



# Pathlight

A newsletter for the Pulmonary Hypertension Association, Inc. (PHA)

Spring 2002  
Volume 11 • Number 1

## PHA's 5th International PH Conference— "Building a Community of Hope"

June 21, 22, & 23, 2002  
Hyatt Regency Irvine  
Irvine, California

June will be here before you know it so you better start now making your plans to attend PHA's Conference 2002. It will be the best yet with all the information that the PH patient "must have" to stay ahead of the odds in his or her quest to live successfully with pulmonary hypertension.

This *Pathlight* is filled with articles from "Travel Tips" to "Conference Scholarships" that will help you have a safe trip and ensure that your pocketbook won't be empty when you return home. PHA conferences are always subsidized to allow as many patients as possible to attend. Generous sponsors are subsidizing many conference and patient support activities (preliminary sponsor list on page 3)—so be sure to stop by their exhibits at the conference and say "Thanks." Donations from members and friends funded PHA's conference scholarships that will defray the cost for many attendees.

*Journeys*, one of the PHA conferences' most popular presentations, will once again take center stage during the opening session on Friday. You will hear PHA-member patients and their physicians discuss the PH experience.

Local attractions such as Disney Land, Knott's Berry Farm, and nearby beaches can make this a fun trip for the entire family. Gentiva will have a freezer on site to keep your gel packs frozen and refrigerators are in every room.

### Sessions

Sessions led by physicians experienced in treating PH patients will teach us about the latest treatments—drugs that were not even on the screen two years ago! Learn how the recently approved Tracleer and Remodulin (in the late stages of the approval process) will become a part of PH therapy. Dr. Lewis Rubin's session—"Is Transition to Oral Therapy Possible?" is sure to be a hit so get there early!

Special sessions are planned for children with PH and the children of patients with PH. There will be children's rooms with entertainment that will be staffed by PH-aware volunteers—and a children's menu will be available.

Sessions for physicians only will be led by PHA-funded researchers for the cure and others who are conducting the clinical trials for new drugs.

Sessions led by long term survivors of PH—eight years or more—will have great tips for living with PH.

Sessions led by caregivers will help you to avoid "caregiver burnout" as you learn how to care for yourself as well as your loved ones.

Sessions will teach patients how to handle stress, deal with family members, and manage insurance issues such as working with PH and disability and PH.

And so much more—over 60 sessions are planned plus the support group sessions!

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### PHA's Scientific Advisory Board

The SAB's involvement has been essential to the success of the conference. Most SAB members will attend and present during patient sessions. Under the guidance of Dr. David Badesch of Colorado, the SAB is coordinating the medical program and its speakers for the physician's sessions.

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## Pulmonary Hypertension Association

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Two on site restaurants

Average temperature on June 21 for last four years—69° F

Attendees can make their own hotel reservations now by calling 1-800-233-1234.

## Tips for the PH Traveler

The most important tip for any traveler is to inform the airline while making your reservations about your special needs whether they include the use of a wheelchair, in-flight oxygen, Flolan or UT-15 pumps, any and all medications, etc. Advance notice of your needs is still the best insurance for a smooth flight.

This article draws its information from a fact sheet from the U.S. Department of Transportation sent to large airlines, aviation associations, and the National Council on Disability. It contains steps to ensure that new security requirements preserve and respect the civil rights of people with disabilities (updated 12/06/01).

## Check-in

Air carriers must provide "meet and assist" service (*e.g.*, assistance to gate or aircraft) at drop-off points. The lack of curbside check-in for certain airlines at some airports has not changed the requirement for "meet and assist" service at drop-off points.

(Continued on page 9)

## PHA Conference Sponsors

PHA gratefully acknowledges and extends its deepest thanks to the following for their support that is helping to make the PHA conference possible. If you are interested in being a sponsor for the PHA Conference 2002, please contact the PHA office at 301-565-3004 and ask for Rino Aldrighetti (rino@phassociation.org).

### Platinum Level Sponsor

Gentiva Health Services

### Gold Level Sponsors

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Bonnie Dukart

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### Bronze Level

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Schill Medical

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Pathlight is the newsletter of the

**Pulmonary Hypertension Association, Inc. (PHA)**

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[www.phassociation.org](http://www.phassociation.org)

## Important Numbers

PHA .....	301-565-3004
FAX .....	301-565-3994
E-mail .....	pha@phassociation.org
Member Services and <i>Pathlight</i> Address Changes .....	301-565-3004
PH Helpline (daytime, please) .....	1-800-748-7274
ACCESS .....	1-888-700-7010
(Social security, insurance, and disability questions)	
Gentiva's Hotline for Flolan .....	1-800-9-FLOLAN
Priority Healthcare Remodulin Hotline .....	1-877-462-6225
TheraCom's Hotline for Flolan .....	1-877-356-5264

## Committee Chairs

### Children with PH/PPH

Nancy Frede, 616-735-5518, Ponyforme@aol.com

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jpwilson@hotmail.com

### New Member Packets, Pins, Brochures, and Cards

Barbara Smith, 813-920-5945, 813-855-4284 fax,  
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### Organization Liaison

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American Thoracic Society: Public Advisory Roundtable  
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Susan Salay, 949-725-8315, ssalay@aol.com

### 800 Number Coordinator

Pat Paton, 561-597-4962, pjpaton@netscape.net

## Conference Volunteers Needed

Room hosts—these are the people that make sure the conference room is set up before hand, make sure the speakers have everything, make sure people are in the right session and that everyone leaves with all their belongings. This year, room hosts will also be handing out survey forms and cards to write questions for presenters. If you are interested in helping, please contact Candi Bleifer at 818-752-8384 or [candibleifer@earthlink.net](mailto:candibleifer@earthlink.net).

## Conference Registration

PHA Conference 2002 registration material will be mailed out to PHA members early in March. If you do not receive yours, call the Patient Helpline (1-800-748-7274) or the PHA office (301-565-3001) for more information or to request a registration packet. You can also register for the conference on line at [www.phassociation.org](http://www.phassociation.org).

## PHA Conference 2002 Scholarships

A limited number of PHA Conference 2002 scholarships are still available for adult pulmonary hypertension patients who plan to attend the 5th International Conference to be held in Irvine, California, in June 2002. Child patients accompanied by a parent will be supported through a special scholarship program supported by the Ronald McDonald House Charities. Three levels of assistance will be granted: A level—full support (travel, registration and lodging); B level—partial (travel or registration and lodging); or C level—(conference registration fees only). Since the amount of funds available for scholarship grants are limited, careful consideration will be given to need. A minimum co-payment of \$25 toward patient costs to attend and \$25 for the companion's conference expenses will be required. Typically, a cap of \$1,000 to \$1,500 will be applied for each patient and companion requesting full support, depending upon travel distances. Scholarship granting decisions will be governed by the following procedures and selection criteria.

To apply a patient should send a written statement to Ed Simpson, Conference Scholarship Coordinator, 84 Bandy Drive, Holiday Island, AR 72631, or e-mail (esimpson@nwaft.com) that includes:

- (1) the patient's name and address and that of a companion (if applicable) who will accompany the patient;
- (2) date of pulmonary hypertension diagnosis and name of the physician currently treating the patient;
- (3) reasons why financial support is needed to attend the conference;
- (4) the type of support needed (*i.e.*, Level A, B, or C above); and
- (5) list of previous PHA international conferences attended.

Special consideration will be given to patients who have been recently diagnosed and those who have not received financial assistance to attend an International Conference in the past. However, all patients who have need of support but are unable to secure help from other sources are encouraged to apply. Scholarship monies will be used to provide help to as many patients as possible requiring assistance. All applicants will be notified about scholarship awards within three weeks after their application is received.

## Outstanding Membership Recognition Awards

PHA is accepting nominations in the following categories to be presented in conjunction with our June 2002 PH Conference:

- Outstanding Doctor
- Outstanding Nurse
- Outstanding Patient
- Outstanding Caregiver
- Outstanding Family
- Outstanding Support Group Leader

Nominations must be received by April 1, 2002. Include a letter explaining in detail your nominee's service to patients and involvement in PHA and why your nominee deserves the award. Please mail your nominations to the Awards Committee, PHA Offices, 850 Sligo Avenue, Suite 800, Silver Spring, MD, 20910.

## New PHA Board Members

**PHA** welcomes JoAnne Sperando-Schmidt and Gail Boyer Hayes as new members to the PHA Board of Trustees.

JoAnne Sperando-Schmidt is from Huntington, New York, and works in the credit card industry. She's the third person in her family to be diagnosed with PPH. JoAnne, diagnosed in 1998 with Primary Pulmonary Hypertension, her brother John (diagnosed in 1995) and their parents formed the Long Island, New York, support group for PH patients and their families. The group has grown to 50 registered patients in the greater New York area and they've participated in various awareness raising and fund raising efforts.

Gail Boyer Hayes is from Seattle, Washington. Her name should be very familiar to our membership as she is the author of *Pulmonary Hypertension: A Patient's Survival Guide* which was recently revised and now has even more helpful information for the PH patient. Gail has also responded to the PH helpline and served as the Northwest Coordinator for PHA.

PHA extends its deepest thanks for the hard work and many contributions of those board members whose terms have expired.

## The Day I Became an “Olympian”

By *Kathy Cruise Forrest*

On a cold sunny morning in Maine last December 28, I carried the Olympic flame two tenths of a mile along a perfectly level and smooth section of historic U.S. Highway 1. I mention the condition of the road because as a PHer and lung transplant candidate, those qualities often mean the difference between misery and manageability as I struggle for breath. I had had a hip replacement a year earlier and it was only after months of practicing my Olympic stroll without my customary cane that I developed sufficient confidence to strike out unaided. The torch itself weighs 3½ pounds, yet never in my practice walks had I been able to manage to carry a three-pound weight the required distance—about four city blocks. I was excited and terrified that I would drop the torch.

My adventure was started for me the previous spring when my daughter, Kirsten Beatty, submitted an essay about me to a nationwide competition in which torch relay sponsors, Coca Cola and Chevrolet, sought 11,500 “inspirational persons” to participate in the torch relay of the Olympic flame as it made its journey from Greece to Salt Lake City. To our amazement, I was chosen to represent the city of Portsmouth, New Hampshire. (Of course, I felt like a skunk when I moved to Pennsylvania shortly before the relay.) Actually, I have lived and worked in seven states and have had the good fortune to travel through 48 out of 50. I have always been a proud American and was incredibly humbled to be selected to represent the United States in this part of the Olympics. Yet in the aftermath of September 11, I also came to realize the interdependence of the U.S. and the global community and with that came a real appreciation of the Olympic spirit of inclusion.

In the weeks before the actual relay, there were many opportunities to discuss pulmonary hypertension and transplantation issues with the press and with Olympic officials. It was my goal to put a face with this rare disease and at the same time inspire other PHers to set goals and take on new challenges, even physical ones.

Once I actually started to move out into the road, it was an adrenalin rush that sustained the physical effort needed to walk the distance—that and the support of my family and friends, not to mention all the spectators freezing on that December morning. I could hear my labored breathing, but I didn’t experience any pain—not in my chest or my joints either. I even held the torch in one hand for part of my walk, waving to the crowd with the other. I wanted the feeling, the exhilaration to go on forever. The people along the road were cheering and waving flags and pennants. Suddenly it was over. I could see the next participant holding her torch up to receive the flame from me. The fire

leaped from my torch to hers. The caravan—advance cars, media truck, torchbearer and runner shuttles, motorcycles and the flame cauldron—continued on without me. Walking back to the car with my family and friends, I was greeted by a dozen or so young people, mostly little kids but some teens too, who asked if they could touch the torch and have their picture taken with me.

It was a magical day.



Kathy Forrest, a 59-year-old grandmother of four from Horsham, PA, waves to well-wishers as she carries the Olympic flame ¼ mile in York, ME, on December 28, 2001. Surrounding her are “guardians of the flame,” support runners who accompany a series of torchbearers.

Kathy was diagnosed with PPH in 1999 and listed for transplant in 2000.



(l to r) Kirsten Forrest Beatty, Katherine Cruise Beatty (two months old and not having a very good time), Kathy Cruise Forrest. The torch is the one Kathy actually used in the relay—note the scorched globe.

## “Bonnie’s Gift” Program Now a Reality!

The Pulmonary Hypertension Association announced the “Bonnie’s Gift” program on the 1st anniversary of Bonnie Dukart’s death. Bonnie died in January 2001 after a long struggle with pulmonary hypertension. Her last hope for survival hinged around a lung transplant, but Bonnie died following a double lung transplant. Before she died, Bonnie made certain that those suffering with this dread disease would have the information she lacked concerning lung transplant, early on.

Bonnie’s dying wish led to the creation of “Bonnie’s Gift.” She requested that donations in her name be used to create a program within PHA related to transplant information and awareness. Since her death, over \$21,000 has been donated to PHA for “Bonnie’s Gift.”

Gary Dukart, Bonnie’s husband warns, “Early listing is a critical issue for those battling PH given the scarcity of available organs. For those living with this disease, it is especially important to list early because of the unpredictability of the progression of PH.”

Rino Aldrighetti, Executive Director of PHA confirms, “‘Bonnie’s Gift’ will be used to tell Bonnie’s story and get the

word out about PH. Relatives and friends of persons living with PH want to find ways to help and show their support. These people often don’t understand much about the illness. “Bonnie’s Gift” will help PH patients explain the illness and will encourage organ donation. It will stress the importance of early listing.”

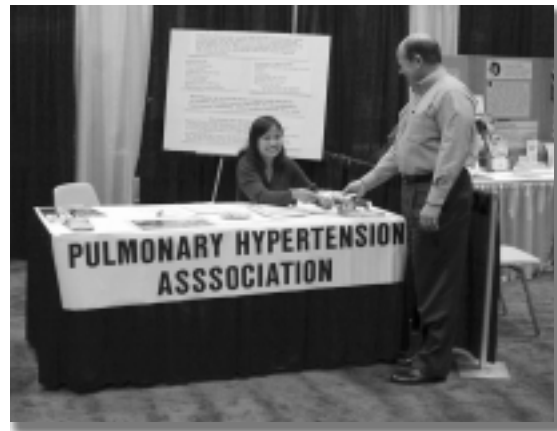
The current Bush administration is making expanded organ donation a key priority through the Department of Health and Human Services under the leadership of Tommy Thompson. PHA is working with the Health Resources and Services Administration of HHS and is a partner in their effort to educate the broader community about the importance of organ donation. It is PHA’s hope that some day there will be enough organs available for those who need them.

Money donated to “Bonnie’s Gift” will be used first to develop a pamphlet to promote organ donor awareness for PH patients, their physicians and families, and the public. It will be sent to all PHA members and will become a part of the PHA new member packet. The booklet will have information about the importance of early listing for transplant, the transplant process and more.

## Dallas Healthfit Expo

In January 2002, representatives from Actelion, Gentiva, and the St. Paul’s Hospital of Dallas PH Support Group staffed a booth at the Healthfit Expo sponsored by NBC and the local affiliate station Channel 5. Over 20,000 people attended the three-day event. Approximately 700 brochures were handed out to the 450+ visitors to the PHA booth. Visitors to the booth included several nurses and other healthcare workers that stated they made a point to visit the booth for information after seeing the PHA listed in the Exhibitors guide that had been published in the local papers several times prior to the day of the event. Additionally, several visitors were individuals recently diagnosed with PH that were not aware of our organization.

NBC is sponsoring five such events around the country in 2002. Expos are scheduled for Philadelphia, Chicago, Sacramento and Providence, RI. The positive benefits of these Expos as a forum to promote awareness are exciting. According to Larry Jennings, Show Manager of Network Events, Inc., NBC hopes to expand the number of cities in 2003 and 2004. Exhibitors may also sell items so the possibility exists to raise funds through the sale of PHA merchandise such as pins, Patient Guides and the holiday/note cards. PHA will assist local support group participation in the cities where these events are scheduled. If your support group is near one of these cities and would like to participate, please contact Jim Wilson, Special Events Coordinator.



Pher Jocelyn Lumbo helps out at the Healthwatch Expo in Dallas.

## NEWS AND ANNOUNCEMENTS

## Julie Paton Hendry Memorial Scholarship Winner

Dena Giddens of Spring, Texas, is this year's recipient of the Julie Paton Hendry Memorial Scholarship which is awarded to a non-patient who has devoted significant time and effort to advance the purposes of PHA. Dena's many PHA activities include serving as a board member, a fund raiser, area director, and *Pathlight* contributor (Caregiver's Corner). She attended and helped with the '96, '98, and '00 conferences, began the Awareness Ribbon campaign, helped organize Awareness Week, and worked with Dr. Jane Morse at Vanderbilt to collect blood samples from the Giddens family for the genetic study.

The Julie Paton Hendry Memorial Scholarship is a cash award used to defray the cost (up to \$1,000) of attending the PHA conference.

## Florida Medicare PHers

Important information for Medicare patients in Florida: If your doctor has prescribed medications produced by Pfizer, Inc., a pharmaceutical company, you may be eligible for their Share Card Program. This program entitles you to pay only \$15 for each 30-day Pfizer prescription with no limit on the number of prescriptions. To be eligible for the card, you must be 65 or older (or otherwise Medicare eligible), have an individual gross income below \$18,000 a year or joint income below \$24,000, and have no other insurance prescription coverage. To apply, call 1-800-717-6005.



JoAnne Schmidt with her nieces, Rachel and Danielle Sperando, attend a garage sale at Janice and Larry Persson's home during PH Awareness Week 2001. JoAnne and her brother John both have PPH.

## CD-ROM and PH Brochure Available

The new PH brochure, an eight-pager titled *Pulmonary Hypertension: Helpful Information for Patients and Families* has been reprinted and is available in quantity from the PHA office. The CD-ROMs have also proven very popular and our initial 5,000 production run has been distributed so the CD-ROMs are also being underwritten for a second production run of approximately 4,000. Thanks to Actelion for underwriting these costs. Contact the PHA office for these great awareness tools.

## Parent Listserv

At Linda Carr's request, Jeremy Isett began a parents' listserv. SAB member Allison Widlitz has agreed to write a once per month update and answer occasional questions. Final details are almost completed, so expect this add-on service to begin soon. Visit the PHA website for details and to sign on.

## A Very Special Gift

A donation from the Mary Linnen Memorial Fund has provided the funds to purchase a DNA sequencer for the New York Presbyterian Pulmonary Hypertension Center under the direction of Dr. Robyn Barst. The DNA sequencer will be used solely to advance the search for the PPH gene(s). Dr. Barst believes finding the gene(s) for PPH will provide a clear handle on the potential cause(s) of this terrible disease.

## Awareness Month

Awareness Week has been extended to Awareness Month. Now you will have more time in which to plan your awareness activities! Check with Lorie Simmons at the PHA office with any questions.



Dr. Brundage explains how the Miami Cure PH Tournament funds will be used for PH research.

FUNDRAISERS

### Upcoming Events

#### The Caleigh Coleman Memorial Cure PH Golf Tournament

March 18, 2002  
Corsicana Country Club  
800 NW County Rd 1050  
Corsicana, TX 75110  
Phone: 903-874-8288  
coleman3@airmail.net

#### 4th Annual Cure PH Golf Tournament and Dinner/Auction

April 4, 2002  
Tournament start: 1:30 p.m.  
Dinner/Auction: 5 p.m.  
The Woodlands Resort and Conference Center  
The Woodlands, Texas  
281-681-5900  
cure4ph@txucom.net

#### Second Annual Cure PH Golf Tournament

May 15, 2002  
Reston National Golf Club  
Reston, Virginia  
703-938-6770  
elyse.murphy@gentiva.com

#### Third Annual Jim Palmer Memorial Cure PH Golf Tournament

June 13, 2002  
Crossgates Golf Course  
Millersville, Pennsylvania  
Lancaster County

#### Jerry P. Selinger Invitational

June 17, 2002  
Pinebrook Golf and Country Club  
Calgary, Canada

### Miami Cure PH Golf Tournament

November 2, 2001, saw 84 golfers including PHA officers, friends and family gathered together for Hannah's Cure PH Golf Tournament in Miami, Florida. Over \$22,000 was raised in the second year of this successful event.



PHA was well represented.



Hannah's Cure PH golfers and helpers.



Lined up and ready to go!

## FUNDRAISERS

## Northern Virginia Golf Tournament

On Monday, September 17, 2001, most of PHA's office staff spent the day helping out at the Northern Virginia Golf Tournament organized by Howie Roman. Howie and his wife Nan organized the event in honor of their daughter Tracy. The Roman family and friends and neighbors who volunteered and played put on a terrific event for the many players who came. To have 86 golfers in the midst of the crisis was an extraordinary achievement and the PHA board joins the staff in thanking them for all they did.

Tips for the PH Traveler (*Continued from page 2*)

### Screener checkpoints

Individuals assisting passengers with disabilities are allowed beyond the screener checkpoints. These individuals may be required to present themselves at the airlines' check-in desk and receive a "pass" allowing them to go through the screener checkpoint without a ticket.

Ticketed passengers with their own oxygen for use on the ground are allowed beyond the screener checkpoints with their oxygen canisters once the canisters have been thoroughly inspected. If there is a request for oxygen at the gate for a qualified passenger with a disability, commercial oxygen providers (Advanced Aero Medical 1-800-346-3556) are allowed beyond the screener checkpoints with oxygen canisters once the canisters have been thoroughly inspected. Commercial oxygen providers may be required to present themselves at the airlines' check-in desk and receive a "pass" allowing them to go through the screener checkpoint without a ticket.

The limit of one carry-on bag and one personal bag (*e.g.*, purse or briefcase) for each traveler does not apply to medical supplies and/or assistive devices. Passengers with disabilities generally may carry medical equipment, medications, and assistive devices on board the aircraft.

All persons allowed beyond the screener checkpoints may be searched. This will usually be done through the use of a hand-held metal detector, whenever possible. Passengers may also be patted down during security screenings, and this is even more likely if the passenger uses a wheelchair and is unable to stand up. Private screenings remain an option for persons in wheelchairs.

Syringes are permitted on board an aircraft once it is determined that the person has a documented medical need for the syringe. To show a documented medical need, a passenger must have in their possession medication requiring the use of

## Awareness Week

Many support groups and other groups had a variety of fund raising events during Awareness Week 2001. PHA extends its thanks to the many individuals for their efforts.

a needle or syringe that has a professionally printed label identifying the medication or a manufacturer's name or pharmaceutical label.

Personal wheelchairs and battery-powered scooters may still be used to reach departure gates after they are inspected to ensure that they do not present a security risk. Any backpack or side pack that is carried on the wheelchair will be manually inspected or put through the X-ray machines.

Personal wheelchairs will still be allowed to be stowed on board an aircraft.

Further information was obtained from recommendations from the American Diabetes Association. MiniMed pumps are used for diabetes patients who need continuous insulin and are now used for UT-15 patients so the information is applicable for the PH patient as well.

While situations may vary at airports and airlines, the American Diabetes Association offers the following recommendations:

Take copies (at least three) of your prescriptions for diabetes (UT-15, Flolan) medications and supplies with you.

The prescription must clearly contain the name of the medication or supply and include complete contact information for your physician.

Call your airline at least one day prior to departure to confirm what their policy is with regard to diabetes (Flolan, UT-15) medication and supplies.

On-board oxygen users will need a copy of their O<sub>2</sub> prescription along with a letter from their doctor that states the liter flow and the travel dates.

Pre-planning is the key to successful flight; booking nonstop flights ensures you won't have to repeat measures over and over.

Again, inform the reservations clerk that you have special needs and they will put you in contact with airline personnel that will tell you the requirements for your situation.

## RESEARCH CORNER

**Sean P. Gaine MD PhD, Mater Misericordiae Hospital, Dublin, Ireland.**

I chose a few science papers from the past three months to review in this edition of *Pathlight* that shed some light on the direction of research in PAH at the moment. These papers are rather complicated but they help identify some of the current “buzz” words from the world of PAH basic molecular research. Given the knowledge gained from the discovery of the gene for familial PPH, the search has intensified for ways to better understand what controls growth and proliferation in the pulmonary vascular lesion in PAH. Only by understanding what makes vessels grow abnormally can we plan targeted therapies to prevent or reverse this.

**p27<sup>Kip1</sup> Is Important in Modulating Pulmonary Artery Smooth Muscle Cell Proliferation**

*Am. J. Respir. Cell Mol. Biol.*, Volume 25, Number 5, November, 2001 652–658

Brian W. Fouty, Bryn Grimison, Karen A. Fagan, Timothy D. Le Cras, Julie W. Harral, Marloes Hoedt-Miller, Robert A. Sclafani, and David M. Rodman

This paper from Dave Rodman’s group at the University of Colorado Health Sciences Center in Denver looks at vascular remodeling in pulmonary hypertension. They note that this vascular remodeling due to pulmonary arterial smooth muscle cell (PASMC) proliferation is central to the development of pulmonary hypertension. Cell proliferation requires the coordinated interaction of cyclins and cyclin-dependent kinases (cdk) to drive cells through the cell cycle. The cell cycle refers to the life cycle of each living cell, which includes periods of growth and rest. Cdk inhibitors, such as p27<sup>Kip1</sup>, can arrest cell growth and proliferation. They looked at p27<sup>Kip1</sup> in proliferating rat pulmonary arterial smooth muscle cells and found that the protein expression of p27<sup>Kip1</sup> decreased to 40% of baseline after growth stimulation. On the other hand, over expression of p27<sup>Kip1</sup> reduced cell counts at 5 days compared with controls. These results suggest an important role for p27<sup>Kip1</sup> in regulating PASMC growth and proliferation. In the future, specific inhibitors might be developed to inhibit cyclins or cdk and thereby arrest the progression of pulmonary hypertension.

**Serotonin transporter overexpression is responsible for pulmonary artery smooth muscle hyperplasia in primary pulmonary hypertension**

*J Clin Invest*, October 2001, Volume 108, Number 8, 1141–1150

Saadia Eddahibi, Marc Humbert, Elie Fadel, Bernadette Raffestin, Michèle Darmon, Frédérique Capron, Gerald Simonneau, Philippe Darteville, Michel Hamon and Serge Adnot

This paper comes from the laboratory of Serge Adnot in France. Another way of looking at growth and proliferation in

PAH is to investigate what turns the process on and makes people with PPH susceptible to this excessive cellular growth in their pulmonary arteries. They found that pulmonary arterial smooth muscle cells (PASMC) taken from patients with PPH grow faster than PASMCs from controls when stimulated by serotonin (remember serotonin and its relationship with diet pills?) due to increased expression of the serotonin transporter (5-HTT). In the presence of 5-HTT inhibitors, the growth stimulatory effects of serotonin were markedly reduced and the difference between growth of PASMCs from patients and controls was no longer observed. The expression of 5-HTT was increased in the lungs of patients with PPH where it predominated in the muscular layer of the thickened pulmonary arteries. Remember, you get one gene variety from each of your parents; if both are identical then you are homozygote, if they are different you are a heterozygote. The L-allelic variant of the 5-HTT gene promoter, which is associated with 5-HTT overexpression and increased PASMC growth, was present in homozygous (LL) form in 65% of patients but in only 27% of controls. They concluded that 5-HTT activity plays a key role in the pathogenesis of PASMC proliferation in PPH and that a 5-HTT polymorphism confers susceptibility to PPH.

This paper helps to clarify a relationship between over expression of the serotonin transporter (5-HTT) and the abnormally proliferative pulmonary artery smooth muscle cells in patients with PPH. This study provides the first clinical relationship between a genetic abnormality and a cellular process that is critical to the pathophysiology of pulmonary arterial hypertension. New therapies that target 5-HTT responses may be developed as treatments for pulmonary hypertension.

**Expression of angiogenesis-related molecules in plexiform lesions in severe pulmonary hypertension: evidence for a process of disordered angiogenesis**

*The Journal of Pathology*, Vol. 195, Issue 3, 2001 Pages: 367–374

Rubin M. Tuder, Mati Chacon, Lori Alger, Jun Wang, Laimute Taraseviciene-Stewart, Yasunori Kasahara, Carlyne D. Cool, Anne E. Bishop, Mark Geraci, Gregg L. Semenza, Magdi Yacoub, Julia M. Polak, Norbert F. Voelkel

While the previous two papers looked at smooth muscle proliferation in PAH, this study looked at the abnormal proliferation of endothelial cells, the so-called plexiform lesion, observed in severe PAH. It was postulated that endothelial cells in plexiform lesions express genes encoding for proteins involved in angiogenesis (new blood vessel formation), in particular, vascular endothelial growth factor (VEGF) and those involved in VEGF receptor-2 (VEGFR-2) signaling. On immunohistochemistry and in situ hybridization, endothelial cells in the plexiform lesions expressed VEGF and overexpressed the receptor VEGFR-2. Furthermore, they discovered the transcription factor HIF-1 (hypoxia inducible

## RESEARCH CORNER

factor), which is responsible for turning on the making of VEGF in response to low levels of oxygen in the blood vessel, was present in these plexiform lesions. Because these markers of active angiogenesis are expressed in plexiform lesions in severe PAH, it is proposed that these lesions may form by a process of disordered angiogenesis. It remains unclear, however, whether this “angiogenesis” is just a marker of severe disease or responsible in some way for disease progression. Until we better understand the proliferation of endothelial cells in PAH, attempts to affect it by new drugs will remain some distance away.

## Passages

Our deepest sympathies to the family and friends of the following individuals. This issue of *Pathlight* is dedicated to their memory. Should there be any omissions or errors, please call 301-565-3004.

Joan S. Anderson	Frank R. Nichols
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## DISCLAIMER

We encourage readers to discuss their health care with their doctors. This newsletter is intended only to provide information on PH/PPH and not to provide medical advice on personal health matters, which should be obtained directly from a physician. PHA will not be responsible for readers' actions taken as a result of their interpretation of information contained in this newsletter.

## United Therapeutics Receives FDA Approvable Letter for Remodulin to Treat Pulmonary Arterial Hypertension

Research Triangle Park, NC and Silver Spring, MD, February 11, 2002—United Therapeutics Corporation (Nasdaq: UTHR) announced today that the U.S. Food and Drug Administration (FDA) has issued an approvable letter for Remodulin (treprostinil sodium) Injection for the treatment of pulmonary arterial hypertension. An approvable letter usually represents the final step before a drug receives FDA clearance for marketing in the United States. The FDA has proposed drug labeling for pulmonary arterial hypertension consistent with the treatment of both primary and secondary pulmonary hypertension in patients with NYHA Class II–IV symptoms. The approvable letter also stated that the FDA intends to approve Remodulin with a requirement that United Therapeutics subsequently conduct a post-marketing controlled clinical trial to verify and further describe the drug's clinical benefit.

United Therapeutics is in final discussions with the FDA, the outcomes of which are expected to form the basis for approval of Remodulin in accordance with the FDA's accelerated approval regulations. Upon approval, Remodulin will be the first FDA-approved therapy for NYHA Class II pulmonary arterial hypertension patients. “There remains a tremendous need for new medications to treat this life-threatening condition,” said Roger Jeffs, Ph.D., President and Chief Operating Officer of United Therapeutics. “We welcome the FDA's action and are obviously very pleased that the application has progressed to an approvable action. We will work diligently with the FDA to satisfy the remaining requirements for approval of Remodulin so that pulmonary arterial hypertension patients will have access to this therapy as quickly as possible.”

United Therapeutics conducted the largest double blind placebo-controlled study in pulmonary arterial hypertension, a disease in which blood pressure in the pulmonary arteries rises to life-threatening levels. Approximately 50,000 people in North America and Europe are afflicted with forms of the disease. On August 9, 2001, FDA's Cardiovascular and Renal Drugs Advisory Committee recommended approval of Remodulin. United Therapeutics has submitted Remodulin marketing applications to health authorities in France, Switzerland and Canada. Additional international filings will follow approval in the U.S. and France. Approximately 450 pulmonary arterial hypertension patients worldwide continue to use Remodulin in open label studies sponsored by United Therapeutics. Remodulin is administered subcutaneously via an infusion device developed by Medtronic MiniMed, Inc. (Nasdaq: MDT). In anticipation of final FDA approval of Remodulin, United Therapeutics entered into drug distribution partnerships in the United States with two companies: Priority Healthcare Corporation (Nasdaq: PHCC) and Gentiva Health Services, Inc. (Nasdaq: GTIV).

## IN MEMORY OF

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Philip B. Milstein  
Richard L. Ranch  
Kathleen A. Wilson

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Jean DeMarco

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PHA's 5th International PH Conference—"Building a Community of Hope" (Continued from page 1)

## New Friends and Old

One of the very best parts about attending a PH conference is the chance to make new friends with people who will truly understand how you feel and all that you are going through with PH in your life. Whether you are "PHers" or their loved ones, you will meet someone that has shared your PH journey. You can finally meet all the pen pal, e-mail, listserv, message board, and web site friends you have made so far. You can also meet many of the people featured in *Pathlight* and *Persistent Voices* over the years—and meet the people who truly make this event possible: the PHA board and volunteers; they are eager to meet you!

You will also find PHers who have attended all or most of the past four conferences. Attending gets in your system and you want to keep coming back to see old friends—plus you don't want to miss out on anything!

## Building a Community of Hope

The PHA Conference 2002 should be the best conference yet. Attending will be a key opportunity for personal interaction with the world's best PH physicians and nurses—even to sit down to dinner with them. Join in with patient support groups and meet and talk with patients from all over the United States and the international community. Don't miss this chance to share your thoughts and discover that there is hope. The place to be this June is PHA's 5th International PH Conference in sunny California!



**Now Appearing for PHA**

**PHA wants to shine a national spotlight on disease awareness through the launch of a celebrity campaign.**

We are asking members if they have a relative, friend or colleague who may be a recognizable actor, entertainer, musician, athlete or literary figure and would agree to be our celebrity spokesperson.

If anyone you know fits the bill, please contact Lorie Simmons, PHA Advocacy and Awareness Director, 301-565-3004, ext. 113

## INTRODUCING

## Advances in Pulmonary Hypertension: The Journal of the Pulmonary Hypertension Association

*Advances in Pulmonary Hypertension: The Journal of the Pulmonary Hypertension Association* will be publishing its first issue in the first quarter of 2002. *Advances* is designed as a publication to educate doctors in areas related to pulmonary hypertension. This new quarterly publication will be sent to all 31,000 cardiologists, pulmonologists and rheumatologists in the United States.

PHA's Scientific Advisory Board has selected Victor Tapson, M.D., as editor. His editorial committee includes Drs. Sean Gaine, Valerie McLaughlin and Ivan Robbins. An outline of the first issue is as follows:

### The diagnosis and classification of PAH

Stuart Rich, MD  
Director, Rush Heart Institute Center for Pulmonary Heart Disease  
Professor of Medicine, Rush Medical College, Chicago

### Treatment guidelines in PAH and new therapies

Lewis J. Rubin, MD  
Professor of Medicine and Physiology  
University of California, San Diego

### Roundtable Discussion on Trends in Treatment/Special Considerations in the Management of PAH

Lewis Rubin, MD (see above)  
Robyn Barst, MD Professor of Pediatrics  
Columbia College of Physicians and Surgeons, New York  
Nazzareno Galie, MD  
Professor of Cardiology  
Istituto di Mallattie del' Apparato Cardiovascolare, Bologna, Italy

Feature article covering highlights from the career of Alfred P. Fishman, MD, William Maul Measey, Professor of Medicine Emeritus, University of Pennsylvania, Philadelphia.

## Pathlight Submissions

Have an article, announcement, quote, photo, or tribute to share? Please send it to us. Work submitted will be printed as space permits. Include a self-addressed stamped envelope with any material you want returned. PHA cannot be held responsible for materials lost. Mail submissions to:

Shirley J. Craig  
5726 Weeping Willow Road  
Houston, TX 77092-3336  
scraig@hal-pc.org

Deadline for the summer issue is April 30, 2002.

## Persistent Voices

*PV* is published twice a year with the fall and spring issues of *Pathlight*. The deadlines are January 31 and July 31. Please send your personal PH story along with pictures, poems, or quotes to:

Jerry Wojciechowski  
24232 Chrisanta Drive  
Mission Viejo, CA 92691  
949-215-1574 (fax)  
wojoj@home.com

Please include your phone number with submissions to *Pathlight* or *Persistent Voices*.

## FROM THE EDITOR

## Pathlight's New Look!

This *Pathlight* comes to you with a new look that I hope you will enjoy.

More people than ever before are receiving PHA's newsletter—over 7,000 with the last issue! This new format still provides our readers with all the important contact information they may need as well as listing our hard working board members—now found on pages 2 and 3. This leaves the back page for exciting articles that may catch the eye of new readers and encourage them to open each issue up and read more! It is my third year as *Pathlight* editor and I want to extend my thanks to all of you for the material you send in and your help—it is all greatly appreciated.

## Finding Hope at the PH Conference

By *Elise Zwicky*

**O**n February 21, 2000—my 13th wedding anniversary—I was officially diagnosed with Primary Pulmonary Hypertension.

I remember Dr. Vallerie McLaughlin, an associate of the highly respected PH specialist Dr. Stuart Rich, telling me I was “unlucky to have the disease but lucky to have it at this particular time” because there had never been more treatment options available nor more research being conducted that offered hope for the future.

I was also lucky to be diagnosed just four months before the PHA conference was to be held in Chicago, a mere 150 miles from my home. I didn’t realize it at the time, but this conference would be an incredible opportunity for me to learn about the disease and how to cope with it from others who have it and from the best PH specialists in the world.

After undergoing my first right heart catheterization on March 6, I learned that my pulmonary artery pressure was 57. The number didn’t mean a lot to me until I found out that a normal pressure is down around 15.

Luckily, I was a responder to calcium channel blockers, so I ended up in the cardiac care unit at Rush-Presbyterian St. Luke’s Medical Center, where I spent the next 24 hours learning how to swallow pills. In my “other life” before PPH, I had never been able to swallow a pill, even resorting to chewing aspirin. Somehow, with God’s help and the encouragement of my husband and a great nurse, I managed to choke down those huge Procardia capsules.

I left the hospital with lots of prescriptions and lots of hope, though I was still very tired and very scared. I also was determined to go to the PHA conference that I kept hearing so much about. Within a few weeks of being back home, I sent in registration forms for myself, my husband Fred, and my sister Rita.

I began to feel a little stronger with each new spring day. I could walk a little further and climb a few more stairs each day without getting short of breath. Two weeks before the conference, Dr. Rich checked me over, announcing that I was responding extremely well to the calcium channel blockers. He said my prognosis was good, much better than the outdated and terrifying survival rate I had read about earlier. Still, when it finally came time to drive to the conference, I felt a mixture of excitement and fear. Would I see my future in other patients who were in the later stages of the disease?

As we headed to our room to unload our luggage, I did glance around at other patients in wheelchairs, some with oxygen, many wearing the Flolan fanny pack. But you know what? They looked vibrant and alive and excited to be there. I had a feeling then that the conference was going to be OK, and it was way more than that.

Fred, Rita and I split up to attend as many different

seminars as we could, learning about such things as social security disability, insurance, transplants, current research, nutrition, how to be a caregiver and how to cope with the diagnosis and the disease.

In my sessions, I was bolstered by the many stories of survivors from all walks of life. Whether they were talking about how to handle acquaintances who say, “But you look so good” or how to deal with clods who don’t think you deserve a handicapped parking space, I saw myself time and again. I began to realize I wasn’t so alone after all. I even was able to meet a few PH friends I had been talking to on the Internet. And once I had an uplifting conversation in the restroom of all places with a 25-year survivor!

One of the most amazing parts about the conference was the opportunity to chat with some of the PH specialists. More than once I found myself in an elevator or walking down the hall with Dr. Rich or Dr. McLaughlin or Dr. Rubin.....and they were all more than willing to answer questions in that casual atmosphere. More than ever I felt that they truly cared about us patients beyond the examination room. My sister and I also were thrilled to be able to give blood as part of a research project headed by Dr. Jane Morse in search of a familial gene that causes PPH. It was hands-on evidence of the ongoing research to find a cure for this disease.

The conference was also a lot of fun. Fred and Rita even won T-shirts at a silly game show event designed to lighten the mood and provide an opportunity to get to know others. Through the sessions, the evening entertainment and during the delicious meals, we met people from all over the country, some of whom I am still in contact with.

By the end of that weekend, I was sad to see the conference end and already couldn’t wait for the next one in two years. It’s hard to believe 2002 is here already, and we’re hoping to attend this year’s conference June 21–23 in Irvine, California, despite the long distance we’ll have to travel.

As a postscript, a few weeks after the 2000 conference, I took a bike stress test to see if I qualified for the Beraprost trial, which was a big topic of discussion in Chicago. To my great surprise, I actually failed the bike test, and Dr. Rich and Dr. McLaughlin thought I might need to go on Flolan after all. I thought I had just panicked on the bike—the tube in my mouth made me feel claustrophobic—but they insisted I have another right heart cath just to be sure of what was going on.

We were all amazed when the RHC showed my pulmonary artery pressure had dropped to 25. I was actually too well to be considered for the Beraprost trial now! A year later in August 2001, another RHC showed my pressure has dropped even further to 22. Miracles do happen, and there is definitely hope. The PH conference is a wonderful place to find that hope