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## Clinic aims to prevent sudden deaths

### Centre to diagnose heart conditions in healthy people

Posted By JENNIFER PRITCHETT,  
 WHIG-STANDARD STAFF WRITER

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When 16-year-old Taylor Allan suddenly died of an undiagnosed fatal heart defect last April, her family and friends were devastated and confused.

It was only after the death of this seemingly healthy young athlete that they learned she had a deadly genetic cardiac abnormality that had gone undetected all her life.

Now, there's new help in Kingston for people who have these unusual cardiac diseases.

Today, a new clinic is opening at Hotel Dieu Hospital to help prevent deaths such as Allan's from happening by



Dr. Chris Simpson, medical director of the cardiac program at Kingston General Hospital and Hotel Dieu Hospital.

Michael Lea/The Whig-Standard

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diagnosing potentially fatal genetic heart problems with a highly specialized series of tests.

Dr. Chris Simpson, medical director of the joint cardiac program at Hotel Dieu and Kingston General hospitals, said that though these conditions are rare, most cases go undiagnosed or underdiagnosed.

"They're much more common than we thought," he said. "So finding them in advance, before people have their sudden death episode, can prevent it."

Simpson estimated there are about four or five deaths from genetic heart conditions in Kingston each year.

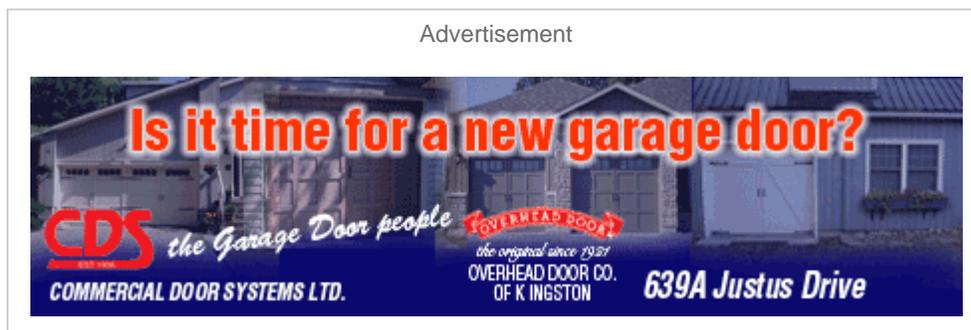
"I think they're all preventable," he said.

Canada only has a handful of specialized genetic heart defect clinics, including ones in Halifax, Ottawa and Toronto.

"This [Kingston] clinic gives us a chance to get the word out there to people that these diseases do exist," said Simpson.

Kingston's Inherited Heart Rhythm Disease Clinic targets patients and their families who need to be tested for genetic heart diseases.

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Known collectively as Sudden Arrhythmia Death Syndromes (SADS), the diseases most often go undetected because they have symptoms such as recurrent fainting spells that can be misdiagnosed.

Simpson urges people who faint or have a seizure associated with physical activity or as the result of emotional excitement, a startle (like a loud noise) or if there is a family history of a young person dropping dead for no apparent reason, to see a doctor for a referral to the new clinic at Hotel Dieu.

The new clinic will offer patients complex genetic testing to help diagnose these often-difficult-to-detect disorders.

"Unlike a lot of conditions, there's no one test that picks this out," Simpson said. "Even the genetic testing, which a lot of people think is very precise, isn't the perfect silver bullet, either, because we don't know all the genes that cause these diseases."

Those diseases that are diagnosed can be treated. Some respond well to medications. Others require what's called a cardioverter defibrillator implant or catheter ablation, which involves applying radiofrequency energy via a catheter to destroy abnormal parts of the heart.

In Kingston, these procedures are done at KGH.

The new Hotel Dieu clinic has arrhythmia specialists, a pediatric cardiologist, a social worker, geneticists and genetic counsellors.

"These are otherwise healthy people who've just found out that they have a potentially life-threatening problem that could make them drop dead -it doesn't get more dramatic than that," Simpson said.

Often it's a whole family that's involved.

"A good percentage of these people are in their teens, sometimes younger or in their early twenties," he said. "Because [these diseases] have a genetic basis, that means that one of the parents must be affected and they may not have realized it," Simpson said.

When clinicians begin asking questions about family history, they often learn about relatives who may have died inexplicably.

"We discover these stories, like an uncle who was a really good swimmer and just drowned inexplicably -or [someone] who had a car accident when the roads were good that day and it was on a straight stretch," Simpson said.

"These things were just put down as tragedies. When the autopsies were done on these family members, [doctors] would find nothing because the defect involved here is at the molecular, or NDA, level and autopsies don't look at that."

In the past, these deaths were considered to have been caused by "natural causes."

"There are no natural causes that kill people when they're 19 years old," Simpson said.

Last summer, Ontario's chief coroner unveiled a new autopsy protocol that should offer some answers to parents who lose a child to sudden cardiac death.

Under new guidelines, every unexplained death in a boy or girl under the age of 18 will be investigated thoroughly, including DNA analysis of the victim's heart tissue. That means pathologists will be required to specifically test for common heart rhythm disorders such as the one that killed Taylor Allan, a Grade 11 student at La Salle Secondary School.

Her father, Ken Allan, was overjoyed to hear about the new clinic opening at Hotel Dieu.

"It's great news -I had no idea this was in the making," he said.

After Taylor's death, the Allan family was contacted by Dr. Simpson, who arranged to have her mother, father and brother tested for similar heart abnormalities.

They're still awaiting the results of those tests.

Allan hopes the new clinic will prevent other deaths from genetic heart disorders.

Allan has spent the months since his daughter's death speaking to as many people as he can about potentially fatal genetic cardiac diseases.

His message is for anyone who faints for no apparent reason to go to their family doctor and ask for a referral to see a cardiologist.

"Go to your doctor and insist [for a referral to a cardiologist] if you have a child that suffers from dizziness," he said.

His daughter had confided to friends that she had bouts of dizziness and blackouts, which are known symptoms of the deadly heart defect called arrhythmogenic right ventricular cardiomyopathy, or ARVC, that was discovered during her autopsy. But those symptoms aren't always flagged as warning signs by physicians.

A year before her death, Taylor was also rushed to hospital after blacking out at a soccer game, yet was sent home without the emergency room staff ordering further tests.

"She was absolutely healthy as can be ... she was always active, she was a dancer," said Allan. "She did all these things. There were no signs whatsoever."

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