

Iron Filings

Alberta in Focus

MLA Fights Hemochromatosis

By Rayne Kuntz

It's Heritage Day in the small community of Rochfort Bridge, Alberta, and MLA George VanderBurg has just finished riding in the parade and chatting with his constituents. He is passionate about public service; he has been a politician for 25 years, so when he was diagnosed with hemochromatosis it was no surprise he was willing to use his public platform to raise awareness about the potentially fatal disease.

He feels hemochromatosis needs to be on every family doctor's radar.

"When someone comes with symptoms of high iron, it should be an automatic check. We check automatically for blood sugar, right?" says George VanderBurg.

About 18 months ago George went to the doctor because he was feeling off. He went from feeling energetic to constantly being exhausted. Chronic fatigue is common with someone with who is overloading in iron. "I am used to going 12, 14, 16 hours a day and all of sudden a 10 hour day was beginning to be a chore to me and when I would go to sleep. I wouldn't go to sleep – I

would pass out. I knew there was something wrong with my body," says VanderBurg. "I told my family doctor I didn't think it had anything to do with my work pace; I am energized by people, and I always have been."

When VanderBurg's blood work came back, his ferritin count was 1200 ng/mL; over 300 ng/mL is considered out of range for men. Strongly suspecting hemochromatosis, his hematologist and good friend, Dr. Bruce Ritchie immediately started a treatment of regular phlebotomies (similar to blood donations).

"Seventeen or 18 pints later, I got down to below a hundred. By then I had my DNA

results." VanderBurg confirms that he tested positive for the two genes necessary to cause hemochromatosis. "We got my sister tested and my brother tested. They are both carriers – they don't have hemochromatosis. We then we got our sons tested. They are both carriers. One had an iron count about 400, the 31 year old. He went to Canadian Blood Services right away and started giving blood."

It's estimated that 1 in 300 Canadians has hemochromatosis, making it the most common genetic disorder in Canada, with the numbers a lot higher in some segments of the population. VanderBurg knows the value of understanding his cultural roots. Most of

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Alberta MLA George VanderBurg chatting with George and Hilda Ralston at the Rochfort Heritage Day parade and fair. Since VanderBurg was diagnosed with hemochromatosis, he has been using his public platform as MLA to raise awareness about the potentially deadly condition. During their chat, VanderBurg shared some information about hemochromatosis. The Ralstons had never heard about the disorder and were surprised to learn it is the most common genetic disorder in Canada.


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Alberta MLA Fights Hemochromatosis (continued)

his constituents and colleagues share his northern European heritage (VanderBurg is Dutch), which increases their risk of having hemochromatosis. After VanderBurg was diagnosed, he found out two of his fellow Conservative caucus members also have hemochromatosis.

"That is three in 83... yes I was surprised," VanderBurg comments. "They came to me after I brought up my condition in caucus."

It's estimated 12,000 Albertans have two copies of the gene that puts them at risk of iron overload and 400,000 Albertans carry one gene (they are called "carriers"). This is

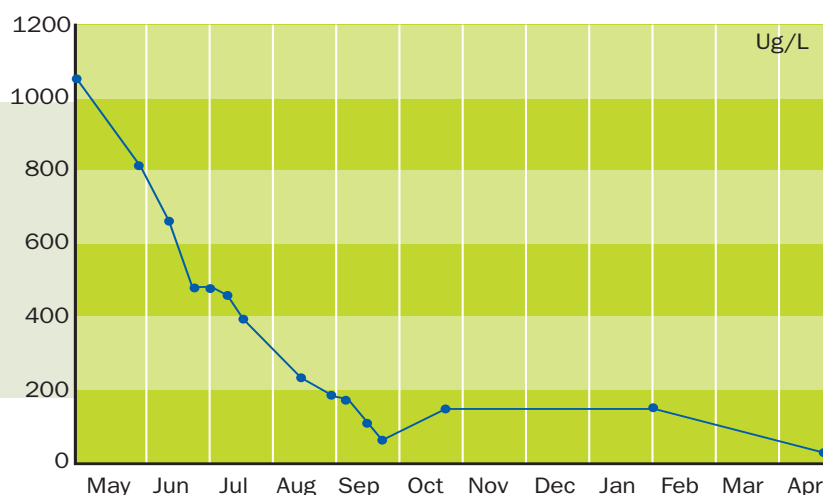
significant because when two carriers have children, the offspring are at risk of inheriting the two hemochromatosis genes.

"I don't think too many days go by when someone doesn't confide in me they have it too - I tell them I was diagnosed 18 months ago with hemochromatosis. It scared the heck out of me, but with good medical advice and through some initiative on my own... the Internet has good information on it and I encourage people to join the Canadian Hemochromatosis Society, they have good newsletters; I mail some of them out to some people myself...With knowledge comes the ability to manage this disease," says VanderBurg.

VanderBurg is thankful for his diagnosis. He feels re-energized and in control of his own health, which is far better off than his father was in his mid-fifties. VanderBurg and his specialist both suspect his father probably had hemochromatosis and the excess iron contributed to his death.

"Knowing that I have something that can be managed so easily... I am blessed. My father had pancreatic cancer, he was written off. If you are going to have a disease this is the one you want."

George VanderBurg monitors his ferritin levels by recording them on a graph.



Alberta's Spirit is Well

Alberta MLA George VanderBurg and Bob Rogers, Executive Director of the Canadian Hemochromatosis Society (CHS), in George's office in the Alberta Legislature. During Hemochromatosis Awareness Month in May, Bob was in Alberta to pick up an Alberta Spirit Grant presented by the Minister of Health and Wellness, Gene Zwozdesky. The meeting with the Minister, which was arranged by George VanderBurg, focused on raising awareness and prevention. It is the first time CHS has had the opportunity to talk to a provincial cabinet minister about hemochromatosis and the important work being done by CHS. See full story on page 3.

Alberta Supports Hemochromatosis Cause

The Government of Alberta gave a large boost to hemochromatosis awareness in the province this past May with a Community Spirit Grant in the sum of \$9808.18.



"Today marks a very important step toward raising a greater awareness about a really important disorder call hemochromatosis," announced Alberta's Minister of Health and Wellness, the Honourable Gene Zwozdesky, as he presented the cheque to Bob Rogers, Executive Director and Chief Executive Officer of the Canadian Hemochromatosis Society on May 5th. "We as a government are very interested in encouraging healthier lifestyles and focusing on the wellness side of the agenda, and so this particular grant of \$9800 will help the Canadian Hemochromatosis Society to better establish themselves here in Alberta," said the Minister.

Dr. Bruce Ritchie, physician to Alberta MLA and hemochromatosis sufferer George VanderBurg, supports more people having their iron levels tested.

"I think this is a model for how we should be doing healthcare," said Dr. Bruce Ritchie, a hematologist at the University of Alberta. "We need to be proactive not reactive." The Community Spirit Grant will be used to

fund community information seminars and continuing medical education throughout Alberta in cooperation with Primary Care Networks (PCNs) at the encouragement of Minister Zwozdesky. Through this outreach, CHS aims to raise more awareness of the disorder.

Information at each seminar is made available through a PowerPoint presentation, medical guidelines, brochures and newsletters. These seminars are beneficial to those who have just found out they have hereditary hemochromatosis, to relatives of patients with hemochromatosis, as well as to those in the at-risk group who may or may not be experiencing symptoms.

Currently, CHS is contacting PCNs to see if they will partner with the Society to promote these opportunities. In addition, CHS is seeking other forums to present information in places where PCNs are not planning to host a seminar in the next 12 months.

Members and supporters of CHS can also help the Society come to their community. If you can assist in finding a venue to hold the information session and aid in promoting the event, please contact the CHS office at healthinfo@toomuchiron.ca or call (604) 279-7135.

Keep an eye on the Society's website, www.toomuchiron.ca, for the schedule of seminars coming to a location near you.

Community Spirit Grant Program

Give back to your community and help make it vibrant and strong! Your donation will be matched by the Alberta Government.

- The Community Spirit Program Donation Grant provides an opportunity for non-profit and charitable organizations such as the Canadian Hemochromatosis Society (CHS) to receive a grant based on the total eligible cash donations received from individual Albertans over a 12-month period.
- CHS can apply to the program once it demonstrates it has received the minimum total of \$1,000 in eligible cash donations from individual Albertans. The maximum grant available is \$25,000 per year, up to a maximum of \$50,000 over three years.
- Based on what CHS has received and the available program funding, the Alberta provincial government will issue a grant that the Society can use to help support programs such as its Community Outreach and Information Seminars, the Physician Referral Network, and Patient Support.

From left to right: The Honourable Gene Zwozdesky, Bob Rogers, George VanderBurg, Dr. Bruce Ritchie. Photo courtesy of the Government of Alberta.



A Million Great Ideas

Bob Rogers, Canadian Hemochromatosis Society Executive Director and CEO

Elizabeth Minish, a Past President of the Canadian Hemochromatosis Society (CHS), once said to me, “Bob, over the years CHS has received or thought of a million great ideas, but CHS doesn’t have the financial resources to do them”. With a budget of \$175,000 in 2011 for all of CHS’s work in Canada, I understand that CHS has limited resources. However, every day CHS is helping people all across the country through our head office and the countless volunteers who provide support to others. So,

I am very pleased that in this issue of Iron Filings we can tell you the good news of new support from the province of Alberta.

For the very first time, CHS has received a Community Spirit Grant from Alberta’s Ministry of Culture and Community Spirit, a grant based upon the support and generosity of individual donors in Alberta. This spring, I was thrilled to meet with the Honourable Gene Zwozdesky, Minister of Health and Wellness for Alberta, and George VanderBurg, MLA for Whitecourt-Ste. Anne. The additional support we are receiving from Alberta this year will allow CHS to begin delivering new and exciting information and awareness programs throughout Alberta starting this fall with the Primary Health Care Networks near Calgary, Lethbridge and Medicine Hat.

CHS is currently seeking for funding from an Ontario foundation. With the large Celtic and Northern European

population in Ontario too, CHS must make new inroads into delivering our services and information there. The path to implementing the one million great ideas may seem uphill and slow, but rest assured that every new dollar CHS receives will be directed to increasing the awareness of hemochromatosis, reducing suffering and saving lives.

I am wondering if you have considered helping others who need help. The Canadian Hemochromatosis Society is a registered non-profit charitable organization in Canada that depends upon individuals supporting its work. For as little as \$10 a month, you can help the Canadian Hemochromatosis Society provide patient support and reach others who are at-risk for this disorder.

I hope when you read the articles and information in this newsletter, you will be encouraged to support our mission throughout Canada and make a vital difference in the health of those who suffer from hemochromatosis. Thank you a million times!



Hemochromatosis and Your Diet

The Canadian Hemochromatosis Society has recently had several requests to provide more information on diet and to promote the hemochromatosis cookbooks that are available on the market. In response, while certain cookbooks may be helpful in regulating iron intake and in the replenishment of nutrients lost through blood-lettings, CHS would like to emphasize that at no time will reducing iron in the diet replace phlebotomies as effective treatment for hemochromatosis. In the maintenance phase, restricting iron intake may increase the time between phlebotomies, but blood-lettings are still the best and most efficient method to remove the excess iron stored in one’s body. Dietary modifications that CHS encourages are:

- ☐ Avoid iron supplements and foods highly fortified in iron such as certain breakfast cereals.
- ☐ Avoid alcohol. Alcohol enhances iron absorption and may harm a compromised liver.
- ☐ Drink plenty of fluids (water, juice, milk) before and after a phlebotomy to replace lost fluids.
- ☐ Vitamin C increases non-heme iron (from vegetables) absorption. It is okay to consume fruits and vegetables containing Vitamin C, but avoid Vitamin C supplements. Consider taking foods high in Vitamin C in between meals.
- ☐ Avoid or cook well raw seafood, deli meats and soft cheeses, which can carry harmful bacteria that can cause life threatening infections in people with hemochromatosis, especially those in the de-ironing phase.
- ☐ Enjoy a well balanced diet that includes a wide variety of fruits and vegetables, whole grains, low fat dairy products, meats and meat alternates.

More information on dietary precautions and nutritional guidelines can be found on the CHS website, www.toomuchiron.ca.



Spotlight on Volunteers - Alberta

Calgary's Commitment to the Cause

By Anne Stang and Dr. Julie Cormacks.

When Anne Stang was diagnosed in 2005, her first thought was to inform her siblings, relatives and ethnic group, the Germans from Russia. Her first activity was to go to her Saskatchewan birthplace where she distributed over 400 pamphlets.

Later, Anne was joined by Amanda Bennett who wanted to help because her father died of hemochromatosis (HHC). Next was Julie Cormack who had just been diagnosed with HHC. The three planned activities – talks and displays at senior's events and at malls. With time, more people contacted the small group to help in activities and to be informed. CHS's Facebook page brought four new members, one of whom designed a very attractive t-shirt. The first meetings

were held in Anne's home but now meetings are in a rent-free room at a Co-op store.

Anne and Julie continue to give talks to interested groups – seniors, cultural societies, church women, service clubs, Canadian Blood Services, etc. The group has also volunteered at a local triathlon, and has arranged for the professional printing of CHS materials (a tri-fold display board, brochures and posters).

"Our informal setup works for us," says Anne. "We all contribute ideas and take part in activities. Commitment to the cause has been the driving force behind our efforts."

Interested in volunteering in Calgary?
Contact Anne Stang at stangam@shaw.ca.

Edmonton Needs Your Help

If you are passionate about furthering the awareness of hereditary hemochromatosis



in and around the Edmonton area, CHS needs you! Donnalea Ferguson is CHS' volunteer Regional Coordinator in Edmonton, and replaces long serving volunteer and past board member Ben McEwen.

Donnalea and a small group of volunteers will soon be planning activities for 2012. If you can help, please contact her at dferguson@clearwave.ca.

Lacombe Group

Interested volunteers in the Lacombe area can contact Pryna Koberstein at ekoberstein@shaw.ca. Pryna has been very active in the past with awareness activities and was featured in the Fall 2007 issue of Iron Filings.



Thank You to Some of CHS' Active Alberta Volunteers

The Canadian Hemochromatosis Society thanks all volunteers in Alberta for supporting the hemochromatosis cause. Special recognition goes to: Ben McEwen, whose active volunteer work in Alberta was instrumental in the development of the provincial protocols for the screening and management of hemochromatosis; Marjorie McKinnon, who lead the process that resulted in CHS becoming an annual recipient of funds from the Cremona & District Community Chest; Stephen Williams, who aids in the translations of CHS newsletters and other media into French; and Rayne Kuntz, past board member and current member of the Communications Task Group.

CHS Snapshots



Gert Madsen of Denmark (left) with Canadian Hemochromatosis Society Executive Director Bob Rogers in the CHS office. Gert, a hemochromatosis sufferer, exhibited symptoms caused by excess iron in the endocrine system: hypothyroidism, feeling cold, hair loss or early graying, fatigue, depression, confusion and memory loss. Gert visited with Bob in late April to gather information and ideas on forming a hemochromatosis association in his home country.



Volunteer Jean Gatan with Tony Barradas, London Drugs Sales Supervisor. Jean provided hemochromatosis awareness at the London Drugs store at Ironwood Plaza in Richmond, BC in conjunction with the Canadian Blood Services Bloodmobile which was also holding a blood donation clinic at the store.

Biolron Conference

Many students and researchers from around the world descended upon Vancouver, BC to present their papers at the Fourth Congress of the International Biolron Society. Presentations included cutting-edge advances in iron biology, iron-related disorders, and diagnostics and therapies related to these disorders. Recent advances in the understanding of the molecular basis of iron disorders are leading to new experimental therapies directed at iron-restrictive anemias and iron overload disorders.

Key-note speaker, Dr. Michael Hayden, Killam Professor of Medical Genetics and the Canada Research Chair in Human Genetics at the University of British Columbia, spoke to the significance of “black swan” events in genetic research, where research directed to looking at “exceptional patients” may give a unique insight into human biology and eventual treatment strategies for disorders of iron metabolism.

The Canadian Hemochromatosis Society was present amongst the international community of hemochromatosis patient associations, and together held a symposium to discuss the opportunities and challenges each country faces in garnering public awareness and support. The symposium concluded with the group agreeing in principle to the formation of the new

International Alliance of Hemochromatosis Associations (IAHA). Together as an international organization, the group will have a larger pool of resources and people with which to create a stronger voice for all hemochromatosis patients worldwide. The Canadian Hemochromatosis Society is extremely pleased to be a founding partner of the IAHA.

Marie Warder Awarded for Lifetime Achievement

In front of 200 guests of the International Biolron Society Awards Dinner held on May 27, 2011, Marie Warder accepted a Lifetime Achievement Award for her work in furthering awareness of hemochromatosis within Canada and internationally.

“I don’t really feel like I deserve this because I don’t recall doing anything except putting one foot in front of the other over a period of years,” said Marie humbly. “I feel it was more of divine intervention that these things happened,” she said, referring to the help she received from numerous authorities on iron overload that enabled her to gain the knowledge she needed to help others affected by hemochromatosis.

Dr. Samuel Krikler, a longtime friend and supporter of Marie, and Bob Rogers, the Executive Director of the Canadian Hemochromatosis Society, paid a tribute to Marie before she was presented with the

award by Dr. Tomas Ganz, president of the International Biolron Society.

Marie founded the Canadian Hemochromatosis Society in 1980, and consequently established the Haemochromatosis Society of South Africa and the International Association of Haemochromatosis Societies. Marie’s beloved husband, Tom Warder, passed away at age 67 due to complications caused by hemochromatosis. [For more photos of the awards dinner, visit blog.toomuchiron.ca.]



Attendees and representatives from international and local hemochromatosis associations at the inaugural IAHA meeting

Alberta Top Blood Collection Region in Western Canada

In the Society's ongoing efforts to inform hemochromatosis patients in the maintenance phase of their treatment that they may be eligible to donate their blood, CHS is pleased to bring you the following article from Canadian Blood Services.

Home to thousands of committed blood donors, Alberta is Canadian Blood Services' third largest blood collection region across the country, and largest in Western Canada.

The western province is home to 68,000 active blood donors who donate about 145,000 units of blood each year. With four permanent clinics in Edmonton, Calgary, Red Deer, and Lethbridge, as well as more than 600 mobile clinics that run across the province each year, Canadian Blood Services provides many opportunities for Albertans to donate blood.

As one of the blood agency's larger collection areas, Alberta is also responsible for supporting the needs of other regions, such as its western neighbour, British Columbia. Sites

in Alberta regularly send red blood cells and platelets to the B.C. & Yukon Region to be used in B.C. hospitals.

Alberta is also the hub for the testing of all blood donations collected across Western Canada. Samples from each unit collected in B.C., Alberta, Saskatchewan, and Manitoba are transported to the Western Consolidated Donor Testing Laboratory in Calgary on a daily basis to be tested for infectious diseases. All donations must pass testing before being released into Canadian Blood Services' national inventory of blood products.

Clinics in Alberta are always in need of more donors. To donate blood in Alberta, visit www.blood.ca or call 1 888 2 DONATE (1-888-236-6283) to find a clinic near you.

The Canadian Hemochromatosis Society is a member of Canadian Blood Services' "Partners for Life" program. If you are in the maintenance phase, you can team up with the Society to save more lives. Here's what you need to do to donate your blood through CHS:

1. Have the CHS Partner ID # ready. This # is CANA002257.
2. Register online by going to our website at www.toomuchiron.ca and clicking on the link that says [CBS Partners for Life Registration Form](#) found in the column to the right on the home page. This is a "one time" process. Once you are registered, your blood donations will automatically be tracked each time you donate blood.
3. Call 1 888 2 DONATE to book an appointment.

The Ins and Outs of the Phlebotomy Bag

Have you ever looked closely at the blood collection bag used for a therapeutic phlebotomy? At a glance it might not look like much more than a sandwich bag with a needle attached. Let us take a closer look...

The phlebotomy procedure itself has evolved beyond leeches and simply draining random amounts of blood into a pan, to a very precisely monitored and safe procedure.

Macopharma is a global supplier of collection bags designed specifically for blood collection and production, as well as therapeutic phlebotomies. In Canada, you can find these phlebotomy bags in use in six provinces and approximately 100 hospitals across the country. The vast majority of these bags are used to treat Hemochromatosis patients.

Safety is a growing concern in all industries, and the medical field is no different. Products are designed and engineered around patient comfort and safety. The safety of the staff member handling the product is equally as important.

Susan Stratton-Penney, Sales Manager of

Western Canada for Macopharma, describes some of the safety features available on the variety of phlebotomy bags available throughout Canada.

"There are a wide number of collection bags available on the market today, the majority of which aim to increase the efficiency of the phlebotomy procedure, while of course, protecting the safety of both the patient and hospital staff.

First of all, the bag should ideally be latex free due to sensitivities and allergies. The bag may have graduation marks on it to improve the accuracy of the volume bled from the patient. An integrated sampling device to obtain blood specimens for testing and blood analysis is an added bonus. This will, in some cases, reduce the need for a second venepuncture. However, in some cases blood testing is required to determine



the actual need for a phlebotomy. An infusion site is also a nice feature available on some bags. This will again reduce the need for a second venepuncture if the patient needs a fluid top up after the procedure. Last but certainly not least, a needle guard is mandatory in most provinces to protect the hospital staff from a needle stick injury after the procedure is complete."

Thankfully, shopping for a phlebotomy bag is not something the patient has to include on their grocery list. Health Authorities are constantly upgrading and looking for the safest available product. However, perhaps this article will simply make you more aware of the research and development that goes into the simple 'life saving' sandwich bag.

Casino Support Rocks CHS



Bob Rogers, Canadian Hemochromatosis Society (CHS) Executive Director and CEO (left), accepts cheque from Rick Duff, River Rock Casino Resort General Manager, Casino Operations. August 18th proved lucky for CHS as it was the day that the Society was presented with \$2500 from the River Rock Casino, part of Great Canadian Gaming Corporation. "River Rock Casino Resort is proud to support the Canadian Hemochromatosis Society in their efforts to spread awareness of this potentially fatal disorder," said Duff. CHS thanks River Rock Casino and Great Canadian Gaming Corp. for their generous community spirit.

CHS Updates

New Address

As of September 1st, the CHS head office has a new address. Located four doors down from the previous office, CHS' new home is located in a slightly larger space but still within the same building that houses other non-profit community service agencies.

When sending correspondence or making a donation to CHS, please change the address on the return envelope to reflect the new address:

#285-7000 Minoru Blvd.
Richmond, BC
V6Y 3Z5

New Board of Directors

The Canadian Hemochromatosis Society elected a new national Board of Directors at its Annual General Meeting held in June. New directors include Warren Funt, Patrick Haney, David Lloyd, and Kelly McQuiggan all of Vancouver, British Columbia, Dr. Samuel Krikler of Richmond, BC, and Shannon Haney of Okotoks, Alberta. Kelly

McQuiggan takes on the additional role of Treasurer on the Executive Committee.

Returning directors are Frank Erschen of Thornhill, Ontario, as President and Chair of the Board, Gloria Haché of Ottawa, Ontario, Pat McParland of Vancouver, BC, and Sabrina Meherally of Richmond, BC. Positions currently vacant on the Executive Committee are Vice President and Secretary.

New Regional Coordinator in British Columbia

CHS is pleased to introduce Sharon Slager as the new volunteer Regional Coordinator for the BC Thompson Okanagan region and Prince George. Sharon hails from Oliver, BC, having recently moved there from Prince George where she served for 12 ½ years as the Executive Officer for the Canadian Home Builders Association – Northern BC. In her new voluntary role,



Sharon will coordinate and support other volunteers in her region in their awareness raising efforts.

"I sincerely look forward to working with each and every one of the volunteers who are willing to donate their time and energy to help educate people about hemochromatosis," says Sharon.

"Together we will be able to bring awareness to the general population as well as medical professionals."

If you live in the Thompson Okanagan or in Prince George, and wish to raise awareness of hereditary hemochromatosis in your home town, please contact Sharon by email at sslager@toomuchiron.ca or by phone at 250.462.7217.