

No.2/December 2011

**MEDIA
PLANET**

PULMONARY HEALTH

3

STEPS

TAKING STRIDES

Bringing awareness to both rare and common pulmonary conditions

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Choose wisely
Finding the
right doctor



Invisible Killer
The truth about
asbestos



What is Cystic
Fibrosis?
Understand
the basics

CHALLENGES

Pulmonary hypertension is an under diagnosed disease, one with an amazing medical story.



Pulmonary Hypertension at a glance

In 1978 Dorothy Olson was changing planes in Cleveland—running for a gate and gasping for breath—when two flight attendants caught her by the arms and told her that she looked too sick to fly. It took some convincing, but the normally healthy Dorothy finally agreed to stay overnight in a hotel before flying home to Indiana. Several days later, while looking out a window and admiring a bunting bird, she fell across her bed and was unable to move a muscle. That was in 1978. The bunting bird sticks in her mind because it was at that moment her life skidded around a sharp corner.

Dorothy was hospitalized, and for five weeks, her problem baffled doctors. In the sixth week, a young resident suggested the possibility of something called pulmonary hypertension (PH), a disease that he vaguely remembered reading a paragraph or two about in a medical text. PH was thought to be so rare that a doctor would seldom, if ever, encounter such a patient.

Her doctors were unable to tell her anything about pulmonary hyper-

tension or why she had it. They did tell her that—if she was very lucky—she might live another two years.

Before 1996, there were no FDA-approved disease-specific treatments. At that time, mean survival for patients was 2.8 years from point of diagnosis. The typical patient was a woman in her child-bearing years.

In 2001, second and third treatments were approved for pulmonary hypertension. Today there are nine FDA-approved treatments. In fact, there are as many or more treatments for PH than there are for all but two of the 7,000 rare diseases identified in the U.S.

Pulmonary hypertension is a disease with a rapidly changing history.

Much of that change is emerging from an unusual and extremely productive partnership between patients, their caregivers and medical professionals.

Working together through the Pulmonary Hypertension Association, this small community of fewer than 30,000 diagnosed patients and those who care for and treat them have been able to:

“There are as many or more treatments for PH than there are for all but two of the 7,000 rare diseases identified in the U.S.”



Rino Aldrighetti,
President, Pulmonary
Hypertension Association

- Organize over 235 patient support groups

- Publish a quarterly medical journal that distributes to all cardiologists, pulmonologists and rheumatologists in the U.S.

- Create over 120 units of patient video and audio education in 18 months through PHA Classroom (www.phassociation.org/classroom)

- Offer the highest quality medical education in the field through PHA Online University (www.phaonlineuniv.org)

- Commit over \$11,500,000 to pulmonary hypertension research through five PHA research programs

It's a time to prove that people working together—even in a disease with a small number of diagnosed patients - can and will make a difference. We encourage you to learn more about pulmonary hypertension and the many ways that we are fighting back by reading this supplement...and then visiting www.phassociation.org.

RINO ALDRIGHETTI

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WE RECOMMEND



Ivan Robbins, MD
helps you further understand pulmonary hypertension

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providing hope for our future

This holiday season help the Barst Fund
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Learn more at www.PHAssociation.org/BarstFund

PHA Pulmonary Hypertension Association
Empowered by hope



An online resource designed for people living with PAH

www.InsightsOnPAH.com

InsightsOnPAH.com was developed to help you learn more about PAH, including its signs and symptoms, how PAH is diagnosed, options for treatment, and useful tips for living with PAH. A variety of materials are available to download—visit InsightsOnPAH.com to learn more about PAH.

Insights
Your PAH Resource

Insights is an educational program designed exclusively for individuals with pulmonary arterial hypertension and those who care for them—brought to you by Gilead Sciences, Inc.



INSPIRATION

Find the right care when it matters

■ **Question:** How important is finding the right doctor?

■ **Answer** Sometimes it can make the difference between life and death.

HOW WE MADE IT

Something isn't right when a baby's feet turn blue. Sonia Bejjani figured this was common sense, but for the first several years of her daughter Christina's life, doctors assured her that it wasn't much to worry about.

"Doctors would dismiss it as nothing serious, but it was a signal that something wasn't right," says Sonia.

A difficult discovery

When Christina fainted during a trip to

the mall at the age of four, Sonia rushed her to the hospital and it was soon discovered that the blue feet had been indicative of something very serious.

Christina was diagnosed with a condition called patent ductus arteriosus, which limits blood control to the lungs. Though surgeons were able to get it under control, the condition instigated pulmonary hypertension (PH), which she would have to carefully manage for the rest of her life.

A second battle

Christina kept her PH under control until she was 18, when she began to experience frequent shortness of breath during every day activities. Her blood pressure started escalating and her

"I know Christina's the hero as the patient, but it takes a good doctor to really work with a patient the way Dr. Mullen did."

Sonia Bejjani

condition radically deteriorated. Once again, the doctors weren't able to identify the problem, so she was referred to Dr. Mary P. Mullen, Associate Director of the Pediatric Pulmonary Hypertension Program at Children's Hospital Boston.

Christina was then informed that she was facing a life and death situation, possibly in need of a lung transplant. But Dr. Mullen devised a unique medication strategy for her that she believed just might make a difference.

"At first we didn't want to try her medication recommendation because it was too invasive," says Sonia.

New hope

Yet they made the decision to trust Dr. Mullen, and once again Christina's life

was saved by a second opinion.

"I know Christina's the hero as the patient, but it takes a good doctor to really work with a patient the way Dr. Mullen did," says Sonia. "Without Dr. Mullen and her team I don't know what we would've done."

Christina was given another chance at life, and she's embracing it enthusiastically. With dreams of becoming an attorney, she's studying law and will receive a degree this summer. It is thanks to the doctors who endeavored to understand her condition that she has a bright future ahead of her.

STEVE ETHERIDGE

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“Pulmonary hypertension feels like being in prison with your own body”

... but with PHA, there's hope

The mission of the Pulmonary Hypertension Association is to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.

If you would like to request more information,
please call 800-255-6430

Learn more at www.PHAssociation.org



Pulmonary Hypertension Association
Empowered by hope



INSIGHT

Ivan Robbins, MD

Position: Director, Pulmonary Vascular Center, Vanderbilt University



QUESTION & ANSWER

Pulmonary hypertension is abnormally high blood pressure in the arteries of the lungs. It makes the right side of the heart need to work harder than normal.

Answers for patients with PAH

What is the future prognosis for pulmonary hypertension patients and what can they look forward to in terms of treatment breakthroughs?

■ I believe the prognosis is improving. Our understanding of this disease continues to improve and new therapies targeting different pathways are, and will be, evaluated. The holy grail presently is an effective and well tolerated oral form of prostaglandin therapy. Prostaglandins have, in general, been the most efficacious medications for the treatment of PAH but presently are not available in a pill form. There is no cure for PAH presently which is the ultimate goal and one that is now, at least, conceivable.

Why is it important for a diagnosed patient to be referred to a larger pulmonary center?

■ Although there are many excellent cardiologists and pulmonologists in the community who can manage a patient's less advanced disease, large centers have additional support that is needed to care for these patients, especially with more advanced disease that requires more complicated therapies. All large centers have nurse

coordinators who work exclusively with PH patients and help obtain patient assistance for medications. They train patients in the proper use of intravenous medications and care of chronic IV access, and trouble shoot problems with medications. At our center, for example, the coordinators frequently spend up to an hour on the phone with an individual patient sorting out problems and providing support. Physicians in the community rarely have this degree of support. In addition to more support at large centers, they have access to investigational medications. Large centers have the expertise to review in detail the diagnosis of each patient and may diagnose additional or alternative conditions that may account for a patient's symptoms. Finally, many large centers have the option of lung transplant which offers a cure for selected patients not responding to maximal medical therapy.

"Although there is no cure for PAH, there have been major improvements in treatment over the last 15 years."

What would you tell a person that has just been diagnosed with PAH?

■ Don't believe all that you read about this disease. Although there is no cure for PAH, there have been major improvements in treatment over the last 15 years. Our understanding of this disease continues to increase, which will ultimately lead to newer and better therapies. You are not alone. There are support groups in every state, multiple support groups in most states. There are large PH centers throughout the country as well which can be found through the Pulmonary Hypertension Association (PHA). PHA is a wonderful patient-run organization that can provide information and support for all PH patients. Nearly all national experts attend the semi-annual national meeting. There is a scientific leadership council comprised of physicians and nurses that provides advice and expertise to the PHA and directs funding and scientific sessions sponsored by the organization. Finally, do not hesitate to seek a second opinion regarding your diagnosis and treatment.

IVAN ROBBINS, MD
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DON'T MISS

Keeping hope alive from Florida to Facebook

When the founders of the Pulmonary Hypertension Association (PHA) gathered around a kitchen table some 20 years ago, there were no treatments for pulmonary hypertension, a life-altering and incurable disease. And there were so few diagnosed patients that most patients lived in total isolation, not knowing another person who was facing the same difficulties and fears.

PHA's founders set out to change all of that ...and they did.

The formal mission of PHA - to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness—came much later, but it is built on the visionary roots laid by the organization's founders. Today there is a wealth of resources available to its community of patients, family members, medical professionals and researchers.

Although the founders didn't know it at the time, they became the first support group. The organization now has more than 235 local support groups across the country, offering patients and family members the opportunity to meet face-to-face and unite in hope. For those who can't attend a support group meeting, there are vibrant online communities, giving patients and

caregivers the chance to connect online anytime, day or night.

For those who prefer to make a one-on-one connection with another patient or caregiver, PHA offers a Patient-to-Patient Support Line as well as email mentors, both run by trained volunteers.

Pulmonary hypertension is a complex disease and providing education is essential to its community. From a comprehensive website that includes a pulmonary hypertension classroom where patients and family members can participate in live webinars or watch them at their leisure after the event, to in-person events and print materials, PHA provides critical updates on diagnosis, treatment and coping with PH to everyone who needs it.

Support, education, and opportunities for involvement are essential to the PH community, but above it all there is one thing that touches everyone: the sense of hope that PHA provides to PH patients and their families.

As PHA heard from the mother of a young child diagnosed with this disease "PHA gave our family hope when the doctors told us there was none."

ADRIENNE DERN,
SENIOR VICE PRESIDENT PULMONARY HYPERTENSION ASSOCIATION

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200,000

■ Pulmonary Hypertension affects less than 200,000 people in the U.S.

INSIGHT



DID YOU KNOW?

Understanding bronchiectasis

■ Bronchiectasis is a lung condition when damaged airways slowly lose the ability to clear out mucous build up in them. Bacteria grow as the mucous continues to clog the airways which lead to repeated lung infections. With every new lung infection, the condition worsens. Mucous build up in airways prevents oxygen flow to vital organs in the body. Bronchiectasis is characterized by a daily cough that produces large amounts of spit where mucous or blood may be present. People with bronchiectasis may experience shortness of breath, wheezing, or chest pain. Today, non-cystic fibrosis bronchiectasis remains a serious health concern for adult's age of onset between 60 and 80.

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CYSTIC FIBROSIS: TAKING STRIDES TOWARDS A CURE

STEP

2

UNDERSTAND
YOUR DISEASE

■ **Question:** What is cystic Fibrosis?

■ **Answer:** It is one of the most common, life-threatening lung diseases in both children and young adults.

Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system of about 30,000 children and adults in the United States. Cystic fibrosis causes thick, sticky mucus to build up in the lungs, digestive tract, and other areas

of the body. The build-up of mucus affects the breathing passages of the lungs, making breathing much more difficult for someone afflicted with the disease. It is one of the most common chronic lung diseases in children and young adults and is a life-threatening disorder. The mucus results in lung infections and serious digestion problems, and can also affect sweat glands and a man's reproductive system. The infections in the lungs are what make the disease so life threatening.

Causes, incidence, and risk factors

Millions of Americans carry the defective CF gene, but do not have the disease. This is because a person with CF must inherit two defective CF genes—one from each parent. An estimated 1 in 29 Caucasian Americans have the CF gene. The disease is the most common, deadly, inherited disorder affecting Caucasians in the United States. In the case of children, most with CF are diagnosed

by the age of two. There are a small amount of patients that have been diagnosed after the age of 18 but these patients usually have a milder form of the disease.

Prognosis for patients

The prognosis for cystic fibrosis in the U.S. has improved due to earlier diagnosis through screening, better treatment and access to health care. Patient compliance is a major factor—patients that are more aggressive in following treatment recommendations live longer. In the 60's, the median age of survival for a child with cystic fibrosis in the United States was six months; currently, it's 37 years. While there is no cure for cystic fibrosis, the strides that have been made over the past decades should prove hopeful for the future.

CYSTIC FIBROSIS STATISTICS

- About 1,000 new cases of cystic fibrosis are diagnosed each year.
- More than 70 percent of patients are diagnosed by age two.
- More than 45 percent of the CF patient population is age 18 or older.
- The predicted median age of survival for a person with CF is in the late 30s.

Symptoms of Cystic Fibrosis

- Salty-tasting skin (which parents often notice when they kiss their child)
- Wheezing or shortness of breath
- Persistent cough and excessive mucus
- Frequent lung infections, such as pneumonia and bronchitis

- Frequent sinus infections (sinusitis)
- Growths in the nose (nasal polyps)
- Poor weight gain and growth
- Foul-smelling, greasy stools
- Swollen belly, accompanied by abdominal gas and discomfort
- Broadening of the fingertips and toes.

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BLOOD INSTITUTE

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NEWS

Your breathing just got easier

Bronchial Thermoplasty: For those with severe asthma, breathing just got easier

More than 22 million Americans suffer from asthma. For some, the disease is little more than a nuisance that can be easily controlled with an inhaler and other medications. But for many, it is a debilitating, life-altering (and even life-threat-

ening) condition that results in 1.8 million emergency room visits, 500,000 hospitalizations and 4,000 deaths every year

Keep symptoms under control

There are numerous medications that help keep asthma symptoms under control. For sudden flare-ups, there are quick relief inhalers that relax and open up your airways but for those with severe

asthma, none of these options may be enough. And that's where the breakthrough procedure called bronchial thermoplasty comes in.

"Only a small fraction of asthmatics will need this, but for those who qualify, it can be a lifesaver," says Kyle Hogarth, MD, medical director of the pulmonary rehabilitation at The University of Chicago Medical Center. "The ideal candidate is one who is doing everything right—taking all of their medications, don't smoke, don't live with pets—but still has uncontrolled symptoms."

The Procedure: When smooth muscles in the airway contract,

they cause the airway to tighten and breathing gets harder. The bronchial thermoplasty procedure uses a catheter to deliver radiofrequency energy to destroy some of that muscle so that it can no longer constrict and impair breathing. It's done in three separate sessions (each working on a different area of the lungs) scheduled three weeks apart to allow for healing time.

Hogarth cautions that it's not a cure. "But it can lead to fewer hospital visits, less missed work and a significantly improved quality of life."

SALLY WADYKA
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TIPS

COPD prevention and advocacy

■ The American Lung Association is leading the effort to prevent COPD by advocating for strong tobacco control policies, regulation of tobacco products and smoke free air laws. Work is being done to increase federal funding for COPD research and treatment programs at the National Institutes of Health, and other federal agencies to ensure COPD patients' quality of life.

AMERICAN LUNG ASSOCIATION

22 million
■ More than 22 million Americans suffer from asthma.

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The Alair® Bronchial Thermoplasty System is indicated for the treatment of severe persistent asthma in patients 18 years and older whose asthma is not well controlled with inhaled corticosteroids and long acting beta agonists. The Alair® System is not for use in patients with an active implantable electronic device or known sensitivity to medications used in bronchoscopy. Previously treated airways of the lung should not be retreated with the Alair® System. Patients should be stable and suitable to undergo bronchoscopy. The most common side effect of Bronchial Thermoplasty is an expected transient increase in the frequency and worsening of respiratory-related symptoms. Asthmatx a Boston Scientific Company ©2011 Boston Scientific Corporation or its affiliates. All rights reserved. Rx Only. 11-011 Rev A

NEWS

STEP

3

KNOW YOUR
RISKS

DID YOU KNOW?

History is a great teacher to those who listen

More than 30 years ago, the International Agency for Research on Cancer declared asbestos to be a human carcinogen. The World Health Organization, International Labor Organization, U.S. Environmental Protection Agency and Surgeon General all agree: asbestos is a human carcinogen and there is no safe level of environmental or occupational asbestos exposure. Asbestos causes respiratory diseases and malignant mesothelioma; lung, laryngeal, and ovarian cancers; and may cause gastrointestinal and other cancers.

Prevent exposure to asbestos

Asbestos is virtually invisible, yet absolutely lethal.

Mesothelioma—can't pronounce it—can't cure it. I want to share a bit about the personal side of my journey— not for sympathy, but so you can better understand the facts about mesothelioma. In 2003, after enduring nine months of symptoms and multiple visits to doctors, my husband, Alan, was diagnosed with mesothelioma. Alan underwent an Extra-Pleural Pneumonectomy (EPP) -- a surgical procedure that removed a rib, left lung, and pericardium and replaced his diaphragm -- in hopes of having more time with his family. But, because of his asbestos exposure, our then-10-

year-old daughter had to watch her father slowly die from a preventable disease. Sadly, our experience is a common one, and the fear, despair, and isolation was paralyzing.

The truth behind asbestos

After Alan's diagnosis, we learned that asbestos causes deadly diseases, and not just mesothelioma. We learned the silent truth: that, when inhaled, these sharp, invisible, odorless, tasteless asbestos fibers can cause permanent damage. Even more shocking is the fact that this has been well known and documented for more than 100 years. Fueled by grief, anger, and bewilderment, I knew I needed to turn my anger

into action, which is why I co-founded the Asbestos Disease Awareness Organization (ADAO) with Doug Larkin. Technological advances have enabled us to build international alliances over 20,000 strong and continue our educational, advocacy, and community support initiatives, including hosting our annual Asbestos Awareness Conferences, testifying at Congressional hearings, and keynote speaking at numerous engagements.

Who is at risk?

Though the profile of victims of asbestos-related disease was once a blue-collar worker, in the United States alone, 30 Americans — men, women and children — die

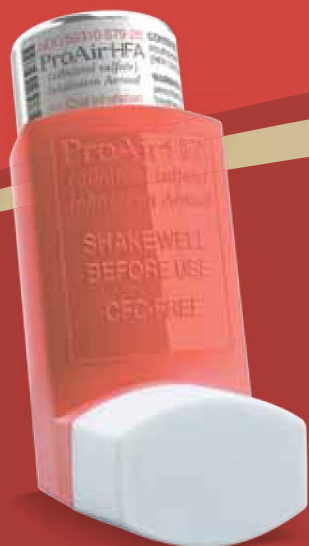
every day from asbestos-caused diseases. Tragically, it is also becoming more and more common to find women in their 50s being diagnosed with mesothelioma.

One life lost to asbestos disease is tragic; hundreds of thousands of lives is unconscionable. Prevention remains the only cure.

For more information and additional resources on the dangers of asbestos, please visit www.asbestosdiseaseawareness.org.

LINDA REINSTEIN,
ADAO PRESIDENT, CO-FOUNDER
AND MESOTHELIOMA WIDOW

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