

## Alberta Media Fact Sheet

### What is Hemochromatosis?

- Inherited hemochromatosis, or iron overload, is Canada's most common genetic disorder.
- An estimated 12,000 Albertans have two copies of the gene that puts them at risk of iron overload. In the entire country, this number is estimated at greater than 110,000 Canadians.
- Over 400,000 Albertans carry one gene (they are called "carriers"). In the entire country, this number is estimated at greater than 3.5 million Canadians. This is significant because when two carriers have children, the offspring are at risk of having both genes, and thus at risk for iron overload.
- It is extremely prevalent in people of northern European and Celtic descent, but others can also be affected.
- It causes the body to absorb two to three times the normal amount of iron.
  - Normally, 10 to 20 mg of iron is ingested daily, of which 1 – 1.5 mg is absorbed in the intestinal tract. The balance is excreted through the bowel.
- 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.
- Complications and diseases include:
  - Chronic fatigue
  - Depression
  - Abdominal pain
  - Aching joints, particularly in the knuckle and first joint of the first and second fingers
  - Loss of sex drive
  - Discolouration or bronzing of the skin
  - Type II Diabetes
  - Hypothyroidism
  - Disease of the heart muscle and arrhythmia, leading to heart failure
  - Liver cirrhosis and cancer
- For men, these complications can appear in their thirties to early forties.
- For women, these complications usually appear after menopause, when there is no more loss of iron during menstruation.

### **Can The Complications and Diseases Due to Hemochromatosis Be Prevented?**

- Yes! Complications, diseases and premature death due to iron overload can be prevented, but early diagnosis and treatment is the key.
- Diagnosing the disorder while still in the early stages, before irreversible damage is done, is extremely important.

### **How Do You Test for Hemochromatosis?**

- There are simple blood tests that a doctor must order which includes serum ferritin and transferrin saturation. These measurements reflect how much iron is stored in the body and how much is being transported.
- If the results come back elevated, hemochromatosis may be indicated.
- Genetic testing will confirm the diagnosis of hemochromatosis.

### **What is the Treatment for Hemochromatosis?**

- Excess iron is removed by a procedure known as a phlebotomy, which is the drawing off of a unit of blood, similar to a blood donation but at a higher frequency.
- This treatment is effective because phlebotomies remove red blood cells which contain iron.
  - Each unit of blood contains approximately 225 mg of iron in hemoglobin, the main component of red blood cells.
  - In the process of making new red blood cells, stored iron in the tissues and organs are pulled out and transported to the bone marrow where red blood cells are produced.
  - This repeated procedure gradually depletes the iron stores and levels fall back to normal.
- Once acceptable iron levels are achieved, these levels can be maintained through regular blood donations at Canadian Blood Services clinics.

### **Who Are Some People in Alberta Who Have Hemochromatosis?**

- George VanderBurg, MLA, Whitecourt-Ste. Anne Constituency
- Rayne Kuntz, Former NAIT Media Relations Director and A-Channel Live at Five Producer

### **What is the Canadian Hemochromatosis Society (CHS)?**

- CHS is a registered non-profit organization, founded in 1980 and incorporated in 1982.
- CHS was established to create awareness of hemochromatosis, to ensure its early recognition, testing and treatment in order to prevent needless suffering and premature death.
- The head office is located in Richmond, BC.
- Executive Director and CEO is Bob Rogers.
- President and Chair of the Board is Frank Erschen.

- There are several volunteers of the Society throughout Alberta.
- Mailing address:  
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