



Pathlight

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

Spring 2001
Volume 10 • Number 1

This issue of Pathlight is dedicated to the life and accomplishments of Bonnie Dukart: April 29, 1956, to January 19, 2001

Bonnie lived in Ambler, Pennsylvania, with her husband and son. She was a former president of PHA and Vice President for Fund Development. Bonnie was diagnosed with PPH in January of 1982 and did well on calcium channel blockers for many years.

Bonnie had worked as a banker—first in operations and then in marketing—for a large New York bank, becoming one of the youngest female vice presidents by the age of 31. Since her PPH was stable, Bonnie and her husband Gary decided to adopt a baby. She worked until her son was 18 months old and then chose to stay home and enjoy being a mother. Volunteer work in community services and a part-time job assisting the comptroller of a local organization was a good mix with motherhood.

In 1992, Bonnie began researching PPH on the Internet. After a few months of phone calls and correspondence with other patients, she flew to Chicago for her first support group meeting. Bonnie had been diagnosed 10 years and was about to meet other PPH patients for the very first time. Bonnie then began volunteering for UPAPH in 1992 by starting a support group in New Jersey and taking calls from patients. She soon began applying the skills she had gained while working in corporate America and set up the mechanics of the hotline and did a limited amount of PR work. She co-chaired two



conferences, found volunteers to set up PHA's first web site, and set the pieces in motion for volunteers to write and review the book, *Pulmonary Hypertension: A Patient's Survival Guide*. Bonnie raised money for PHA's first leadership training seminar, hired PHA's first employee, and steered PHA from a kitchen table organization to the point where it needed and hired an executive director.

Bonnie was PHA President from 1996 to 1999 and then became Administrative Vice President for Fund Development. With the help of many able volunteers, enough money was raised in one year to award three grants to researchers in the field thus firmly establishing PHA as fundraisers and research supporters.

Facing a decline, she entered the UT-15 study in 1999 but switched to Flolan in 2000. Bonnie died following a double lung transplant at Duke University Medical Center.

Bonnie Dukart Memorial Fund

The Bonnie Dukart Memorial Fund has been established at the request of her family. The Fund will be used to further Bonnie's vision, including education on the importance of the early listing of PH patients for transplant. In recent months, Bonnie's interest in transplant issues had grown. Bonnie Dukart, former president of PHA, died on January 19, 2001. Contributions should be marked for "Bonnie Dukart Memorial Fund" and may be sent to:

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

IN THIS ISSUE

Tribute to Bonnie	1
Scleroderma and Transplanting	3
Fundraising	7
Board Biographies	8
Donation Acknowledgments	14
What's New at www.phassociation.org ?	16

“I cannot begin to express my gratitude for all your group has done in the days following my niece, Bonnie Dukart's untimely passing. We hope that you will be able to continue her work, as it was so very important to her to be able to fund research, support others and to generally be available for those affected by PH. Thank you.”

—Sue and Elliott Leavitt

A Personal Story about Transplanting

By *Bonnie Dukart*

In her own words and what have become her last thoughts for us, Bonnie's concern for others is overwhelming.

Here I sit, waiting for a phone call to tell me that my lungs are here. I am on oxygen all the time. Personal hygiene and dressing are tough. Sometimes, my husband needs to help me perform basic tasks. He basically does everything. Our son is living with friends. We've moved to be near a transplant center where I have a chance of getting lungs in time.

Will I survive? The odds are that yes, I will survive and will actually do well with new lungs, if I get them in time. But let's face it, the odds were that I would do well on Flolan, too. I have lost so many friends who never had that chance to transplant. Many didn't get on the transplant list when their doctors told them to list. Some were at centers that had long waiting lists, and they didn't know about transferring their time to a center with a shorter list. They died waiting. Some fought insurance companies to get listed at a center closer to home, not realizing that they should just get listed and fight later. Perhaps some doctors didn't want to give up on Flolan and tell a patient to transplant. As an active PHA member, I was surprised at how many misconceptions I had and at the lack of knowledge in the PH community. This has to change.

In the meantime, I beg you: Ask your doctor if you should get listed for transplant. If he or she says "yes," do it. Deal with the consequences later. Is it emotionally difficult? For me, it was. I cried. It meant admitting that perhaps medicine wasn't working. I had survived so long. How could this be happening? What happened? No one really knows. Four months ago, I was dancing at my son's Bar Mitzvah. One month ago, my PPH doc told me that my right ventricle was so damaged that Flolan couldn't help me.

I only had eleven months of time on a transplant list—not enough in my home region. We moved and I listed at Duke. Luckily, time on a transplant list is transferable. I have a chance of getting lungs in time. Hopefully, I will write a follow-up to this article and tell you how great it feels to have lungs that work. If not, you know what to do. GET LISTED. Give yourself another chance at life, an insurance policy if you need it.

1/17/01

Comments from those whose lives Bonnie touched:

"Bonnie's life was a gift to the PH community. She was the rock upon which PHA was built."

—Linda Carr

"She was a remarkable person, and I will greatly miss her."

—Gail Hayes

"Bonnie did more good in her life than most people come close to. If there is any victory in death, then it is hers. We have all lost a valuable friend."

—Rino Aldrighetti

"Without the contribution of people like Bonnie who took it upon herself to really make a difference for those affected by PH, we know our situation would not be as it is now. We thank God for what Bonnie did for the PH community and pray that He will give peace and comfort to her family and friends."

—Richard and Louise Griffiths

"I am sure we will forever miss her and all she did. She was so inspiring to me."

—Sharren Yamron

"This is a great loss to the PH community and we have lost a dear friend. I would like to think she is in a better place where she is running and breathing without difficulty and smiling at all of us."

—Carmen Skurdahl

"She was one of the kindest, most giving people I've ever had the privilege to know and we had become great friends. When I was first diagnosed with PPH, she was the second person I met with PH, and between talking with her and Lenna, they saved my life. And I know she has saved many others, either by giving her support and encouragement or by directing them to the right place to get proper treatment. She has left behind a great legacy and she really made a difference."

—Jan Travioli

"I am very sorry to hear about Bonnie's passing. She conversed often with Teresa in the early days of PHA, and the growth of the organization while and since she was president is incredible. Everyone is better for the knowing of her."

—Bob Knazik

"She was always a source of strength and hope for me because she had lived with PPH for so long. I am proud to see she was fighting and optimistic until the end. I am very sorry for her family, and I will pray for them."

—Kathy Levitt

"Please convey my deepest sympathy to Bonnie's family. She turned what we know to be a terrible illness into an opportunity to help and inspire others."

—Adaani Frost, MD

"I will miss Bonnie tremendously. She was a wonderful and special human being."

—Greg Elliott, MD

Correspondence may be sent to Bonnie's husband and son or her parents.

Gary and Brian Dukart
1714 Benjamin Drive
Ambler, PA 19002

Selma and Robert Smith
11 Ruey Place
Plainview, NY 11803-3216



“I was saddened tonight to read of the death of Bonnie Dukart, a long and heroic founder and supporter of PHA. Bonnie was the first real PHA patient I talked to when I was diagnosed in 6/99, having been given her number by a friend of my daughter-in-law’s. When I called, Bonnie was having a “couch day” but she was nonetheless helpful, encouraging, and most importantly, she turned me onto the PHA bulletin board and other web sites. She urged me to get listed for transplant, if I could, as insurance for the future. Shortly before my 58th birthday I did get listed even though I manage pretty well currently. She gave me courage and the belief that I could have a future even though I had been given the usual message by my docs—“retire, put your affairs in order and we think you’ll live 2-3 years.” She was a remarkable, generous and talented woman. I never met her, but my gratitude to her is boundless and she will be in my thoughts forever.”

—Kathy Forrest
Portsmouth, New Hampshire
(posted to the PHA Message Board, January 2001)

Persistent Voices

Being diagnosed with pulmonary hypertension and striving to live a quality life with the challenges that accompany such a serious illness is difficult at best. But we all manage to do it for as long as we can. All of us seem to find some way to get through each day.

Stories of personal courage and dignity in *Persistent Voices* allow others to benefit from your experiences. Please take this opportunity to have your story published. Pictures, poems, and drawings are welcome. *Persistent Voices* is your venue to the world—your chance to say, “I was here!”

Please include a self-addressed stamped envelope for anything you want returned and send submissions with your phone number to:

Brad Belliston
P.O. Box 18127
Kearns, UT 84118
801-968-2869 (also fax)
bbelliston@uswest.net

Transplanting and the Scleroderma PH Patient

By Holly Tucker

For eight and one-half years after being diagnosed with scleroderma, I had lived a normal life, not without problems, but I was able to complete 30 years of teaching in June of '98. My husband, Tom, decided to take early retirement at age 55 after having survived a liver transplant at the University of Chicago in 1994. Our dream was about to come true! We moved to New Mexico and lived in our cabin in the northern mountains while awaiting the move into our newly built home north of Albuquerque. We eagerly anticipated the beginning of our new “retired” life.

Shortly after moving, my breathing became labored, and in the fall of 1998, I was diagnosed with mild to moderate interstitial lung disease at the University of New Mexico Hospitals. Follow-up CT scans and pulmonary function tests showed that the disease appeared to be stable.

Tom and I made numerous trips to our cabin during the next summer and fall. By the end of October, I could barely walk across a room or prepare meals. Fortunately, I had previously made an appointment at National Jewish Medical and Research Center in Denver, Colorado. I wanted a pulmonary specialist at one of the finest respiratory centers in the country to evaluate my interstitial lung disease: National Jewish has been ranked #1 globally in respiratory diseases for the past three years.

After several days of testing, a cause for my severe breathing problems could not be explained. My interstitial lung disease had not progressed since the diagnosis. I was sent to see a cardiologist at the University of Colorado several miles away. The doctors there work jointly with the doctors at the National Jewish Center. On a bleak November day, Tom and I received the news that I had severe pulmonary hypertension. A right heart catheterization confirmed the diagnosis. I was given the option to begin Flolan therapy as soon as possible. I would do *anything* to extend my life. I asked about the possibility of having a lung transplant, and I was told that since I had scleroderma, I could not be listed at the University of Colorado. I asked where I could go to get a transplant, but none of my doctors knew for certain of any hospital currently accepting scleroderma patients. For that reason, I decided to write this article. Hopefully, it can be of help to those of you who face a similar situation.

I have never been one to not work vigorously at something that mattered to me. I have always tried to achieve excellence in anything I did. Now, my life was on the line. I began Flolan therapy, and slowly my exercise tolerance improved, but I knew that I needed an insurance policy in case my condition deteriorated. I wanted to be evaluated for a lung transplant, but where?

With a little luck and plenty of work, I learned of two hospitals that have been performing lung transplants on scleroderma patients for approximately 10 years: the University of Pittsburgh and the University of Texas at San Antonio. I called both institutions and was told to send my medical records

(Continued on page 4)

Transplanting and the Scleroderma PH Patient, *continued from page 3*

for review by their transplant teams. Shortly thereafter, I was invited to be evaluated at both hospitals. We chose Pittsburgh because family members live nearby. On March 10, 2000, my name was officially added to the lung transplant list at the University of Pittsburgh. What a victory!

Many months of fighting with our insurance company ensued. I was told I had to have the operation at one of the dozen centers which they considered to be their lung transplant “centers of excellence.” It took many months, letters, calls, and moments of total frustration before I could make the insurance company review board understand that my operation would not be a “normal” lung transplant. Scleroderma complicates the procedure due to problems with the esophagus which most scleroderma patients experience. The fear is that because of esophageal dysmotility, contents of the stomach might aspirate into the lung causing infection or pneumonia, which is difficult to fight while taking drugs to suppress the immune system. Fortunately, I “passed” all of the tests needed to be placed on the lung transplant list, including the dreaded 24 hours pH probe to measure the acidity in the stomach (I do take Prevacid daily). What I was told probably couldn’t be done became a reality this past June when I received a call from my insurance company. I was granted a waiver for transplantation at the University of Pittsburgh!

I have discovered *many* things about my disease, doctors, hospitals, insurance companies, and myself during the past nine months. Let me share some of what I’ve learned and what I’ve felt during that time.

1. Seek out the best physicians for your medical condition. These doctors practice, for the most part, at major medical centers. Even if you have to scrimp and save to travel, do it. It’s your life! Don’t let final diagnoses and decisions be made by your family physicians, no matter how much you might love them. They might make the correct diagnosis, but then it’s time for an expert second opinion. Let the specialists decide on a course of action. A concerned family physician knows that. My internist correctly told me that I had *crest*, but then said it was time to have a specialist evaluate me. Time is the key. Don’t wait!

2. After finding a physician, make sure you trust that person. Ask questions: How can I reach you? Are you willing to give me phone numbers where I can actually talk with you? You’re looking for a doctor who treats you as a very important *person*, not just as a patient.

3. Even the best doctors don’t know all of the answers. *Never take no for an answer.* Fight for yourself, or if you’re too ill, have someone fight for you. Search, research! Read, call, use the Internet. Do this until you are satisfied. The head of pulmonology at a prominent hospital did not know about Flolan when I mentioned it. Remember, doctors are highly intelligent people, but no one can know *everything*!

4. Be compliant. When your doctors advise you to do or not to do something, make sure that you follow their instructions. I do *not* like having a tube protruding from my chest in order that

I can receive Flolan. I do *not* like having to carry the pump with me as if it’s a part of my body. I do *not* like having to use oxygen 24 hours a day, *but I do!* Remember, it’s your life, and you might have to sacrifice many things. Tom and I have to move to sea level because of the high altitude where we live in New Mexico. I also need to be near a pulmonary hypertension center. I can’t go back to our cabin in the mountains, but as difficult as it is to do things or not to do them, I do what is best for me!

5. If you are put on a transplant list, and you have difficulty with your insurance company deciding to cover the procedure, don’t give up. There are several things you can do. The center where you are listed can do most of the work for you. They provide the insurance company with the needed information in order for them to make a decision. I also found it is extremely beneficial to speak with the same person when discussing issues. It’s very difficult to explain your situation over and over again to different people. I asked my other doctors to write letters on my behalf explaining why the University of Pittsburgh was an excellent choice for me based on their record of performing transplants on scleroderma patients, even though Pittsburgh is not on their list. I made weekly phone calls to my case manager to find out where we were in the decision process. After months had elapsed, I became concerned. Several of my physicians recommended that we seek an attorney to “make our case” to our insurance company if we did not receive a positive answer. My internist told me that studies have been done indicating that insurance companies tend to make favorable decisions when nudged by the threat of legal action if the situation is warranted. Thankfully, Tom and I received the answer for which we had waited before that became necessary.

Our adversity has become a learning experience. During the past months, I have met or spoken with many wonderful people. Larry Rolfe, a long-term single-lung transplant survivor whose surgery was performed at the University of Texas at San Antonio, celebrated his 10th anniversary in July. His surgery was the second transplant on a scleroderma patient at that center. His story was published in the Fall 1998 issue of the *Scleroderma Foundation Newslines*. Larry can be reached at 936-321-2789.

Bill Settino received a double-lung transplant in October 1999 at the University of Pittsburgh. When we last spoke, Bill was feeling terrific. He is willing to speak with people about his experiences. He can be reached at 412-486-5119.

Tammy Campbell received her new lung at the University of Alabama in Birmingham last April. Feel free to contact her at 205-934-5400.

I am doing well on Flolan. My pulmonary artery pressures have decreased, my heart has decreased in size, and my exercise tolerance has increased. I still use oxygen 24 hours a day, but when we move to sea level, I will only have to use it while I sleep. Each day that goes by, I am accumulating days on the transplant list at Pittsburgh. All of my doctors, including the Pittsburgh transplant team, told me to undergo surgery only if my condition deteriorates. “Keep your own lungs as long as you possibly can,” they said. However, I was also told I had done

Transplanting and the Scleroderma PH Patient , *continued from page 4*

exactly the right thing by getting my name on a transplant list. If my name comes to the top, and I am offered a lung, I can say no and still remain at the top of the list. If I deny it again, I will probably be placed on the inactive list, but would not lose my "place in line." Hopefully, if the time comes, I will receive the Gift of Life!

Because of the difficulty I had in locating lung transplant centers that will evaluate and transplant scleroderma patients, I did some research and have compiled the following list. Remember that there are no guarantees that you will be accepted as a candidate. Each case is evaluated on an individual basis no matter where you go, but the following institutions will not *automatically* say no because you have scleroderma.

I am listing the following centers with the University of Pittsburgh and the University of Texas at San Antonio at the top because they have the most experience transplanting scleroderma patients. Included in each listing are the most recent statistics I was able to obtain from the lung transplant coordinators at each institution. The listing includes the transplant coordinators' names or other contact people, a phone number where they can be reached, the number of *total* lung transplants for any reason—any disease during the last 10 years or since their program began, and the number of scleroderma patients who have been transplanted. These statistics are approximate in some cases.

1. **The University of Pittsburgh Medical Center: Presbyterian University Hospital**
Judy Vensak, Jan Mansetti
412-648-9136
Total # of lung transplants: 636 since 1982
Number of scleroderma patients: 15
2. **The University of Texas at San Antonio**
Tricia Jones, Terri Cronin
210-567-5777
Total # of lung transplants: 155 since 1988
Number of scleroderma patients: 5
3. **Cleveland Clinic**
Kathy Hague, one of 4 coordinators
800-223-2273, ext.51756
Total # of lung transplants: 214
Number of scleroderma patients: 2
4. **Duke University**
Julia Curl, Jean Rea, Cindy Lawrence
800-249-5864 or 919-684-2240
Total # of lung transplants: 294 since 1992
Number of scleroderma patients: 1
5. **The University of Alabama in Birmingham**
Trina Smith
205-975-8615
Dr. Randy Young
205-934-5400
Total # of lung transplants: 223 since 1989
Number of scleroderma patients: 1 listed
6. **The Methodist Hospital—Baylor College of Medicine**
Ann Marie Elston
713-790-2501
Total # of lung transplants: 147 since 1987
Number of scleroderma patients: 1
7. **Vanderbilt University Medical Center, Nashville**
Andrea Morgan
615-936-1350
Total # of lung transplants: N/A
Number of scleroderma patients: 1
8. **The University of Washington in Seattle**
Kim Hoffman, Becky Stermer
206-543-3093
Total # of lung transplants: 128 since 1992
Number of scleroderma patients: 0 transplanted/1 listed
9. **Methodist Hospital of Indianapolis, Indiana**
Wendy Johnson
800-510-2725
Total # of lung transplants: 168
Number of scleroderma patients: 0 transplanted/1 listed
10. **USC University Hospital, Los Angeles**
Jay Onga
323-442-8419
Total # of lung transplants: N/A
Number of scleroderma patients: 0 transplanted/1 listed
11. **The University of Wisconsin Hospital and Clinics, Madison Lung Transplant Center**
608-263-7832
Total # of lung transplants: 163 from 1992-99
Number of scleroderma patients: 0 transplanted

If anyone else has other pertinent information, I urge you to contact The Scleroderma Foundation.

Good luck to those of you who are in a similar situation as I am. The most important thing is not to wait! Act now. Find a transplant center while you are still healthy enough to endure the waiting time on the list. Remember to fight the good fight!

If you have any questions, or would just like to talk, my name is Holly Tucker. By the time this article is published, Tom and I will have moved to the San Diego area: great pulmonary hypertension center and located at sea level! Our new phone number is 760-451-2767 and my e-mail is tuck@tfb.com.

It is very important for PH scleroderma patients to check out this information for themselves. Make the calls! Find out...

Organ Donation Statistics

On January 20, 2001, the UNOS national patient waiting list for organ transplant included the following:

Type of Transplant	Patients Waiting for Transplant
kidney transplant	47,622
liver transplant	16,861
pancreas transplant	1,040
pancreas islet cell transplant	179
kidney-pancreas transplant	2,439
intestine transplant	150
heart transplant	4,162
heart-lung transplant	208
lung transplant	3,690
Total	*Total Patients: 74,039

NOTE: UNOS policies allow patients to be listed with more than one transplant center (multiple-listing). Thus, the number of registrations is greater than the actual number of patients.

*Some patients are waiting for more than one organ, therefore the total number of patients is less than the sum of patients waiting for each organ

Number of Transplants Performed in 1999

Type of Transplant	Number
kidney alone transplants (4,457 were living donors)	12,488
liver transplants	4,697
pancreas alone transplants	362
kidney-pancreas transplants	930
intestine transplants	70
heart transplants	2,182
heart-lung transplants	49
lung transplants	877
Total	21,655

Number of Donors Recovered, 1999

Type of Donor Recovered	Number
Cadaveric	5,859
Living	4,717
Total	10,576

http://www.unos.org/Newsroom/critdata_main.htm#transplants

Drug Study Trial Updates

Tracleer™ known in studies as bosentan, was submitted for approval to the FDA in late 2000. In early study results, Dr. Lewis Rubin stated “The improvements were significant enough that 43 percent of patients (9 of 21) receiving Tracleer™ were reclassified as ‘moderate’ from their previous ‘severe’ status, as compared to only 9 percent of patients (1 of 11) receiving placebo.” Tracleer™ is in development as the first oral dual endothelin receptor antagonist. Endothelin is the most potent vasoconstrictor known, and endothelin levels appear to be abnormally elevated in pulmonary hypertension (PHT) and acute and chronic heart failure (AHF and CHF). In PHT, the pivotal clinical trial of Tracleer™ showed encouraging results when compared to placebo, with adverse events being similar in type and frequency between the two groups.

—Excerpted from First Oral Therapy for Pulmonary Hypertension Shows Positive Results in Phase III Trial

Editor's Note:

United Therapeutics has requested approval from the FDA for a name change from Uniprost (UT-15) to Remodulin™ —if all goes well, Remodulin™ should be approved by spring.

Tracleer™ (bosentan) is in the process of going through the FDA; total clinical trial results should be submitted this fall.

FUNDRAISING

Fundraisers and Updates

Houston Golf Tournament

The third Cure PH Golf Tournament will be Thursday, March 29, 2001, at the Cypresswood Golf Club with the Gala following on March 31 at the Westin Oaks Hotel in the Galleria Shopping Center. Contact Jack Stibbs (281-367-2222) or Jim Wilson (972-931-9311) for more information.

Mall Fund Raiser

by JoAnne Sperando Schmidt

The Greater New York Support Group participated in an annual fund raising event sponsored by the Westfield-owned malls on November 19, 2000. One day in November of each year, Westfield closes its doors at normal closing time and re-opens an hour later, admitting only people who've purchased a ticket from a participating charity. The stores offer discounts, door prizes, and other contests; there may be entertainment or a celebrity signing autographs and Santa is always there for the kids.

Participating charities sell tickets for \$5, all of which goes to the organization you've selected. Members of the New York support group sold tickets to friends, family and co-workers. We pooled all the ticket sales and raised over \$3,000 for PHA and asked that it be earmarked for research.

The night of the event, we all wore our PH T-shirts and jackets. One of our members even put a sign on her wheelchair to thank everyone who purchased tickets in her honor. It was the easiest way of raising money that we've seen so far! We plan to do it again next year and are looking into additional malls since our membership is fairly spread out. Ask your local shopping mall if they sponsor any fund raising events!

Garage Sale

by Marti Wheeler

The Saverino and Wheeler families of Indianapolis, Indiana, pooled their goods and hosted a garage sale on October 6, 2000. In addition to raising funds for a good cause, the families of Roxanne Saverino and Marti Wheeler (both PH patients) also focused on raising community awareness about pulmonary hypertension. \$300 was collected and donated to PHA. Roxanne and Marti are now putting their energy into founding a local support group in Indiana with their first meeting on January 10. Contact Roxanne at 317-887-8471 for more information.

Update: 'Racing for a Good Cause'

by JoAnne Sperando-Schmidt

A special guest, George Stack, was on hand at the surprise 40th birthday party thrown for John Sperando by his family. George and his wife attended and he presented us with a \$1200 check for PHA. This money represents George's winnings from a national race in September where he placed second out of 130 cars. John and I were at the race and in the final match the announcer said, "And here's George Stack of Northport, New York, with his Pulmonary Hypertension racing car—racing for a good cause!" Of course, we were flabbergasted when George gave us this check. You see, he's done all the customization to his car out of his own pocket. He had also been buying our PH T-shirts and giving them away to all his racing friends so we saw people with PH T-shirts all around the race track! George's generosity knows no bounds, and we are so grateful to have him as our friend. "See *Racing for a Cure*" in the Winter 2000 issue of *Pathlight*.

NEXT ISSUE!

- Read about two cousins who were diagnosed within a year of each other.
- More about the web site changes.
- Research Corner returns.



C u r r e n t O f f i c e r s &

Meet the people who put in many tireless hours on behalf of PHA's members.

Linda Carr, President, 2004



Linda lives in Miami Springs, Florida, with her attorney husband, Austin, and three children—Cody, Hannah, and Abby. Hannah, now an active teenager, was diagnosed with PPH in 1993 and has been treated with Flolan since 1994. Linda graduated with honors from the State University of New York at Potsdam in 1979. She worked as a teacher and in the entertainment industry in Los Angeles before starting her family. Linda has been active in various school, sports, and church organizations. She has been a member of the Pulmonary Hypertension Association board of trustees since 1997. She coordinated the childcare at the 1996 and 1998 PHA Conferences and served as nominating committee chair in 1997 and 1998. She served on the Burroughs Wellcome new drug (Flolan) advisory committee as a patient advocate. Linda and her husband organized the first "Miami Cure PH" golf tournament in April 2000. She was elected PHA president in January 2000.

Candi Bleifer, Vice President, VP of Education, Nominating Committee Chair, Planning Committee, 2003



Candi lives in Studio City, California, and was diagnosed with PPH in January of 1997 as a result of being on the Phen-fen diet. She has been on UT-15 for two years. Having PPH has robbed Candi of a lot of the opportunities that most moms take for granted, like carrying her children around and playing chase with them at the park. Her primary motivation in working with PHA and the Board of Trustees is to further awareness of pulmonary hypertension. Candi and her husband Scott are both attorneys. Candi was able to continue to practice law, doing estate planning, wills, trusts, corporate, and non-profit law for the first two and a half years after her diagnosis. In July of 1999 she made the decision to devote her limited energy to her family and to fighting for a cure for PH. Candi has been in charge of responding to all of the inquiries that come into the PHA web site since March of 1998. She enjoys this aspect of volunteering for PHA because through the Internet she is able to help newly diagnosed patients find the knowledge they need to get proper treatment with doctors that understand and treat this disease. Candi was the Southern California support group leader. Candi is vice president and reviews PHA's legal issues.

Jack Stibbs, Vice President of Advocacy, Personnel Committee Chair, 2002



Jack lives in The Woodlands, Texas, with his wife Marcia and two children. His eight-year-old daughter has PPH. Jack is a lawyer and handles many legal matters for PHA. Jack joined the PHA board in 1999 and is administrative vice president for advocacy. He also organized PHA's largest research fundraiser, the annual Cure PH Houston Area Golf Tournament and Gala, now going into its third year. Jack has been working closely with Congressman Brady (TX) on several Advocacy issues with the main focus being the introduction of the Pulmonary Hypertension Research Bill of 2000 into Congress. Another focal point is an increase in funding to the National Institute of Health for PH research, a joint venture with the National Heart, Lung, and Blood Institute to leverage public money with PHA private money for increased PH research.

Betty Wojciechowski, Vice President of Support, Secretary, Conference 2002 Committee, 2003



Betty, a mother of four, lives in Mission Viejo, California, with her husband Jerry, a PPH patient. Betty and Jerry lost their youngest son Matthew at age four to PH in 1983 and their oldest son Michael at age 24 to PH in 1997. Children Michelle and Mark and granddaughter Christiana receive yearly echocardiograms to detect any signs of PPH. After Jerry's diagnosis in 1994, the entire family became involved with PHA (then UPAPH) and formed a support group at UCLA-Harbor. They published the newsletter "Lung and Times" that was sent to more than 120 PH patients in California. Jerry was a part of the Flolan clinical trials and was on the patient advisory board to Glaxo Wellcome. Jerry and Betty were also the National Support Group Coordinators. Since 1995, the family has been involved with the International Study of Familial PPH located at Vanderbilt University and the University of Utah in Salt Lake City. Betty was elected to the board in 1996 and later became the second VP, working closely with her dear friend Bonnie Dukart. Jerry and Betty were involved in the leadership conference in June of 1997, and both have worked as presenters, hosts, and moderators at PH conferences. Betty's words say it best: "I want to be a light to the world and especially to those walking the road we have already walked. I want to bring them the all-important messages that 'You are not alone!' and 'Together we can make all the difference in each other's lives!'"

Board Members 2001

**Jerry Paton, Treasurer, Finance Committee Chair,
Personnel Committee, 2002**



Jerry lives with his wife Pat, a PH patient, in Indiantown, Florida. Jerry and Pat are founders of PHA. Jerry was a member of the original board and co-treasurer during PHA's first two years and is treasurer today. Jerry has worked with exacting budgets during his business career. He owned and operated Paton's Dairy Queen

Brazier stores and has worked in sales management for several radio stations.

Carol A. Wilson, Assistant Treasurer, 2004



Carol lives in Tucson, Arizona, where she works as an accountant for a large firm. She is the stepdaughter of Dorothy Olson, one of the founders of PHA. Carol was aware of the organization and its work from the beginning and became actively involved when elected to the board in January of 1996. Carol is serving in her

third term as assistant treasurer for PHA. Her responsibilities include preparing the financial statements and overseeing the audit and the tax return. Carol has served on various committees including by-laws, support groups, caregiver award, and accounting for the 2000 conference.

**Diane Adkins, Volunteer Coordinator,
800-number Coordinator, 2003**



Diane lives in Florida during the winter months and returns to her home in Bridgeton, Missouri, for the summer. She was diagnosed with PH in 1995 and decided to continue working outside the home. Diane is in sales and travels about 50,000 to 60,000 miles per year putting in about 60 hours a week. Part of her job involves training

so she looks forward to training the 800-number volunteers during conferences. Continuing to work is very important to Diane and her independence from PPH. Flolan helps her maintain her busy lifestyle. Through PHA, Diane has met the most wonderful and devoted people of her entire life.

**Bruce Brundage, MD, Scientific Advisory Board Chair,
Research Funding Committee, 2003**



Dr. Brundage lives with his family in Bend, Oregon, and sees patients at the Bend Memorial Clinic. Before moving to Oregon, he treated PH patients at the UCLA-Harbor Medical Center in California. Dr. Brundage has treated many PH patients and has encouraged other doctors to study this disease. Dr. Brundage has been a part

of PHA's Scientific Advisory Board from its inception and was elected by his peers to be the SAB's chairman. Dr. Brundage has always been willing to help in any way asked—from looking over press releases to be sure the medical explanations were accurate to serving on the PHA board. He was awarded the Kenneth Moser Physician's Award for his outstanding contributions to PHA during the Fourth International PH Conference held in Chicago in June 2000.

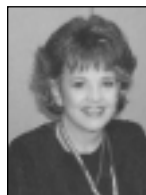
Laura Hoyt D'Anna, on leave of absence, 2004



Laura has more than a decade of experience in the development and administration of public and community health agencies and programs. She currently serves as VP of community affairs for Planned Parenthood of Orange and San Bernardino Counties in California. Among other things, Laura is responsible for fund

development activities including government and private foundation grant administration, board development, community partnership building, personal solicitations and special events for a non-profit 501(c)3, community-based clinic with an \$11-million annual basis. She also plays a key role in the agency's strategic planning, program and service implementation, and budgeting activities. Laura earned a BA degree from Whittier College and a master of public administration from California State University, Long Beach. She is in the process of completing a doctorate in public health from UCLA. Laura's sister lost her battle with PH several years ago.

Pat Gunn, Conference 2002 Committee, 2004



Pat lives in San Antonio, Texas. In 1993, while living on a ranch in West Texas, Pat's husband David was diagnosed with PPH. They sought treatment and information that soon led them to PHA, where they both came to be very supportive volunteers. David sent out new-member packets and organized board

meetings while Pat took on organizing conferences as the 1998 and 2000 Conference Co-chair. Pat also served as secretary of PHA. David lost his battle with PH in 1999; Pat remains part of the PHA family as a board member.

C u r r e n t O f f i c e r s &

Mark Jeter, Finance Committee, 2004



Mark is president of TCF National Bank Minnesota, headquartered in Minneapolis. He was named to this post on October 1, 2000, after serving as president of TCF National Bank in Michigan. He graduated from the University of Minnesota with a degree in business administration and economics. He is also a

graduate of Stonior School of Banking, a distinguished school for executive management in the financial services industries. Mark will continue his active involvement in the community. Key appointments include the boards of directors of the Metropolitan Housing Corporation, the Minnesota Chapter of the March of Dimes, and the Minneapolis Downtown Council. Mark and his wife have a five-year-old daughter with PPH who is currently on Flolan. He and his family have been very helpful in raising money for research.

Thomas F. Linnen, Planning Committee, Organization Restructuring Committee, Advocacy Committee, 2003



Tom lives with his wife Mary Jo in Ponte Vedra Beach, Florida. Tom and Mary Jo lost their youngest daughter Mary to PPH on February 22, 1997. Tom is a General Partner in MLM LP. He has had a long career in business and government having served as Vice Chairman and President of an international strategic

management consulting group serving industrial and Fortune 500 companies. He has also worked in various upper management positions with an international NYSE administrative and data based information company, in a special assignment with the Central Intelligence Agency, as an aide for three U.S Congressmen on Capitol Hill, as an aide in the Office of the Secretary Army, and as a public relations assistant to the President of a major eastern university. He has held commissioned officer rank in the U.S. Air Force and the U.S. Army and holds the rank of Major, USAR. He has served actively on several corporate, college, and institutional Boards and has been active in national presidential campaigns, civic fund raising campaigns, and in community and church affairs. Tom and Mary Jo have established within the PHA the *Mary Linnen Memorial Fund* that helped launch the PHA's Advocacy Project in 2001. He was appointed to complete Bonnie Dukart's term as a Trustee-at-Large.

Sally Maddox, Conference 2002 Committee, 2002



Sally lives in Rome, Georgia, where she worked as a full time insurance agent for State Farm for six years. Recently, Sally was able to put her BS in math education to work by returning to teaching math at a public alternative school, something she did not think she would be able to do. Sally has served as PHA's vice president of education and a board member for two years. Sally has been the Georgia Support Group Leader for three years, on the PHA Conference 2000 Committee, and involved with PHA for more than seven years. She is the editor of *PHAnews*, a bi-weekly Internet information resource for patients and caregivers. She is a 10-year PPH patient on calcium channel blockers and coumadin. Sally is involved at home as publicity chair and church clerk for her church and volunteers for the Red Cross Disaster and Crisis Pregnancy Center.

Dorothy Olson, Nominating/Board Development Committee, Personnel Committee, 2003



Dorothy lives in Sebring, Florida, and has been on the Board of Trustees from PHA's beginning. She remains a familiar figure and voice to many PH patients. Dorothy worked as an office manager for Agway and reviewed procedures in other Agway offices to facilitate operations as needed. Dorothy is one of the founders of PHA and has continued to make major contributions throughout the past 10 years. She has worked on the *Pathlight* newsletter, served as secretary, and chaired many committees, such as "By-laws and Articles of Incorporation." Dorothy regularly takes a turn answering the 800-number hot line, sharing all she has learned about coping with PH.

Susan Salay, Conference 2002 Committee, 2004



Susan has more than 20 years of experience in sales and marketing. Before "retiring" last year due to her PPH, she owned her own consulting company called The Channel Group. She has owned her own retail businesses and has an enviable record of handling sales and marketing for numerous successful start-up companies. At Ingram Micro (an international multi-billion dollar computer products distributor) for 10 years, she served as VP of marketing, with responsibilities that included product and strategic marketing and managing a staff of more than 45 marketing professionals. As an independent consultant, she has worked with companies in the fields of educational software, computer memory, CPU's, Internet products, networking,

Board Members 2001

telephony, peripherals and others. Susan is a graduate of Pepperdine University with a degree in business. She has had PPH for about 4½ years and has been doing well on UT-15 for the past 18 months.

Edwin L. Simpson, Planning Committee Chair, 2002



Ed lives in Holiday Island, Arkansas, and has been a part of PHA since its inception more than 10 years ago. He was a Professor and Director of Faculty Development for 30 years at Northern Illinois University. He is a co-founder of the United Patients Association for Pulmonary Hypertension (later to become the PHA). Ed was co-chair and the designer/planner of two International Pulmonary Hypertension Conferences—the first in 1994, then 1996, both held at Stone Mountain, Georgia. Ed was the grant writer and chair of the first Pulmonary Hypertension Association Leadership Conference held in Chicago, Illinois, in June of 1997. Ed has served as vice president of PHA in 1996 and 1997 and as president in 1999. Ed also served on the board of directors for the National Organization for Rare Disorders (NORD) in Fairfield, Connecticut, from 1994 to 1999.

Barbara L. Smith, Conference 2002 Committee, 2002



Barbara lives in Odessa, Florida, and has been a PHA member since 1996. She was diagnosed with PPH in 1995 and has been on Flolan treatment since early 1996. She has volunteered for PHA in various capacities since joining. Barbara's PH is familial, having lost a sister and a daughter to PH prior to her diagnosis. Barbara

has been on the PHA conference committees and works hard to ensure their success. She also sends out new-member packets, pins, and "Art from the Heart" Cards. Barbara works with her husband operating an electrical contracting company in Oldsmar, Florida.

Jan Travioli, Transplant Issues Committee Chair, 2004

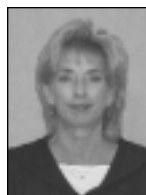


Jan lives in Durham, North Carolina, and was diagnosed with PPH in December of 1995. She was immediately listed for transplant and went on Flolan in March of 1996. After being connected with a few members of the PHA board of trustees, she got involved with PHA by attending the 1996 conference in Stone

Mountain. In 1997, Jan took over as editor and publisher of the *Pathlight* newsletter until spring of 2000. During this time she also designed many other publications for PHA, such as brochures, flyers, and conferences booklets. She helped with web site development as well. Because of her PPH progressing,

Jan reactivated on the transplant list, had a double-lung transplant in July of 2000 and is doing well. She plans to become involved again with PHA as her health permits.

Lenna West, Research Funding Committee Chair, 2004



Lenna lives in Greenville, North Carolina, and was a practicing nurse until 1995 when she was diagnosed with PPH. She has been on Flolan for more than four years. Lenna has served on various committees, such as working with the American Heart Association and PHA to develop criteria for choosing recipients for PHA's first fellowship grants. She organized the lists for the gifts section of the *Pathlight* and sent thank-you notes to all donors. Lenna is also PHA's liaison with the National Organization for Rare Disorders and chair of the research funding committee.

Jim Wilson, Events Coordinator, 2004



Jim is retired from the Air Force and lives in Dallas, Texas, with his wife Debbie who was diagnosed with PPH in December 1997. He has been involved in healthcare operations and management and telecommunications for more than 26 years. His education includes a master's degree in administration and a bachelor of science in business management. He serves as the tournament director for the Dallas/Ft. Worth Cure PH Golf Tournament and provides assistance to any group wishing to conduct a golf tournament to raise money for PH research through his "Golf in a Box" program. Jim is now the events coordinator for all PHA fundraiser events.

Kathy Windhorn, At Large, 2002

Kathy lives in Columbia, South Carolina, and serves as the librarian for PHA. She is also the state coordinator for South Carolina. As librarian, Kathy catalogs articles, books, and medical journals featuring material about pulmonary hypertension and keeps it available for lending to the PHA membership. Kathy also processes the orders for the conference video and audio tapes for members wanting to purchase or borrow them. She has helped to coordinate the 800-number volunteers and also hosts and moderates at the PH conferences. Kathy was diagnosed in July 1994 and faces the challenges of living with PH every day.

Current Officers & Board Members 2001

Board Emeritus

Harry J. Olson, Caregiver's Committee Chair



Harry lives in Sebring, Florida, with his wife Dorothy, a long-time PH survivor. Harry worked in industrial air-conditioning as a design and service representative. He retired in 1980, moving from Indiana to Florida when Dorothy was diagnosed with embolic pulmonary hypertension. Harry enjoys fishing and trap shooting. Both Harry and Dorothy were original founders of UPAPH/PHA, with Harry serving on the board until 1997. Along with caregiver activities, he is still actively involved working along with Dorothy and attending all board meetings. Harry has served in various capacities at all PH conferences and received the first PHA Caregiver Award in 1998. Harry now chairs the caregiver committee and sponsors the Olson Caregiver Award. Harry designed and commissioned the PHA "Kitchen Table" banner that was presented to PHA at the 2000 conference.

Pat Paton, Finance Committee



Pat lives in Indiantown, Florida, with her husband Jerry. Both have been a part of PHA from the beginning, with the first organizational meeting being held at Pat and Jerry's home in December of 1990—the original "kitchen table." Pat has served in many capacities with UPAPH/PHA, including assistant treasurer and board member. At conferences, Pat has been a host, moderator, and presenter. She regularly contributed to the *Pathlight* when it began publishing. Pat assists Jerry in his office as treasurer.

Pathlight Submissions

Have an article, announcement, quote, photo, or tribute to share? Please send it to us with your phone number. Work submitted will be published as space permits. If you would like your manuscript returned to you, please include a self-addressed, stamped envelope. PHA cannot be held responsible for materials lost. Mail submissions to:

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

Deadline for the Summer issue is April 30.

Judith A. Simpson, Nominating/Board Development Committee, Research Funding Committee



Judy lives in Holiday Island, Arkansas, with her husband Ed. Judy has been a pediatric nurse for 44 years and taught pediatric nursing at Kishwaukee Community College in Malta, Illinois. Judy was the founding president of UPAPH, now PHA. Judy and Ed have both served as board members and officers. Judy was a part of the "kitchen table" with her sister, Pat Paton, who has had PH since 1997. Judy was a Treatment Investigation New Drug Advisory Committee member for Burroughs Wellcome Company as patient advocate and testified before the Senate Judiciary Committee on the need for research for rare disorders. She was a member of the National Institutes of Health, Heart, Lung and Blood Institute Advisory Council as a patient advocate. Judy relates that "PHA has set a new paradigm in the way a support group collaborates with physicians, researchers, pharmaceuticals, home health agencies, and government, making us a model many support groups now are following."

Rino Aldrighetti, Executive Director of PHA



Rino was hired as PHA's first professional staff person on January 1, 1999. He worked as PHA's executive director on a part-time basis for two years. During that time, he continued to operate his consulting business. In 2001, Rino became a full-time PHA employee.

Rino's background is in fundraising, association management, and community organizing. He has led a number of organizations. These include National Voluntary Organizations Active in Disaster, an association of 34 of the major US disaster responders, and Neighborhoods Together, an association of 118 community, labor, and religious groups that he founded in Maryland. He also established new development departments for the National Alliance for the Mentally Ill and the National Council for Adoption.

Through his consulting work over the past decade, Rino has provided management and fundraising services to non-profit and religious organizations in Terre Haute, Indiana; Cincinnati, Ohio; Boston and Worcester, Massachusetts; Lansing, Michigan; Washington, D.C.; and Toronto, Canada.

He has also been an elected official serving as a city council member in Takoma Park, Maryland, and serving on various state government and regional Council of Government committees.

Rino is eager to continue building the organization as a clear voice for public education on PH, as a center able to provide strong patient and family support, and as an advocate for and direct funder of research for better treatments and a cure.

An Invitation

Recently, we have each pledged \$5,000 toward a \$35,000 goal. When this goal is met, PHA will hire a legislative advocacy firm.

This year, PHA has made extraordinary advances in this area. The National Heart, Lung, and Blood Institute pulmonary hypertension research portfolio has increased to \$15,000,000. We got the PH Research Act of 2000 introduced in Congress. We have also worked hard on the federal budget. The results have included a mandate for the Centers for Disease Control to educate doctors and the public about PH.

These are great starts, and the addition of an Advocacy and Public Awareness coordinator on staff to mobilize our membership is a real help.

But we need more.

We need continuous and direct contact in the halls of power. The support we received last year was given by professionals, willingly and without cost to PHA. It was a short-term gift. The results we got were tangible, affecting federal appropriations for research and awareness and keeping Congress focused on PH. Without support now from our PH community, this resource will not continue.

We are looking for three to five members or friends to join us by matching our pledge and making this goal a reality.

If you would like to discuss what we are trying to do and how you might help, please call either of us and help to move this important agenda forward.

Thank you!

Jack Stibbs, 281-367-2222
Mark Jeter, 612-661-6565

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.

James Drinkward
Bonnie Dukart
Patricia Hayden
Jim "Apple" Kelly
Celeste Rose Lavelli
Rebekah A. Puzen
Richard Roberts
Lucille Schilling

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.

Pittsburgh Moving Forward!

January 25, 2001

Now is the time to make the New Year's plans. First, we look back on the events that brought us into the new millenium. We had a wonderful Holiday party along with Gentiva Health Services on December 2. It was a great meeting for fellowship and support with forty plus members of the Pittsburgh support group.

Hats off to all of the group that participated in the fundraiser as well. Amy Palmer with her great pie selling skill,

and oh what fabulous pies they were! Thanks to Deb Smarr, Shelli Schlafhauser, Michele Svitek, Jim and the Gentiva crew for getting everything off to a great start again. We are planning more fun in the months to come including the Spring-Fling Picnic. Meetings will be held every other month at either the Wexford Gentiva site or UPMC with some interesting speakers and topics. Thanks you PHA for all the support and further education along with a complete understanding of the patient's point of view. We want to keep you informed and like the mentors who started PHA, a fellowship and advocacy group for YOU the patient. Thanks, PHA, for another year of HOPE. For further information about the Pittsburgh Support Group, please contact Sharren Yamron at sher@sgi.net or call 412-829-0069.

IN MEMORY OF

Vernice Adams

Morrie Baldwin
 Mary & Ricky Baldwin
 Daryl Chamberlain
 Sean Hadley
 Robert & Helen Hadley
 Bill Magrum
 Kelly McCarthy
 Henry & Patricia Pety
 Ralph & Victoria Williams
 Marion & Gene Winters
 Raymond & Nancy Wright

Andrea Bennett

Brian Loncar

Melinda Berkman

Maria Lilly

Valerie Brady

Charles Marootian

Stephanie Michelle Burks

Barbara & Hope Reese

Kristen Cote

Albert & Margaret Cordeiro

Timothy Donohue

The Donohue Family
 Paula Hallberg

Jim Drinkward

Robert & Carole Campbell
 Ljepa Miletich Survivors Trust
 Moore, Bryan & Schroff
 John A. Neu

Jennifer Fabian

Premium Promotionals
 Margaret & David Vanloan

Tina Louise Firth

Odina A. Blanchard

Cristin Gildea

Kenneth & Joan Hackett

Eve Giulianetti

Leah Giulianetti

Patricia Hayden

David Burton Family
 Debbie & Corky Carney
 Donald & Ann Helton
 Douglas & Cheryl Malmberg
 Denise Nichols
 Ursuline Sisters
 Richard & Joyce Young

Julie Paton Hendry

Tanya Lundy
 Joan Lybrook

Rachel Hoyt

Laura Hoyt D'Anna

Angela Smith Kline

S & S Electric Co., Inc.
 Vern & Barbara Smith

Cynthia Landry

Alice & Mary Burke
 Janet & Gerald Dube Family

Kathleen Laynette

Robert & Patricia Redden

Patricia Lilly

Mr. & Mrs. Lawrence Gallagher

Gerald & Barbara Hasenstab
 Mr. & Mrs. Charles Juengel
 Stephanie Kombrink
 Karen Manso
 Jennifer Roberts
 Joseph & Anna Schmidt
 Ellra Silleny
 Larry & Cynthia Yobby

Rachel Ann Loomis

S & S Electric Co., Inc.

Teresa Lovell

Craig & Cindy Bailey
 Andrew & Wendy Blackwell
 Gerald J. Blake
 Nancy & Larry Blanchard
 Michelle Bolick
 Sue Carlyle
 Gerald & Staci Carlyle
 Mr. & Mrs. John L. Conner
 Co-workers of Tricia Nichols
 Tom & Dinah Cox
 Kathy & Richard Depestel
 Stephen & Kathy Deville
 Joey & Dee Dee DuPree
 Engineering Product Development &
 NSMteams, McLeod USA
 Jan L. Fisher
 James & Amelia Garth
 Kimberly Gilmartin
 Gary F. Keltner
 Valerie J. Lee
 Dee & Larry Lovell
 Robert & Tamara Ollerton
 Dean & Cindy Sides
 Dan & Jennifer Slater
 Ricardo & Marcia Tanaka
 Third Generation Consulting
 Roger & Donna Wilmot
 David & Lori Workman

Teresa Merriam

David Merriam

Miyara & Hoyt Fellowship

Linda Betke
 Peter & Pat D'Anna
 D. J. & Nina Santo
 Susan Sawashima
 Paula Stewart

Kipp Palmer

Shirley Myers
 Donna Porter

James & Kim Peck

Park Hills School Staff

Barbara Popeney

Ernest & Young Foundation

Kathryn Rosselli

James & Meredith Rosselli

Gary Rotter

J. Wesley Atwood, MD
 Babbitt Bearing Co., Inc.
 Frank & Betty Campos
 Cardinale Moving & Storage
 Providence Cardinali
 Salvatore Cardomale
 Gary & Shari Costanti
 Doug Forzani

Edward Kurtz
 R. J. & Joan Lavaun
 Edward & Margaret Magner, III
 Theodora & Jack McKay, III
 Anna Monteleone
 Monterey Lions Club
 Kathryn Duayne Ostergard
 Kathy & Michael Rotter
 Robert & Tamara Rotter
 James & Jennifer Rotter
 Dick Rotter
 Anne Rotter
 Louis & Janice Russo
 Eugene & Jean Sanchez
 Namiko Uyeda
 Cynthia Windsor

Mary Scanlon

Peter Comey
 Cheryl A. Gwinn

Lucille Schilling

Thomas & Ruth Drummond
 Eugene & Elizabeth Plassmann
 Agnes & Bill May
 Howard L. Wilson, MD
 John & Marilyn Asbridge
 Bob & Doe Johnston
 Carole & John Oldemeyer
 William & Joan Humiston
 Paul & Gaye Kloster
 Dean & Madelein Blandow
 Fred Schilling
 Frances V. Lawhead
 Dick & Dena Archer

Rand Schumaker

Pauline Kawamoto

Giacomina Scottorn

Huachuca City Lions Club

Diane Karjala Poppas Sexton

Nancy McIntire

Joan Smith

Paulette Gillant

Nicholas Stikeleather

Dwayne & Tisch Hellard

Roxane VanAntwerp

Mr. & Mrs. Don Sherman
 Doug & Dianna Stevenson
 Marcia & Walt Wood

Steve Weisz

Sanford Kempner

Catherine Whitaker

Phyllis Koch

Shirley Whited

Richard Whited

Kathleen Wooley

Skip & Margo Atkins
 Frank & Loys Bonner
 Daniel & Reah Carmichael
 Jody & Irwin Greenwald
 Jim & Laurie Phillips
 Lynne Reinschreiber
 John & Judy Stoll
 Kenneth & Margaret Whitehead

Maxine Young

Glenn & Sylvia

I N H O N O R O F

Charles Andree
Jessie & Robin Taylor

Kenya Beaudoin
Kenya Beaudoin

Nathan Dickman
Harold & Ruth Dickman
The Alan Dickman Family

Pat Dodge
Robert & Carole Capmbell
Ljepa Miletich Survivors Trust.
John A. Neu

Karen Dominguez
Dawn Preston

Bonnie Dukart
Harvey Gitlin TTEE

Jeff Falcone
Jackie & Randy Harding

Florian Goetz
Terry J. Schreiner, DDS

Madeline Graham
Joan & Roy Graham
John Higgins
Beth Pedersen
James & Francine Pederson

Anna Jeter
Linda & Victor Jegers
Laurie Jeter
Kathy Sheppard
Shirley & Harry Winters

Pat Paton
Joan Lybrook
Jerry Paton
Zionville Church Christian Women's Fellowship

Salena Quihuiz
Lori Villaloboz
Heather Rexford
John & Kristine Kline

JoAnne Schmidt
Sherry & Mike Mulea
John P. & Antionette Sperando
George & Connie Stack

John Sperando
John P. & Antionette Sperando
George & Connie Stack

G E N E R A L D O N A T I O N S

Diane Adkins
Stephen & Mary Aldritt
Peggy Anderson
Sandra Asercion
David Badesch, M.D.
David Baratz, M.D.
Thomas Brady
Elizabeth Bulkley
James & Carolyn Burden
Christa Byrne
Norvella Caimi
Bruce & Janie Cavitt
Tammy Chapman
Laura D'Anna
Peter Engel, M.D.
Debra Fertel, M.D.
Judith E. Fletcher
Foley's Charity Day
Maria Freidman
Pam Gau
Charles Gildea III
Tom & Norene Gonsiewski
Patricia Guillen-Loth
William & Irene Hall
Terri Hamm
Ginny Hinderliter
Sandra Hott
Asako Igawa
Akira Imamura
Mark Jeter
Carolyn Kennedy
Patricia King
Dave & Dianne Klingensmith
Harold & Joyce Kopins
Evelyn Lewis
Karen Lichtenberg
Philip Albert Ludbrook, M.D.
Guy Macgowan, M.D.
Thomas Mahrer, M.D.
Diane Mashek
Ron Mason, Sr.
Betty McPherson
Steve Nathan, M.D.
New York Support Gp.
Paul & Claudia Nihei
Mary Ann O'Horo
Harold Palevsky, M.D.
Daniel Pipoly, M.D.
Barbara Purcell
Maryann & Wilfredo Rivera

Mark Robbins, M.D.
Olga Roecklein
Suse Rosenstock
S & S Electric Co. Inc
Jean Sajna
Ginger Schmidt
Dan Schuller, M.D.
Richard Lawrence Sellman, M.D.
Susan M. Silbermann
Marc A. Silver, MD
Rosemarie Stanieich
Jack Stibbs
Marjorie Stimson
Dan Stowers
Charlene Sweazey
Angela Tunales
Adella Venneman
Myriam Vinas
Debbie Walker
Florence Weiss
Deborah Wilson
Sue Adams
Orien "Lindy" Brandt
Ginger Coleman
James and Becky Copsy
April and Glenn Dalton TTEE
J. Doherty
Karen Durbin
Mary L. Edwards
Clifton and Joyce Ellsworth
Joyce Estes
Mr. and Mrs. Jan Farley
Mary Jo Festle
Financial Federal Trust and Savings Bank
Kerry Foster
Mr. and Mrs. Bobby Fry
W. Bruce and Vicki Fullerton
Tabetha Garofalo
Gentiva Health Services
Claudia Germann
Anna Greathouse
Mr. and Mrs. Mark Greenberg
Sandra Griffin
Gwen Gugins
Gweneth and Charles Gugins
Kerry Haggerty
Sam and Jeanie Hall
Ronald and Kathleen Hartgrove
Denis Hayes
Michelle Hicks

Honor Trophies and Awards
Chris Hutchison, SIMS Deltec, Inc.
Dinia Gail Jones
Donald C. Kaley
Recilla Koblintz
Madeline Kosky
H. H. and Fay Kramer
Mr. and Mrs. Steve Kramer
Luc Leoni
Sally Li
Sonia Liddell
Lynda Logan
Mr. and Mrs. Steven Lorenz
Madan, Mossman and Sriron, P.C.
Cheryl and Vernon Maddox
Marilyn Mannina
Kenneth Melber
Rachel Millin
Renee Morgan
Carol Nelson
Patricia G. Palone
Mr. and Mrs. James Perry
Penny Pfeffer
Michael and Linda Plant
Angelica Pogson
Michelle Ranum
Maryann and Wilfredo Rivera
The Rush Heart Institute Center For Pulmonary
Heart Disease
Cynthia Sherman Scott and Tammy Smith
Darryl Springs
Priscilla Stimpson
TCF National Bank Minnesota
The Bullitt Foundation
Helen Warnock
Thomas Wells
Melissa and Jeffery Whitmoyer
Kenneth Wiley
Carter and Priscilla Wellford
Judith A. Williams
Chris Wilson

What's New at WWW.PHAssociation.org? Web Merger!

The Pulmonary Hypertension Association and Priority Healthcare have entered into an agreement to coordinate web sites. The www.phassociation.org and www.phneighborhood.com partnership will complement both web sites. The tentative date for PHA's external site launch is on or about March 29. Both PHA and Priority are working to insure that our membership and anyone surfing the web for information about Pulmonary Hypertension will find the answers they need. Our goal is to maintain the PHAssociation.org "brand", coordinate the design with PH Neighborhood, and continue to bring people to the PHA site where PH Neighborhood will become an integrated link. The PHA site redesign will take place over the next few weeks. When visitors to the PHA site click on PH Neighborhood for the first time, they will be taken to a registration page. Once they register and give some basic information, they will gain access to a host of new services such as being able to ask questions of doctors, nurses, and nutritionists. By registering, you will be helping PHA in its advocacy efforts. Medical professionals and others such as insurance experts will be schedule for chats with patients and family members. A Kids section will also be available. The PH Neighborhood site is set up like a small community featuring a cafe, a food market, a clinic, a theater, a research center, and others. This site will also allow us to encourage visits from physicians in addition to the doctors affiliated with the PH community.

Committee Chairs

Children with PH/PPH	Nancy Frede	616-363-6575
Events Coordinator	Jim Wilson	972-931-9311 972-931-8616 fax jpwilson@hotmail.com
Librarian	Kathy Windhorn	803-699-0223 (phone/fax)
New Member Packets, Pins, Brochures, and Cards	Barbara Smith	813-920-5945 813-855-4284 fax
Organ Donor Awareness	Sharren Yamron	412-829-0069
<i>Organization Liaison</i> National Organization for Rare Disorders	Lenna West	252-355-2867 413-383-8393 fax
National Institutes of Health Advisory Heart, Lung and Blood	Judy Simpson	501-253-0082 (phone/fax)
PATHLIGHT	Shirley J. Craig, Editor	713-688-7543 775-855-3043 fax
	Victor Tapson, Medical Editor	919-684-6237
	Starfall Graphics, Layout	www.starfallgraphics.com
Persistent Voices	Brad Belliston	801-967-2869
Support Group Coordinator	Betty Wojciechowski	949-215-1573
800 Number Coordinator	Diane Adkins	561-229-2427 winter 314-770-2427 summer
Web Site Guest Book Coordinator	Candi Bleifer	818-752-8384 818-753-9724 fax candibleifer@earthlink.net
Volunteer Coordinator	Diane Adkins	561-229-2427 winter 314-770-2427 summer

New Committee!

Jim Wilson is the chair for the newly created committee for special events—Events Coordinator. Jim already has experience in this area as he has hosted the Dallas Golf Tournament for two years now and recently put together the "Golf in a Box" kit designed to help anyone organize a charity golf tournament. Jim can be reached at the following address:

Jim Wilson	972-931-9311
6314 Riverview Lane	972-931-8616 fax
Dallas, TX 75248	jpwilson@hotmail.com

Pulmonary Hypertension Association, Inc. (PHA)

Board of Trustees

President Linda Carr 1048 Ibis Avenue Miami Springs, FL 33166-3214 305-888-4254 305-883-5258 fax	Executive Director Rino Aldrighetti PHA Administrative Office 850 Sligo Avenue, Suite 800 Silver Spring, MD 20910 301-565-3004 301-565-3994 fax	Member Services Director Laura Nelson Director of Internet Services Michael Vassiliev Advocacy Director Lorie Simmons
Vice President	Candi Bleifer	
Admin. Vice President, Advocacy	Jack Stibbs	
Admin. Vice President, Education	Candi Bleifer	
Admin. Vice President, Fund Development		
Admin. Vice President, Support	Betty Wojciechowski	
Secretary	Betty Wojciechowski	
Treasurer	Jerry Paton	
Assistant Treasurer	Carol Wilson	

Trustees-At-Large

Diane Adkins	Mark Jeter	Susan Salay	Lenna West
Bruce Brundage, MD	Tom Linnen	Ed Simpson	Jim Wilson
Laura Hoyt D'Anna	Sally Maddox	Barbara Smith	Kathy Windhorn
Pat Gunn	Dorothy Olson	Jan Travioli	

Board Emeritus

Harry Olson Pat Paton Judy Simpson

Scientific Advisory Board

Chairman: Bruce H. Brundage, MD—*Bend Memorial Clinic, Bend, OR*
 David B. Badesch, MD—*University of Colorado, Denver, CO*
 Robyn J. Barst, MD—*Columbia Presbyterian Babies Hospital, New York, NY*
 Joy Beckmann, RN, MSN—*UCLA Harbor, Torrance, CA*
 C. Gregory Elliott, MD—*LDS Hospital, University of Utah, Salt Lake City, UT*
 Alfred P. Fishman, MD—*University of Pennsylvania Medical Center, Philadelphia, PA*
 Adaani Frost, MD—*Baylor College of Medicine, Houston, TX*
 Sean Gaine, MD—*Mater Misericordiae Hospital, Dublin, Ireland*
 Nazzareno Galie, MD—*Universita di Bologna, Italy*
 Abby Krichman, RRT—*Duke University Medical Center, Durham, NC*
 David Langleben, MD—*Jewish General Hospital, Montreal, Quebec, Canada*
 James E. Loyd, MD—*Vanderbilt University, Nashville, TN*
 Michael D. McGoon, MD—*Mayo Clinic, Rochester, MN*
 John H. Newman, MD—*Nashville VA Hospital, Nashville, TN*
 Harold Palevsky, MD—*University of Pennsylvania Medical Center, Philadelphia, PA*
 Stuart Rich, MD—*Rush Heart Institute, Chicago, IL*
 Ivan Robbins, MD—*Vanderbilt University, Nashville, TN*
 Lewis Rubin, MD—*University of California, San Diego, CA*
 Carmen Skurdal, RN, BSN—*Gentiva Health Services, Edgewater, MD*
 Cathy J. Severson, RN—*Mayo Clinic, Rochester, MN*
 Victor F. Tapson, MD—*Duke University Medical Center, Durham, NC*
 Carol E. Vreim, Ph.D.—*National Institutes of Health, Bethesda, MD*
 Dianne L. Zwick, MD—*University of Wisconsin, Milwaukee, WI*