

HEALTH/SOCIETY

Youth share stories of IBD

Doctors say bowel diseases often painful and embarrassing

By DANETTE DOOLEY

SPECIAL TO THE TELEGRAM

Fifteen-year-old Jordan Steinhauer has been living with Crohn's disease for more than half her life.

What she remembers most of dealing with the disease when diagnosed at age seven, she said, were the numerous blood tests she had to undergo in hospital.

Born in St. John's, her family was living in New Brunswick at the time.

"I used to hide in the bathroom. I had very small veins and I remember the nurses spending an hour trying to get the needle in," she recalls.

When first diagnosed, Steinhauer had a tube inserted in her nose for nutritional purposes.

"I got really sick of the tube because it was always a reminder that I was sick and that there was something different about me because people would point to it when I was out in public," Steinhauer said.

At age 10, physicians removed the tube and permanently placed it in her stomach.

"I've been healthy ever since so I can't complain," Steinhauer smiles going on to touch upon some of the drugs she uses to stay healthy.

Crohn's disease and ulcerative colitis are two forms of inflammatory bowel disease (IBD) that are as painful as they are embarrassing. Symptoms of IBM include abdominal pain, cramping, fatigue, weight loss, diarrhea and vomiting.

A member of the Crohn's and Colitis Foundation of Canada (CCFC) youth advisory council, Steinhauer was one of several youth who told their stories of living with IBD during the foundation's annual symposium at the Sheraton Hotel in St. John's Saturday.

"A lot of youth are being diagnosed ... We want to let them know that they're not alone, that we are here for them," Steinhauer said of the role of the youth advisory council.

The CCFC is a non-profit, medical research foundation dedicated to finding a cure for IBD - a disease that affects more than 200,000 Canadians and more than 5,000 people living in this province.

Since its inception in 1974, the foundation has invested more than \$61 million in major medical research projects.

During his symposium presentation local gastroenterologist Dr. Jerry McGrath



Fifteen-year-old Jordan Steinhauer (centre) chats with Dr. George Tolomiczenko, executive director, CCFC IBD Research Institute in Toronto (left) and local gastroenterologist Dr. Jerry McGrath.

— Photo by Danette Dooley/Special to The Telegram

talked about a multi-centre CCFC research project he is involved with.

The objective of the genetic, environmental and microbial (GEM) project is to recruit and follow for several years, siblings and children of people diagnosed with Crohn's disease.

McGrath described people with IBD often have to take as "as powerful as chemotherapy."

During an interview prior to his presentation, he said, the challenge comes in seeking funding for new medications.

"Some of the new drugs can be quite expensive, ranging from \$20,000-\$30,000 per year. So, even if someone has a drug plan that covers 80 per cent, this can be like having to buy a new car or truck every single year," he said.

Events such as Saturday's symposium raise awareness and helps remove the stigma associated with IBD, said CCFC regional director Julie Bowering.

"People want to talk to others who have gone through the disease. Self-help and self-management is important," Bowering said.

Symposium speakers included Dr. George Tolomiczenko, executive director, CCFC IBD Research Institute in Toronto, Andrea Clark, a registered dietician at Toronto's Mount Sinai Hospital, Adam Baker, scientific director of New Lab Life

Sciences, St. John's, and Amanda Maynard of Energy Works in St. John's.

Tolomiczenko works with physicians and researchers across the country to help find a cure for IBD.

It's important, he said, to inform donors how their money is spent as well as to show them how Canada's research compares to the rest of the world.

"If you look at how much clout we have internationally, based on publications and science adding to the body of knowledge that will be necessary to find cures, Canada punches about its weight," Tolomiczenko said.

Donor funds are often matched at the provincial and federal level, enabling researchers to broaden the scope of their research, he said.

While a cure for IBD has yet to be found, Tolomiczenko feels researchers are moving in the right direction.

"We understand far more of the basic science that will lead us to a cure quicker. It's really a matter of finding the right pathway and pursuing that with all our might."

For information on the GEM project call 709-777-4972. For information on IBD call 1-800-563-4843 or visit www.ccfc.ca <<http://www.ccfc.ca>

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