

Growing up with Crohn's

Teen doing her part to help raise awareness of the disease that changed her life

By DANETTE DOOLEY

SPECIAL TO THE TELEGRAM

Jordan Steinhauer doesn't remember much about her stay at the Janeway that led to her being diagnosed with Crohn's disease.

"I was only about seven and I was feeling really sick," the 14-year-old recalls during an interview at her St. John's home.

"I wasn't growing much at all and I was getting really skinny and wasn't gaining any weight."

After spending a week in the Janeway, Jordan was sent to the IWK Health Centre in Halifax where doctors confirmed she had Crohn's disease.

Crohn's is an inflammatory bowel disease (IBD) that can affect any part of the intestinal tract, from the mouth to the anus. The inflammation can extend through every layer of affected bowel tissue.

While there is no cure for Crohn's, medications can relieve symptoms of the disease.

Jordan has her own way of describing the disease, which is most severe when people have an overactive immune system.

"It beats me up inside," she said. "So, if I eat something like an apple, I won't get any nutrients because (the disease) will beat it up."

Initially, when Jordan was very sick, she was on "bowel rest" and couldn't be fed orally.

Instead, she was given a nutritional supplement through a tube in her nose.

She now takes the supplement throughout the night through a tube in her stomach.

And Jordan can eat anything she chooses these days, because her Crohn's is well-controlled with a combination of the nutritional supplement and a daily regime of pills.

"Some things bother me a little bit, but not a lot. But when I'm feeling

sick, I start to feel weak and my stomach hurts. But I haven't been sick for a long time," she says.

She says the illness doesn't get in the way of anything she wants to accomplish.

A Grade 8 student at St. Paul's Junior High School, she's an avid singer and guitar player and takes voice lessons from Spirit of Newfoundland's Peter MacDonald.

"I like singing songs from musicals and I just finished a recital," Jordan says.

She's also an enthusiastic volunteer with the Eastern Avalon chapter of the Crohn's and Colitis Foundation of Canada (CCFC) and will be participating in two major fundraisers this

year.

The 20th annual M & M Meat Shops charity barbecue takes place Saturday, May 10 at the shops on Portugal Cove and Topsail roads in St. John's.

John Efford, a former provincial and federal cabinet minister, is the chapter's honorary chair.

M & M Meat Shops have raised over \$14 million for IBD research so far.

The 13th annual Heel 'n' Wheel-a-Thon is being held in Bowring Park June 8. The event

runs in more than 80 communities across Canada and collected more than \$1.6 million for CCFC last year.

Jordan is the Heel 'n' Wheel-a-Thon youth honorary chair for the CCFC Eastern Avalon Chapter.

And she's already pinned down her career, even though she hasn't even started high school yet.

"I want to be a pediatric gastroenterologist so I can help other people who have Crohn's disease," she says.

When asked what advice she'd give other young people with IBD, she says, "Don't let it get you down. You can get through it."

For more information on IBD, call 579-3700 or toll free at 1-800-563-4843 or visit www.ccfc.ca.

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Jordan Steinhauer doesn't want her life to be ruled by Chron's disease. "Don't let it get you down. You can get through it."

— Photo by Danette Dooley/Special to The Telegram

ABOUT IBD

- ▶ Inflammatory bowel disease (IBD) describes two similar yet distinct conditions called Crohn's disease and ulcerative colitis.
- ▶ Crohn's and Colitis Foundation of Canada (CCFC) is a voluntary, non-profit medical research foundation dedicated to finding a cure for IBD.
- ▶ Approximately 200,000 Canadians suffer from IBD.
- ▶ IBD is unpredictable. Most people experience periods of remission and flare-ups of the disease, often requiring long-term medication, hospitalization or surgery.
- ▶ In addition to raising research funds, CCFC provides information on IBD to patients, families and health professionals.
- ▶ CCFC has more than 65,000 supporters in 90 volunteer groups across the country.

Source: Crohn's and Colitis Foundation of Canada