



# Pathlight

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

Summer 2001  
Volume 10 • Number 2

## Mark Your Calendars for PH Awareness Week 2001: September 15–23

PH Awareness Week is just around the corner. And what an Awareness Week this will be! From Cure PH golf tournaments to Pizza-in-a-Box fundraisers and much more. Major events are being scheduled in and around the 50 states and we hope that each support group will be eager to sponsor an event, big or small, as well. The more events we can schedule, the greater the level of awareness we can create.

PH Awareness Week 2001 will be focusing, once again, on getting the word out in the local community. PHA staff is ready to assist support group leaders and members with planning outreach through local area schools, through hospitals, libraries, and to state governments and legislative bodies. As the momentum builds at the local level, PHA staff will encourage national media to focus on several of the larger events around the country. PHA now has more than 50 support groups around the country. If each one of these undertakes a single awareness program which results in just one local newspaper article, just imagine the impact we can have in making early diagnosis for new PH patients a reality. This will make it possible for many more people to have the opportunity to get the help they need, like the woman who read the article about board member and patient, Candi Bleifer, in the *Torrance (CA) Daily Breeze*, and on the basis of the information provided in that article was diagnosed

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## PHA Advocacy Brings Big Rewards to the PH Community

The Pulmonary Hypertension Act of 2001 was introduced in Congress by Representative Kevin Brady (R-Texas) on March 29, 2001. This is the second consecutive year that such a bill was introduced. Last year, introduction of a similar bill resulted in increased dollars to NHLBI (National Heart, Lung, and Blood Institute) and first-time money for PH going to the CDC (Centers for Disease Control). Over the last two years alone, money for the NHLBI research portfolio has gone from approximately \$12 million to \$18 million, an increase of 50%. PHA is very fortunate to have Representative Brady in our corner, and we anticipate that this year's efforts will open the door to even more funding for NHLBI for PH research and funding for CDC for a public and professional awareness initiative about PH.

In conjunction with Congressman Brady's efforts and working with our new lobbyists, PHA submitted testimony before the House and Senate Appropriations Committees to request additional funding in the FY 02 budget for both NHLBI and the CDC. This has provided greater opportunity for PHA and its members to make their needs and concerns heard by people with the power to make changes for the benefit of the PH community.

In addition, with the assistance of Congressman Brady, PHA was able to meet directly with the leadership from the CDC. At that meeting we began a dialogue that will help shape a memorandum of understanding and a partnership to accomplish

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## PHA Launches New Web Site

Have you visited PHA's new web site lately? It has a brand new look, and thanks to Priority Healthcare, a brand new section, PHNeighborhood, you won't want to miss! Check it out at [www.phassociation.org](http://www.phassociation.org). Take a minute to register and become a member of PHNeighborhood too, so you can access all the new information available.

## Houston PH Golf Tournament

Excerpts from the *Conroe Courier*, April 23, 2001  
 “Cure PH Fund Raiser” by Michael Moore  
 and the *Woodlands Online* “Cure PH Benefit A Success”



When Jack Stibbs finished cleaning up after the third annual Cure PH Golf Tournament and “Wine and Roses” gala in March, he knew the event was a success. But it wasn’t until all the checks recently

finished rolling in and a gross total had been established that Stibbs realized just how successful it had been.

More than \$190,000 was raised by the Cure PH Golf Tournament and Gala, which will be used to help fund research efforts toward finding a cure for pulmonary hypertension, a rare disease of the heart and lungs. “It was an overwhelming success,” said Stibbs, national officer of the PH Association. “People were incredibly generous this year.”

Approximately 219 golfers and 330 supporters turned out for the golf tournament and gala, respectively. Stibbs said he never expected the events to be this successful. “I thought it was going to be a softer year because of the shakiness of the economy,” Stibbs said. “But in fact, it looks like we’ll net more than we did last year.”

The golf tournament, held March 29 at Cypresswood Golf Club, featured a golf clinic by Mark Steinbauer, director of golf at The Club at Carlton Woods. The winning golf team included Darwin Barnett, Scott Vicknair, Mitch Vicknair, and Steve Sanders. The golf outing wrapped up with a buffet by Carraba’s with a lively golf raffle.

The elegant auction gala, which was held the following Saturday at the Westin Oaks Galleria Hotel, featured a “Wine and Roses” theme inspired by Larry Blanton, owner of ImageSetters and his newest venture, the Spring Creek Winery.



Serving as Honoree at the gala was U.S. Representative Kevin Brady, R-The Woodlands, who has tirelessly adopted the PH cause as a priority on his legislative agenda. He has been instrumental in increasing the research money for PH through the National Institute of Health (NIH) and establishing a joint venture with NIH and the Pulmonary Hypertension Association to leverage public research funds. In addition, he has sponsored the Pulmonary Hypertension Research Act of 2001 in the House of Representatives to secure supplementary research funds. Congressman Brady also spearheaded successful efforts to have \$1 million dollars in the budget of the Center for Disease Control earmarked for educating physicians on the symptoms and diagnosis for PH. “Kevin Brady’s work has been critical,”

Stibbs said. “The focus that he has put on this and other rare diseases in Washington really made people aware of the plight of the rare disease in this country.”



Lindsay, Hannah ready to play

## PHA Well Represented

Linda Carr, PHA president, attended the event in Houston with her daughter. Hannah (14) has been on Flolan for seven years and wanted to play in the tournament. Linda commented, “Although the golf tournament had a wet start, it turned out to be a good day for hitting the ball. All who stuck around to play had a great time. One of the most touching things that happened involved Deb Wilson and Marcia Stibbs. One of the local Christian radio stations was doing their morning broadcast from the golf course. A lady driving down the highway heard the broadcast and turned around and came to the course. She started asking whom she could talk to about PPH. Seems her grandmother in Kansas has recently been diagnosed with PPH and the granddaughter had not been able to find out anything other than the scariest stuff you read on the Internet when you do a search on the disease. She was able to talk with Deb (PH) and Marcia (daughter with PH). They gave her encouragement that she was not alone in her quest for information and were able to give her the phone numbers and information on the resources available to find out everything that she needed to know. Shelly, one of the volunteers, is sending her a complete package of information about PHA and PPH. Talk about a testimony to Awareness!”

## A Family Affair

Jack Hudson, proud grandparent of Emily, Lisa, and Jake, has a talent—he is a wood carver. Emily was diagnosed with PH a few years ago. So, for the past three years, Hudson has carved wooden trophies depicting old-fashioned Scottish golfers in plaid golf attire to present to the winners of the Cure PH Golf Tournament. Hudson carves eight trophies for the tournament each year. Emily’s parents, Jack and Marcia Stibbs, were frustrated at the lack of research for PH and established the Cure PH Foundation and began the golf tournaments in 1999.



Winning Team!! First Place

## NEWS AND ANNOUNCEMENTS

## California PH Forum

San Diego, California, will again be the site for the California PH Forum. It will be held at the Holiday Inn San Diego Bay Side on the weekend of June 23–24, 2001. Space is limited so call the Holiday Inn for reservations (1-800-662-8899) specifying that you will be attending the PH Forum. Hotel rooms are \$119 per night. Dr. Richard Channick and Dr. Ronald Oudiz are expected to present programs on such topics as diet drugs and catheter care. Alternative therapies will be covered as well. Conference registration will be \$90 at the door; \$85 by June 1; \$80 by May 15. Call or email the following for more information and to receive a flyer and registration form. Judy Vucci at 415-884-9062, email [vucci@aol.com](mailto:vucci@aol.com); Toni Fourte at 650-968-7418, email [LadyT2000@att.net](mailto:LadyT2000@att.net); or Rita Grounds at 925-552-7824.

## PHA Board Meeting

The PHA Board is meeting for strategic planning and a business meeting in Irvine, California, on June 15–16, 2001. Please contact Linda Carr to reserve seating if you wish to attend the business meeting. 305-888-4254 or [CarrMiami@aol.com](mailto:CarrMiami@aol.com).

## FUNDRAISING

### Dallas Golf Tournament

Volunteers at the 2000 Dallas/Ft. Worth “Cure PH” golf tournament proudly wear the official periwinkle volunteer’s T-shirts. Over 40 family, friends, and medical caregivers supported PH patients Debbie Wilson, Patty Holt, and Wynde Mobley by acting as marshals, auction coordinators, and performing the myriad other jobs necessary to host a successful golf tournament.

Major corporate team sponsors included Glaxo Wellcome, Sims Deltec, Gentiva, and Texas Biotechnology. Actelion provided logo hats and golf balls for each golfer and committed to sponsoring logo hats for all future Cure PH tournaments. The Dallas event drew 72 golfers and netted \$19,200 of the over \$181,000 raised for research by the four Cure PH golf tournaments held in 2000.



## Upcoming Events

Golf tournaments have been scheduled for the following dates in these areas.

- June 15—Lancaster, Pennsylvania  
(Kipp Palmer Memorial Tournament)
- June 18—Calgary, Canada
- September 17—Leesburg, Virginia
- October 1—Dallas, Texas
- October 26—Miami, Florida

Look to the PHA web site for more details about the wonderful events that are being planned. Go to [www.phassociation.org](http://www.phassociation.org) and click on Calendar (on the right) to get more information about these events. Or you can contact Jim Wilson, PHA’s special events coordinator by email at [jpwilson@hotmail.com](mailto:jpwilson@hotmail.com) or by snailmail at 6314 Riverview Lane, Dallas, TX 75248. Phone: (972) 931-9311. Fax: (972) 931-8616. Jim is ready to help you with planning any of your fund raising activities. He will answer your questions regarding use of the PHA tax-exempt ID number, administrative, and other organizational questions. He can keep track of the events, post them to the web page, and keep them updated. Jim has available the Golf in a Box kit that gives step by step instructions for organizing a charity golf tournament. Jim is currently working with members organizing a fun run that you will read about in the next Pathlight.

## Dinner Dance

On September 7, 2001, Dr. McGoon, Cathy Severson, Louise Durst, Susan Tointon and families will host a dinner/dance at the Radisson Hotel in Rochester, Minnesota, and a raffle. All proceeds will go directly to PHA’s patient support efforts. We are proud to promote this cause and hope you will consider joining us to have a great time for a great purpose. For more information, please contact the Pulmonary Hypertension Clinic

## New Board Nominations

The PHA Nominating Committee is accepting suggestions for nominations until September 15 for new members to the PHA Board of Trustees to be elected in November. The new members will start in January of 2002 and will serve for three years. In particular, we would like (but it is not required) new board members with a background in business, finance, accounting, or fundraising. Board members must be willing and able to travel to two meetings per year. Please send your nominations with a short biography to Candi Bleifer, 4381 Lemp Avenue, Studio City, CA 91604, or by fax to (818) 753-9724 or by email to [candibleifer@earthlink.net](mailto:candibleifer@earthlink.net).

## Cousins with PH

*My Story about my PPH*

By Cheryl Tharp

It all started in 1997. At 42, my cousin Deb Sampsel got real sick after she had her baby. She was having a hard time with breathing. She started to swell up in her legs, face, etc. Then she started turning blue. She was going to doctors, hospitals, and emergency rooms. Then, they finally sent her to a major hospital and did a lot of testing and found out she had this disease called pulmonary hypertension—high blood pressure in her lungs. So they sent her to a special doctor in the Cleveland Clinic who was working with this disease. Well, she had to have numerous things done and she would be on a medicine called Flolan. Wow, she had to mix her own meds and wear a pump and just do all sorts of things to keep well.

Well, I helped her out by taking her meals and visiting her and doing my part to help. Everyone was just wonderful to her. Her first year was a real trial with infections and her catheter falling out. She was in the hospital quite a bit then she started getting along better after her year was up.

In 1999, my job shift changed and I went to first shift. I was always on the night shift but decided it was time for a change. When they asked me to go days, I said, “Yes.” After a few months of being on days, I started feeling tired all the time and blamed it on the shift change. Then I started getting this fullness in my stomach and when I would bend over, I felt like I would explode.

A couple of months passed and I was having a hard time walking out to my car at the end of the shift. By the time I got there, I would have to sit for a while just to catch my breath and for my heart to stop pounding before I could go anywhere.

Things started getting worse so I went to my family doctor who said it was asthma and allergies. She gave me inhalers to use and other meds. Then it started getting worse and I went to the emergency room. They did EKGs and chest x-rays. My doctor said that my EKGs had not changed in 25 years so she sent me to a pulmonary specialist. He said, “Yes, I did have asthma.” Then I went to the ER again and he ordered an echocardiogram. He called me to come to his office the next week where he told me my echogram showed my pulmonary pressures to be 84 and that he was sending me to see Dr. Schilz because he thought I had PH. Well, I cried—I knew what it was from my experiences with Deb.

So now, they do the echogram in Cleveland and my pulmonary pressures are 97 so they scheduled me for a heart cath and to put in my cath for Flolan. My heart cath showed my pressures to be 137 and they had a very hard time. They lost my BP that night and it was a touchy subject for 24 hours—then the Flolan started kicking in and I started feeling much better. They told me that there was only one other person that had a pressure higher than that and it was a boy whose pressures were 145. They were surprised I lived long enough to even make it to try



Deb and Cheryl

the Flolan. But God wasn't ready for me yet.

It has been almost a year now—I will be going in February 5 for a heart cath to see how my pressures are after being on the Flolan a year. I had a rough year also with infections; my cath not being in right and I wasn't getting my Flolan. But now I am pretty stable and am able to do housework and sewing and reading. I had to quit my job because it was too hard on me. So I filed for disability and started getting it so I am a housewife; something I never got to be full time and it's great. Plus, I have three grandchildren and I try to see them as often as I can.

Life is different now, but it is not bad. I pray a lot and thank God every day for giving me another chance at being a wife, mother, and grandmother. I am not angry because it got me, and I am thankful I have Deb when I need her and she's got me if she needs me. I just hope and pray that they come up with a cure soon.

### PHA Advocacy Brings Big Rewards to the PH Community

*(continued from page 1)*

the education and awareness initiative as intended in the appropriations bill. Language in support of this initiative will be included in this year's appropriations bill as well. An advocacy campaign to support the increase in appropriations for both of these agencies is planned to help insure that money continues to flow to NHLBI and the CDC for the programs PHA develops in partnership with these agencies. More information about this will be found on the PHA web site.

Now the time is right for PHA members to support our efforts by requesting additional funding for NHLBI and the CDC in this year's budget. PHA members can contact their congressman and request that money be included in the FY 02 budget for PH research at the NHLBI and for an ongoing public and professional awareness program through the CDC. You can find out who your Congressman is and how to contact him or her quite easily on our new PHA website by going to [www.phassociation.org](http://www.phassociation.org), clicking on Awareness & Advocacy, then on the box “Find Your Congressman.” That link will take you to a site where you can confirm the congressional district in which you reside and who your Representative or Senator is. If you have any questions about how to do this, you can request assistance from [Lorie@phassociation.org](mailto:Lorie@phassociation.org) or call Lorie Simmons, PHA Advocacy and Awareness Director, at 301-565-3004 in the PHA offices.

At gala, Marcia and Jack receiving PH Bill from Representative Kevin Brady (R-Texas)



Bonnie's parents and siblings, Brian, and I would like to thank PHA and the PH community for the wonderful tribute to Bonnie in the previous issue of Pathlight. The articles and comments were very moving. We would also like to thank everyone that sent us notes and made contributions to PHA in her memory. We appreciate your words of support at this difficult time and your contributions that will enable PHA to move forward with Bonnie's plans to increase organ donor awareness and help educate PH patients about transplant issues. The work that PHA does was so important to her. The Bonnie Dukart Memorial Fund will allow Bonnie to continue to help the PH community, truly a fitting tribute to an amazing person. It is comforting for us at this time of loss knowing that this is part of the legacy that Bonnie left.

Sincerely,

Gary Dukart

## Patient's Guide Almost Ready!

COMING This Summer—the newly revised *Patient's Guide to Pulmonary Hypertension*, Second Edition.

- Including the latest information
- Written by Gail Boyer Hayes
- Reviewed by PHA's Scientific Advisory Board
- Now more than 200 pages

Publication will be announced at [www.phassociation.org](http://www.phassociation.org) and in the next *Pathlight*.

## Special Bulletin for Flolan Users

In the past few weeks, television ads have been running in various U.S. markets asking anyone on Flolan to call a certain number. This paid advertisement appears to imply that there is a danger to being on Flolan. Many of you who saw this ad called the number and the PHA offices. This seems to be a round about way of "flushing out" former phen-fen users so that this lawyer can seek to be a legal representative for these PH patients. Both Glaxo Wellcome and PHA are aware of this ad. PHA sent a letter to this lawyer asking that he please change the message in his ads so that the ads do not continue to create stress for Flolan users. This law firm has since responded to PHA's letter and said that they realized that their language was a mistake and that language has been changed to clarify that Flolan and UT-15 are effective treatments.

## PH Awareness Week 2001 (continued from page 1)

with PH, provided with the proper treatment program, and able to attend a support group meeting all within a matter of weeks.

So what is in store for this year? First, it will be easier than ever before for anyone who wants to run an event or get the attention of the press to do so. PHA is developing a CD, "All About Pulmonary Hypertension." In addition to providing information about the disease (symptoms, diagnosis, how it affects patients, potential available treatments), this will be a tool that will make it easy to bring information to a local government leader or the local press. For the event planner, it will contain model press releases and most of the tools you need to run an Awareness Week special event. All the information will be quick and easy to access and simple to understand for the planner and for anyone who is in need of information about PH.

As Awareness Week draws closer, PHA staff will be looking to PHA members and support group leaders to help make this the most effective Awareness Week ever. If you have questions about PH Awareness Week, contact Lorie Simmons at the PHA office at 301-565-3004, or send them by e-mail to [Lorie@phassociation.org](mailto:Lorie@phassociation.org).

Please contact Lorie Simmons if:

- you are planning or are interested in planning an Awareness Week event and have any questions about the planning process or the event itself.
- there is an event in the works. PHA needs to know the type of event, time, and place information so we can post it on our calendar on the PHA website.
- you are willing to do an event but are looking for ideas or need help in planning an event.
- an event is too great an undertaking, but you are willing to participate in a smaller outreach initiative or would like to create a PH press opportunity in your local community.

## A Great Idea: Wedding Favors!

Robyn Telep was devastated when she was diagnosed with Primary Pulmonary Hypertension—a physically and emotionally draining situation for someone who was only 19. After following several avenues of research and treatments, she felt fortunate to find Dr. Barst at Columbia Presbyterian who put Robyn on the then experimental drug, Prostacyclin. Seven years later, Robyn is leading a full life and is looking forward to a prosperous future.

Robyn wrote the PHA offices with a request and a check for 250 PH Awareness Pins that she will give to her wedding guests as favors on her wedding day on May 12, 2001. Congratulations, Robyn, and best wishes to you and your groom! What a great idea!

## ACCESS

For free assistance with question about Social Security disability benefits and/or insurance, call ACCESS at 1-888-700-7010.

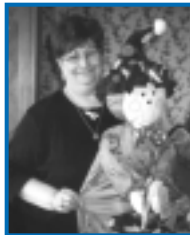
## Minnesota Metro Area Pulmonary Hypertension Support Group is Up and Running...

By Stephanie Layer and Cindy Wangerud

Minnesota's Metro Area Pulmonary Hypertension Support Group had its first successful meeting on February 24, 2001. Despite a nasty snowstorm, there was a great turnout of PH'ers and their family members. Our second meeting was March 31, 2001, at Old Country Buffet Restaurant in Maplewood, MN, where a tremendous amount of PH'ers and family members attended. Both were a complete success. At the first two meetings, everyone greeted each other and shared stories and experiences. Patients being treated with both Flolan and CCBs attended as well as recently diagnosed patients looking for hope and answers. We even had one member that has had PH for 28 years and this was the first time she had met another patient! At our first meeting, Gentiva Representative Bethann Marka, who helps us quite often, was present to meet the patients and families and help answer some questions. We received many ideas and plans for future meetings. Everyone is very excited about getting together. Our main objective is total support for patient, family, and caregivers. Together we give strength, knowledge, and hope to face this horrible disease. No one ever has to deal with PH alone, it is a "we" disease.

Stephanie Layer of Maplewood created a wonderful clown to help lift our spirits in times of need. She named her clown PLENTY HUGS (PH). The purpose of Plenty Hugs is to provide comfort and hugs in time of need for anybody in our group. We plan to send Plenty Hugs to the hospital if any of our members are admitted or if somebody needs some extra support at home, Plenty Hugs will provide it. Each month, somebody different will sign up and take Plenty Hugs home with him or her. Stephanie also has created many PH Awareness Ribbons that she hands out at our meetings.

Marilyn Manor, a Gentiva nurse, will be speaking about Remodulin during our April 28 meeting which many people are interested in hearing about. ACCESS will be speaking at our May meeting regarding disability, Social Security, and insurance. We are also hoping to pull together a wonderful summer picnic. We would like to take this time to thank Gentiva for all of the help they have given us getting our meeting letters out to the PH patients and all the help they give us during meetings. Also, I would like to give a special thanks to Kathy Minnema of the University of Minnesota who distributes our meeting letters to new patients. If anybody is interested in attending one of our meetings, please contact Cindy Wangerud at 763-757-4608.



## Tips to Help You Through Your PH Day

Submitted by PH Friends list serv and others with experience

### Bathing/Hair Washing/Showering

I used to be able to do the shower, blow dry, curling iron everyday. Now I shower at night and go to bed and then curl my hair in the morning and I do this every other day. I just let my hair air dry. This was one of the things that told me I had better really cut back on activities. I really have to plan if I want to go somewhere special and look my best and have energy. I also find I can now fall asleep anywhere, airports, taxis, my mother-in-law's, this just astonishes me!—*Pip*

This used to bother me very much, but now I have it down to a fine art. I shower at night. I cover my site with a dressing called Airstrip, basically it is a giant bandage. I use two or three, cut them in half, and put them directly over my dressing at the site. Because my sister is an ob-gyn nurse and this is what they use to cover c-section scars after having a baby. I just put them on and take a shower as usual, but I try to do it fast and not spend too much time with the water directly on my left side. The pump, of course, stays outside the shower.

After I finish, I change my dressing, taking off the big bandage all at once, it usually pulls off the other dressing underneath. I change my dressing and I'm off, since the process takes a good hour and 15, I do it at night and take my time.—*Mel*

One helpful accommodation was to get a hand-held shower hose. But the primary change is that I do not shower every day and I wash my hair twice a week. I hate it.—*Carol A.*

I basically shower once a week when I change my dressing, which we were taught to change once a week. So, I take baths. I even burn candles in the tub to really relax. Then I just wash my hair every morning in the sink.—*Cindy*

Starting the day with a shower, shampoo, etc., used to be a pick-me-upper. It left me raring to go. Then, I came to realize that it is not only the energy it takes (shampoo days leave me like a limp dishrag), but the water temperature that greatly affects how I feel afterward. No more hot baths for me. It acts like a sauna and elevates blood pressure, etc., critically. Even a warm bath leaves me flushed and ill.

I recently discovered though that if I give myself a cool-down at the end it really helps all the symptoms. I could not stand a cold shower or bath but finish up by running cold water over my feet and ankles and splash my legs for a while. You can actually feel the cool-down effect it has on your system. The recovery rate after the bath is not near as long.

I also have limited those once-daily refreshing, relaxing baths/showers. Of course, all activities of daily living are now limited—cooking, laundry, etc. Sometimes I get so excited over

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## PHA's Scientific Advisory Board

After careful consideration of many qualified applicants, the SAB announces four new members to its Board and extends its deepest thanks to those whose terms have expired. Dr. Bruce Brundage of Bend, OR; Carmen Skurdahl, RN, BSN, Edgewater, MD; Dr. Al Fishman, Philadelphia, PA; and Dr. Diane Zwicke, Milwaukee, WI. Both PHA and the SAB appreciate their expertise, dedication, hard work, and contributions during their years of service. Dr. Fishman and Dr. Brundage (who remain on the PHA board) have been appointed as SAB members emeriti.

The new members are:

*Trish Eells*, Certified Pediatric Nurse Practitioner, Coordinator for the Pediatric Heart Lung Center, The Children's Hospital, Denver, Colorado

*Horst Olschewski, MD*, Justus-Liebig Universitat, Giessen, Germany

*Norbert Voelkel, MD*, University of Colorado Health Sciences Center, Denver, Colorado

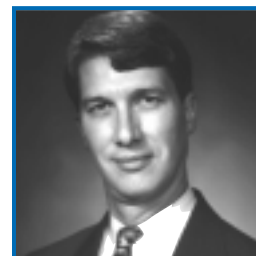
*Allison Widlitz, PA*, Pediatric Cardiology, New York Presbyterian Hospital, New York, New York

## New SAB Chairman and Vice Chairman: Their Own Words



**Dr. C. Greg Elliott,  
Chairman**

Newly appointed SAB Chairman is Dr. C. Greg Elliott of the LDS Hospital at the University of Utah, Salt Lake City, Utah.



**Dr. Michael D. McGoon,  
Vice Chairman**

Dr. Michael D. McGoon at the Mayo Clinic in Rochester, Minnesota, fills the newly created Vice Chairman position of the SAB.

I first heard about PHA before the first conference in Stone Mountain early in 1994. I had a long-standing interest in pulmonary hypertension, having been the principal investigator for one of the original NIH Registry for PPH sites. I was particularly interested in the genetics of PPH, and in particular the idea that many patients with PPH had an inherited predisposition to this disease. I saw an opportunity to advance our understanding of PH at the conference by educating patients and families and by collecting specimens. I called Ed Simpson to ask if anyone had proposed for research to be done at the meeting. He said no, and then checked with the board who thought this was a good idea. We participated actively in the first conference (and subsequent conferences) by helping to educate patients and their family members about ongoing research, and by collecting blood specimens to bank and store DNA for subsequent studies. The human side of PH has always touched me. I felt a need to serve others and supporting PHA is one way that I can fulfill that commitment. I have been at the LDS Hospital and the University of Utah since 1980. My research continues to focus on the genetics of PH as well as in clinical trials of new therapies such as Bosentan and UT-15 (Remodulin). I was an undergraduate at Brown University, MD, then the University of Maryland School of Medicine and my Fellowship was at the University of Utah.

My first awareness of PHA came through one of my patients who was a founder, Pat Paton, and the Simpsons via my nurse Cathy Severson. Multiple factors led to my affiliation with PHA as it is my belief that PHA provides the milieu to accomplish numerous objectives simultaneously. These range from solidifying collegial professional relationships; having a formal venue for discussing clinical and research issues; promoting education (both learning and teaching); gaining and giving insights about political, socioeconomic, and emotional issues involving PH; promoting medical and societal awareness of PH; and perhaps most especially having the opportunity to gain the unique insights that come from interacting as people rather than purely as practitioners and patients.

I've been at the Mayo Clinic since 1979 when I came for cardiology training. I went on staff in 1983. The Pulmonary Hypertension Clinic (PHC) began in 1996. We have been involved in the Flolan studies with PPH and secondary PH, UT-15, Beraprost and Bosentan. We are currently studying the effect of a drug called CI-1034. We will be involved in clinical studies of Sitaxsentan. We enrolled into the SOPHIA registry. Members of the PHC have special research interests in portopulmonary hypertension, neurohumoral profile of pulmonary hypertension, and right ventricular function. We are preparing to study special ways to continuously monitor pulmonary hemodynamics. I was an undergraduate of Harvard College in 1973, then attended Johns Hopkins School of Medicine in Maryland in 1977.

### Save the Date!

Fifth International Pulmonary Hypertension Conference  
June 21-23, 2002 ■ Irvine, California  
Details in next Pathlight

**Tips to Help You** (continued from page 1)

a yummy cookie recipe, etc., but then comes the reality check. What a life, but then, I thank God there is a life to complain about.—*Martha*

I too must confess to showering and washing my hair only twice per week...on Mondays and Thursdays when I change my batteries and extension line. I always plan to take a nap in the afternoon also; otherwise, I'd never make it through the day. Long ago, my husband installed a hand-held shower for me, so on the other five days I take a "bottom shower." And I use very tepid water...never hot. Picture this: Flolan pump hanging on the towel bar, and off my chest, O2 cannula in my nose and the shower wand in my hand.—*Shirl*

When I was first diagnosed with PH in 1986, my cardiologist told me not to do anything strenuous. I asked him to define strenuous and the three things I remember most are:

**DON'T RAISE YOUR HANDS ABOVE YOUR HEAD!**

This is very strenuous to us and that is why we have a difficult time washing hair, etc. I get perms so I no longer have to blow dry or curl my hair. I also wear my hair short. When we had a respiratory therapist talk to us about oxygen at our last support group meeting, she did mention that bathing was very strenuous and we should always turn up our oxygen. So, if you are on oxygen and you remember, turn it up. I find drying my hair with the towel after my shower is very strenuous, too.

The other two things that come to mind are not to bend over, which we all find difficult and also not to lift over 10 pounds. I'm sure glad my oxygen and nitric oxide tank only weigh about four pounds each.—*Pat K.*

A few years back before I started UT-15, my showers were becoming more and more difficult until a good friend bought me a shower seat. Using my hand-held showerhead, I was able to sit and do a complete shower from head to toe. I would also towel dry while seated as well. A 10 to 15 minute rest at this point and I would be ready to dress and continue my day. As my hair will usually stay fresh for three days, I often do a "hip bath" using a wash cloth with soap and water applied to all the necessary areas. Then, I apply my roll-on deodorant in areas that tend to chaff.

—*Shirley*

**Flolan Gel Packs**

Larry Moody found a material known as Reflectix™ that insulates the gel packs in his wife's Flolan pack. Reflectix™ keeps the gel packs colder longer while protecting her hip from becoming chilled as well. This material is sold in building supply stores, but Larry will send you a supply precut to fit the Flolan case. Mailing him a SASE with 55-cent postage is optional but appreciated. Larry & Karen Moody, (lmoody@pa.net) 7 Fox Hollow Lane, Carlisle, PA 17013.

Use a larger gel pack at night. You can sleep longer without worrying so much about thawed packs. We found some Rubbermaid® Blue Ice® 7"x5" gel packs at Wal-Mart® for about \$1 each (some other stores also carry them). They have

more gel in them than the large packs provided to us by Gentiva®. At first glance, they appear to be too large. And they are too large...Just fold one end over, pushing all the gel into one end, and freeze them. The heavier gel packs aren't a problem when the pump is sitting on a table beside the bed. Go ahead. Sleep late tomorrow morning!

For those intermediate outings when you know one pair of gel packs won't last long enough, and you don't want to drag around an ice chest, consider the following. We found a small insulated flexible lunch bag (Wal-Mart again) that we lined inside with more Reflectix™ insulating material (same as the pads). It easily holds six to eight of the regular gel packs. The four on the outside keep the packs on the inside solidly frozen until needed. Easy and quick. No muss, no fuss!—*Larry Moody*

**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.

- |                   |                  |                    |
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**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 sraig@hal-pc.org  
Houston, Texas 77092-3336

Deadline for the Fall issue is July 31, 2001.

**D I S C L A I M E R**

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.

## RESEARCH CORNER

*From Sean P. Gaine, MD, PhD, at The Mater Hospital, Dublin, and Traci Houston-Harris, RN, MS, at the Johns Hopkins Hospital, Baltimore.*

Welcome to Research Corner. There have been a number of very interesting research developments since the last “Corner.” Perhaps the most topical is the preliminary results of the endothelin antagonist (Bosentan) study in pulmonary hypertension which will be presented at the International Society of Heart and Lung Transplantation meeting in Vancouver in late April. We hope to have a report on that meeting and the Bosentan study and a discussion of how and why endothelin is important in pulmonary hypertension in our next “Corner.”

### 1. Abnormal Pulmonary Artery Pressure Response in Asymptomatic Carriers of Primary Pulmonary Hypertension Gene

Authors: Grunig E; Janssen B; Mereles D; Barth U; Borst MM; Vogt IR; Fischer C; Olschewski H; Kuecherer HF; Kubler W. *Circulation*, Volume 102, Issue 10, pages 1145–1150 (2000)

This German study was performed to examine whether asymptomatic carriers of a mutated PPH gene can be identified at an early stage by their pulmonary artery systolic pressure (PASP) response to exercise. To test this theory, the authors performed exercise echocardiography during supine bicycle exercise and genetic linkage analysis on 52 members of two families with PPH. Fourteen family members with normal PASP at rest revealed an abnormal PASP response to exercise (from 23 to 56 mm Hg) without secondary cause (abnormal response group [AR]). Twenty-seven other members revealed a normal PASP response to exercise (NR group). All 14 AR but only two NR members shared the risk haplotype with the PPH patients. The molecular genetic analysis supported linkage to chromosome 2q31-32, the region where the PPH gene resides. The authors concluded that the pathological rise of PASP in asymptomatic family members is linked to chromosome 2q31-32 and is probably an early sign of PPH. However, it is very important to remember that none of the patients who had increases in PASP with exercise had any symptoms of pulmonary hypertension. Also, since these patients have not been followed over time it is not known whether these patients will progress to having symptoms or to having pulmonary hypertension at rest. More research is certainly needed in this group of patients. It can be seen how discovery of the gene for familial PPH will open up new avenues of research into our understanding of this disease.

### British PH Conference

The first British PH Conference is September 22, 2001, at the Posthouse Hotel Leicester which is in the center of the UK. More details will be at the PHA web site or contact Kay Yeowart at [kay@yeowartfamily.demon.co.uk](mailto:kay@yeowartfamily.demon.co.uk).

### 2. Gene Expression Patterns in the Lungs of Patients with Primary Pulmonary Hypertension: A Gene Microarray Analysis

Authors: Mark W. Geraci; Mark Moore; Tracy Gesell; Michael E. Yeager; Lori Alger; Heiko Golpon; Bifeng Gao; James E. Loyd; Rubin M. Tuder; Norbert F. Voelkel. *Circulation Research*, Volume 88, Issue 6, pages: 555–562 (2001)

These authors proposed that genetic RNA extracted from lung biopsy fragments from patients may provide meaningful information regarding the changes in gene expression pattern in PPH when compared with normal lung tissue. Using sophisticated oligonucleotide microarray technology, they characterized the expression pattern in the lung tissue obtained from six patients with PPH—including two patients with the familial form of PPH (FPPH)—and from six patients with histologically normal lungs. For the data analysis, gene clusters were generated and the gene expression pattern differences between PPH and normal lung tissue and between PPH and FPPH lung tissue were compared. All PPH lung tissue samples showed a decreased expression of genes encoding several kinases and phosphatases, whereas several oncogenes and genes coding for ion channel proteins were upregulated in their expression. Importantly, sporadic PPH and FPPH had different patterns, because alterations in the expression of transforming growth factor- $\beta$  receptor III, bone morphogenic protein 2 (the recently discovered familial PPH gene), mitogen-activated protein kinase 5, RACK 1, apolipoprotein C-III, and the gene encoding the laminin receptor 1 were only found in the samples from patients with sporadic PPH, but not in FPPH samples. This microarray gene expression technique is a new and useful molecular tool that provides novel information pertinent to a better characterization and understanding of the pathobiology of the distinct clinical phenotypes of pulmonary hypertension.

In layman’s terms, this group took tissue from PPH lungs, FPPH and normal lungs and shook all the active genes out on the table to see what ones were active and inactive in each case. This is so much easier than the old way of doing things where you would have to think of a possible scenario for the cause of PPH and then go looking for those specific genes, one by one, as your theories were either discounted (usually!) or proven. Now you see what genes are active and ask why are they, and how can I propose a scenario to explain what I have found. A much quicker and more efficient approach.

### NEXT ISSUE!

SAB: History and Future  
Coast to Coast: Awareness Week Activities  
Research Awards recipients’ progress

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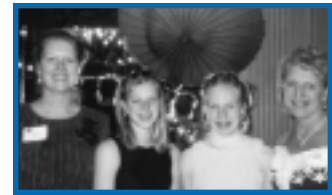
## United Therapeutics Receives 90-Day Extension to Remodulin NDA Review

Silver Spring, Maryland, and Research Triangle Park, North Carolina, April 12, 2001—United Therapeutics Corporation (NASDAQ: UTHR) announced today that the company and the Food and Drug Administration (FDA) have agreed to extend for up to 90 days the priority review period for the New Drug Application (NDA) for Remodulin (formerly UT-15) for the treatment of pulmonary arterial hypertension. This decision was made to provide the FDA with time to review additional information submitted by United Therapeutics in support of the NDA.

As a result of this extension for the Remodulin NDA review period, United Therapeutics' previously-released revenue forecasts are no longer accurate. A replacement forecast will be made upon FDA action on the Remodulin NDA.

United Therapeutics is a biotechnology company focused on combating cardiovascular, inflammatory and infectious disease with unique therapeutic products. United Therapeutics is a member of the Russell 3000 Index and is included in the iShares Nasdaq Biotechnology Index Fund (NBI).

For Further Information Contact:  
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Linda, Hannah, Lindsay, Betty at Tournament and Gala

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