



Pathlight

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

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Life Is Sweet: An Account of Being Transplanted Twice

Part I

By Sharren Yamron

When once just isn't enough! There are many things you do once in life and lung transplantation was one, or so I thought. This is my account of having a bilateral lung transplant in 1995 and discovering that I was in need of a second transplant soon thereafter.

I was diagnosed with primary pulmonary hypertension idiopathic in 1993. The typical symptoms for me were being short of breath, tired and overweight. It was soon after that I found it was much more serious than just weight and stress. The routine regimen was close doctor supervision along with a new drug being used for PPH called Flolan. It stabilized my condition for what was down the road—a bi-lateral transplant. There are always little test runs for the big day, like getting up at 5 a.m. and rushing to the hospital to get prepped and ready for surgery—then finding the lungs weren't viable or something just wasn't right. It would take days of recovery to get back to normal stress levels again.

Well it finally happened; I received my transplant on July 29, 1995. There was a very long road to recovery with many

complications. After a long stay in the hospital and months of rehab and further recuperation at home, I was finally off oxygen for a little while. My health was limited, but I still wanted to regain my strength and some semblance of normalcy in my life. Unfortunately it was not to be, for I had numerous infections, pneumonia and rejection. Due to all the complications and further injury to my lungs, my lung capacity was limited. My lung function decreased steadily month after month due to rejection and O.B. (obliterative bronchiolitis). It was time to discuss serious issues. Was it possible to start all over again? Could I endure another major surgery? Would I even be able to get listed or transplanted again?

These overwhelming questions frustrated me because I have come so far through so much and to have the outcome be so limiting was unacceptable to me. The conflict I felt was internal—could I put my family through this again and hold my hand when I was so needy? Would I be strong enough to walk down that road again and deal with the long recovery and constant dependency on others for so long? Would my body betray me and not work toward a common goal? Could I take what was already a limited resource knowing it is needed so badly by others as well? All these things seemed to touch me so deeply, but I had to ask them of my supporters and myself.

Once you decide you want to live and that you will endure anything to gain another day, that is when you start to structure

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Sharren and Larry Yamron

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PHA President's Message

Bruce Brundage, MD

Year end is a time to look back...

We have accomplished much in 2002.

I cannot think of another rare illness association that has been able to launch its own medical journal as PHA did this year.

I cannot think of another rare illness association that has developed as strong a Scientific Leadership Council as PHA. In 2002, the SLC created nine consensus statements, a great service towards better and more consistent treatment of patients. Now, they are working on expanding PH education for fellow physicians and on building a consortium approach to moving research forward more rapidly.

I cannot think of another rare illness association where a patient can pick up the phone for a helpline and speak to another patient as counselor and friend...or go on the Internet and find the quality and breadth of information being provided on www.phassociation.org...or have the choice of over 100 local support groups...or attend a Conference that seamlessly mixes patients, family members and medical professionals for the good of all.

There is so much more that has happened and PHA has already sent a mailing that will include PHA's annual report to our members and friends. The letter with that report encourages you to renew your membership in PHA or make an end-of-year donation.

Year end is also a time to look forward.

We still have much to do. Anyone who was at our June 2002 International Conference knows that the mood of our community is far better than ever before. Doctors are seeing many new advances in treatment and more on the horizon. Through PHA we are harmonizing our work to take maximum advantage of opportunities.

We need you. We need your time. We need your talent.

We need your generous support.

PH is a rare illness. This means that the population of supporters we can draw from is limited. Yet, our hearts are large. How else could we have advanced so far?

You can always renew your membership or make a donation to PHA online, please go to "How Can I Help?" at www.phassociation.org or call the office at 301-565-3004.

For those of you who are able, I invite you to join me as members of the Committee of 10. This is a special group that is able and willing to commit \$1,000 per year to help drive our cause forward. Remember, no one is turned away from PHA membership. We know this is an expensive illness and appreciate whatever our members and donors are able to give.

Thank you and may we all advance further and faster in 2003.



PHA Welcomes New Staff Members

PHA is continuing to grow in order to serve the PH community better. Two new staff members have been hired this fall, and PHA expects to hire a Volunteer Services Manager in early 2003. The Volunteer Services Manager will work with volunteers and encourage and support special events.

Peter Alan Farmer joined PHA as Director of Finance and Database Services in September. Peter has worked for a number of non-profits over the past dozen years including Self-Help for Hard-of-Hearing People, Make-a-Wish Foundation of Metro New York, and Gay Men's Health Crisis. Peter has a BS in Accounting summa cum laude from Southeastern University and a BS in Psychology from the University of Maryland. Most importantly for PHA, in two previous positions he has been responsible for both finance and database management using the same programs we use at PHA.

Don Clark came to PHA in October as the Medical Services Director to work with the Scientific Leadership Council and Pulmonary Hypertension Resource Network. Don spent ten years as Executive Director of the American Academy of Otolaryngic Allergy. The association had 2,300 member doctors. He was also responsible for management and support of a 500 member affiliated association of nurses and other medical professionals. Most recently, he spent four years at the American Society for Clinical Nutrition where he was responsible for the production of a monthly peer-reviewed scientific journal.

Joining PHA has special significance to Don because of his own family's experience with the disease. In 1965, his 13 year old sister was diagnosed with PPH and died four months later. In 1985, he lost his three-year-old nephew to the illness. He is excited to be working with the medical community as PHA strives to increase PH awareness and fund valuable research.

Please join us in welcoming Peter and Don to the PHA staff!



Don Clark



Peter Farmer



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E-mail	pha@phassociation.org
Member Services and Pathlight Address Changes	301-565-3004
PH Helpline (daytime, please)	1-800-748-7274
ACCESS	1-888-700-7010
(Social security, insurance, and disability questions)	
Accredo's Hotline for Flolan	1-800-9-FLOLAN
TheraCom's Hotline for Flolan	1-877-356-5264
Priority Healthcare Remodulin Hotline	1-877-462-6225

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SLC Executive Committee Holds First Meeting

A historic meeting took place on October 15. The new Executive Committee of PHA’s Scientific Leadership Council met in Silver Spring, Maryland. Participants in the meeting included Michael McGoon, MD of the Mayo Clinic (SLC Chair); Robyn Barst, MD of Columbia Presbyterian (SLC Vice-Chair); David Badesch, MD of the University of Colorado (Nominations Committee Chair); Greg Elliott, MD of the University of Utah (Publications Committee Chair); Ivan Robbins, MD of Vanderbilt (Consensus Committee Chair); Stuart Rich, MD of Rush Heart Institute (Research Committee Vice-Chair); and Victor Tapson, MD of Duke (Editor of PHA’s medical journal *Advances in Pulmonary Hypertension*).

The SLC was formerly known as PHA’s Scientific Advisory Board. The name change was approved by PHA’s Board in June 2002 to reflect the increasingly active role they are playing in bringing together the PH medical community.

Covering a broad range of issues, the October meeting was designed to develop a platform upon which PH doctors can work more collaboratively to accelerate research and medical education regarding PH. Dr. McGoon, who chaired the meeting, said, “The SLC is in an excellent position to coordinate work among PH medical professionals and centers. We have excellent medical minds from five nations, a history of cooperative effort and PHA is investing the resources and making the connections to help develop and move our agenda forward at a rapid pace.”

During the meeting, the SLC leadership addressed issues ranging from collaborative research opportunities and the creation of a scientific conference to the development of new Consensus Statements, drug costs and insurance coverage, and the development of an ethics policy.

Following the meeting, Drs. McGoon, Elliott, and Badesch and PHA staff members Rino Aldrighetti (Executive Director), Lorie Simmons (Awareness and Advocacy Director) and Don Clark (Medical Services Director) met with Stephen Groft, Pharm.D., Director of the Office of Rare Diseases. It was a very positive meeting. Dr. Groft was supportive of items in the SLC’s agenda and suggested several areas where ORD and PHA can work together in the future. Follow up activity is planned.

On the following morning, most of the same group was able to meet with Claude Lenfant, MD, Director of the National Heart Lung and Blood Institute and Carol Vreim, PhD, Deputy Director NHLBI Division of Lung Diseases. NHLBI’s PH research portfolio continues to grow quickly and is now at \$19,300,000. Dr. Lenfant offered several opportunities which PHA will be following up on.

The next step in SLC activity is planning the four 2003 issues of the PHA medical journal. The editorial committee for *Advances in Pulmonary Hypertension* will be meeting in Chicago in late November.



L-R: Greg Elliot, MD, Robyn Barst, MD, Ivan Robbins, MD



L-R: Robyn Barst, MD, Ivan Robbins, MD, Stuart Rich, MD



L-R: David B. Badesch, MD, Vic Tapson, MD



Michael McGoon, MD



L-R: Rino, Don, David B. Badesch, MD, Vic Tapson, MD

ADVOCACY AND AWARENESS

Awareness Month Moves Forward

November is PHA's first official Awareness Month. Support groups and other members have organized events all over the country. The PHA website is featuring a U.S. map with symbols representing events planned in many states—16 events were posted as we went to press and more are being listed each day. Be sure you report your event to Lorie Simmons, PHA Advocacy and Awareness Director, and Jeremy Isett, PHA Internet Services Manager, to add it to the map. You can find out what all the symbols mean and check for new events to be added at the PHA website www.phassociation.org. Find Advocacy and Awareness on the left of the home page and then click on "Awareness Month."

This year PHA is working with a PR firm which helped PHA in placing an article in *Parade* magazine and with finding a celebrity spokesperson. See the article in the next *Pathlight* on Debbie Black, WNBA Miami Sol basketball player and PHA's new celebrity spokesperson.

Garage sales are an easy event for support groups to organize as a fundraising and awareness event. Just pick a house or several to host it and look through your house/garage/attic for items to sell. PHA is encouraging members to have a garage sale in every state. You can learn how to do a PHA garage sale "funraiser" by going to the PHA website and reading an easy to use tutorial on running a special event. This is a preview of the new interactive Special Events Fundraising CD-ROM that PHA will be offering to anyone wishing to do a "funraiser." Although November is Awareness Month, this PHA garage sale tutorial can be used any time during the year. So give it a try at www.phassociation.org—click on Awareness Month and then click on the box with the words "Meet Champ and get info..."

Step by step, PHA is doing more and more for awareness and advocacy to promote attention to the PH community. Your help is essential.

PH Bills Move through Government with your Help

At the end of September, the call for help went out via e-mails to PHA members for their help with getting several bills beneficial to PH through the legislative process. You were first asked to call your Congressional representative, then your state's Senators, and finally to call the White House to ask the President to sign the two bills.

The first bill, H.R. 4014, increases the authorization level at FDA's Orphan Products Research Grant program to \$25 million. The second, H.R. 4013, provides statutory authority for NIH's Office of Rare Disease Research and authorizes the Office to support additional spending for grants and cooperative agreements for Rare Diseases Centers of Excellence.

The bills passed through the legislature in October. On November 7, 2002, President Bush signed both bills into legislation.



Race for PH—California—Dr. Brundage and friends



Race for PH—California—a great crew

Awareness Month Activities

Send your pictures and reports of your awareness events for coverage in the next issue of *Pathlight*.

These photos preview the Race for PH held at Stanford University in Palo Alto, California—an early and successful launch for PHA's November Awareness Month. Dr. Brundage, PHA president, raced with many others on Sunday, October 27. Read all about it in the next issue.

NEWS AND ANNOUNCEMENTS

Committee of Correspondence a Success...More Participants Sought

This fall, Betty Lou and Jerry Wojciechowski of Mission Viejo, California, became pioneers for PHA.

They were the first members to test a new letter writing program to raise awareness and funds for PH. The proceeds of the program support PHA's research grants and PHA programs like support groups and the hotline.

"Jerry and I were nervous at first," said Betty Lou. "We kept putting off mailing the letters to our friends, family and neighbors. What if nobody responded? What if our friends were annoyed by our letters?"

By August, Jerry and Betty Lou had worked through their jitters. They were ready to put their letters in the mail.

Betty Lou continued, "PHA made the project simple. They have a great fact sheet that advised us on a number of key points—like setting a contributions goal and mentioning it in the letters. PHA also provided sample letters with a spot for us to drop in our own story. A PHA staff member was even available to help with that part...since not everyone is comfortable writing."

"Picking a donation goal wasn't easy for us. We're school teachers. We have a lot of friends but, like us, they aren't rich. We finally pulled a \$10,000 goal out of the air."

"Our letters dropped in the mail on August 14. We sent out 150. Within a week, we started getting the most wonderful letters and notes. It was incredible. Friends and family, who may or may not have understood PH before, certainly did now. All these people we knew were there for us, wanting to help our cause...and they sent checks, large and small."

"By early October, we had raised over \$4,400. Then, we received a call on October 8 from friends we hadn't heard from in awhile. They said that they were moved to donate \$5,000 to PHA! In their words, 'We love your family as much as we hate this disease.' We were floored! We never thought we would reach what seemed to us such an enormous goal...and here we are on the verge of going over the top! This was such a great experience for us and, from everything we can see, for our family and friends. They had always wanted a way to help, and when we gave them the opportunity through our letters, they jumped at the chance and actually thanked us for letting them help PHA find a cure!"

Jerry and Betty Lou Wojciechowski are courageous people who know only too well the importance of fighting this illness. They lost their youngest son Matthew at age 4½ to PH in 1983 and their oldest son Michael at age 24 to PH in 1997. Jerry was diagnosed in 1994. Now, their children Michelle and Mark and granddaughter Cristiana receive yearly echocardiograms to detect any signs of PPH.

"If we don't fight this PH, who will?" says Jerry. "Sure, we wanted to use this new program to raise money and awareness. Even more, we wanted to show others that the impossible is possible. Now we want to encourage others to use this program—to make our stream of support grow into a river. It's great to know, **we are not alone!**"

Building on Betty Lou and Jerry's success, PHA is hoping to recruit 25 *volunteers* to participate in the new **Committee of Correspondence program** in 2003.



If you would like more information on how the program works, contact (no obligation) Karri Boyer at 301-565-3004 ext. 110 or karri@phassociation.org

Working together, even "the impossible is possible."

Please contact PHA today.

"Understanding Pulmonary Hypertension" CD-ROM, Version 2.0, Ready to be Shipped

The latest version of the PHA **CD-ROM** "Understanding Pulmonary Hypertension" is ready for shipping. In the 2.0 version, we have completely redone the "Treatments" section. The recent approval of two new treatments for PH by the FDA—Tracleer and Remodulin—provides PH patients with treatment options for the first time. This is a major breakthrough for patients fighting this disease. With that in mind, it was felt that making a video available on the CD that shows how Flolan and Remodulin are administered would be of assistance to those faced with decision-making about the treatment options available. As Tracleer is an oral medication, there is no video showing how this drug is administered.

This CD is probably one of the most important tools that PHA makes available to PH patients and the broader community. To date we have shipped in excess of 10,000 version 1.0 CDs and anticipate that we will ship at least that many of version 2.0.

The CD can be used to heighten awareness in the broader community. Sharing it with the media makes it easy for them to understand what happens to the individual who has the disease. Sharing it with those who might be experiencing some of the symptoms of the disease helps them rule in or rule out the possibility that they might have PH. Early diagnosis helps

NEWS AND ANNOUNCEMENTS

because it allows for early treatment and early treatment means better quality of life and the possibility of an improved prognosis for those with the disease.

If you are eager to get the word out about PH, let us know how many of the CD "Understanding Pulmonary Hypertension" version 2.0 you will need. The CDs are free as they are produced with funding from corporate sponsors. You can order the CDs on line at www.phassociation.org or by contacting Doris Green at Doris@phassociation.org, or by phone at 301-565-3004, ext 106.

Parade Magazine Article Due to the Efforts of Many in the PH Community

When the article on PH appeared in *Parade* magazine August 18, 2002, PHA staff was pretty pleased with themselves. More than a year ago, August 10, 2001, working with a PR firm on loan to PHA, we made contact with *Parade* magazine in the hope of having them run an article on PH for Awareness Week in September of 2001. So, finally, one year later, our efforts paid off. Staff here worked with *Parade* magazine staff to help make certain the information they were working with was current and accurate; and it was. When we read the article, we figured we had done a really good job. Of course, we wondered why the article had not appeared a year earlier. But we were still quite pleased.

On the Monday after the article appeared, the calls and e-mails began arriving at the PHA office—from PH patients and PHA members all around the country, each of them telling us how they had worked so hard to get *Parade* to write the article on PH. They had called and written to the editor and to Dr. Isadore Rosenfeld who writes the medical articles for *Parade*. The messages came to PHA from Florida, California, New York, Pennsylvania, Ohio, and on and on. What a surprise for us. But, what a wonderful event. All of us, from around the country, working together, were able to accomplish what none of us individually could have accomplished—the publication of an article about PH in *Parade* magazine which has a circulation of 37.1 million. It is that community of spirit that makes this organization so unique and so effective. Congratulations to the PH Community, who together made the *Parade* magazine article happen!

PHA (UK)

PHA (UK) held its second conference on October 11, 12, and 13, 2002, at the Thistle Hotel, Castle Donington, Derby. Programs were presented for professionals, patients, and caregivers. Check out their website at www.pha-uk.com for more information.

PHA's Founding President Wins Award

Washington Regional Medical Center has announced the winners of the **2002 Amethyst Awards**. These awards, formerly known as the Woman of the Year Awards, were established to recognize four women—representing Benton, Carroll, Madison and Washington counties—who have helped make the Northwest Arkansas community a better place. The Amethyst Awards were formally presented at Washington Regional's Speaking of Women's Health conference on Saturday, October 5, at the Northwest Arkansas Convention Center in Springdale.

Judith Simpson, of Holiday Island, is the Amethyst Award winner representing Carroll County. A life-threatening diagnosis for a beloved sister inspired her to become a founder of the Pulmonary Hypertension Association. In little more than a decade, PHA has grown from three members to more than 4500 worldwide. Simpson, who is also a registered nurse, currently serves on the PHA Board of Trustees Emeritus and is a member of the American Thoracic Society Round Table Advisory Council.

PH Grandfather Wins Award

Jack Hudson of The Woodlands, Texas, was chosen as one of the 2002 Volunteer Excellence Award Winners by Duke Energy's Volunteers in Action Program. Mr. Hudson is grandfather to ten-year-old Emily Stibbs who has been diagnosed with pulmonary hypertension.

"Jack has been our special volunteer each year when he creates eight most unique and wonderful hand carved trophies for the annual PHA Cure PH Golf Tournament. These trophies have attracted hundreds of golfers to our tournaments and helped us raise thousands of dollars for research for a cure for PH," says Rino Aldrighetti, PHA's Executive Director.

NIH: Heart, Lung and Blood Institute Report

By Judy Simpson

The third National Heart Lung and Blood Institute Public Interest Organization meeting will be held in Bethesda on February 5, 2003. Last year several of our PHA staff joined Linda Carr, PHA president, and me at this meeting. It is an opportunity for face-to-face meetings with NHLBI staff and to meet with leaders of organizations with like purposes. I expect there will also be a meeting of organizations that deal with lung diseases to explore possible joint endeavors.

NEWS AND ANNOUNCEMENTS

PHA's Website

PHA has kept the ball rolling on updates and new features on the website. New Message boards were introduced in early September. Users can reserve a "handle" and track messages; reply notifications can be sent automatically via e-mail, and much more.

www.phassociation.org/Message_Boards/

PHA set out to give special focus to the Medical Community by creating the Medical Resources Section. Of course everyone is invited to check out sections like the *Advances in PH* journal, PH bibliography, and more.

www.phassociation.org/Medical/

The Medical Community has also given back to the PH Community. Recently PHA's own Scientific Leadership Council (SLC) published nine Consensus Statements. These informative statements cover topics like Flolan, travel, surgery, and more.

www.phassociation.org/learn/Consensus_Statements/
 PHA encourages all of its members to take advantage of the resources featured on the website. You can support the efforts of PHA through the website. Click on "How Can I Help" on the left-hand side of the homepage to make an online donation, renew your membership, visit the PHA store, learn about other giving opportunities, or sign up to be a volunteer.

Please update my mailing list information as follows:
(Please print.)

Mr. Mrs. Dr.
 Miss Ms. Name

Business (if any)

Address

City State ZIP
 Please check here if this is a change of address.

Phone Fax

E-mail

I am a: patient caregiver parent of child with PH

medical (title and affiliation):

Mail or fax the completed form to:
 PHA • 850 Sligo Ave, Suite 800 • Silver Spring, MD 20910
 Fax: 301-565-3994

You may also submit a change of address online at
www.phassociation.org/contact.htm

PH Journal

The second edition of *Advances in Pulmonary Hypertension*, Volume 1, Number 2, Autumn 2002, was mailed to physicians in August. This journal has received support from the professional sector as well as Actelion and Accredo who have committed to funding the journal for the next year. This issue focuses on scleroderma and the PH patient. You can read and print out the PH Journal online at www.phassociation.org.



Persistent Voices

PV is published twice a year with the fall and spring issues of *Pathlight*. The deadline is January 31, 2003. Please send your personal PH story along with pictures, poems, or quotes to:

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

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

FUNDRAISERS

New CD-ROM

Look for the launch of PHA's new "Funraising©" CD-ROM in the next issue of *Pathlight*. It is a great step-by-step guide designed to make it easy for anyone to plan and carry out their own fundraiser for PHA.

Reston Tournament

The Northern Virginia Golf Tournament was held on May 15, 2002, at the Reston National Golf Club in Reston, Virginia. It was their second successful tournament in less than a year.



Northern VA volunteers contribute to tournament success.

Upcoming Events

2nd Annual Caleigh Coleman Memorial Golf Tournament

Monday, March 31, 2003
 Corsicana Country Club
 Corsicana, Texas
 Contact: Tonia Coleman

Houston Cure PH Golf Tournament

Friday, April 11, 2003
 Fish Creek Golf Club
 Montgomery, Texas
 Contact: Jack Stibbs

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.

The 2nd Annual Jerry P. Selinger Invitational Golf Tournament: A Huge Success

The second annual Jerry P. Selinger Invitational Golf Tournament was held on June 17, 2002, at the Pinebrook Golf and Country Club in Calgary, Alberta. The tournament was a great success in raising over \$68,000 and providing a great day of golf for everyone who attended.

Jerry Selinger, Q. C., Calgary's former Chief Crown Prosecutor, was committed to social justice and actively involved in a number of community initiatives. Jerry died on May 2, 2000, at 50 years of age as a result of complications arising from primary pulmonary hypertension. Jerry's family, friends and colleagues organized the 2001 and 2002 tournaments to carry on Jerry's dedication to the community by raising funds for worthy causes, one being the Peter Lougheed Hospital's Primary Pulmonary Hypertension Clinic Greatest Needs Fund. The Peter Lougheed Hospital Clinic is the only facility in southern Alberta that provides treatment to patients with primary pulmonary hypertension. Funds raised by this year's tournament will provide:

Assistance with the development of a post lung transplant clinic to benefit all patients living in the Calgary Health Region who have undergone lung transplant.

Support when needed to patients with primary pulmonary hypertension.

Plans for the 2003 Jerry P. Selinger Invitational are already under way.



Staff Sergeant Allan Hargreaves, Calgary Police Services, prepares to signal the players to their carts at the 2002 Jerry P. Selinger Invitational.

SLC's Consensus Statements

The Consensus Committee of PHA's Scientific Leadership Council has just published nine consensus statements relating to pulmonary hypertension. The statements are available at www.phassociation.org/learn/Consensus_Statements/ and are listed below.

1. Recommendations for Patient Referral to a PH Specialist
2. Summary and Explanation of Common Tests for Pulmonary Hypertension
3. Guidelines Regarding Flolan
4. Sodium Restriction for Patients with Pulmonary Arterial Hypertension
5. Recommendations on Over-the-Counter Medications in Patients with Pulmonary Arterial Hypertension
6. Recommendations for Exercise in Patients with PAH
7. Travel Recommendations for Patients with PAH
8. Elective Surgery
9. Birth Control and Hormonal Therapy in Pulmonary Arterial Hypertension

These Consensus Statements were compiled and approved in June and July of 2002.

Pathlight will publish statements in following issues. Great information from the SLC—visit the PHA website to read all of the statements.

Generous Grant from the Medtronic Foundation

PHA was recently awarded a \$50,000 *Patient Link* grant from the Medtronic Foundation. The grant is for expansion of PHA's patient-to-patient support services.

PHA will use the funds to develop better training tools, support materials, and recruitment methods for helpline and support group volunteers. More patients are using the helpline than ever before and the number of local support groups has more than doubled in the last year. The Medtronic Foundation's grant will help these programs continue to grow.

Mike McGoon, MD, chair of PHA's Scientific Leadership Council, made the original contact with the Medtronic Foundation on behalf of PHA. PHA has had opportunities to open dialogues with several foundations and corporations through members who find organizations with goals and priorities similar to those of PHA.

If you have contacts which you would like to introduce to PHA, please contact Karri at karri@phassociation.org or call 301-565-3004 x110.

Recommendations for Exercise in Patients with PAH (July 2002)

There are no published data in the medical literature regarding routine exercise in patients with PAH. However, there are considerable data available from studies evaluating the effects of exercise in patients with left heart failure that suggest physical activity and a regular exercise program are helpful in maintaining muscle tone, physical (and mental) well-being, and in some cases, improving long-term survival. There is also some data suggesting that physical inactivity may be detrimental to patients with left heart failure. Because right heart failure in PAH leads to effects on the body similar to that seen with left heart failure, exercise in PAH patients may have similar benefits. However, the actual benefit of exercise in patients with PAH has not been well studied. In general, several important points can be made about exercise in PAH:

1. Many PAH specialists agree that some form of exercise is not harmful for PAH patients and may be helpful.
2. Patients with PAH should speak with their doctor before beginning any exercise program.
3. Patients with PAH should not over-exercise at any time. In other words, do not exercise to the point where symptoms such as light-headedness, chest pain, or severe shortness of breath develop. To determine how much exercise is reasonable, each patient should talk with his/her PH specialist to develop an individualized exercise plan.
4. Exercise such as light resistance training of small muscle groups (no heavy lifting), and light to moderate aerobic activity (walking, swimming, etc.) are the recommended forms of exercise for PAH patients.
5. Except in those PAH patients with minimal or no symptoms, it is inadvisable to exercise upper and lower limbs at the same time (for example as with a Nordic track machine).
6. In general, patients with severe limitation of activity, and/or a history of dizziness and/or fainting during exercise should not continue with, or plan to begin, a regular exercise program.
7. A clinic or hospital-based exercise facility to perform regular exercise should be considered when starting an exercise program but is not required.
8. Outdoor exercise should be avoided during hot or humid weather.

In summary, a regular exercise program is likely to be helpful for patients with PAH, and probably not harmful, provided patients discuss the type of activity with their PH specialist prior to starting any exercise program.

 Under 21: Traveling to Children's PH Centers (continued from page 20)

minimal charge. Some have kitchens for use if you want to cook or have a picky eater.

Ask your hospital social worker or physician's nurse for more details on lodging arrangements and what services they provide. They usually know where families have stayed before and have been happy with the arrangements. Shuttle service may be available to the hospital with prior arrangement. Ask about cost. If you stay in a hotel, ask if they have a refrigerator available for medications.

Lodging at or near the Hospital: Talk to your physician, their nurse, or the hospital social worker about lodging for family members while their child is in the hospital. Some hospitals will have web sites with information that can make a hospital stay or visit easier. Find out what is included in the room, how much advance notice is required to reserve a room, and who can make those reservations. Also ask about the sleeping and showering arrangements available for the parent staying with the child overnight.

After Camille is admitted, she asks if she can see the 'Child Life Therapist.' He/She can provide age appropriate videos, games, arts and crafts, a schedule when the trained dogs are visiting and when tea parties are planned and where to go.

Fun things to do: When going from department to department for different testing procedures, they don't always have a good selection of age appropriate movies or books. We bring our own.

It's a great time to bring out some surprise package for all to enjoy such as bubbles, playing cards, small nerf balls that stick to a bulls-eye target, washable tattoos, extremely sour candy that is handed out to the doctors or nurses and see them squirm. Camille enjoys that. She wore blue nail polish once since that is her favorite color. Scary for the doctors when they come in to evaluate her. I made sure to bring polish remover for the oxygen saturation monitor. Find out if other kids with PPH are being seen in the hospital. Usually these kids have very few opportunities like the adults to attend support groups. If they can capture some time to provide support to each other while staying in the hospital, those arrangements can be made

Usually your physician or their nurse can coordinate if they feel it would be appropriate. Somehow families end up finding each other. It is a great time for the kids to compare notes, encourage each other and share addresses. We have had a family leave a surprise package for Camille to find when she got to the hospital and we did the same. Whatever it takes to make it easier for the kids.

Take a pre-printed list of the medications if you get tired of repeating yourself. That way you can hand it to them and get back to doing arts and crafts with your child.

Insurance: Our visits require pre-authorization so I inform the insurance company regarding what dates we will be outpatient and inpatient. I request a letter of authorization prior to going.

I keep a copy with me so if the departments ask, I can let them make a copy. Insurance companies are more likely to cover

a stay or procedure if it is prior authorized. It is not a guarantee. Any bills you have to pay out of pocket, make sure to ask for a receipt. Submit it to the insurance company. Keep track of when you sent it in. Always keep a copy for your records. If you call the insurance company, make sure to write down the persons name and the date you spoke with them and a note regarding the conversation. If there is any question about what happened, that little bit of information goes a long way. Again, it's not a guarantee, but if they know that you are organized enough to keep that information, maybe it was their mistake.

Taxes: Ask your accountant about write-offs available for medical expenses. Travel, food, lodging, etc... I keep all receipts while traveling so that they can be added up at the end of the year. If you reach a certain percentage, there is a deduction that is given.

Length of stay affects school/homework: Taking Camille out of school is added stress for her and for us. Teachers are usually pretty good about helping her get caught up. She doesn't have a lot of time to work on homework during the trip. Sometimes she will get the work ahead of time, but most often we have to catch up. We usually make sure that we help the teachers communicate so that she doesn't end up studying for 4 make up tests in one night.

Siblings: We make sure to either leave some small surprise for them under their pillow or a note. Camille has opened her suitcase and found some nice things from her brothers. That makes her feel closer to home. We bring pictures of those we have left behind to show doctors and nurses. It helps the doctors and nurses realize that these kids are attached to a network of growth and fun things to do. Sometimes we bring a sibling. They are much better company than mom or dad. They don't get tied up in all the stress. It helps them realize that their brother or sister isn't having the time of his or her life while they are in the hospital, either. Maybe they do deserve that extra toy or time off when they get back.

Classmates: We did a video on our last visit. Camille will be showing her 7th grade class all the different tests she has done and different people she meets. We are hoping it will help her class to better understand more about PPH.

This is a small portion of what we can share. Each time I talk to a parent of a child with PPH, I learn something new—and often, a better way to help our daughter and children with PPH.

Children's Directory

A children's directory is available for families of children diagnosed with PH. The directory includes information such as family's name, address, child's age, diagnosis, physician and current medication. If you would like to be included in the directory or would like a copy, please contact Laurie Jeter at mjeter1@aol.com or call 952-380-4999.

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The **Sarah Ing Patient Helpline Fund** has been created based on the wishes of her husband. Donations in Sarah's memory will be used to support the toll-free, patient-to-patient Helpline for which Sarah was an active volunteer. The Helpline is one of the earliest services established by PHA and allows patients living with the illness to assist and comfort other patients, many of whom have recently been diagnosed. If you wish to contribute to this fund, please call 301-565-3004 or mail your contribution (with a note indicating your wishes) to the PHA office.

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Laraine Fondiler

Jeffrey D. Schwartz

Lou Ann Gibbs

Barbara Kousky
Alexandra L. Kribs
Helen F. Matthews
Judith A. McConnell
Jane Pubols

Patricia Hernandez

Elizabeth T. McNamee Memorial Fund, Inc.

Anna Jeter

TCF National Bank, Minnesota

Leo Klein

Lester G. Fondiler

Madelaine B. Collins

Susan Silbermann
Pfizer Inc., Italy

Caroline Morgan

Sharon A. Gariepy

Louise Morrison

Stephen Sargent

Melissa Motiwalla

Shafi Motiwalla

PH Support Group: Tyler Chapter

Melissa J. Sham
H. T. Spratlin
Quitman Ford

David A. Rocco

Nancy J. Meinert

JoAnne Sperando Schmidt

John P. Sperando

Stephen Sentina

Maureen Moore
McDonald's 1955 Corporation—Hylan Blvd.

Kathleen Sheffer

Charles J. Kawas
Wendy Niles

John Ralph Sperando

John P. Sperando

Emily Stibbs

Jack Stibbs

Marcella Tuttle

Rebecca J. Tuttle

Mary K. Viscounty

Dolores M. Clarke
Diana R. Hasenfuss

Deborah G. Wilson

Bunco Babes

Shirley M. Winters

Martha Walker

Jerry Wojciechowski

Joyce Barquist
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Kathryn A. Beckwith
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Joan L. Cantrell
Sandra K. Carlos
Lila G. Dalton

Dennis D'Heilly

Antoinette D'Heilly
Ann E. Dockins
Joanne S. Eichhorst
William H. Gallienne
Scott Garland
Jodie Glowin
Toni L. Grotzky
Patricia Gryskiewicz
Michael D. Hatcher
Thomas Havlena
Ruth Heineman
Joan K. Hindman
Nicole D. Jackson
Bonnie Jones-Peirce
N. D. Kelley
Janet S. Lisle
Martha A. Lissi
James M. Maloof
Kathy McCamment
Janet M. McGough
Mary W. Monroe
Susana C. Montgomery
Jeanne M. Peace
Michelle A. Raasch
P. Sandoval
Shirley Sherreitt
Grace M. Smith
Carol S. Vopat
Vivian A. Walz
Harriette G. Watson
Tiger Johns, Inc.
Stahr Concrete Construction

Elise M. Zwicky

Kristen Zwicky

American Thoracic Society: Public Advisory Roundtable (PAR)

By Judy Simpson

I was asked to continue my seat on PAR for another year. Currently I sit on the American Thoracic Society (ATS) Education Committee and chair the PAR Education Committee which is working with ATS staff to have patient educational materials placed on the ATS website. The goal is to have credible information available for patients which will include how to reach the appropriate patient organization. PAR is working on a virtual incubator to aid new and established lung organizations on the “how to do it” in areas significant to not-for-profits.

The PAR Symposium met during the ATS International Conference in May in Atlanta. I quote from the ATS News what Dr. Thomas Martin, ATS President said, “Meeting highlights included a successful symposium on bioterrorism developments and an outstanding scientific symposium sponsored by the members of the ATS Public Advisory Roundtable. This program brought patients and lay advocacy groups together with premier scientists and drew a large and enthusiastic audience. The success of this program is leading the Program Committee to consider ways to incorporate our Public Advisory Roundtable members and the patients they represent into the International Conference Program next year.”

I plan to have a PH patient speak at the ATS International Conference in Seattle in May, 2003.

ATS is listening to PAR and acting.

Life Is Sweet: An Account of Being Transplanted Twice (continued from page 1)

your life to do what you need to do—to find a doctor who would listen, to find a hospital that would entertain the transplant, to find the compassion and support needed to get through another transplant. I had a job and this was something that meant my survival, so with my self doubts put to rest, I sought out the people who would listen.

I was first transplanted at UPMC in Pittsburgh, Pennsylvania. The hospital staff and doctors worked closely with me and knew my history, so it seemed like the most logical place to start. They did hear my request and seemed to want the same thing I did, a chance to breathe normally. With Pittsburgh being such a major center for transplants, it was also a very long waiting list. I was told it might take two or three years until my name would even begin to reach the top of the list. Time can be so hard when you count each breath and time isn't on your side. I was told to search for alternatives. In other words, it was highly unlikely they could reach me when I needed the transplant most. This was just another hurdle for me. Most transplant centers won't even entertain the thought of taking a patient who is already transplanted and give them a second chance at transplantation. My husband sought information on all the transplant centers in the entire USA to see who would even see us, let alone put me on the list.

My husband wasn't giving up hope and he took on the task of searching out a center for another transplant. It was his willingness to do so much above and beyond that helped me stay determined.

We had seen Dr. Lewis Rubin at the University of Maryland Medical Center when I was first diagnosed in 1993 for a second opinion. He was willing to see me again and listened to my account and my plea for a second transplant. I was then introduced to Dr. Jonathan Orens, who was the head of the lung transplant team at the University of Maryland. Dr. Orens took his time and listened to my case. He saw I was a fighter and made countless inquiries about everything that would give me

the opportunity to be transplanted again. It was the many visits and check ups and close maintenance that kept me status quo and able to wait the many months for another chance. Dr. Orens then introduced me to Dr. John Conte, the surgeon who would do my transplant. This was the most positive meeting and it affected me very deeply. They all had taken an interest in me and were willing to stick their necks out for me...a patient! I knew the risks were high and the controversy was also something to consider. Do I get a chance to have a second transplant and how do I live with this decision day to day? Dr. Conte, who would do the surgery, was the man who had the final say. He met my husband, my son and me and we talked for a long time. I let him know how much I wanted another chance! I wanted to work with him to reach this goal. He decided that I should be discussed at the next transplant meeting, and it was there they would make a decision on my life.

Sharren's story will be continued in the next issue of *Pathlight*.



Dr. Jonathan Orens

Room Mates at Conference

By Shirley Craig

Wanting to save myself a few dollars, I e-mailed Barbara Smith requesting a room mate for the PH conference. She sent the name and e-mail address of Wendy Duff from New Zealand. Now, being a person who loves meeting new people and especially from other countries, I was excited to try this out. I sent an e-mail and we shared our PH stories. When I heard that she would be on Iloprost and would have to do inhalation treatments every four hours, I was a little hesitant as falling asleep is oftentimes hard for me to do even at home in my own bed! Wendy thought she wouldn't have to start it until she returned home so we went for it and put our reservations together and continued to email. I called the 800# for X-Press Shuttle at LAX so she wouldn't have such a long distance bill and made her reservation. Then, in a last visit to her doctor in Auckland, he told her she should start the Iloprost now. She said she would "stretch" the treatments out from midnight to 6 a.m. which is about all I usually sleep anyway. So, we were going for it!

Wendy arrived Wednesday and visited the local shopping mall—it was winter in New Zealand and due to a successful run at Weight Watchers, she had no summer clothes that would fit so shopping was a "requirement!" I arrived Thursday afternoon and we didn't stop talking until midnight when she turned on her inhaler for her Iloprost treatment—it sounded like those old window unit air conditioners turning on. The treatment lasted about 10 minutes and left Wendy flushed and with a head ache. As Iloprost is also a prostacyclin, many side effects are the same as the Flolan and Remodulin. We both conked out for some much needed rest.

Wendy's PH comes from portal hypertension. She has a small tumor in her liver in a position that is inoperable so a transplant was in order. She was on the operating table being prepped for a liver transplant when the cath into her heart revealed extremely high pulmonary pressures. Transplant procedures were stopped immediately. A request was made within New Zealand and then put to Australia to look at the possibility of a combined lung and liver transplant, but this was declined as it was seen to be too risky. It is hoped that the Iloprost along with Sildenafil (Viagra) will bring her PH pressures down so that she can have the liver transplant—then hope that her PH pressures may go away altogether!

Wendy is no stranger to challenges. Five years ago, her three year old son was diagnosed with autism following an MMR shot he received after suffering a viral infection. Internationally, research is being done into a possible link between Autism and the MMR vaccine. New Zealand's population is well educated and has a high standard of living with an excellent public health program; however, when Elliott was diagnosed with autism, there were no professionals in New Zealand to analyze his condition. Wendy took him to Australia to be assessed by an expert in the field. After much researching, Wendy and her husband Mark subscribed into an American

Home Based Program—Center for Autistic Related Disorders and Elliott began a long, intense, individualized six-year educational program. Fifteen other families in NZ soon tapped into this as well. But Wendy did not stand still—a school for the autistic was needed. She developed a classroom for eight autistic children attached to a mainstream school where the children could work on their individual programs and at their own pace be introduced into the mainstream education. Since then, she has become a member of the board of Autism NZ and has assisted in organizing international conferences for the 3,000 families with members affected with Autism Spectrum Disorder.

So, when PH came into Wendy's life, she went on line and soon found the Pulmonary Hypertension Association with an upcoming conference. She didn't wait to collect dust but found a way to attend that conference. She was able to actually meet and discuss the Iloprost treatment with Dr. Horst Olschewski who developed the inhalation therapy in Germany. She has much information to share with her doctor in New Zealand, and she bought several of the tapes so that he could listen to sessions that related to her conditions.

Wendy is a bright, articulate, energetic person—her days in Auckland begin at 6 a.m. and she is on the go often until midnight. She works 3–4 long days in order to have Mondays and Fridays off to take Elliott to physical therapy which can involve horse riding and ice skating that seem beneficial to autistic children. Now, she has added six Iloprost treatments a day to her routine in addition to keeping house and home together.

Though New Zealand's public health system is excellent, it makes decisions concerning the medications it will allow for its citizens—and expense is often a factor in making these decisions. Thus, Flolan, Remodulin, and Tracleer are deemed too expensive or the delivery systems too dangerous to be approved for use there—so Viagra and Iloprost are the government approved treatments for now.

Wendy returned home safe and sound to Auckland armed with important information for her PH treatment—and with many new friends that wish her all the best. Hope we can see you again in 2004!

Pathlight Submissions

Have an article, announcement, quote, photo, or tribute to share? Please send it to us. Work submitted will be printed as space permits. Include a self-addressed stamped envelope with any material you want returned. PHA cannot be held responsible for materials lost. Mail submissions to:

Shirley J. Craig
5726 Weeping Willow Road
Houston, TX 77092-3336
scraig@hal-pc.org

Deadline for the spring issue is January 31, 2003.

RESEARCH CORNER

Research Corner

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

In this edition of Research Corner, we look to research into a category of pulmonary hypertension that is far more common than pulmonary arterial hypertension (PAH). That category is “disorders of the respiratory system and/or hypoxemia” under the Evian classification system. While so much attention has focused recently on the new therapies for PAH, such as bosentan, treprostinol, iloprost and perhaps sildenafil, it isn’t known whether any of the newer agents will have effects in other forms of PH than PAH.

Sildenafil for treatment of lung fibrosis and pulmonary hypertension: a randomised controlled trial.

Ghofrani HA, Wiedemann R, Rose F, Schermuly RT, Olschewski H, Weissmann N, Gunther A, Walmrath D, Seeger W, Grimminger F, *Lancet* 2002 Sept. 21;360(9337):895–900

This study comes from the same group in Germany that brought us the inhaled iloprost studies recently. In this paper they describe their experience with sildenafil, or Viagra in lung pulmonary hypertension caused by disorders of the respiratory system and/or hypoxemia under the Evian classification system. Lung fibrosis can be complicated by pulmonary hypertension, limiting exercise tolerance and life expectancy. However, there is considerable reluctance to using vasodilators as they might cause further deterioration in gas exchange by increasing the shunting of “blue” blood through the scarred lung. The authors compared the acute effects of sildenafil, nitric oxide, and epoprostenol in individuals with pulmonary hypertension secondary to lung fibrosis. This was a randomised controlled, open-label trial in 16 individuals with pulmonary hypertension secondary to lung fibrosis. After inhalation of nitric oxide (10–20 ppm), patients were assigned to either maximum tolerated dose of intravenous prostacyclin (mean 8.0 ng/kg per min; n=8) or oral sildenafil (50 mg; n=8). Pulmonary vascular resistance index was reduced by nitric oxide (–21.9%), epoprostenol (–36.9%), and sildenafil (–32.5%). However, the ratio of pulmonary to systemic vascular resistance decreased only in individuals who received nitric oxide and sildenafil. Using the multiple-inert-gas elimination test it was shown that prostacyclin increased V/Q mismatch and decreased arterial oxygenation. By contrast, nitric oxide and sildenafil maintained V/Q matching, with raised arterial partial pressure of oxygen (14.3 mmHg) noted for sildenafil. There were no recorded adverse events. The authors conclude that Sildenafil causes preferential pulmonary vasodilation and improves gas exchange in patients with severe lung fibrosis and secondary pulmonary hypertension. This is somewhat unexpected and very

encouraging. While the Viagra study is currently enrolling patients around the world, this study further supports the lung specific action of this drug. It begs the question whether it might therefore have a role in other disorders of the respiratory system and/or hypoxemia such as COPD. Only time, and a carefully conducted study, will tell.

The effect of amlodipine on exercise-induced pulmonary hypertension and right heart function in patients with chronic obstructive pulmonary disease.

Franz IW, Van Der Meyden J, Schaupp S, Tonnesmann U. Z *Kardiol* 2002 Oct;91(10):833–9

This study, also from Germany, visits an area in pulmonary hypertension research that has been somewhat neglected more recently as our attention has focused on pulmonary arterial hypertension (PAH). The aim of the study was to investigate the effect of the calcium channel blocker amlodipine in patients with clinically stable chronic obstructive pulmonary disease (COPD) and pulmonary hypertension (PH). This form of pulmonary hypertension also falls into the category of “disorders of the respiratory system and/or hypoxemia” under the Evian classification system. Many patients with COPD develop PH and indeed Cor Pulmonale, or right heart failure secondary to severe lung disease is far more common in everyday clinical practice than PAH. In twenty male patients with clinically stable COPD and PH, they investigated whether amlodipine could effectively decrease pulmonary vascular resistance (PVR) and pulmonary arterial pressure (PAP) and improve right heart function. PAP and cardiac output were determined during right heart catheterisation at rest and during exercise. In addition, blood gas values were determined from the capillary blood of the earlobe. Measurements were done before and after 18 days of chronic treatment: with 10 mg amlodipine once daily starting with 5 mg in the first week. At a mean maximal achieved workload of 71.3+/-20 Watts, amlodipine achieved a significant reduction in PVR (–13.4%; p<0.01) and PAP (–12.1%; p<0.001) implying an improved right heart function assessed by a significant reduction in mean right atrial pressure (–20.6%; p<0.05). The authors claim that amlodipine is a safe and effective pulmonary vasodilator in COPD patients with PH and leads to an improvement in right heart function with no significant changes in pulmonary gas exchange. While we would like the study to be completed in a placebo controlled format and to see whether the treatment resulted in clinically important improvements in six-minute walk and dyspnoea scores, it is good to see a renewed interest in this important area of PH research.

Cyclooxygenase-2 acts as an endogenous brake on endothelin-1 release by human pulmonary artery smooth muscle cells: implications for pulmonary hypertension.

Wort SJ, Woods M, Warner TD, Evans TW, Mitchell JA. *Mol Pharmacol* 2002 Nov; 62(5):1147–53

(Continued on page 19)

RESEARCH CORNER

This study comes from the Royal Brompton Hospital, in London, and looks at the control of endothelin, the substance we block with Bosentan. Endothelin-1 is a potent vasoconstrictor and also causes proliferation of vascular smooth muscle and has been implicated in pulmonary vascular remodeling and in the development of pulmonary hypertension. Prostacyclin has been shown to be an effective therapy for human pulmonary hypertension, reducing morbidity and mortality, although the mechanism of its action is unknown. The authors show that the combination of TNF-alpha and interferon (IFN)-gamma induces the release of endothelin-1 from human pulmonary artery smooth muscle cells via increased transcription of endothelin-1. The release of endothelin-1 and the transcription of endothelin-1 mRNA were inhibited by the activity of cyclooxygenase-2 which was also induced in response to the IFN and TNF. Endothelin-1 release was also inhibited by a prostacyclin-mimetic (cicaprost). Thus, under inflammatory conditions, in which vascular smooth muscle is an important source of endothelin-1, the induction of cyclooxygenase-2 represents an endogenous “braking” mechanism. In addition, the beneficial effects of prostacyclin in the treatment of pulmonary hypertension may be caused, at least in part, by the inhibition of endothelin-1 release. The authors also suggest that these observations may lead to some caution when prescribing non-steroidal anti-inflammatories to individuals with severe PH as it may lead to an increase in endothelin when the “brake” is removed. This mechanism is probably balanced by the beneficial effect these drugs have of reducing the vasoconstrictor, thromboxane.

Help PHA Move Forward

LCD Projector Needed

PHA is being invited to give an increasing number of presentations at meetings and events. Since we use PowerPoint and the Internet to present our work, PHA is seeking the donation of a light-weight (suitable for travel) LCD projector. If your company is upgrading and may have an older model to donate...or if you work for a company that makes or sells such products, please contact Karri Boyer at 301-565-3004 x110 or karri@phassociation.org.

Laptop Computer(s)

As we grow, PHA’s staff is traveling more—and mobile computing is becoming more important to us. If you or your company has one or more laptop computers or other office equipment you are able to contribute, please contact Karri Boyer at 301-565-3004 x110 or karri@phassociation.org.

Equipment contributions to PHA are tax deductible for the fair market value of the item.

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.

Carolyn L. Barra	Charlotte Martin
Warren Bobholz	Adele A. Matteson
Teresa Bodie	Regina Muller
Katheryn G. Bornost	Marcella Ocampo
Beatrice Brya	Helen Pellegrino
Robert Cherry	Mechthild M. Pladars
Barbara B. Covenah	Irving Pollak
Johana Fernandez	Eileen Przybylski
Floyd J. Green	Melissa B. Purdy
Connie Gutierrez	Angelina Renaldo
Earl D. Gutting	Valerie Saucedo
Sarah Ing	Sheila Small
Rose Jonez	Robert H. Smith
Alicia A. Judd	Henry J. Sockbeson
Mary L. LaBella	Nancy Toth
Marlene A. Lack	Thomas Veitch
Roderick L. Levesque	Robert L. Whitaker
John J. Majewski	Betty Whitsell
Lisa Marino	Neil Ziroll

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

Tip for Oxygen Users

Laura Strapp of Spring, Texas, recently began using oxygen full time and immediately felt the discomfort of sore ears from the tubing. She also wondered how other long time users kept from tripping over the tubing or stepping on it and suddenly having the cannula jerked from their faces!

After much thought, her daughter came up with a creative solution for the sore ears (from the tubing). She got a pacifier holder in the infant department of a local department store. “The one I like best is clear plastic, with a subtle giraffe on one side (but I turn that side in anyway). Clamping the holder to my shirt and looping a bit of tubing through the loop has taken all the pressure off my ears, and if I step on the tubing, it just tightens the loop a bit and tugs on my shirt rather than on my ears. I do plan to replace the bright yellow ribbon with a darker more adult one, but this has really helped!” wrote Laura in an e-mail to Shirley Craig.

Under 21



Under 21: Traveling to Children's PH Centers

*Nancy Frede, RN, Pathlight Children's Editor
Formerly PHA's Children's Committee Chair, Nancy has some helpful hints from traveling with her daughter Camille to New York City's Presbyterian Hospital and also includes tips from other parents' experiences.*

Traveling out of town/state/country to see your physician for Pulmonary Hypertension with your child? Few of us are fortunate enough to have the specialty physician within 30 minutes away. That means making travel plans, added costs and time to coordinate supplies needed etc...

Airlines: There are some agencies that will provide air travel for the child and one parent. You need to learn about the agencies and their requirements. Some examples are Miracle Flights, Wings of Mercy, and Operation Liftoff. Some schools/churches will ask families to donate those flight miles earned for a family so that medical care can be provided.

Oxygen: Be sure to make the oxygen arrangements when you order your airline tickets. Confirm with the airlines 48-72 hours before the date. If the airlines forgot, they still could make arrangements. Turn the oxygen payment into the insurance company; if they routinely reimburse for oxygen at home, they

should reimburse for the oxygen used while flying. Your oxygen company can make arrangements for the oxygen to be delivered to your hotel destination if you are being seen on an outpatient basis. Usually, medical companies are paid a flat monthly fee to provide you with oxygen. It is their responsibility to provide you with oxygen while you travel. If the oxygen company tells you that the cost of the oxygen will be your responsibility while traveling, check with your insurance company regarding covered services in the contract. The oxygen company makes the arrangements and lets us know who to call just in case our flight has been canceled at the last minute and we need oxygen at the airport hotel or the oxygen company waits to deliver the tank until we arrive to the hotel.

Lodging: Some hospitals may have access to putting you on a reservation list for a room at a local Ronald McDonald House. As rooms become available, those on the reservation list move to the top of the list. I call the Ronald McDonald House the week before to see where we are on the list. Sometimes it takes one-two months before your name is moved to the top to reserve the date you requested. Sometimes we don't make it to the top of the list. I make hotel reservations, too, just in case. The advantages are: The kids have play options in their free time such as video games with no charge, arts and crafts activities, free tickets to social events if available, interaction with other kids, free internet access for older children and parents, and kid programs on TV. The cost is usually minimal, for example, in NYC—\$20 a night. Parents are expected to launder their bed sheets before checking out. Refrigeration and freezers are available for medications. Washer and dryers are accessible for a

(Continued on page 11)

We would like to create a reference list of parents that could be contacted for questions about PPH centers/hospitals that could recommend great places to visit with the kids, places to eat, fun things to do for a number of locations. If you are interested, please let me know. For example:

NYC:

Favorite restaurants: Mars 2112, Serendipity, MacKenzie-Childs, Stardust Diner, Planet Hollywood—New York.

Favorite places to go: IMAX at Museum of Natural History, FAO Schwartz, Staten Island Ferry, Central Park Zoo

Museums: All.

Hotel: Excelsior or Ronald McDonald House

Families of kids under 21 have so much to offer, and we need your help. If you have suggestions, requests, ideas of things that we should continue to do or things that should be changed, stories to share in the newsletter, etc., we want to hear about it. Any of these can be mailed to:

Nancy Frede
2133 Maplerow
Walker, MI 49544
nancy.frede@metrogr.org

Teenagers and children are welcome to send in ideas. Your input and help would be appreciated.