

PULMONARY HYPERTENSION NEWSLETTER

University of Colorado at the Anschutz Medical Campus



November 2012







In City Park, a Hugely Successful 2012 Colorado "Run for PHun"!

The third Annual "PHun Run" (Pulmonary Hypertension Run) for Colorado was held in Denver's City Park on Sunday, September 16. The event serves as a fundraiser, an awareness event, and an educational program. It benefits the University of Colorado Pulmonary Hypertension Program, the Pulmonary Hypertension Program at Children's Hospital Colorado, and the Pulmonary Hypertension Association (PHA), and is one of the larger such events in the U.S. This year's event occurred on one of those very special sunny Colorado mornings in early September, and the course chosen was a beautiful, sinuous pathway through City Park. The pre- and postwalk/run activities occurred in the Pavilion at the park, including a silent auction, educational booths, and an educational program. With approximately 470 participants and 40 volunteers, this was the largest Colorado PH event to date. Special guests included PHA President Rino Aldrighetti, PHA Board Member John Hess, and Department of Medicine Chair David Schwartz. Most importantly, though, many patients,

family members, loved ones, and providers joined together for a terrific event. So how does such a special event come to pass? Through the tireless work and dedication of three very special leaders (Deb McCollister, Beth Coleman, and Robin Hohsfield), the efforts of many more volunteers, and the support of a number of major sponsors.

The first PH fundraiser was a dinner gala conceived four years ago by Deb McCollister. Following the model of joint sponsorship created then, two subsequent walk/runs were held on the Anshutz Medical Campus in September 2010 and September 2011. This year's event, for logistical reasons, was held in City Park, and it proved to be such a nice venue that future events might also be held there. The event has grown each year, and while all fundraisers are important, the Colorado PHun Run stands out as one of the very most successful. To all those who participated and volunteered, a very big **Thank You!**

P.S. The date for next year's "PHun Run" will be on Sunday, Sept. 15, 2013.



Department of Medicine Chair Dr. David Schwartz, Dr. Todd Bull, Dr. David Badesch, Pulmonary Hypertension Association Board Member John Hess, PHA President Rino Aldrighetti, Dr. Dunbar Ivy.



Deb McCollister, Beth Coleman & Robin Hohsfield were the extremely competent "event organizers" and a principal reason for the successful "Run for PHun"







THE RESEARCH TEAM OF THE PULMONARY HYPERTENSION PROGRAM

The research team of the Pulmonary Hypertension Program is always busy pursuing new advances that will benefit our patients and the PH community at large. Since Dr. Badesch assisted with the first Flolan trials in the early 1990's, Colorado has been internationally recognized as a center committed to excellence in research. At present, our research team includes four physicians, one nurse practitioner and four coordinators--they work on approximately 20 research studies.

Our research team is involved in research protocols sponsored by the National Institutes of Health and various pharmaceutical companies. Many of the studies are directed towards new therapies for pulmonary hypertension; these are treatments that have not yet been approved by the FDA. Present studies in this category include clinical trials of inhaled gases, intravenous medications and oral

treatments. The research team is also involved in studies that evaluate the effect of other approved therapies, given singularly or in combination. Additionally, the research staff maintain several long-term registry studies. These databases are designed to provide the PH community with extended data on patients throughout the course of their disease. In combination with one of the long-term registries, a biobank has been established from which researchers around the world can request cell samples for their scientific pursuits.

The research team is very grateful to all the patients who have participated in our clinical studies and registries. If you are interested in participating in a study, please discuss this with your provider at your next clinic visit. As always, study involvement is optional and refusal will not affect your future care.

PULMONARY HYPERTENSION SUPPORT GROUPS

Pulmonary Hypertension Support Groups--local "chapters" of the Pulmonary Hypertension Association (PHA)--provide important points of contact for patients and caregivers. These meetings create an opportunity for sharing information with one another, and receiving education from healthcare providers. Nurses, research coordinators, and physicians from the University of Colorado Pulmonary Hypertension Program attend these meetings from time to time to provide education on the disease state, diagnostic evaluation, treatment options, psychosocial support, and research studies. Deb McCollister, RN, BSN, lead clinical research coordinator for the Pulmonary Hypertension

Program, has recently met with the support groups in New Mexico and Colorado Springs, and is planning to meet with the group in Idaho in the near future. Robin Hohsfield, RN, has attended meetings of the support groups in Denver and Colorado Springs. And David Badesch, MD, has attended meetings of the Denver Area Support group in September, and the Southern Colorado Support Group in October. These meetings afford opportunities for patients and their caregivers to interact in a casual, open forum with healthcare providers. They also provide a connection to the larger umbrella organization, the Pulmonary Hypertension Association (PHA).



Gentle Arnez, Dr. David Badesch, Deb McCollister



Dr. Todd Bull



Debbie Zupancic, NP

IT TAKES A COMPLETE TEAM

It takes a team to care for patients with a complex illness like pulmonary hypertension, and the Pulmonary Hypertension Program at the University of Colorado has one of the best in the field. The core group consists of three clinical nurses, a nurse practitioner, four research coordinators, an administrative assistant and four physicians (see Table). In addition, the Cardiac and Vascular Center (C&V Center) at the University of Colorado Hospital (UCH) has a team of Care Team Assistants and Medical Assistants to provide scheduling services and check-in and check-out from the clinic. We receive much-appreciated support from the C&V Center and UCH administration.

The care of patients with pulmonary hypertension often requires assistance from providers in other specialties, such as cardiology, rheumatology, radiology, cardiothoracic surgery, lung transplantation, dietary, cardiopulmonary rehabilitation, physical therapy, and others. We are fortunate to be able to involve providers from all of these areas to provide a truly comprehensive, multidisciplinary approach to care, offering a complete range of treatment options.



First Row (**L to R**): Kelly Moulden, Lisa Robertson, Robin Hohsfield **2nd Row** (**L to R**): Lindsay Morehouse, Gentle Arnez, Laura Sanchez, Brenda Kuiphoff, Debbie Zupancic, Deb McCollister, Bruce Hoskinson



The Pulmonary Hypertension Team

Clinical Nurses: Robin Hohsfield, RN Lisa Robertson, RN Kelly Moulden, RN

Nurse Practitioner: Debbie Zupancic, RN, NP

Research Coordinators:
Deb McCollister, RN
Gentle Arnez, RN
Brenda Kuiphoff, RN
Lindsay Morehouse, MSPH

Administrative Assistant: Laura Sanchez

> Volunteer: Bruce Hoskinson

Physicians:
David Badesch, MD
Todd Bull, MD
Edward (Jack) Dempsey, MD
Brian Graham, MD



Pulmonary Hypertension Program University of Colorado Denver Anschutz Medical Campus 12401 E. 17th Avenue; Box L-957 Aurora, CO 80045



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TIPS FOR HEALTHIER LIVING

Ensure your vaccinations are current

The flu season is upon us and now is the time to get your flu shot! Seasonal influenza vaccine provides the best protection available from seasonal flu, even when the vaccine does not closely match circulating flu strains, and even when the person getting the vaccine has a weakened immune system. Vaccination can lessen illness severity and is important for people at high risk for serious flurelated complications, such as those with pulmonary hypertension.

- Avoid exposure to sick individuals
- Practice good handwashing
- Avoid vasoconstricting decongestants

HOW TO OPTIMIZE COMMUNICATIONS

- HEALTH ISSUES: address non-emergent health issues during regular office hours
- PRESCRIPTION REFILLS: Remember to call well in advance for any needed refills
- APPOINTMENTS: For appointments, call scheduling at (720) 848-5300
- EMERGENCIES: call 911, and ask that the Pulmonary Hypertension physician on call be notified through the University Hospital operator (720) 848-0000