Robyn J. Barst, MD

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On April 19, 2013, Robyn J. Barst – wife to Sam, mother to Nomi and Lindsey, grandmother to Tobias, physician to many adults and children with pulmonary hypertension, and a friend and colleague of mine for more than 25 years – passed away at her home in Scarsdale, New York after a protracted illness. She was 62 years old.

I can't recall exactly when I first met Robyn, but I will never forget when we last collaborated. It was only a few months ago, in February of this year, at the Fifth World Symposium on Pulmonary Hypertension, held in Nice, France. Robyn had been on the organising committee of the previous four symposia, and we had shared the primary responsibility and workload for the fourth symposium, held in Dana Point, CA, USA, but Robyn was too ill to travel for the most recent meeting. Despite the rapid deterioration in her condition, she organised a teleconference with the two task forces to which she had been assigned, and spent over 8 hours over a 2-day period on the phone with her colleagues, giving her usual insight and providing suggestions for future directions. Everyone in that conference room was entranced by her tenacity, dedication to future patients with pulmonary hypertension, and her ability to draw energy for work at a time when she knew her life was ebbing. When we were ready to close the conference call, I suspected this might be the last time I would thank her for her efforts and say goodbye, and indeed it was.

Robyn's early years were spent in Southern California. After her undergraduate studies at the University of Rochester (the difference in winter weather must have come as a shock), she studied medicine at the University of North Carolina in Chapel Hill, where she was to be later recognised as alumna of the year in 2011. She then moved to New York, where she trained in paediatrics and, subsequently, paediatric cardiology and pulmonary medicine at Columbia University. With the exception of a brief time at New York Medical College to explore her potential interest in a career in basic science with the assistance of grants from the National Institutes of Health and the American Heart Association, her entire career was spent at Columbia, where she remained as a professor emeritus until her death. It was at Columbia where she developed her remarkable clinical skills, her passion for the care of patients with pulmonary hypertension, and her unstinting commitment to improve the treatment of this lethal disease.

Our first collaboration was with the initial studies using continuous intravenous epoprostenol for primary (now idiopathic) pulmonary hypertension. Robyn, Mike McGoon at the Mayo Clinic, and I collaborated with basic and clinical scientists at Burroughs Wellcome in following the initial report by Tim Higenbottam at Cambridge describing the use of a continuous infusion of epoprostenol (prostacyclin) in a patient with primary pulmonary hypertension. Things did not go well at the start; of the first few patients we started on epoprostenol, one developed a transient ischaemic attack from a paradoxical embolism, one died suddenly, and the third developed pulmonary oedema and died from what we eventually realised was pulmonary veno-occlusive disease. Thankfully, we persisted, and eventually completed the first randomised trial in this disease, which ultimately led to the approval of epoprostenol for the treatment of pulmonary artery hypertension. The results of this trial were published in the *New England Journal of Medicine* in 1996, with Robyn Barst as the first author.

The subsequent years were busy for Robyn: in addition to her responsibilities at home, she continued to be the leading expert in paediatric pulmonary hypertension, with patients referred to her from around the globe. She could often be found in the middle of the night at the bedside of a sick child in the intensive care unit struggling to find something new and better. She was one of the first to use inhaled nitric oxide in this condition and intravenous epoprostenol in children with primary pulmonary hypertension. As remarkable as it was back then to see ambulatory adult patients with an infusion pump and central catheter, it was

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absolutely stunning to see children who had previously been syncopal now running around the waiting room at Columbia Childrens' Hospital carrying a backpack with their pump.

Over the subsequent years, Robyn played a major role in the studies of the genetics of inherited pulmonary hypertension and in the development of most of the other drugs that now comprise our armamentarium against pulmonary hypertension. Even during the past few years, Robyn was actively involved in clinical trials targeting new approaches to therapy such as tyrosine kinase inhibitors and ambulatory inhaled nitric oxide. Publications arising from these and other studies will continue to have her name listed as a co-author for years after her death.

Furthermore, the European Respiratory Society will recognise Robyn's body of work with the ERS Award for Lifetime Achievement in Pulmonary Arterial Hypertension, with the award to be presented to the Robyn Barst Pediatric Pulmonary Hypertension Research and Mentoring Fund at this year's ERS Congress in Barcelona.

As notable as these accomplishments are, perhaps her most enduring achievement was the result of her passionate advocacy for progress for children with pulmonary hypertension. She lobbied Congress for greater funding for research, collaborated with the Food and Drug Administration in designing studies leading to registration of drugs for children with pulmonary hypertension and exploring valid surrogate end-points for clinical trials in children, and was a tireless supporter of patient organisations.

Robyn Barst's legacy is clear: she transformed the field of pulmonary hypertension through her energy, persistence and creativity into a discipline that has blossomed with exciting basic and clinical research that will achieve better therapies and, ultimately, a cure. I am fortunate to have been one of the many people whose life she touched.

DOI: 10.1183/09031936.00073513