



The ICD Support Group of Manitoba

THE ICD SUPPORT
GROUP OF MANITOBA

Volume 8 - May 2011

SPRING MEETING - SATURDAY JUNE 18, 2011

Please join us for a presentation and discussion with Dr. Omar Sultan and Mary Wilson RN from the Defibrillator Clinic. We will also have the opportunity to hear from Garry Frankel, an ICD patient and survivor of Sudden Cardiac Arrest.

RECEPTION: 1:30 P.M.
GUEST SPEAKERS: 2:15 P.M. - 3:30 P.M.
ST. BONIFACE GENERAL HOSPITAL RESEARCH CENTRE
G. CAMPBELL MACLEAN BUILDING
351 TACHE AVENUE
SAMUEL N. COHEN AUDITORIUM, MAIN FLOOR

The closest parking lot is at the south end of the Hospital (near Emergency). The Research Centre is the large building at the south end of the Hospital closest to Tache Ave.

There is no need to confirm your attendance.

Changes at the Pacemaker/Defibrillator Clinic

Things are changing at the Pacemaker/Defibrillator Clinic. We are now close to having 1,000 patients with ICD's. This means more nurses will be trained to follow you and your device. The familiar faces will still be here for support and guidance.

Congratulations to Lisa Kalic, clinic receptionist on the birth of a baby boy on February 28, 2011. Austin and family are doing just fine. Welcome to Jennifer Forbes who is filling in while Lisa is on maternity leave.

A note from the Pacemaker/Defibrillator Clinic

On the following page is a letter outlining the experience of Terrence Sutherland, an ICD patient living in rural Manitoba. It is his account of the care he received when the lead (wire) from his device to his heart failed, resulting in multiple shocks. This is not meant to increase your anxiety or frighten you, but to allow you as the patient or family member to discuss with your physician and/or local Emergency Department if they are prepared to appropriately look after you. The risk of this occurring is very small, approximately 1%. Included with this newsletter to rural patients are two "fact sheets" for you to take to your physician and/or Emergency Department to initiate this discussion. Over the coming months the Pacemaker/Defibrillator Clinic will be following up with the rural Regional Health Authorities to provide education on ICD's. For those of you living in Winnipeg, the Emergency Departments are equipped and knowledgeable to look after you. To all of you, please don't hesitate to call or discuss with us at your next visit any concerns you may have.

From: Dr. Kevin Wolfe & Kerry Liebrecht, Nursing Coordinator.

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“A Shocking Experience” - by Terrence Sutherland, ICD patient

I am writing this letter in hopes that all persons with an ICD are made aware of what they need to know, and have assurances that their medical team has that knowledge and training to handle each and every occurrence.

Receiving a single shock is a traumatic experience. Receiving multiple shocks is a horrific experience. Receiving shocks by the dozens is an experience that no words can describe.

On the morning of January 25, 2011, my wife and I were working on a small project in the basement of our home. I received 8 shocks in as many seconds. My wife called for the ambulance immediately and I was transported to the local hospital. My wife is acutely aware and immediately brought the remote monitor to the hospital with us. The device was interrogated and the Defibrillator Clinic contacted by the attending physician shortly thereafter. It is my understanding that a cardiologist was contacted and advised by the Defibrillator Clinic that the lead had failed. The cardiologist then advised the attending physician to turn the ICD off and have me transported to St. Boniface Hospital. The attending physician did not know how and was advised to get a magnet and place it over the ICD. When the correct magnet was not available they went to the local hardware and purchased magnetic strips. These had no effect and the shocks were coming every five minutes. During this time, since arriving at the hospital and being connected to the heart monitor the physician saw no indication of any arrhythmias.

The Medevac airplane, paramedic/nurse arrived and attempted to transport me to the airport. Every movement, every bump in the road resulted in a shock. I must have received 40 shocks by the time the paramedic/nurse requested the ambulance to return to the hospital. Now the heart monitor was erratic and the paramedic/nurse stated “the shocks were appropriate” and advised the attending physician, due to my unstable condition to contact Life Flight. His statements further added to my trauma and argument “the lead has failed – follow the advice of the cardiologist”. I thought I was going to die.

I would also like to note that during this time the correct magnet had been located from a hospital two hours plus away and was being transported to my local hospital.

Two hours later, numerous shocks, I have now lost count; the Life Flight doctor and nurse arrive. I am medicated and to my memory I did not feel another shock. The first words of encouragement came from the Life Flight doctor “the shocks won’t kill you”. As I was being loaded into the ambulance to be transported to the airport for the flight to St. Boniface Hospital, the correct magnet arrived and was given to the Life Flight doctor.

Finally, after eleven hours and 88 shocks, the ICD is shut off by the cardiologist.

Although this summary leaves a lot of questions as to training, procedure and protocol it is not my intention to point or accuse anyone of fault. I am the worst fault as I assumed my health team knew what to do. As I stated earlier “It is my hope that every person who has an ICD will read this letter, take action and get assurances their medical teams are trained and have the proper equipment in place at all rural and remote hospitals and nursing stations to handle all occurrences”.

Meet Garry Frankel, ICD patient and Sudden Cardiac Arrest Survivor

Garry Frankel, a photographer from Winnipeg was visiting Minnesota for an international youth soccer tournament when on July 19, 2009, he suffered a sudden cardiac arrest (SCA) in his motel room. His wife woke up at 1 a.m. to a gurgling sound coming from Garry. He had stopped breathing and was unresponsive. Mrs. Frankel called for help, and two security guards who had taken CPR classes just two weeks earlier started chest compressions. An ambulance was on scene in three minutes and shocked Garry out of the fatal heart rhythm. While in hospital he underwent therapeutic cooling and received two stents, however he continued to have life threatening heart rhythms that required numerous shocks to break. He then had an ICD implanted. Ultimately once he was stabilized, Garry was transferred to St. Boniface Hospital by air ambulance, some 13 days after he was first hospitalized. He is now fully recovered but he still does not know what actually caused the cardiac arrest. As a former paramedic for the Winnipeg Ambulance Service from 1975 to 1981, Garry has always been a strong advocate for CPR training but today he is even more active in promoting CPR and AED training. “I have a mission now. Somebody bothered to teach these guys CPR and because of that I am alive today. Now I have to pay it forward,” he said.



DID YOU KNOW.....??

Organ / Tissue Donation

National Organ Donor Week took place last month. There was considerable media attention surrounding this important event. No doubt, many of you heard about how Kristin Miller, a 27 year old woman has to constantly stay connected to a battery operated heart pump while waiting for a heart transplant or Jessica Bondar, a 19 year old Winnipeg girl who passed away on April 13th while waiting for a heart transplant. An organ and tissue donation can save or enhance more than 50 lives. Did you know that the following organs / tissues can be used for transplant? Eyes / cornea / heart / heart valves / lungs / liver / bone marrow / stem cells / bone / pancreas / kidney / small intestine / skin / tendons. The Province of Manitoba recently announced it is creating a new, electronic registry so Manitobans can easily register their wishes about organ and tissue donation. Clearly the decision to participate in organ/tissue donation is a personal one. If you choose to offer this "gift of life" then it is critical that you sign the enclosed donor card now - don't put it off until tomorrow. You also need to ensure your family members are aware of your wishes. Additional donor cards can be obtained from any Manitoba Public Insurance office in the province or by downloading one from www.transplantmanitoba.ca.

Manitoba Pharmacare Program

Pharmacare provides drug cost assistance to eligible Manitobans who do not have coverage under a federal or other provincial program. Pharmacare is income based, which means a deductible is calculated based on the total adjusted family income. Once the yearly deductible has been reached through the purchase of eligible prescription drugs at a pharmacy, Pharmacare will pay 100% of eligible prescription costs for the remainder of the benefit year. The benefit year is April 1 to March 31 the following year. The minimum deductible is \$100 with no maximum deductible. It is based on Canada Revenue Agency income information from 2 years ago. Example: for the 2011/2012 Pharmacare benefit year, the income information used would be from the 2009 tax year. The Deductible Installment Payment Program can help reduce financial hardship for individuals and families whose eligible drug costs are a significant portion of their monthly family income. This option will give Manitobans who have high monthly drug costs compared to their monthly income a way to pay their Pharmacare deductible in interest free monthly installments as part of their monthly Manitoba Hydro energy bill. The financing program is administered by Manitoba Health. Manitoba Hydro also participates in the program and its role is to withdraw monthly payments from your account with your bank or credit union for the bill payment portion of the program. Forms to apply are available online at www.gov.mb.ca/health/pharmacare, by contacting the payment program at 945-1733 (in Winnipeg) or toll free at 1-888-519-3492 (outside Winnipeg), or at Manitoba pharmacies.

Pacemaker/Defibrillator Clinic using new Electronic Data Base

Up until recently all patient records at the Clinic were paper based. They now have a fully functional electronic data base which is a much quicker and more accurate way to manage patient information. When information on a patient is required it is now at the staff's fingertips – no more looking for a paper patient file. On occasions when an advisory is issued by a manufacturer, clinic staff can quickly determine who may be impacted and take proactive action. The system is also very beneficial for the Doctor on call during weekends and evenings when a patient emergency arises. The data base allows the clinic to compile statistics, study trends etc. And of course, all information is secure and only accessible to Clinic staff.

Health Care Directive, also known as "The Living Will"

As a Manitoba citizen you have the right to accept or refuse medical treatment at any time. "The Health Care Directives Act" allows you to express your wishes about the amount and type of health care and treatment you want to receive should you become unable to speak or otherwise communicate this yourself. It also allows you to give another person the power to make medical decisions for you should you ever be unable to make them yourself. The Manitoba government has prepared a form that serves as a guide for providing the appropriate information. However, any paper that is signed, dated and provides the same information may be used. A copy of the form is available on the Province of Manitoba's website: www.gov.mb.ca/health/livingwill.html.

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**THE ICD SUPPORT GROUP OF
MANITOBA**

CONTACT INFORMATION

MAILING ADDRESS:

The ICD Support Group of Manitoba
c/o Pacemaker Clinic
St. Boniface General Hospital, Y2045
409 Tache Avenue
Winnipeg, Mb. R2H 2A6

CLINIC PHONE #:

(204) 237-2431

Board Members - Contact List

Larry Sherman

- 889-4029
- larrysh@mts.net

Bob Mondy

- 896-4513
- bcmondy@gmail.com

Greg Smith

- 654-4393
- lmd3smith@yahoo.ca

Health Care Directive (continued from page 3)

It is strongly recommended you talk to your doctor before completing the directive. This will ensure your instructions are clear and easily understood by those who provide treatment. A Health Care Directive should be a record of your current wishes. If at any time you wish to change the content, all copies of your old directive should be destroyed and a new directive written. The foregoing information was obtained from the Province of Manitoba's website.

WEB SITES OF INTEREST:

- HeartLinks Manitoba provides heart recipients, patients on waiting lists, their families and caregivers with encouragement, support and guidance during each stage of the heart transplant journey.
 - www.heartlinksmanitoba.com

IN APPRECIATION

- Our thanks go out to Robert Mondy for his cash donation to assist with the mailing of this newsletter.
- We appreciate the donation of "goodies" for this meeting by the nurses in the Pacemaker/Defibrillator Clinic

VOLUNTEER PLEA

Once again we are appealing to the ICD audience for ongoing assistance with running this support group. Duties are not onerous. We get together a few times during the year to discuss meeting topics, items for the newsletter, finances, future direction of the group and so on. The main skill set required is simply the desire to help other ICD patients and their families. If you would like to help out or obtain more information please contact Larry Sherman.