Runners, Walkers, Volunteers, and Supportive Bystanders Needed!!!

Come join us on the beautiful Stanford campus on September 21st at 9:00 a.m. for the third annual RACE AGAINST PULMONARY HYPERTENSION. One of our core missions at the Vera Moulton Wall Center is to raise awareness about pulmonary hypertension and help support research, which we hope will lead to a cure for this debilitating disease. This 5k fun run/walk is a great way for the pulmonary hypertension community—patients, friends, family, and healthcare providers—to help. Proceeds from the race will benefit the Ewing Family Fund for Pulmonary Hypertension Research at Stanford.

We gratefully acknowledge the support of our corporate sponsors Actelion Pharmaceuticals, Accredo Therapeutics, JIBE Marketing, e-Agency, Studio 1.2.0.4, Andronico's Market, Hobee's California Restaurants, and Starbucks Coffee (University Avenue). If you or your company are interested in corporate sponsorship, there is still room for your support.

For additional information contact the Wall Center at 800.640.9255. To register on-line or to make a donation visit www.raceforph.org or www.active.com (keyword: PH race).

Hope to see you in September!
Caring for someone with PH can be difficult, both physically and emotionally. If you are caring for a patient with PH, you need to use these strategies to maintain balance in your own life while you continue to assist your loved one.

Don’t give up that balance. This is most important to you, even if you have to modify them.

- Learn all you can about your loved one’s condition in order to provide the most meaningful care.
- Have a backup caregiver lined up for times you are sick yourself, away from home, or just need a break. You may also consider carrying the number of a neighbor who is home during the day and could help in an emergency.
- Accept the offer of help from your family and friends, be specific with them as to what specifically would be of help to you.
- Counseling and a good support group can help you as much as they can help your loved one; call the Pulmonary Hypertension Association (PHA) at (800)748-7274 to find the group nearest you.
- If you have children, encourage them to help out around the house.
- Prioritize and accept the fact that some things just won’t get done.
- Hire a house cleaner, gardener, babysitter, or other support occasionally.
- Order groceries on the Web; they’re often delivered right to your kitchen counter.
- Encourage the patient to do the things he or she is still capable of doing—such as mixing Flolan and filling pillboxes.
- Live, breathe, and recognize yourself for the hard job you are doing.
- Accept thanks graciously (this will be important to you).
- When in doubt as to how much help, open the communication back and forth.
- Be alert to signs of depression and seek professional help if you need it.

Many PH patients can also assist their caregivers in maintaining a balanced life through the following:

- Ask about the caregiver’s day; talk about current events, the children, or favorite interests.
- Try to take over some of the sedentary things the caregiver must do, such as paying the bills, doing the taxes, or addressing holiday cards.
- Let your support person know what you think are reasonable needs and have a dialogue about these issues.
- Remember to say “thank you” to your caregiver—it goes a long way.

Adapted from the Pulmonary Hypertension Association’s Patient’s Survival Guide (Second Edition).

PO Sildenafil (Viagra®)
Simvastatin (Zocor®).
study period. For additional information, please contact Val Scott at 650.725.8082.

Patients will receive study medication and study related testing free of charge during the study period. For additional information, please contact Val Scott at 650.725.8082.

For the treatment of high cholesterol. The study lasts 12 weeks and involves 4 visits to the study center. Also, patients must be able to take a pill once a day and have a fasting triglyceride level of 150 mg/dL or less.

Exercise Capacity in Patients with Pulmonary Hypertension.

A Randomized, Double-Blind, Placebo-Controlled Trial of the Effect of Simvastatin on Exercise Capacity in Patients with Pulmonary Hypertension.

We currently have 3 clinical trials (one for adults, 2 for minors) open for enrollment.

- A Randomized, Multicenter, Double-Blind, Placebo-Controlled, Dose-Ranging, Parallel Group Study of Oral Sildenafil in the Treatment of Children, Aged 1 to 16 Years, With Pulmonary Arterial Hypertension.
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Mari Manumura lived the typical, active life of a 17-year-old in Japan. She was a member of the tennis team and had big dreams of becoming an astronaut orsomething exciting. She then started training. As she climbed the stairs, the granting the care to them.

At times, Mari experienced dizziness, shortness of breath, and irregular heartbeats. Her family noticed that Mari’s skin often looked blue during tennis practice.

Then one day, Mari fainted in school. She quickly went to a local doctor, who took an electrocardiogram (EKG) of her heart. As he reviewed the test results, Mari knew the doctor’s furrowed brow was a sign of something very wrong. The doctor referred her to a local cardiologist, who subsequently admitted Mari to the hospital for further testing. “That was the most afraid I, Mari remembers, “because they don’t keep you in the hospital that long unless your condition is serious.” She received a heart catheterization and a CT scan of her chest. Luckily, the cardiologist was then able to accurately diagnose Mari’s condition as pulmonary hypertension (PH).

“The doctors kept telling me what the statistics were in terms of survival, but that didn’t bother me,” recalls Mari. “What frightened me was my future. Being the age I am, it is being active again. The only image I had of sick people was one of confinement in bed and total dependence on others.”

Mari received another referral to a PHP specialist in Tokyo, who strongly urged her to go on Flolan—a medication that must be continuously infused into the bloodstream. Mari would have to wear Flolan around her waist in a pump, which would send the drug inside her body via a permanent chest catheter. She felt overwhelmed at the thought of the treatment. Mari wondered how a person could live indefinitely with a catheter in her chest: swimming would be out of the question, and even her daily bath would be a struggle.

Once Mari’s parents heard the diagnosis, they thought of Stanford University Medical Center. Mari’s father had attended the Stanford Graduate School of Business years before, and he knew of the University’s reputation as a leader in cutting-edge medical care and research. Despite her doctors’ cautious words against moving away, Mari knew she needed Flolan and suggested additional treatment options. “I really appreciated the way the treatment was logically explained to me. It made sense,” notes Mari. “The most important difference was Dr. Doyle’s encouragement to do what I could and listen to my body.” After returning to Japan and beginning Flolan treatment, Mari and her entire family eventually made the decision to move to California, where they could be closer to Stanford.

Now a 20-year-old university student, Mari has transitioned to life in the United States, becoming proficient in a new language and making new friends. She counted on the Wall Center doctors and staff for motivating her to live positively and encouraging her to watch her diet, maintain her weight, and exercise regularly. The combined efforts of Mari and her doctors have paid off: her pulmonary pressures, which used to be over 100, were down to 50 by the time she was 18. Mari’s improved health has allowed her to continue to do the things she enjoys most, such as watching movies, chatting with friends, and taking walks.

“I guess I can’t be an astronaut anymore; I don’t think my lungs can handle the altitude changes,” jokes Mari. However, she still dreams big dreams of entering the medical field one day. Above all, Mari is happy that she can keep pursuing her goals—even if it means wearing a pump every day.

In the meantime, Trembath concluded, his lab is looking at several potential consequences for patients like Nicola, who chose to undergo genetic testing nearly ten years following her first visit to Trembath. After learning she had inherited the BMPR2 mutation, Nicola gave birth to her first child in February 2002. Nicola had a miscarriage during her first pregnancy,

Mari was one of the patients who participated in the PH Research at Stanford. She has received numerous international awards for lung disease research, including the Cecil Lehman Research award from the American College of Chest Physicians. In his free time, Dr. Faul enjoys modern art, tennis, golf, and running.

Dr. Faul’s research interests include the effects of anti-proliferative therapies on pulmonary arterial hypertension. “This is exciting work,” he says. “It promises to lead to therapies that cure pulmonary hypertension rather than just improve symptoms.”

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Simvastatin (Zocor®)

A Randomized, Double-Blind, Placebo-Controlled Trial of the Effect of Simvastatin on Exercise Capacity in Patients with Pulmonary Hypertension.

This is a Stanford-initiated, randomized, double-blind, placebo-controlled study of simvastatin in NYHA class II/III patients. The study starts after surgery and lasts for up to 2 days.

A Randomized, Multicenter, Double-Blind, Placebo-Controlled, Dose-Ranging, Parallel Group Study of Oral Sildenafil in the Treatment of Children, Aged 1 to 16 Years, With Pulmonary Arterial Hypertension.

IV Sildenafil (Viagra®)

A Randomized, Multicenter, Double-Blind, Placebo-Controlled, Dose-Ranging, Parallel Group Study of Intravenous Sildenafil in the Treatment of Children, Aged 0 to 17 With Pulmonary Hypertension After Corrective Cardiac Surgery.

This study is open to patients 0-17 years of age with PHT after corrective cardiac surgery. The study starts after surgery and lasts for up to 2 days.

PO Sildenafil (Viagra®)

A Randomized, Multicenter, Double-Blind, Placebo-Controlled, Dose-Ranging, Parallel Group Study of Oral Sildenafil in the Treatment of Children, Aged 1 to 16 Years, With Pulmonary Arterial Hypertension.