

A heart-stopping finish that changed a life

Heather Cartwright was an elite rower with dreams of the Olympics when cardiomyopathy turned her world upside down. Now, her sister Meredith, and brother Brian, have turned a difficult diagnosis into hope for others at risk

By **Shelley White**

HEATHER CARTWRIGHT WAS RACING TO THE FINISH LINE the first time heart disease threatened her life.

As a 20-year-old elite athlete on Western University's varsity women's eight rowing team, Ms. Cartwright was competing in a regatta at Trent University in Peterborough, Ont. Her crew

was heading into the last 1,000 metres of a four-kilometre race when she was hit with a crushing wave of muscle fatigue.

"I remember not being able to pull any harder and feeling really odd, like, How come I can't apply any pressure?" says Ms. Cartwright, now 47. "I was still keeping the rhythm up with my

team, but [I was] feeling like I couldn't pull, and [I was] losing my vision. Everything sort of narrowed and went white."

Ms. Cartwright was conscious as the boat crossed the finish line, but when she tried to disembark, she found herself unable to stand and fell into her coach's arms. St. John

Ambulance volunteers working at the event were unable to get a heart rate because her heart was racing so fast, and Ms. Cartwright was rushed to the hospital.

"I was really scared," she says, still emotional at the memory. "I couldn't see; I was blacking out. And I remember them getting me out of the ambulance, and I didn't want them to cut my crew jacket off, because only varsity got to wear the crew jacket. And I had earned that, so they had to take it [off] over my head."

At the hospital, Ms. Cartwright was diagnosed with tachycardia – a condition that occurs when an abnormality in the heart causes a faster than normal heart rate. Though it would take several years before she would find out the underlying cause of her heart condition, she was put on a beta blocker and advised to stop all competitive sports.

It was devastating news for an elite athlete who had aspirations of being selected for the

Canadian Olympic rowing team.

"That was really challenging for me because I was 20; I was rebellious," she remembers. "I had a lot of episodes where I would do some pickup basketball or other activities that would land me in the hospital. I didn't want to accept it, and there was a lot of denial in the beginning that this was as serious as it was."

Ms. Cartwright was diagnosed in 1996 with arrhythmogenic right ventricular cardiomyopathy (ARVC), a condition in which there is an abnormality in the myocardium, the muscular wall of the heart. ARVC is a genetic condition, which means it gets passed down from generation to generation through mutations in a single gene or a combination of genes. (In Ms. Cartwright's case, ARVC was caused by a mutation in the PKP2 gene, which she suspects came from her father's side of the family.)

With ARVC, the proteins that hold the cells of the heart muscle together do not develop properly and are replaced with fatty deposits. This causes abnormal heart rhythms that can increase the risk of sudden death.

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Dr. Danna Spears,
Cardiac Electrophysiologist

every 2,500 people," says Dr. Danna Spears, a Cardiac Electrophysiologist at the Peter Munk Cardiac Centre (PMCC) and Ms. Cartwright's physician. "In certain inherited cardiomyopathies, although sudden death and arrhythmias can happen at any time, they happen more commonly during

physical exertion. ARVC is one of these inherited conditions that we have good evidence where it is actually made worse by high-intensity physical activity."

To control her abnormal heart rhythms, Ms. Cartwright had an internal defibrillator implanted. ("I'm on my fifth and I've used them often," she says.) Though participating in rowing was no longer possible after her diagnosis, Ms. Cartwright became a successful rowing coach at Western, then at places like Princeton University, Harvard University, and Boston University, as well as for provincial and national teams in Canada.

Then in 2014, Dr. Spears and Dr. Heather Ross, a Cardiologist at the PMCC, diagnosed Ms. Cartwright with heart failure, a result of the progression of her ARVC. She will likely need a heart transplant at some point down the road.

"It was pretty shocking to hear," says Ms. Cartwright. "I think when you get a diagnosis like that, it can be an identity you take on. And so I've tried to cope with learning that about myself by not saying, 'I have heart failure,' but saying, 'I want to be the healthiest person with this heart condition and keep this so-called bad heart for as long as I can.'"

One of Ms. Cartwright's current passions is the Heather Cartwright Inherited Cardiomyopathy and Arrhythmia Project (CICAP), a groundbreaking initiative she founded with Dr. Spears and Dr. Ross. The project, which was established through a \$500,000 gift from Heather, her sister Meredith and brother Brian, studies cardiac patients using genetic testing and imaging to identify genetic biomarkers that could indicate causes for cardiomyopathies that run within families. CICAP

also aims to create a registry of families with inherited cardiomyopathies. Dr. Spears says that Ms. Cartwright's support has enabled them to create a large database of families with inherited cardiomyopathies and arrhythmias, and offer extensive screening to their relatives.

"When we're able to identify through a genetic test other people who might be at risk – the siblings and children of the people who are affected – from there we extend the screening. We call it cascade screening," she says. Researchers can work backward, looking for a parent who is a carrier of the gene, then look to grandparents and great-aunts and great-uncles to identify cousins and more distant relatives who might also be potentially at risk.

Dr. Spears says they also hope to facilitate gene discovery through CICAP because she believes they've only seen the "tip of the iceberg" when it comes to the complexity of these diseases.

"At the very beginning, very few genes were identified to cause an inherited and arrhythmogenic cardiomyopathy. And now we have many, many genes that we know can cause this disease that puts you at risk for dying suddenly," she says. "If we are able to identify large families who all have the same condition, but conventional genetic testing hasn't found anything, then that is when we embark on looking for new genes because clearly it's there, and the genetic tests we have today are limited by the genes we know."

Ms. Cartwright says one of the reasons she founded CICAP was with the hope that it could help prevent the deaths of young people who don't know they have ARVC or other cardiac diseases exacerbated by high-intensity exercise.

"Every time there's an event where there's a young person who collapses and dies, it crushes me," she says. "I was very fortunate with the first incident and the subsequent incidents that I didn't die. But there are so many kids who are not as fortunate.

"Over time, we might get to a way to treat it and cure it. But at this stage, we're in life-saving mode."



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02 Dr. Danna Spears is a cardiac electrophysiologist and Heather Cartwright's physician.

