



Pulmonary Vascular Research Institute

Supporting global understanding of Pulmonary Vascular Diseases

Background

Pulmonary hypertension is a debilitating condition that affects people of all ages, races, and socioeconomic groups. Physicians often think of pulmonary hypertension as the rare disease that affects 1-2 people per million inhabitants. However, a recent publication by the Center for Disease Control and Prevention reported 260,000 hospitalizations in the U.S. for pulmonary hypertension in 2002, a 300% increase over the past 20 years. Because this is a fatal illness, one should expect even more attention to be paid to pulmonary vascular disease by governmental health agencies and industry in the upcoming years.

The Millennium Development Goals outlined by the United Nations have rightly pointed to the inequities of health care between Western countries and the third world. Indeed, there are an estimated 120,000 patients with pulmonary arterial hypertension in the Western world, with 7 approved therapies and 10 more in the pipeline. Compare that to an estimated 35 million affected patients in poor countries with little or no therapy available. We feel that this is an appropriate time for the academic leaders in this field to respond to this challenge.

The mission

The Pulmonary Vascular Research Institute (PVRI) is an international academic medical center, a novel concept which may change the face of academic medical research in the future. The Institute is assembling clinical scientists in pulmonary vascular disease in thematic research that will be all encompassing, but focusing on underserved populations of the world. Our activities incorporate the traditional triad of research, education, and clinical care, but the research will focus on pulmonary vascular disease, and the education and clinical care will be targeted to countries with healthcare disparities. The need for such an organization has arisen from concerns that interest in pulmonary vascular diseases is growing rapidly in the scientific, clinical and pharmaceutical arenas, but there is lacking a leadership organization to help foster progress in a way that will best serve the academic community and patients, particularly in underserved areas of the world. As we make progress in understanding pulmonary hypertension in those countries, we expect that the knowledge gained will be applicable to managing this disease in the Western world as well.

The unique strength of the PVRI is that it will bring together academic leaders representing a wide array of specialties from around the world into a single focused institute, with the resources and expertise to conduct basic and translational clinical research at a level that no single academic institution could accomplish. Although some of our work will be conducted in these underserved areas, much of it will be conducted in

our own universities. Central to the PVRI mission is a focus on countries and regions with health care disparities. The need is great in those areas, and the funding opportunities from the many health foundations are equally great. We are planning that foundation money will be our greatest resource.

The leadership of the PVRI resides in the Council of Senior Fellows, currently 24 physicians from around the world who are recognized experts in a variety of areas related to pulmonary vascular disease. The PVRI will address its objectives primarily by the establishment of focused taskforces that will design and conduct projects across the broad spectrum of research, education and clinical care related to PVD. The taskforces have been categorized as disease focused, region focused, and education focused. Twelve have been formed, but more will be created in the years to come.

Disease Focused Taskforces

These taskforces are targeted to a specific etiology of pulmonary vascular disease that is common in the third world, and where our understanding of the pathobiology and treatment is inadequate. In general, the taskforces will follow an approach to:

- Better determine the epidemiology of the disease in affected regions by working with local health authorities.
- Study the pathobiology of the disease process by providing tissue and/or clinical information to international research centers with appropriate expertise.
- Establish a patient database and biobanks to store blood samples.
- Work with local experts to develop clinics where patients can be screened.
- Create centers of excellence to manage affected patients.
- Conduct clinical trials to determine the most appropriate and cost-effective treatments.

One of our disease focused taskforces will be to study the epidemiology, pathobiology, clinical characteristics and treatment of pulmonary hypertension from schistosomiasis, a parasitic disease that is endemic in Brazil and the Middle East, and the most common cause of pulmonary hypertension worldwide. That disease is affecting over 30 million people, and we know almost nothing about how it presents, who is susceptible, and how to treat it. We plan to conduct research on the biologic mechanisms that lead to pulmonary hypertension, educate local physicians about the proper diagnostic assessments, and conduct clinical trials on targeted therapy. We envision collective funding from governmental agencies, global healthcare foundations, pharmaceutical companies and granting agencies. The other disease focused taskforces that have been created include:

- Pulmonary Hypertension Associated With HIV
- Pulmonary Hypertension Associated With Congenital Heart Disease
- Pulmonary Hypertension Associated With High Altitude and Hypoxia
- Pulmonary Hypertension Associated With COPD

Regional Taskforces

The regional taskforces are targeted to areas where healthcare disparities are marked, and the need is great. Using a “ground-up” approach, the PVRI will work with local physicians to determine their specific needs and how best to work within the existing healthcare system to make effective progress. The risk factors for PVD are highly varied between the regions of the world. A common strategy will be to

- Initiate the activities with a major symposium where state-of-the-art lectures will be presented by the PVRI faculty to interested physicians.
- Meet with regional experts to create an effective dialogue and common understanding of the issues and how best to approach them.
- Working closely with these experts, help establish centers of excellence in PVD in the most appropriate areas.
- By continuing to share advances in PVD with these experts, support their efforts to teach and train their own physicians, to eventually create a network of national, regional and local referral centers for affected patients.
- Utilize the PVRI database to help identify the unique characteristics of patients in a particular region with specific risk factors.
- Offer PVRI international fellowships to interested physicians to receive medical training in PVD at recognized international centers so that they may become experts in their own countries.

One of our regional taskforces is developing a strategy to educate physicians about pulmonary hypertension in China. We have been invited to conduct a joint symposium with the Chinese Association of Medicine in October 2007. Our plan is to work with our Chinese colleagues by establishing a series of symposia and workshops in many cities, eventually conducted by the doctors we have educated. Ultimately we hope to establish several Centers of Excellence in pulmonary hypertension throughout the country. The other region focused taskforces that have been created include:

- Pulmonary Vascular Disease in the Middle East and North Africa
- Pulmonary Vascular Disease in the Indian Subcontinent

Educational Taskforces

The educational taskforces will focus on specific activities that are knowledge based, and applicable to all of the other taskforces within the PVRI. While these taskforces can stand alone, their interaction with the Disease and Regional Taskforces are essential to their mission.

One of our educational taskforces will be developing a web-based textbook, which will be multilingual (English/French/Spanish/Japanese/Chinese/Arabic/etc). This will allow the knowledge of pulmonary hypertension to be disseminated to physicians in countries removed from the major academic centers where they may not be fluent enough in English to benefit from the classical textbooks. The table of contents has already been assembled. The other education focused taskforces that have been created include:

- International Patient Database on Pulmonary Hypertension
- PVRI Sponsored International Fellowships
- International Biobank and Biomarker Laboratories

Oversight of the PVRI will be provided by our **Board of Directors**, internationally prominent and influential people who provide leadership. Prof. Dr. Magdi Yacoub, Mr. Peter Raymond, Mr. Alec Craig and Dr. Declan Doogan have already accepted.

We have also formed a **Corporate Roundtable**, where we are inviting industry to join with us. It is being created in the spirit of industry-academic alliances that have become so successful, and rewarding to both parties. Many of the major pharmaceutical companies are now members.

There is nothing in existence that is similar to the PVRI in its vision, mission, academic strengths, and potential to make major changes in the health of people living in underserved areas of the world. We are making alliances with the major academic societies, global health agencies, and non-governmental agencies. To learn more about the PVRI and its mission, please visit our website (www.pvri.net).

Administrative office:

Pulmonary Vascular Research Institute
Division of Cardiopulmonary Sciences; KIMHS; University of Kent
Canterbury Kent CT2 7PD United Kingdom

Website: www.pvri.net