AMONG OURSELVES

Newsletter of the Canadian Hemochromatosis Society

Member of the International Association of Hemochromatosis Societies

From Your President...

The meeting of the International Society, Cairns 2001. *From Left:* **Chris Kieffer**, IDI USA Vice President; **Patricia Martinez,** Members of the society in France, **Margaret Rankin;** Australian President, **Janet Fernau;** UK President, **Dr. Sam Krikler;** Medical Advisor and Director of our Society, **Philip de Sterke;** Netherlands President, **Charm Cottingham;** CHS President, **Elizabeth Larking;** President of HFV Foundation Australia, **Berit Borch-Iohnsen;** Board member of Norway, **Ron Hubery;** Australian Society Member.

I have just returned from Australia where I attended the World Congress on Iron in Cairns from August 18 to 23rd. Present were 350 delegates from 24 countries, 12 of whom were from Canada. There were 120 presentations and 221 posters displayed. The most interesting one for our Society was the panel discussion on whether to screen the general population for hemochromatosis. Most doctors agree that a screening program is necessary but can't agree on what the test should be: a genetic or a biochemical one. So the debate rages on with no conclusions. In one Australian city, screening is going to be carried out on personnel in large businesses by cheek scrapings using the genetic test. The biggest opponent to genetic testing is the United States because they say it will affect people's insurance coverage. And of course many people with the two genes might never store iron. There was also a very interesting lecture by Dr. J. O'Connor linking hemochromatosis to neurological diseases such as Alzheimer's, Parkinson's, and dementia. There was a poster on the cost effectiveness of screening for HHC in Spain. Their conclusion was, of course that it would be cost effective if done on people age 35 to 40 and the test cost kept under $10.00 . The Australian Society held a 2-day seminar across the street from the main congress. About 100 of their members were in attendance. Many doctors gave presentations at this seminar covering many subjects all related to hemochromatosis, all of which I attended. Great Britain, Ireland, Holland, France, New Zealand, the USA and myself representing Canada told what was happening in each of our organizations. A doctor from the Australian Red Cross also explained how blood donations were given in that country. A meeting was held of the International Hemochromatosis Society with 7 countries being represented. Margaret Rankin, the Australian President was elected to head this Society for the next 2 years. I took the minutes.

The highlight of the Social activities was a trip out to the Great Barrier Reef. Many people donned snorkeling equipment while the rest of us viewed the coral and brightly colored fish from glass bottomed boats. On another night we were taken to an Aboriginal Cultural center for dinner and a show. I finished my week with a safari into the Daintree Rain forest and then had 5 days touring around Sydney and its beautiful harbor and opera house. Four of us – Janet Fernau, UK President, Margaret Rankin, Australian President, Chris Kieffer, Vice-President, IDI, USA and myself shared an apartment in Cairns, and exchanged many ideas and problems. We also met and shared time with Dr. Aideen O'Sullivan from Ireland. The most valuable result of the 5 days is always the new knowledge you gain along with the people you meet, among them Dr Chris Whittington from Langley, and the connections made.

The next congress will be held in Washington in 2003 and in Prague in 2005. Dr. Krikler and I presented posters with the message that we would like to host this congress in 2007 but this will not be decided until the Washington congress.

All of us feel that at last hemochromatosis is on the world stage and can no longer be ignored by governments and medical communities, and that world screening is just around the corner with the saving of the quality of many, many peoples' lives.

Charm Cottingham

NEW!

THE IRON DISORDERS INSTITUTE

GUIDE TO HEMOCHROMATOSIS

"Early detection of iron overload disease (such as Hemochromatosis) represents a major chronic disease prevention opportunity. Detection and treatment (phlebotomy) for iron overload early in the course of the illness can substantially reduce the severity of the symptoms, organ damage, and death from associated chronic diseases." -Dr. David Satcher U.S. Surgeon General

To order contact www.irondisorders.org, or your local bookstore.

DOCTOR ALERT

A Guide for the investigation and management of Iron Overload has been developed by a guidelines and protocols advisory committee, approved by the BC Medical Association and adopted by the Medical Services Commission. This guideline is being distributed to BC doctors. It is available on both our website and at: www.health.gov.bc.ca/msp/. Please ask your own Doctor to obtain and read this valuable information.

Hemochromatosis In the News

IN PRINT

Oprah Magazine, Sept 2001 issue, "Minding Your Body" page 208.
Community Press, Surry BC, March 2001.
Surry North Delta Leader BC, Oct 2000**.**
Rotary North News, Sault Ste Marie ON, Oct 2000.
Delta Voice, Delta BC, Sept 2000.
Calendar of Designated Dates, AB, Sept 2001.
Newsletter, South Fraser Health Region BC, Sept 2001.
The Daily Gleaner, Fredericton, NB, June 2000.
Nutrition Science News, Penton Media, Ohio, June 2000.
New Era, Melita MB, May 2000.

ON THE AIR

BC TV 6 o'clock News featured Rohan Hazelton giving a blood donation at the Canadian Blood Services on May 30th 2001.
CBC News World, Health Matters, Norma Lee McLeod, May 31st and June 1st 2001.
CHFI, The Erin Davis Show, aired on all Rogers station's from London to Ottawa, throughout the GTA up to Barrie, aired our PSA's up to three times a day, May threw summer 2001
The New PL, local London TV station, aired our PSA.
CJXX, Grande Prairie AB, Our Education and Development Coordinator Marguie Nordman was interviewed, May 2001.
CHTM, Thompson MB, interviewed Marguie Nordmand in June 2001.
Dr. Hister had an interview with Dr. Krikler, May 2001.
West Midland England, Dr. Jeremy Shearman and Ed Doolan, Jun 2000
CKOV in Kelowna
BCTV in Vancouver

Mood Swings

The pituitary gland is attached to the hypothalamus (situated in the 3rd ventricle of the brain). The gland is larger in females than in males and becomes larger during pregnancy. Functions of the pituitary are the production of hormones that help regulate growth, reproduction and certain metabolic processes. *Front section regulates*:- growth and physical development, and stimulates adrenal function, thyroid function and reproduction. *Back section*:- produces hormones that regulate water balance and stimulate uterine contractions. In hemochromatosis, excess iron can accumulate in the pituitary gland and can cause hypothyroidism. Hypothyroidism causes symptoms such as loss of sex drive, moodiness, low blood pressure, slow pulse, chronic fatigue, aching muscles, and joint stiffness.

Hormonal imbalance can also be expected when iron accumulates in the pituitary gland. Therefore because the pituitary is responsible for the production of hormones, the regulation of these hormones can produce mood swings and general behavior changes, and even depression. There is not absolute evidence of data to prove this.

Given the insidious nature of iron accumulation, and the known tissue injury that does occur, it makes sense to assume that disturbance in the pituitary region would cause mood swings, infertility, depression, etc.

This article was taken from idInsight newsletter.
Ironoverload Disorders, Greensville SC. USA

Transferrin Iron Saturation Percentage
Different in Newborns, Know Why?

Why is transferrin highly saturated with iron in early infancy? About seven weeks prior to birth a developing offspring has a dramatic increased requirement for iron. Natural processes needed to accommodate this demand begin to emerge. Iron is essential for formation of DNA and for many energy producing reactions. Rapidly growing tissues need a large supply of the metal. Therefore, the pregnant mother sends a great amount through the placenta, especially as the time of birth approaches. Iron must be carried through the blood by a protein called transferrin. The "normal" amount of iron saturation of transferrin is 25-35%. However, the large quantity sent to the child near birth causes a doubling of the percentage. Within a month or two after birth, the percentage has decreased to the level of 25-35% where it should remain during a healthy lifetime.

In addition to transporting iron throughout the body, transferrin has a second function. It must withhold the metal potential bacterial pathogens. At a high percentage of iron saturation, the antibacterial function of transferrin is diminished. In order to protect the infant during the early months of life from bacterial infections, the mother secretes a protein called lactoferrin into her milk. Lactoferrin prevents growth of pathogenic bacteria in the intestine by withholding iron. Thus lactoferrin substitutes for the antibacterial action of transferrin until such time as the iron saturation of transferrin goes down to normal. The mother also secretes antibodies into the milk to provide additional protection to the infant. Furthermore, she places a small but adequate amount of iron in the milk that apparently is combined with a compound that allows the metal to be readily absorbed. Unfortunately, cow's milk has very little lactoferrin and milk formula has none at all.

For mothers who are unable to breast feed, low-iron formulas are the best choice. Cow's milk should not be considered for newborns or any child younger than two. Cow's milk can actually be harmful to a newborn or young child as it irritates the intestinal tract, causing bleeding.

Cow's milk has low lactoferrin because the mother cow welcomes bacteria into the gut of its calf so that it can digest grasses and other forms of cellulose. For humans the presence of this bacteria could make a newborn critically ill or even cause death.

Serum iron, ferritin and transferrin iron saturation percentage drop dramatically when the newborn is about two to three months of age. These relatively low values represent a normal development change rather than indicate iron deficiency. Newborns age two to four months continue to produce hemoglobin above 11.0g/dL which rises to 12.0 during the first year of life.

Given adequate calories in a balanced meal infants should not become anemic or require iron supplements.

www.irondisorders.org

Could Giving Blood Cut Your Risk of Heart Attack?

Mention blood donation and most people think of a selfless, sometimes lifesaving gesture that helps others who need a transfusion. Yet blood donation may have important personal health benefits in lowering the risk of heart attacks and other diseases. The scientific evidence has been quietly accumulating for almost 20 years. During the past few years, it has grown strong enough for some experts to advise public action. Listen to Dr. Jerome Sullivan, of the University of Florida at Gainesville, who pioneered research into the field: "A strong case could be made for recommending blood donation as a way to lower iron levels, thus lowering heart-attack risk."

What's the connection between blood donation, iron and heart attacks?

Humans have an emergency system for coping with sudden loss of blood. They absorb iron from food and store it in the body. If a large loss of blood occurs, the body taps that iron stockpile to manufacture hemoglobin, the pigment that gives blood a red colour. Hemoglobin contains iron, and the body draws down its iron bank account to synthesize new hemoglobin to replace that lost during bleeding. The system helped prehumans and modern humans survive serious injuries and other conditions. In modern society, however, blood transfusions have made the iron-storage system a relic. Healthy people have no known need for large amounts of stored iron. Yes, it does sound like nutritional heresy. People associate iron with strength and good health. They remember vitamin and health-tonic advertisements warning of "iron-deficiency anemia." But iron deficiency is rare, thanks to fortification of foods with iron.

Scientists have plenty of evidence that large amounts of stored iron can be harmful. It suggests that the danger is more common than previously believed. Excess iron once was regarded as a threat only to people with a hereditary disease, hemochromatosis. People with the condition store too much iron in the heart, liver and other organs. And they have a high risk of heart disease, liver cancer and other diseases. Studies published last year by the American Heart Association showed the gene defect behind hemochromatisis affects more people than previously believed. Scientists thought that iron overload was a problem only in 1 out of 200 people who inherit both copies of the hemochromatosis gene. The 1999 studies found that problems also occur in 1 in 10 people who inherit just one copy of the gene. Research also suggests that iron overload may increase the risk for other diseases, including age-related brain disorders such as Alzheimer's disease and Parkinson's disease.

Regular blood donation may reduce the risk for a simple reason. Blood loss is the only way to eliminate stored iron from the body. Women lose blood during much of their life through menstruation, which keeps their iron stockpile in balance. Experts cite menstruation as one possible reason why women have a lower heart-attack risk than men. After menopause, women's heart-attack risk starts to climb. Men, in contrast, have no way of losing blood, and their iron stockpile increases throughout life. No way, that is , aside from donating blood to help humanity, and maybe themselves, as well.

By Michael Woods,
The Globe and Mail, Tuesday, December 12, 2000

PARKINSON'S & IRON

Although the precise mechanism which results in nerve cell death in Parkinson's Disease (PD) has yet to be determined, oxidative stress and iron mismanagement in the brain appear to be important factors in its evolution. The evidence implicating iron involvement in PD can be appreciated at several levels. Pathologically, abnormal levels of iron have been reported in involved regions as well as in association with the pathological changes at the microscopic level. Furthermore, iron is essential for synthesis of the chemical communicatory, dopamine, which is deficient (as a result of cell death) in PD. The benefits of antioxidant treatment in PD have not been established. One problem with an antioxidant therapeutic approach in PD may be the amount of damage that has already occurred in the brain before the patient becomes symptomatic. Thus, antioxidant therapy cannot salvage what is not there, or iron levels in the affected area may be too high for antioxidants to be effective. More studies are required to understand the relationship between iron and oxidative stress in PD, including understanding how so much iron can accumulate in the affected region in the first place.

Limiting the availability of iron to the brain in PD must take into account that the chemical communicator, dopamine, already deficient in the PD brain, requires iron.

The response of ferritin to iron accumulation in a Parkinson's diseased brain may be similar to that seen in Alzheimer's disease, although the reports of ferritin in the brain in PD patients is conflicting. One reason for the conflicting reports of ferritin levels in PD may have to do with the age of onset of the disease. Here again the advantages of MRI could improve our insights into the role of iron and ferritin in PD because MRI will allow longitudinal analysis of the same patients as opposed to the postmortem analysis of brain tissue at the end stage of the disease.

These neurological disorders (Alzheimer's and Parkinson's) are clear indications that loss of iron balance occurs in the brain and can contribute to the progression of the disease or may even cause the disease.

Courtesy of Iron Disorders Institute
James Connor, Ph.D.
Neuroscientist, Penn State University

Many, many thanks to all those who contributed to making the Seymour Ladies Golf Tournament on July 12th such a huge success. We will be receiving a cheque for approximately $20, 000 for which we are so grateful.

Mailbag

We have taken the liberty of excerpting from some of the many letters we received from our readers. Thank you all for writing.

I am a 52 year-old white male of exactly fifty percent each of English/ Welsh and German ancestry. Two years ago, during the course of a normal annual physical, my physician conducted a blood test for ferritin. Mine came to 1024 ng/litre. It was regarded as high but not critical. A year later, during the course of another annual physical with a different doctor who had the results from the previous physical, another ferritin test was performed and the level had risen to 1328 ng/litre. This physician decided to be more aggressive. He is a family practice physician and decided that this situation required a specialist for diagnosis, so he sent me to a hepatologist. Another blood test was taken for ferritin and iron saturation. A third test (a DNA test) was done. This test revealed that I had the genes for hereditary hemochromatosis. I am currently in the course of having weekly phlebotomies.

When I was being diagnosed the doctor introduced me to a young man, in his 30's, who is an immigrant from Sweden. He had not experienced any symptoms of any kind until he was leaving the United States for a vacation visit back to Sweden. Going through the airport security system, he set off the alarm. Thinking it was just excess metal, he removed his watch, keys, pocket change, all the usual metal and still the alarm went off. He then removed his belt (metal buckle), his shoes (metal lace loops), glasses (metal frames) and still the alarm went off. Finally, they manually searched him and cleared him for the flight but when he returned he went to his doctor who referred him to the same specialist. His ferritin level was over 3500 ng/litre and he told me he had a regimen of phlebotomies which were twice per week for over eight months. He estimated he had lost eight gallons of blood during that time. Some liver damage was revealed via a biopsy but, otherwise, he has managed to survive and now gets a phlebotomy every two to three months.

The fact that the test for this condition is very easy to take and can easily be added to a normal annual physical leaves me wondering why it is so very rarely done. The test for the gene need only be done once in a lifetime and birth would seem to be the most appropriate time to do it. Now in the age of gene therapy, the potential exists that an actual treatment or cure may be found.

-G.K.W, Utica MI, USA

Your society has been our rock and our lifeline since my husband, was diagnosed in 1995. I don't know what we would have done without you.

Since we have moved around the country a lot, getting good consistent therapy and treatment has been a problem at times, but you have been there for us. You may add our names to your list of resource people in this area. We would be thrilled to share our knowledge and acquired expertise with anyone needing it.

Thank you once again for all your support and information over the years.

-M.H & M.H, Drayton Valley, AB

Since we last met I have continued with phlebotomy treatments and my ferritin has dropped from 600 to 450.

My sister has been diagnosed with HH and has had 2 phlebotomy treatments. My parents have been diagnosed as both being carriers (no surprise there).

My husband has just received his results and he is a carrier– that was a surprise. Our doctor is sending us to a geneticist next week to see what he thinks about the impact on our 3 daughters. I am quite upset about this development. No one wants to pass something onto their children. I need to come to terms with this one still.

And if that wasn't enough. My brother-in-law (husband's brother) wasn't well and had a physical and his ferritin is excessively high and we are awaiting his results.

I hadn't heard about this until last November and now it is through my family (both of my parent's families) and also my husband's family. It looks like all four of my kids grandparents are carriers quite possibly. I am overwhelmed.

I just thought you would want to know about the rate of diagnosis being made. I am finding this overwhelming, but it is also impressing upon me the need for testing, accurate information and increased awareness. It would be nicer not to have HH, but if people out there have it they need to know.

-K.M, E-mail message

In February of 2000 my GP suspected I might have HH because my ferritin level was aprox 500. By April I found out that I have two genes for HH. Then I went to see an internal specialist, and she was not convinced that I actually had symptoms of HH, so I was sent to a liver specialist, and had an MRI and was finally told in December that I should start phlebotomies once a month. The medical wheels turn slowly. It must be very frustrating for people diagnosed with a rapidly progressing illness. I am thankful that our local GP was aware of HH and caught it before I developed any long term damage. Unfortunately a couple of people in our area died because the iron loading in their systems was not detected soon enough. Thank you for the support and information.

-G.E, E-mail message

G.E.'s Spouse wrote:

G.E.'s ferrtin levels are dropping with each phlebotomy he has. He says he is feeling better than he has in the last five years and definitely I have noticed he has his old energy level back. As for me and the kids our ferrtin levels are all low right now. I will have an iron profile each year when I have a physical, and the kids are to go once every three years for an iron profile until they are 18 and then once a year.

Thank you for caring, your Society has been a great help to us. Especially after I found out I had two genes as well. I was able to contact Dr. Lockitch in Vancouver and ask a ton of questions about our kids and what to expect with them living with HH. I got her name off your site

-N.E, E-mail message.

In reference to the statement that when one person is found with HH, an entire family may be saved:
I was diagnosed in November 2000 when my ferritin level was at 1380, both parents apparently had it so I am a full fledged HH. I have 4 brothers and 5 sister's. So far since my diagnosis, I have 3 brothers and one sister and my mother now receiving regular phlebotomy's. Not everyone has been tested yet, still have to contact cousins etc in this extremely large family. Many have saved years of agony and early certain death.

-C.S, Ottawa, ON, E-mail message

FROM THE EDITOR

For those of you who have a computer I would like to let you know that we have been working very hard to update our website and add the items that are most frequently asked for, such as our sheets on diet and genetics. And look at our new guide for doctors, which is being sent to doctors in BC and has been adopted by the Medical Services Commission. One of the most common problems with hemochromatosis is that many doctors have limited experience in testing and treating HHC. This new guide has been put together by a team of doctors who are doing the latest research on hemochromatosis and it addresses the above problem beautifully. Please download it and take it to your family doctor if you are encountering this situation. I have also added our Canadian Contact List. This is a list of volunteer people who have experience with HHC and are available to support you and direct you to local resources and information. We will be including our International Contact List in the near future for those of you who are moving, traveling or simply wish to know what's happening around the world with hemochromatosis. Our newsletters are also on the website now. If you prefer that format please let us know, so we can save the cost of mailing it to you.

I encourage all of you to make full use of our site and our email. If you don't have a computer, then perhaps a friend or family member does. As we only do two newsletters per year, this is our way of keeping you up on the latest information and responding to your questions in a faster, cheaper and more efficient manner. Of course we will continue to respond to your needs by phone and mail.

Have you changed your address, telephone number, email? Please let us know. We maintain a registry of 3,000 files with two part time staff and it is only with your co-operation that we can keep our information up to date. Of course, we always encourage you to share your experience, comments, concerns or suggestions with other members of the Society. So consider submitting a letter to the editor for inclusion in this bi-annual publication. Since space is limited, please keep your comments relatively brief. In order to publish as many letters as possible, we retain the right to edit your contribution for length.

Candance Rutherford

"Find us one person and we have hope of saving a family"

A Personal Viewpoint …...

I was diagnosed with hereditary haemochromatosis (HH) last year at the age of 37. I was the first person in my family to be diagnosed and the first case I'd come across as a doctor. My story is yet another example of the pitfalls of doctors treating themselves. Some years ago when I was fresh out of medical school I ordered a few tests on myself. I did not expect to find that my ferritin was 400ug/L and the transferrin saturation (TS) was 96%! However, the laboratory report commented only that the results "were consistent with iron-replacement therapy" -so no alarm bells rang and I can remember thinking "at least I'm not iron deficient."

Last year, the memory of my abnormal iron studies was triggered by seeing a patient with similar results and reading an article about the gene test for HH. This time I visited my GP and had the tests repeated. These iron studies showed a ferritin of 540ug/L and TS of 78% with the comment of iron overload. I saw a gastroenterologist, who was sure I had HH on the basis of these results and sent me for the relatively new gene test. It confirmed the diagnosis. I commenced weekly venesection and after six months my ferritin levels are in the normal range.

" I had become so used to feeling tired and having aches and pains that I thought it was normal for me."

Although I was diagnosed because of an incidental finding, since treatment I have felt better than I have for years. I had become so used to feeling tired and having aches and pains that I thought it was normal for me. I'd been particularly tired over the last couple of years but had attributed it to having three young children. I'd also noticed dark rings under my eyes. It hadn't occurred to me that I might have a medical condition.

It's wonderful to have an explanation and treatment and I'm thankful that despite the delay in following up the initial abnormal test results, no serious complications have occurred. Having a condition that is caused by a genetic mistake takes the pressure off trying to answer "why me?" and "did I do anything to contribute to this condition?" The availability of the gene test means that patients like myself who are diagnosed in the early stages of iron-overload due to HH do not need to undergo a liver biopsy. In addition my children's risk of developing HH will be easily clarified

General Information on Hemochromatosis

What is it? The excess storage of iron in the body.
What is the cause? Primarily hereditary.
Most common symptoms are chronic fatigue, joint pain, irregular heart beat, mood swings and confusion, bronzing of the skin and abdominal pain.
Most common complications are liver and heart disease, diabetes, arthritis and hormonal irregularities.
Tests required for diagnosis are the Iron Profile Blood Test (which includes serum ferritin and transferrin saturation percentage) and genetic testing.
Treatment is phlebotomy treatments (bloodletting) which is ongoing for life-LITERALLY!
Reference reading *The Bronze Killer* and *The Iron Elephant*

Members in the Spotlight

Marjorie Lounder: Profile

I was born and brought up in Sydney, Nova Scotia. I left there to enter nurse's training at the Victoria General Hospital in Halifax in 1950. In October 1953 I married Jim Lounder, a medical student I'd met earlier that year. We were married halfway through his internship, and our first child, a daughter, was born in August 1945. Jim was in the military and we were posted to Germany in November 1954. Our second child was born in September 1955 in Iserlohn, Germany, and we returned to Canada in November 1956.

I remember at this point, when Jim was busy taking out insurance as we were expecting a third child, that he was told that he was running an elevated blood sugar level. His mother's family, as he had mentioned many times, had a history of diabetes and arthritis.

Other than that, Jim always seemed the picture of good health and had tremendous energy, and a tan all year long. This continued until the late 1970's and early 1980's when he began on the oral, and within a year, the insulin treatments for diabetes. Arthritis had become a painful reality by then– hands, ankles and then the hips. He also complained of abdominal pain during this period and began to experience chronic fatigue. In 1985 he had hip replacement for the most damaged hip joint and the surgery produced good results. I remember that his internist told him at the time of the surgery that some test had cast doubts on his liver function, but this was never followed up.

Jim was an anaesthetist, and also a stoic - a typical doctor looking after everyone but himself. He was convinced his mothers family history (she developed diabetes and arthritis in middle age) was the problem that plagued him and must just be endured. Jim was an active man, we had five children, a large home, a cottage, and active lives.

By the late 1980's, exhausted, he had begun job-sharing with two other anaesthetisits. He was in his late 50's at the time, and that arrangement continued until he fully retired in the summer of 1991...at age 63. By this time he was in constant discomfort, getting very little sleep at night, constantly exhausted. The second hip required replacement in 1995. Three weeks post-operatively this hip dislocated and he then spent the long hot summer in a cast. He began to notice some mental confusion at times– dealing with numbers, reading maps– and certainly there were more and more mood swings. In February of 1997 we went to Cuba for a holiday and I realized on our return that further trips would have to be by wheelchair– he was exhausted, and unsteady on his feet. On return he complained of diarrhea and began to notice abdominal distension– we thought he had perhaps picked up a parasite– but we buried him three weeks to the day of our return. His death was attributed to liver cancer at the time. Autopsy reports a month later disclosed the hemochromatosis. In a space of three weeks, Jim had fallen ill and died: the family was shocked at the swift decline, and the determination to learn more about the cause of decline and death was formed.

I began to learn everything I could about hemochromatosis, and began the process of alerting family members to the risk that they might also be running. Within a very short period of time his brother– 5 years younger, was diagnosed and began treatment. He seems to have escaped the terrible damage suffered by Jim, and is healthy today. His sister, the youngest of three siblings, remains free of symptoms and is preparing for the gene test. So, in a way, we have prevented another hemochromatosis death: but the knowledge that allowed us to alert his brother, came at the expense of Jim's death.

To date, of our five children, only my eldest son has been confirmed as a carrier. Testing of the extended and immediate family continues. A retrospective study of the family history suggests a long encounter over many generations with hemochromatsis. The scourge of hemochromatosis seems to trace a deadly path through the history of our family.

"I am pained to think that a simple blood test done years ago could have prevented the tragedy of his loss."

Since Jim's death, and as a response to the loss I have had, I've tried to involve myself in spreading word of the condition. With much help from others involved with this condition, we have formed a local support group in Ottawa. The group is intended to serve the objectives of helping sufferers understand and better live with the condition, and to prevent the premature deaths of people like Jim; someone who should have lived much longer. I am pained to think that a simple blood test done years ago could have prevented the tragedy of his loss. Get yourself tested.

Interested persons in the Ottawa / Eastern Ontario area are invited to contact the group through the address and phone numbers below:

Canadian Hemochromatiosis Society
Ottawa Support Group Marjorie Lounder
505-1510 Riverside Drive,
Ottawa Ontario
K1G 4X5
Tel 613-739-9277

There are support groups being established in Ottawa ON and Richmond BC. If you are interested in joining one or starting one in your area, contact our office.
Support groups provide an opportunity to share ideas, get information, hear speakers, and are for people with HHC as well as for family, friends, and interested people.

Memorial Remembrances of Loved Ones

Our deepest condolences to the families and friends who have lost loved ones and our thanks to the many listed below who have sent memorial gifts.

In Memory of Alice Maria Bailey
Mary Knight, Vapor Rail Inc.

In Memory of Gordon W. Cooper
Robert Stewart

In Memory of Darcy E Drab
Beatrice & Edward Drab

In Memory of Theresa L Johnson
Judy Leppky

In Memory of Harry Stanley Keeler
Pat Foster

In Memory of Mary F McKnight
Harrold Mcknight, Barbara Parrot, Mr. & Mrs David Rose, Mr & Mrs Douglas Sellers, Dorothy & Hugh Evans, Gladys & Don Stuart, Edward Cyples, Madeline Hoffar, Diana Robinson, Dr. AE & Marylee Alway, Carol & Ray Purdy, Irene Welsh, Viola King, Dianne & Ken Parneu, John & June Robertson, Margaret Morris, Harry & Iris Quist, Rod & Louise Lammers, Creative Enterprises, Al's Tire & staff, Hickory Hills Community Residents, Reg & Joan Ort, Gwen & Budd Gowan, Ruth & Ray Foran, James Kennedy

In Memory of Ross Miles
Catherine Easun

In Memory of J. C. Moore
Nina Moore

In Memory of Barry Prytulak
Stephen & Laura Prytulak

In Memory of Ken Rogerson
Eileen Rogerson

In Memory of John Sutherland
Edith Sutherland, Dorothy Graham

In Memory of William H Thompson
Donna Stroud

From a Devoted Husband…….

My wife Mary F McKnight passed on May 16, 2001 in her 77th year at the Maple Manor Nursing Home in Tillsonburg Ontario. She was diagnosed with HH in 1991 when her iron levels were running at 2800. Through a series of phlebotomies the iron levels retuned to a sub-normal level and remained at that until she died. Dr. Paul Adams of London, Ontario was involved with her and could not explain nor understand the reasons for this situation.

She slowly lost her mobility over time and retained all her cognitive powers until the end. She was a strong proponent of your society and talked to many doctors and friends about the debilitating effects of the inherited disease and how prevalent carriers were among the population. She did not wish an elaborate funeral but made a request for anyone to send money to your society in lieu of flowers in memory of her.

As a tribute to her she wanted me to send this cheque to your organization to assist in your efforts to make this deadly killer better known and understood by the public and the medical profession. Good luck in your endeavors, and Mary would be pleased about my actions of offering this gift on her behalf.

Sincerely, Harold R McKnight

Make a Lasting Difference in the future of our country……..

Leave a Legacy

Are you aware that by making a gift in your will or estate plan to our non-profit society you will be contributing immeasurably to saving families from the misery caused by hemochromatosis? For more info please contact our office.

Welcome to our New Members

Robert Arsenault,Grand-Barachois NB
Richard Cammer, Abbotsford BC
John Maynard Campbell, Halifax NS
Tom Cigolotti, St. Stephen NB
Austin Dale, Toronto ON
Dorothy Daley, Fonthill ON
Donna Damery, Mississauga ON
Lena Dimitrenko, Burlington AB
Ruth Dolls, North Vanouver BC
Carolyn Dow, Godfrey ON
Carmel Doyle, Chaplin Island Road NB
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