

Iron Filings

Providing information, awareness and support

Raising Awareness is Plagued With Frustration

BY RAYNE KUNTZ

Society as a whole doesn't seem to care about prevention – we don't act until we are sick. It seems we would rather pay the huge personal, financial and societal costs of treating disease.

It is a sad and frustrating truth I have come to realize after spending most of the past two years trying to raise awareness about hemochromatosis – the most common genetic disorder in Canada. Hemochromatosis can lead to iron overload. Without diagnosis (a simple blood test) and treatment (a simple act of giving blood) the excess iron can destroy your organs leading to diseases such as diabetes, liver disease, heart disease and cancer.

People are needlessly suffering and dying from hemochromatosis everyday.

So if it is so common and it is so simple to test for iron overload, why aren't more people getting tested?

It doesn't appear to be on the radar of many family physicians and people don't know or are reluctant to ask for the test.

I was lucky to be diagnosed before my iron hit dangerous levels. My doctor actually thought I may be anemic because I was so tired (an early sign of hemochromatosis). The iron test came back showing I had high iron not low.

After my diagnosis I joined the board of the Canadian Hemochromatosis Society (CHS) because I felt I should do everything I could to tell people to get their iron tested.

I thought if 1 in 300 Canadians (primarily Northern European and Celtic descent) could be walking around like me, carrying a ticking time bomb of toxic iron building up in their bodies and not even know it, I had to do something.

But almost 21 months later – I realize dedicated volunteers have been spreading the same message as I have for years (CHS is 30 years old this year) and what seems like a common sense message doesn't seem to be resonating with people; I have even struggled at times to communicate it within my own family. So as another year rolls around again – I don't know what to do other than to keep telling people to get tested and hope my story moves at least one person to act.



Rayne Kuntz with CityTV cameraperson



You can help **iron out Hemochromatosis** in Canada.
Find out more at www.toomuchiron.ca

Hello?

Help us be heard

How can the Canadian Hemochromatosis Society create a strong voice to be heard throughout the country?

The answer is simple: through your membership and support.

Through membership, not only will you receive voting privileges at the next AGM, but you also align yourself with CHS' mission to create awareness in Canada so that early diagnosis and treatment of hemochromatosis will become the rule rather than the exception. Most importantly, membership creates strength in numbers, so that CHS can bolster awareness amongst all Canadians including government, medical professionals and the general public.

To that end, we at the Society will be conducting a telephone campaign through the months of September to December to reach all our current and past supporters to thank them, renew their interest in our mission, and listen to their ideas and experiences with hemochromatosis. Allen Boolinoff is the project coordinator for this campaign and will be making the majority of the calls. If you are a past supporter, and you believe in the work of the Canadian Hemochromatosis Society, please take the opportunity to say so, and sign up for a membership when Allen calls you.

Did you know that 80% of CHS' funds are provided through individual donations and memberships? We need your support!

Staff Updates

Vicky Tse Walker has joined the staff as Bookkeeper and Donor Relations Clerk. Vicky had been volunteering with CHS for the past two years performing the same duties, and CHS is pleased that Vicky has agreed to continue her work at the Society as an employee. Vicky's employment adds stability and continuity to these two important positions.

Brenda Ohara has returned from her maternity leave and is now filling the new position of Communications Coordinator. Her previous role as Administrative Assistant is being filled by new volunteer recruit, **Corbin Mountford**. Corbin is currently studying Business Administration in Entrepreneur Leadership at Kwantlen University.

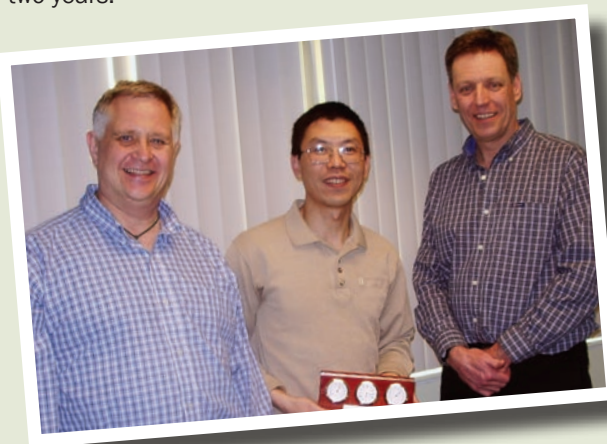
CHS is embarking on a public relations project this fall and has recruited **Allen Boolinoff** to be the coordinator. Read about his project in the article, "Hello? Help Us Be Heard".

Tina Macgowan has been busy volunteering her time at the CHS office as a human resources consultant and helping to prepare for the fall public relations project.

Stephen Williams of Edmonton and **Diane Jodouin** of Ottawa have been translating the Iron Filings newsletter into French since the Fall 2009 issue.

After two years, **Henry Chen** has left his volunteer position as CHS' supervising bookkeeper. CHS was very fortunate that he was able to squeeze in the time between work and CGA studies to ensure that proper accounting procedures were put in place and to be a big part in grant applications. Thank you very much, Henry, for your dedication and hard work!

Replacing Henry is **Brian To**. Brian is currently working on an accounting degree at BCIT and a CGA designation, all while being employed with the Health Services Authority of BC. Brian has also committed to volunteering with CHS for a minimum of two years.



Henry Chen Receiving Award From
Bob Rogers and Ross Gilley

New Approach to Screening & Early Diagnosis

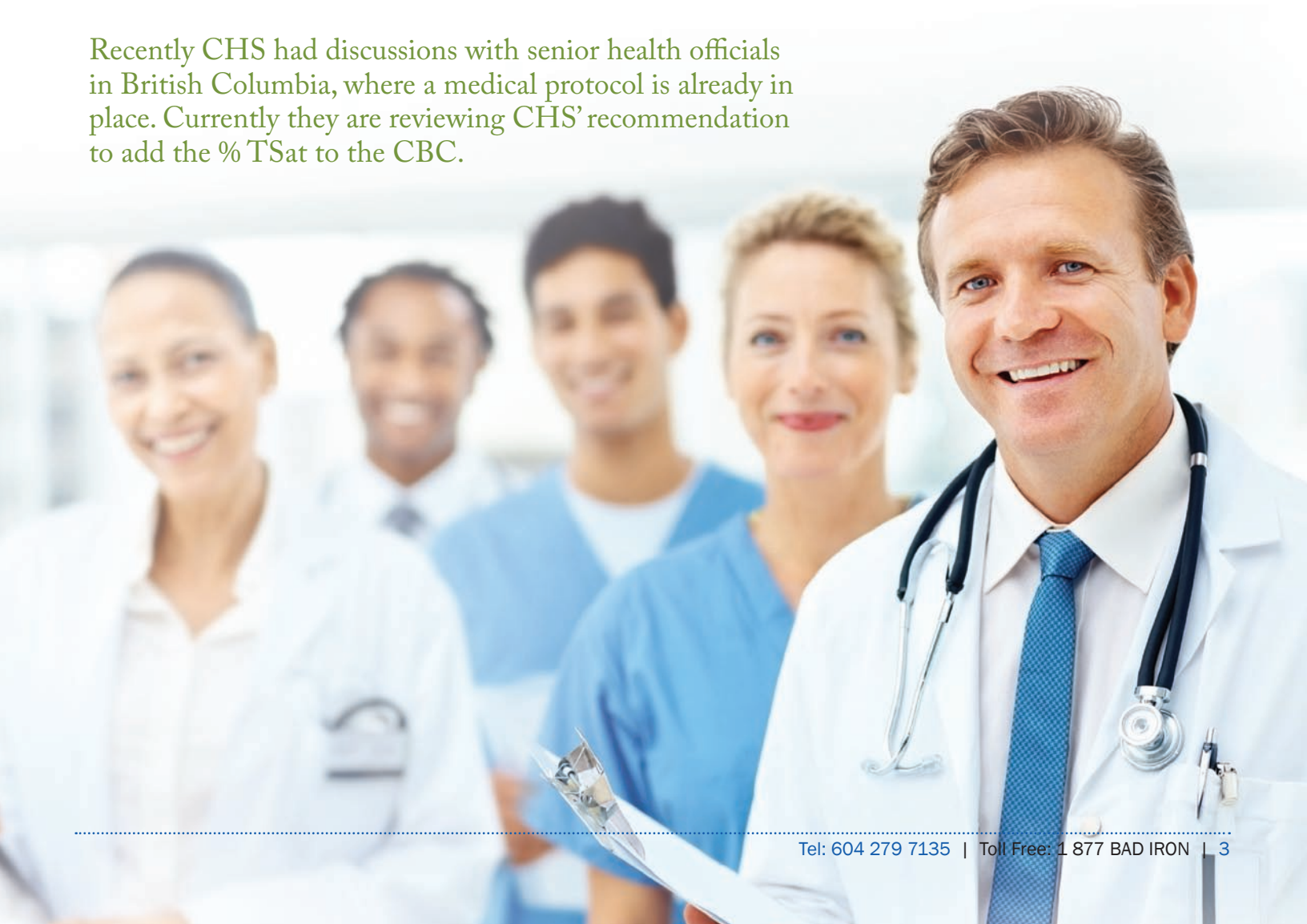
A new national strategy to raise awareness of hemochromatosis has recently been approved by the Board of Directors of CHS. The goal of this national strategy is to work towards adding the percent transferrin saturation test (% TSat) to the standard bloodwork, also known as the complete blood count (CBC), so that more early diagnoses will be made. The benefit to provincial governments will be that less healthcare dollars will be spent treating iron overload in its early stages with simple phlebotomies (blood-letting) versus treating hemochromatosis-induced diseases at a much higher cost to healthcare and society.

This strategy starts with a targeted approach to create medical screening protocols in every province, thus leading to greater awareness amongst government health authorities, physicians and the general public. Each protocol would recommend the use of a % TSat which is the best blood test for genetic hemochromatosis. When a % TSat is in excess of 45%, hereditary hemochromatosis is suspected.

The strategy will be implemented initially in most of the Atlantic Provinces where the expression of hemochromatosis is high due to the strong Celtic ethnicity. CHS will collaborate with medical teams to create a screening and management protocol to be approved by the appropriate medical society or college. CHS expects that these protocols will take approximately one year to develop and implement.

Over the next 5 years, CHS will work with medical educational institutions to facilitate continuing education for family physicians, and deliver extensive public education through multi-media and presentations. A substantial amount of % TSat tests will have been performed in each of these provinces during this timeframe and at the end of five years, the provincial health ministries will evaluate the results. Based on their findings, the various health authorities will determine the cost benefit of adding this test to the CBC. The provinces are expected to confirm their participation in this strategy within the next few months.

Recently CHS had discussions with senior health officials in British Columbia, where a medical protocol is already in place. Currently they are reviewing CHS' recommendation to add the % TSat to the CBC.



Genetic Testing, Iron Levels and Risk

Dawna Gilchrist MD FRCPC FCCMG DHMSA

Professor and Clinical Geneticist, Medical Genetics, University of Alberta

What information can be gained by genetic testing?

DNA (usually from a blood sample) is tested for the presence of mutations in the HFE gene. Mutations in this gene are responsible for predisposition to the common form of hemochromatosis.

All genes come in pairs – one from mother, one from father. There are three forms of the HFE gene – normal, C282Y (severe malfunction) and H63D (minor malfunction). Therefore the combinations are:

Normal with Normal	Normal
Normal with C282Y	Normal, but with high normal ferritin levels
Normal with H63D	Normal, but with high normal ferritin levels
C282Y with C282Y	Highest risk for end organ damage
C282Y with H63D	Some risk for end organ damage
H63D with H63D	Tiny risk for end organ damage

It is **very important to note** that there are many other causes of all these conditions that are **MORE LIKELY** to cause trouble. For example, the commonest cause of cirrhosis of the liver is alcoholism. The commonest causes of heart failure are heart attacks, untreated high blood pressure and/or leaky heart valves. The commonest causes of diabetes are aging, obesity and lack of exercise. For most of these conditions, there is no way of ascertaining whether the cause is iron overload or something else that is more common (or a combination of factors). However, a liver biopsy can ascertain liver iron stores and can be helpful in determining the cause(s) of liver disease.

I have been told I have a genetic predisposition to hemochromatosis. Will I develop end organ damage?

There is much more to developing iron overload and end organ damage than the genetic abnormality. There are certainly other genetic modifiers that we have not yet defined. Many personal factors such as age, diet, and personal habits (such as overuse of alcohol) may contribute.

Up to 30% of individuals with C282Y/C282Y may develop iron overload related end organ damage. Men are much more likely to be affected than women. The risk for C282Y/H63D individuals is much lower and the risk for H63D/H63D individuals is very low. It is currently not possible to predict who will develop damage and who will not. Following lifelong with serial blood work, particularly ferritin levels, is recommended.

If I have the genetic predisposition, what should my ferritin level be?

End organ damage due to iron overload is seldom seen unless ferritin levels exceed 1000ug/L or there is another contributor (eg. overuse of alcohol with liver damage). If there is evidence of end organ damage (due to iron overload or some other problem), then ferritin should be kept low. The level recommended is 50ug/L providing that hemoglobin remains above 110g/L. This will likely require medical phlebotomy.

What is meant by “end organ damage”?

The likeliest organ to be damaged by iron overload is the liver. There may be even more risk for damage if there is another disorder which affects the liver eg. fatty liver, overuse of alcohol, viral hepatitis.

Other organs that may be damaged by iron overload are:

Heart	causes weakening of heart muscle with heart failure. Does NOT cause heart attacks
Pancreas	diabetes
Joints	arthritis, particularly small joints of hand
Hormone secreting glands	resulting in low thyroid or low sex hormones
Skin	discoloration

If there is no evidence of end organ damage, then ferritin should be kept within normal range ie. <200ug/L for females and <300ug/L for males. This can usually be managed by regular blood donation.

Is ethnicity a factor in hemochromatosis?

The common form of hemochromatosis is almost entirely a disorder of Northern Europeans. The C282Y mutation is found almost exclusively amongst Northern Europeans; the H63D mutation can be found in other populations.

Individuals from Asia, Africa and the Indian subcontinent often have naturally higher ferritin levels than Northern Europeans, but are at little risk from the common genetic form of hemochromatosis.

My iron levels are high but my genetic tests show that I don't have hemochromatosis.

There are several possible explanations for this:

1. You might have a high ferritin because of other personal factors – age, size, diet, ethnicity
2. Your ferritin level might be high because of some other disorder. Ferritin is an acute phase reactant and can be elevated in acute and chronic infection, inflammation or cancer.
3. You might have a rare form of hemochromatosis. The test that is currently done applies ONLY to the common, HFE related, hemochromatosis.

If in doubt, your family doctor can refer you to a specialist, depending on your specific signs and symptoms.



1 in 9 Canadians carries the mutated gene for Hemochromatosis

Dawna Gilchrist (right) works to promote awareness with Rayne Kuntz (left).



Aeroplan Campaign a Success

Awareness Month had a true coast-to-coast flavour this past May, thanks to the generosity of members donating their Aeroplan Miles. CHS received 195,702 Aeroplan Miles towards the goal of 250,000 Miles in this year's inaugural Aeroplan Campaign. This was enough miles to send CHS Executive Director Bob Rogers from BC to Newfoundland & Labrador, Nova Scotia, Prince Edward Island, Ontario and Alberta.

This year, CHS focused on meeting with the various provincial Ministers of Health, government policy makers and health practitioners in order to identify plans to develop protocols for the screening and management of hemochromatosis. Protocols are a set of recommendations for doctors to follow in order to diagnose and treat a medical condition. Having a protocol in every province would raise the awareness of hemochromatosis with physicians and promote early testing, diagnosis and treatment. Read "New Approach to Screening & Early Diagnosis" in this newsletter for more information on a new strategy that CHS is developing in regards to protocols.

A special "Thank You!" goes out to our donors who donated their Aeroplan Miles so that CHS could raise awareness across Canada. Our next Aeroplan Campaign will be held in February 2011.

CHS thanks each and every one of you who go out of your way to help make hemochromatosis a household word.

In addition to these meetings, Bob attended awareness raising activities:

Newfoundland & Labrador

- Interviewed for two articles in The Telegram in St. John's
- Interviewed for a segment on St. John's Morning Show on CBC Radio

Nova Scotia

- Spoke with large group at Halifax's IWK Health Centre Genetic Counseling Session for newly diagnosed patients of hemochromatosis

Prince Edward Island

- Interviewed for a segment on CBC Radio Morning Show
- Interviewed for a television segment on CBC News: Compass
- Spoke at a hemochromatosis information seminar in Montague, organized by local volunteer Seana Evans-Renaud

Ontario

- Met with volunteers and donors to discuss fundraising and awareness activities

Alberta

- Met with the Calgary group of volunteers headed by Anne Stang, and attended the Aging and Active Living Expo where Anne's group has held a booth for the past three years.
- Spoke at a well attended hemochromatosis information session in Bonnyville, an event promoted by the local Primary Care Network.

Other awareness raising activities included Rayne Kuntz (featured in our cover story) being interviewed during a phlebotomy and broadcasted in 11 different media outlets including CKEM Breakfast Television in Edmonton, Shaw TV Edmonton, CITV Global News at 6 and 11, The Edmonton Sun and 24 Hours Edmonton. Many of these media outlets also posted the video or article on their corresponding websites, reaching a national audience. Dr. Dawna Gilchrist, professor and clinical geneticist with the University of Alberta, was also on hand during the interviews to discuss the importance of the serum ferritin and percent transferrin saturation tests.

Anne Stang in Calgary wrote an article that appeared in both the Calgary Herald and CalgaryHerald.com, entitled "Displays Spotlight Genetic Disorder", where she discussed hemochromatosis symptoms and treatments, and provided details on information booths that she and local volunteers were hosting around Calgary.

In British Columbia, volunteers hosted an information booth for the second year in a row at Burnaby's Eurofest, a festival that celebrates European cultures, and an ideal location to raise awareness of a disorder that mostly affects people of northern European descent. Additional activities in BC included bottle drives and car washes put on by the CHS student volunteer group.

Many other awareness raising activities were held across Canada, too numerous to mention them all here.



MARK YOUR CALENDAR

International Biolron Society Conference To Be Held In Vancouver May 2011

The International Biolron Society (IBIS) is a society founded to promote research and public education of iron metabolism, including disorders due to iron excess or deficiency. Current board members serve from around the world: Austria, Australia, Canada, France, Germany, Israel, Italy, and the United States.

The Biolron conference is held every two years, with the next conference occurring May 22 – 26, 2011 in Vancouver, BC. This conference will be an excellent source for current research into hemochromatosis, and will give CHS an opportunity to promote its efforts to raise awareness.

The Bioiron Conference is the main national and international forum for comprehensive presentation and discussion of cutting-edge advances in iron biology, iron-related diseases (iron overload disorders, iron-restrictive anemias, and others), and diagnostics and therapies related to these diseases. The health-related aspects of iron biology will be the primary priority of the 2011 conference. In addition to a broad overview of state-of-the-art iron pathobiology, the 2011 program will

specifically highlight recent advances in our understanding of molecular iron sensing, intracellular iron transport, iron regulation including by hepcidin, ferroportin and microRNAs, pathogenesis of iron overload in iron-loading anemias, genetics of hereditary hemochromatosis and iron deficiency, localized disorders of iron homeostasis, and iron diagnostics and therapeutics. More than 500 international participants are expected to attend, including most of the leading scientists and physicians involved in research in iron biology and iron-related diseases.

(Source: International Biolron Society)

Biolron Conference

May 22 – 26, 2011

Sheraton Vancouver Wall
Centre Hotel

1088 Burrard Street,
Vancouver, BC

Check www.toomuchiron.ca
for conference updates.

The general public may register and attend this conference; a link to the IBIS website and registration information can be found on the CHS website, www.toomuchiron.ca.



Canadian
HEMOCHROMATOSIS
SOCIETY

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to eliminate the suffering and
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Hemochromatosis

VERY COMMON • VIRTUALLY UNKNOWN • POTENTIALLY FATAL • EASILY TREATABLE

What is it?

The excess storage of iron in the body.

What is the cause?

Primarily hereditary.

Most common symptoms

Chronic fatigue, joint pain, irregular heart beat, mood swings, confusion, bronzing of the skin, loss of libido and abdominal pain.

Most common complications

Liver and heart disease, diabetes, arthritis and hormonal irregularities.

Tests required for diagnosis

Serum ferritin, transferrin saturation percentage and genetic testing.

Treatment

Phlebotomy treatments (bloodletting) which are ongoing for life.

Reference reading

The Bronze Killer;
Ironic Health; Iron Disorders
Institute Guide to Hemochromatosis

Hereditary Hemochromatosis (HHC)
is a genetic disorder that affects
over 3,000,000 people in Canada.

**There is a cure.
Awareness.**

**Please forward this
newsletter onto
your family and
friends**



Support CHS and help prevent needless suffering and early death

Donation

\$ _____

Annual Membership

- ☐ Regular _____ @ **\$30**
☐ Senior _____ @ **\$20**
☐ Family (same address) _____ @ **\$45**

☐ Yes, please renew my annual membership
automatically by using my credit card info

- ☐ Senior's Lifetime (55 +) _____ @ **\$295**
☐ Lifetime _____ @ **\$500**

Books & Accessories

- ☐ The Bronze Killer _____ @ **\$20**
☐ Ironic Health _____ @ **\$22**
☐ Wristband _____ @ **\$8**
☐ Hemochromatosis DVD _____ @ **\$21**
☐ Too Much Iron DVD _____ @ **\$10**

Total \$ _____

- ☐ Credit card ☐ Cheque/Money order
(use credit card info area to the right)

- ☐ I have Hemochromatosis (HHC)
☐ I have a blood relative with HHC

- ☐ I would like my support acknowledged in
the newsletter
☐ I would like to receive the E-Newsletter,
The Magnet
☐ Send me information about planned giving
or leaving a bequest in my will.

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Official Revenue Canada receipts are issued for all memberships and donations.

Donation Options

I would like to make a ☐ Monthly ☐ Quarterly ☐ Annually ☐ Other _____
donation in the amount of \$

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Card Number: _____ Expiry date: _____

Signature: _____

☐ **I am enclosing** _____ **postdated cheques in the amount of \$** _____
to the Canadian Hemochromatosis Society.

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Tel: 604 279 7135 | Toll Free: 1 877 BAD IRON

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