

Legacy Girls breast cancer study following 900 girls in North America

Mount Sinai participating in research on kids aged 6 to 13 to determine environmental and lifestyle factors that affect health later in life.



GLENN LOWSON FOR THE TORONTO STAR

Aurora Demerjian with her daughters, Stephanie 14, left, and Christina 10. The Hamilton woman, who battled breast cancer, has enrolled both of her daughters in a landmark study that aims to find ways to prevent the disease.

By: [Isabel Teotonio](#) Living reporter, Published on Fri May 10 2013

Stephanie Demerjian is a 14-year-old budding scientist who is determined to do all she can to further breast cancer research.

After all, her mother was diagnosed with the disease 15 years ago, so she understands the toll breast cancer can take.

That's why she's participating in the [Legacy Girls Study](#), a long-term breast cancer study involving about 900 girls from across North America, half of whom come from families with a history of the disease.

In Ontario, the study is being led by Mount Sinai Hospital, which has enrolled 180 girls.

"I want to further cancer research so that people don't have to live through the sickness and what they think is, probably, the worst time of their life," said Stephanie at the family's Hamilton home.

"I hope that they will find a cure or, at least, another source (of treatment) to kill cancer."

Stephanie's sister Christina, 10, is also participating. The mere topic of cancer can be "scary," says the little girl, holding the hand of her mommy, who is now cancer-free. But she too wants to prevent the disease and help others.

Researchers recruited girls aged 6 to 13, to study how lifestyle, environment and biology affect their growth and development. By measuring changes over time, they hope to learn how childhood factors may impact their risk of breast cancer in the future.

The study, which rolled out earlier this year, is being done at the Breast Cancer Family Registry sites in Toronto, the San Francisco Bay Area, New York City, Philadelphia and Salt Lake City. It is the first study to look at girls whose families have had breast cancer and is currently fully funded for five years by the U.S. National Institutes of Health. There is the hope that future funding will allow them to follow girls into adulthood.

"The end goal is to prevent breast cancer," says [Dr. Irene Andrulis](#), a molecular geneticist at Mount Sinai's Samuel Lunenfeld Research Institute, who is also one of the study's principal investigators. "If we can understand why cancer develops then hopefully we'll be able to think of ways to prevent cancer."

"Say, we found, that one of the lifestyle factors, smoking or exercise, was associated with breast development and ultimately with breast cancer, well when do you want to change that? You want to change it when the girls are young. The hope is that we can identify a modifiable factor that someone will actually accept to change."

Andrulis was motivated to help develop Legacy — an acronym for Lessons in Epidemiology and Genetics of Adult Cancer from Youth — after being routinely asked by women with breast cancer how to protect their daughters from the disease.

It's a question that also troubles Stephanie and Christina's mom, Aurora Demerjian. That's why she jumped at the chance to get her girls enrolled in the study.

There is no history of the disease in Demerjian's family, and she has tested negative for the breast cancer gene BRCA1 and BRCA2. Yet, at age 33 — before her daughters were born — she was diagnosed with sporadic breast cancer, which is not hereditary, and underwent a lumpectomy and radiation treatment. She wonders what influence environmental and lifestyle factors may have played in the development of the disease.

Legacy researchers have similar questions.

To help answer them, the girls fill out questionnaires every six months about their behaviour and lifestyle, including exercise and diet. And the Ontario girls visit [Princess Margaret Hospital](#) to give urine, blood and saliva samples and record body measurements, such as body fat, height and foot size.

The analysis takes place at [Mount Sinai](#), where researchers are poring over data, comparing developmental differences in girls who have a history of familial breast cancer with those who don't. Initial results should be available by year's end.

A unique aspect to the Toronto study is the use of the optical spectroscopy, a non-invasive light technique to study breast tissue composition, which was created by [Dr. Lothar Lilge](#), a senior scientist at the Ontario Cancer Institute and a study investigator.

Toronto mom Christina Stamatopoulos-Edwards has no history of cancer in the family but enrolled her daughters — Olivia, 6, Anastasia, 10, and Isabella, 12 — because she feels this is important research. Plus, she figured her girls would enjoy the experience. She was right.

"I like it because it helps other people," says Isabella. "Also it's good for me, too, to (learn) about myself ... It keeps us aware."

Anastasia likes returning to the hospital to see how much she has grown between visits.

"It's really kind of exciting for me to see that I'm actually growing up," she says. "Everyone says I'm getting so tall ... but for me it just feels like I'm the same (height)."

The three sisters say the experience has brought them closer to their mom, and they relish the time spent with her filling out questionnaires, visiting the hospital and giggling about some of the things they're asked to do as part of the study.

The staff keep the girls engaged with initiatives such as the Junior Scientist Program, which takes place after the assessments. That's when the girls, wearing white lab coats and goggles, are taken into Mount Sinai labs to see how their samples are tested and stored. They're also given science activities to better understand what the researchers do.

"That is really awesome," says Anastasia. "You usually just see (labs) in movies."

She's not the only junior scientist impressed with the program. Back in Hamilton, at the Demerjian home, Christina speaks excitedly about an activity she recently did: A DNA charm necklace made with DNA from her own saliva.

She proudly displays the black string necklace, which has a dangling pendant containing white bits of her DNA.

"It's cool," beams Christina. "I've worn it to school."

PHOTOS: Legacy Girls breast cancer study following 900 girls in North America



Photo: 2 of 2

RENE JOHNSTON / TORONTO STAR

Christina Stamatopoulos-Edwards and her 3 daughters, from left, Olivia 6, Isabella, 12, and Anastasia 10 are all enrolled in Legacy Girls study.