

Awareness Month Events 2004

- Oct-Nov** **Minnesota Metro Area Support Group Herberger's Department Store Fundraiser**
The Minnesota Metro Area PH Support Group sold coupons for Herberger's Department store during their "Community Days" sale. The coupons sold for \$5.00 and all of that entire \$5.00 goes to whatever non profit is selling them. The proceeds went to the PHA. They also staffed tables for 3 hour shifts on multiple days in October at Herberger's where they displayed all of their PH material and posters for PH Awareness month. They worked a total of 15 hours at Herberger's to sell coupons in addition to selling outside of the store to the larger community.
- Oct 16** **Awareness Month Potluck with Cardio Pulmonary Nurse Specialist, Albuquerque, NM**
Hosting their awareness month event early, the Albuquerque PH Support Group welcomed Elisabeth Ravazzolo, RN, BSN as their special guest speaker during this potluck luncheon. Elisabeth is a Cardio Pulmonary Nurse Specialist with Accredo and hosted a Q&A session with PH Support Group Members, giving updates on medical treatments of PH.
- Oct 23** **Tyler Shelly Benefit Event, Ketchum, ID**
Tyler Shelly was diagnosed with Pulmonary Hypertension in May, recently underwent a lung transplant, and is fighting for his life. While he is under the excellent care of doctors at the University of Utah Hospital in Salt Lake City, his community back home held a benefit fundraiser in Ketchum, Idaho. His mom Julia and sister Cassi staffed a table with information on Pulmonary Hypertension. For increased awareness about Pulmonary Hypertension, their local newspaper ran articles about PH.
- Nov 5** **PH Support Group of N.W. Ohio Medical Seminar, Columbus, OH***
PH patient and physician Kushala Hegde, M.D., a leader of the PH Support Group of N.W. Ohio, has organized an awareness month Medical Seminar with special speaker Dr. Melvyn Rubenfire. Dr. Hegde and the group is also planning an indoor walk to raise funds for PHA as well as holding another medical seminar in the spring (his previous event brought together over 125 physicians.)
- Oct 29** **PH Lube-A-Thon: Oil Change for a Cause, Ennis and Corsicana, TX**
Texas PH survivor Scott Rider and his wife, Brenda Rider, decided a store opening was a great time to support PH research and patient services. As owners of Valvoline Express Care of Ennis and Corsicana, Texas, they planned on raising funds for PH research as part of their store's Grand Opening Week Celebration. On Friday October 29th and Friday, November 5th, they gave a \$10.00 donation split 50/50 to Make A Wish Foundation and the Pulmonary Hypertension Association from every customer's oil, maintenance, or certain other services. In addition, the Valvoline Company, Dallas covered the cost of goods for the oil & filter on these days!
- Scott was already participating in the "106.9 The Ranch" local radio station Bus Tour and Penny Drop-Million Dollar fundraiser for the Make a Wish Foundation. Knowing that the Bus Tour would stop at his centers - with on-air radio personalities attending their grand opening - Scott and Brenda decided that all the publicity from these events offered a great time to educate their community about pulmonary hypertension while raising funds for research!
- Month-wide** **Arizona State Government Recognizes November as PH Awareness Month**
For the second year in a row, the Arizona State Government has agreed to officially recognize November as PH Awareness Month! Dr. David Baratz submitted a request last year and followed up this year to ensure that the state recognized November as PH awareness month!
- Month-wide** **New Jersey State Government Recognizes November as PH Awareness Month**
After receiving multiple requests to make November PH Awareness Month, the Governor's Office called PHA to inform us that the state recognized November and proclaim the month PH Awareness Month!

- Month-wide Memorial Fundraiser, Waldorf, MD**
As a special memorial to honor her daughter, who recently passed away due to Pulmonary Hypertension, Tina Auten is donating the entirety of her November sales of Longaberger Specialty Gift Baskets and Holiday Goods during Awareness Month to the Pulmonary Hypertension Association.
- Month-wide Kerry Bardorf Fundraiser, Conyers, GA**
Vince Frankson and other PH friends are leading a fundraising drive on behalf of Kerry Bardorf, a recently diagnosed PH patient who is aggressively fighting PH. With a goal of raising \$25,000 on her behalf, they have been undertaking a Committees of Correspondence letter writing campaign in addition to other events.
- Month-wide Mercer Area Support Group, New Castle, PA**
The Mercer Area Support Group in Pennsylvania handed out information on PHA and PH at the Jameson Memorial Hospital in New Castle, Pa. and at the Women Care Center (affiliated with Magee Hospital-UPMC Pittsburgh, PA). The group also arranged for the PH awareness poster to appear for one week on their local TV station. The group also hosted 2 fundraisers: 1) A Mary Kay cosmetic party with 10% of the proceeds going for PHA and 2) a Candle Sale, with candles priced at \$6.00 each.
- Nov 1 Temple University Hospital Pulmonary Hypertension Conference Philadelphia, PA**
After having recently started a Pulmonary Hypertension clinic in combination with Rheumatology, Cardiology and Cardiothoracic surgery at Temple University Hospital, the Clinic put together a conference for Pulmonary Hypertension, targeting physicians as well as patients and care givers. The conference was organized in hopes of expanding the scope of these lectures and in the future, traveling to other communities for the purpose of informing other physicians and patients about Pulmonary Hypertension awareness, available clinical trials, and new drug therapies.
- Nov 1 North Texas 2nd Annual PH Conference, Dallas, TX**
The North Texas PH Support Group Presented a special Awareness Month Dinner and Symposium with **Dr. Fernando Torres** of St. Paul University Hospital and **Jack Stibbs**, the Chair of the Board of Trustees for the Pulmonary Hypertension Association. Actelion sponsored the meal and the Speaker's Honorarium (a nearly \$1500 sponsorship). Oxy-View donated a gift certificate of 300 dollars for purchase of a pair of their Oxygen eyewear as a raffle prize. Priority, Theracom, United Therapeutics, and Life Support Systems supported by purchasing tables at the event and were on hand to pass out information about their products and services; Oxy-View and other health organizations tabled with information, and a local Support Group member staffed a table with PHA and PH literature for additional education during the event.
- Nov 3 Awareness Month Education/Outreach Booth at Local Hospital, New Orleans, LA**
New Orleans Support Group educated their community through a table at Ochsner Hospital.
- Nov 4 Kick-off Support Group Awareness Month Dinner, Memphis, TN**
The Mid-South Area Tennessee PH Support Group hosted a special Awareness Month Dinner, with sponsorship from Accredo, which purchased dinner for the event. About 35 people met up at the classic hall and reception facility for this special dinner. Support Group Leader Barbara Thompson drafted a press release as part of their awareness media outreach effort and disseminated the release to local newspapers and television stations. Many thanks were given to Accredo for providing the hors d'oeuvres and dinner for this event.

- Nov 4 Educational Exhibit Booth at High School Health Fair***
Special Events Volunteer Linda Rocco participated in a local-area high school's health fair. One thousand North Allegheny students and community members explored and learned about various charitable organizations, including the Pulmonary Hypertension Association. Within minutes, Linda sold every PH Awareness Pin and at the end of the day, she had given out her entire table's worth of information and materials.
- Nov 4 Asheville Support Group Information Booth at County Health Fair, Clyde, NC***
The Asheville Support Group hosted an information booth at the Haywood County Health Fair, located at Haywood Community College in Clyde, NC on November 4 from 8:00-2:00. The booth will be staffed with a PH member and 2 representatives from Accredo Therapeutics.
- Nov 5 Tucson Support Group Education Booth, UMC Hospital Tucson, AZ**
From 11-2pm on Friday, November 5th, the Tucson PH Support Group staffed a PH Education and Awareness Booth at the University Medical Center a private, nonprofit hospital located at the Arizona Health Sciences Center, near the University of Arizona in Tucson.
- Nov 6-7 Mountain Bike Race and Educational Booth at the 15th Subaru Iceman Cometh Challenge, Kalkaska, MI**
Showing support and honoring his daughter Camille, who was diagnosed with Pulmonary Hypertension 11 years ago when she was 4 years old, Eric Frede rode alongside 2000 amateur and professional riders from across the country and Canada and participated in the largest one-day event for mountain bike races in North America at the 15th *Subaru Iceman Cometh Challenge!* Starting in the village of Kalkaska, Michigan, the Subaru Iceman trail consisted of paved roads, dirt roads, two tracks, abandoned railroad beds, and the world-famous VASA cross-country ski trail. The finish line came 27 miles later just outside of Traverse City at Timber Ridge Campground and Nordic Center!
- He also received a free booth during the entire weekend of the festivities, Nov 6-7, and used his time to educate, raise awareness, and fundraise for PHA. He' gave out PH brochures and PHA information and also shared his daughter's PH story with a framed picture of her along a framed picture of her life story and her experience with overcoming the many physical and emotional obstacles with having PH, especially as a child.
- Nov 6 "Journey's with Pulmonary Hypertension: A day of education and sharing for patients and families" Baltimore, MD**
This event was formed by a multi-center group to provide an all day PH Education and Awareness Conference. The event will be held in Baltimore on Saturday, November 6 from 9:00am to 5:00pm at Johns Hopkins University's Bayview Campus. The planning committee includes physicians, nurses and patient representatives from Johns Hopkins, the University of Pennsylvania and Virginia Commonwealth University.
- Nov 6 Awareness Month Education and Outreach Booth at Local Mall, New Orleans, LA**
New Orleans Support Group educated and outreached to their community through a booth with nurses on hand to check blood pressure and to answer questions at the most popular New Orleans-metro area Shopping Center The booth was also staffed by PH members with family help and Phyllis Wilkinson with Accredo.
- Nov 7 "4th Annual Race Against PH," Stanford, CA**
Stanford's Vera Moulton Wall Center presented their "4th Annual Race Against PH," bringing together medical providers, pharmaceutical and therapeutic companies, patients, families and friends to raise awareness about this disease. **Dr. Bruce Brundage**, the Immediate past Chair of the Board of Trustees for the Pulmonary Hypertension Association, was the keynote speaker. Proceeds benefited PHA and the Ewing Family Research Fund at Stanford, a fund dedicated to supporting PH research and named in memory of the race's founders. The event has raised 100,000 dollars since its inception in 2001.

- Nov 7** **PH Support Group Meeting with Dr. Steve Trombold, Wichita, Benton, KS***
Bringing together over 25 local PH patients, family members, friends, and several Accredo representatives from Kansas City, the PH Support Group of Kansas hosted a very special meeting introducing Dr. Steve Trombold who is opening a local PH clinic in Wichita.
- Nov 8** **Florida Support Groups Conference, Sarasota, FL**
On Monday evening, Sarasota PH Support Group with the Community Education Foundation of Suncoast Lung Center, Inc., started their evening's event with a "Meet and Greet Reception" at the Hyatt of Sarasota, FL. Soon following the Meet and Greet, participants enjoyed a "sit down" dinner program with guest speaker, **Dr. Michael Poon**, MD, FACC Chief of Cardiology Cabrini Medical and well known Pulmonary Hypertension expert. PH Co-Founder **Dorothy Olson** was honored during the event, and Pulmonary Hypertension Association Volunteer Services Director, **Debbie Castro**, was on hand to represent the organization and talk about its newest resources for Support Groups and PH patients.
- Nov 9** **Port Charlotte Support Group Meeting with PHA Volunteer Services Director**
PH patients and their families came to Support Group Leader Penny Engel's home in North Charlotte for special Awareness Month Support Group meeting with representatives and advocates from PHA, United Therapeutics, CareMark, and Accredo. A local reporter participated in the duration of the 2 hour event and wrote up an article for their community paper. PH Volunteer Services Director Debbie Castro spoke about ways to educate and raise awareness and funds for Pulmonary Hypertension, as well as discuss connecting doctor's to the growing network of PH specialists through PH Doctor and Pulmonary Hypertension Resource Network. Ginny Adams, Community Advocate from CareMark, was also on hand to take questions about PH medical treatments and provided a sumptuous lunch buffet for the event.
- Nov 11** **Local News Interviews PH Doctor and Patient**
Local Phoenix area station, Channel 12 News, interviewed Dr. David Baratz and PH Patient Trish Dorrell, discussing Pulmonary Hypertension, giving a basic run down of what the disease is and its prevalence, along with medical information and Trish's perspective as a patient.
- Nov 12** **PH Support Group Education and Outreach at Good Samaritan Hospital, Phoenix, AZ**
The Phoenix PH Support Group educated and outreached to their community through a booth at the Good Samaritan Hospital. The booth was staffed by PH members with family help. The hospital also agreed to post PH information on their internal staff intranet to further educate doctors and staff with the latest information about PH.
- Nov 13** **"Georgia Fun-Walk for a Cure" Peachtree City, GA**
Support Group Leaders Sally Maddox and Robin Merritt organized a major all day Fun-Walk in their community to raise money for PH research and PHA services. Priority Healthcare, Myogen, and United Therapeutics provided a generous financial contribution; local eatery Zaxby's Chicken provided free lunch catering; Publics Grocery Store donated bottled water; and all walkers received a free shirt and other goodies! Priority Health Care among other pharmaceutical companies, showed support and were on hand at the event with an informational booth. Joining them in informational tabling were the folks at the Mckelvey Lung Transplant Center at Emory University. The Peachtree City Community Paper ran free advertisements leading up to the event. Kinko's donated a banner for the event and local businesses including hair salons, office supply stores, and a local photographer also donated for their raffle. Staples donated an office chair for the raffle, and AirTran airlines donated a 1,000 dollar gift certificate for travel!

- Nov 13 Michigan PH Awareness Luncheon and Conference, MI**
The Michigan Support Group planned an Awareness Luncheon, Conference and Special Event Raffle. This marks the 4th year for their luncheon and the 2nd year for the raffle in which the grand prize was a beautiful home-made quilt hand-crafted by a local PH artisan (and brought in 1500 dollars last year alone!)
- Nov 13 PH Children's Day at Children's Hospital, Washington DC**
The medical professionals of DC Children's Hospital invite families affected by PH to come, have fun, and learn more about living with pulmonary hypertension. Food and entertainment will be provided.
- Nov 13 UCLA Silent Auction Fundraiser for PH, Torrance, CA**
The Los Angeles PH Support Group held their annual Silent Auction at the Harbor UCLA Hospital in Torrance, CA. They received a great response from their community and raised money for Pulmonary Hypertension Association's research fund and patient services.
- Nov 13 Supper, Dance, and Prize Draw, Falstone Village, UK***
Held in Falstone Village Hall participants danced to the live band Blue Grass Plus and took part in a raffle with the chance to win prizes like two weeks in a villa in Florida for up to six people, tickets for Alnwick Garden, hair and beauty vouchers, and tickets for the Newcastle Sports Arena events, to name just a few. All the money raised benefited the Pulmonary Hypertension Association UK.
- Nov 13 Ph Support Group Houston Meeting with 3 Special Medical Guest Speakers, TX**
Hosting a very special 2 hour Awareness Month meeting at the St. Luke's Lung Institute adjacent the Texas Medical Center in Houston, the PH Support Group of Houston, Texas, invited doctors Harish Seethamraju, MD (Baylor College of Medicine), Alexander Duarte, MD (UT Medical Branch @ Galveston), Felix Shardonofsky, MD (Texas Children's Hospital) to speak on topics including new PH treatments, research and what the future holds, treatment in pediatrics vs. adults, transplant issues, and PH symptoms in children.
- Nov 13 Mary Kay Open House, Charlotte Hall, Maryland**
PH Patient Cindy Hallett is having an all day Mary Kay party at her home, with food, drinks, door prizes, as well as donating 25% of all sales on this day to go to PH research for a cure and new medications for all suffering with pulmonary hypertension (PH).
- Nov 16 PHA's First Congressional Awareness Luncheon, Washington, DC**
Our friends on Capitol Hill will be speaking about the Pulmonary Hypertension Research Act (H.R. 1316) and encouraging other members of the House to co-sponsor the legislation. Physicians local to the Washington, DC area will educate attendees about PH basics. A patient representative will also speak about experiences living with PH. Patients and caregivers are invited to attend.
- Nov 17 Awareness Month Education and Outreach Booth, Phoenix, AZ**
The PH Support Group in Phoenix Arizona participated in an all-day special Lung Health Education Fair at St Joseph's Hospital. From 10:30am-6:30pm doctors and staff discussed Pulmonary Hypertension and Awareness, Lung Cancer Awareness, and Smoking Cessation programs. The hospital allowed Support Group members to sell popcorn for a local fundraiser!
- Nov 17 2nd Annual Update in Pulmonary Hypertension Symposium Boston, MA**
Hosted at the Doubletree Guest Suites in Boston, MA, this 1-day symposium aimed at providing an in-depth perspective on current state-of-the-art practice and emerging concepts in pulmonary hypertension. Jointly sponsored by Tufts University School of Medicine and Tufts- New England Medical Center, this one day update was designed for physicians, physician assistants, nurses, and members of the pulmonary hypertension community and offered the opportunity to

consolidate current knowledge and avenues of investigation that lead to the education of all participants, exploration of new areas of inquiry, and critical analysis of the state of knowledge in this evolving field. This dynamic conference attracted some 175 pulmonary and critical care physicians, nurses, respiratory therapists, and other community members from throughout the Eastern region of the U.S. The course was structured with state-of-the-art lectures delivered by internationally recognized experts from North America and Europe. PHA's own Scientific Leadership Council Chair Robyn J. Barst, M.D., presented on New Developments with Pulmonary Hypertension in Children, and also debated Scientific Leadership Council member David Langleben, M.D., on hot topics in PH medicine and treatments.

Lead Conference Organizer, Nicholas S. Hill, M.D., Division of Pulmonary, Critical Care and Sleep Medicine, Tufts/New England Medical Center, hoped to see this conference grow to a nationally recognized symposium that will benefit all who suffer from pulmonary hypertension and those who research and treat it. Conference organizers created a website listing speakers, resources, and other information, for more information visit www.pulmhypertension.com.

- Nov 18** **Orange County Support Group Italian Restaurant Fundraiser, Lake Forest, CA**
On Thursday, November 18th, Scarantino's Sicilian Café in Lake Forest California will hold their 2nd Annual PHA Italian Night. 100% of the evenings proceeds are going to PHA. If anyone needs more information, they can also contact Betty Lou Wojciechowski at bettylouwojo@cox.net.
- Nov 19** **Accredo Open House, Totowa, NJ**
On the evening of November 19, Accredo will be hosting an open house for all of their patients and other PAH patients to meet staff and learn how they offer patients special clinical care. Pharmacists, nurses and the rest of the staff will be present to explain what they contribute to the aid of PH patients. Branch tours will be given and the event will also feature several guest speakers. At 5pm the nurses will speak on infection and flu prevention and at 7pm there will be a PAH support group meeting with Dr Roxana Sulica, who will be present to answer questions and speak on PAH. There will also be several sales representatives handing out information on new treatments and current treatments.
- Nov 19** **Blue Jeans for PH, Gauntt & Krupstadt - The Woodlands, TX**
- Nov 23** **PH Benefit Day, Easthampton, MA**
Cassie Tessier & Pizza, Wings, and Things have organized their first Pulmonary Hypertension Benefit Day! ALL DAY! All customers who mention "Cassie's Cause" will have 50% of the proceeds from the order donated to PHA's Research Fund.
http://cassiescause.com/home/index.php?option=com_frontpage&Itemid=1
- Nov 23-24** **Awareness booth - Victoria General Hospital, British Columbia, Canada***
- Nov 26** **Kathleen Richardson's Cross-Florida Bike Ride for PH**
Kathleen Richardson was diagnosed with PH in 2001 and wanted to make a difference for the PH community. To help increase awareness of this disease and raise money for research, she and her husband are going to ride their bikes across Florida from the Atlantic to the Gulf Coast. The 160-mile ride will take 4 days and start in Daytona Beach going through Deland, Sanford, Mt. Dora, Howey-in-the-Hills and Brooksville, and ending at Bayport on the Gulf Coast. Kathleen and her husband Jody will meet up with PH patients, family and supporters along the way.

Event Type	State	SG	Social	Awareness	Advocacy	Education	Special Event	Fund raising	Press	Docs
Blue Jeans to Work	TX	X		X		X		X		
Open House	NJ		X			X				X
Conference	MA									X
Educational Booth	AZ	X		X		X				X
PHA Congressional Luncheon	DC			X	X	X				X
Mary Kay Fundraiser	MD							X		
Medical Guest Speakers @ Support Grp Mtg	TX	X				X				X
Children's Day at Hospital Luncheon/Conference	DC		X	X		X				X
Fun-Walk	MI	X	X	X		X		X		
Educational Booth	GA	X	X	X		X	X	X	X	
TV Interview	AZ	X		X					X	X
Dinner	FL	X	X			X				X
Race Against PH	CA		X	X			X	X		X
Educational Booth	LA	X		X		X				X
Journey's Conference	MD			X		X				X
Mountain Bike Race Luncheon	MI			X		X	X	X		
Educational Booth	TN	X	X						X	
Educational Booth	AZ	X		X		X				X
Educational Booth	LA	X		X		X				X
Conference	TX	X	X	X		X		X		X
Conference	PA			X		X				X
Mary Kay Fundraiser	PA	X						X		
PH Posters on TV	PA	X		X		X			X	
Educational Booth	PA	X		X		X				
Educational Booth	PA	X		X		X				
Candle Sale	PA	X						X		
State Proclamation PH Month	AZ	X		X	X	X				
State Proclamation of PH Month	NJ			X	X	X				
Lube-A-Thon	TX		X	X		X	X	X	X	
Benefit Concert	ID		X	X		X	X	X		
Medical Guest Speakers @ Support Group Meeting-potluck	NM	X				X				X
Herberger's Department Store Fundraiser	MN	X		X		X		X		
Committees of Correspondence	GA							X		
Educational Booth	Canada-			X		X				
Memorial Fundraiser	MD					X		X		
Booth at High School	PA			X		X		X		
Educational Booth	NC	X		X		X				
Medical Guest Speakers @ Support Group Meeting	KS	X				X				X
Dinner Dance	UK		X	X		X	X	X	X	
Bike Across Florida	FL			X			X	X	X	
Medical Seminar	OH	X		X		X		X	X	X
Silent Auction	CA	X					X	X		
Restaurant Fundraiser	CA	X	X	X				X		
TOTAL	44	26	12	31	3	33	7	19	8	19

44 Awareness Month events in 19 States and 2 countries:

One event: ID, KS, MA, MN, NC, NM, OH, TN, Canada, UK
Multiple events: CA-2, DC-2, GA-2, LA-2, MI-2, NJ-2, FL-3, MD-3, TX-4, AZ-5, PA-7

26 events were organized by Support Groups
12 events had a social component
31 events raised awareness
3 events were advocacy related
33 events had an educational component
7 events were Special Events fundraisers
19 were smaller-scaled fundraisers
8 events garnered press (that we know to date)
19 events had doctor's involvement and participation