



# Pathlight

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

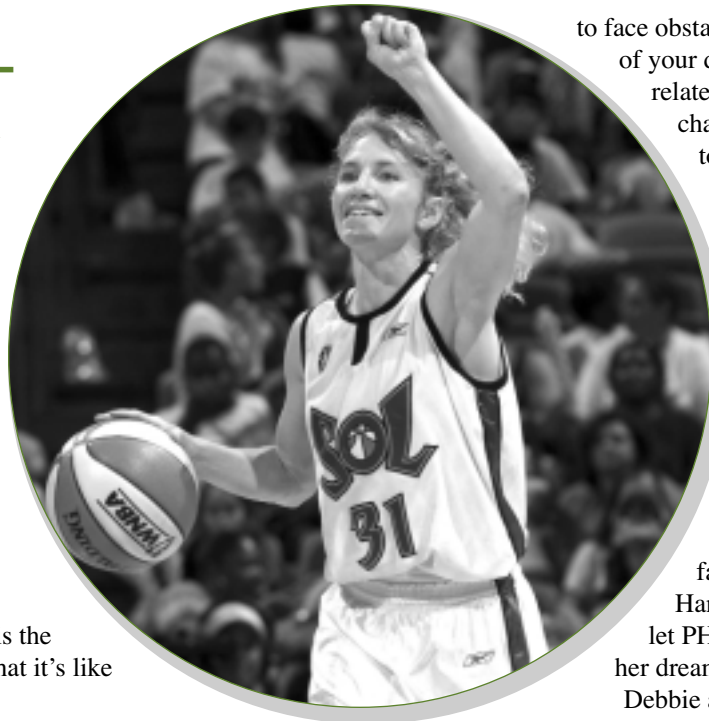
Spring 2003  
Volume 12 • Number 1

## PHA's Awareness Month Celebrity Spokesperson— Miami Sol's Debbie Black

The Miami Sol's Debbie Black, the reigning WNBA Defensive Player of the Year, is working with PHA to help raise awareness for PH. As part of Pulmonary Hypertension Awareness Month, Debbie joined doctors and PH patients in speaking out about PH.

Debbie Black became involved with PHA after meeting Hannah Carr, a PH patient (and daughter of Linda Carr, past president of PHA) who was recently honored for her courage and determination during halftime at a Miami Sol game. "Hannah is a remarkable young lady who has not let PH prevent her from following her dream to play basketball," said Black.

At five feet three inches tall, Debbie Black is the shortest player in the WNBA and understands what it's like



to face obstacles placed in front of your dreams. "I can relate to Hannah's challenge of being told you can't play basketball—because growing up, everyone told me I was too short to play ball. Hannah's challenge, like that of all PH patients, is so much greater than the one I faced. I admire Hannah's drive to not let PH get in the way of her dream."

Debbie and Hannah have been working together—this tandem approach has been well received by the press with exposure on TV and in the printed media. PHA anticipates more coverage as the WNBA season begins in June.

PHA is extremely happy to have Debbie Black, an individual with tremendous courage and determination of her own, on its side to help raise awareness for pulmonary hypertension.

Photo courtesy of the WNBA

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## President's Message

By Dr. Bruce H. Brundage



As we begin the new year, I make this pledge to you.

*In 2003, PHA will increase our communication with you, our members and friends.*

Communication is everything. It allows us to move from a passive position to a community driving hard toward necessary improvements. As a PHA member you will continue to receive four Pathlight newsletters this year. You will also receive two Persistent Voices, the newsletter that shares our stories. You will also receive at least four letters from PHA, bringing you information and ways to get involved and help.

I also have a request.

We above most others know the uncertainty of life. This year, that uncertainty goes beyond living with a rare illness. As I write this, we face the possibility of war. We are vigilant toward further terrorist attack. We live with an economy continuing to react to the stresses of our day.

In the midst of this, we are building a strong organization, making an impact on the lives of patients and their families, advancing research, diagnosis and treatments. We cannot let ourselves take a step back.

My request then is this. Be an active, not passive, member of PHA. Commit yourself to help PHA in whatever way you are best able. Whether you give of your time, your talent or your treasure in this pivotal year, it will be gratefully received. It will make a difference.




Donate your car, truck, RV or boat to PHA and help us improve the lives of all those affected by PH.

## PHA now accepts car donations.

Your car doesn't even have to be in working condition.

Call 1-800-324-7413 to make arrangements and schedule a free pick-up anywhere in the U.S.



Vehicle donations to PHA are tax deductible.

## Keep the Pot Boiling

Here is a quick story...followed by an important request.

In 1891, Salvation Army Captain Joseph McFee wanted to raise money so he could feed the poor a Christmas dinner. On Christmas Eve he put a pot at the Oakland Ferry Landing at the foot of Market Street in San Francisco. He put a sign next to the pot. It had four words, "Keep the pot boiling."

He fed 1,000 people in one night from the proceeds of that one kettle.

Last year, the Salvation Army put out 20,000 kettles. The total generated was \$91,000,000.

In 2002, PHA began our Committees of Correspondence project with three brave members who took a risk and wrote to their friends, asking for help. To their surprise and pleasure, these friends were ready and eager to help.



This year, we ask your help to "keep the pot boiling," to help PHA as we continue to grow to make a difference in the struggle against PH. Our goal for 2003 is to work with 25 members who are willing to send letters to friends to help us raise funds. We have a "how to" packet that explains the fundraiser and PHA's staff is available to help you throughout the process.

It just takes one person to make a difference...if that person is you.

To receive the introductory packet, with no obligation, contact Karri Boyer at 301-565-3004 x110 or [karri@phassociation.org](mailto:karri@phassociation.org).

## Persistent Voices

PV is published twice a year with the fall and spring issues of *Pathlight*. The deadline for the next issue is July 31, 2003. 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@cox.net](mailto:wojoj@cox.net)

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

### 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.



Pathlight is the newsletter of the

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FAX .....	301-565-3994
E-mail .....	<a href="mailto:pha@phassociation.org">pha@phassociation.org</a>
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)	
Accredo's Hotline for Flolan .....	1-800-9-FLOLAN 1-866-FIGHT PH
TheraCom's Hotline for Flolan .....	1-877-356-5264
Priority Healthcare Remodulin Hotline .....	1-877-462-6225
Tracleer Access Program .....	1-866-228-3546

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Laurie Jeter, 952-380-4999, [mjeterl@aol.com](mailto:mjeterl@aol.com)

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Jim Wilson, 972-931-9311, 972-931-8616 fax,  
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#### **2004 Conference Chair**

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## A D V O C A C Y   A N D   A W A R E N E S S

## Awareness Month 2002—Best Ever in Creating PH Awareness!

This year Awareness Week became PH Awareness Month in the hope this would give PHA patients and members more time to create broader awareness among those with no previous knowledge or understanding of this disease. PHA hopes to have a resolution before Congress for a National PH Awareness Month next year. In Louisiana, there was a proclamation signed by Governor M. J. “Mike” Foster, Jr., declaring November PH Awareness Week in that state.

The overall effect of expanding Awareness Week to Awareness Month was positive. There were more events than in previous years and PHA staff was able to support more of those willing to undertake events. The first of the awareness events actually began before November 1, 2002, and many were scheduled way beyond the end of November. The ideal situation exists when awareness activities are scheduled throughout the year. Moving from one week to one month has given PHA patients who are willing to become involved more flexibility in scheduling, enabling them to hold more events.

This year PHA was again fortunate to have on loan, through the generosity of Actelion, one of the top ranked PR firms in the country to help PHA in its efforts to attract the attention of local and national media. The PR firm of Weber Shandwick helped PHA to markedly increase the effectiveness of November’s awareness activities. It was Weber Shandwick that brought us together with Debbie Black, the WNBA women’s pro basketball player, who became our celebrity spokesperson for PH Awareness Month. Debbie and PHA’s own basketball superstar, Hannah Carr (daughter of Linda Carr, VP of PHA) made the airwaves on several occasions and were featured in numerous print articles as well.

In addition to press coverage featuring Hannah and Debbie, Debbie Black’s celebrity brought the attention of the media to PH and PHA at various times throughout the month with outlets in Texas, Utah, Florida, and Arizona picking up the stories placed. The Associated Press picked up the items as well. In addition, PH and PHA stories made the web on several different sites. PH was featured in an article in the *New York Times* on December 1 “The Neediest Cases,” and in the Northwest Airlines *World Traveler*, “To Heal a Heart.”

We know that many of those who ran events this year were able to attract the attention of their local media, and PHA would like to know if an event was featured in the local media outlet or in a community newspaper or newsletter. Please share that information with PHA by sending a copy to the PHA office.

Overall, PH Awareness Month events that were reported to PHA were varied and extremely interesting. They ran the gamut from expanded, educational Support Group meetings with a special luncheon or dinner in honor of someone or celebrating the PH Awareness Month effort, to hospital wellness/information tables and training sessions at various centers around the

country. Below is a summary of those events with which PHA staff had the opportunity to be involved. Please send a summary to PHA if you participated in an event that is not listed here. We have time and space to list your event in future *Pathlights* and on the PHA website. Each event provides the inspiration to create new awareness events, even if they do not occur during Awareness Month.

## PH Awareness Month 2002 Events:

California Race for PH—Stanford, California, October 26, 2002  
*[See separate article with photos.]*

Long Island New York Support Group Luncheon and Silent Auction *[See separate article with photo.]*

### Los Angeles Support Group

Liu Center for PH—Torrance, California—Raffle raised awareness and funds for PHA during November 9 luncheon meeting.

### Las Vegas Support Group—busy month!

November 1—TV interview with Linda Ocker at home “A day in the life of a PH patient.”

November 6—Members were at an information table in the Galleria Mall.

November 13—Desert Springs Hospital ER—Accredo sponsored an information session/question and answer period.

November 14—PAH in-service for the EMS team at the Henderson Training Center.

November 18—in-service for both day and night shift nurses at Sunrise Hospital ER.

November 22—Lake Mead Hospital ER—display table with information for nursing competency day with PH patient and Accredo advocate.

### Mary Kay in Nevada

Carol Staab hosted Mary Kay make-up parties to raise money for PHA during the month of November and throughout the year. She donated products that were raffled off and also gave a percentage of the proceeds of her Mary Kay sales to PHA. Carol did “Mommy and Me” make-overs for mother/daughter duos and will donate a part of each make-over duo she does. She will be doing these “face-a-thons” for PHA during Awareness Month and beyond. Contact Carol at 520-886-4067.

### Minnesota Fundraiser/Information Booths/Awareness Tables

The Minnesota group worked with Herberger’s Department Stores selling discount coupon books for \$5 each filled with coupons for Herberger’s stores with proceeds going to PHA. A PH Information Booth was set up at the Med Center One in

## ADVOCACY AND AWARENESS

Bismarck, North Dakota, on November 18. Another was in Alexandria, Minnesota, at the Douglas County Hospital. Awareness tables were also located at the Mayo Clinic and the University of Minnesota Hospital in mid-November.

### Milwaukee Group Meeting

The Milwaukee area support groups met at the Pfister Hotel in downtown Milwaukee bringing together more than 60 PH patients from various treatment centers and support groups in the area for brunch. Rita Conway was the featured speaker who spoke on the "Practice of Mindfulness: Techniques for focusing on your present." This event was sponsored by Accredo Therapeutics and Actelion Pharmaceuticals.

### Painting a Brighter Future for PAH Patients in Wisconsin

On November 8, the Gingrass Gallery in Milwaukee, Wisconsin, along with the Medical College of Wisconsin, Froedtert Memorial Lutheran Hospital, and Children's Hospital of Wisconsin hosted an educational program highlighting early diagnosis and innovative treatment options for pulmonary arterial hypertension. Over 100 pulmonologists, primary care physicians, cardiologists, and rheumatologists attended. The gallery donated a percentage of the evening's sales to PHA.

### Michigan Support Group

A raffle and luncheon was hosted by the Michigan Support Group on November 23 at the Holiday Inn South in Lansing, Michigan.

### Louisville Events

PHA members in Louisville organized several hospital information tables. Thelma Rice was interviewed with her PH doctor on a local Health Talk TV show answering call-in questions.

### Louisville/Indianapolis/Cincinnati Dinner

Regional support group dinner meeting for educational training at the Kingsgate Marriott—rescheduled for mid-spring.

### Arkansas Support Group

Awareness table at a Little Rock shopping mall in mid-November.

### Houston PH Support Group

Members were on hand at an awareness table in Northwest Mall to sell tickets for the Magical Night of Giving raising funds for PHA and supporting awareness by handing out PH and PHA material.

### West Central, Florida, Support Group Meeting

PH Support Group meeting was November 16, 2002. Candy Smith, Clinical Educator with Priority Health Services, presented information on Remodulin, the newest treatment available for PH.

### New Jersey and New York Events

PH Health and Awareness tables were scheduled for major hospitals from Totowa, New Jersey, to upstate New York throughout November.

### Stony Brook Awareness Table

This New York Support Group hosted a community awareness table just outside of the cafeteria at Stony Brook University Hospital on Long Island, New York.

### Boston Area Support Group Meeting

Members were encouraged to attend their Support Group meeting during awareness month at the Boston University Medical Center School.

### Loganville Support Group near Atlanta, Georgia

A group meeting was held in support of parents of children with PH.

### Theracom

Theracom mailed awareness pins to each of their Flolan patients emphasizing how useful an accessory like the pin can be for raising awareness.

Theracom also held an in-house "PH Awareness Month Recognition Day" with onsite training about PH and Flolan therapy.

### Long Island Fundraiser

On November 3, 2002, the Long Island, NY, PHA support group held its first high-end fundraiser at The Douglaston Club in Douglaston, Queens, NY. The luncheon and raffle were a rousing success!

We couldn't have had the event without the support of club member and PH patient, Marta Brown. Marta and her husband Russ worked closely with The Douglaston Club to coordinate all the important details of hosting an event for PH patients and their families. We were also very fortunate to have the help of one of Marta's dear friends, Ann Aiston. Ann's experience with

fundraising event planning was a blessing and she guided a large part of the event as well as coordinating the very successful raffle.

We were very fortunate to have two guest speakers. Dr. Michael Poon of Mt. Sinai Hospital in New York spoke to the group



Event Co-chairs for Long Island Luncheon were Marta Brown, JoAnne Sperando-Schmidt and Ann Aiston (l-r).

*(Continued on page 6)*

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Long Island Fundraiser (continued from page 5)

about his experiences in PH research and patient treatment. Rino Aldrighetti, PHA's executive director, also addressed the group about the Association's mission and latest efforts.

All told, this event raised over \$9,000 for the PHA and the Long Island Support Group plans to make this an annual event.

Awareness Year Round!

Members of the North Texas PHA Support Group staffed an information booth at the 2003 Healthfit Expo hosted by NBC and the local affiliate Channel 5. The event was held January 11-12 at the Dallas Convention Center. Over 30,000 people visited the two day health fair and fitness exposition.

While thousands passed the booth area and viewed the display, over 500 people stopped to ask questions of the volunteers and take literature about PH, according to PHA Board of Trustee member Jim Wilson. "This is the second year we have participated in this event," said Jim. "In the last two days, we've been asked by five other organizations to bring our booth to health fairs they are planning for their communities. We see this as a great opportunity to increase awareness of the disease in the North Texas area."

One of the events is going to focus on the Hispanic population. "We are in the process of having PHA's handouts translated into Spanish, and I believe this will be the first time PHA will have been involved in an event focused solely on the Spanish-speaking community."

NBC hosts five such Healthfit Expos around the country annually, according to Jim. He strongly encourages other support groups to participate in this highly visible community event. To find out if your area is having an NBC Healthfit Expo, e-mail Larry Jennings at [ljennings@networkevents.tv](mailto:ljennings@networkevents.tv) or call him at 301-754-2654.



Jim Wilson and PH patients Laine Smith and Aundria Colgrave work the awareness booth at the Healthfit Expo in Dallas.

Great Start for Awareness Month!

**What:** Second Annual Race for PH  
**Where:** Stanford University in Palo Alto, California  
**When:** Sunday, October 27, 2002

When Patti Ewing was diagnosed with pulmonary hypertension, her family felt they had been given the same diagnosis—and they wanted to find a way to help. Patti's daughter Katie and her friends, Eddie Davis and Paige Dunn, organized the Race for PH. They worked hard and their efforts were successful. The race's earnings will benefit the Vera Moulton Research Center and the Pulmonary Hypertension Association. Many came out to have fun in support of a good cause—raising awareness throughout the community.



Race for PH organizers and their guests relax while going over the final details.



The finish line in the Stanford Stadium! Eddie Davis, Paige Dunn, Dr. Jeff Feinstein, Dr. Bruce Brundage (PHA president) Patti Ewing (PHer), Dr. Ramona Doyle (l-r)

Many were on hand for the race!



## NEWS AND ANNOUNCEMENTS

## Save the Date:

**2004 PHA Conference Scheduled for Miami!**

The 2004 PHA Conference will be held at the Hotel Inter-Continental Miami, **June 25–27, 2004**, in Miami, Florida. PHA has arranged for a very special room rate of \$129 per night. This 34-story property (640 rooms) is located directly on the bay and has incredible room views. It's a four-star business hotel with great food and service ([www.miami.interconti.com](http://www.miami.interconti.com)). The Hotel Inter-Continental Miami is within easy walking distance of Bayside Marketplace (nine restaurants, food court, shopping, sight-seeing cruises, and outdoor entertainment, [www.baysidemarketplace.com](http://www.baysidemarketplace.com)).

PHA will once again be the largest group on the site, and the meeting space layout is excellent. Miami International Airport offers direct access from throughout the United States, Central and South America; and Ft. Lauderdale Airport with numerous low-fare carriers is an option especially if you rent a car—and only 40 minutes north. For a vacation before or after the conference, Miami Beach and Key Biscayne beaches are only 20 minutes away—and for theme park fans, Orlando is less than five hours away by car. Mark your calendars now and make plans to attend PHA's Sixth International Conference!

**PH Patient to Speak at American Thoracic Society Conference**

Gail Boyer Hayes will be PHA's PH patient speaker for the American Thoracic Society Public Advisory Roundtable Seminar which will be in Seattle, Washington. Gail will be excellent in presenting a patient's perspective of PAH. She is the author of the *PH Survival Guide First and Second Editions*. The PAR Seminar for the ATS International Conference will be Sunday, May 18, 2003, 8:30–11:00 a.m.

**California PH Forum 2003**

The third California PH Forum will be June 28–29, 2003, at the Embassy Suites Hotel, 150 Anza Boulevard, Burlingame, California, 94010, near the San Francisco Airport. Please call the Embassy Hotel at 1-800-686-2894 or 1-650-342-4600 to make your reservations.

This conference occurs in the summers opposite the national PHA conference. For more information, e-mail Judy Vucci at [CAPHForum@aol.com](mailto:CAPHForum@aol.com) or call Rita Orth at 925-552-7824. You can also find out more at the PHA web site.

**PHA Announces 2002 Postdoctoral Fellowship Award Recipients**

The goal of the PHA Postdoctoral Fellowship Program is to attract bright young researchers at the beginning of their careers to PH research in the hope that they will continue in the field. PHA awards two or three of these grants annually for two years of research.

Hideyuki Beppu, MD, PhD  
Massachusetts General Hospital  
Sponsor: En Li, PhD

"The Genetic Basis of Pulmonary Hypertension—Studies in Genetically Modified Mice"  
Term: July 1, 2002–June 30, 2004

Wai Patrick Wong, PhD  
Columbia University  
Sponsor: James A. Knowles, MD, PhD

"Molecular Genetic Studies of Primary Pulmonary Hypertension: Gene Identification and Functional Analysis"  
Term: October 1, 2002–September 30, 2004

**PHA Will Sponsor Poster Award at International PH Symposium**

PHA will sponsor a scientific poster session award at the Third "World PH Symposium" to be held in Venice, Italy, this spring. The award winner will receive travel, lodging and registration for the 2004 PHA Conference where the winning poster will again be displayed.

PHA materials such as brochures, explanations of our research awards, and medical journals will be available to doctors from around the world at the symposium.

**New Look for Features at PHA Web Site**

PHA would like to encourage all members to sign up for its e-mail newsletter *PHA News*. This e-mail resource is sent out bimonthly and includes links to relevant articles about pulmonary hypertension. *PHA News* will keep you up to date on happenings in the PH community regarding medicine, people, and current events. It also highlights the PHA website, letting you know about online chats, new services, and more. You can get to the sign-up page by going to PHA's home page at <http://www.phassociation.org> and then clicking on the link on the right side of the home page. Encourage your family and friends to sign up for PHA News, too!

Be sure you look over the redesigned Our Journeys section, too. PHA has incorporated an attractive piece of art originally created for a PH fundraising event to help tell touching and hopeful stories from the PH community. The Our Journeys section is located at [http://www.phassociation.org/Our\\_Journeys](http://www.phassociation.org/Our_Journeys).

## FUNDRAISERS

### Upcoming Events

Houston Cure PH Golf  
Tournament  
Friday, April 11, 2003  
Fish Creek Golf Club  
Montgomery, Texas  
Contact: Jack Stibbs  
281-681-5900  
9 a.m. Registration  
11 a.m. Shotgun Start

2nd Annual Caleigh Coleman  
Memorial Golf Tournament  
Monday, May 12\*, 2003  
(\*new date)  
Corsicana Country Club  
Corsicana, Texas  
Contact: Tonia Coleman  
903-872-6098  
coleman3@pflash.net

4th Annual Kipp Palmer  
Memorial Golf Tournament  
Friday, June 20, 2003  
Crossgates Golf Course  
1 Crossland Pass, Millersville,  
Pennsylvania  
Contact: Joel Langdon  
888-696-7690

3rd Annual Jerry P. Selinger  
Golf Tournament  
Thursday, June 26, 2003  
Elks Lodge & Golf Club  
Calgary, Alberta, Canada  
Contact: Terry Selinger  
t.selinger@shaw.ca

### 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.

June Blair	Mary McCartney
Minerva M. Boehlen	Gauvin McCullough
Ronald Briggs	Joey Nelson
Luis R. Carrillo	David Nolen
Anne Coleman	Myra L. Paulsen
Jerome E. Connelly	Barbara Perttunen
Christen W. Cranford	Nancy Toth
Aaron D. Forrest	Carmen Vassallo
Madeline Graham	Ellen Yamin
Sylvia C. Klinger	Nancy L. Zimmerman
Diana E. Kobilan	

Contact the PHA office to have your loved one's name listed in Passages.

### When to Transplant?

*This is from the summary of the 2002 PHA conference session "When to Transplant?" presented by Harold Palevsky, MD, Christine Archer-Chicko, RN, Gordon Yung, MD, Mary Ganikos, PhD, Robert Frantz, MD.*

Dr. Gordon Yung, UCSD Medical Center, San Diego, California:

The issue is when to be listed more than when to transplant. If you need a transplant now, it is too late for listing. The national waiting time is about two years. No one can really predict how a PH patient will do in two or three years' time. Declining Class III or IV patients need transplants usually. Until we have a better handle on how long which patients will survive with new therapies, it's best to get listed.

Chris Archer-Chicko, RN, Presbyterian Medical Center, Philadelphia:

PH can progress quickly and the patient can get too sick to be eligible for transplant. Patients need to be emotionally and psychologically prepared to be transplanted as they may have ups and downs after transplant and need to be ready to face them with a fighting spirit.

### National Organ and Tissue Donor Awareness Week (NOTDAW)—Third full week of April\*, Sunday–Saturday

This is a week of increased activities to promote donation awareness in government agencies and communities across the nation. Organ procurement organizations, transplant centers, and other donation and non-donation related organizations sponsor special awareness events and donor recognition ceremonies during this week. ([www.organdonor.gov](http://www.organdonor.gov))

\*April 20–26, 2003

### 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, 2003.

**UNDER 21** (continued from back cover)

**Form Letter to Personnel Who May Work with your Child**

Letters can be given to school personnel including nurses, teachers, and coaches which includes substitutes or athletic trainers. Parents may promise to have one parent present at all games both home and away and present or nearby during all practices.

Parents could add that “the child should be allowed to rest if she/he becomes very short of breath or tired” depending on the child’s age. If the school doesn’t have a nurse, educate the secretaries or whoever is working with your child for recess or gym activities. Here is a sample form letter to help parents get started writing their own:

(Date)

Dear (Name):

Important medical information about (Child’s name):

(Child’s name) has a rare disease, **Primary Pulmonary Hypertension**. She/he wears a medicine pump, 24/7, in a belt pack (or strapped to her/his leg under her/his clothes) which gives her/him a continuous IV infusion of the drug FLOLAN (epoprostenol sodium) through a small catheter implanted in her/his chest. Her/his other medications are: Coumadin (etc...).

If (child’s name) has a problem with her/his pump or catheter, it is a medical emergency. Her/his situation is very complex and her/his parents must be called immediately. Rebound Pulmonary Hypertension may occur with discontinuation of the IV drug. No one should turn off the pump for any reason. The IV drug (Flolan) may be infused by a peripheral line, if necessary.

Mother’s name	Home number
	Cell number
	Pager number

Father’s name	Work number
	Cell number
	Pager Number

Also call \_\_\_\_\_, a medical help line to speak with a trained nurse about (Child’s name) drug, the pump or her/his catheter.

(Child’s Name) must be permitted to call her/his parents immediately if she/he is not feeling well. Her/His disease and treatment are complex and unusual, and emergency personnel are not likely to have experience with pulmonary hypertension patients using her/his IV medication.

(Child’s name) pulmonary hypertension specialist is {Physician at Hospital, City, State, (area code) phone number}.

Her/his local doctor is {Name (area code) phone number}. Our hospital of preference for him/her is (hospital name, city).

Please contact us with any questions you may have.

Sincerely,

Mr./Mrs. \_\_\_\_\_

**Planning for a Better Tomorrow...**

We all know the struggle against pulmonary hypertension is difficult. Since PHA’s founding, we have seen advances—first slow and now much more rapid—in the struggle against this terrible illness. PHA is deeply grateful to all the members of our community who are accelerating our ability to make a difference through research, public awareness and patient services.

If you are considering a legacy gift to support PHA’s mission in the future, we have resources to help.

- Please send me the brochure, *Guide to Estate Planning Strategies*.
- Please send me information on how to include PHA in my estate plan.
- I have already made provisions for PHA in my estate plan through:
  - My will     A trust arrangement
  - An insurance policy
  - Other \_\_\_\_\_

Please have someone call me to discuss giving opportunities.

Mr.  Mrs.  Dr.  Miss  Ms.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_

ZIP \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

Please return to:

PHA  
850 Sligo Ave, Suite 800  
Silver Spring, MD 20910

Or by fax to 301-565-3994.



## Please Distribute to Your Allied Healthcare Professional (Nurses, pharmacists, respiratory therapists and technicians)

Dear Colleague:

PH Resource Network (PHRN) is a group of healthcare professionals within the Pulmonary Hypertension Association (PHA) who support communication, advocacy, education and research. We are currently updating and expanding the PH Resource Network database. Along with a journal subscription to *Advances in Pulmonary Hypertension*, PH Resource Network membership offers access to the PH Resource Network website and list serve, along with educational seminars at PHA conferences. As we grow, it is our goal to develop standards of care, explore the feasibility of certification and expand this professional network internationally.

Now is the time to build the PH Resource Network. We are delighted to have a Medical Services Director, Don Clark, who will be assisting with CEUs, program development and research funding. Membership is limited to professionals employed in the care of PH patients. Your PHA membership donation of \$15 or more entitles you to joint membership in PHA and the PH Resource Network.

Please complete and return the questionnaire below, noting whether you are a current or new member. Current members who have already paid for 2003 need only to complete the survey information.

—Cathy Severson, R.N., for the PH Resource Network Organizing Committee

### 2003 PHRN Survey

- I want to join PHA's PH Resource Network.
- New Member       Renewal with 2003 payment       Renewal/Survey only
- Enclosed is my dues contribution: \$15 (U.S., individual).
- I would like to help PHRN with an additional contribution of \_\_\_\_\_.

**Total enclosed:** \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

E-mail \_\_\_\_\_

Profession \_\_\_\_\_ License # \_\_\_\_\_ State \_\_\_\_\_

Place of Employment \_\_\_\_\_

Name of physician affiliated with \_\_\_\_\_

Years of experience with PH patients \_\_\_\_\_ # of PH patients in practice \_\_\_\_\_

Contributions are tax deductible to the extent permitted by law. Please make checks payable to PHA and return with this form to:

PHA/PHRN  
850 Sligo Ave., #800  
Silver Spring, MD 20910

Prefer to join on-line? Go to [www.phassociation.org/PHRN](http://www.phassociation.org/PHRN).

Questions? Please call 301-565-3004, ext. 104.

*Please copy as needed.*

## Consensus Statement

*The information below is for general information only. These guidelines may not apply to your individual situation. You should rely on the information and instructions given specifically to you by your PH specialist and/or the nurses at your PH Center. This information is general in nature and may not apply to your specific situation. It is not intended as legal, medical or other professional advice, and should not be relied upon as a substitute for consultations with qualified professionals who are familiar with your individual needs.*

### Recommendations on Over-the-Counter Medications in Patients with Pulmonary Arterial Hypertension

When using non-prescription, over-the-counter (OTC) medications, care should be taken as these agents may have a direct effect on the heart and lungs or may interact with medications commonly prescribed for patients with PAH.

Cold, flu, sinus, allergy, decongestant and headache medications frequently contain ingredients such as pseudoephedrine that have stimulant-like properties. These medications cause blood vessels to vasoconstrict (narrow), and may worsen PH and increase blood pressure and heart rate. They may also cause palpitations and irregular heart rhythms. These medications may also contain significant doses of caffeine, which can have similar actions on the heart. Therefore, all decongestants and medications that contain stimulants should be avoided in patients with PAH. They are marketed as tablets, caplets, liqui-gels, liquids or nasal sprays. As a general rule, if any ingredient is contraindicated in patients with high blood pressure, then it is contraindicated in patients with PAH. If there is uncertainty regarding the contents of specific formulations, ask a pharmacist for assistance. Medications that contain antihistamines (e.g., diphenhydramine, Benadryl, Claritin) may be used to treat cold symptoms, allergies, and hay fever, provided that they do not also contain decongestants.

Aspirin and medications classified as “non-steroidal anti-inflammatory agents” (e.g., Advil, Motrin, Naprosyn, etc.) may increase the risk of bleeding in patients taking warfarin (Coumadin). These medications are typically found in analgesics (pain medications), but may also be present in cold, allergy, and sinus medications. They should be used with caution and only for short periods of time. Large doses of acetaminophen (Tylenol) may cause liver damage, and may interact with warfarin. Whether acetaminophen increases the potential for liver damage in patients taking bosentan (Tracleer) is unknown.

The use of herbal medications has become increasingly popular. Unfortunately, there is limited information on many of these products, and there are no established standards to regulate their production. As a general rule, a product marketed as “natural” should not be assumed to be safe. Like the OTC medications described above, herbal medications can affect heart and lung function, and interact with prescribed medications. The list of herbal medications is extensive, precluding a statement on

each formula; instead, we will comment briefly on some of the more commonly used agents:

Ephedra (ma huang) contains ingredients with stimulant-like properties. It should be avoided in patients with PAH. Ephedra, don quai, and St. John’s Wort may increase or decrease the actions of calcium channel blockers. St. John’s Wort and ginseng may affect digoxin concentrations.

Numerous agents affect the function of platelets (cells needed to clot the blood), which can increase the risk of bleeding in patients receiving warfarin or Flolan. Examples of such compounds include garlic, ginkgo, and ginseng. Some herbal medications can interact directly with warfarin, either increasing (e.g., danshen, dong quai, papaya extract, vitamins A and E) or decreasing its effects (e.g., ginseng, St. John’s Wort, vitamin K).

Liver damage has been reported in patients using kava and Echinacea, and valerian may cause liver injury as well. Whether these compounds can increase the risk of developing liver damage in patients treated with Tracleer is unknown.

In summary, OTC medications and herbal therapies may be harmful, and should be used cautiously in patients with PAH. Herbal therapies should be viewed as drugs, not simply as “natural supplements.” It is recommended that prior to taking any of these drugs; you discuss them with your PH specialist.

\*All of the SLC Consensus Statements can be viewed online at [www.phassociation.org](http://www.phassociation.org).

*PH consensus statements were developed by the Consensus Committee of PHA’s Scientific Leadership Council and reviewed and approved by the SLC in the summer of 2002.*

#### Please update my mailing list information as follows:

*(Please print.)*

Mr.  Mrs.  Dr.  
 Miss  Ms. Name \_\_\_\_\_

Business (if any) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Please check here if this is a change of address.

Phone \_\_\_\_\_ Fax \_\_\_\_\_

E-mail \_\_\_\_\_

I am a:  patient  caregiver  parent of child with PH

medical (title and affiliation): \_\_\_\_\_

Mail or fax the completed form to:

PHA • 850 Sligo Ave, Suite 800 • Silver Spring, MD 20910  
 Fax: 301-565-3994

You may also submit a change of address online at  
[www.phassociation.org/contact.htm](http://www.phassociation.org/contact.htm)

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**Sean P. Gaine MD, PhD at the Mater Misericordiae Hospital, Dublin, Ireland and Traci Houston-Harris RN, MS, Priority Healthcare**

**Predictors of end stage lung disease in a cohort of patients with scleroderma.**

Morgan C, Knight C, Lunt M, Black CM, Silman AJ. *Annals of the Rheumatic Diseases* 2003; 62:146–150

ARC Epidemiology Unit, University of Manchester Medical School, Manchester, UK Rheumatology Unit, Royal Free Hospital, London, UK.

The researchers sought to estimate the incidence of severe lung disease in patients with scleroderma and identify the combination(s) of features present at first assessment, which would be useful to predict future risk of severe end stage lung disease. End stage lung disease was defined as pulmonary hypertension requiring continuous ambulatory iloprost, or pulmonary fibrosis requiring continuous oxygen, or death from a scleroderma-related lung disease. The medical records of 561 patients with scleroderma diagnosed on or after January 1, 1982, with disease duration of less than five years before the first assessment were reviewed. Detailed clinical and laboratory assessments were undertaken at the initial visit. The records were re-evaluated at the end of 1997 to determine the patients' status. In all, 24 patients reached end stage lung disease. The cumulative incidences were 4%, 6%, and 12% at five, seven, and 14 years respectively. As expected, the lung function tests at baseline, including being in the lowest third of either diffusing lung capacity, or of forced vital capacity, were highly significant predictors of end stage lung disease. Interestingly, apart from the presence of proteinuria, none of the other baseline variables, including the extent of skin disease and serological markers, were predictive of severe lung disease. End stage lung disease was infrequent in this large cohort, and much lower than some other reported estimates. However, the cumulative incidence increased importantly with time. The risk can be predicted from baseline assessment of pulmonary function. In particular, those with completely normal pulmonary function at baseline are at very low risk.

**Pulmonary hypertension in scleroderma spectrum of disease: lack of bone morphogenetic protein receptor 2 mutations.**

Morse J, Barst R, Horn E, Cuervo N, Deng Z, Knowles J. *Journal of Rheumatology* 2002 Nov; 29(11):2379–81.

Department of Medicine, Columbia University, New York, New York

In 2000 researchers discovered the gene responsible for familial (inherited) Primary Pulmonary Hypertension (PPH). It is called BMPR2. Additional testing has looked at PPH patients without a family history of the disease (sporadic PPH) and found that about 25% have the gene mutation. In this study, Dr. Morse

and her colleagues wanted to determine if patients with Pulmonary Arterial Hypertension (PAH) related to scleroderma also had these gene mutations. The researchers studied 24 patients with pulmonary arterial hypertension related to the scleroderma spectrum of disease and compared them to two control groups that consisted of 96 healthy North American individuals and 100 Israeli Ashkenazi Jews. The patients also had antinuclear antibody determinations and underwent right heart catheterization. All were tested for BMPR2 gene mutations. Of the 24 scleroderma patients studied, only one had BMPR2 mutations and that case may represent a polymorphism because the same mutation was found in a healthy matched control. The authors have concluded that PAH related to scleroderma was **not** associated with mutations of BMPR2 as it is in familial PPH.

**Simvastatin attenuates smooth muscle neointimal proliferation and pulmonary hypertension in rats.**

Nishimura T, Faul JL, Berry GJ, Vaszar LT, Qiu D, Pearl RG, Kao PN. *American Journal of Respiratory and Critical Care Medicine* 2002 Nov 15; 166(10):1403–8

This research was carried out at Stanford University in California and looks at the effect of a commonly prescribed cholesterol lowering drug in animals with pulmonary hypertension. Simvastatin is also known as Zocor®. The authors note that pulmonary vascular disease is characterized by abnormal proliferation of vascular endothelial and smooth muscle cells, leading to occlusion of pulmonary arterioles. They hypothesized that drugs with antiproliferative effects on vascular endothelial and smooth muscle cells, such as the cholesterol lowering HMG-CoA reductase inhibitors, may prevent the development of experimental pulmonary hypertension. Rats who have had one lung removed and who are injected with the toxin, monocrotaline, develop severe pulmonary vascular disease at seven days. Rats were randomized to receive either placebo or treatment with the HMG-CoA reductase inhibitor simvastatin (2 mg/kg per day). By Day 35, rats that received placebo had higher mean pulmonary arterial pressures ( $53 \pm 2$  mm Hg) and right ventricular hypertrophy than rats that received simvastatin from Day 5 to 35 ( $27 \pm 3$  mm Hg). Pulmonary vascular remodeling was more severe in placebo-treated rats than in simvastatin-treated rats. In addition, lung endothelial nitric oxide synthase gene expression (the gene responsible for nitric oxide production in lung blood vessels) was decreased in placebo-treated animals but was restored toward normal levels in simvastatin-treated animals. Therefore the authors conclude that the cholesterol lowering agent simvastatin attenuates monocrotaline-induced pulmonary vascular remodeling, pulmonary arterial hypertension, and right ventricular hypertrophy in rats. It is only a matter of time before the role of these widely prescribed medications will be explored comprehensively in individuals with pulmonary hypertension.

## Life Is Sweet: Conclusion

By Sharren Yamron

I finally got listed for a second lung transplant at the University of Maryland in Baltimore, and the anxious wait began. It was more difficult this time because my breathing was already so labored and the risk of rejection and infection again could make me too ill for another transplant. I tried to be cautious and stay away from things that could do harm to me; to relieve stress, I would enjoy every day as much as I could. I saw my doctors in Baltimore every few months and kept up hope that my lung function would stay stable.

To my surprise I received a notice that my doctors at the University Of Maryland would be transferring their practice to the Johns Hopkins Hospital. I was asked if I would consider following them, thereby being relisted for transplant at Johns Hopkins. With the hospital's reputation preceding it, I jumped at the chance and, fortunately, the time I had already spent waiting was credited.

I had numerous false alarm calls, which is common for someone who has to travel a long distance to their hospital. The transplant team needs you on your way to the hospital before they are even sure if the organs they are harvesting are viable. A few times we were on the road for an hour or two until we got a call on our cell phone that something wasn't right with the organs and we should go back home. On one occasion I was prepared for surgery and practically under the knife when the word came in that the organs were not any good. The false alarms made the situation even more stressful. But it was just a few more bumps in an already bumpy roller coaster ride.

Needing six liters of oxygen was draining and very hard for me, but I persevered. I got back to Pittsburgh and waited again. We even stayed in Baltimore one summer with the hope that I would be called sooner, but it didn't happen.

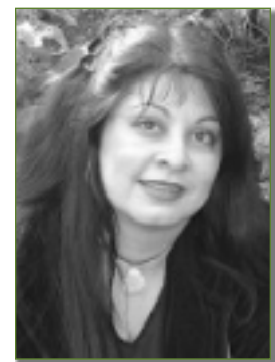
After a three-year wait, I finally got the call on April 12, 2001, at one o'clock in the morning. It was a slow and arduous journey to Baltimore. My husband dealt with driving in heavy rain and thick fog, while I tried to deal with all the hopes and worries of surgery. I knew this time everything was coming to fruition for me.

I was again prepped for surgery, but this time I was searching for a look in the eyes of doctors, nurses, and my family. It is the look of trust, hope and confidence; it is the look that this is really it—that everything is going to be all right and everyone around me is going to care for me. It is the knowledge that you are loved and you will go on living. I felt hopeful and confident and ready for the show. My son gave me a kiss and a smile, my husband kissed me and wished me good health, and I was rolled into the operating room.

After about four hours Dr. Conte, my surgeon, came out to the waiting room and told my husband and son that everything went well and that I would soon be in the ICU. The second transplant was a single right lung, and the surgery only took four hours. Luckily there were no complications or set backs and I seemed to sail through it. It was later that day I woke up.

I remember faces slightly but I wasn't fully coherent yet. I couldn't figure out how it was the same day and how it was all over.

What I was aware of was that I didn't feel out of breath or have to struggle for air like before. I wasn't tired from drawing in each breath. I didn't feel dizzy from not getting enough oxygen. Simply said, this is what I had been waiting for. It was both exciting and scary. I was excited I was breathing in a somewhat normal fashion, but the breathing tube and the ventilator were hell. I knew it was necessary for my recovery, but that did not mean I had to like it. The ventilator also stopped me from talking, but I tried anyway.



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Each day the nurses got me active and each task was met with new enthusiasm. Wow, I can breathe, I can inhale and not feel like it was such hard work. I can get out of bed, stand, and move around. With luck I will be dancing soon! With each little improvement I became excited to do more. My body wasn't letting me down. Just put a task in front of me and watch me try to achieve it. The challenges were my assurance now and how I loved meeting them. I was happy to try and do whatever the doctors and nurses asked. With close watch by my doctors I got better and finally I was able to have the breathing tube out. I smiled from ear to ear when I got that thing out. My husband remembers how I grinned and seeing his face light up was my reward.

The doctors saw me every day and were pleased with what we accomplished. I can never thank them enough for the overwhelming feeling of being given a breath of life. How can I ever thank someone for that? To the donor, doctors, nurses, aids, therapists: I owe my life. This is a wonderful gift I was bestowed. All I can do is respect life and give back to all who supported me on my journey.

It has been over a year now and I am close to my second anniversary. I am doing well and only had one setback which is normal for the first year. I can go out and do normal things in moderation; I help with the PHA organization and help run the support group here in Pittsburgh. I want to make people aware of becoming donors and the right to seek a second transplant. It has been and continues to be a difficult journey, but the reward—life—is worth the struggle not only for me but for all those my life touches.

For me, life is so sweet and I owe deepest thanks to Dr. Rubin, Dr. Orens, Dr. Conte, and the entire staff who worked with me at Johns Hopkins. Also I would like to thank Dr. Dauber and Dr. Iacono at UPMC who have and continue to help me so much. Also I want to thank the transplant coordinators and nurses. My husband's employer, IBM, also deserves a great deal of thanks for its understanding and allowing him time off every time I needed to travel. With each breath I take, I know I never could have done it without all of them.

# UNDEER

Information for our younger members and their families



## Summer Camps for PH Kids

Planning ahead for summer camps can be possible for kids with PH, too. At right is a list of camps for kids with complex heart diseases and chronic illnesses. The camps are staffed with clinical support teams. *Be sure to call first to see if PH is an acceptable diagnosis since some camps are sponsored specifically by diagnosis.*

Staff may need added training especially if the child is on Flolan or Remodulin. Camp Systole in Kansas City, Missouri, is located near the Accredo Therapeutics call center. The nurses have volunteered to educate the camp staff if the request is made. The Boggy Creek Gang Camp in Florida has provided some fun experiences and comes highly recommended from our PPH kids.



Congratulations to the 7th grade girls' cheerleading squad, who took third place at the city-wide Central Invitational in Grand Rapids, Michigan. There were 50 teams competing at the 5th through 8th grade levels.



Camille Frede (center) wears a Flolan pack as she cheers for the home team. Her mother made sure that the cheerleader sponsors received a letter similar to the one printed on page 9.

Camp Del Corazón, California  
818-754-0312  
<http://www.campdelcorazon.org/>

Camp Bon Coeur, Louisiana  
337-233-8437  
<http://www.heartcamp.com/apply.shtml>

Camp Braveheart, Georgia  
1-888-988-9979 or 770-919-2775  
<http://www.geocities.com/campbraveheart/>

Camp Kaleidoscope, Henderson, North Carolina  
1-888-ASK DUKE (toll free)  
[http://dukehealth.org/childrens\\_services/campk.asp](http://dukehealth.org/childrens_services/campk.asp)

Camp Odayin, Cross Lake, Minnesota  
651-998-1333  
<http://www.campodayin.com/>

Camp Systole, Kansas City, Missouri  
1-800-800-7300  
<http://www.childrens-mercy.org/mso/dept/lnav/view.asp?nav=450>

Hope with Heart, Fair Lawn, New Jersey  
973-728-3854  
<http://www.hopewithheart.com/>

The Edward Madden Memorial Open Hearts Camp  
Great Barrington, Massachusetts  
413-528-2229 or 1-888-611-1113  
<http://www.openheartscamp.org/>

Heart Camp, Fombell, Pennsylvania  
412-692-5540  
[http://www.chp.edu/centers/03heart\\_camp.php](http://www.chp.edu/centers/03heart_camp.php)

Camp Taylor, Livermore, California  
209-545-4715  
<http://www.kidsheartcamp.org/>

The Boggy Creek Gang, Eustis, Florida  
352-483-4200  
<http://www.boggycreek.org/>

The Painted Turtle Camp  
Malibu, California  
310-456-6350

The Double "H" Hole in the Woods Ranch  
Lake Luzerne, New York  
518-696-5676

The Barrestown Gang Camp  
County Kildare, Ireland  
(353) 45 86 41 15

L'Envol, chateau de Boulains  
Echouboulains, France  
(331) 60 73 58 58

For a sample "Form Letter to Personnel Who May Work with your Child," see page 9.