King resident spearheads hemochromatosis awareness, holds golf tourney

Hereditary hemochromatosis, is tough to say. It's iron overload. It's an iron metabolism disorder common in people of northern European descent particularly whose forefathers came from the Britain, Ireland or Northern France.

The disorder causes the body to absorb two to four times the normal amount of iron. Left untreated, the excess iron builds up in vital organs, tissues and joints, where it can cause a number of debilitating and potentially fatal complications and diseases.

An estimated 125,000 Canadians have two copies of the mutated gene that puts them at risk for hereditary hemochromatosis. Over 3.5 million Canadians carry one copy of the mutated gene; these individuals are called ?carriers.? This number is significant because when two carriers have children, the offspring are at risk of having both genes, and thus at risk for iron overload.

Once diagnosed treatment is generally straight forward. Blood is taken to remove iron from the body. Stored iron is used to make new red blood cells. Blood which is removed can often be given to Canadian Blood Services to save lives. On reaching normal iron levels, one simply goes to have regular checks for ferritin , a measure of iron in the body, and phlebotomies when needed.

Ian Hilley, a volunteer, King resident, former resident of Caledon and Ontario Director for the Canadian Hemochromatosis Society, is excited about a Canadian-developed app for smart phones to help those with hemochromatosis monitor their disorder.

?There are so many people suffering from this disorder who aren't diagnosed,? he said.

Two Canadian university professors and their students have created the mobile application that will help people with hemochromatosis track their ferritin levels as they continue through their lifelong treatment. Dr. Gary Grewal, of the University of Guelph, along with Dr. Andrew Hamilton-Wright, of Mount Allison University, in partnership with the Canadian Hemochromatosis Society, led the development of the Iron Tracker app to fill a need for people to monitor their de-ironing progress and iron levels during their maintenance phase. Grewal, whose mother is Scottish and father from northern India, was diagnosed with hereditary hemochromatosis in 2010 after feeling extremely ill for about a year. His symptoms included chronic fatigue and abdominal pain and swelling. Blood tests revealed a high level of ferritin. He was referred to a liver specialist, who diagnosed him with hemochromatosis. He underwent treatment that involved regularly scheduled bloodlettings, also known as phlebotomies. He began to monitor his condition using a spreadsheet but later decided to develop an app that could help others with the condition.

?I felt it would be useful to have a mobile app to keep track of my progress,? he sayid. ?I had a sense of my own wellness. There's nothing out there like this,? said Grewal of the app, which helps patients keep track of their blood work, monitor their de-ironing progress using a graph, and predict when their next phlebotomy will be needed.

The app also helps patients keep track of their appointments and which arm was drawn from during their last phlebotomy.

?This app is one of the tools we'll use to support those who have hemochromatosis and to increase awareness. Gary, Andrew and their team are making a big difference in people's lives,? Hilley added.

The Iron Tracker app is free to all users and is available for download through the Google PlayTM Store and App Store. More information and instructions on how to use the app can be found at www.irontracker.ca.

Hilley has also been busy organizing the Society's first ever parliamentary reception in Ottawa to bring the disorder to the attention of our federal politicians and is trying to mobilize volunteers to support increasing awareness of hemochromatosis in Peel, York and Toronto.

To that end he is also excited because the Canadian Hemochromatosis Society is holding it's first ever social golf event, ?Irons 4 Iron? May 21 at Royal Woodbine Golf Club. It's a friend and fundraiser for the Society.

?The Society is trying to increase awareness of this common, yet commonly undiagnosed disorder in Ontario,? Hilley added. ?I invite folks to join us for lunch and a great afternoon.?

Call him at 647-964-6942 for information on hemochromatosis or to register for the golf.

Awareness is the cure.

For information on hereditary hemochromatosis, visit www.toomuchiron.ca.