PEOPLE: *Doctors can do little to help seven-year-old boy*

Boy fights 'rare orphan disease'

BY JENNIFER BROWN
Staff Writer

Storm Peschel's ultimate dream in life is to swim with sharks in Australia before he dies.

Just thinking about the danger such an adventure would involve gives his mom Georgia a shiver of fear.

But on second thought, she knows it can't be any more life-threatening than the mysterious disease that attacks her seven-year-old son's body every day. A disease that is slowly fusing his fingers and other joints together, robbing him of his hearing, his eyesight and the simple joy of riding his bike.

Storm has multiple synostosis syndrome — a progressive disease which causes fusion of the bones. It is an affliction referred to by doctors as a rare orphan disease — a one of a-kind.

It's a disease that brings on debilitating pain for the little boy, who doesn't understand why no one can help him.

Especially at night.

Bedtime haunts parents Georgia and Norm Peschel, knowing their son will inevitably wake up in excruciating pain — sometimes for three hours at a time, expressing his pain in

STORM PESCHEL

words that slice like knives into his parent's hearts.

"He says things like he wants to die. He says he doesn't know why God is doing this and why can't the doctors fix him? He asks me to make it go away and of course, I can't," said Georgia, fighting back tears. "He even asked us if the doctors could take his legs off."

Doctors at The Toronto Hospital for Sick Children have told the Peschels there is little they can do to help Storm. His disease is so rare, few know anything about it.

But despite his pain, Storm musters the energy only a child can, to play during the day. He also attends Grade 2 in a special hearing impaired program at St. Paul Catholic Elementary School in Newmarket.

Teachers and therapists thought Storm's inability to speak at age two was simply because he was a late bloomer. Now his parents know the disease was attacking him almost from birth.

After years of begging doctors to find a name for what was causing Storm so much pain, in May doctors at Sick Kids diagnosed him with multiple synostoses syndrome after comparing new X-rays of Storm to bone scans taken when he was younger.

"He is the only one at Sick Kids with it," said Peschel.

But the diagnoses only brought more of the unknown. Sick Kids has told the Peschels to bring Storm once a year to monitor his disease, but they insist there is nothing they can do.

"I'm terrified to go to Sick Kids because every time we go we have bad news," said Peschel. "I'm terrified because I think he's going to die and I'm afraid because they can't answer my question — 'Is he going to die?' and how painful is it going to be? If it is progressive, that means the pain is going to be worse."

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