

# Observations and Inspiration

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While I have been a member of PHPN since my career as a pediatric nurse practitioner shifted to pediatric pulmonary hypertension (PH) in 2016, this year was my first experience at the Pulmonary Hypertension Association's (PHA) International Conference and Scientific Sessions. It is powerful to have medical providers, patients, families, and industry members come together in celebration of treatment of a disease that we all fight every day. When put into practice, it generates an energy that is palpable. This year's theme, "PHinding Your Hope," seemed all too fitting. I recognized hope in the research presented, the strength of the community, and the stories of the patients—showing how far we have advanced in the treatment of pulmonary vascular disease.

I arrived at the Renaissance Orlando on Thursday afternoon, ready to present my pediatric case study at the poster session. Even before setting up, I was struck by the closeness of the PH community. I stood at check-in with one of my former patients as she pointed out "PHriends": other patients she knew from the growing online community, many of whom she had not even met in person. However, they all knew each other's stories. There were immediate hugs and laughter and natural conversation, and it seemed like they had just seen each other last week.

The poster session brought together not only PH providers, basic scientists, and industry representatives, but patients and families interested in the newest innovations in pulmonary vascular disease. Many questions on my case study came from adult patients in the form of, "What is it like to treat kids?" or "They

use Remodulin on infants too?" In addition to asking questions, these patients also shared personal experiences. There were many tales of survival told. I heard from a woman, now in her 30s, who has PH from Eisenmenger's physiology related to an unrepaired congenital cardiac defect. She stated that she is enjoying her life despite her "continuous medication, oxygen use, and blue lips." It was my first exposure to the array of patient stories I would hear over the next several days.

I spoke with the father of a now adult patient about their family's journey living with a chronic illness. They have relied on this conference as part of their support system through the years. He articulated to me the importance of the lasting friendships they have made. While they only see each other at Conference, they maintain contact via mail, email, and now social media. His daughter has developed from a child seeking connection and normalcy to a young woman who is now leading patient sessions as a role model for the next generation of pediatric patients. We discussed the difficulty of transition and moving from pediatric to adult care. He offered valuable insight about the importance of early discussions about transition. He eloquently emphasized that detachment from the pediatric care team can be just as difficult for mom and dad as for the patient.

On Friday morning, the scientific sessions opened with a poignant keynote lecture from Dr Roham Zamanian. He discussed the enormous potential for precision medicine in the future for the treatment of pulmonary vascular disease. The longer I serve as a practitioner in

this field, the more I appreciate the heterogeneity of the disease within my own patient population. There isn't a "typical" response to treatment. As we look to more novel therapies, it appears that individually tailored treatment may be the direction our field is headed. As a pediatric provider, I appreciated the well-rounded conference agenda, inclusive of many pediatric-focused topics. Dr Stephanie Handler gave a nice overview of "Congenital Heart Disease and PH: Novel Treatment Approaches," where she discussed more controversial approaches such as "treat and repair" and prostacyclin therapy for the single ventricle. Dr Uyen Troung's colorful 3-D MRI images highlighted the difference in flow patterns of children with pulmonary vascular disease in her talk, "Imaging the Right Ventricle."

Throughout the weekend, the exhibit hall was filled with people donning purple-dyed hair and zebra-print everything. It was a place of socialization and connection for patients and professionals alike. The VIPHaware pin collection spread among the vendors made visiting the booths seem like a fun scavenger hunt, with the added benefit of obtaining pharmaceutical information with your collectable. If you met the right people on the conference floor, you may have encountered a few special pins, including a tribute to Sean Wyman and a PH Warrior pin designed by PH patient Jenny Janzer. Other activities such as face painting and healthy cooking demonstrations were popular with adults and children alike.

There was a constant crowd surrounding the Team PHenomenal Hope booth, where 2 Peloton® stationary bikes were

set for a stream of cyclists riding for patients in their “Let Me Be Your Lungs” program. Team PHenomenal Hope is a nonprofit group committed to increasing awareness about PH, raising funds for medical research and patient services, and creating a stronger PH community. Team members are volunteer endurance athletes who generate funds and awareness through races of their own choosing. They are paired with PH patients who do not have the exercise tolerance to complete the race themselves. Patients were present in the booth, cheering on their surrogates as they raised money toward research and Team PHenomenal Hope's new patient fund. The enthusiasm of Dr Patricia George, Team PHenomenal Hope's cofounder, was infectious as she urged participants to go farther than they expected they could go—although it was difficult to keep up with her energy and miles as she topped the leaderboard. I even got to participate in the action, riding for one of my own patients. I hopped on the bike after getting a high five from Carl Hicks, PHA's former executive vice president, who had just finished his own PHenomenal ride.

One of the advantages of attending an event like PHA's International Conference and Scientific Sessions as a provider is the opportunity to participate in some of the patient-led sessions. Hearing their perspective on living with PH is something we can't learn from a textbook or a research-based lecture. I listened to my former patient, now a UCLA nursing student, discuss her experiences with “Dating, School, and Work With PH.” She and 2 other young adults presented strategies for work-life balance, conserving energy with a busy schedule, and how to talk to professors/employers/partners about illness. Watching these successful young adults reminded me that we are ushering a new generation of pediatric PH patients toward a future that includes college, careers, and marriage. It wasn't long ago that we didn't have the treatments available to guide pediatric PH patients to adulthood. Now we are working on transition programs to empower adolescents to take ownership of their health as they move in the direction of independence. To see a former patient

successfully focusing on new opportunities brings me such pride as well as hope for my other patients as they head into adulthood.

There is a unique relationship between pediatric PH patients and their providers. We are with the patient and their family from a life-changing diagnosis through their treatment course until they are old enough to move on. We are with them through ICU stays and well visits. We know their siblings, visit their schools, and know where they go on vacation. We cheer on their successes. We are with them on their journey. As we develop more advanced PH therapies, we are offering them hope. There was no sweeter example of this at the conference than Dr Russel Hirsch and his young patient, Riley, presenting their story at the Journey's Lunch. When it was Riley's turn to speak, she giggled nervously and waited for Dr Hirsch's whispered prompt. “My doctor is the best!” she exclaimed. As Dr Hirsch recounted Riley's PH journey, she tapped him on the arm and whispered in his ear, to which he responded, “My patient is the best!”