

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 mi-

nuses 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.

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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

- Expanding number of chronic thromboembolic pulmonary hypertension (CTEPH) centers around the world
- National Institutes of Health-sponsored effort to deeply phenotype many different forms of PH, which has the potential to redefine the disease and the field
- Sixth World Symposium on PH in Nice, France

But in the face of these and many other achievements and under the watchful eye of numerous relevant stakeholders such as pharmaceutical companies, patient-advocacy groups, medical societies, and regulatory authorities, the delivery of health care and the long-term outcomes achieved in PH have also been transformed significantly—and not always for the better. This issue spotlights the recent re-emergence of center-based care and the efforts to elevate the overall quality of care in PH, which has been spearheaded by the Pulmonary Hypertension Association's (PHA) Pulmonary Hypertension Care Centers (PHCC) initiative.

This issue kicks off with an enlightened historical overview of PH by Dr

Ron Oudiz (Harbor-UCLA Medical Center). Dr Oudiz interjects personal observations from his long career in PH—spanning almost 30 years—and delineates some of the challenges the PH community currently faces. Next, you'll get a fascinating European perspective on PH care from Professors Simon Gibbs (United Kingdom) and Olivier Sitbon (France), as patients in their respective countries are managed primarily in a limited number of expert centers and participate in national registries that have yielded unparalleled epidemiologic data. Next, Dr. Stephen Mathai (Johns Hopkins University) illuminates how the cystic fibrosis community embraced center-based care decades ago and leveraged their dedication into developing a pervasive patient-centered registry; he specifically makes a case for applying that same model to help overcome some of the current challenges faced by the PH community.

Then, Michael Gray (Senior Director of Medical Services at PHA), Olivia Onyeador (PHCC Program Manager), Joel Wirth (Tufts University), and Steve Kawut (University of

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Pennsylvania) provide the centerpiece 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 prospec-

tive 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.

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