A MOTHER’S STORY: TURNING A TRAGEDY INTO A LEGACY

Remembering Jordan Boyd and his lasting impact on the hearts and health of Atlantic Canadians

"Your life can change in a heartbeat. We know that better than anyone now." - Debbie Boyd

Arythymogenic right ventricular cardiomyopathy (ARVC).

"Before Jordan's death, I had no idea what this thing was, what this gene was that took my son's life," Debbie Boyd says.

On August 12, 2013, Debbie and her husband Stephen were sitting in the K.C. Irving Regional Centre in Bathurst, N.B. – home of the Acadie-Bathurst Titan. Jordan Boyd, their 16-year-old son and a promising hockey prospect, made his debut at the Acadie-Bathurst Titan's training camp. “It was the happiest day of Jordan's life,” Debbie says. It was the continuation of Jordan's hockey journey and passion; to play for the Quebec Major Junior Hockey League (QMJHL) and ultimately open the doors to more opportunities with the game he loved. As his parents watched from the stands on his first day of training, they couldn't have been more proud.

Ten minutes into the practice, Jordan collapsed on the ice – responders, unable to revive him.

Following this tragedy, many unanswered questions lingered. How could a young athlete, in the best shape of his life, suddenly collapse with no prior health problems?

Through medical testing, it was determined Jordan had arrhythmogenic right ventricular cardiomyopathy (ARVC), a rare, inherited heart disease that causes abnormal heart rhythms over time. On that fateful day, Jordan had fallen into sudden cardiac arrest.

A person carrying the ARVC gene has a 50 percent chance of passing the gene on to their siblings, aunts, uncles, cousins, grandparents – anyone from that side of the family is at risk of the gene; Jordan's mother or father. From that, cardiologists at the QEII's Inherited Heart Disease Clinic. Through various types of genetic testing, Dr. Martin Gardner and his team of family – still in mourning – began working closely with Dr. Martin Gardner and his team of cardiologists at the QEII's Inherited Heart Disease Clinic. “Dr. Gardner provided world-leading research, diagnosis and treatment of patients living with genetic cardiac conditions, like the Boyd family. There is currently no cure for ARVC. “Dr. Gardner described the only solution for my condition as a ‘Band-Aid fix,’ ” Debbie explains. For this solution, Debbie would undergo an operation to have an internal defibrillator, a small device, placed under her skin to keep track of her heart rate. If an abnormal heart rhythm is detected, the device delivers an electronic shock and restores a normal heart beat.

This ‘Band-Aid fix’ could save Debbie's life, should she fall into sudden cardiac arrest.

One can only imagine how overwhelming this was; from losing a son, to the discovery of a rare genetic heart condition and now a life-saving operation.

However, Dr. Gardner and his team offered Debbie and her family more than just medical advice. They were, and continue to be, a support team for the Boyd family. “I wouldn't be where I am today without the support from Dr. Martin Gardner and all of the cardiologists at the QEII's Inherited Heart Disease Clinic,” she says. “I feel like I'm part of their family. And they are part of ours.”

On May 28, 2015, Debbie had a successful operation at the QEII Health Sciences Centre to have the internal defibrillator implanted.

This wasn't just an ordinary defibrillator. On the morning of Debbie's operation, her defibrillator was flown into Halifax from the Netherlands and delivered to the QEII. Debbie's defibrillator was unique in the sense that it is MRI compatible.

"You could say I'm a unique European gadget girl," Debbie laughs. "Your life can change in a heartbeat." - Debbie Boyd

The Boyd’s Mission

In 2014, on the first anniversary of Jordan's passing, the Boyd family wanted to honour their son by celebrating his life and love for the game of hockey.

The Jordan Boyd Celebrity Hockey Challenge was born with the mission by the awareness of inherited heart disease and help ensure other families could avoid similar tragedies. In partnership with the QEII Foundation, Jordan's family, friends and community hockey players come together each year to raise funds and awareness for this condition.

Debbie smiles when asked how Jordan is remembered by those who knew him best. Jordan was a kind person, who always had a smile on his face. His known to be "goofy" and that he always made a point to make the people around him laugh. With his passion for hockey, he believed in giving back and did so with his teams.

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