

# Conference 2016 Recap: 25 Years of Progress

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The theme of the 2016 PHA International PH Conference and Scientific Sessions was “25 Years of Progress: Changing the History of PH,” and it was a celebration befitting this momentous achievement. The year 2016 marked a personal milestone for me, as well: a decade as a PH nurse and proud member of PHA. The last 10 years have provided me the opportunity to attend 3 PHA international conferences. To me, Conference is a time to collaborate with other medical professionals, catch up with former patients and their families, and expand my knowledge of PH. As the theme suggests, a great deal of change has occurred over the past 25 years in the treatment, management, and outcomes of patients with PH. Everyone’s hard work in the journey with PH culminates in the excitement and anticipation associated with Conference, which is enhanced by the realization that there is so much more to come. With all of this in mind, I arrived at the Omni Dallas Hotel excited to learn and collaborate with those responsible for the progress and change we celebrate.

To kick off Conference on Thursday, I attended the PH Care Center (PHCC) Workshop. Since the initiative launched, 44 centers in 27 states have achieved PHCC accreditation—history in the making! PHCC Committee members and reviewers led the workshop, explaining the required criteria for PHCC accreditation, the application process, and the site visit. Attendees ranged from those wanting to learn more about accreditation to others in various stages of the application process, and even some already accredited. Panel and audience members shared advice from their own

experiences navigating the process. As I am in the beginning stages of my own application, the workshop was extremely helpful and alleviated my anxiety and stress. With my mind at ease, I arrived at the PHPN dinner, where speakers shared interesting case presentations and honored Glenna Traiger with the Outstanding Allied Health Professional Award.

Friday is one of my favorite days at Conference. The scientific sessions present an exceptional opportunity to learn from expert clinicians and researchers in PAH, and this year’s focus was on PH around the world. As in previous years, the presentations were balanced with preclinical and clinical research, experience, and expertise. The day began with a presentation by Vallerie McLaughlin, MD, titled “What Has Happened in the Last 25 Years: Global Perspective/20 Years of Prostacyclins.” She reviewed how PAH treatment and outcomes have progressed over the past 25 years, from only calcium channel blocker and supportive therapies to more than a dozen approved PAH-specific therapies. Following each educational presentation, basic science and clinical abstracts were presented by the authors. Zhiyu Dai, PhD, from the University of Illinois College of Medicine shared his team’s work on the role of PHD2 deficiency in the mechanisms of severe PAH with irreversible vascular remodeling, suggesting that targeting PHD2/HIF-2 signaling is a promising strategy to reverse vascular remodeling for treatment of PAH. David Badesch, MD, FACP, presented a review of the modern global registries. Information obtained from various registries worldwide has impact-

ed our awareness, understanding, treatment, and outcome for PAH. During the presentation on “Etiologies of PH Across the World,” it was fascinating to learn more about schistosomiasis, the most common cause of PH worldwide, from Ghazwan Butrous, MB, ChB, PhD, FESC, FRSA, of the University of Kent. Other educational sessions covered salvage therapies for PH in Europe and the United States vs elsewhere, the differences between pediatric and adult PAH and care, and a panel discussion on access to PAH medications in developing countries. The last presentation of the day really helped tie together the basic science abstracts with the clinical content. “From Bench to Bedside: Which Novel Pathways are Most Likely to be Harnessed Therapeutically in the Next 25 Years” was presented by Prof. Martin Wilkins from the Imperial College London. He discussed the novel pathways on the horizon and how to choose which one to target as “we seek to arrest and reverse the course of PAH over the next 25 years.”

While I was involved in the scientific sessions, thousands of patients and caregivers were arriving for the opening luncheon and official start of Conference. This year I focused primarily on the PH Fundamentals: Continuing Education for Medical Professionals segment. Erika Berman Rosenzweig, MD, addressed the management and treatment of pediatric PAH, while Martha Kingman, FNP-C, DNP, covered complex medication transitions. One presentation that was particularly timely for my own clinical practice was “Management of PH in the ICU,” presented by Yon Sung, MD. She delivered an ex-

cellent overview of the complex medical management involved in caring for PAH patients in acute right ventricular failure in the ICU setting, including the role of invasive hemodynamic monitoring, “to Swan or not to Swan,” and advantages and disadvantages of using specific medication. During breaks, I walked over to the main exhibit hall to mingle with my “phriends” and colleagues. The patients that I spoke to thoroughly enjoyed the patient-led and medically led sessions they attended. They remarked that the conversation generated among the audience and panelists provided invaluable information and a safe place to consid-

er issues they haven’t felt comfortable discussing with their family, friends, or even health care providers. A few of the session topics included women’s reproductive health, intimacy, traveling with oxygen, and transitioning from pediatric to adult care. I believe these subjects speak volumes to the progress that has been achieved over the past 25 years. Patients are truly *living* with PAH.

Other conference highlights included a beautiful performance by Chloe Temtchine and premiere of her music video, “Be Brave.” We also bid an emotional farewell to PHA’s president, Rino Aldrighetti, and welcomed the incoming

president, Brad Wong. The 25th anniversary Conference was an outstanding success! The aspect I most enjoyed was the space for patients, caregivers, and medical professionals to interact with others facing the same challenges and struggles. At Conference, you are not the only person with PH; you are not the only concerned family member or friend; you are not the only nurse or doctor that cares for PH patients. I departed Sunday afternoon with a full brain and heart, pondering how much has been accomplished and all that is yet to come—here’s to another 25 years of progress and a cure!