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Little Porter White of Belgium still has a frightening breathing disorder, but he has survived daunting health challenges and during his first Christmas season at home things are looking up for the cute, blue-eyed, blond 14-month-old and his relieved parents

At 14 months, Porter White of Belgium has had a dozen operations, including open-heart surgery. He's been in and out of Children's Hospital of Wisconsin in Wauwatosa, often in the neonatal intensive care unit, since his birth on Oct. 22, 2009.

Three times his mother Monique Ingelse White revived him when he stopped breathing — the first time the day of his baptism on Dec. 13, 2009.

"We were on our way from the church to the American Legion Hall (in Belgium) for his party, when he stopped breathing. He turned blue and was unresponsive," White said. "We were in the parking lot. I rushed him into the hall and did CPR on the counter."

The other two times her husband Todd assisted in reviving their son. Almost every holiday or special event has been spent in a hospital room, White said.

But 2011 holds promise of a less eventful year for the happy, blue-eyed child who enjoyed his first Christmas at home.

Porter's cheerfulness has endeared him to doctors and nurses and made it easier for his parents.

"He's awesome," White said. "He's been a real trooper through everything. He enjoys going to the hospital. We walk in and he gets very happy. He loves his doctors and nurses. He gets spoiled there."

But when he sees someone in blue surgical scrubs and a mask, he gets upset, his mother said. He also doesn't like wearing a hospital gown.

Porter's had several good check-ups since he came home Dec. 3. Christmas was fun this year Porter got a big, orange Mack tow truck just like the Lanser Towing trucks owned by his grandparents Randy and Donna Ingelse. Porter lives next door to the family-run towing operation and rushes to the window when he hears the big rigs.

Porter loves people and giggles at almost anything. He's on the verge of walking and says a few words, a seemingly healthy boy.

But Porter requires 24-hour monitoring to make sure he doesn't stop breathing for longer than five seconds.

"Everybody says, 'He doesn't look sick.' He isn't sick. He just has a poor airway," White said.

"If he stops breathing, we have to count 1-100, 2-100, up to 5-100. One time, I was prepared to do CPR and pinched his nose. That startled him and he started breathing on his own."

Those five seconds seem like an eternity, she said.

Porter coughs frequently, causing some to think he has a bad cold.

But his parents call it Porter's joyful noise. A friend wrote a poem about the cough that someone said sounds like a dog barking.

White learned when she was pregnant that her umbilical cord had only two blood vessels instead of the normal three.

That meant Porter was getting less blood and there was a likelihood something would be underdeveloped or develop incorrectly, she said.

"I had an ultrasound and everything looked OK, but I was put on the high-risk birth list," White said.

When Porter was born at Columbia St. Mary's Ozaukee Hospital in Mequon, he was blue and listless.

“They let me look at him, then whisked him to the nurse’s station. We thought he just had a lot of mucus, but it was more than that,” White said.

Porter had several birth defects, some of which would not be discovered until later.

His esophagus ended in a pouch rather than his stomach so he wasn’t getting any food. He also had a trachealesophageal fistula. His trachea and
esophagus were connected, which meant food or liquids could get into his lungs.

In addition, he had a small hole in his heart between the right and left ventricles. That is common and usually repairs itself in a year, White said.

Porter was transferred to Children’s Hospital shortly after his birth. On Oct. 24, 2009, he had surgeries to connect the esophagus to the stomach and to separate it from the trachea.

Porter, who weighed 5 pounds, 15 ounces at birth and was 21 inches long, was in the neonatal intensive care unit for 4-1/2 weeks. White was by his side from 6 a.m. to 11 p.m. the entire time. She slept at a nearby hotel.

Todd, who is a machinist at Sharon Cutwell Industries in the Town of Belgium, spent weekends at the hospital.

The couple brought Porter home, but his incision became infected Nov. 24 and he was back in the hospital for two days.

Everything appeared fine until his baptismal day, when he had his first apnea episode and was taken back to the hospital. He had surgery to repair a reflux condition on Dec. 15, 2009, resulting in a three-week hospitalization.

He was home a few days, but on Jan. 8, he stopped breathing twice and was admitted for observation. A CT scan on Jan. 19 showed his aorta was pushing against his trachea, reducing his airway by 70%.

On Jan. 21, Porter underwent open-heart surgery to repair the defect. He was in the hospital for a week, then developed a viral infection in February, requiring five more days in the hospital.

So the year went with recurring life-threatening infections, pneumonia, tracheomalacia (a soft, floppy trachea that causes breathing problems) and apnea events.

In April, he had a tracheostomy and feeding tube installed. In July, he had more operations to correct his digestive system.

“The longest he was ever home was three weeks,” his mother said. “He would be doing fine, then something would happen and he would be back in the hospital. It became our way of life.”

On Nov. 30, Porter stopped breathing again and was taken to Children’s Hospital. He had the

croup and was in the hospital until Dec. 3.

Since then, Porter's been home, where he receives physical and respiratory therapy. He uses an inhaler and has high-frequency chest compressions twicea day. A vest filled with air vibrates his chest, and high-frequency waves clear his lungs, White said.

Porter laughs during the therapy, which replaced the chest pounding he didn't like, his father said.

Home-care nurses are with Porter from 6 a.m. to 3 p.m. and 10 p.m. to 6 a.m., which allows the couple to sleep and White to run errands or have a little time for herself. She's seldom away from her son for long.

The Whites have developed close friendships with Porter's nurses. The nurses sometimes baby sit for him, including a special night this week.

For the first time since Porter was born, the couple had a one-night getaway to celebrate their second anniversary on Dec. 27.

"It's hard to get baby sitters. We need someone who knows what to do if he stops breathing," White said. "My mother could do it in an emergency, but she's afraid to be alone with him. Most people are afraid to be alone with him.

"Most children with tracheomalacia outgrow it by the time they are 3, but because he had so much surgical work done to his trachea, we were told he could be dealing with these episodes until he's 7 or 8."

Todd knew nothing about medical procedures before his son was born, but learned quickly and has helped his wife revive their son. He could do it on his own, but hopes that's not necessary.

White was a certified nursing assistant in the intensive care unit at Columbia St. Mary's Ozaukee until Porter was born.

"I learned a lot in the ICU, which really helps. I know what the medical terms mean. I don't know how I would have reacted when they started throwing them at us if I hadn't known what they meant," White said.

"I always wanted to be a stay-at-home mom, but not for this reason. I'm just thankful I knew what to do, otherwise Porter might not be with us.

"My wish for the New Year is that we have all positive steps, that we go forward rather than go backward."