EDITOR’S MEMO

For this issue of Advances in Pulmonary Hypertension, we are examining the delivery of care to pulmonary arterial hypertension (PAH) patients and the development of PAH/Pulmonary Hypertension (PH) Centers of Excellence for improving that care. With a disease such as PAH—in which the numbers are relatively small, but the consequences of poor or fragmented care are potentially huge—this is an extremely important topic.

I thank Murali Chakinala for serving as Guest Editor for this issue; he has assembled an outstanding group of contributors and has covered this subject exceedingly well. I think one of the more interesting aspects of this issue is the difference in PAH/PH care and treatment between countries in Europe and the United States. The true centralization of PAH/PH care in the UK and France is clearly different from that currently available in the United States: is it better or is it more limiting? One could argue that, in a rare disease, limiting who can see, diagnose, and treat PAH/PH patients engenders better care for such a complex illness, promotes standardization of care, and prevents treatment of inappropriate patients. On the flip side, one could argue that having such a centralized system allows some patients with the diagnosis to be missed; forces many to travel a distance for care and treatment; and can thus be inconvenient and often cumbersome. There are obviously pluses and minuses to both systems; we want you to read this issue with an open mind and consider the possibilities. However, the development of Centers of Excellence for PAH/PH in the United States may be perceived as a tacit acknowledgment that the European system is a better overall way to manage rare diseases. Murali and I hope you enjoy reading this issue and that it compels you to contemplate what is the best way to care for these complex patients and work toward achieving that goal.

Harrison (Hap) Farber, MD
Professor of Medicine
Director, Pulmonary Hypertension Center
Boston University/Boston Medical Center
Boston, Massachusetts

GUEST EDITOR’S MEMO

I had the distinct privilege of serving as Guest Editor for this very unique and special issue of Advances in Pulmonary Hypertension, focusing on center-based care. I’d like to thank Dr Harrison Farber and the rest of the journal’s editorial advisory board for devoting an issue to this timely topic and entrusting me to bring together this excellent roster of authors.

The pulmonary hypertension (PH) world continues to evolve at a remarkable rate. Make no mistake, the field has clearly entered a later stage of its maturation. In just the last couple of years, we’ve witnessed some remarkable achievements:

• 20-year anniversary of intravenous epoprostenol
• Long-term, event-driven phase 3 clinical trials
• FDA approval of the 14th medication for pulmonary arterial hypertension (in the United States)
• The first medication approved for non-Group 1 PH
• Numerous multicenter registries, such as the PH Biobank, CTEPH Registry, US PH Scientific Registry, and others

CONTINUED on page 204


---

**GUEST EDITOR’S MEMO CONTINUED from page 158**

Pennsylvania) provide the centerpiecees to the issue through their updates on the PHCC program and the PHA Registry (PHAR). These intertwined projects have been in development for more than 5 years and are leading the charge for center-based care and a focus on improving the quality of care for PH patients in the United States. They discuss the genesis of these endeavors and highlight the early achievements, while also identifying ongoing challenges.

As part of the journal’s enduring commitment to the members of the Pulmonary Hypertension Professional Network (PHPN), Traci Houston and Glenna Traiger provide an excellent “roadmap” to accreditation for prospective PHCCs. With their vast experiences as center coordinators and as members of the PHCC Review Committee, they are well poised to provide sage advice about the various stages of the accreditation process, from the initial application all the way through the site visit. Finally, I had the immense pleasure of facilitating an insightful roundtable discussion centered on the evolving PH patient, the complexity of PH care, and the impact of contemporary center-based care. I’m particularly proud to have recruited a multidisciplinary panel for the roundtable, including a long-time PH patient.

I think you’ll find this to be a very unique and timely issue of *Advances in Pulmonary Hypertension*. I hope you’ll have a deeper appreciation of some of the challenges we face as a community and how a renewed dedication to center-based care and quality improvement will help us meet these challenges in the coming decades. And perhaps another disease-centered community (in 20 years) will look upon what we’re currently doing in PH as a guiding light for their own cause.

**Murali M. Chakinala, MD, FCCP**
Associate Professor of Medicine
Washington University School of Medicine Division of Pulmonary and Critical Care
St. Louis, MO