



Pathlight

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

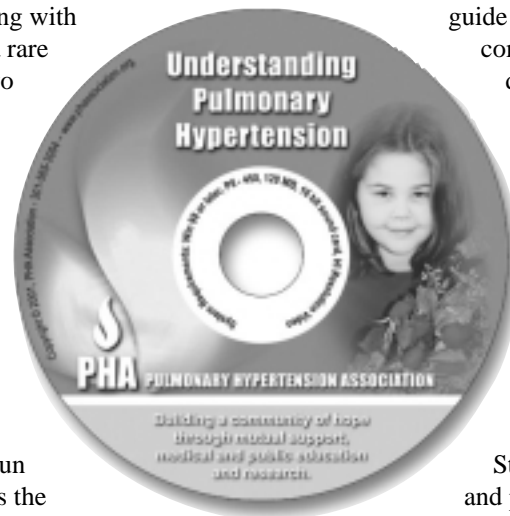
Fall 2001
Volume 10 • Number 3

PH Association Goes Hi-Tech to Help Find a Cure

March 17, 2001, The Woodlands, Texas—Imagine going to your doctor’s office with your young daughter who is experiencing shortness of breath, and leaving with a diagnosis of Pulmonary Hypertension—a rare and, as of yet, incurable disease. “These two words changed our lives,” said Marcia Stibbs, whose daughter Emily was diagnosed with PH three years ago when she was just six years old. “I left the office wanting to know everything about the disease and how we were going to battle it,” continued Jack Stibbs, Emily’s dad.

The Stibbs found an organization that could help—The Pulmonary Hypertension Association (www.phassociation.org). The PHA is truly like an extended family. It is run by a network of volunteers, scattered across the country, who keep in touch by phone, newsletter, support groups, and the Internet. The Stibbs family became active members in the organization, spearheading fundraising events. Today Jack sits on their Board of Directors as Vice President of Advocacy. “You see, the good news is, we firmly believe that through intensive research, a cure for PH can be found, and Emily can lead a long and healthy life.”

Jack’s job in the organization is to help find individuals, companies and other organizations that are willing to get involved in a variety of ways to help find a cure. Jack wanted a tool that could help him explain the disease to everyone from a Congressman to an elementary school child. He felt the best way to do this was to create a multimedia CD-ROM guide and use the incredible power of a personal computer to tell this story. To make this dream happen, he turned to an old friend and neighbor, Vic Cherubini, President of the epic software group in The Woodlands, Texas.



“I visited epic’s new multimedia studio and was amazed at both the quality and quantity of information that could be placed on a CD-ROM. 3D animation, video, high quality audio, photographs, web links, and hundreds of pages of helpful reference materials could easily fit on a single CD,” said Stibbs.

Stibbs and the epic team of artists, animators and programmers then brainstormed on creating the “Encarta of Pulmonary Hypertension,” just the kind of resource guide he would have found so helpful on the day he learned of Emily’s diagnosis.

Work is now underway by the PH Association to collect the information needed for the CD-ROM, and epic is busy producing the program. The CD is scheduled for release in September of this year, and will be distributed free of charge to anyone who requests a copy.

Strong Support for PHA's New CD-ROM...

Using a website look, PHA’s newly designed CD utilizes high quality graphics and sound to invite users to explore this fascinating CD. Intended for patients, doctors, caregivers or people simply interested in learning more about pulmonary hypertension, this CD delivers a comprehensive look at the

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Report of the American Thoracic Society International Conference

By Judy Simpson, RN

The American Thoracic Society (ATS) met in San Francisco on May 18–23, 2001. It was an excellent meeting with over 17,000 pulmonologists and researchers in attendance.

I represented the Public Advisory Roundtable (PAR) by speaking to the ATS Educational Committee, setting up and manning the PAR Poster Session, and attending the second meeting of PAR. I also attended the LAM Medical Advisory board luncheon meeting by invitation.

Topics covered relevant to PH was a mini-symposium on New Developments in PH Therapy chaired by Lewis Rubin and Tim Higgenbotham of Sheffield, England, (who was very instrumental in the development of prostacyclin and cutting edge PH research) with presentations from England, Scotland, Germany, Austria, and the US (St. Louis) groups. PAR groups had a Poster Session display to educate physicians—Lorie Simmons, PHA’s Advocacy and Awareness Director, made a wonderful, comprehensive 4x8 PHA poster composite which was well received and can be used again. I spoke to the ATS Education Committee for PAR to educate the Committee about PAR and needs of patients. PHA and other organizations can submit their educational materials for review to be approved and put on the ATS web site with a link to PHA’s web site.

What PHA got from representation at the ATS conference was (1) Education opportunities—superb for both the attendees and for PHA, (2) Exposure for PHA—excellent, (3) Networking—very good. But the most important thing I bring to you is hope: research in the area of PH is booming... much more is happening than I expected. So many are working for our cause; let’s spread the word!

Recommendations

- PHA should have representation at ATS and AHA meetings.
- PHA should submit its educational material to the ATS for review.

- Consider submitting a research proposal to the American Lung Association (ALA) for matching funding when our resources permit.

- Consider using ATS to review research grants when appropriate; they charge no fees.

- Consider using ATS Education Committee to facilitate the process of obtaining CEUs for the PHA International Conference when this service becomes available.

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.

Awareness Week 2001

Planning is ongoing for Awareness Week 2001 with many activities to choose from such as fun runs, pizza-in-a-box school parties, dinner dances, special speakers, and more. Be sure to check with your local PH support groups for what is happening in your area. Gentiva continues to play an active role in support of all PH activities.

Support Group Leaders: Your pictures and reports (100 words or less) of your Awareness Week activities should be sent in by October 31 for the next issue of *Pathlight*.

800 # Help Line

by Pat Paton

When I was first diagnosed with PPH in 1987, it took two years for my family to find another person with this rare disease. During that time, I felt alone and isolated and I knew other patients must feel the same way. So in 1991 when three patients and their families met to talk about forming a national patient’s association, one of our goals was to provide a network of support for patients and their families.

One way we were able to do this was to establish the 800 # in late 1994 to be answered by trained volunteers who live throughout the country. Most of the volunteers are PH patients or family members of PH patients who are willing to spend time and energy each day talking to others about PH. Call forwarding routes the 800 # calls to each person’s home as the schedule changes.

Today we receive between 200 and 250 calls per month and cover topics that are of interest to all PH patients. This includes support groups, current treatments, research efforts, education, advocacy, and PH physicians.

We currently have 15 people answering the 800 # for one-week periods. If you are home during the day and would like to help with this rewarding experience, please call Pat Paton at 561-597-4962 to get information about the next training period.

And remember, when you call the 800 # HELP LINE, please limit calling hours to 10:00 a.m. to 9:00 p.m. EST.

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

PH Association Goes Hi-Tech...(continued from page 1)

disease, its symptoms, possible treatments, where to get help and a whole lot more.

About the Authors: the epic software group

The epic software group is a ten-year-old multimedia production company located in The Woodlands, Texas. The artists, animators, programmers and support staff who work at the company create interactive electronic catalogs, multimedia presentations, 3D graphics and animated short features. epic software group is located at 701 Sawdust, The Woodlands, Texas. 281-363-3742 (phone), 281-292-9700 (fax), epic@epicsoftware.com (e-mail) and website at: www.epicsoftware.com site.

thanks

PHA extends its sincerest thanks to CD-ROM sponsors: **Actelion, Gentiva Health Services, GlaxoSmithKline, Texas Biotech, United Therapeutics and the Stibbs family.** Their generous support will allow PHA to launch the CD-ROM during PH Awareness Week September 15–23. The CDs will be mailed to PHA’s 3,700 members, PH-treating medical professionals, hospitals, media outlets and libraries.

**Patient's Survival Guide
Second Edition Available Now!**

Known as “The Book” to PH patients, family members and medical professionals, *Pulmonary Hypertension: A Patient's Survival Guide* was an immediate success, selling several thousand copies since PHA published it in 1998.

Now the *all new* and *expanded Pulmonary Hypertension: A Patient's Survival Guide—Second Edition* is available.

Written in easy-to-understand language

Clear descriptions of the disease process and latest medical advances and treatments

Extensive list of references, support organizations and other patient resource material

Written by acclaimed author and PH patient Gail Boyer Hayes

Edited by Bruce Brundage, M.D., and former chair of PHA’s Scientific Advisory Board

Over 200 pages (twice the size of the previous edition)

To order, go to the PHA website at www.phassociation.org or call 301-565-3004. The cost is \$15 per copy for PHA members or \$25 per copy for non-members or outside U.S. Price includes shipping. All payments must be in U.S. dollars.

NHLBI Update

By Rino Aldrighetti

Congressman Kevin Brady, David Malech (Rep. Brady’s legislative assistant), our lobbyists Dale Dirks and Gavin Lindberg and Lorie and I met with Dr. Claude Lenfant, Dr. Carol Vreim and Sandra Lindsay of NHLBI on the afternoon of May 1. The meeting was very cordial and Dr. Lenfant presented the increases in the PH research portfolio at NHLBI. He said the portfolio is now over \$18,000,000 for PH research and he spoke about both the quality of the work and the fact that more researchers are entering the field. He also spoke about the K08 grants (our mentored research grant partnership with NHLBI) and the importance of PHA encouraging applications through our SAB, board and staff spreading the word.

His feeling is that the field has been changing fast since our last meeting two years ago, with more researchers entering our area and good applications increasing. Over the past two years, the PH research and training budget has increased from \$12,000,000 to over \$18,000,000, an increase of fifty percent.

Dr. Brundage was unable to attend due to a family emergency, so we went forward in his absence, raising the issue of a registry. Dr. Lenfant raised the caution of looking forward rather than back in this time of great change. However, when we

spoke about the possibility of a planning grant under the leadership of our SAB to allow the medical professionals to come together to frame the wisdom of an agreed-upon structure for a registry, he suggested we might consider applying for a conference grant. He expanded the concept of a coming together of doctors beyond a registry discussion. He suggested that the SAB might want to meet to develop an overall plan of action. We responded that this could relate to several areas of current SAB activity, including the SAB Strategic Planning and Research Committees.

Conversation after the meeting helped us understand that to get through peer review, a conference grant is best formed around bringing medical professionals together to discuss the latest in basic and clinical research and the future directions of research. We will be talking more with SAB leadership about this shortly.

In answer to a closing question from David Malech, Dr. Lenfant said that he felt we were two to five years from moving from basic to clinical research. He said that we still need to know more about the mechanisms of the illness and that information is being gathered by the research being funded now. We felt very good about the meeting, our continuing relationship with NHLBI and, of course, Congressman Brady’s unwavering interest and support.

Pulmonary Hypertension Association of Israel

By Shiri Padmore

The Israeli Pulmonary Hypertension Association was founded at the beginning of 2001 with the goal of forming an independent body devoted to the needs and interests of Pulmonary Hypertension patients and their families. The main concept behind our work was to provide help and means of empowerment to both patients and family members through personal counseling, emotional support and education.



Like any other country, Israel has its unique problems. Because of the many sectors in Israeli society, we need to find a way to reach and help patients that do not speak Hebrew, and to provide updated information in several languages including Hebrew, Arabic, Russian and Amharic (spoken by

Ethiopian immigrants). Another more recent problem is that, due to current events, we have a problem contacting both Palestinian patients and doctors.

On the 21st of June, a warm Thursday afternoon we held our first Israeli PH association conference. Eighty people attended the conference including patients, family members, doctors, nurses and representatives of pharmaceutical companies. The first part of the evening was dedicated to administrative issues that had to do with the association: approving our codex, electing of board members and addressing the association's goals.

We then took a half-hour break, giving people an opportunity to get to know one another, which was one of the goals we set for the conference. The second part of the evening was a lecture held by Professor M. Kramer on the topic of "Current Treatments for Pulmonary Hypertension."

During the evening thirty people signed up as members, including a lot of caretakers and family members, bringing the membership in the Israeli association to over fifty.

In conclusion, the Israeli PH Association has been launched, and we are happy to join the efforts of an international community dedicated to promoting the welfare of Pulmonary Hypertension patients.

NEXT ISSUE!

Awareness Week Reports from PH membership
Conference Information

PHA Conference 2002

June 21, 22, 23, 2002

Hyatt Regency, Irvine, California (southern California)

The June 2001 PHA Board of Trustees meeting was held at the site of the upcoming Fifth International PH Conference—the Hyatt Regency Hotel in Irvine, California. It gave the Conference Committee a good look at the hotel and its amenities. Over 800 people attended the last conference in Chicago and even more are expected to attend this one.

The Conference Committee would like to ask for your help. We are planning sessions which are of the greatest interest to the members of PHA and would welcome your input and advice. We will be reviewing the sessions from the 2000 conference and repeating some of the best ones while discontinuing others. If you have suggestions for new topics or for topics which should be repeated or omitted, send your ideas to our professionals and patient planners by October 31, 2001.

Please send your input to Susan Salay, PHA Conference 2002 Committee member at ssalay@aol.com or write Susan Salay, 29 Hillgrass, Irvine, CA 92612.

More details will be in later issues of *Pathlight*. Members can expect conference registration packets to arrive early next year. There will also be a form at the PHA website that you can print, fill out, and mail so keep checking at www.phassociation.org.



PHA Conference Committee hard at work.

Pre-Conference Golf Tournament

If you are planning to attend the 2002 PH Conference in Irvine, California, would you be interested in taking part in a golf tournament fundraiser before the conference begins? The tournament would be on Thursday, June 20, at the Strawberry Farms Golf Club, which is about 15 minutes from the conference hotel. Cost would be in the neighborhood of \$135 per player, which includes golf, box lunch, buffet dinner and a tee gift. Please contact Jim Wilson if you are interested in having an event like this. Jim can be reached by email at jpwilson@hotmail.com or by phone at 972-931-9311.

FUNDRAISING

Santa Rosa Walk-A-Thon

Florence Sheffer of Santa Rosa, California, recently represented the PHA in a local walk-a-thon. This is an annual event staged by the Community Service Center. The Center keeps a portion of the pledges as payment for organizing the event. This benefits their operating budget and the individual charities the participants designate.

Florence had several sponsors contact her after she was required to turn in the official pledge sheet and raised over \$5000 with the help of family and friends!

Kipp Palmer Memorial Tournament 2001

Friday, June 15, 2001.

Lancaster, PA.

The Crossgates Golf Course in Millersville, Lancaster County, Pennsylvania, once again was the site of the only Pennsylvania PPH Tournament. It may lack in corporate sponsors but makes up for it with reunions, memories, family loyalty, and learning about the disease that took Kipp Palmer, who passed away on July 4, 1999, at Johns Hopkins in Baltimore.

Kipp's presence is felt throughout the course as each player swings—his 'foursome' of many years continues with a

new player. Kipp's wife, children, grandchildren, mother, sister, and nephew were on hand to have fun and to assist Kipp's close friend, Joel Langdon, the conference coordinator.

The tournament netted close to \$6000 and plans for another tournament and possible improvements are already under discussion for the following year. The 2001 tournament is over, but donations are still being given in Kipp's memory. If you are from the east coast, you might want to join in playing in next year's tournament.

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.

Robert W. Altendorf
Keith Badger
Edna Barge
Jean Battle
Hilda Budley
Shirley Cohen
George T. Deswein
Emilia Diaz

Susan Lynn Freeman
Lynn Hawthorne
Eluned Samuel
Gail Shaw
Kaye Schraedter
Gerald H. Wark
Val Ziegenhorn Woodruff



Kipp's children, Grant, Kimberly and Todd (l-r) were on hand to help and to enjoy the day.



Kipp's wife (center in black), and friends register participants for June 15 Tournament

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. Send 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 scraig@hal-pc.org
Houston, Texas 77092-3336

Deadline for the Winter issue is October 31, 2001.

NEWS AND ANNOUNCEMENTS

Julie Paton Hendry Memorial Scholarship

The Julie Paton Hendry Memorial Scholarship was established in 1998 to honor the memory of Julie, daughter of Pat and Jerry Paton, a dedicated PHA volunteer. The fund provides a scholarship to help a non-patient volunteer attend the PHA International Conference held biannually. Conference fees, hotel and travel up to \$1000 may be covered.

Non-patient volunteers interested in being considered for the Julie Paton Hendry Memorial Scholarship should send a letter describing their PHA voluntary efforts to Judy Simpson, Chair, 84 Bandy Drive, Holiday Island, Arkansas, 72631. Letters are due by December 31, 2001. The recipient will be named January 15, 2002.

News from Capitol Hill— FY 2002 House Appropriations Hearings

Pulmonary Hypertension Research Act of 2001 (H.R. 1297)

A new bill has been introduced that includes provisions relevant to the NHLBI. The Pulmonary Hypertension Research Act of 2001 (**H.R. 1297**) would provide for expansion of NHLBI pulmonary hypertension research and coordination of that research with similar activities of other NIH institutes and centers. <http://www.nhlbi.nih.gov/public/may01/newsitms.htm>

In addition to U.S. Representative Kevin Brady of Texas, who wrote this measure, U.S. Representative Lincoln Diaz-Balart of Miami, Florida, has agreed to co-sponsor the PH Research Act of 2001.

Now is the time for the PHA membership to support this measure. Please write your local congressperson and senators to let them know how important this measure is to all PH patients.

American Thoracic Society

The American Thoracic Society Public Advisory Roundtable selected Judy Simpson, R.N., as one of its 12 members. It is a new concept and the first public advisory group to a doctor's group. Judy Simpson is one of the founders of PHA and its first president. She continues to contribute to the PH community in many ways.

FDA Advisory Committee Recommends Approval of Remodulin for Pulmonary Arterial Hypertension

SILVER SPRING, Maryland, August 9, 2001—United Therapeutics (Nasdaq: UTHR) announced today that the Cardiovascular and Renal Drugs Advisory Committee of the U.S. Food and Drug Administration (FDA) recommended approval of Remodulin (treprostinil sodium) Injection for the treatment of pulmonary arterial hypertension by a vote of 6 to 3. The

"Medical Answers" Taping

Linda Carr, PHA president, has been invited by Actelion's PR firm to be part of "Medical Answers," a PBS TV show. The taping will take place in Alexandria, Virginia, on Saturday, July 21. Dr. Lewis Rubin of the University of California at the San Diego Medical Center is also appearing on the show. The topic will be pulmonary hypertension. It should air on most local PBS affiliates during PH Awareness Week in September.



(l-r) Dr. Lewis Rubin, UCSD Medical Center and PHA SAB member; Linda Carr, PHA President; and Dr. Brian Doyle, Georgetown University Medical Center and host of "Medical Answers". Dr. Rubin and Mrs. Carr met with Dr. Doyle to tape a half hour segment for "Medical Answers" all about Pulmonary Hypertension.

Persistent Voices

Persistent Voices is now under the guidance of Jerry Wojciechowski of California. Jerry and his wife are long-time PHA members and both are teachers. Jerry and Betty organized the first California PH Support Group and Jerry published a newsletter for its membership, the "Lung 'N Times." Jerry is eager to get PV back into regular publication. You can help by sending your personal PH story to Jerry along with pictures, poems, or quotes. Send your stories to:

Jerry Wojciechowski
24232 Chrisanta Drive
Mission Viejo, CA 92691
(949) 215-1573 (home)
(949) 215-1574 (fax)
wojoj@home.com

Advisory Committee's recommendation will be considered by the FDA in making its final market approval decision.

"We are very pleased that the Advisory Committee recommended approval of Remodulin," said Roger Jeffs, Ph.D., President and Chief Operating Officer of United Therapeutics.

(Continued on page 9)

Thank You...

Support for Pulmonary Hypertension Resource Network...

In early 1999, a group of nurses and medical practitioners came together with the idea that medical professionals treating PH patients could greatly benefit from a section within PHA designed to provide an exchange of information and the growth of fellowship in their community. By late 1999, this group of professionals, in cooperation with PHA leadership organized the Pulmonary Hypertension Resource Network ("PHRN") special group. So far a brochure has been written, an active electronic discussion group has been established and regional meetings have taken place.

PHA is very grateful and wishes to extend a sincere thank you to Carmen Skurdal at **Gentiva Health Services**. Thanks also go out to Mark Hansan and Nancy Pilcher at **TheraCom**. Their generous support will allow PHA to develop and maintain a vital member service.

PHA able to purchase Modern Database System...

To keep pace with the rapid growth demands that PHA is currently experiencing, PHA's board of trustees recently approved the purchase of a state-of-the-art database system. A hearty thank you goes to Michelle Florin at **Actelion** and **Genentech**, in a joint grant, for funding most of its purchase price. PHA's response time to member requests and PHA's ability to provide adequate recognition to donors and volunteers will be greatly enhanced through the database. This is especially critical as PHA increases the number of special events such as golf tournaments and fun runs. The system also plays an integral part in maintaining accurate financial records for PHA.

PHA Executive Director, Rino Aldrighetti, said, "We're very excited about this important new tool. In the midst of so many exciting things happening here at PHA, our inability to thank our donors properly has been a huge frustration. That is about to change."

Generous Gift to PHA made through Mary Linnen Memorial Fund...

Dispensing with the Truth, written by Alicia Mundy, is a new book about one of the landmark legal cases relating to the Fen-Phen tragedy. It is a story of truth and lies regarding what the drug companies and the FDA knew about Fen-Phen before its approval. It is also the story of Mary Linnen, who died of PH after taking the drug for a short time, and her attorneys, **Robinson & Cole LLP**, a Northeastern law firm. **Robinson & Cole** has recently made a generous donation to PHA in Mary Linnen's memory and through the Mary Linnen Memorial Fund. **Tom Linnen**, Mary's father and a PHA board member, has announced that the Mary Linnen Memorial Fund will match the law firm's gift by the end of this year. This gift follows an earlier one made by Amy Eskin and Nancy Hersh of the San Francisco law firm of **Hersh and Hersh**. **Hersh and Hersh** represented Candi Bleifer, PHA Board of Trustees member, in her Fen-Phen lawsuit.

...And, thank you to all our donors large and small who are helping PHA fund more research, provide expanded patient services and public education and awareness in our march toward the cure.

PHA Announces Formation of New Corporate Committee...

PHA welcomes **Actelion**, **Gentiva Health Services**, **GlaxoSmithKline** and **United Therapeutics** as founding members of our new Corporate Committee.

PHA has come to realize that, while we are dealing with many companies individually, the synergy of bringing together pharmaceutical and health care companies with PHA patient and medical leadership creates a powerful new dialogue to find areas where we can and should work together. Potential items for discussion with this new group range from the creation of a patient registry to advocacy on insurance issues to building awareness of the illness and better diagnosis within the broader medical community.

PHA is working hard to build a scholarship fund for the next PH International Conference...and beyond. These funds will be made available to PH patients and their families to pay for conference registration fees, hotel accommodations and travel expenses.

Do you work for a company or have contacts with a foundation that might be interested in helping?

If so, please contact Anita Blake at 301-565-3004 x110 or anita@phassociation.org

Research Update

By Lenna West, PHA Research Committee Chair

Pulmonary Hypertension research has become very exciting over the past year. We are currently finishing up our first year of PHA grants. Our first Pulmonary Hypertension researchers are finalizing their progress reports for the past year. As you recall, our first researchers and their projects were:

Rezaie Majd, Shahrzad, MD, VA Medical Center, Minneapolis, MN
“The Role of Neuroendocrine Cells in the Pathogenesis of Pulmonary Hypertension”

Manalo, Dominador, PhD, Johns Hopkins University, Baltimore, MD
“Role of HiF-1 in Mice in Regulation of Endothelin-1 Expression During Hypoxia-Induced Pulmonary Hypertension”

Benisty, Jacques, MD, Childrens Hospital, Boston, MA
“The Role of Angiogenic Growth Factors in Pulmonary Hypertension”

We wish them luck and hope to see their research published in the future.

This July 1, we offered three more two-year (2001–2003), \$35,000 grants to new applicants. I am pleased to announce that they accepted our grants. Our new researchers are:

Deng, Zemin, PhD, Columbia University, New York
“Genetic Studies of Primary Pulmonary Hypertension: Gene Identification and Mutation Analysis”

Bull, Todd, MD, University of Colorado, Denver
“Characterization of Circulating Endothelial Cells in Severe Pulmonary Hypertension”

El-Bizri, Nesrine, PhD, Hospital for Sick Children, Toronto
“Mts 1 and the Pathobiology of Pulmonary Vascular Disease”

Congratulations to our new researchers.

We are currently in the process of aligning ourselves with the National Heart Lung and Blood Institute with the NIH in a joint research grant for young scientists. This will be one five-year, \$162,500/year grant. We currently have several applicants and the review process will begin in October and the grant will be offered in March 2002. It will be activated July 1, 2002. So look for a new announcement next year for a young researcher with our new grant.

As you can see, our research programs have really grown over the past year. I think there are many exciting things to come in the future. We must not forget that we still need to support our current programs and hope for better treatments and possibly the “big dream” of a cure.

FDA Advisory Committee Votes Unanimously to Recommend Approval of Tracleer™ for Treatment of Pulmonary Arterial Hypertension

ALLSCHWIL, SWITZERLAND, August 10, 2001—Actelion Ltd. (SWX New Market: ATLN) today announced that the Cardiovascular and Renal Drugs Advisory Committee voted unanimously to recommend to the U.S. Food and Drug Administration (FDA) the approval of the oral dual endothelin receptor antagonist Tracleer™ (bosentan) for the treatment of pulmonary arterial hypertension (PAH). PAH is a life-threatening chronic condition that can severely compromise the function of the lungs and heart. While the FDA is not bound by the recommendation, it traditionally follows the Committee’s advice.

“We will continue to work closely with the FDA to ensure that we can bring Tracleer, the first oral therapy for pulmonary arterial hypertension, to patients in an expeditious manner,” said Jean-Paul Clozel, CEO of Actelion. “The FDA Advisory Committee recommendation validates our belief in the therapeutic potential of endothelin receptor antagonism.”

The Committee based their recommendation to approve Tracleer on two successfully concluded pivotal trials, the larger of which is known as the BREATHE-1 (Bosentan: Randomized Trial of Endothelin Receptor Antagonist THERapy) trial. BREATHE-1 principle investigator Lewis Rubin, MD, Professor of Medicine and Director, Pulmonary and Critical Care Medicine, University of California at San Diego commented: “We are nearing a milestone in the treatment of pulmonary arterial hypertension. For the first time, patients and their

families can have realistic hope that an oral treatment demonstrating very promising results may soon be made available.”

Actelion submitted a New Drug Application (NDA) for Tracleer in pulmonary arterial hypertension to the U.S. Food and Drug Administration in November 2000 and to the European Authorities in February 2001. Tracleer also is currently under review in Switzerland, Canada and Australia. U.S., European and Australian regulatory authorities have granted Tracleer Orphan Drug status in pulmonary arterial hypertension. The company is further studying Tracleer for children suffering from PAH, as well as the concomitant use of Tracleer in patients who receive intravenous prostacyclin therapy.

Actelion Ltd., a biopharmaceutical company headquartered in Allschwil/Basel, Switzerland, is a leading player in creative science related to the endothelium—the single layer of cells separating every blood vessel from the blood stream. Actelion concentrates on developing and bringing innovative drugs to patients. Tracleer™ and Veletri™ are in development for several cardiovascular disorders, including chronic and acute heart failure as well as pulmonary arterial hypertension. In addition, Actelion is conducting drug discovery programs in cardiovascular diseases, malaria, Alzheimer’s disease and cancer. Actelion is quoted on the SWX Swiss Exchange (SWX New Market: ATLN).

PHA to Award Conference 2002 Scholarships

Adult pulmonary hypertension patients traveling with or without a significant other who plan to attend the 5th International PH Conference to be held in Irvine, California, in June 2002 may be eligible for financial assistance through a limited number of scholarships to be awarded by PHA. (Children with PH will be supported through a separate scholarship program to be announced soon.) 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). Since the amount of funds available for scholarship grants are limited, careful consideration will be given to need. A minimum co-payment of \$25 toward patient costs to attend and \$25 for the companion's conference expenses will be required. Typically, a cap of \$1,000 to \$1,500 will be applied for each patient and companion requesting full support, depending upon travel distances.

Scholarship granting decisions will be governed by the following procedures and selection criteria. To apply, a patient should send a written statement 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.

All applicants must be PHA members.

Special consideration will be given to patients who have been recently diagnosed and those who have not received financial assistance to attend an International Conference in the past. However, all patients who have need of support but are unable to secure help from other sources are encouraged to apply. Scholarship monies will be used to provide help to as many patients as possible requiring assistance. All applicants will be notified by February 15, 2002, about scholarship awards.

Upcoming Events

Long Island Support Group Fund Raiser

NEW YORK: The Long Island Support Group is planning a fundraising luncheon with a silent auction for October 28, 2001, at the Douglaston Club, 600 West Drive, Douglaston, New York, 11363. Guest speakers will include Rino Aldrighetti, PHA's Executive Director. The Long Island group is asking for help, especially with items for the silent auction such as tickets to theatre or sporting events, restaurant gift certificates, jewelry, crystal, vacation lodges, etc. Please call or email JoAnne Schmidt with any questions at 631-427-4586 or joanne64@optonline.net.

First Annual Run for PH

The First Annual RACE FOR PH, a four-mile walk/fun run, will take place on Sunday, October 28, 2001, at Lake Merced in San Francisco, California, and will start at 9 a.m.

Friends and family of Patti Ewing have come together to organize the first RACE FOR PH.

More information can be found at the following website www.raceforph.org. To register, go directly to our event page at http://www.active.com/event_detail.cfm?event_id=963202. Feel free to contact us should you need any more information.

Katie Ewing—Katie@raceforph.org—650-255-2071
 Paige Dunn—paige@raceforph.org—310-422-4279
 Eddie Davis—eddie@raceforph.org—408-218-0628

FDA Advisory Committee Recommends Approval of Remodulin for Pulmonary Arterial Hypertension... *(continued from page 6)*

"We refiled the Remodulin New Drug Application this afternoon and we look forward to working with the Agency in the coming weeks to finalize the labeling."

Data was presented to the Advisory Committee by Stuart Rich, M.D., Professor of Medicine and Director Rush Heart Institute Center for Pulmonary Heart Disease at Rush Presbyterian-St. Luke's Medical Center, and Robyn Barst, M.D., Professor of Pediatric Cardiology and Director, Pulmonary Hypertension Center, of Columbia Presbyterian Medical Center. Drs. Rich and Barst were members of the steering committee for the Remodulin trials and are leading U.S. experts in the highly-specialized field of pulmonary hypertension.

Over 500 pulmonary arterial hypertension patients worldwide continue to use Remodulin in open label studies sponsored by United Therapeutics. Remodulin is administered subcutaneously via an infusion device developed by MiniMed, Inc. (Nasdaq: MNMD). In anticipation of final FDA approval of Remodulin, United Therapeutics entered into drug distribution partnerships in the United States with two companies: Priority Healthcare Corporation (Nasdaq: PHCC) and Gentiva Health Services, Inc. (Nasdaq: GTIV). United Therapeutics has also formed Remodulin distribution partnerships in Europe, Canada, Australia, South America and Israel. United Therapeutics also has a marketing application under review in France and expects action toward the end of this year. Additional international filings will occur upon approval in the U.S. and France.

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If roses grow in Heaven, Lord,
 please pick a bouquet for me.
 Place them in Susie's arms
 and tell her they are from Georgi.

Tell her that I love and miss her,
 and when she turns and smiles,
 place a kiss upon her cheek,
 and hold her for a while.

Remembering her is easy,
 because I do it everyday. But Lord,
 there's an ache within my heart
 that will never go away.

I miss you "Susie" and
 love you so very much.

—Author unknown,
 modified for Susan Freeman

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