Huntington disease: Stealing lives, generation by generation

A Wawota woman outlines her experience with a genetic neurological disorder that has a 50 per cent chance of moving on to the descendants of a victim.

At one time Barbara Dennis The Wawota resident's grandmother and great-uncle suffered from a variety of symptoms related to what they later realized was a degenerative genetic disorder

generation "All of us knew growing up that there was this 'thing' in the family," Dennis says.

"Great-Uncle Irving couldn't sit still. He was always moving. There was always something And then my earliest memories of Grandma were this little lady who was just moving all the time There was always this skeleton in the closet and I can't recall when we first heard the name Hunting-

Huntington disease (HD) is a genetic brain disorder that kills cells in specific parts of the brain. The disease affects one in every 10.000 Canadians, but touches the lives of one in 1,000 through caregivers family members friends and people at risk of carrying the disease. There is a 50 per cent chance the dominant gene holding the disease will be passed to the children of a Huntington

A juvenile form of HD hits peoyoung as five have been diag-nosed with the disease, which in its invenile form is primarily a movement disorder that differs from the adult version.

Adult symptoms of HD are wide ranging, hitting patients whatever had to be done to help both physically and mentally. him make that dream a reality. At

Vancouver for a Huntington Society of Canada national conference. This was after the disease had claimed Den-

nis's grandmother and uncle, and her mother, Marjorie McCaw was diagnosed with it.

"When somebody pays your airfare to Vancouver and gives you a three-day conference, you kind of feel oblig-

ated to the cause," she says.

"Not that I'm not obligated anyway. If people affected by the disease are not going to do anything about it, then why should anybody else?"

It's been years since she accepted that invitation, but Dennis, the Huntington Society and Scotlabank will host

the first annual Marjorie's Daughters and Friends Dinner and Silent Auction to benefit the society. Funds will be

like an inability to focus, memory decisions: and physical deteriora tion, such as weight loss, involun an inability to walk, talk or swal-

that moves from generation to eventually kills its victims. There is currently no cure for HD, but some drugs and treatments can quell the symptoms ssociated with the disease In the case of Dennis's grand mother, she could never sit still.

> "She was the love of my grand father's life and he did a wor the symptoms, it seemed other people in the family had this, bu

jorie McCaw was in her 60s, she started to show the same symp toms as her mother. She was diagnosed with HD in the early

committed to fulfilling her duties to her home and family. In 1959,

the same time, she was involved

Later, her personality changed and she was ultimately placed in

ful job of caring for my grand-mother," Dennis said. "But in the "When she started to display obody knew what it was."
When Dennis's mother, Mar

Mariorie was a homemaker

she and her husband bought a farm in the Mountney district near Wawota. Marjorie wanted nothing more than to support her husband in his dream to own and

"She supported him totally in that," Dennis said. "She did

Marjorie was a member of the Mountney Ladies Club, a service organization that supported Mountney School District facili-

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ties and activities and raised funds for the Wawota Hospital. "She connected there to meet the neighbors, become part of the fabric of life and also to support the hospital," Dennis said. she knitted sewed or quilted for Red Cross seked of her "She was very artistic with the needle and thread. She did all kinds of things; needlework, petit oint, cross stitch, she hooked rugs," Dennis said. "She basically

and with the Red Cross, where

tried her hand at everything and she loved to piece quilt." Dennis's father was a Second Marjorie regularly made World War veteran and was clothes for her five children. Once involved with the Royal Canadi- these items were no longer use-My earliest memories of

Grandma were this little ladv who was just moving all the time. There was always this skeleton in the closet and I can't recall when we first heard the name Huntington.

Barbara Dennis

an Legion. Mariorie followed him able, she'd recycle the material by there with her participation with the Legion Auxiliary. Legion functions, particularly monthly meetings and cere-monies surrounding November

11, were a large part of the McCaw household. "I can remember Remembranc Day services from the age of four," said Dennis. "It's just

something that was sacred to my father. That's what you did on November 11.

cutting them into two-inch squares and sewing the pieces into quilts. This left the McCaws and other families and with a wide variety of blankets blazed "This was before the time that didn't go to the store and buy yards of fabric, come home and cut them up. You used what you

November 11."

After having her last child in Marjorie was also involved in her 40s, Marjorie started to havvolunteer activities, specifically in ing trouble walking up and down the region's health care system stairs. When she needed some-

flight of stairs, she'd ask one of the children to do it for her. Dennis is not sure if this was related ac well

she does find it somewhat omi-The diagnosis of HD came when Mariorie was in her 70s. Her symptoms were basically an inability to control her move-

"Her resource worker identified mother as the victim with the most movement that she'd ever seen anybody have." Dennis said. "A lot of HD people that I see, their movement is very static reality that she lives with every

little bit that way, but her moveent was much more fluid than what I've seen in other people."
Although they found medications to help Marjorie control the movement, they couldn't eliminate it totally. HD forced her to give up the things she'd lived for as a wife and homemaker.
"In 1994, my father was diag-

nosed with terminal cancer. Prior to that, mother had given up cooking. She said, basically, 'Here father, You can do it.'" said Den-

stress related to that, her movement became more pronounced. As he got weaker and wasn't able to function as well, she did take on the role of meal-maker again and bless her heart for that. Mariorie eventually died from the disease in September, 2005. She was almost 82 years old. "If there's a silver lining to the

disease in our family, it's that," Dennis said. "She was able to

established. For many Hunti ton victims, their usual age is 39 to 45 and there is a juvenile form

tims, their children suffer with

the thought that there is a 50 per gene that carries the disease After watching HD cripple, inca-pacitate then kill their mother or father, these children must then overcome the realization that they may suffer the same fate. Donnie admite it's a difficult

robot-like. Mother's got to be a Before she really knew wha was victimizing her family, Der nis recalls attending a medical was 19 that was put on by some researchers from Saskatoon. At the time, there was no way of diagnosing HD until a postortem test was completed. The families of anyone suspected of having the disease were inter-viewed and examined. "There was something in the

works and you hope against hope that your loved one isn't going to be affected," Dennis said. "For s.
"But with his diagnosis and the many years. I lived that way: if we don't know about it, we don't have to deal with it. That has changed for me." What others find to be the

day life are crushing reminder that leads to the disease that killed her mother. "I know as an at-risk person

every time you forget a name every time you end up wonder-ing why you're where you're at. you're thinking, 'Is this the dis-ease? Is this the disease? Is this the disease?," she said. "I suspect that mother would have thought of that as well."

Dennis has endured the two-

year process required to deter-mine if she carries the gene. It's a simple blood test, but at-risk per ple must also be prepared for the

Much of the two-year process includes psychological coun-selling. Dennis chose not to reveal the results of her predic-

"You have to qualify to receive this news. If you're on the edge of suicide, they're not going to give you the gun." said Dennis. "If you have the gene, you will develop the disease unless some thing else takes you first." that her mother lived into her 80s, a full life that allowed her to wit This realization is too much to

handle for some descendants of ness her children grow, marry and have children of their own. Through her involvement in Generally, the carriers of the gene will be hit under the same the Huntington Society of Canacircumstances as the family memda Dennis was exposed to the Huntington community outside her own family. Here, she discovbers who suffered from HD "As bad as her movement was,

ered that for many people, just the potential of having the dis-ease determines how they live their lives "Whereas the child of someon who has the disease at 35 and is dren because they might be a car-rier. Tragically, however, others institutionalized and bed ridden at age 43, that, I think, would be nitted suicide over the totally different for a 20-year-old prospect of having gene that

she did live to be 82." Dennis

Moosomin Mayor Larry Miskiman signs a proclamation marking May as Huntington Disease Awareness Month alongside Lynn McGonigal (left) and Barbara Dennis. The women are the daughters of Mariorie McCaw, who died from Huntington disease in 2005. That was totally new to

and it really made me think about my attitude: 'Well. I'll just May proclaimed Huntington go on and live my life and if I gel the disease, I get the disease," **Disease Awareness Month** If there is a blessing in her

> nities across Canada in proclaiming May as Hunt- 2006, Canadian researchers were able to cure HD in ington Disease Awareness Month Every child born to a parent with Huntingt gene that carries it. With Huntington, the future holds no surprises:

· Huntington disease is an inherited brain disorder that causes cells in specific parts of the brain to

 The disease's symptoms include: · involuntary movements denression

pacitation and, eventually, death.

 loss of ability to recall information loss of attention · difficulty with decision making The disease eventually leads to complete inca-

breathrough has been possible and it offers real togethar the care of hossible and it offers real hope that HD can be cured in humans. The Huntington Society of Canada aspires to a world free of Huntington disease. The society maxi-mizes the quality of life of people living with HD by delivering services, enables others to understand

the disease, and furthers research to slow and to prevent HD. The Huntington Society of Canada is a national network of volunteers and professionals working to find new treatments and ultimately a cure for

Huntington disease and improve the quality of life for people with HD and their families. If you want to know more about the Huntingtor Society of Canada and Huntington disease, more information is available at www.curehd.ca.

Dinner and silent auction planned for May 10

Marjorie's Daughters and Friends hope to raise

involved with the community in the Wawota area as a ets are available at Scotiabank until May 7. They are also genetic neurological disorder—it was an invitation from the founder of the Huntington Society of Canada that made her feel obligated to help raise money for family member of the Mountney Ladies Club and the Royal Canadian Legion Auxiliary. She also volunteered in othsupport and research into the disease. In the early 1990s, Ralph Walker invited Dennis to

\$15.000 for Huntington Society of Canada

er areas, such as for the Red Cross "The older you get, the more you appreciate your par-ents, and I realize this woman just did everything. She had many, many productive years in many different areas; to her community, to herself, to the arts, lots of dif-ferent facets," Dennis said. "The last few years of her life, when we were strug-gling so much to just deal with her and her disease, I lost

touch with what a tremendous contributing member of society she was. I wanted to regain that for myself and I thought, why couldn't I do that for the commit well. This woman was a very valuable, contra member of her community."

Huntington disease is a genetic brain disorder that is

passed from generation to generation. There is a 50 per cent chance that a victim's descendants will get the dis-ease, which includes severe symptoms, both physical used for research into a cure for Huntington disease and provide support for families associated with it. The event is scheduled for May 10 at the Wawota and clumsiness, depression and obsessiveness, loss of

Town Hall and will include a catered meal by the Mountney Ladies, a silent auction with about 50 items up for sale, and music from the Regina Mandolin Orchestra. memory, a change in behavior or personality, loss of attention and difficulty with decision-making. The dinner and silent auction will begin at 5 p.m. Ticknis's mother, Marjorie McCaw, who died of Huntington ets are \$25 per person, while corporate tables are being disease in September, 2005. McCaw was heavily sold for \$190 for eight, or \$225 for 10. In Moosomin, tick-

available at Wawota Agencies, Kenosee Mini-Mart King's Department Store in Carlyle and from Joanne

Dennis originally thought the event could bring ir \$5,000 for the Huntington Society, but Scotiabank came on board to match that \$5,000, putting the event's

fundraising tally over \$10,000. "So I'm thinking let's go for \$15,000," she said. A wide variety of items will be available for purchase through the silent auction. Among them are 20 joints of

through the sistent auction. Among mem are 20 joints or used drill stem from Talisman Energy, a "Pamper Your Mother" Mary Kay cosmetic luxury basket, a recipricating saw from Borderland Co-op, a crocheted baby quilt and toy, a "Stars for Marjorie" piece quilt made by Marjorio Husband, and a sweater knitted by Marjorie's older sister, Aleatha Cobbe.

sister, Aleatha Cobbe.

An awareness campaign has also been launched by the Huntington Society of Canada. The month of May has been designated Huntington Disease Awareness Month in communities across the country. Moscomin Mayor Larry Miskiman has signed a proclamation for the

town's participation in the campaign.

The proclamation urges all citizens to support the Huntington Society of Canada in the organization's efforts to "unravel, not only the mystery of Huntingtor disease, but also a wide range of other genetic, neurolog-ical and psychiatric disorders affecting the lives of sc many Canadians."