## **Table of Contents**

## Guest Editors for this issue:

## Olivier Sitbon, MD

Consultant
Center for Pulmonary Vascular Diseases
Respiratory and Intensive Care Unit
Antoine Beclere Hospital
Paris-Sud University
Clamart, France

#### Robert Schilz, MD

Medical Director of Lung Transplantation and Pulmonary Vascular Disease University Hospital of Cleveland Case Western Reserve University Cleveland, Ohio

- 4 Profiles in PH: Sheila Haworth, MD
- 13 Managing Idiopathic PAH in Children
- 22 Persistent PH of the Newborn: Pathophysiology and Treatment
- 31 PAH Associated with Congenital Heart Disease
- 36 Roundtable Discussion:
  Consulting the Experts on the
  Spectrum of Disease and
  Aggressive Treatment

## **Publisher**

Pulmonary Hypertension Association Michael D. McGoon, MD, Chair of the Board Rino Aldrighetti, President Justine Elliot, Director of Medical Services

## **Publishing Staff**

Stu Chapman, Executive Editor Susan Chapman, Managing Editor Heidi Green, Associate Editor Gloria Catalano, Production Director Michael McClain, Design Director

## **PHA Office**

Pulmonary Hypertension Association 801 Roeder Rd. Suite 400 Silver Spring, MD 20910-4496 301-565-3004, 301-565-3994 (fax)

## www.phassociation.org

© 2006 by Pulmonary Hypertension Association. All rights reserved. None of the contents may be reproduced in any form whatsoever without the written permission of PHA.

## Editorial Offices

Advances in Pulmonary Hypertension, DataMedica, P.O. Box 1688, Westhampton Beach, NY 11978 Tel (631) 288-7733 Fax (631) 288-7744 E-mail: sbelsonchapman@aol.com

Advances in Pulmonary Hypertension is circulated to cardiologists, pulmonologists, rheumatologists and other selected physicians by the Pulmonary Hypertension Association. The contents are independently determined by the Editor and the Editorial Advisory Board.

## Cover image:

Pediatric patients in the Pulmonary Hypertension Program at New York Presbyterian Hospital. Photos provided courtesy of Robyn Barst, MD, Director, Pulmonary Hypertension Program.

## Editor's Memo

# Hands Across the Ocean: Building a Bridge to an International Pulmonary Hypertension Community



A vision that began 6 years ago in Chicago has become a dynamic reality. At the end of its conference in June 2000 the Pulmonary Hypertension Association (PHA) called its first meeting of international attendees. About a dozen international registrants initiated the formation of new relationships marked by continuing contact with PHA. Those of us who met with our internationally based colleagues at the Seventh International Pulmonary Hypertension Conference, held from June 23 to 25 in Minneapolis this year,

realized how far we have come since that conference 6 years ago. We could only marvel at how the concept of an international meeting has grown.

A flourishing network of 20 associations in countries throughout the world is now linked with PHA, working toward cooperative strategies, and exchanging ideas and information on research. Groups are now serving patients in countries as diverse as Japan, The Netherlands, Israel, Italy, Singapore, Canada, Australia, Austria, Belgium, China, France, Germany, the United Kingdom, Ireland, Mexico, Portugal, and South Africa.

From that first meeting in 2000 the concept of an international pulmonary hypertension community, joined by organizations in many countries, quickly began to take shape. By 2002 more than 80 people from nations in Asia, Europe, North America, and Latin America, as well as New Zealand and Australia, attended an international planning session. Two years later, at the Sixth International Pulmonary Hypertension Conference, the agenda was expanded to include two separate sessions.

We are delighted to see these ideas moving forward, spearheaded by PHA in the United States, which accepted the challenge and agreed to act as the hub for organizations throughout the world. To facilitate and coordinate the growth of the international pulmonary hypertension community, PHA created an International Desk and hired an international program associate.

The next issue of *Advances in Pulmonary Hypertension* will feature comprehensive coverage of the Scientific Sessions during which a full day was devoted to presentations from nationally and internationally renowned experts. Many of these experts know firsthand the results produced by pulmonary hypertension associations in their respective countries.

Although they differ in their approach, thinking globally but acting locally to adapt to the particular needs of the pulmonary hypertension community within their country, they share PHA's mission to increase awareness of and information about pulmonary hypertension, advocate for those with the disease, facilitate access to health services, promote research at leading academic centers, and provide patients, families, and medical professionals with an environment of education, friendship, and support.

As diverse as our international constituency has become, these differences begin to disappear at the international conferences where the underlying takehome message emerges time and again: Pulmonary hypertension is not a selective disease or endemic to any part of the world. By bringing together the resources from all of the countries affected we can indeed more effectively pursue a "Roadmap to a Cure," the theme of this year's international PHA conference.

Vallerie V. McLaughlin, MD Editor-in-Chief