

We've Come—and Are Going—a Long Way. . .

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As I stepped out of the taxi at the entrance of the Renaissance Hotel at the PHA's 10th International Conference, I ran into a couple of mothers of former patients of mine. The last conference I attended was in 2008, so this felt like a homecoming for me. They asked me: "Have you seen the girls?" The girls they were referring to were their 2 daughters plus 5 of their friends. All had pulmonary hypertension (PH) and had become friends through their shared experience of living with the disease. When I started treating PH patients 10 years ago, these girls were aged 7-15 years. I turned around, and there they were—"my girls" (as I would always think of them), now 17-25 years old. They are beautiful young women living fulfilling lives; they are college and nursing students, wives—even a mom among them.

We have come so far in this fight, and seeing my former patients made me think back to when I first started working in PH in 2002. At that time, Flolan and Tracleer were the only 2 therapies approved for the treatment of PH. Since then we have added 7 more therapies to our armamentarium in various forms, with additional therapies currently under clinical investigation. With the advent of additional therapies came the questions: Is monotherapy or combination therapy more effective? Is up-front combination therapy better than add-on therapy? Clinical trials are currently underway geared toward trying to answer these very questions. Registries such as REVEAL and TOPP are helping bridge the gap between science and clinical practice. These registries allow practitioners access to invaluable information that will help guide the future of PH treatment and perhaps lead us in the direction of a cure. In addition, more and more clinical trials are looking at appropriate dosing for the pediatric population. A lot has happened in the

last 10 years and the PHA conference has continued to grow and expand, providing patients with the most up-to-date information available and a chance to meet up with old and new "PHriends."

The theme of this year's conference, The Power of One: From a Kitchen Table to Around the World, was a powerful message for all the attendees. What started with 4 women at a kitchen table has evolved into a community of 30,000 from all over the world working toward the same goals. The patient- and family-led sessions are a true testament to the patients and their caregivers working together to advocate for themselves and their loved ones. Not letting PH define you was a message that wound its way through many of the sessions. Sessions titled *9 to 5 With PH*; *School and PH*; and *PH Goes to College* addressed working or attending school with PH, and provided tips and lively discussions for how to be successful while managing your PH. A parent of a newly diagnosed 6-year-old told me she attended the *PH Goes to College* session because it brought her hope that one day her own child would be attending college. She left armed with the knowledge that there is life after a diagnosis of PH. *Family Affair* was an important session that highlighted the message that having PH doesn't preclude you from having a family. It is well known in the PH community that pregnancy should be avoided; unfortunately, upon hearing this many patients think that being a parent is not an option for them. During the session the many avenues available were discussed, and valuable information was provided for all in attendance.

As medical professionals in the field of PH, we are often so focused on treating our patients, finding new therapies, or searching for a cure that we can lose sight

of what some of the other issues for our patients might be. Attending patient-/family-led sessions gives medical professionals the opportunity to learn from patients and to see beyond their therapies and hear about their other core concerns.

I had the privilege to speak at a medically led session titled *New Medical Therapy for Children With PH*. The session discussed targeted therapies for children with pulmonary arterial hypertension (PAH) and how they work, combination therapies, and pediatric studies currently underway. It was well attended with many familiar faces and many new faces. As a panel we really wanted to have an interactive discussion with the families, so we allowed the audience to guide the course of the discussion. What evolved was an honest and robust discussion among the panel members and the families about how we can move the field of pediatric PH forward. Everyone was interested in new research on the horizon, where we thought the field was heading, and my favorite question: "How can we help?" We discussed fundraising and donating to pediatric research funds, and the importance of participating in clinical trials. One father shared that his young daughter had recently been diagnosed—within weeks of the conference—and really wanted to know what he could do to help. Someone in the audience answered first by welcoming him to the conference and the PH family, and assured him that everyone here is available to help him and his family through their journey. This person then said, "If you really want to help, you can start today by going over to the research room at the end of this session to give a blood sample." With that one invitation, I watched after the session as a whole group of families walked over together to the research room to provide blood samples. One small suggestion led to a collective movement: the power of one, indeed.

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