

THESE PHENOMENAL KIDS AND THEIR FAMILIES ARE PUTTING UP A PHENOMENAL FIGHT ...

Octopus Medicine, Butterfly Pinches & Rattle Snake Bracelets

Lucas Van Wormer's PH Path from Pre-school to Kindergarten

Our son, Lucas Miles Van Wormer, was only four years old when he was diagnosed with Idiopathic PAH in November 2006. It had been a difficult year, health-wise. We'd been in and out of the doctor's office many times that year, as his "asthma medicine" seemed to be working less effectively by the day. (We had been living with the misdiagnosis that Lucas suffered from 'exercise induced' asthma.) One particular morning, he was under the weather more than usual. Lucas' regular doctor was out that day. As fate would have it, we saw an on-call pediatrician who suggested a chest X-ray to ensure his lungs were not infected. Fortunately, Lucas didn't have pneumonia, but the X-ray revealed something else – an enlarged heart. We were quickly referred to a pediatric cardiologist. My wife, Marina, and I thought we'd be in and out of that office with a dismissal of "it's nothing to worry about." Many hours and many tests later, we were told the most difficult news of our lives – that Lucas had PH.

On one of the long stressful evenings, as we waited to see a specialist at UCLA's Children's Hospital, Lucas woke us at 4 a.m. He said his "heart was hurting." We raced to the E.R. He had an extremely elevated heartbeat and low oxygen saturation, and was subsequently transferred by ambulance to UCLA. One heart cath later, little Lucas received a firm diagnosis and began treatment: Revatio, Tracleer and oxygen therapy.

As parents, we were devastated. Lucas is our only child. Marina and I began the education process to learn all we could about PH, so we could also teach our friends and family about it. We gained our greatest strength from our blessed boy, Lucas Miles. We chose these names because they mean "Soldier of Light." How fitting the name turned out to be. Lucas is ages beyond his years. During those first months, he taught us how to live with PH through his easy-going nature, taking his meds, never questioning, never complaining. He's become fascinated by and

in-tune with his body. We read a lot of science books together about how the body works. He knows which activities "make his heart go fast." Lucas no longer takes after school sports classes but rather enjoys two different yoga classes. He's happily traded Disneyland's Matterhorn and Space Mountain for Pirates of the Caribbean and Haunted Mansion.



Patient Lucas Van Wormer doesn't let his PH slow him down.

Since beginning treatment, Lucas has responded so very well to his meds. It's like we have a different child. He calls the Revatio his "Octopus Medicine" because it tastes like Octopus! (Perhaps because he's a huge Beatles fan.) He's been such a brave boy every time he gets his Tracleer liver function test, where he asks for the "butterfly pinch." He also thinks his Medic Alert "Rattle Snake" bracelet is super cool. Further, as we read about studies that show animal companions help lower blood pressure, we rescued "Buddy," a most wonderful dog, who has turned out to be this little boy's best friend!

Last fall, Lucas started kindergarten — another stressful time of year — with a new school, new teacher, and new explanations for everyone. Luckily, it's only a couple of blocks away. The walk there is now even less strenuous, as Lucas has just mastered riding his new "electric" Razor scooter, which helps him get around just as fast as everyone else.

Marina and I know every day is a gift. We have tremendous hope for the future, as we see the advances in treatments and research as well as the reversal of symptoms his drugs have already brought him. We are excited to celebrate Lucas's 6th birthday on January 28! ♦

By Steve Van Wormer
PH parent