change that. From October 19-25, 2003, American Association for Respiratory Care (AARC) state societies and health care facilities will organize activities ranging from lectures to spirometry screenings and fun runs. Special emphasis will be placed on Lung Health Day (October 22), originated by the AARC to promote awareness, testing, and disseminating information about available treatments, including those designed to improve the quality of life. Contact the state respiratory care society or your local health care facility to see what is planned.

Good Advice

Don't know if exercise would really make you feel better? Can't find a physician who will refer you to a rehabilitation program? Interested in satisfying sexual activity?

If you answered "yes" to any of the above questions, *Frontline Advice for COPD Patients* (James T. Good, Jr., MD, and Thomas L. Petty, MD, editors, with eight additional authors) provides the answers via pictures of real people with emphysema/COPD or via drawings.

Additional topics, many of them illustrated, include:

- Presentation of how chronic bronchitis and emphysema affect the lungs
- Importance of early identification of COPD and of smoking cessation
- Effective medical treatments, including supplementary oxygen, pulmonary rehabilitation, surgery, nutrition, combating depression, and patient support groups
- Practical advice about end-of-life issues

Frontline Advice for COPD Patients will be posted (with others written by a team of pulmonary physicians for the Frontline series) on www.lungcancerfrontiers.org or www.NLHEP.org. Based on a Snowdrift Pulmonary Conference, the book is provided to physicians as an educational service by Boehringer Ingelheim Pharmaceuticals, Inc., which also prepares and distributes *COPD News*.

COPD Peer Support Programs Receive *Frontline Advice* with $25 Membership Fee

The first 100 COPD peer support programs that pay $25 to join NECA will receive a free copy of *Frontline Advice for COPD Patients*, courtesy of Boehringer Ingelheim Pharmaceuticals, Inc. Groups may also provide information for the print and electronic lung peer support program directory planned for late 2003.

Currently, there is no single publication or database with information about peer support programs and resources for people with emphysema/COPD, other lung diseases, or related conditions. NECA requests information about groups for sleep apnea, smoking cessation, diseases frequently occurring with COPD, addictions, etc., for its *Lung Peer Support Program Directory and Resource Guide.* "Lessons learned" about achieving a high quality of life with COPD will be featured in *NECANews*.

Peer support programs wishing to be listed in the *Directory* may contact Daryl Isenberg or Hannah Hedrick, dipeace@aol.com or HHedrick@NECACommunity.org.

Empowered Patients Personify "ANSWERS"

Advocacy

ALPHA 1 Foundation, AlphaNet As Models

John Walsh, Alpha 1 Foundation
(www.alphaone.org)
AlphaNet (www.alphanet.org)

In 1991, John Walsh founded the Alpha-1 Foundation to improve, through support, education, and research, the quality of life of people in the US affected by alpha-1 antitrypsin deficiency (alpha-1) (6,000 diagnosed and 94,000 undiagnosed cases). A common serious genetic disorder worldwide, alpha-1 can cause severe lung and/or liver disease and is a leading reason for transplantation. In 1995, John, Sarah Lindsey, and Susan Stanley founded AlphaNet, through which "Alphas" coordinate and consolidate therapeutic and social health services for others with alpha-1. They provide total disease management, including networking, education, reimbursement referrals, and assistance with therapeutic modalities for nearly 3,000 Alphas. AlphaNet channels a major portion of after-expense revenue to the Foundation's efforts to find a cure and to help develop less expensive, more available treatment options.

Networking

Vlady Networks via COPD-ALERT

www.geocities.com/wrozenba/COPD.html

Vlady Rozenbaum, NECA Board and Patient/Family Advisory Board member, owns and manages COPD-ALERT, an internet-based, non-profit, support and activist group for people with COPD, caregivers, medical professionals, and others who care. Members provide support through discussions on symptoms, disease management, medicines, treatment, respiratory equipment, research on COPD, medical news, family and social aspects of COPD, providers, insurance carriers, and available medical benefits.

COPD-ALERT maintains a list for "members only" at www.yahoogroups.com/group/COPD-ALERT. There group members discuss their symptoms and a variety of COPD-related topics. Additionally, the site is a repository of medical information from reputable sources and a multitude of helpful Internet addresses. The site also has a "chat" option so members can discuss topics in small groups.

Vlady helps mobilize members of COPD-ALERT to participate in functions close to their homes, such as "Better Breathers"-type groups. Members distribute the COPD-ALERT pamphlet/COPD fact sheet, write letters, and make calls. Vlady is a model for empowering people impacted by emphysema/COPD by identifying all kinds of resources and describing them via COPD-ALERT. COPD-ALERT is a member of the US COPD Coalition and American Thoracic Society's Public Advisory Roundtable and is an NHLBI Public Interest Organization.

Vlady and COPD-ALERT, like the other activists in this section, reflect most of the "**ANSWERS**" letters. For the last year, COPD-ALERT has offered "special action web pages," with sample letters and links to Congress via www.geocities.com/wrozenba/CALLS.html.

Vlady, NECA Board and Patient/Family Advisory Board member, immerses himself in an effective COPD therapy without adverse effects: patient support, net-working, advocacy, and education via COPD-ALERT.

Support

ARDSUSA@aol.com, www.ardsusa.org,
312 749-7047
Doris Peterson, Chicago Southside Sarcoidosis Support Group,
dpete77032@aol.com

Eileen Zacharias, ARDS (Acute Respiratory Distress Syndrome) Foundation, and Doris Peterson, Chicago Southside Sarcoidosis Support Group, work through the Chicago NECA Network Coordinating Committee to involve their communities in NECA initiatives, including October Lung Health Events. Both use various media to promote NECA and other patient-centered organizations.

Eileen, who also serves on the Patient/Family Advisory Board, provides a forum for ARDS patients and families around the world to support one another via the website and ARDS Foundation Online Newsletter. Composed of individuals personally affected by ARDS, the Foundation increases public awareness and provides financial support to medical research projects.

Doris Peterson, who has sarcoidosis and Parkinson's, provides support through the group as well as through hosting a weekly PBS radio program that features various lung diseases.

Wellness

Vijai Sharma: Breathing/Stretching Exercises

Dr.Sharma@mindpub.com

Vijai Sharma, NECA Board and Patient/Family Advisory Board member, is developing a video series of yoga-based breathing and stretching exercises appropriate

“ANSWERS”

for people with emphysema/COPD for NECA's Self-Care/Peer Support Program. Vijai learned yoga in India to correct spinal defects caused by osteomyelitis, a bone disease diagnosed when he was 2. He now uses yoga to compensate for reduced lung capacity (30%) due to emphysema; he can function almost as well as people with normal lung capacity. He teaches yoga at the Cleveland Family YMCA, communicates and educates via his website, and directs the Behavioral Medicine Center in Cleveland, Tennessee. His website has a special section with “self-care” references.

Education

Helping Ventilator-Users Thrive

Barbara Rogers, President, Respiratory Resources Inc. breethezy@aol.com, BRogers@NECACommunity.org www.breethezy.org

Scoliosis and asthma compromise breathing for Barb Rogers, first NECA President and Board chair; she sleeps each night with a portable positive pressure ventilator with nasal pillows. Her early years of trial and error navigating the health care system included a suggestion that she abort her pregnancy. Thanks to encouragement from Gerard Turino, MD, Barb is the proud mother of a firefighter who participated in rescue efforts at the World Trade Center during the 9/11 attacks (seven members of his Truck were lost that day).

Norma Braun, MD, another “lifesaver” for Barbara, shocked Barbara into using the ventilator gathering dust in her bedroom by asking her to donate her body to science because she would soon die. Barb overcame her fear of sleeping while a machine did her breathing, and since then has helped hundreds of people find the right equipment, settings, and other services via Breethezy, an education, recovery, and support program, and Respiratory Resources, a patient support network and education agency to teach clinicians about starting patients on ventilators. (See “Thriving, Not Just Surviving,” *The Quiet Killer*, Scarecrow Press, 2002.)

In 1999, Barb became involved in American Institute symposia that led to the incorporation of NECA in September 2001. Barb serves on the Board of the Lovelace Respiratory Research Institute and chairs the American Association for Respiratory Care Consumer Roundtable.

Research

Items throughout this issue of *NECANews* report the hope being generated through research at Lovelace Respiratory Research Institute; National Heart, Lung, and Blood Institute; National Jewish Medical and Research Center, and elsewhere.

October's *NECANews* will include an item on “Clinical Research in COPD” by Robert A. Wise, MD, Director, Johns Hopkins Asthma and Allergy Center, Baltimore, MD, a member of NECA's Medical Advisory Board. The article will focus on how clinical COPD research takes place, including protections for patients. NECA invites other researchers to send information of interest to patients.

Service

Big Island's “Auntie Kaiwi” Embodies “Aloha”

Having emphysema has not slowed down “Auntie” Kaiwi Perkins of Fern Forest, who is helping to organize the first NECA Network in the Hawaiian Islands. Auntie Kaiwi is a one-woman support system for her neighbors with life-threatening illnesses, including COPD, diabetes, and heart conditions, in this rural area in the hills 25 miles from Hilo. She drives the rutted dirt roads to distribute Food Bank supplies and water. They also seek her support in her “office,” a picnic table outside Hirano's General Store.

The Fern Forest Hui (neighborhood organization) awarded Kaiwi an honorary membership for generous contributions of labor and items during 2002 and hailed her as “Fern Forest Volunteer of the Year.” Whether picking up roadside trash, pulling weeds or painting at the Hui Lot, or teaching the ancient art of “lauhala” (basket) weaving, Kaiwi provides a model of service for people of all ages.

“Every day feels like Christmas when I help my neighbors.”

Patient "Stories" with Testimonials

NECA is committed to presenting the “stories” of people impacted by emphysema/COPD so they can benefit from sharing personal experiences. People will be asked to refrain from including "testimonials" related to treatments and other forms of care. When new or controversial treatments are in the news, NECA can provide balanced viewpoints by having a committee select varied examples of testimonials on both sides of an issue, quantifying the responses, and publishing these figures, along with representative samples.

"Mutual Aid" via Community Building

NECA's Community-Building Meetings focus on a "mutual aid" approach. Patient groups and others are encouraged to share information about their needs and contributions.

NECA's first meeting, held in conjunction with the annual meeting of the American Thoracic Society, produced a communication network. Meetings in Chicago in August and October 2002 and February 2003, hosted by the American Lung Association of Metropolitan Chicago, created a cadre of more than 50 patients, health care professionals and institutional representatives, human service providers, educators, corporations, and others.

ALAMC: Model of Cooperation

The American Lung Association of Metropolitan Chicago (ALAMC) serves as a model of collaboration for emphysema-COPD "community-building" and lung health events. Since May 2002, the ALAMC has hosted numerous planning sessions, including three NECA Emphysema-COPD Community-Building Meetings.

Under the leadership of Kitty McAndrews, Deputy Executive Director, Professional Services and Research, the ALAMC has developed plans to cultivate, assist, and partner with Chicago support groups and to work with the NECA Network to develop a Lung Health Exposition in October 2003. Current and planned activities include

- Updating lists of local support groups and rehabilitation centers for the ALAMC website, Call Center, and distribution at Lung Health Events
- Working with support groups and the NECA Network to identify materials for the Chicago Lung Support Group Tool Kit, a prototype for a national Tool Kit
- Offering free subscriptions to ALAMC's newsletter and other appropriate publication from which groups can copy and distribute articles
- Helping groups access online resources, such as ALA's electronic newsletters, *Breathe Easy/Asthma Digest* and *Weekly Breather,* LUNG NET, etc.
- Distributing Call Center pamphlets and free ALA pamphlets, as well as information about Chicago Thoracic Society/ALAMC lectures

Support Group Members "Give Back"

The support group network session on October 29, 2002, in Chicago focused on "stories" of why patients and patient groups "do what they do." The self-help group "helper therapy" principle was demonstrated as support group members reported that in "giving back" through the group, they got more than they gave.

Patients and professionals stressed the importance of learning about their own vulnerabilities, developing compassion, "having fun," joining with others to "fight for their lives," increasing visibility of lung disease, delivering a message of hope, and culturally appropriate care.

Participants passed around a "talking stick" to encourage listening respectfully, honoring boundaries, and giving others their turn. Shared coping techniques included restoring hope, tips for dealing with symptoms, and support in taking charge of their own health.

A common theme was lack of sensitivity in delivering diagnoses and prognoses. Patients asked for programs to increase physician sensitivity during disease stages, including end-of-life and bereavement.

> ***Patients would like to help physicians develop more sensitivity in communicating with patients, especially about diagnosis and prognosis.***
>
> *Common theme of patient comments*

"Reverse the Curve"

Jim Kiley, MD, Director of the Division of Lung Diseases of the National Heart, Lung and Blood Institutes inspired participants in the October 30, 2002, meeting in Chicago.

Dr. Kiley called on attendees to "reverse the direction of the emphysema/COPD mortality curve." He urged them to develop a "collective community rallied around this growing, underrecognized, underdiagnosed, and undertreated disease." One obstacle to developing a "collective community" is the common attitude that patients "did it to themselves."

> ***" 'Collective Community' needed to reverse mortality curve"***

James Kiley, MD, Director, Division of Lung Diseases--NHLBI

Arizona/New Mexico Lung Association Coordinating Lung Health Event

Nancy Cangemi, Vice President of Programs, American Lung Association of Arizona/New Mexico, is working with NECA, respiratory care practitioners, lung patient groups, tobacco prevention and cessation coordinators, educators, and others to coordinate a Lung Health Event in Fall 2003. To attend a planning meeting and to identify how the Lung Health Event fits with the mission and strategic plans of your organization, contact Nancy (ncangemi@lungaz.org).

Treatment, Tobacco Cessation Resources

American Association of Cardiovascular and Pulmonary Rehabilitation: Provides information on nearly 850 centers, arranged by state, on www.AACVPR.org.

American College of Chest Physicians: A “treasure chest” of anti-tobacco materials was presented at the November 2002 ACCP meeting. Resources of special note include: “Don't Let the Lives of Women and Girls Go Up in Smoke”-annotated slides with presentation tips, activities, pre and post-tests from the Task Force on Women & Girls, Tobacco, & Lung Cancer; http://speakerskit.chestnet.org
Tobacco Cessation Tool Kit for Physicians - various tools to assess level of addiction, define the need for pharmacotherapies, and determine follow-up and relapse techniques. Includes AHRQ Guideline on Tobacco Use and Dependence and patient motivational brochures. Sandra Zelman Lewis, PhD, 847 498-1400.

American Legacy Foundation tobacco cessation: www.americanlegacy.org/greatstart/html/home.html

American Lung Association/American Thoracic Society Advocacy Resources
The joint ALA/ATS Washington Office advocates on legislative and regulatory issues by enabling state and local ATS and ALA volunteers, members, and staff to participate in grassroots advocacy on public policy initiatives. These advocates are kept informed via Public Policy Briefs, the weekly *Washington Letter* (1726 M Street, NW, Washington, DC 20036; 202 785-3355.

American Lung Association Call Centers/Websites, COPD Patient Profiler, E-Advocacy, and “How to Quit” Training Program: http://www.lungusa.org:
Staffed by registered nurses and respiratory therapists, ALA call centers (telephone or website) respond to submitted questions within 24-28 hours. COPD profiler tools assist patients and their physicians to better understand treatment options and medical evidence.

Centers for Disease Control and Prevention Tobacco Cessation: www.cdc.gov/tobacco/how2quit.htm

National Heart, Lung, and Blood Institute, NIH
Chronic Obstructive Pulmonary Disease (COPD)
(Publication No. 95-202) provides a detailed look at COPD, including diagrams of the airways and descriptions of disease symptoms, methods of detection, and treatment. Special attention is given to coping strategies for patients, families.
http://www.nhlbi.nih.gov/health/public/lung/other/copd/index.htm

Medline Plus Health Information Website: Latest COPD news, overviews, statistics, anatomy/physiology, clinical trials, treatments/disease management, and other resources. http://www.nlm.nih.gov/medlineplus/copdchronicobstructivepulmonarydisease.html

COPD workshop: Results of deliberations of an expert panel that examined enigmas and apparent contradictions in COPD research. Identifies the potential for new pharmaceuticals. Available in *Am. J. Resp. Crit. Care Med.,* Volume 165, Issue 6, and at http://www.nhlbi.nih.gov/meetings/workshops/copdwksp.html.

National Jewish Medical and Research Center
- www.nationaljewish.org gets 60,000 visitors a month, with about 90% looking for patient information
- “Lung Line” (800 222-LUNG): Nurses respond to calls
- “Lung Facts” (800 522-LUNG): more than 70 messages
- “Medfacts”: Sixty-four fact sheets, free via the website
- Nine booklets: NJMRC Lung Line Information Service, Room M300, 1400 Jackson Street, Denver, CO 80206
- “Physician Line” (800 NJC-9555): 7,000 calls a year

National Women's Health Information Center
www.4woman.gov/quitsmoking

Smoke-Free Families (pregnant smokers)
www.smokefreefamilies.org

Spirometry Testing Programs

Rush University Medical College, Chicago, Illinois, offers “Performing Office-Based Spirometry Using the Latest Technology” and “Interpretation of Office Spirometry,” directed by Robert Cohen, MD, and “Practicum on Performance of Office Spirometry,” Moises Ortega, CMLT; Gail Harris, CRT, RPFT; and Don Dyson, MS.

Walgreens Spirometry Pilot Program

For information on Walgreens Spirometry Pilot Program, contact Tim Buckley, Director, Respiratory Services, Walgreens Health Initiatives, tim.buckley@walgreens.com

Peer-Support Resources

Acute Respiratory Distress Syndrome Foundation
“Pamphlet for Families, Friends, and Patients,” ardsusa@aol.com.

American Self-Help Clearinghouse
- Provides information and contacts by phone, keyword searchable database via the Internet, or *Sourcebook* (see below) on
  - How to find, start, maintain and evaluate face-to-face and online groups
  - National self-help groups, model groups
  - Self-help group clearinghouses worldwide
  - 300 national tool-free specialty helplines
- Distributes inexpensive publications ($8-$15) on developing specific types of groups
- *Your Guide to Community and Online Support Groups,* seventh edition; www.selfhelpgroups.org, 973 326-6789

University of Puget Sound, *Arches*, Winter 2003: “A Turnabout for 'Top-Down'“: Report on the value of Internet and face-to-face support groups that “unite and empower people with disabilities.”

Practitioners, Researchers Offer Hope

Collaborative Management = Empowerment

To learn the meaning of NECA's mission statement, "empower people with COPD," talk with Medical Advisory Board member Bart Celli, MD, Chief of Pulmonary, Critical Care, and Sleep Medicine at St. Elizabeth's Medical Center, Boston. At national and international conferences, Dr. Celli promotes "collaborative management," in which patients actively participate in decisions about treatment options.

> *"I will continue to work to help people with COPD get what they deserve:* ***hope and a chance****."*
>
> **Bartolome Celli,** NECA Medical Advisory Board

At the Pacific Rim COPD Meeting on the Big Island of Hawaii on January 10-12, 2003, Dr. Celli delivered a message of hope. He challenged comments questioning early diagnosis of COPD and claims that physicians had few useful treatment options.

Lamenting the "unjustified nihilistic therapeutic attitude of many health care providers," Dr. Celli urged his colleagues to move from presenting COPD as a "terminal" illness to one that is "largely preventable and treatable." Dr. Celli's interventions that improve survival and symptoms include

- Smoking cessation
- Long-term oxygen therapy when indicated
- Non-invasive ventilation for acute chronic respiratory failure
- Pharmacotherapy
- Rehabilitation (education, training and exercise, psychological support)
- Surgery (pneumoplasty/lung volume reduction, transplants)

COPD Research Creates New Optimism

Robert Rubin, PhD, President and CEO
Lovelace Respiratory Research Institute, Albuquerque, NM

COPD, a serious public health problem that annually claims the lives of nearly 120,000 Americans and disables millions more, is one of the most understudied chronic human illnesses. Fortunately, advances in cellular and molecular immunology have given scientists new ways of looking at lung disease. Research into the human genome may help explain why some people have a higher risk of developing COPD than others.

Clinical Trials for New Medications for COPD

Currently prescribed medications for COPD include home oxygen therapy, bronchodilators (help to open narrow passageways), and corticosteroids (decreased airway inflammation). A number of therapies in clinical trials show promise. These include muscarinic antagonists/ cholinergics (e.g., Spiriva), beta 2 adrenoreceptor agonists (bronchodilators), particularly in combination with other drugs such as corticosteroids (e.g., Advair), and phosphodiesterase inhibitors (e.g., Airflo). A list of COPD US clinical trials is available at www.centerwatch.com/patient/studies/cat44.html.

Pharmaceuticals to Prevent Cancer

A number of pharmaceutical companies are trying inhaled retinoids to prevent cancer. LRRI scientists have shown recently that inhaled corticosteroids prolong life in emphysema. They are working on some inhaled agents to improve the immune system that appear to prevent overproduction of mucus. LRRI scientists working on the use of selenium as a preventive for lung cancer believe it may have efficacy in emphysema/COPD/emphysema as well. Scientists are also examining the efficacy of green tea and its antioxidents in early lung disease and lung cancer prevention that may be of use in chemoprevention for COPD.

To test new pharmaceuticals that slow the onset of COPD, reduce the rate of decline in lung function, and possibly reverse existing damage, Dr. Thomas March is using a mouse model of emphysema caused by cigarette smoke. Mice that inhale cigarette smoke and develop emphysema not only show the lung changes and tissue destruction seen in human emphysema, but the same chronic inflammation and deposits of tar. Drugs that are beneficial in this animal model are likely to be effective in humans.

Genetic Studies

While the genetics of COPD are largely unknown, differences in genetics probably explain why only 15-20% of the people at risk will develop emphysema. LRRI scientists have identified certain genes that appear to signal susceptibility to COPD and thus serve as a means to predict who will get the disease.

LRRI scientist Dr. Yohannes Tesfaigzi is using molecular biology techniques to find alternative forms of suspect genes known as genetic polymorphisms. Hundreds of smokers with and without emphysema are being screened for these gene variants. Volunteers are given a physical and have blood taken for subsequent genetic analysis. If COPD genes are found, the results might suggest gene therapies to turn off these genes or drugs that might attack the gene products directly.

Tobacco Awareness Campaign

As part of its Tobacco Awareness Campaign, NECA requests information about successful tobacco prevention/cessation programs across the country to include in its lung peer support group "tool kit" and directory. We are especially interested in programs with a peer support component.
Contact Ron Peterson, ronpete111@hotmail.com, 830 896-9145

Patients and Families Wonder . . .

Q: Why do doctors often prescribe corticosteroidsfor patients with COPD? (A December 2000 NHLBI study concluded that inhaled corticosteroids do not slow the progression of COPD.)

A: Although corticosteroids may not improve actual lung capacity, they are potent anti-inflammatory agents that reduce airway inflammation, decrease mucus secretion, and reduce airway hyper-sensitivity. All of these factors contribute to the onset and progression of COPD, and suggest that use of corticosteroids might be beneficial.

Dr. Floyd Frost and colleagues at the LRRI Center for Pharmacoeconomic and Outcomes Research have been conducting epidemiological studies of COPD patients to learn how different COPD treatments affect health outcomes. Their findings, presented at the November 2002 annual meeting of the American College of Chest Physicians, indicate that inhaled corticosteroid use is associated with longer survival. Dr. Frost's team is also studying patients with a history of acute respiratory infections and antibiotic use to determine if COPD can be identified and treated in early stages, before symptoms become severe. (Jo-Von Tucker, *Cape Cod COPD Support Group Newsletter,* reminds readers that a prescribed inhaled corticosteroid should be taken by people who use Serevent.)

Q: Why do COPD patients with chronic bronchitis produce so much mucus, restricting airflow and causing chronic coughing?

A: Excess mucus provides an ideal breeding place for infections. Controlling excess mucus production may therefore be one strategy for treating chronic bronchitis. Cigarette smoking and other environmental toxins can change the normal proportion of cell types in airways and lead to greater production of mucus-producing cells. At LRRI, Dr. Yohannes Tesfaigzi is exploring the use of new drug therapies, such as topically applied gamma-interferon, to help reverse these changes and bring cell populations back to normal proportions.

Q: Why do only 15-20% of cigarette smokers develop emphysema?

A: While cigarette smoking is the biggest risk factor for emphysema, a gene may explain emphysema susceptibility. A scientific team at the University of California at San Francisco has discovered how a group of proteins might confer this susceptibility. The team's research with mice (*Nature,* March 13, 2003) has identified transforming growth factor- (TGF-) as one of the critical proteins. TGF- has already been linked to a different kind of lung disease, called fibrosis. TGF- interacts with other proteins called integrins in complex ways that can result in lung disease.
The new work in mice suggests that a newly identified gene that reduces the amount of TGF- is involved in both fibrosis and emphysema. This reduction leads to emphysema because TGF- inhibits enzymes that destroy the connective tissue of the lungs. If a recently initiated human study indicates the same situation in humans, it may lead to the development of drugs to treat or prevent emphysema.

Researchers Open to Adding "Value of Peer Support Groups" to Research Agenda

At the Pacific Rim COPD conference, the NHLBI PIO meeting, and other national venues, researchers agreed to add "Value of Peer Support Groups" to the list of topics in which research is needed. They also agreed that "quality of life" and psychosocial issues merit more attention.

Long-Term Oxygen Therapy and CO_2 Retention

***Joseph Lewarsky,** BS, RRT, forwarded the following comments by Tom Petty, MD.*

"The concept that long-term oxygen therapy (LTOT) will lead to clinically significant CO_2 retention is wrong. It is a common myth, based on inadequate clinical observations.

"The story goes that the hypoxic drive is all that is keeping people with advanced COPD breathing. Wrong. The hypoxic drive is a weak drive for respiration except at high altitudes. Then it becomes a drive in the face of hypocapnia.

"If you give 100% oxygen to patients with COPD, the minute ventilation actually increases, which proves that the hypoxic drive is a myth. But with 100% oxygen, the PCO_2 rises considerably, due to 'absorptive atelectasis' from nitrogen washout. The CO_2 retention is caused by VA/Q mismatch as a consequence of absorptive atelectasis, which is a microatelectasis.

"With controlled low flow oxygen at 1-3 LPM, CO_2 retention rarely occurs (see Bigelow et al., *Am. Rev. Respir. Dis.*, 1967:96:28-34, and Cherniack, *JAMA*, about the same year). In the rare instances that CO_2 goes up due to hypoventilation, it is due to a serious derangement in the respiratory center, such as in the old cases of bulbar poliomyelitis and the extremely rare syringomyelia.

"You do not have to repeat blood gases after starting oxygen on advanced COPD patients if the oxygen is begun while the patient is in a clinical steady state. Not so with acute exacerbations, however. Here CO_2 retention occurs commonly when oxygen is given, because of respiratory muscle fatigue due to the increased work of breathing from bronchospasm, heart failure, thromboembolism, pneumonia, etc. - whatever caused the exacerbation."

“Mutual Aid” Opportunities/Models

National Emphysema/COPD Association

- Work with NECA Network Coordinating Committees or Lung Health Event Planning Committees
- Contribute materials for regional and national Lung Peer Support Group Tool Kits, Fall 2003
- Solicit materials for *NECANews and website*
- Incorporate lung activities in wellness fairs/health screenings (frequently not included!)
- Identify patient group needs, concerns, and contributions

Global Initiative for Chronic Obstructive Lung Disease (GOLD) (www.goldcopd.com)

- “Pocket Guide to COPD Diagnosis, Management, and Prevention: A Guide for Physicians and Nurses” (April 2001)
- *Global Initiative for Chronic Obstructive Lung Disease: Global Strategy for the Diagnosis, Management, and Prevention of COPD* (April 2001)

National Heart, Lung, and Blood Institute

- Public Interest Organization annual meeting: Claude L'Enfant, MD, Director, NHLBI, encourages patient groups to communicate with and assist one another by drawing on “their own experiences to offer concrete suggestions” specific to their needs.
- *FYI from the NHLBI:* public interest newsletter with upcoming events, research advances, news from Capitol Hill, “Media Tips,” etc.

NECA Directory Will “Get the Word Out”

Patient groups place “getting the word out” high on their wish list of needed services. NECA's *Lung Peer Support Program Directory and Resource Guide* is being developed to do just that.

Contents will help people with emphysema/COPD and other chronic lung diseases:

1. Find a “buddy” in person or online to help you follow medical advice or keep you company
2. Access and find local or national self-help/peer support groups (peer or professionally led)
3. Use online peer support resources
4. Identify local and nationwide resources, including suggestions for developing groups and networks

Contact Hannah Hedrick, 808 968-7013 HHedrick@NECACommunity.org or Daryl Isenberg, dipeace@aol.com.

Can you help?

NECA needs help in four areas:

- Coordinate collection of consistent information
- Enter collected data in a relational database
- Edit entries
- Print a quality publication

NATIONAL LUNG HEALTH EDUCATION PROGRAM (NLHEP) PROMOTES SPIROMETRY TESTING

nlhep@aol.com; www.nlhep.org

Readers of *NECANews* and visitors to *www.NECACommunity.org* are familiar with the tireless outreach efforts of NLHEP founder Tom Petty, MD, on behalf of people with emphysema/COPD. NLHEP priorities include early identification of people with COPD to provide opportunities for improved care and quality of life (See book review, page 6).

NLHEP has agreed to be identified as a “partner” in NECA's Fall 2003 Lung Health Events. Collaborative events (seven are currently in the planning stages) and specific sites will be encouraged to include spirometry testing, advocated in NLHEP's “Test Your Lungs, Know Your Numbers” campaign. A special effort will be made to conduct spirometry testing at the headquarters of national health care professional organizations and at health care and educational institutions.

For information about NLHEP's campaign to have spirometry testing available in the office of every primary care and specialist health care worker, visit www.nlhep.org. For copies of the revised NLHEP flyer, contact Gretchen Lawrence, gl-lungs@swbell.net.

USCOPD
COALITION
Helping Americans Breathe Free™

National Chronic Obstructive Pulmonary Disease Conference

November 13-15, 2003, Washington, DC

The US COPD National Conference is being organized by the US COPD Coalition to provide a multidisciplinary forum to improve the recognition of the impact of COPD in the United States, and to identify effective strategies to reduce its impact. Registration will be only $50 for people with COPD. The program includes lectures, workshops, roundtable discussions, posters, and abstract presentations. These and other Conference activities will address the challenges related to the program goals for COPD in *Healthy People 2010* and will develop action items.The conference brochure is available at www.uscopd.com. Other resources include “Helping Americans Breathe Free.”

For information on the recently formed International COPD Coalition, contact Katie Grouse, grousek@eircom.net.

International Leaders Pro "Empowerment"

***Carl Wiezalis,** MS, RRT, Professor, Respiratory Care*
Upstate Medical Center, Syracuse, New York
International Affairs Liasion

Since NECA's early organizational days, leaders at meetings around the world have expressed interest in NECA's mission of empowering people with emphysema/COPD to improve the quality of care and of their lives.

Canada
Janet Taylor, Novia Scotia, has served on NECA's Patient/ Family Advisory Board since February 2002. At NECA's October 2002 Community-Building Meeting in Chicago, Nancy Brown displayed the Michener Institute's COPD Educator Certification program educator materials, including a multi-media program for classroom and Internet instruction and certification of COPD educators. A November 2002 conference focused on COPD "from prevention to disability," including an end-of-life segment. Additional contacts have been made with the Canada COPD Alliance, a central repository for information.

Mexico
We are exploring with Hector Leon Garza, MD, a motive force in pulmonary medicine in Mexico, how NECA can interface with organizations in that country.

Republic of China-Taiwan
"Respiratory Care" is a newly recognized health discipline in the Republic of China-Taiwan. Respiratory care leaders, attracted by similarities between NECA's empowerment mission and their own COPD agenda, want to be active in world initiatives in COPD and other respiratory challenges.

European Respiratory Society (ERS)
During the ERS International Congresses in Berlin (2001), Stockholm (2002), and Stressa, Italy (2003), respiratory care professionals expressed interest in joining NECA as Individual or Organizational Members.

The March 2003 ERS 4th International Conference on Advances in Pulmonary Rehabilitation and Management of Chronic Respiratory Failure attracted respiratory experts from around the world, including NECA Medical Advisory Board member Bart Celli. The conference was chaired by Claudio Donner, MD, of the Fondazione Salvatore Maugeri, which supports a group of rehabilitation hospitals in Italy.

NECA representatives also met with Italian physiotherapists who specialize in respiratory care, including Marta Lazzeri, President of the Italian Affiliate of the Amercan Association for Respiratory Care (AARC); Giovanni Oliva, Vice President of the Italian Association for Physio-therapy; and Pamela Fragerio. Pamela, a former International Fellow with AARC, is organizing specialist respiratory physiotherapists in Italy and Europe.

Support Groups: "Coordinate Advocacy"

NECA's Community-Building Meetings produced recommendations for developing coordinated advocacy programs. Participants urged collaborative efforts to correct, improve, or support the following areas:

1. Financial disincentives
   - proposed Competitive Bidding legislation,
   - increased co-pays,
   - Medicaid cuts in nursing home care, and
   - inadequate coverage of care by respiratory care professionals
2. Access to pulmonary or respiratory rehabilitation and/or therapy and to home care services
3. Portability and travel
4. "Tobacco Awareness" programs
5. The National Lung Health Education Program's "Test Your Lungs, Know Your Numbers"
6. Improvements along the continuum: critical care, long-term care, end-of-life care (including earlier hospice referrals), and bereavement

Peer Support Group Priorities Reflected

Lung Health Event planning sessions across the country will include priorities suggested by persons with lung disease during NECA's 2002-2003 Community-Building Meetings. Participants will be asked for information about lung peer support programs and networks, to suggest materials for the "Lung Peer Support Group Tool Boxes," and to identify tobacco prevention and cessation activities and materials.

Priorities established during 2002-2003 by people with lung diseases include:

- Involve people with lung diseases in self-help groups or networks, including wellness, smoking cessation, etc.
- Provide leadership training and support programs for group leaders
- Develop specific collaborative projects for 2003
- Communicate to the emphysema/COPD community the important aspects of peer support programs

Contact: Hannah Hedrick,
HHedrick@NECACommunity.org

Abilities Expositions

Persons impaired by lung disease may benefit from attending the following "Abilities Expositions" (AbilitiesExpo.com):
June 6-8, Long Beach Convention Center, **Long Beach, CA**
August 15-17, Stephens Convention Center, **Rosemont, IL**
September 12-14, World Trade Center, **Boston, MA**
October 17-19, Broward Country Convention Center**,** **Fort Lauderdale, FL**
November 14-16, San Mateo County Expo Center, **San Mateo, CA**

Awards, Acknowledgments

The American Thoracic Society has selected ***Sreedhar Nair, MD****, to receive its World Lung Health Award for 2003. The award recognizes "outstanding contributions to world lung health in the area of basic or clinical research, delivery of health care, continuing education, or care of patients with lung disease." Dr. Nair currently serves as President of the National Emphysema Foundation, a clinical professor at the Yale University School of Medicine, and Head of the Beulah Hinds Center for Lung Studies and Health Informatics at the Norwalk Hospital, Norwalk, CT.*

The American Thoracic Society and the American Lung Association have selected ***Gerard M. Turino, MD****, to receive the Edward Livingston Trudeau Medal for 2003. The medal is presented to physicians who have made lifelong, major contributions to the prevention, diagnosis, and treatment of lung diseases. Dr. Turino is Founder/Director of Research of the James P. Mara Center for Lung Disease at St. Luke's and Roosevelt Hospital, New York, NY.*

American Lung Association of Metropolitan Chicago*: NECA gratefully acknowledges staff of the ALAMC, under the leadership of Kitty McAndrews, Deputy Executive Director, Professional Services and Research, for organizational, programmatic, and networking contributions to Community-Building Meetings and lung support groups.*

Dey LP*: A specialty pharmaceutical company focused on products for treating selected respiratory diseases and allergies, Dey LP demonstrated its support for empowering people with COPD via a grant in early 2002 to help establish an independent association and another in October 2002 to support NECA's outreach, education, and community-building programs. Dey staff contribute to planning meetings for collaborative Lung Health Events, including identifying and assessing materials for the Lung Peer Support Group Tool Kit. Dey also hosted the Medical Advisory Board meeting, NECA reception, and NECA Board meeting at the American Thoracic Society International Conference.*

Lovelace Respiratory Research Institute*: NECA continues to benefit immeasurably from the administrative and technical support provided by Robert Rubin, PhD, and numerous staff at LRRI. They make it possible to produce NECANews, continue to develop NECACommunity.org, maintain financial records, fulfill legal requirements, develop flyers and materials for exhibits, and develop and maintain a membership fulfillment process.*

National Emphysema Foundation (NEF)*: An unrestricted NEF grant in May 2002 enabled NECA to establish structures essential to an independent organization. Additional NEF financial support for NECA's Emphysema/COPD Community-Building Meetings, as well as consultation about relationships with national and international organizations, have contributed greatly to NECA's progress during the past year.*

American Institute of Life-Threatening Illness and Loss Symposia

On May 29-30, the American Institute for Life-Threatening Illness and Loss will present a symposium, "Emphysema/Chronic Obstructive Pulmonary Disease: Meeting the Challenges of Educating Medical and Other Healthcare Professionals." To be held at Columbia-Presbyterian Medical Center in New York City, the symposium will focus on profiling patient-centered care.

Future American Institute symposia will include "Sleep Complications and Issues Encountered in Emphysema/COPD" (June 26-27, 2003, Hackensack University Medical Center, Hackensack, NJ) and "Early Detection of Emphysema/COPD" (September 19-20, 2003, Columbia-Presbyterian Medical Center, New York City).

Living Legacy

Please consult www.NECACommunity.org if you wish to make a donation in memory of a loved one with emphysema/COPD. The family of Omar Smith of Riverside, Washington, established the first memorial fund.

Emphysema/COPD: The Journal of Patient Centered Care

Emphysema/COPD: The Journal of Patient-Centered Care is being developed as an outcome of the 2000 Emphysema/COPD symposium held at Columbia-Presbyterian Medical Center by The American Institute of Life-Threatening Illness and Loss. Co-editors Jo-Von Tucker and Hormoz Ashtyani, MD, and Executive Editor, Dr. Austin H. Kutscher, are creating a central repository for a broad spectrum of emphysema/COPD information and literature.

Articles reviewed by the Manuscript Quality Assurance Committee will be complemented by sections devoted to abstracts; "experts" responses to questions; book and journal reviews; letters to the editor; case reports; clinical interventions; common mistakes; editorials; essays; selected forum topics; ideas and innovations; selected interviews; and medical news and perspectives. The electronic version is planned for November 2003 and the print version for 2004.

If interested, please contact Vickie Scott, 321 723-3977; fax 321 409-1128; vlscott@bellsouth.net.

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National Emphysema/COPD Association

Membership Form

NECA is pleased to offer **FREE membership to all persons with COPD**; go to www.NECACommunity.org to enroll online. Peer support groups pay only $25. Family members, health and human service professionals, scientists, educators, local and federal government agencies, and others may select other options.

Name ________________________

Address ______________________

____

Phone __________________
Fax _____________________

Email __________________

____**COPD Patient** **Complimentary**

____**Individual $25** ____**Fixed income $15**

____**NECA Supporter $100**

I am a ___COPD patient/family member ___COPD patient advocate
___Health care provider ___Other
___Peer Support Group

_____**Regional Organization Member/Supporter $100/$400**
_____**National/International Member/Supporter $250/$1,000**

Patients enroll free at www.NECACommunity.org or mail form and check to NECA, 2425 Ridgecrest Drive SE, Albuquerque, NM 87108

NECANews
National Emphysema/COPD Association

NECA
2425 Ridgecrest Drive SE
Albuquerque, NM 87108