



Pathlight

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

Winter 2001
Volume 10 • Number 4

PHA Awareness Week 2001 Recap

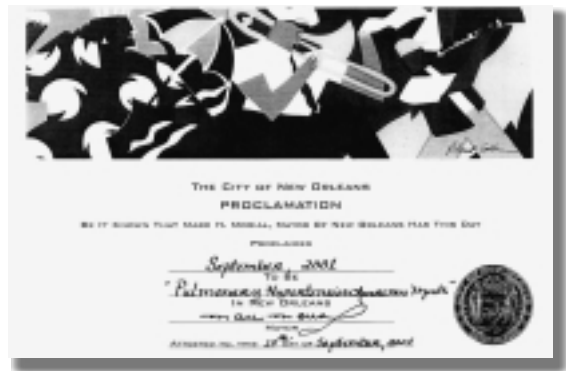
By Lorie Simmons, PHA Advocacy Director

Despite the tragic events that took us all by surprise, the courage of the PH community prevailed and PH Awareness Week 2001 activities raised awareness about PH and touched more people than ever before.

The plan this year was to launch a comprehensive set of PHA tools and awareness-building activities with the focus on educating the local community. Awareness Week began just four days after the tragic events of September 11. So while national media was focused elsewhere, PHA was successful in attracting the attention of a number of local and regional newspapers and radio and TV stations.

In advance of Awareness Week, PHA provided each Support Group Leader with a revised Support Group Leadership manual. In addition, during the summer months, PHA provided each Support Group (and some of you who were not able to find a local Support Group) with an Awareness Week 2001 Manual, which contained the easy-to-use-tools for conducting Awareness Week activities. Among these was the CD, *Understanding Pulmonary Hypertension* (displayed on computers on information table tops in hospitals and libraries and dropped in goodie bags), a 30 second Public Service Announcement CD for contacting the local media, letters for contacting your local elected officials, and a formatted proclamation proclaiming PH Awareness Week 2001. From the PHA website PHA members and patients were able to download this year's iron-on design and directions for making an Awareness Week 2001 tee shirt.

Special kudos go to Support Groups and PHA members and families around the country who used the new tools to do an outstanding job of raising awareness about PH. These hard working groups set up tables at hospitals and libraries throughout America, distributed awareness materials and generated local press coverage. Less than a year ago there were only 45 support groups. Today there are 75 organized groups providing support for patients and family members of patients with PH. These groups were the backbone of Awareness Week 2001, reaching out not only to their neighbors, but to the media and local and national elected officials, as well.



Awareness/Advocacy Highlights

Proclamations from local governments declaring the week of September 15–23 to be PH Awareness Week 2001 were presented to groups in Louisiana, Colorado, and Florida. PHA will be hanging copies of these in PHA offices for all to see. If September 15–23 was proclaimed Awareness Week in your

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Delegates at first PH Conference in the United Kingdom.

community, please send PHA a copy of your proclamation. Hopefully, next year we will have proclamations from at least 75 jurisdictions!

A letter from a PH patient family member to her congressman from Minnesota resulted in a letter back indicating that the Congressman was now aware of PH and will monitor bill HR 1297.

Awareness Events Highlights

Northern Virginia Support Group—Golf Tournament—On September 17, most of our PHA staff participated in a local golf tournament in Northern Virginia. This First Annual Northern Virginia Golf Tournament proved to be fun for all, despite the national circumstances.

Pittsburgh, PA—University of Pittsburgh Medical Center where over 1000 pamphlets were distributed. Press coverage and videos of TV coverage were shown.

Sacramento Support Group meeting held to kick off the week.
Port Charlotte, Florida Support Group—Support Group meeting with Dr. John W. Schwisher presenting on Pulmonary Hypertension, the Challenges of Diagnosis and Treatment. Also information tables at local hospitals throughout the week and a TV interview with Penny Engel, new Port Charlotte Support Group Leader, and press coverage as well.

Boston, MA—Support Group sponsored an information table at Mass General hospital. Sold awareness pins and PHA cards with proceeds going to PHA.

Chicago, IL—Dr. Stuart Rich and Dr. Vallerie McLaughlin presented Curing the Incurable, Breakthroughs in Treating Pulmonary Hypertension at a cocktail reception and dinner sponsored by Gentiva and The Rush Heart Institute Center for Pulmonary Disease. Patients and members from the Chicago Support Group participated and attended.

Indiana Support Group—“Out of Uniform Day” in a local parochial school, one dollar was paid by each student to come to school out of uniform. In addition there was a booth at a local health fair.

Romney, West VA—Hospital information table, information provided for patients at two physician’s offices and a medical

center and for an additional medical clinic in the nearby town of Winchester, VA.

The United Kingdom held their first PH Conference which coincided with PHA Awareness Week. Congratulations!

Michigan Support Group—Raffle in which patients sold tickets for a handmade quilt donated by a PH patient. The raffle tickets gave information about PH.

Houston, TX—Support Group meeting. Dr. Felix Shardonofsky spoke about PH and Children and Dr. Remzi Bag spoke on New Treatments for PH.

National and Local Media Attention

Actelion, manufacturer of the oral drug Tracleer, provided welcome assistance with PHA’s Awareness Week media campaigns. Working with Actelion’s PR firm enabled PHA to reach more outlets than we ever could have on our own. Naturally, with the news of the attacks, we got less national coverage than originally hoped. This has proven to be only delays and based on a report that we received on October 30, 2001, these have played out well and probably will continue to do so over the next several months.

Media Highlights

Over 10,000 newspapers received pre-formatted articles about PH and PHA

Over 1,000 radio stations received public service announcements

A TV show on PBS, Medical Answers, devoted a half hour to interviewing PHA president Linda Carr and Dr. Lewis Rubin about PH

Linda Carr did six news interviews by satellite, which aired in various markets around the country.

11 PH patients were interviewed around the country with the intent of running the interviews in the local publications or attracting the attention of local TV stations for further interviews. Articles have appeared on Jessica Kale in New Jersey, April Wade in Chicago, and Penny Engel in Florida. There have been TV interviews with the Wubbens family in Iowa and Penny Engel in Florida.

National Media Campaign Results through 10/31/01

A general press release of the pre-formatted articles about PH and PHA did hit major markets such as New York, LA and San Francisco. This release generated 68 newspaper articles in 13

(Continued on page 5)

PHA, Moving Forward

By Lorie Simmons, PHA Advocacy Director

In the face of all that has happened these past several months, it is good to see our nation standing strong and moving forward. PHA is no exception.

PHA is pleased to announce that we now have a new 8-page brochure titled *Pulmonary Hypertension: Helpful Information for Patients and Families*. This new brochure, which focuses on the medical aspects of PH, was made possible with a grant from Actelion and Genentech. Copies are available in quantity from the PHA office or you can download it from our website at www.phassociation.org (It's in PDF format, so you will need Acrobat Reader to do so.)

By now many of you have had the opportunity to view the PHA CD, *Understanding Pulmonary Hypertension*. More than 5,000 copies were distributed in the U.S. and abroad. We are currently out of stock but expect to begin shipping again before the end of November. Actelion has generously offered to help PHA produce 4,000 additional copies. In the meantime, PHA has already begun work on the next version, 2.0, which will be ready for distribution in time for the PHA International Conference in June 2002. As an added piece of good news, PHA anticipates working with the Transplant Division of the Health Resources and Services Administration (HRSA is part of Health and Human Services) to develop a segment on organ donation and transplant for the new CD.

As a result of PHA's effort to reach out to Federal agencies that can enhance our efforts at public awareness and provide funding for research, PHA was invited by the Centers for Disease Control to participate in their first annual Conference, "Building and Expanding State-Based Cardiovascular Health Programs". The primary audience for the Conference was state health officials. The only non-profit agencies invited to have booths were PHA and the American Heart Association. State health officials stopped at our booth and generated ideas on how we might work with them in the future. This event also gave the CDC the opportunity to fulfill their mandate from Congress (Thank you Congressman Kevin Brady!) to enhance public awareness about PH, which was a part of the FY 01 congressional appropriations committee recommendation. We expect to see this as a part of FY 02 recommendation, too.

On September 7, many PHA members, PH patients and Board members attended a Gala Dinner in Rochester, MN, organized by Dr. Mike McGoon, his wife Bonnie, Cathy Severson and all the great folks at the Mayo PH Clinic. More than \$39,000 was raised. Quite a first event! Dr. McGoon announced that the Mayo Gala will benefit patient services delivery by PHA. During Awareness Week, the first Virginia Golf Tournament was held and, as we go to press, the first Race

for PH in San Francisco raised funds for research. ...So we have doctors and nurses raising funds for patient services and patients and family members raising funds for medical research!

The PHA web site has been experiencing more regular updates and a new look since August 1. That is due to the efforts of Jeremy Isett who is PHA's new Internet Services Manager. What you haven't seen is all the work that has been going into development of the updated PHA website scheduled for a mid-December launch. In addition to the new look, we are anticipating that the new website will allow us to offer on-line conference registration and membership renewal. That will be a big change for us all and a big convenience.

A new subcommittee of the Scientific Advisory Board, the SAB Publications Committee, met and developed the idea for a new publication, *Advances in Pulmonary Hypertension: the Journal of the Pulmonary Hypertension Association*. Funds have been raised for the first issue, which is scheduled for mailing in January 2002. Dr. Victor Tapson is editor. Drs. McLaughlin, Gaines and Robbins are the editorial committee. Distribution will be to more than 31,000 cardiologists, pulmonologists and rheumatologists. The first issue is being made possible through grants from Gentiva and Actelion. This will be a meaningful contribution for physicians treating PH patients.

During the summer of 2001, PHA began to invite companies interested in pulmonary hypertension to join its newly created Corporate Committee. Those joining by December 31, 2001, will become founding members. To date, Actelion, Gentiva, GlaxoSmithKline, the Pharmaceutical Manufacturers Association of America (PhRMA) and United Therapeutics have joined.

In mid-September, PHA of the United Kingdom joined PHA of Israel as nations hosting PH Conferences. Congratulations PHA, UK.

Attention all! The membership renewal mailing, which has over the past two years been gradually calendared into becoming an end-of-year mailing, will be arriving soon. Don't be surprised if its arrival coincides with your receipt of this Pathlight. Please look for it. Your membership in PHA is what keeps you tied to the PH community. Your dues help PHA bring you the 800# patient help-line, Pathlight, Persistent Voices, CDs, the PHA website, our 2 brochures, Awareness Week Kits, Support Group Manuals, the Patient's Guide, research for better treatments and a cure, and all the services that make the PHA community so unique. Renew, and while you're at it, encourage patients and their families who are new to the PH Community to join, so they can take advantage of the many benefits PHA offers.

Michigan PH Support Group

By Beverly Lipmyer

The Michigan PH Support Group held a raffle this year to raise awareness and funding for research. One of our patients, Betty Pratt, donated a beautiful handmade quilt of Michigan lighthouses. Patients sold over 2000 tickets (which had information about pulmonary hypertension printed on them) for \$1.00 each from mid August to September 15. We were very excited that the raffle raised \$2390.00 for research and to know so many patients took time to get involved. We also had our 3rd annual Awareness Picnic on September 15. Over 75 patients, family, and friends gathered to share experiences, offer support to others and have some good fun on what turned out to be a beautiful day! Our picnic was held at patient Debbie Densmore's home and everyone enjoyed the festivities including pony rides, a bonfire, and other activities. And along with the help from Gentiva Health Services who donated all the food, beverages, and some door prizes and Theracom who supplied the tent, tables and chairs, the day was a great success! Thanks to everyone who took part in the raffle sales and the planning of the picnic.



Lighthouse quilt awarded in a raffle sponsored by Michigan Support Group.



(from left to right) Jack Stibbs, Dr. Shardonofsky, Angie Eldam, Victoria Geihl, Dr. Bag attend Houston meeting.

Houston PH Support Group

By Angie Eldam

On Sunday, September 16, over 40 people attended the Houston PH Support Group Awareness 2002 Meeting. Refreshments were graciously provided by Gentiva and the Stibbs family. Dr. Felix Shardonofsky spoke about "PH and Children" and Dr. Remzi Bag presented "New Treatments for PH." Both were well received. It was good to see patients meeting others with PH for the first time and coming away feeling that they were not alone in their battle with PH. Jack Stibbs demonstrated the new CD-ROM "Understanding Pulmonary Hypertension." What a great advocacy tool that will be for everyone!

Pittsburgh PH Support Group

By Sharren Yamron

The Pittsburgh support group worked hard during PHA Awareness Week. We set up two tables at the University of Pittsburgh Medical Center (UPMC) cafeteria with plenty of information and passed out over 1000 pamphlets to medical students, doctors, nurses, hospital personnel and visitors. We served up plenty of baked goods, cookies, brownies, pizzelles and Danish to get the attention of people walking by. We were staffed daily with patients, support people, Gentiva Pharmaceutical employees and Dr. Murali's staff. All this made a wonderful experience for all who attended. We even had a representative from Mexico who helped man the table, our international connection. Videos of patients who were featured on the local news were shown and posters of others who were written about in our local paper were displayed. The CD about PH came just in time for Awareness week and we had it on a laptop computer and displayed it throughout the week. This year's Awareness Week was a complete success for us here in Pittsburgh. For more info, e-mail me at sher@sgi.net.



Raising Awareness: Rebeca Doscif of Mexico at Pittsburgh meeting.

Pulmonary Hypertension Week in the Pikes Peak Region

By Cheryl Massaro

Fall in Colorado Springs is always crisp, clear, and beautiful! So little did we expect so many wonderful volunteers to sit inside the Citadel Shopping Mall to man our Southern Colorado Pulmonary Hypertension Support Group awareness booth for two entire days! Thanks to the coordinating efforts of Helen and Fred Forrest, volunteers shared two-to-four hour shifts greeting and conversing with the many mall passersby. It was a time of great camaraderie and friendship!

The particular weekend we presented our awareness booth also turned out to be the one following the attack on America. We had almost considered canceling the booth due to the tragedy. It did, however, turn out to be a successful weekend because of the varied patriotic displays and presentations held honoring those lost. PHA provided a well-worded statement that we posted on our booth. The wording of the statement: "PHA knows the pain of loss. We grieve with the families and our nation for what has been done through cruelty and evil." American flags were proudly displayed on our table alongside the PH materials.

Robin Murdock, our local Gentiva representative, provided an appropriate banner for use with our display as well as the candy for distribution to young and old alike. She traveled over 60 miles that Saturday morning to participate with us! And, Pat Patterson, PH patient and support group member, made over 750 periwinkle blue ribbons to distribute.

To add to our awareness campaign, PH support group members, family, and friends appeared before the Colorado Springs' Mayor, Mary Lou Makepeace, on Tuesday, September

18. At that time, we were able to "educate" our Mayor on this life-threatening illness. Via formal Proclamation, she declared September 15-23 Pulmonary Hypertension Awareness Week in Colorado Springs. A copy of that Proclamation is displayed on the PHA website. The Proclamation is now framed, awaiting the possibility of a wall to hang it upon should our support group grow into an office space!

As we were to find out, there are many PH patients and caregivers in the community who were not aware of our support group. In conversations held with those that lingered at our booth, the Colorado Springs' medical and patient community still has a major journey relative to PH awareness. In the efforts of PH Awareness Week, we were able to reach out to these PH patients and caregivers who were unaware of the support available in the Pikes Peak Region, and a month later, those same individuals joined us for our October support group meeting. And isn't that what awareness is all about?

For more information about this support group, call Cheryl Massaro at 719-550-9098 or email at offroadmama@msn.com.

Central California Support Group

By Rita Orth

On October 20, 2001, we held our third annual outreach picnic. We had it in Manteca, California, at one of our support group member's house. There were over 30 people who attended. We had PH patients that were as young as 34 and as old as 72! There were several people from the newly formed Sacramento area support group who attended. Encouragement was given and experiences shared by everyone. New friends were made and a good time was had by all.

National Media Campaign...(continued from page 2)

different states and reached a readership of 5,707,840. The PSA ran on 16 radio stations with a total audience reached of 1,469,900. These both have an extended shelf life and we may see even more media play in the future. At this time we do not have any numbers on how many people were reached with the TV interviews. Together, these gave PHA an extraordinary audience for raising awareness about PH.

Some of our coverage and events ran beyond the week and we know that there were many more events than those captured here. PHA would still like to hear from you. Over the next several months we would like to share your stories about Awareness Week 2001 with PHA members by posting them on the PHA website. So please keep sending your information. We will publish it. Your stories will lay the foundation for next year's expanded awareness activities 2002.



Houston SG members visit with friends old and new!

Conference 2002

Plans are well underway for our 5th PHA Conference. Remember to save the dates and plan to attend (June 21-23).

The schedule is “growing”, and we can confirm that some of the world’s best and most knowledgeable medical professionals will be speaking, answering questions, and even learning from their colleagues in their own meetings. We have an ambitious schedule which, we hope, covers everything we ever wanted to know about PH!

The Hyatt Hotel in Irvine is an experienced conference center and the staff there is looking forward to hosting us. We are making plans to ensure that all our special needs are taken care of including activities for children and teens. Please read “Scholarships for the Conference” for information on our scholarship program which provides funding to bring some of our members to this conference.

The registration form and full details of this forthcoming event will be mailed to all PHA members in February of 2002. In the interim, please feel free to contact the PHA web site for any questions you may have or contact Susan Salay, Chairperson, at ssalay@aol.com.

Scholarships for the Conference

Scholarship granting decisions will be governed by the following procedures and selection criteria. Three levels of assistance to adults will be granted: A level—full support (travel, registration and lodging); B level- partial (travel or registration & lodging); or C level- (conference registration fees only). A minimum co-payment of \$25 toward patient costs to attend and \$25 for the companion’s conference expenses will be required.

To apply, a patient should send a written statement by January 15, 2002, to Ed Simpson, Conference Scholarship Coordinator, 850 Sligo Ave, Suite 800, Silver Spring, MD, 20910, or e-mail (esimpson@nwaft.com) that includes:

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

Note: All applicants must be PHA members.

Applicants will be notified by February 15, 2002, about scholarship awards.

Travel We Must...

During the past year, it has become necessary for PHA leadership and staff to travel much more than they have in the past. As the organization continues to grow so rapidly, we anticipate this need continuing.

PHA is seeking donations of frequent flyer miles to help meet these expanding travel requirements. If you are an individual with surplus miles you don’t anticipate using for your personal needs—please consider donating your extra miles to PHA.

How the Plan Works

Most airlines will allow an individual to “purchase” a round-trip ticket for a non-family member with their excess frequent flyer miles. Key elements of transferring miles include:

The owner of the frequent flyer miles must call the airline to book the flight.

The donor must have the recipient’s name, address, and flight information such as travel dates and departure/destination cities.

PHA will act as a clearinghouse, collecting detailed information from people willing to donate miles.

When travel needs are confirmed, PHA will provide the necessary information so that the donor can book the flight directly.

Please logon to the PHA website at www.phassociation.org to register as a frequent flyer donor today or call Jennifer Becker at 301-565-3004 ext. 106 to register or for more details.

Outstanding Membership Recognition Awards

PHA is accepting nominations in the following categories to be presented in conjunction with our June 2002 PH Conference. Nominations must be received by March 15, 2001. Include a letter explaining in detail your nominee’s service to patients and involvement in PHA and why your nominee deserves the award. Please mail your nominations to the Awards Committee, PHA Offices, 850 Sligo Avenue, Suite 800, Silver Spring, MD, 20910.

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

NEWS AND ANNOUNCEMENTS

Bonnie Dukart Scholarship Fund

On October 24, Dr. Gary Dukart; PHA Executive Director Rino Aldrighetti; Craig Mears, Carmen Skurdal and Karen Bowe of Gentiva; and Access' Kim Bernstein met in a restaurant in Spring House, Pennsylvania, to launch a new memorial fund in memory of former PHA president Bonnie Dukart. The Fund was created through an Awareness Week Raffle held at Gentiva sites around the U.S. in recognition of Bonnie's great contributions to the PH community.

Staff participation was matched by Gentiva and over \$10,000 was raised. In the midst of fond exchanges of stories about Bonnie's accomplishments and toasts to her memory, Bonnie's husband, Gary, drew the winning tickets. Craig Mears announced that the raffle will become an annual Gentiva event to support Bonnie's Fund. This year's proceeds will be used to scholarship patients to Conference 2002 in Irvine, CA.

This is the second Fund in Bonnie's memory. PHA will soon be announcing the direction of a new transplant-related program for a Fund created by Bonnie's family, friends and many admirers.

United Kingdom Conference Off to a Great Start

By Kay Yeowart

Patients, carers and medics travelled from all over the UK for the largest ever Pulmonary Hypertension gathering in the UK.

The Specialist Nurses, in conjunction with committee members of the Association, also organized a well-supported and informative PH Forum for members of the medical profession. This was an ideal opportunity for the recent National Guidelines for PH care in the UK to be outlined and explained. The focus of the day was also to provide information, to educate, and to raise PH awareness. The event was then followed the next day by the main conference for patients and carers.

We were extremely fortunate to be accompanied by such excellent speakers, including Professor Higenbottam, Dr. Sean Gaine and Professor Richard Trembath. It was encouraging to learn how much progress has been achieved even since the PHA conference in Chicago concerning genetics, the understanding of the disease and the new treatments.

Unfortunately, Dr Dunbar Ivy was unable to attend following the atrocities in the U.S. on September 11. However we were delighted and very grateful that he was able to send us his presentation via e-mail and conduct the session via a speakerphone. The wonders of modern technology!

The benefits of the conference were immense to everyone who attended. The support, information and fellowship received has enriched many lives and we hope to repeat the event next year. We are very grateful to our sponsors for their generous support, Glaxo-SmithKline, BOC Gases, Graseby International and Schill Medical.

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.

- | | |
|--------------------|---------------------------|
| Jean S. Anderson | Janet Lanning |
| Carol Aserinsky | Venise Marin |
| Tracy Byrd | Frederick Myers III |
| Hannah Ross Carter | Danny "Jake" Noonan |
| Nancy Kay Cobb | Elvira Ratte |
| Beth Deserano | Colleen A. Richman |
| Nancy Fyrie | Harriet Millicent Solomon |
| Adela Guzman | Margaret E. Williams |
| Jim Hastings | |



Nurse Conference Question Panel (L-R) Dr. Simon Gibbs, Dr. Sean Gain, Ann Mainwood, Agnes Crozier at the UK PH Conference

Upcoming Events

PHA Board of Trustees Meeting

February 15, 16, & 17, 2002
Orlando, Florida

The Caleigh Coleman Memorial "Cure" PH Golf Tournament

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

PHA Golf Tournament, Dinner, & Auction

April 4, 2002, 1 p.m.
The Woodlands Resort and Conference Center
The Woodlands, Texas

Cure PH is hosting its 4th annual golf tournament at The Woodlands Resort and Conference Center. PHA's first golf fund raiser has now raised over \$300,000 for PH research since its inception. You can help make this event even more successful by donating items for the auction. Some popular items up for bid in past auctions were sports memorabilia, art work, dining out coupons, gift certificates, and condo vacations. If you have something you can donate, please contact Marcia Stibbs by emailing her at cure4ph@txucom.net.

Double your Donations—Corporate Matching Gifts

Are you aware that you can double your contribution to PHA by taking advantage of your employer's matching gift program?

Companies that offer a matching gift program to employees will usually match a gift made to any 501c3 (nonprofit) organization. Once an initial gift has been made, many companies will then include the nonprofit on a list of eligible charitable organizations for employees to select from. So far, in calendar year 2001, PHA has received \$18,605 in contributions through corporate matching gift programs. Some of the larger matching gift programs in the U.S. include IBM, Wal-Mart, General Motors, Merrill Lynch & Co., McDonald's Corporation and hundreds of other businesses, large and small.

If you're thinking about making an end of year gift to PHA—please check with your employer for details about a possible matching gift program.

Minnesota Pulmonary Event Raised \$40,000

By *Cathy J. Severson*

The organizing committee for the Pulmonary Hypertension Association Dinner/Dance/Raffle at the Radisson Plaza on September 7 wishes to acknowledge with gratitude the participation and contributions of all those who made this event a success. A first for PH healthcare providers—Dr. Michael McGoon, his wife Bonnie, and Cathy Severson planned carefully to be sure everything was a success, and it was! The funds will be used for patient support, also a first.

The effort to defeat pulmonary hypertension and to provide patients and their families with support and hope was tremendously advanced by the generosity of the community, corporate sponsors and caregivers who together accounted for more than \$40,000 being raised for this cause.

This was a great way to honor National Pulmonary Hypertension Awareness Week, to assist with the battle against a devastating illness, and to participate in an enjoyable event. And the lucky winner of the raffle grand prize is enjoying her Corvette! Thank you for your support.



Dr. McGoon hosts gala for PH at Rochester.



First dance for lovely young lady at PH fundraiser.



First PH Gala in Rochester, MN, draws a large crowd.

Research Update

By Lenna West

It has been a busy time for research. We are currently in the process of gearing up for our PHA Fellowship grants for 2002. Announcements are out and our deadline for applications is January 25, 2002. So let's get busy and submit those applications for our two \$35,000 grants to be awarded in July 2002.

During the month of October our Young Scientist applicants were being reviewed by the NHLBI. They will be reviewed again by NHLBI and PHA in February 2002 and awarded in July 2002.

Our three Fellowship grant awardees from July 2001 have just completed their first quarter of research. As you can see, the money donated to PHA for research is being put to great use and now we can sit back and pray for better treatments and a CURE!!!

Late Breaking News: Tracleer Approved

ALLSCHWIL, SWITZERLAND, November 20, 2001— Actelion Ltd. (SWX New Market: ATLN) today announced that the U.S. Food and Drug Administration (FDA) has approved Tracleer (bosentan), an orally active endothelin receptor antagonist, for the treatment of pulmonary arterial hypertension (PAH). Tracleer is indicated to improve exercise ability and decrease the rate of clinical worsening in PAH patients with significant limitation of physical activity (WHO class III and IV).

Tracleer 125mg, taken twice a day, is the first approved oral treatment for patients suffering from PAH and is expected to be available to patients in the United States in early December. Tracleer may be prescribed only through the Tracleer Access Program by calling 1-866-228-3546. (For more information about endothelin, please read Dr. Gaine's article in Research Corner on page 10.)

Important Numbers

PHA (office hours 10 a.m. to 4 p.m.) 301-565-3004
 FAX or e-mail preferred, FAX: 301-565-3994
 E-mail: pha@phassociation.org
 Member Services and
 Pathlight Address Changes 301-565-3004
 PH Help Line 1-800-748-7274
 (10 a.m. to 9 p.m. EST)
 ACCESS 1-888-700-7010
 (Social security, insurance, and
 disability questions)
 Gentiva's Hotline for Flolan 1-800-9-FLOLAN
 Priority Healthcare Remodulin Hotline 1-877-462-6225
 TheraCom's Hotline for Flolan 1-877-356-5264

Reminders

"Patient's Survival Guide" Second Edition Now Available

The second edition is over 200 pages filled with clear descriptions of the disease process and the latest medical advances and treatments. It includes an extended list of references, support organizations, and other patient resource material-and for the same low price of \$15 for PHA members or \$25 for non-members or outside of the U.S. (payments must be in U.S. dollars).

To order, go to the PHA website at www.phassociation.org or call 301-565-3004.

Julie Paton Hendry Memorial Scholarship

Funding for this scholarship was established in 1998 to send a non-patient volunteer to the International PH Conference. Please send a letter detailing your volunteer efforts on behalf of PHA to Judy Simpson, Chair, 84 Bandy Drive, Holiday Island, AR, 72631, by December 31, 2001. The recipient will be named January 15, 2002.



Professor Tim Higenbottam: Medical speaker at the UK PH Conference

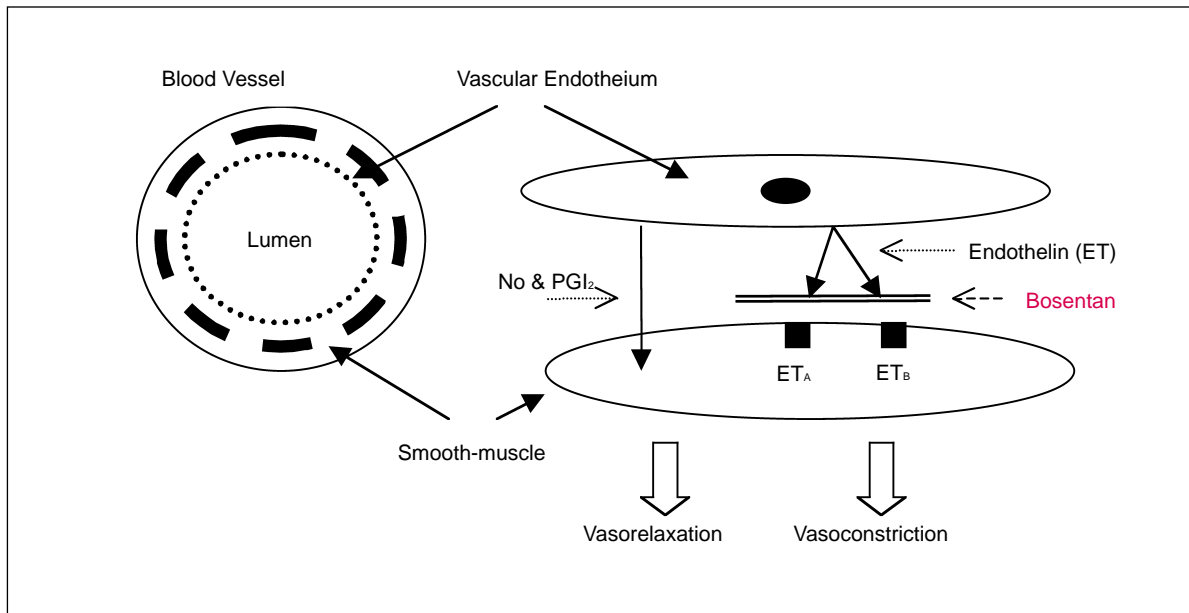
RESEARCH CORNER

From Dr. Sean Gaine, MD, PhD, at The Mater Hospital, Dublin, Ireland.

Update on Endothelin

Endothelin has become a new hot topic in pulmonary hypertension clinics over the past year. Bosentan, an endothelin blocker, has become the first FDA approved orally active drug for the treatment of severe pulmonary hypertension.

By blocking the endothelin receptors it is hoped to reduce the vasoconstriction and reduce the amount of proliferation. The recently completed study (Channick et al) of Bosentan in patients with PPH or with pulmonary hypertension due to scleroderma demonstrated a significant reduction in pulmonary vascular resistance and an improvement in the exercise capacity of patients treated with the drug. It remains to be determined whether similar benefits will be obtained in other types of pulmonary arterial hypertension, such as congenital heart disease. Currently there is a study looking at combining



Endothelial cells produce a number of factors to control the flow of blood through the blood vessel. Some of these factors promote vasorelaxation and better flow, such as nitric oxide (NO) and Prostacyclin (PGI₂). However there are other substances released that impede that flow, such as endothelin. Endothelin, a molecule released by endothelial cells, is a potent vasoconstrictor and smooth-muscle mitogen that can increase the pressure in blood vessels and lead to chronic changes in the vascular wall. Endothelin acts on two receptor subtypes, ET_A and ET_B. ET_A is predominately responsible for the vasoconstriction and proliferation, while the ET_B acts as a brake on the system preventing the bad ET_A effects from predominating. In patients with PPH or scleroderma, high concentrations of endothelin are present in the blood, and the higher the levels the worse the outlook.

Bosentan is an orally active non-peptide antagonist (blocker) of both endothelin receptor subtypes (ET_A and ET_B).

Bosentan with prostacyclin to determine whether combination therapy can improve the response to prostacyclin. A number of new endothelin blockers are also being evaluated including some that have no effect on the ET_B receptor. By not blocking the B receptor it is hoped it can still function as a 'brake' on endothelin production and effects. However it is not known yet whether there will be any advantage to this approach. Endothelin blockers are newcomers to pulmonary hypertension therapy and are here to stay.

Effects of the dual endothelin-receptor antagonist bosentan in patients with pulmonary hypertension: a randomized placebo-controlled study. Channick, RN; Simonneau, G; Sitbon, IM; Frost, A; Tapson, VF; Badesch, DB; Roux, S; Rainisio, M; Bodin, F; and Rubin, LJ; Lancet 2001; 358:119-23

Scientific Advisory Board: Past, Present, and Future

By Dr. C. Greg Elliott, Chairman of SAB

Past

The Scientific Advisory Board (SAB) of PHA is a resource to the membership and the Board of PHA on scientific matters. The original SAB was announced in Volume 3 of Pathlight (1992). The SAB consisted of 16 physicians and nurses, all from medical centers in the United States. The SAB was organized by the Board of PHA. Members of the SAB responded to questions posed by patients and family members. Many of these helpful comments appeared in early editions of Pathlight titled "Ask the Doctor" or "Sounding Board". As the organization grew, it became obvious that the SAB needed a leader who could facilitate communication between the Board of PHA and the SAB. In 1996, Bruce Brundage, MD, became the first chair of the SAB. Under Dr. Brundage's leadership, the SAB and PHA developed ambitious plans for funding research and for developing a journal dedicated to advancing knowledge and education in the management of pulmonary hypertension.

Present

The SAB has grown as PHA has grown. The board now consists of 23 health professionals from major medical centers in the United States and around the world. The SAB continues to serve PHA as a resource on scientific matters. However, the SAB role has expanded. The SAB provides scientifically based information to the PHA Board and membership. The SAB also provides support for PHA advocacy efforts, provides insight into current research related to pulmonary hypertension ("Research Corner" in Pathlight) and advises the Board with respect to funding research aimed at better understanding and treatment of

pulmonary hypertension. The SAB also supports the PHA bi-annual conference by participating as panelists and speakers.

The SAB now has five active subcommittees. The first is a Consensus Committee, chaired by Ivan Robbins, MD. The Consensus Committee will develop position statements related to the management of PH on behalf of the SAB. The second committee is the Research Committee, chaired by Lewis Rubin, MD. The Research Committee will advise the PHA Board on directions for future research consistent with the mission of the PHA Board to fund research aimed at finding a cure for PH. The third committee is the PHA Program Committee, chaired by David Badesch, MD. This committee will plan participation of SAB members in the Fifth International Pulmonary Hypertension Conference, and it will plan a scientific program for members of the SAB who attend the conference. The fourth committee is the Publications Committee, chaired by Bruce Brundage, MD. This committee will launch a new journal, *Advances in Pulmonary Hypertension: The Official Journal of the Pulmonary Hypertension Association*. Dr. Victor Tapson has agreed to serve as the editor for this journal. The fifth committee is the Strategic Planning Committee. Dr. Michael McGoon, current vice chair of the SAB, is the chair of this committee. The Strategic Planning Committee will plan future efforts of the SAB and PHA.

Future

The future of the SAB depends upon the continued efforts of its members. Dr. Michael McGoon, the current Vice Chairman of the SAB, will become the chair in June 2002 and a new vice chairman will be nominated and approved. These steps should provide for continued leadership as the SAB continues to serve the membership and board of PHA.



Pittsburg SG Members: Shelli Schlafhauser, Sharren Yamron, Dr. Srinivas Murali

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.

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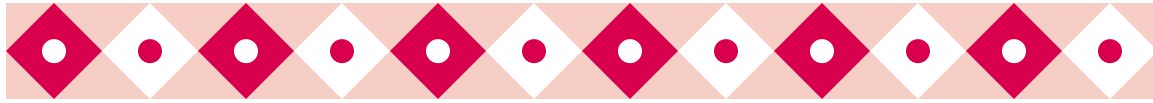
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Deadline for the spring issue is January 31, 2002.

Persistent Voices

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

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