



Pathlight

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

Summer 2002
Volume 11 • Number 2

PHA Publishes First PH Medical Journal

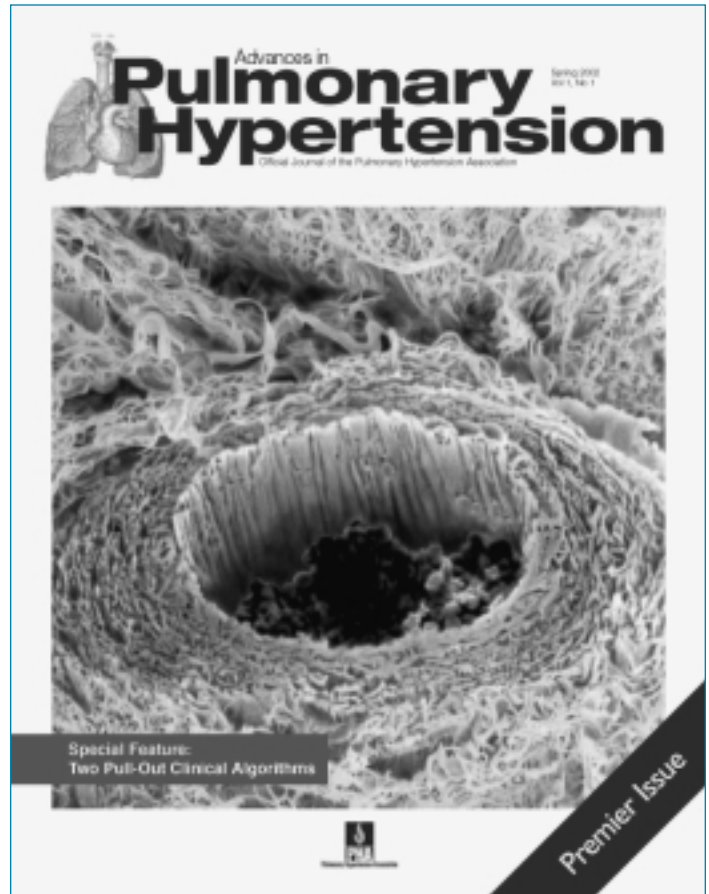
In mid-April 2002, the first issue of *Advances in Pulmonary Hypertension: Official Journal of the Pulmonary Hypertension Association* rolled off the presses.

It was mailed directly to all 31,000 pulmonologists, cardiologists and rheumatologists in the United States. Separate smaller mailings were also made to nurses and doctors in other countries. The complete issue is also available on the Internet at www.phassociation.org.

Why did PHA go to the extraordinary effort and expense it took to create the first medical journal dedicated to pulmonary hypertension? There were three reasons.

The Timing Was Right

In August 2001, the FDA Advisory Committee voted unanimously to recommend approval of two new drugs. One (Tracleer) has already moved to market, while the second (Remodulin) is awaiting a final decision (which is expected about the time you receive this newsletter). These are the first new drug treatments specifically for PH since the 1994 development of Flolan. Other new drugs are going through or



preparing for PH trials. These include: Sitaxsentan, Ambrisentan (BSF 208075) and Sildenafil (Viagra).

In addition to this new pharmaceutical activity, PHA began direct funding of PH research in 2000. Additionally, the organization has been working with the National Heart, Lung and Blood Institute which has significantly expanded its PH research portfolio in the past several years and entered a research partnership with PHA in 2001.

(Continued on page 15)

IN THIS ISSUE

Conference Notes	2
PHA Conference Sponsors	3
News and Announcements	4
New Look and Features for PHA's Website	5
Fundraisers	6
Awareness Month	7
Fourth Annual Cure PH Golf Tournament and Dinner/Auction	8
Donation Acknowledgements	10
The Volunteer Spirit of PHA	14
PHA Receives First Bequest	16

Pulmonary Hypertension Association

Board of Trustees—Executive Committee

Linda Carr President Miami, FL	Betty Lou Wojciechowski Secretary & Administrative Vice-President of Support Mission Viejo, CA
Candi Bleifer Vice-President Studio City, CA	Jerry Paton Treasurer Indiantown, FL
Jack Stibbs Administrative Vice-President of Advocacy The Woodlands, TX	

Trustees-at-Large

Bruce Brundage, MD Bend, OR	Sally Maddox Rome, GA	JoAnne Sperando-Schmidt Huntington, NY
Laura D'Anna Long Beach, CA	Michael D. McGoon, MD Rochester, MN	Jan Travioli Waxhaw, NC
C. Gregory Elliot, MD Salt Lake City, UT	Dorothy Olson Sebring, FL	Lenna West Greenville, NC
Pat Gunn San Antonio, TX	Susan Salay Irvine, CA	Carol Wilson Green Valley, AZ
Gail Boyer Hayes Seattle, WA	Barbara Smith Odessa, FL	Jim Wilson Dallas, TX
Thomas Linnen Ponte Vedra Beach, FL		

Board Emeritus

Harry Olson Sebring, FL	Edwin Simpson Holiday Island, AR
Pat Paton Indiantown, FL	Judith Simpson Holiday Island, AR

Scientific Advisory Board

Chairman: C. Gregory Elliott, MD
LDS Hospital, University of Utah, Salt Lake City, Utah
Vice-Chairman: Michael D. McGoon, MD
Mayo Clinic, Rochester, Minnesota

David B. Badesch, MD University of Colorado Denver, CO	Horst Olschewski, MD Justus-Liebig Universitat Giessen, Germany
Robyn J. Barst, MD New York Presbyterian Hospital New York, NY	Harold Palevsky, MD University of Pennsylvania Medical Center Philadelphia, PA
Joy Beckmann, RN, MSN UCLA-Harbor Medical Center Torrance, CA	Stuart Rich, MD Rush Heart Institute Chicago, IL
Adaani Frost, MD Baylor College of Medicine Houston, TX	Ivan Robbins, MD Vanderbilt University Nashville, TN
Sean Gaine, MD Mater Misericordiae Hospital Dublin, Ireland	Lewis Rubin, MD University of California San Diego, CA
Nazzareno Galié, MD Universita de Bologna Italy	Cathy J. Severson, RN Mayo Clinic Rochester, MN
Abby Krichman, RRT Duke University Medical Center Durham, NC	Victor F. Tapson, MD Duke University Medical Center Durham, NC
David Langleben, MD Jewish General Hospital Montreal, Quebec, Canada	Norbert Voelkel, MD Univ. of Colorado Health Sciences Center Denver, CO
James E. Loyd, MD Vanderbilt University Nashville, TN	Carol E. Vreim, PhD National Institutes of Health Bethesda, MD
John H. Newman, MD Nashville VA Hospital Nashville, TN	Allison Widlitz, MS, PA New York Presbyterian Hospital New York, NY

Emeritus

Bruce Brundage, MD Bend Memorial Clinic Bend, OR	Alfred P. Fishman, MD University of Pennsylvania Medical Center Philadelphia, PA
---	---

Staff

Rino Aldrighetti Executive Director rino@phassociation.org	Jeremy Isett Internet Services Manager jeremy@phassociation.org
Lorie Simmons Advocacy and Awareness Director lorie@phassociation.org	Larry Simmons Database Manager larry@phassociation.org
Doris Green Office Manager doris@phassociation.org	Karri Boyer Development Associate karri@phassociation.org

CONFERENCE NOTES

Childcare at Conference

Parents who are bringing children to be enrolled in the children's program need to e-mail Marcia Stibbs at cure4ph@txucom.net or call 936-321-1486 to let her know the names, ages, and how many children they want to register. There will be special meeting rooms for the young, not-quite-so-young, and teenagers. They can meet, be taken care of by responsible volunteers, socialize, relax together, make friends, and join fun activities. Additionally, the hotel has a wonderful pool where you can take them. Children will also have a special menu of their favorite foods.

Hotel Reservations

Please note that for this year's conference you must make your own hotel reservation with the Hyatt Regency Irvine by calling 1-800-233-1234. The hotel address is 17900 Jamboree Road, Irvine, CA 92614. The PHA discount conference rate for a room remains effective until May 27, 2002.

On-Site Conference Registration

You may register on site at the Hyatt Regency for a \$25 processing fee in addition to the following applicable fees: PH patient \$125; companion/family member \$225; children 12 and under \$125 (age 5 and under FREE); non-patient \$295.

Registration fees include access to all breakout and support group sessions; Friday dinner; Saturday and Sunday continental breakfast; Saturday lunch and dinner; and Friday, Saturday, and Sunday breaks.

On-site registration will be in the Hyatt Regency Irvine Lobby Thursday 1–6 p.m., Friday and Saturday 8 a.m. to 6 p.m. You should book your hotel reservations now if you plan to stay at the Hyatt Regency Irvine (1-800-233-1234). The PHA discount conference rate for a room remains effective until May 27, 2002.

Conference Volunteers Needed

If you are attending the conference and are willing to volunteer an hour or more of your time to help out, please contact Candi Bleifer at candibleifer@earthlink.net or call 818-752-8384.

Conference Golf

A day of golf is planned for Thursday afternoon. A 1 p.m. tee time has been reserved at the Strawberry Hills Golf Club (about 15 minutes from the hotel). Call or email Jim Wilson if you are interested in playing. 972-931-9311, jpwilson@hotmail.com

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 Sponsors

Accredo Health
Pfizer

Gold Level Sponsors

Actelion Ltd.
GlaxoSmithKline
TheraCom

Silver Level Sponsors

Dean and Tammy Hazen
Rochester MN Gala
Ronald McDonald House Charities in memory of
Bonnie Dukart
Texas Biotechnology Corporation/ICOS

Bronze Level Sponsors

The Family of Shirley Cohen
Deltec, Inc.
Medtronic MiniMed/United Therapeutics
Myogen
Priority Healthcare Corporation
Research and Education Institute at Harbor-UCLA
Medical Center
Rush Heart Institute Center for Pulmonary Heart Disease
Schill Medical (UK)
S & S Electric Company, Inc.
Southbay Casino Rentals—Ron and Kallie Varnell



Pathlight is the newsletter of the
Pulmonary Hypertension Association, Inc. (PHA)
850 Sligo Avenue, Suite 800 • Silver Spring, MD 20910
301-565-3004 • 301-565-3994 fax
www.phassociation.org

Important Numbers

PHA	301-565-3004
FAX	301-565-3994
E-mail	pha@phassociation.org
Member Services and Pathlight 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
TheraCom's Hotline for Flolan	1-877-356-5264
Priority Healthcare Remodulin Hotline	1-877-462-6225

Committee Chairs

Children with PH/PPH

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

Events Coordinator

Jim Wilson, 972-931-9311, 972-931-8616 fax,
jpwilson@hotmail.com

New Member Packets, Pins, Brochures, and Cards

Barbara Smith, 813-920-5945, 813-855-4284 fax,
BSmith@ss-electric.com

Organ Donor Awareness

Sharren Yamron, 412-829-0069, sher@sgi.net

Organization Liaison

National Institutes of Health: Heart, Lung and Blood Institutes and
American Thoracic Society: Public Advisory Roundtable
Judy Simpson, 501-253-0082 (phone/fax),
jsimpson@nwaft.com

PATHLIGHT

Shirley J. Craig, Editor, 713-688-7543, 775-855-3043 fax
Victor Tapson, Medical Editor, 919-684-6237
Starfall Graphics, Layout, www.starfallgraphics.com

Persistent Voices

Jerry Wojciechowski, 949-215-1573, wojoj@cox.net

Support Group Coordinator

Betty Wojciechowski, 949-215-1573, wojoj@cox.net

Volunteer Coordinator

Pat Gunn, 830-980-4432, childdept@uumcsatx.org

Web Site Coordinator

Candi Bleifer, 818-752-8384, candibleifer@earthlink.net

Year 2002 PHA Conference Coordinator

Susan Salay, 949-725-8315, ssalay@aol.com

800 Number Coordinator

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

CORRECTION

Dallas Healthwatch Expo (*Spring 2002, Vol. 11 #1, page 6*)
should have been Dallas Healthfit Expo.
The Pathlight editor apologizes for incorrectly
identifying this worthy event. —sjc

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.

NEWS AND ANNOUNCEMENTS

Chicago Mini-Conference Report

By *Elise Zwicky*

CHICAGO—Almost 100 patients of Drs. Stuart Rich and Vallerie McLaughlin at the Rush Heart Institute Center for Pulmonary Heart Disease were treated to a free pulmonary hypertension mini-conference in April at the University Hyatt in Chicago. “We think of you all as our family, and it’s nice that the family could get together for dinner tonight,” Dr. McLaughlin told the group, which also included almost 100 patient family members. The four-hour seminar included a free buffet dinner.

During an update on new medical therapies, Dr. Rich reported that clinical trials are currently ongoing in the United States for a new oral drug called Sitaxsentan, which is a selective endothelin-A receptor blocker. One 12-week clinical trial of Sitaxsentan with 180 patients is expected to be completed in September. “We’re hopeful this will be a winner,” Dr. Rich said. Large clinical trials are also expected to begin this fall for the drug Sildenafil (Viagra) in treating pulmonary hypertension. Dr. Rich said one study will include patients taking no other drugs, while a second study will include patients currently on other treatments. “It seems to be very promising,” Dr. Rich said. Enrollment for a study of the effect of L-Arginine, found in the Heart Bar, is beginning now. Patients in that study cannot be on Flolan or Tracleer. Regarding Inhaled Iloprost, Dr. Rich said it is currently available in Europe on a compassionate use basis, but there are no plans to develop it for the U.S. market. While clinical trials in Europe showed patients had better exercise tolerance after three months, the effectiveness was less than that seen with Flolan and the treatment required up to 10 inhalations per day, each lasting 15 to 20 minutes. Aside from current medical therapies, Dr. Elliott S. Cohen said most pulmonary hypertension patients could benefit from a pulmonary rehabilitation program, which requires a doctor’s referral and is usually covered by insurance. He recommended checking out the website for the American Academy of Cardiovascular and Pulmonary Rehabilitation at www.aacvpr.org. During an extended question-and-answer session, the doctors agreed that Internet data about life expectancy for pulmonary hypertension patients is old. Dr. McLaughlin noted that the first data about PH was collected in the 1980s when the average life expectancy without treatment was 2½ years. Today 60 to 70 percent of Flolan patients are still alive after five years, she noted. Patients at the conference were impressed, especially those unable to attend the upcoming PHA conference in California. “As a Flolan patient, I was very hopeful about one day getting off of Flolan and onto something else,” said Diane Van Noort of Indiana. “Many of my questions were answered that I have read about online. And it was so great to see friends and visit.” Whitney Decker of Illinois added, “The conference reaffirmed how wonderful both Drs. Rich and McLaughlin are and how much they really care for their patients.

The work that (nurses) Patty, Christine and (manager) Jennifer put into the presentations was outstanding. It was both

informative and encouraging.” Also contributing financially to the conference were Gentiva and Actelion Pharmaceuticals.

Advocating for PH and the PH Community—On the Hill

Over the past several months, PHA has been working with our lobbyists and in coalition with other groups to have legislation introduced that would improve Medicare coverage by including oral medications for rare diseases like PH. PHA sees any legislation that allows even for incremental steps forward as an improvement that will ultimately help take us down the path toward full prescription coverage under Medicare. PHA is taking the position that it just doesn’t make sense for Medicare eligible patients to have access to life-saving, IV-administered medications that are extremely expensive but have no coverage for less costly, less invasive oral medications like those that were recently FDA approved for the treatment of PH. With this in mind, PHA is pursuing legislation that would provide Medicare coverage for the new, life-improving, cost effective medications when the medications replace an IV administered medication.

PHA has met with legislative staff to Senator Graham (D-Florida), one of the nation’s leaders in modernizing the Medicare program to include a prescription drug benefit. We have asked that the Senator consider including a non-cancer, oral therapy provision for rare diseases should he decide to move forward with the introduction of an improved prescription drug benefit Medicare bill.

Legislation has been introduced, the Rockefeller-Snowe Greater Access to Cancer Therapies Act, S. 913/HR. 1624, which would amend current law to ensure that any oral alternatives to IV cancer medications would be covered under the Medicare program. If this legislation can be amended to include medications that are used to treat rare diseases, then the oral medication for the treatment of PH would be included. PHA will be working with the coalition to have such an amendment added to S. 913 and HR. 1624.

As this issue of *Pathlight* goes to press, we are hoping for the best and doing our utmost to make the congressmen aware of the need for this legislation. The political process is unpredictable at best. For an up-to-date report on what is happening and how you can help, check the PHA Advocacy website at www.phassociation.org. This may be the right time for you to lobby your congressman and that site will give you all the information you need, including a draft letter, to contact them.

Want to see the latest Conference program updates and speakers? Go to www.phassociation.org and click on the Conference banner.

New Look and Features for PHA's Website

If you've browsed by PHA's website recently, you may have noticed some changes. An attractive combination of royal blue, yellow, and periwinkle blue now greets the eyes when arriving at PHA's site. Of course the changes to the site are more than skin deep.

PHA's site now offers more services than ever before. Simple enhancements like online forms will improve the communication between PHA and the community. Employing the power of the Internet to connect users with database information will also bring PHA's website to a new level of service.

In particular, the online PHA Support Group List has given the community a valuable resource. Now a person can search for a PHA support group by viewing pages dedicated to each of the groups. What's more, the Support Group Leaders now have the power to update the information on their own group's page whether it's contact, group, or event info.

PHA's Doctor List has also recently undergone an extensive face lift. Using a form created by Dr. Michael McGoan, PHA's webmaster has been collecting and posting expanded information from many PH doctors. A number of easy-to-search options have also been added to the section. And after you've browsed the Doctor's List, you might want to take a look at the full text of PHA's new medical journal.

The message boards continue to be the most widely used feature on PHA's website, drawing over 300 postings per week. The newly redesigned boards are without pop-up or banner ads. Users have expressed thankfulness for the new ad-free design, and future improvements are expected.

PHA is now hosting its own chat room. Users are invited to stop in and chat with each other any time of the day. Clicking on the microphone on the front-page will open the chat, then simply type in your name and start chatting. There's even an online support group that meets every Saturday night in the chat room.

PHA has harnessed the transaction power of the Internet. People can join PHA and current members can renew their membership through the online membership form. Family and friends can donate in the name of loved ones to PHA through the online donation form. And everyone can purchase the *Survival Guide*, awareness pins, note cards and other official PHA items through the online store.

Anyone attending PHA's 2002 Conference should check out the conference section of the website for the latest information. To help you plan for the event, many of the dates and speakers of the conference are now posted in the Sessions section of the online brochure. For people who haven't signed up, please take advantage of our online registration.

There's a lot happening online at www.phassociation.org. Be sure to check the site frequently to use the valuable resources and see what's new. Special thanks to all in the PH community for helping make this website possible.

Comments About www.phassociation.org

"I'm very impressed with the huge amount of information that's available on the site. I remember when we first found the website two years ago when I was diagnosed with PPH. I believe it saved my life then because it pointed us to Dr. Stuart Rich in Chicago.

"Now the website has even more information and it's organized so well. I have to say I like everything about it, especially the "Headlines" section where you can get up-to-date information about anything related to PH. I also like the personal stories, and I'm looking forward to reading more of those. I like the way the section on PH specialists has been set up so you can see at a glance on the map where the specialists are located.

"I guess my favorite section, though, is still the message board. I can't tell you how much that board has helped me. And I'd like to think I've helped others through the board as well...."

—*Elise Zwicky*

"The new website is great. The tag lines to updated information are fun to use and the site contents are attractively displayed. My favorite section has always been the message board. I love the new format...."

—*Kathy Forrest*

Please update my mailing list information as follows:

Name

Address

City

State

ZIP

Phone

Fax

E-mail

I am a: patient caregiver other

medical (title and affiliation):

Birthdate

Make my name available for networking purposes: Yes No

These are skills I have that can help. Contact me when and if you need help in these areas:

Please print. Mail or fax the completed form to:

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

FUNDRAISERS

San Francisco's Race for PH

Bay Area residents joined hundreds of participants on Sunday, October 28, 2001, for the first annual Race for PH, a four-mile fun-run/walk around San Francisco's Lake Merced. The race was started in an effort to raise money and awareness for pulmonary hypertension. Paige Dunn, Katie Ewing and Eddie Davis organized the Race for PH. Katie's mother has suffered from the disease for several years, and the three decided they wanted to do whatever they could to help the cause.

"Our goal was to raise awareness so that early diagnosis for this rare and incurable disease increases. Early diagnosis and treatment extend a patient's life span and quality of life. Having hundreds of supporters out running or walking and using their lungs to their full capacity was the perfect fit to help support our cause," said Paige Dunn, a Race for PH founder.

The race was a huge success in the eyes of the founders and the PH community. The Race for PH raised over \$50,000 which was split between the Pulmonary Hypertension Association

(PHA) and the Ewing Fund for Research at Stanford Medical Center in Palo Alto, California. Look for details of the second annual Race for PH in Fall 2002.



Caleigh Coleman Memorial Cure PH Golf Tournament

A memorial golf tournament with a silent auction and dinner was held on March 18, 2002, in honor of Caleigh Coleman. The tournament took place in Corsicana, Texas (one hour south of Dallas). The event was organized by Caleigh's parents, Bobby and Tonia Coleman, with the help of Jim Wilson, PHA's Events Coordinator. Jack Stibbs (PHA VP of Advocacy) and his wife, Marcia, whose daughter has PH, attended from Houston. Nearly 50 golfers participated in the tournament which grossed over \$21,000. Caleigh passed away on March 20, 2001, at only 19 months of age. Caleigh's entire family has joined in the fight to find a cure for PH.



Periwinkle balloons brighten the start of the golf tournament in Corsicana, Texas.



Tonia and Bobby Coleman listen as Jim Wilson gives instructions for the golfers.

Need help planning your "phfun" raiser—contact Lorie Simmons at the PHA office 301-565-3004.

FUNDRAISERS

Hypertension Racing!

Want to do a good deed—be a part of a winning team—associate with race car drivers? How about this? George Stack, quarter-mile Super Gas racer and recently voted Man of the Year by the NHRA, needs a sponsor. Interested?

As you can see in the photo, George's car is an awareness vehicle for PH with "Hypertension Racing" on the doors and a PHA awareness ribbon beside "Pulmonary Hypertension—Racing for a Cure" on the upper rear quarter panels with PHA's 800 number! Thousands of race fans see these words with every race that George enters—so if you can help him "stay in the race," then contact JoAnne Sperando Schmidt by e-mail at joanne64@optonline.net, or call 631-427-4586.



Are you an accountant or CPA? If so, are you willing to volunteer a little time and expertise to PHA's finance committee? Contact Pat Paton at 561-597-4962 or pjpaton@netscape.net.

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.

- | | |
|------------------|---------------------|
| Elaine Barbakoff | Nicole McWilliams |
| Mary F. Bynum | Eugene T. Motschke |
| Nathan Dickman | Suse Rosenstock |
| Laura Hough | Onalee Schwartz |
| Yvonne M. Hughes | Ronald W. Timmons |
| Megan E. Kelly | Andrei Tsyryulnikov |
| Heather Massey | Jill Wasserman |
| Julia McCarthy | Shirley Whited |
| Byron McCartney | |

Mark Your Calendars for November—Awareness Month!

November is PHA Awareness Month this year! This expanded one-month timeframe should give us a greater opportunity to broaden awareness around the country. More good news—Congressman Kevin Brady (R–Texas) has introduced a resolution before Congress to designate November as Awareness Month. If the resolution passes, we should be in a wonderful position to attract the attention of the local and national media. This should serve us in good stead as we work to heighten awareness about PH and raise more money for research and PHA support services.

And if you are looking for some ideas to generate awareness and dollars for PH, PHA is in the process of developing a new CD-ROM for Special Events Fundraising. This wonderful new tutorial on how to run a special event fundraiser is a quick-guide, point-and-click, easy-to-use tool that will take you down the road to a successful event. Everything you need to know about running a golf tournament, a gala, an auction, hoops and hops and four more events will be at your fingertips. Enough information will be on the CD so you can design your very own special event. These all-new CD-ROMs will be available to PHA members in June, which should give you plenty of time to plan for November.

With Awareness Month and a CD-ROM tutorial on Special Events, this should be the best Awareness initiative in the history of PHA. But, please remember, you don't have to wait until November to raise awareness. Anytime you have an opportunity to reach out to your community or the press and inform them about this disease, its symptoms, the way it's diagnosed and the treatments that are available, take it. If you need brochures or "Understanding Pulmonary Hypertension" CDs, just let the PHA office know how many. We can send you all you need. Or if you need help in getting started with an event before June, just call 301-565-3004 and ask for Lorie Simmons.

Please send any articles concerning PH awareness or fundraising activities or pulmonary hypertension to the PHA office for archival purposes and include the date and source of the material.

Pulmonary Hypertension Association
850 Sligo Avenue Suite 800
Silver Spring, MD 20910

Fourth Annual



1 Golfers are ready for 1:30 p.m. shotgun start.

PHA's first fundraiser, the longest running and most successful Cure PH Golf Tournament

PHA's first fundraiser, the longest running and most successful Cure PH Golf Tournament, hosted 172 golfers for a day of fun at The Woodlands Resort and Conference Center on April 4. Friends and family of the golfers as well as of the event planners and volunteers were on hand for the dinner/auction honoring the Quinn Family.

PHA officers and staff arrived from Florida, Minnesota, Maryland and Texas to lend a hand, though Jack and Marcia Stibbs and their dedicated volunteers had things well in hand.

Approximately 27 teams played on the TPC and 16 teams on The Pines. The first place teams were: TPC—Arlin Maddox, Ray Burgess, Scott McManis and Brian Ammerman and for The Pines—Scott Lile, Craig Wakefield, Greg Sharp and Mike Janic.



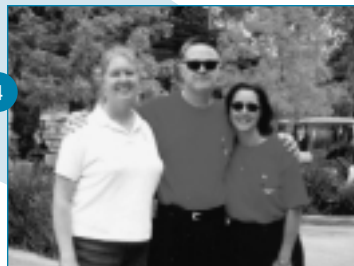
2 Hole in One Challenge



3 Golfers try to "beat the pro" on one of the par 3 holes.



5 Registration is winding down with help from Lisa Buckley, Shelli Larson, Lorie Simmons, Bonnie McGoon, and Linda Carr (l-r).



4 Linda Carr (PHA president), Jack Stibbs, Tournament Organizer (PHA vice-president), Candace Simmons, Gala Chair (l-r)



6 Auction countdown—preparations are under way. Debbie Wilson and Marcia Stibbs grab a quick bite as they catalog auction items (center l-r).

Tournament & Dinner



10

Auction countdown transformation completed and ready for action. (Between \$45K and \$50K was later raised.)



12

PHA officers and staff enjoy the Gala after a day of hard work—Linda Carr, Bonnie McGoon, and Lorie Simmons.



11

Dena Giddens and Lisa Buckley, Steering Committee Members, look over the Dining Raffle Table (l-r).



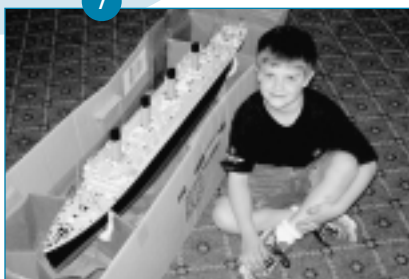
9

The Woodlands High School Interact Club provided volunteers to assist the auction team as “runners.” The chocolate cocker spaniel was sold in live auction and brought \$1,200!



8

Emily Stibbs standing beside a framed photo card of the Twin Towers signed by the firefighters of the New York City Fire Dept. Rescue 1. It raised \$750 at the auction and created a lot of interest.



7

Jake Stibbs sits by Titanic replica to be auctioned later.

PHA Salutes the Many Dedicated Volunteers of the Houston Cure PH Golf Tournament and Dinner/Auction

...such as **the Stibbs family**, whose family life is pretty much on hold during the planning stage of the event. Key volunteers include **Matacha Saul**, Jack’s legal secretary for many years. Matacha is the catalyst for it all, devoting endless hours. **Jamie Eichelberger**, the volunteer coordinator for the fourth year straight, coordinated volunteers’ assignments and schedules. **Candace Simmons** was gala chairman once again and coordinated the logistics of the gala, menu, entertainment, etc. **Shelli Larson** was co-chair with Candace and this year put together all the ladies’ gift bags and the golfers’ snack sacks. **Tracy Daniels** has been a volunteer for several years and this year was the volunteer who coordinated corporate sponsorships. **Cindy Cagle**, another repeat volunteer, acted as our overall coordinator, keeping us on track and focused in our meetings—and as organized as a bunch of volunteers can be! **Dennis Livesay** and **Lisa Buckley** with ProEvent Management have gone beyond their professional involvement every year. PHer **Gary Giddens** and his wife **Dena** have been on hand for every tournament helping wherever needed. Over 80 good folks were on the volunteer list with 50–60 on hand for the day.

It truly takes a lot of time and commitment to pull this type of event off. Thanks to everyone!



IN MEMORY OF

Joyce Bame

Karen Bame

Elaine Barbakoff

Lori Feigenbaum
Esther Fisch
Estelle Goldman
Shirley Kayle
Lorraine Okun
Sheila Reinstein
Bernyce Shimberg

Robert Beck

Josephine M. Waddle

JoAnne Benedict

Fidelity Investments
James C. Benedict

Lucy Branzetti

Harriet Gunches

Betty Brennan

Frances M. Brady

Mary Bynum

First Presbyterian Church
First Presbyterian Church of
Mount Holly
Edith G. Carpenter
Rhonda K. Martin
Sara P. McIntosh
Yates L. Pryor
Sarah Reece
Wilson P. Rhoton

Lulu Carter

Kelley A. Edwards
Donna M. Kuhnen

Joyce Clark

Dwight Canfield
Joseph Caruso
Gwynn L. Clark
William Constable
Herbert Cozad
Sienna L. Davis
Richard Duffield
Robert Klesken
Joan K. Krug
Patricia L. Kuda
Ginny Olsen
Roberts Philips
Vickie A. Tandy
Floyd Thompson
Gregory Williams
Robert Yahnke
Thomas Young

Winifred Clifford

Marguerite Guerra

Caleigh Coleman

Jane B. Tune

Nathan Dickman

Dolores E. Blust
Shawn Lockery
Carrie Patterson

Bonnie Dukart

Gentiva Health Services
Leonard Dukart
Glenda M. Ellis
Robert H. Smith

Joseph Falcone

Genesee Co. Career Center
O.T.B. Dial-A-Bet Employees
Ruth E. Arnold
John Ball
Kenneth B. Barlow
Sally Case
Steve Cerefin
Bill Dombroski
Dennis Elmore
Joseph Falcone
Nick Farlcone

Joe Gerace

Diane M. Johnson

Lyn Maute

Lillian Moscicki

Dan Plapus

George Rider

Sandra Schildwaster

Philip W. Sepi

Bob Smith

Paul Tomski

Angelo Viscuso

Kenneth Foltarz

Elvira Foltarz

Dolly Forte

Roy C. Davenport

Susan Freeman

Georgia L. Felix

May Goetz

Douglas Kepplinger

Harris Gunches

Ellena B. O'Toole

Lynn Hawthorne

Jerrie L. Michaelson

Patricia Holt

Robert Driscoll

Jeffrey S. Holt

Elizabeth A. Miller

Yvonne Hughes

Annette Faris

Graeme C. Leggatt

Sarah Ingram

James A. Ingram

Jeanne Kaley

Donald C. Kaley

Megan Kelly

ExxonMobil Lubricants &
Specialties Company
ELF Lubricants North America, Inc.
Aspen Chemical, Inc.

OSI, Strategic Receivables

Management

Roma Federal Savings Bank

Specialty Products Company

Pennsbury High School

Roadway Express, Inc.

Terry Bazydlo

Lorraine P. Bender

Christian Cabrol

Lois J. Cariss

Robert P. Ceresi

Ralph Chaump

R. K. Cotton

John Cunningham

Beth N. Curtiss

Paula Cutter

Jocelyn D'Amico

Robert C. Devenney

Walt Disney

Vincent Eckel

Susan D. Frantz

Lorraine Gasirowski

Valerie G. Heartsfield

Marian T. Herb

Christos Ioannidi

Beth A. Jacobs

Thomas Jemas

Michelle A. Jerue

Maureen E. Kantner

Rosemarie Karbowski

Susan R. Keller

George Kelly

Donna L. Kelly

Peter Konopi

Anna M. Landgraf

Eileen M. Lang

Kelly Lanigan

Xiaohong Lin

Erin D. Maguire

Ann M. Mathieus

John S. McCollister

Christina Moore

C. E. Munoz

Melissa M. Peitranonio

Rita-Jo Preschel

William C. Reinbott

Wes Schluter

David A. Sims

Marie Soriano

Mary E. Squeglia

Sandra F. Stabingas

Doris Stabingas

Robert C. Williams

Jeanne M. Woods

Teresa Knazik

Larry E. Wessinger

Teresa Lovell

Gayle J. Van Auken

Jean March

Pesco Pest & Termite Services, Inc.
Florida-Online-Realty.com, Inc.

Weavers Guild

Jere W. Annis

Joseph Baskinger

Ann Belcher

Gloria G. Blodgett

Lloyd W. Bucher

Paul A. Bucher

Karen E. Butterfield

Brian K. Deming

John R. Dietel

Martin J. Dietel

Frances L. Ellis

Windle LaFever

Marian A. Lamb

Gale A. Leonard

Suzanne I. Madigan

William H. Mc Clure

Richard L. Phagan

Ellen M. Zinzeleta

Heather Massey

Nichole Lema

John E. Nino

Paul Pinto

Juanita E. Webb

Julia McCarthy

Joseph E. Farrell

Horace Herzog

Nicole McWilliams

Concept Food Sales, Inc.

ExpoServices

Exhibitgroup Giltspur

National Micro Rentals, Inc.

Mark B. Bauer

R. G. Braund

Marilyn J. Brown

Theresa A. Campanaro

John W. Clemenza

Louisa Dematteis

Denise A. Drabeck

Lorena L. Hamara

Linda L. Hillard

Beverly R. Karwoski

Linda S. Knox

Ruth M. Maguire

Sydney A. Manning

Suzanne M. McWilliams

Mary Ann Mudron

Linda L. Smyda

Andrea L. Vargo

Gabrielle Miyara

Caitlin O'Toole

Elvira Ratte

David A. Ratte

Dorothy Robb

Claudine Ashcraft
Christie Breault
Iris Cox-Pearce
Earl R. Dauer
Martha L. Dunham
Jane M. Janssen
Seretha Johnson
Jerry L. Kessler
Ron Kessler
Peggy G. Masslich
Gary L. Matteson
Jo Ellen Merriman
Bonnie Merriman
Marie G. Nelson
Cecil D. Palmer
John M. Robb
James S. Robb
Marilyn R. Robb
Dorothy M. Sager
Joyce L. Satterlee
Willia Siedow
Sandra S. Stephenson

Linda Roberts

Wilma Day
Virginia Eversole
Pamela A. Hickman
Ralph M. Poplin
Marie B. Poplin

Suse Rosenstock

Gary Adler
Anne Borbely
Harold M. Bruskin
Ann D. Carlisle
Michael V. Dowging
Ruth L. Finegold
Trudy Herz
Jarvis Klein
Edith Pagelson
Marilyn Schultz
Julia Waixel

Peggy Rubel

Margaret Schmidt

Harvey Silbermann

Ellen Daniel
Joi Denenberg

Andrei Tsyryulnikov

R. P. Fairman

Diane Tucker

Maynard W. Tucker

J. R. Wallace

Jack Stibbs

Gerald Wark

Joyce M. Wark

Jill Wasserman

Martin B. Freedman
Les Surnitsky

GENERAL DONATIONS

S&S Electric Co., Inc.
 GlaxoSmithKline
 Actelion Pharmaceuticals US, Inc.
 United Therapeutics Corporation
 Gentiva Health Services
 Memorial Hermann The Woodlands
 Hospital
 Pharmaceutical Research and
 Manufacturers of America
 Deltec, Inc.
 The Bullitt Foundation
 Samsung Austin Semiconductor, L.P.
 TCF Financial Corporation
 United Way Capital Area
 United Way of Tri-State, Merck
 Employee Giving Campaign
 United Way of Porter County, Inc.
 The Marlene W. Neiswender Trust
 Microsoft Giving Campaign Program
 PipeVine, Inc.
 The Helen Matchett DeMario
 Foundation, Inc.
 Lehigh Cement Company
 PconCorp
 Medtronic MiniMed
 Actelion Pharmaceuticals, France
 Charlotte Medical Supply a Division of
 Rotech
 Bon Secours—St. Joseph Hospital
 Integrated Health Services, Inc.
 Tandem Health Care
 Touch of Class Car Wash I
 Pfizer Inc.
 Nelson-Putman Propane
 Net Cruiser Technologies, Inc.
 Cisco Systems, Inc.
 Ronald McDonald House Charities
 Webster Five Cents Savings Bank
 Fidelity Investments
 Dinah Abbott
 Bernice Abee
 Margaret L. Abel
 Christine A. Adams
 Diane R. Adkins
 Howard Aibel
 Rino Aldrighetti
 Kathleen M. Alfano
 Betty O. Allison
 Susie Alvarez
 Francisco Alvarez
 Esther Ancel
 Charlene R. Anderson
 Judy Anderson
 Charlotte Andrews
 Wyoma J. Anthony
 Paulina Z. Arancibia
 Christine Archer-Chicko
 R. D. Arnold
 Robert B. Atherton
 Suzanne E. Aubele
 Gertrude E. Austin
 David B. Badesch
 Sarah J. Baker
 Gail Baker
 Michael H. Baker
 Lillian Baker
 Samuel J. Bame
 Marsha Bankston
 Mary H. Barbosa

Shirley Barenholtz
 Robyn J. Barst
 Wanell J. Barton
 Gary C. Bates
 Angela Beadle
 Morry M. Behar
 Wendy Behr
 Catherine Bell
 Brad Belliston
 Cynthia Bennett
 Hope Bennett
 Harvey Berg
 Lisa Bills
 Wendy Bitzel
 Barbara A. Blair
 Gerald J. Blake
 Debra J. Blank
 Candi C. Bleifer
 Gloria G. Blodgett
 Chester W. Bockstedt
 Anna A. Bogden
 Lois A. Bonney
 Harold D. Booth
 Melissa Boothe
 Susan O. Boskey
 Jill A. Boss
 Walter Botkins
 Douglas S. Boucher
 Robert C. Bourge
 Ann M. Bouvier
 Linda A. Bowman
 Geraldine Boyd
 Sara Bracco
 Marilyn Bradbury
 Thomas A. Brady
 Barbara Brant
 Dijon C. Brewster
 Ellen G. Brookbank
 Leta Brown
 Donna Brown
 Bruce Brundage
 Gail A. Bucci
 Nancy A. Buckbee
 Robyn H. Buffalino
 Carol Burgess
 Dirk Burns
 Carole D. Busam
 Rhonda Busam
 Christa Byrne
 Maria Cacis
 Anne Caesar
 Norvella Caimi
 L. A. C. Caldwell
 Timothy L. Calkins
 Myriam A. Calles Vinas
 Kristen D. Caouette
 Lydia V. Caponiti
 Monica Carletto
 Linda M. Carr
 Donald Carter
 Terry L. Casey-Cato
 Carolyn M. Catalon
 Lora Caule
 Cecil K. Cave
 Daniel Cave
 Cherie A. Cave
 Janie C. Cavitt
 Ining Chiu
 James W. Chu

Gwynn L. Clark
 Jack Clark
 Shirley Cohen
 Michele F. Cohen
 Cindy L. Coldwell
 Paul M. Cole
 Ardith Coleman
 Jane M. Collins
 Norma J. Collins
 Carol Collins
 David Cometz
 Rita Connell
 Carmen C. Conti
 Debbie Cook
 Wendy L. Corbella
 Leah Cormier
 Kathleen Costello
 Arlene Cota
 Nathan L. Cox
 Anne Crawford
 John Cregan
 Linda S. Crisci
 Elizabeth Crittenden
 Harold P. Crothers
 Mary V. Crumpler
 Laura L. Cullen
 Jill Q. Cunningham
 Carolyn A. Cunningham
 Debra A. Curran
 Margaret Curran
 Francine Curtis-Harris
 Gary W. Curtright
 Marlene Cusick
 Sherrie S. Cutler
 Janice A. Cyr
 Dee Czaykowski
 Barbara Dalburg
 April Dalton
 Roy C. Davenport
 Edward C. Davis
 Melissa A. Davis
 Darlene M. DeBouvre
 Mike Deeley
 Anthony Defrino
 Gail Defrino
 Tina V. Deitchman
 Antonia Dellas
 Patrick Dembski
 Roland Deprez
 Marcia E. DeSerres
 Patricia Dettenmeier
 Cathy Deveraux
 Sandra Devorss
 Marjorie A. Dewey
 Alan Dickman
 LaDonna J. Diller
 Robert F. Dimarco
 Herbert Dimondstein
 Eugene Dingess
 Dorthea Dinning
 Mark B. Dorman
 Robert J. Doyle
 Wendy Draime
 Requel K. Drap
 Robert K. Dressing
 Lanette Dudley
 Wendy Duff
 Gary Dukart
 Rebecca L. Dworkin

Mary L. Edwards
 Terry A. Eichelberger
 Paul Ejangu
 Angela Eldam
 C. G. Elliott
 Patricia A. Ellison
 Debora Elstein
 Penny R. Engel
 Betsy A. English
 Sandra L. Eseltine
 Judy A. Esola
 Joan A. Esplin
 Maribeth Evens
 Carolyn S. Everett
 Judy L. Eyolfson
 R. P. Fairman
 Robyn Falcone
 James W. Fallon
 Jacqueline Farrar
 James F. Farrell
 Joan M. Fausz-Vinicky
 Georgia L. Felix
 Mary Felkel
 Judith Felts
 Elizabeth Fennell
 Penny L. Fields
 Alfred P. Fishman
 Beverly Fitts
 Michael L. Fitzgerald
 Nancy Flanagan
 Judy Fletcher
 Michelle Florin
 Carol Fohl
 Farng-Yang Foo
 Georgia L. Fortney
 Gladys S. Foster
 Kerry Foster
 Toni M. Fourte
 Judith K. Fox
 Brenda Fracker
 Pat Franklin
 Nancy A. Frede
 Deb Frederiksen
 Martin Frost
 Valentin Fuster
 Kenneth E. Gadson
 Kimberly S. Gallilher
 Steve Garcia
 Vivian R. Garcia
 Genevieve R. Gardea
 Rose Gaspardino
 Pamela D. Gau
 Marie-Therese Gautier
 Lise Gelernter
 Blossom Gelernter
 Amanda M. Gertcher
 Lou A. Gibbs
 Loveta M. Gilley
 Linda Gilmer
 Leah Giulianetti
 Susan Giulianetti
 Walter E. Goddard
 Karen Goldman
 Norene Gonsiewski
 Anita Gonzales
 Joanne Gordon
 Glen Gordon
 Kiendl Gordon
 Robert Gorga

GENERAL DONATIONS

James R. Gossage	Katherine B. Ingle	Brenda L. Lawrence	Karen McGarrity	Kleda Owens
Linda Graves	Lester L. Ishado	Ernest C. Lawrence	Linda McGeever	Patricia Owens
Ruth Gray	Dunbar D. Ivy	Susan Layne	Theresa A. McGraw	Patricia A. Page
Marnie F. Green	Mike Jablonicky	Paula L. LeBlanc	Donald G. McGuire	Robin Palmieri
Jacqueline Greenberg	Susan J. Jackson	Norma Leeg	Linette McHenry	Patricia G. Palone
Edna Greil	Paul S. Jacobs	Marie C. Lefebvre	Eleanor R. McKeown	Aisha A. Parker
Felix J. Gruosso	Jules Jammal	Lezlie Lehman	Kathie McKune	William M. Partch
Jan Guarino	Jawando	Delcia Lemay	Ellen McLaughlin	Elizabeth Pass
Rhonda Guilin	Janet Jenkins	Ronald C. Lemon	May G. McNair	Jean Patarozzi
Patricia Guillen-Loth	Mark Jeter	Lee A. Lendt	Betty C. McPherson	Paula Patty
Pat Gunn	Shirley E. Jewett	Lilian H. Leung	Suzanne M. McWilliams	Elaine D. Payette
Jerry M. Gunter	Johnny Jimenez	Nancy C. Lewis	John H. Menefee	F. B. Pearce
Charles A. Hales	Graime Johannessen	Shirley T. Li	Albert H. Meyer	Janice Peck
Portia Hall	Tandra Johnson	Sally T. Li	Sally A. Meyers	Francine N. Pedersen
Vonnie K. Hall	Amy Johnson	Karen A. Lichtenberg	Madeline M. Michael	Sheila Pence
Irene M. Hall	Mary Jo M. Johnson	Sonia Liddell	Jerrie L. Michaelson	Gale L. Perkins
Cindy Hallett	Alice L. Johnson	Joan Lienert	Kathy Miller	Meryl B. Perlman
Rhonda Halstead	Frances C. Johnson	Margaret P. Lincoln	Sallie Miller	Loraine C. Perrego
Rachael R. Hamilton	Kelly M. Johnson	Dauna M. Lindbeck	Anne P. Miller	Lawrence Persson
Greg Hamm	Amy Johnson	Cindy Link	Suzanne H. Mills	Barbara Perttunen
Sandy G. Hanebutt	Perian Joiner	Thomas F. Linnen	Kathy Mitchell	Joseph N. Peskin
Karen Harder	Marcia L. Jones	Beverly Lipmyer	Christiy L. Mitchell	Patricia H. Peters
Will Harkins	Clarence A. Jones	William Lisante	Victoria Miyara	John A. Phillips
Stephanie J. Harris	Stephen M. Jones	Judith A. Lisante	Barbara L. Montgomery	Linda M. Pieper
Louise K. Hartman	Ray Jonez	Janet S. Lisle	Bob Montgomery	George D. Pierce
Paul J. Harvey	David Jugan	Judith A. Lloyd	Cynthia L. Moody	Valerie E. Pierce-Rich
Donna B. Haselden	David P. Justin	Donald Lobacz	Karen Moody	Monica Pineda
Mary P. Haselhorst	Mary E. Kalbac	Peter Lodewick	Elrid Moody	Marie E. Pope
Melody Hatfield	Martin Kale	Alan R. Lofting	Tweetie L. Moore	Kelly K. Poplar
Denis A. Hayes	Bonne L. Kalyn	Colleen Long	Rosalinda S. Moore	Clyde Porter
James E. Haynes	Kazuo Kato	Rachel A. Longenecker	Julia B. Morgan	Charlene N. Porter
Linda D. Heiser	James B. Kautz	Kenneth A. Loomis	Michael Morrill	Carol J. Posner
Rosemary Held	Ava S. Kearney	Sharon A. Loomis	Jeanette Morrill	Lisa H. Powell
Ellen J. Henderson	Donna Kearney	Joyce A. Lorow	Jane H. Morse	Katherine L. Preuss
Amie Hennen	Ava S. Kearney	Lynn Lubitz	Linda Morton	Vandana Punj
Clare A. Henry	Maria G. Kebr	Edward Lundstedt	Gloria C. Mossiman	Mary Lou Quinn
Raymond Henry	Carol Keeling	Debbie Lynch	Joyce L. Mowrer	Joyce Rahn
Cheryl Herdejürgen	Gary C. Keene	Geraldine Macks	Fern L. Murphy	Patricia J. Ranta
Harriet E. Herlihy	Jennifer Keller	Jayne Mackta	Robbin L. Murray	Elisabeth Ravazzolo
Marian Hernandez	Brenda L. Kelly	Emma H. Maes	Bernadette G. Musselwhite	Joan Redgate
Patricia Hernandez	Ellen H. Kelsch	Patricia D. Magee	Marilyn J. Mutter	Tom Reichenberger
Marshall Hertz	Carolyn S. Kennedy	Paul H. Magoon	Kathleen M. Myer	Janette T. Reyes
Dina Hess	Kim Kerr	Diana Malott	Irma Nabors	Rosa L. Reyes
Vickie L. Heywood	William H. Kessler	Marilyn A. Mannina	Pearl Naistadt	Booker T. Rice
Carl Hicks	Marjatta Ketonen	Martha L. Mantel	Daniel P. Navales	Stuart Rich
Janet M. Higgins	Marta S. Kibble	William M. March	Cleal M. Neal	LaVerne Richter
John F. Hill	Kusy Kimberly	Claire G. Marsh	Frederick Neelman	Patricia M. Roberts
Angela R. Hill	Patricia J. King	Michael R. Marshall	Alina R. Negron	Tonya T. Robertson
Virginia M. Hinderliter	Lora M. Kittle	Bonnie Marshall	Sonja A. Neil	Robert L. Roden
Margaret Hlinka	Miriam S. Kleinberger	Kale Marty	Lavonne M. Nelson	Amy D. Roettger
Mary L. Hobbs	Andrew Klettker	Wendi Mason	K. C. Nesseth	Dorthea Rogers
Vivian J. Hoff	Sylvia C. Klinger	Cheryl Massaro	Jan Neumann	John C. Roller
Jeanne Holleran	Alice N. Klucsarits	Amber Massey	Don Newman	Howard P. Roman
Lynda H. Homes	Lila A. Klussmann	Corrine Massey	John H. Newman	Margaret L. Roos
Evelyn M. Horn	Nancy Kniffin-Jennings	George M. Matuschak	Pamela B. Nicely	Gloria Rosenberg
Patrick E. Hosford	Rhonda Knight	Ryna K. Mayorga	Mary K. Nicodemus	Mary E. Rosenberg
Susan K. Hosford	Luba Kobzeff	Carol A. Mazur	John Nicol	Elizabeth M. Rossi
Rita House	Susan S. Koenig	Joann McAfee	Paul M. Nihei	Cecil Rotto
Traci Houston-Harris	Kathy Kolke	Elizabeth A. McCall	Danny J. Noonan	Barbara J. Roupe
Wayne Howell	Sandra Kosienski	Helen V. McCarney	Jean Noonan	Brandae Rouse
Patti Hoyle	Madeline Kosky	Jane F. McCartney	Vanessa Norris-Nalle	Melvyn Rubenfire
Cindy Huang	Susan T. L. Kreiser	Leo P. McCaskey	Grace C. Nycz	Elaine Rubin
Donald Hubert	Jean V. Kroening	Tim McCormick	Susan E. O'Hair	Tai A. Rumbold
S. D. Hull	Michael J. Krowka	Alice W. McCormick	Anna L. Oliver	Doreen Ruotolo
Brandon Hunt	Don R. Kuhn	James R. McCoy	Harry and Dorothy Olson	Linda Sadler
Joan A. Hurtt	Johannes J. Kuiper	Marie F. McCreary	Michael M. O'Neal	Michelle Saez
Mary Hutchison	Mary Kurisko	Susanne E. McDevitt	Konstance M. O'Neal	Susan Salay
Asako U. Igawa	Kari Lain	Nancy R. McDonnell	Carey L. Overby	Shawn M. Saline
Sarah Ing	Frances Lawless	Katherine P. McElaney	Barbara Overholtzer	Grace Salvatore

GENERAL DONATIONS

Donna Samuels
 Darcie Sandbank
 Helen R. Sanders
 Patsy L. Sanzo
 Lynn Sargent
 Carole Saunders
 Gwen E. Sayer
 June A. Scales
 Mary J. Scanlon
 Pamela Scarborough
 Mary K. Schafer
 Judith L. Schenkkan
 Thomas R. Schidel
 JoAnne S. Schmidt
 Irene W. Schonberger
 Carol Schwanke
 Onalee Schwartz
 Robert S. Schwartz
 Catherine M. Scivinsky
 Mary Ann Scott
 Kay M. Scruggs
 William Sears
 Dan K. Seilheimer
 Virginia Seiling
 Mark A. Self
 Rene M. Sewell
 Eileen Shalit
 Paula Shea
 Florence M. Sheffer
 Hilda Shelton
 Cynthia L. Sherman
 Alissa J. Shirley
 Jeff A. Short
 Richard L. Short
 Susan R. Sibert
 Karen Sidoti
 Henry Silbermann
 Susan Silbermann
 Edwin L. Simpson
 Judith Simpson
 Gregory L. Simpson
 Carole A. Skor
 Barbara Smith
 Dale R. Smith
 Lorraine Smith
 Ginnie Smith
 Amanda Smith
 Donald W. Smith

Suanja M. Smith
 Alcott L. Smith
 Barbara Smoot
 Twyla Snow
 Carmen C. Sours
 Sharon D. Spaulding
 Judith J. Speaks
 John R. Sperando
 John P. Sperando
 Laura A. Sponaugle
 Margaret A. Sprague
 Rosemarie Staniech
 Louise G. Stellrecht
 Dennis Stenshorn
 Gail Sternemann
 Roberta K. Stevens
 Jack Stibbs
 Marcia Stibbs
 Priscilla W. Stimpson
 Marjorie Stimson
 Steven Stites
 Jay F. Stokes
 Mark L. Stone
 Cheryl Stone
 Daniel R. Stowers
 Deanne J. Stratte
 Kingman P. Strohl
 Alice Strom
 Elizabeth Stutzman
 Donnie R. Sullivan
 Warren R. Summer
 Sally M. Sundheim
 R. D. Sutherland
 Barbara Sutton
 Jean K. Swartling
 Judy Swerline
 Claire Sylvia
 Janelle Szymanski
 Gina Tackett
 Jackie Taiwo
 Kay R. Tallerico
 Gerard Tarantino
 Ruby M. Taylor
 Myla R. Teeple
 Sharon L. Thake
 Ketan B. Thakkar
 Cheryl A. Tharp
 Gene Thompson

Susan K. Tointon
 Audrey I. Toker
 Nancy Toth
 Robin Toyne
 Glenna R. Traiger
 Bich Ngoc Tran-Muchowski
 Linda H. Travis
 Ann Z. Tremel
 Frank L. Trevino
 Patricia Turner
 Orin W. Turner
 June Tyson
 Amanda Uhlhorn
 Tom Ulseth
 Carol Ungar
 Virginia Utt
 Georgina Valentine
 Wim Van Griensven
 Rina VanKleef
 Diane VanNoort
 Diane Vassallo
 Lisa Vellanoweth
 Adella A. Venneman
 Just Vernon
 Lori M. Villaloboz
 Alfred Villaloboz
 Joan Vinicky
 Shirley C. Volkman
 Joann Volpe
 Judith M. Vucci
 Randolyn Wadman
 Martha E. Wagnon
 Lewis Walden
 William Walker
 Neil Walker
 Barbara Walker
 Joseph Wallace
 Mary Ward
 Graeme C. Warner
 Helen Warnock
 LuAnne L. Washburn
 Joyce G. Washington
 Shirley Wasileski
 Charlene Watts
 Melynda M. Webb
 Leslie A. Weber
 Ray E. Weber
 Mary L. Wedel

Nancy Weiss
 Robert L. Whitaker
 Stephen L. White
 Mary K. White
 Lynn H. White
 Mindy White
 Lynn H. White
 Richard Whited
 Tara L. Whitledge
 Carol J. Whitmer
 Amanda Whitney
 Pat Wick
 Nikki Wild
 Patricia A. Wilds
 Rose C. Wilkeson
 Carla Wilkinson
 James N. Williams
 Clinton Williams
 Susan L. Williams
 James P. Wilson
 Carol A. Wilson
 Kelly Wilson
 Shirley M. Winters
 Brenda Winters
 Debbie Wirth
 Kathryn G. Wohlbiel
 Betty L. Wojciechowski
 Marc A. Wolff
 Patricia J. Wolfrum
 Jane Wood
 Carol L. Woods
 Sharon Woods
 Jessica Wortham
 Laura Wright
 Alan T. Wright
 Betty Wubben
 Richard Z. Yan
 Kay M. Yeowart
 Martha Young-Evans
 Mary L. Yount
 Dorothy Zey
 Emilie E. Zimmerman
 Ali Zimran
 Charlotte M. Zinser
 Steve Zinz
 Nancy Zurich
 Elise M. Zwicky

IN HONOR OF

Hannah Carr
 Marjorie Carr
Jeffrey Falcone
 Ruth E. Arnold
Donna Haselden
 Paula B. Gatlin

Anna Jeter
 TCF National Bank, Minnesota
 Robert Digby
 Sara Evers
 Ronald Palmer
 Shirley M. Winters
Patricia Paton
 Vicki E. Beck

Anne Remedios
 Richard Remdios
John Sperando
 John P. Sperando
Emily Stibbs
 Pam Scates
Sheri Swanson
 Stacy Swanson-Cramer

Jennifer Sykes
 Temple K. Harvey
 Marilyn I. Holcomb
Joey Teets
 Edna G. Burge
 Frank H. Eastman
Gerald Wojciechowski
 Kathryn A. Skjei

The Volunteer Spirit of PHA

By Cheryl Massaro

By now, members of PHA have received their comprehensive blue and white promotional material on the June 21–23 Pulmonary Hypertension Association Conference. It certainly looks like those conference planners have organized a motivational conference in sunny California! Conference attendees from all walks of life will gather from international locations to listen to the who, what, where, when, and why of amazing developments in the PH world. And, it's packed into three days of education, support, camaraderie, and great fun amongst PHers, caregivers, medical professionals, exhibitors, and observers.

Think again—it's not only those three days! Have you considered the time and effort that have been put forth during the two years prior to the conference? How many times has a calendar been consulted, working backwards from June 21, 2002, to make certain every minute detail has been covered? How many times have the planners lain awake at night with yet other details popping up at 2 a.m.?

Typically, conference planning is accomplished by professional conference planners—people who get paid major compensation to design a conference of this magnitude. Think again, not this conference! This event is created from square one by a group of dedicated volunteers and professional PHA staff.

And, think again—most of them also carry a physical burden. They are inflicted with an “invisible” life-threatening health problem—pulmonary hypertension. Typically, these people, of every age and background, are labeled “fatigued”, “breathless,” “dizzy,” and sometimes “helpless.” Conference volunteers may not look sick, and amazingly enough, probably don't act sick!

I checked the definition of the word “volunteer” in Merriam-Webster's Collegiate Dictionary. “Volunteer,” as a noun, means “one who renders a service or takes part in a transaction while having no legal concern or interest.” Now, having been a “professional” volunteer for over 30 years myself in everything from the arts, education, children, and public service, I at least thought I had “some” interest in the things I was doing for these various organizations. I gave of myself—“to offer or bestow voluntarily,” the verb definition of “volunteer.”

According to Maribeth McCarthy, the Chicago PH Support Group Leader, PH volunteers were invaluable in the areas of daycare, registration, room hosting, and public relations during the PHA Conference held two years ago in their city. Why did they do it, those dedicated volunteers who could have rendered the conference unsuccessful? When asked this same question of “Why?” Susan Salay, Year 2002 PHA Conference Coordinator, said, “I personally received a lot of help from PHA volunteers when I was first diagnosed with PH. They helped me adjust to my diagnosis in a positive fashion and truly made a difference. I was grateful to them for the one-on-one calm, relaxed, and positive manner in which they helped me. It really made a difference. This is my way of giving back.”

This is significantly true of volunteers throughout the Pulmonary Hypertension Association. Their volunteers, many of whom have given up powerful corporate careers and expertise in numerous professional areas, lend helping hands in places where PHA needs the assistance. Susan reflected on how she has applied her previous work expertise in the corporate working world of a multi-billion dollar computer company to planning the conference. “It's a corporate world at my PH pace,” Susan said.

Susan was also very appreciative of the efforts exhibited by our talented PH specialists and nurses who have given of their valuable time to the medical portion of the conference. She has been impressed with the number of inquiries from these professionals who have volunteered repeatedly, “What can I do to help?”

The dictionary also defines “volunteer” as an adjective: “growing spontaneously without direct human control or supervision especially from seeds lost from a previous crop.” (If you've farming in your background, you're familiar with this definition.) Think again about this definition—doesn't it also describe how volunteers feel after they've rendered themselves to a cause? Volunteers come away from the volunteer experience having grown spontaneously. When giving of the heart without prior expectation of what you will gain, you receive in return a gift without monetary value...the gift of satisfaction of a job well-done and the gratification you will carry with you.

Think once again, please! Have you expressed a few words of appreciation to a conference volunteer for the efforts put forth in creating the much-awaited 2002 Pulmonary Hypertension Association Conference? They deserve our heartfelt thanks!

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 July 31, 2002.

Persistent Voices

PV is published twice a year with the fall and spring issues of Pathlight. The deadline is July 31, 2002. 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*.

PHA Publishes First PH Medical Journal (Continued from page 1)

As new opportunities emerge and PH is viewed as more treatable by the medical community, there is growing interest in understanding and diagnosing the illness.

Recent examples of this were seen at the American Heart Association and CHEST medical meetings, where sessions on new treatments drew over 300 doctors, and in Milwaukee, where a session drew almost 100. In order to encourage early diagnosis and appropriate treatment, it is important that cardiologists, pulmonologists and rheumatologists particularly know more about PH and its complexities and understand the importance of referring to PH specialists. As increased interest develops, the new medical journal is positioned to provide the necessary information to educate the medical community.

The Team Was Right

From its founding in 1988, PHA's patient leadership understood the importance of working with the medical community. In the early 1990s a Scientific Advisory Board was founded. For a number of years, it functioned as a committee of the whole. By 2000, that was beginning to change. Dr. Brundage began to develop a committee system and his successor as SAB Chair, Gregory Elliott, MD, continued the expansion of that structure. With six active committees, chaired by SAB members but also including other medical leaders, the ability of the SAB to take on a broader spectrum of issues was growing. The committees include Research, Consensus, Strategic Planning, Conference and Publications. The fact that the SAB currently includes members from five nations also means that its reach into what is going on in PH research and treatment world wide is very strong.

During the PHA Conference 2000 in Chicago, PHA executive director Rino Aldrighetti and Bruce Brundage, MD, the founding chair of PHA's Scientific Advisory Board, met with Craig Mears of Gentiva Health Services to discuss the possibility and economics of a medical journal dedicated to PH. Out of that meeting Gentiva offered to become a sponsor of the publication. They were soon joined by Actelion.

The SAB Publications Committee then began to discuss how the *Journal* would be structured. It was felt that, rather than a peer-reviewed research journal, the greatest need was for an educational journal that would reach out and educate doctors who need to know more about the illness and its diagnosis and treatments. The SAB approved this approach and the Publications Committee invited Victor Tapson, MD, of Duke Medical Center to serve as editor-in-chief. Dr. Tapson's editorial committee includes Sean Gaine, MD, PhD (University College, Dublin, Ireland), Vallerie McLaughlin, MD (Rush Heart Institute), and Ivan Robbins, MD (Vanderbilt University).

The 24-page first issue includes both a pull-out treatment algorithm (chart) by Drs. Sean Gaine and Lewis Rubin and a treatment algorithm by Drs. Tapson, McLaughlin, Robbins, Gaine and Rubin. Featured articles include *A New Classification of Pulmonary Hypertension* by Stuart Rich, MD (Rush Heart

Institute) and *Endothelin Receptor Antagonism: a New Era in the Treatment of Pulmonary Arterial Hypertension* by Richard Channick, MD, and Lewis Rubin, MD, both of the University of California, San Diego. The premier issue also includes a celebration of the career of Alfred P. Fishman, MD (University of Pennsylvania), often described as the father of PH research, and a roundtable discussion on the growing spectrum of PH therapy and future strategies. Roundtable participants included Lewis Rubin, MD (UCSD), Dr. Robyn Barst, MD (Columbia University), and Nazzareno Galie, MD (University of Bologna, Italy).

The *Journal* is off to a great start with great support and leadership from the PH medical community and on track to become a quarterly publication in 2003.

The Need Is Great

It is true that treatment options are improving for PH patients, and that is wonderful news. But it is also true that PH is still a terrible illness where too many people are diagnosed late, if at all, and where too many in the medical profession know too little about its appropriate and complex treatments.

Knowledge is the key. With the support of the best specialists in PH in the world, PHA is now better positioned to push this knowledge out to the broader medical community. And with the support of our current sponsors, Gentiva and Actelion, who are helping us provide a first year budget for the *Journal* that is significantly larger than PHA's entire budget was only four years ago, we are well on our way!

Help Wanted on Patient's Survival Guide

Do you seek fame and immortality? Or maybe you'd just like a small task you can do at home, something that will help other PH patients?

Gail Hayes, author of *Pulmonary Hypertension: A Patient's Survival Guide*, would like help preparing a third edition (for possible publication in late 2003 or early 2004). She hopes to find another author or authors to replace her for subsequent editions. Help is now needed to gather material to keep each chapter up-to-date. Tasks (such as collecting anecdotes from patients, fact-checking, research, writing, and making new drawings) can be tailored to fit your skills and particular interests. We would also love to find a volunteer with skill in formatting the book (by computer) to give it a more professional look.

If you can help, seek Gail out at the June conference in Irvine, CA, or contact her at BoyerHayes@attbi.com. You can also reach her by writing to her c/o PHA (850 Sligo Ave., Suite 800, Silver Spring, MD 20910), or call the PH Helpline (800-748-7274) and ask the volunteer who answers the line to have Gail call you.

PHA Receives First Bequest

Dan Walsh made an extraordinary decision before he passed away in September 1999. He chose to donate half of his estate to PHA. In January 2002, as Dan's estate settled, this became the first gift of this type the organization has ever received.

At the time he became ill, Dan was managing the marketing of his family's business, Walsh Title and Real Estate, in Edina, Minnesota. He continued to work for a couple of years until his condition forced him to stop working in 1997. Dan spent his free time with friends and family and developed a strong network of supporters. He is remembered for being very positive and upbeat and for having a great influence on people.

Dan attended PHA's 1998 Conference in Dallas, Texas, where he met other patients. A Flolan patient, Dan was optimistic about transplant and very much wanted others to understand the importance of organ donation.

Dan respected the work of PHA and felt his gift could forward the association's mission in important ways. Dan's family is very supportive of his generous decision and views the donation as a great gesture.

"Dan's decision was a wonderful surprise for PHA. His gift will support the type of tremendous growth that has allowed us to recently launch the first medical journal, greatly expand website services, double the number of support groups, and so many other things," says Linda Carr, PHA's President. "As a mother of a child with PH, I am deeply touched by Dan's commitment to helping improve the lives of others affected by this illness."



Left: Dan Walsh.

Below: Drawing by Dan's nephew showing Dan as an angel with the red-flushed face and wearing his Flolan pack!



Check From Gentiva Raffle Will Fund PHA Conference Scholarships!



Left: Craig Mears of Gentiva Health Services presents a check for \$10,215 to Gary Dukart and PHA's executive director, Rino Aldrighetti. The check represents funds raised in a raffle by Gentiva employees and matched by the company in memory of Gary's wife and former PHA president, Bonnie Dukart. These funds have been targeted for scholarships to bring patients to the upcoming PHA Conference 2002 in Irvine, California. PHA office



manager Doris Green is at left and PHA's founding president Judy Simpson is at right.

Right: Gary Dukart and PHA executive director, Rino Aldrighetti, receive a check for \$10,215 from Gentiva Health Services employees.