



Nora McCormack

PULMONARY HYPERTENSION

By Claire A. McCormack, Nora's mother

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Our daughter, Nora, was diagnosed with pulmonary arterial hypertension when she was three months old.

Nora's journey started well before that diagnosis. Despite being a healthy woman with no risk factors for having a premature baby, my pregnancy was complicated by a placenta previa. My water broke at about 22 weeks gestation. Nora was born at 25 weeks, weighing only 575 grams. She had an APGAR score of 1 at birth and she was immediately intubated. Initially, she was on a conventional ventilator, but within a few days, she graduated to an oscillator.

She battled daily for survival, underwent multiple surgeries, and struggled to gain enough weight to be released from the hospital. Somehow, she pulled through. One day at home, she turned blue. We went to the ER, and the radiology technician discovered she had PH. We were discharged with an oxygen concentrator, a nebulizer and a follow-up appointment with a pulmonologist.

Specialists in PH at University of California, San Francisco, prescribed sildenafil, bosentan, and oxygen. This treatment plan made a big difference with Nora. She seemed more energetic and alert than she had in months.

While Nora was an infant, having her on oxygen was not that big of an inconvenience. We have a 50-foot tube connected to the concentrator and we live in a flat. So we could drag the tube to wherever she was playing pretty easily or we could pack a portable tank of oxygen under the stroller for a walk. Once Nora started crawling and walking, oxygen management became more challenging.

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- While women are four times more likely than men to be diagnosed with pulmonary hypertension, PH affects people of all ages, races, and ethnic backgrounds.
- Many patients will see three or more different physicians over a three year period before they are properly diagnosed with pulmonary arterial hypertension.
- Confirmation of diagnosis is made by a right heart catheterization.
- Research and treatments for this complex disease are developing rapidly. Therefore, pulmonary hypertension patients are encouraged to seek treatment from a PH specialist.

Source: Pulmonary Hypertension Association—www.phassociation.org

We see other parents sitting on the periphery at the playground while their toddlers play. We can never do that—we have to carry the oxygen and follow her everywhere, whether it's down a slide or through a tunnel.

We also see other parents at play dates sitting and talking to each other. We also can't do that. As you probably know, toddlers don't move in a straight line. We always have to keep one eye on her to make sure we are moving at the same time and in the same direction that she is.

In the house, we can't leave Nora in her bedroom alone while we go into the kitchen. The tube can get stuck under a heavy book or catch on the doorway and pull Nora down. There is nothing worse than seeing Nora gleefully running down the hallway only to get yanked backwards and fall down because the tube got stuck on something.

Kids of all ages notice that Nora is wearing oxygen—little kids often want to play with the tube and older kids are fascinated by the portable tanks and the concentrator. But they don't seem to treat her differently. They pretty quickly realize that they have to watch out for the tube, and often the older kids will try to keep it from getting stuck on anything.

Despite all of these challenges, Nora is doing well developmentally. She has done everything late—crawling, walking, and talking. But she has eventually caught up on everything. She has good balance, likes kicking and throwing a ball, enjoys painting and drawing, and has started talking in full sentences in both Swedish and English.

Claire McCormack spoke at the 2012 ATS International Conference in San Francisco, Calif.