

## 5th ANNUAL RACE AGAINST PH

*Come out and join the fun!*

Please join us on the beautiful Stanford campus Sunday, November 6th at 9:00 a.m. for the 5th Annual Race Against PH.

One of our core missions at the Vera Moulton Wall Center is to raise awareness about PH. The race is a great way for the pulmonary hypertension community—patients, friends, family, and healthcare providers—to show their support. Proceeds from the race will benefit the Ewing Family Fund for PH Research at Stanford and the Pulmonary Hypertension Association.

The Race Against PH was started in 2001 by a patient and her family in an effort to promote awareness about this devastating illness. The funds raised support research



Raising **awareness** and funds for the **fight** against **Pulmonary Hypertension**

efforts dedicated to finding new treatments and, ultimately, a cure for PH.

We would like to thank our corporate sponsors: **Pfizer, Accredo, Actelion, Ino Therapeutics, Encysive, CoTherix, Priority Healthcare, and United Therapeutics** for their generous support.

For additional information, contact the Wall Center at 800.640.9255 or visit [wallcenter.stanford.edu/race.html](http://wallcenter.stanford.edu/race.html)

### The Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford

Lucile Packard Children's Hospital and Stanford Hospital and Clinics are one of the few combined centers in the United States currently offering diagnostic and advanced therapeutic services to both adults and children with pulmonary hypertension. In the fall of 2000, through the generous gift of an anonymous donor, the Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford was established.

The Wall Center seeks to serve as a leader in both the clinical treatment and research of pulmonary vascular disease, while also providing advanced training opportunities for researchers and clinicians. The Wall Center Update is published in the spring and fall. For information, consultation, or referral:

Phone: 800.640.WALL (9255)  
E-mail: [wallcenter@stanford.edu](mailto:wallcenter@stanford.edu)  
Web: [wallcenter.stanford.edu](http://wallcenter.stanford.edu)

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# WALL CENTER UPDATE

Fall 2005

VERA MOULTON WALL CENTER FOR PULMONARY VASCULAR DISEASE AT STANFORD

## Transpacific Collaboration

by Juliana Liu, ANP



Allyson and Juliana (center front) and Dr. Satoh (2nd row, 2nd from left) with meeting attendees



Nurse Ishii with Juliana and Allyson in Japan's Keio University Medical Center

*In March 2005, Wall Center team members—nurse practitioner Juliana Liu and social worker Allyson Rupp—flew to Tokyo, Japan where they participated in a cross-cultural effort to improve the health of the country's PH patients. Juliana Liu recounted details of their enlightening visit:*

On March 13, Allyson and I gave a presentation at the Japanese Pulmonary Hypertension Nurse's Meeting, which took place at Keio University Medical Center in Tokyo. The meeting drew physicians and nurses from across Japan who are involved in the care of pulmonary hypertension patients. Overall, the meeting was a great success, as we shared our collective experiences with treating patients who suffer from this life-threatening illness.

A large amount of learning occurred on both sides. For example, our Japanese colleagues were amazed when we told them that a five-day stay at the Wall Center was long enough to teach a patient to administer his or her own Flolan. In Japan, the same process lasted from 10 days to one month. We were humbled by the hard work and dedication of the Japanese physicians and nurses who rely on minimal resources to care for PH pa-

tients. For instance, we learned that Dr. Satoh (lead pulmonary hypertension physician at Keio University Medical Center) sees more than 50 patients in his outpatient clinics each Saturday.

Another highlight of the trip was our visit to the coronary care unit, where we met two patients who were just beginning Flolan treatments. Our discussions revealed striking similarities in the issues and struggles that PH patients face—regardless of where they lived. We were also reminded of how fortunate we were in the U.S. to have so many treatment options for the disease: in Japan, only Flolan, bosentan, and beraprost (an oral prostacyclin) are available, and heart/lung transplantations are rarely performed. The two patients were delighted to hear about new treatments and research underway in the U.S., and hoped to hear of a cure one day.

## VMWC Calendar of Events 2005-2006

### october

PH Support Group, October 4  
Clinical Conference, October 10, 24  
Research-in-Progress, October 20, 27

### november

**5th Annual Race Against PH, November 6**  
PH Support Group, November 1  
Clinical Conference, November 14, 28  
Research-in-Progress, November 3, 10, 17

### december

PH Support Group, December 6  
Clinical Conference, December 12  
Research-in-Progress, December 1, 8, 15, 22

### january

PH Support Group, January 3  
Clinical Conference, January 9, 23  
Research-in-Progress, January 5, 12, 19, 26

### february

PH Support Group, February 7  
Clinical Conference, February 13, 27  
Research-in-Progress, February 16, 23

### march

PH Support Group, March 7  
Clinical Conference, March 13, 27  
Research-in-Progress, March 2, 9, 16, 23, 30

### Clinical Conference

2nd & 4th Monday  
4:00 - 5:00 p.m.  
Call 800.640.9255 for location

### Cardiopulmonary

Research-in-Progress Seminar  
Every Thursday, 4:00 - 5:00 p.m.  
CCSR Room 4150\*  
\*Location may vary  
Visit [med.stanford.edu/labs/rabinovitchbland/seminars.html](http://med.stanford.edu/labs/rabinovitchbland/seminars.html) for more information



Lucile Packard Children's Hospital  
STANFORD UNIVERSITY MEDICAL CENTER

VERA MOULTON WALL CENTER  
FOR PULMONARY VASCULAR DISEASE  
AT STANFORD

770 Welch Road, Suite 400, Palo Alto, CA 94304-5715  
800.640.WALL (9255)



## 5th Annual Dunlevie Family Lecture

Translating Research Progress into Clinical Realities

The Wall Center was honored to welcome renowned researcher and clinician Sheila G. Haworth, M.D., F.R.C.P. as the speaker at the 5th Annual Dunlevie Family Lecture in Pediatric Cardiopulmonary Medicine where she presented her initiatives to bring research progress on PH into the clinical realm.

Dr. Haworth is the British Heart Foundation Professor of Developmental Cardiology, Head of Cardiorespiratory Sciences, and Head of the Unit of Vascular Biology

and Pharmacology at the Institute for Child Health, University College London. Early in her career, she held a fellowship in fetal and perinatal physiology at Columbia University. Dr. Haworth then completed her training in pediatric cardiology at London's Brompton Hospital where she also became a staff member. Since that time, she has become a leading researcher and clinician responsible for standardizing the care of children with PH across the United Kingdom. In addition, she is a prolific contributor to major journals

and symposia in the field of pulmonary vascular disease.

She began her presentation by noting that only within the past few years has the prognosis for children with PH improved, largely due to the advent of epoprostenol (Flolan) and heart/lung transplantation as treatments for the disease. But, because these methods encumber the lives of patients, they are far from ideal solutions—which has lead Dr. Haworth to conduct deeper investigations

*Continued on page 3*

## Meet Our Team

### Social Workers



**Allyson Rupp, MSW, ACSW**

Allyson Rupp, MSW, ACSW, is one of the Wall Center's clinical social workers. She focuses on assisting the center's adult patients and their families. Allyson also serves as the heart/lung transplant social

worker at Stanford Hospital and Clinics, where she facilitates two support groups. Each group meets on a monthly basis, providing care and encouragement for PH patients and their loved ones.

Allyson earned her master's degree in social work from the University of California, Berkeley. She then completed her clinical social work training in the Pediatric Liver Transplant Program at Lucile Packard Children's Hospital. Prior to joining the Wall Center and Stanford Hospital in 2003, Allyson held social work po-

sitions in the cardiac/critical care units and emergency rooms at two alternate medical centers.

In addition, Allyson has given presentations on several topics at conferences held in Miami, Florida; Tokyo, Japan; and San Francisco, California. These topics include adjusting to chronic illness and managing post-transplant issues, such as intimacy, quality of life, and psychosocial treatment. She is particularly interested in the impact of chronic illness on individual and family systems; the development of solid, sustainable support resources for patients and their families; and the equitable distribution of healthcare resources.

Allyson currently resides in San Francisco—the home of her lifelong favorite Giants baseball team—and enjoys running and kayaking. ✓



**Jaimie Lyons, MSW, ACSW**

Jaimie Lyons, MSW, ACSW, is the pediatric clinical social worker for the Wall Center, as well as the pediatric heart/lung transplant social worker for Stanford Hospital and Clinics. Jaimie supports children with pulmonary disease who seek treatment at the center and hospital, helping these patients and their families to handle the many issues that arise as a result of the disease.

Jaimie received her bachelor's degree in sociology from the University of California, Irvine and her master's degree in social work from Loyola University in Chicago. Upon completion of her clinical training,

Jaimie joined the Wall Center and Stanford Hospital.

While Jaimie provides assistance to all pediatric PH patients and their families, she is especially interested in guiding recently diagnosed patients and their families through all of the new issues they encounter. To that end, she offers assistance with everything from transportation and housing to applying for financial aid. Her objective is to enable parents to focus on their children's health rather than worry about logistical and financial matters. Jaimie is also developing new pediatric support groups through the center for both patients and their parents/caregivers.

A native of the San Francisco Bay Area, Jaimie likes to travel, cook, and participate in triathlons. ✓

## Current Clinical Trials for PH

We currently have four clinical trials open for enrollment. Patients will receive study medication and study-related testing free of charge during the study period. Please contact Val Scott, RN, Clinical Coordinator at (650) 725-8082 for additional information.

### Intravenous Remodulin

As adjunctive therapy to subjects currently receiving Sildenafil, Bosentan or the combination of Sildenafil and Bosentan for the treatment of adults, ages 18 to 65, with PAH

### Simvastatin (Zocor®)

A randomized, double-blind, placebo-controlled trial of the effect of Simvastatin on exercise capacity in patients with pulmonary hypertension

### Expression of Mts1 in Adults with Pulmonary Arterial Hypertension

Preliminary studies have identified that the protein Mts1 may be involved in the development of pulmonary arterial hypertension (PAH). We are currently investigating whether Mts1 can be used as a marker for severity and cause of disease in patients with PAH. Participation in this study requires a one time blood draw.

### PO Sildenafil (Viagra®)

A randomized, multicenter, double-blind, placebo-controlled, dose-ranging, parallel group study of oral Sildenafil in the treatment of children, ages 1 to 16, with pulmonary arterial hypertension

## Stacy Thomas

### Approaching Good Health from all Angles



"...Keep your head up, and you'll feel better. A lot of power comes from within."

Coping with PH can be easier for patients who take an all-encompassing approach to their health, using everything from medications to stress-relieving techniques. Stacy Thomas is a living example of this method. Drawing on the various resources she found at Stanford's Vera Moulton Wall Center, Stacy has developed a lifestyle that keeps her feeling great—both physically and emotionally.

Stacy's problems with breathing date back to her birth, when she was diagnosed with an ASD (atrial septal defect), a hole in the wall that separates the heart's two upper chambers. At age 8, Stacy underwent open heart surgery to repair the hole. Yet even after the surgery, she remembers thinking that she couldn't quite breathe right. "I always avoided any exertion," she recalls. Still, she continued to thrive, growing up in her hometown of Soquel, California and becoming a successful human resources professional.

Following the birth of her daughter Reese in July 2003 Stacy noticed that her nagging shortness of breath had become more pronounced. She initially chalked it up to the weight she'd gained during her pregnancy, but then realized it was something more serious. "I thought I was moving so slowly and getting short of breath because of the weight gain," says Stacy, "but then I really started feeling awful. I couldn't walk for 50 feet without losing my breath and feeling nauseous." Stacy's general practitioner referred her to a local cardiologist, who diagnosed her with PH and sent her to the Wall Center.

A few days later Stacy was meeting with the Wall Center team who would quickly become her collective resource for achieving and maintaining good health. One of her first interactions was with Dr. Jeremy Feldman, the PH fellow at the time, who immediately made her "feel more comfortable." Dr. Feldman and Dr. Ramona Doyle, Co-Director of the Wall Center, checked Stacy into the hospital and started her on intravenous Flolan, which helped her feel better almost at once.

Stacy also met Juliana Liu, the Wall Center's adult nurse practitioner. "Juliana gave me a big packet of information about PH," Stacy says. "The information included everything from facts about the disease to new medicines I could try. We also had some frank talks about issues I'd be encountering, like how to deal with intimate situations. I now call Juliana constantly—she's just so helpful."

Wall Center social worker, Allyson Rupp, was there for support as well. "Allyson was also a big help," notes Stacy "and my mom absolutely loves her."



This comprehensive approach to care has paid off for Stacy: her pressures have dropped and she continues to chase after the now two-year-old Reese. While Stacy also went back to work soon after her diagnosis, she is currently on a three-month break to explore new ways of enhancing her life, such as with meditation.

Through it all, Stacy stays focused on her own important contribution to her health: staying positive. "Some people really let it get them down," she says, "but you gotta do the best you can. I always say, 'Keep your head up, and you'll feel better.' A lot of power comes from within." ✓

### Dr. Haworth continued from page 1



Dr. Haworth (front row, 2nd from right) and her team

into the root causes of the disease itself.

Dr. Haworth's research has helped reveal that PH does not develop due to a single cause but is "a disease of multiple etiologies and different pathological endpoints." Thus, treatments must be tailored to the individual patient,

which represents a significant challenge to PH scientists going forward. Dr. Haworth noted that she and her team have already made important discoveries which have influenced the development of new therapies like bosentan (a medication which reduces the occurrence of vessel-constricting endothelin) as a potentially effective medication

for children with PH. At the conclusion of her lecture, Dr. Haworth called for continued exploration of strategies to reverse the damage done by PH. She also displayed video footage of a young boy with PH, enjoying himself at a swim park while wearing a Flolan pump underneath a wet suit, demonstrating that Flolan and other therapies can vastly improve quality-of-life for patients with PH—especially active young children. ✓

For current news, research information, patient links, and our latest calendar of events, visit our website at [wallcenter.stanford.edu](http://wallcenter.stanford.edu)