

# Adult survivors of childhood heart defects returning to hospital

By Barbara Turnbull

Nathalie Lacoste-Hofmann was born with serious health problems.

The 44-year-old Whitby elementary school teacher and mother of two, is one of thousands of adults alive thanks to childhood surgery that corrected a congenital heart defect — something that affects 1 per cent of Canadians.

A half century ago, only 20 per cent of those born with a heart defect survived to adulthood but with medical advances today's survival rate is 95 per cent.

However, this success has resulted in a rapid increase in cases of congenital heart defects in adults and these surgeries are complex, says Dr. Erwin Oechslin of the adult congenital cardiac clinic at University Health Network's Toronto General Hospital. In fact, the TGH's database shows a 70 per cent growth in congenital cardiac patients at the centre since 2006.

The cardiac clinic sees 500 new patients each year. The average patient is 33 years old, says Oechslin.

"There are about 180,000 patients with congenital heart disease in Canada, 40,000 in Ontario. Fifty per cent of the patients are at moderate to high risk," Oechslin says.

A congenital heart defect can be defined in many ways. It can be an abnormally structured heart or vessels. It may be incomplete or missing parts. The heart may just be put together the wrong way, with holes between chamber partitions, narrow or leaky valves.

Lacoste-Hofmann had a single ventricle pulmonary atresia and transposition of the great arteries. Surgeries at 9 months, 7 and 10 years of age opened up a world of normal childhood activities.

"I could even do sprints in the track and field at my school and I could play a bit of tag," she says.

Lacoste-Hofmann did well until her mid-20s, then started having problems on and off, mostly arrhythmias. She needed procedures that restore heart rhythm several times a year.

"Some were successful and afforded many years of relief, some were not as successful," she says.

Then last year further surgery became necessary when "even going around the block was troublesome."

"I wasn't able to do even a fraction of what I was able to do before," she says.

Surgery enlarged her right atrium and conduits from her vena cava superior and inferior were connected outside of her heart, directly to her lungs. Doctors installed a pacemaker that kicks in when needed.

Oechslin cautions those born with congenital cardiac defects that the original fix is not a cure and regular checks by a specialist are important.

"Surgeons only repair the heart, so these patients have ongoing problems and usually the problems are getting evident in the 20s or 30s," Oechslin says.

He says only 25 per cent of adult Canadians with congenital heart disease are seen regularly by a specialist.

"Some of them find their way back to the health care system when they present as an emergency," he says. "Some of them probably die suddenly."

And when complications arise in adults — heart rhythm problems, heart failure, leaky valves and conduits — the fixes are proving to be complex and resource-draining, Oechslin says.

"Surgeries are taking much longer," he says. "Many of our patients are in the OR the whole day to do a procedure." Heart surgeries for other patients take half the time, he says.

Now Lacoste-Hofmann walks five kilometres most days. She is back to work and family activities and feels great. "The difference between a year ago and now is just unbelievable," Lacoste-Hofmann says.