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Join the fight to cure broken hearts this Valentines Day

Valentine's Day and hearts are eternally linked, but this year

By Dominique Milburn
Signal-Star Staff
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Valentine's Day and hearts are eternally linked, but this year, Shelly Stinson and her family want to bring the subject of a broken heart into new light.

Everything was going smoothly while Stinson prepared to give birth to her second child in early July 2005, a baby boy who would be named Maxwell. But, just 24 hours after his world debut at St. Joseph's Hospital in London, little Max became the centre of a whirlwind fight for his heart.

"The nurse whisked him away and that was it," recalled Stinson last week. For her, it was a surreal experience that left her with vague information about the condition of her new baby. "We were told that he was breathing too quickly," she said. "He was taken to the ICU, so we knew it must be something serious."

What may seem to be a little known fact to some parents is that an estimated one in every 100 babies born have a Congenital Heart Defect (CHD). There are many types of CHDs, with effects ranging from a heart murmur, to inadequate blood pumping that can result in congestive heart failure. For Stinson and her husband, Tim, it came as a complete shock that such a common defect was unknown to them before Max's birth.

"Few people realize more babies are born with congenital heart defects than there are with Spina Bifida, Down's syndrome and hearing loss," said Stinson. "All I knew about the heart before Max came along was what I had learned in high school, it has four chambers and things like that. I feel like I've gotten a free medical education out of this."

After testing was done on Max's tiny body in London, he was diagnosed with Hypoplastic Left Heart Syndrome (HLHS.)

"If you were looking at a list of CHDs, this would be the last one in the book— this is the one you don't want," said Stinson of Max's condition, the most severe of CHDs. HLHS is a combination of defects in the hearts main pumping chamber, making it too small to support life. This defect is the most common cause of death from CHD.

Max was taken by helicopter to the Hospital for Sick Children (SickKids) in Toronto where, at just nine days old, he endured his first of three open heart surgeries as part of the Norwood Procedure treatment. Through these surgeries, Max's heart has been reduced to a two chamber organ, essentially, half of a heart.

"This will make him more comfortable, but he will be out of breath more," explained Stinson. "You can hear him breathing so he can't sneak up on you."

The long term outlook for children with HLHS is uncertain, however Stinson said that through awareness and research, treatment options are steadily becoming more abundant, and effective.

"The oldest living person I know of with HLHS is a 19-year-old woman in the States," said Stinson. "Some will end up living into their 30s and 40s, but eventually they will wear their heart out."

Stinson said Max won't be able to take part in competitive sports, but promising advances in stem-cell research has given her some hope that in time, Max will be able to enjoy a normal, healthy life.

"They're trying new things all the time. Now they're actually finding that some rats are developing the ability to re-grow their own organs. Maybe someday Max will be able to re-grow his heart."

Although Stinson and her family have endured an emotional roller coaster since Max's birth, she maintains a bright outlook.

"There are no answers for what the future holds, and no statistics to cling to as predictors," she said. "But what I'm hoping to do for now is to let people know that they can help."

Stinson wants to see expectant parents aware of CHDs to save them the instant shock of having to deal with a diagnosis at birth. Some CHDs, she said, can even go undiagnosed for years.



"I'd like to see more testing done on newborns for heart defects," she said. "They test for so many things, I don't see why they aren't checking the heart routinely."

Echocardiology can be used before birth to accurately identify many heart defects. If present, the mother can be treated with medications. In cases where the defect can't be treated before birth, parents and health care providers can plan the delivery so that the baby can receive necessary treatment soon after.

Stinson has since become part of the Congenital Heart Information Network, a U.S. based organization that works to promote CHD education and treatment. The Network has worked to have the week of Feb. 7 to 14 known as Congenital Heart Defect Week in North America. During the heart holiday, members hope to raise awareness.

"It's not just the elderly who are effected with a heart condition," said Stinson. "It's a concern for all ages. I hope that people will do what they can to help out."

And what can be done, said Stinson, starts as simply as signing your donor card, so that patients in need of transplants don't have a dangerously long wait for an organ.

"Give blood, it's pretty simple to do as well, or you can contact me just to learn more about it." The Stinson family is hoping that Valentines Day brings attention to all the needs of the heart, and said that anyone effected by CHDs or would like to learn more can contact them at 519-524-2169 or by e-mail at shelly@cablead.on.ca.



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