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BULL VALLEY – Christopher Barrette always looked like a healthy child with his bright blond hair, green eyes and contagious smile.

But within weeks of being born, he started having seemingly unrelated medical problems.

First it was his lack of a cough reflex.

“He was drinking his formula and it was going straight down into his lungs and we didn’t know,” said his mom, Theresa Barrette.

Then, the family tried to have him circumcised only to discover that his blood didn’t clot.

“He almost died,” she said.

Finally, at 3 months old, he was diagnosed with a partial duplication of chromosome 13. But the diagnosis was just the beginning of what would result in more than two years of hospital stays, family stress, and eventually, on July 11, 2004, Christopher’s death.

He was only three months shy of his 3rd birthday.

“When you lose a child, that’s not natural,” Theresa Barrette said. “You have to find a way to take this experience and make it positive and to remember them and carry on their legacy.”

That thought process prompted Theresa and her husband, Roger, to put up \$25,000 of their own money and start the Christopher Barrette Memorial Fund for Pediatric Palliative Care Education.

The fund is an effort to spread information about a relatively new medical theory for children with life-threatening conditions – palliative care.

The term refers to a holistic approach to treating children who could die as well as their families, said David M. Browning, director of the Initiative for Pediatric Palliative Care, a program of Education Development Center Inc. in Newton, Mass.

Browning said the idea of using it for pediatrics had been around for only about five years.

“It started primarily in the world of cancer patients for children,” he said. “But it has really branched out quite a bit.”

A palliative team can include counselors, but also can provide centralized medical personnel to help the family.

The Barrettes first started working with their palliative team at Children’s Hospital of Wisconsin in Milwaukee on Christopher’s first birthday, which doctors originally said he never would see.

“The pediatrician came in and said, ‘Given his diagnosis, has anybody ever approached you about doing a DNR?’ ” Theresa Barrette said. “And I looked at her, and I went ‘no.’ ”

The shock and stress on Theresa’s face prompted the doctor to bring in the palliative team.

“So they came in the next day, and everything changed,” she said. “It seems that once we had somebody to walk us through this process of having a child who had a terminal illness, they gave us the ability and the strength to see the focus needs to be on quality and not necessarily the quantity of life.”

Roger Barrette said the treatment method helped his family have one place to go with concerns, because the specialized nature of care needed meant Christopher couldn’t go to just one pediatrician.

“What palliative offered us is a place to go. We could pick up the phone and say, ‘This is what we’re experiencing’ and ... they would get all the ducks in line,” he said.

The team also helped the family make difficult medical decisions.

“When a doctor says to you, ‘We need to put your 1-year-old child on Methadone for his pain.’ ... Where do you go with that?” Theresa Barrette said. “And they helped us process that.”

The care is different from hospice care in that it’s not focused on the end of life.

“[A child] might be diagnosed with a serious illness at the age of 2, and be alive with it for 10 years,” Browning said. “So it’s not just about death at all.”

Theresa Barrette said she believed the common misconception that it was related only to death had stunted the spread of information on palliative care.

"Nobody wants to talk about the children who are terminal and when we can't cure them," she said. "But palliative care is not just for the terminally ill children ... it's for those children and those families ... where they have to make life or death choices."

Aside from Christopher's medical issues, the Barrettes also raised his twin sister, Kimberly, who did not have the chromosome duplication but did have a bleeding disorder.

"It was incredibly stressful ... at the end of it, I can understand why families get divorced," Theresa Barrette said. "And I will tell you that if I didn't have the palliative team there for me I don't know where we would be today."

Since starting the foundation, the Barrettes have raised money for conferences, and speakers for the hospital. They also hope to encourage financial support from the government for palliative care programs.

"It shouldn't be for just the terminally ill children because you have to pick and choose how many children you can care for," she said. "It should be for every child, any parent who has to receive that diagnosis of leukemia, of a cancer, or of diabetes, or of a heart murmur. They need that support system, that go-to team."

To donate to the Christopher Barrette Memorial Fund for Pediatric Palliative Care Education, call Rhonda Plotkin at Children's Hospital and Health Systems Foundation at 414-266-6110.

For information on Palliative care, visit www.chw.org, then click on "Find a specialty clinic for treatment" on the left side, then click on "Palliative Care Program."

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