

Mother celebrates her son's triumphs

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Jacob Trossman is seen with the book *The Boy Who Can*, and his mother, Marcy White, who wrote the book about him.

TORONTO — Nothing in life can prepare new parents for the experience they are about to have. But for Andrew Trossman and Marcy White, the birth of Jacob, their first child, was like riding a roller-coaster that never stopped.

In May 2002, Jacob was born with paralyzed vocal cords; severe stridor, a high-pitched, wheezing sound caused by disrupted airflow in the throat or larynx; and an inability to swallow without aspirating. He spent the first three months of his life in Toronto's Hospital for Sick Children.

It took a further seven months to get a diagnosis.

Jacob has a rare disorder called Pelizaeus-Merzbacher disease (PMD), which affects approximately one in 100,000 live births worldwide and is not limited to any particular demographic population. It is a progressive, degenerative central nervous system disorder in which co-ordination, motor abilities and intellectual function deteriorate.

PMD is categorized as a myelin disorder, in the same family as multiple sclerosis and is inherited as an X-linked recessive trait. The affected individuals are male, but the mothers are the carriers.

Marcy White, Jacob's mother, recently launched her first book, *The Boy Who Can: The Jacob Trossman Story*.

The medical professionals were not optimistic that Jacob would have the ability to learn or to understand what was going on around him. Part survival manual, part parent-child love story, *The Boy Who Can* is a chronicle of a mother's refusal to accept the limitations placed on her son. Each chapter of the book begins with a meaningful quote that summarizes its main theme.

"One hundred per cent of the proceeds of the book will fund Jacob's care. He has extensive medical needs, with 24-hour nursing care and special equipment, medicine and supplies. Not much is understood about PMD, with virtually no research in Canada. Jacob is not given the best outlook, but what both we and the doctors have seen is that Jacob can do – he is capable and he needs academic stimulation."

"White 'tells it as it is' [in her book]," said Dr. Tom Chau, senior scientist and vice-president of research at Holland Bloorview Kids Rehabilitation Hospital. "She openly acknowledges her own brokenness, weaknesses, fears, dashed hopes and disappointments. These are counterbalanced by glimpses of possibility and celebration in precious moments."

Chau created a communication device, an iPod, just for Jacob, which has opened a whole world for the child. On the outside, it appears to be a regular iPod, but the inner workings are programmed with several main categories and sub-categories that Jacob can activate with just a slight movement of his head.

Jacob is now 11 years old. He is in a wheelchair and can't walk, but he can move his head a little with some purposeful movements. His vocal chords are paralyzed, and although he can neither swallow nor speak, he can make sounds.

"Breathing is a challenge, and making himself understood is frustrating," White said. "Parenting Jake is immensely hard, and watching other children thrive sometimes makes me want to run away and hide."

But despite the hardships, and there are many, Jacob has managed to experience some very typical rites of passage.

Jacob is a Grade 5 student at Elkhorn Public School, where he has a helper and a nurse at his side. He loves to learn and his favourite subject is French.

He also attends Hebrew school at the Hebrew Academy of North York and has become a fixture at Yedidus, a program run at Bais Yaakov High School every Sunday morning by Jewish teenage girls.

"Some of the most phenomenal examples of compassion and love are showered on Jacob when these kids play with him, talk to him and spin him in circles to make him laugh," White said.

Jacob can communicate by opening his mouth for yes and making a sound for no. He loves to swim, ski and be around people.

"If I had one wish for Jacob, it would be to talk. If he could talk, he could tell us what he really wants and what is going on in his mind."

She knows their time together is limited. "His life span is short. There are numbers that are talked about, but I can't bring myself to say those numbers. His condition will worsen as he ages. We have already seen that start to happen," White said.

The Boy Who Can is available in soft cover and ebook. Visit: www.theboywhocan.com to purchase the book and www.curepmd.com to learn more about PMD.

- See more at: <http://www.cjnews.com/node/123986#sthash.IOECKJsX.dpuf>