

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*

Arrhythmogenic 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 biological children. The ARVC gene can either be active or inactive. In Jordan’s case, the gene was active – though undiagnosed. Just six-weeks prior, Jordan had a mandatory QMJHL medical exam that did not reveal any issues.

In the months following Jordan’s death, the Boyd family – still in mourning – began working closely with Dr. Martin Gardner and his team of cardiologists at the QEII’s Inherited Heart Disease Clinic. Through various types of genetic testing, the team needed to pin point who was the carrier of the gene; Jordan’s mother or father. From that, individual genetic testing would start – children, siblings, aunts, uncles, cousins, grandparents – anyone from that side of the family was at risk of inheriting ARVC; active or inactive. The genetic testing results showed that the carrier of the ARVC gene was Jordan’s mom, Debbie. Not only was she the carrier, but the gene was active – just as it was in Jordan.

“It’s hard to describe. Prior to Jordan, we had no family history of heart disease, heart conditions, not a single symptom or issue from as far back as I can remember,” says Debbie.

Dr. Gardner founded the QEII’s Inherited Heart Disease Clinic in 2004 – the first of its kind established in Canada. As Nova Scotia has the second highest incidence of ARVC in Canada, the Clinic provides 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.

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 was 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.

On Saturday, July 29 at the BMO Centre in Bedford, the fourth annual Jordan Boyd Celebrity Hockey Challenge will bring together a community to help honour Jordan’s legacy and celebrate his life. Jordan’s friends, family, and professional hockey players will gather to play the game Jordan loved.

“It’s important for us to share Jordan’s story to try and prevent another family from going through what we did,” Debbie explains. “From a mother who didn’t know – I want to bring awareness to inherited heart disease and stress for families to look into their history.”

“Your life can change in a heartbeat.”

Be part of a community. Together, we can help prevent sudden death from cardiac arrest through the QEII’s Inherited Heart Disease Clinic. To learn more, visit www.JBCHC.ca.



The Boyd’s Mission

In 2014, as the first anniversary of Jordan’s passing approached, 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 to raise 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 celebrity hockey players come together each year to raise awareness and funds, all while playing the game Jordan loved.

To date, the tournament has raised \$400,000 net for research at the QEII’s Inherited Heart Disease Clinic, specifically in ARVC.



Impact the hearts and health of Atlantic Canadians by supporting inherited heart disease research at the QEII Health Sciences Centre.

Honour Jordan
Jordan Boyd Celebrity Hockey Challenge



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