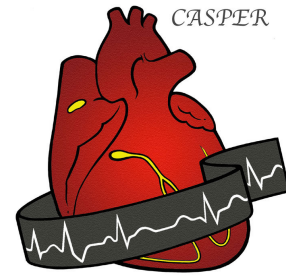


Cardiac Arrest Survivors with Preserved Ejection Fraction Registry (CASPER)



A young woman was attending her first day of law school in London, ON when she experienced a cardiac arrest – a serious medical emergency in which a person stops breathing and his or her heart stops beating, affecting approximately 40,000 Canadians each year. Thanks to speedy emergency care, including CPR performed by a bystander, the young woman’s life was saved.

Although 70 per cent of cardiac arrests occur in homes and public places, such as a school or the sports field, less than five per cent of people who experience cardiac arrest outside of a hospital survive.

Today this young woman is healthy and thriving, and she is participating along with her family in a unique Canada-wide program based at London Health Sciences Centre.

CASPER: an overview

CASPER is a national study funded from several sources including the Heart and Stroke Foundation of Ontario and Boston Scientific. Through a standardized testing protocol, CASPER aims to detect rare genetic conditions in children and adults with an unexplained cardiac arrest, as well as their family members. Such conditions, which can go undetected, can lead to cardiac arrest and sudden death.

“CASPER allows us to better understand what causes people to have a cardiac arrest, and to identify the cause within families and therefore prevent further cardiac arrests in family members,” said LHSC arrhythmia cardiologist Dr. Andrew Krahn, a national leader in researching the genetic causes of heart rhythm problems who heads the team of Canadian physician-researchers involved in CASPER. “In most cases, when a genetic condition is identified, it can be treated – and lives are saved.”

Specifically, accurate testing after a cardiac arrest is needed in order to detect inherited heart conditions in children and adults; identify these conditions in family members who have not experienced symptoms; direct genetic testing; and deliver effective treatment. This process involves standardized clinical testing, such as Holter monitoring, echocardiography and MRI, as well as genetic testing, in which a tablespoon of blood is analyzed for one of the 11 different genetic causes of cardiac arrest that researchers have identified.

Through her involvement in CASPER, the young woman who survived a cardiac arrest was able to have her heart abnormality identified and to begin receiving the appropriate treatment, allowing her to live a normal life. This program aims to detect such conditions in family members as well, although they may appear to

be completely healthy. The young woman's mother, father and sister were tested – resulting in the identification and subsequent treatment of the same heart abnormality in her mother.

CASPER by the numbers

Approximately 230 children and adults are currently enrolled in CASPER. Of the 230, approximately half are patients who have experienced a cardiac arrest and half are family members. Study participants at LHSC include a young athlete who went into distress during a hockey game and survived due to quick actions taken by medically-trained bystanders, as well as his family.

CASPER is the only study of its kind in Canada and is relatively unique in the world. Ontarians are particularly fortunate, as our province has shown leadership in Canada where genetic testing is available to patients for some of these conditions.

In addition to LHSC, eight Canadian academic health care centers are involved in the program, including centers in British Columbia, Alberta, Ontario, Quebec and Nova Scotia. Through CASPER, Dr. Krahn and his colleagues are establishing a significant research network across the country to study these genetic conditions in children and adults.

“Ten years ago many of the cases now involved in CASPER would have been unexplained cardiac arrests,” said Dr. Krahn. “Now, because of CASPER, we’re able to explain and identify inherited conditions in half of cases, and detect and treat the problem in their families before they can get in harm’s way.”

Although the original plan was to continue enrollment in CASPER through 2009, the program's success has encouraged Dr. Krahn and his colleagues to look toward further expansion, with the goal of extending the program to 2013 and enrolling 500 patients.

Information about centers that are participating in CASPER, along with an emerging network of Inherited Heart Rhythm Clinics across Canada can be accessed at: <http://www.heartrhythmresearch.ca/public/index.htm>