

The ICD Support Group of Manitoba

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SUPPORT GROUP MEETINGS

Our meeting on June 8, 2013 featured Lynnsey Reich from the Wellness Institute at Seven Oaks Hospital. Lynnsey is a Chronic Disease Coordinator/Kinesiologist and she spoke on the benefits of the Cardiac Rehab program which is available at both the Wellness Institute and the Rehfit Centre. It is a sixteen week comprehensive education and supervised exercise program for anyone diagnosed with cardiac disease including people with an implanted ICD. Some of the topics covered during the program are: risk factor modification and self management techniques, heart healthy diet, managing stress and psychosocial factors, medications, heart anatomy, importance of exercise and more. Since approximately 30% of cardiac rehab patients have diabetes staff are fully knowledgeable regarding the specific needs of people with diabetes. Some of the benefits to the cardiac rehab program are: improved exercise levels, decreased symptoms, improved lipid profile, and improved blood pressure. One benefit that really stands out is: across North America research shows 50% decreased mortality over 3 years for cardiac rehab participants. Unfortunately only about 30% of people referred to the cardiac rehab program actually attend the 16 week program. The cost of the program is \$230 plus GST. Some insurance companies will cover all or a portion of the program and there is a subsidy available for those unable to pay based on personal income. For more information contact the Wellness Institute at (204) 632-3907 or the Reh-Fit Centre at (204) 488-8023.

During the reception before the presentation we were joined by Kelly Brink, Pharmacist and Joyce Lehman, Dietician who circulated around the tables providing information and answering questions.

FALL MEETING - SATURDAY OCTOBER 26, 2013

Please join us for refreshments, fellowship and information. The reception prior to the meeting is a great way to meet others living with an ICD. We encourage you to bring along a family member or guest.

Our guest speaker will be Dr. Clarence Khoo from the Pacemaker / Defibrillator Clinic at St. Boniface Hospital. Dr. Khoo recently moved to Winnipeg from Vancouver. We've asked him to speak on several of the topics identified by those attending the June meeting (see page 3).

RECEPTION : 1:00 P.M. GUEST SPEAKER: 2:15 P.M. - 3:00 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 southwest end of the Hospital closest to Tache Ave.

There is no need to confirm your attendance.

CHANGES AT THE PACEMAKER/DEFIBRILLATOR CLINIC

Welcome to Dr. Clarence Khoo who joins the clinic having recently relocated here from B.C. Recent nursing changes include Marge and Kelly joining the Pacemaker/ICD nursing staff and Helga working in the implant room.

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VOLUNTEER BOARD OF DIRECTORS

- Larry Sherman, President
- Greg Smith, Volunteer Coordinator & Director
- Jake Suderman, Director
- Ruthe Penner, Director
- Dianne Brown, Director
- Bob Mawson, Director
- Jerry Samels, Director

IN MEMORIUM - Bob Mondy

Robert (Bob) Mondy passed away on May I, 2013. Bob was the catalyst behind the formation of The ICD Support Group of Manitoba. One of the first things that Bob did was put together "the Patient's Guide to the Implantable Cardioverter Defibrillator" booklet which continues to be provided to each new ICD recipient. Bob was clearly an inspiration in many ways. Despite his own health challenges over the past 40+ years Bob maintained an amazing outlook on life. He truly enjoyed helping others and was an active volunteer / supporter of many organizations and causes. Bob really enjoyed his chats with ICD patients and those waiting for their implant. He also sat on the board of Heart Links, a support group for people waiting for a heart transplant. He put together a presentation about his life with heart disease and spoke to hundreds of people around Winnipeg about the importance of organ donation. Three years ago he had an LVAD (left ventricular assist device) implanted and he was often asked to speak to others who were recommended to have one



implanted. Bob was a highly respected member of our board of directors from the very beginning. His wisdom, knowledge, humor, and zest for life are deeply missed.

Meet Larry Sherman - ICD patient and Support Group Board Member

My personal introduction to heart disease came just before the September long weekend in 2002 while doing something that I love – playing golf with one of my closest friends. As I was walking off the 12th hole at Clear Lake Golf Course in Riding Mountain National Park I suddenly felt like there was an elephant sitting on my chest. In retrospect, I consider myself lucky that I had this "obvious" symptom of a heart attack. At first I didn't really want to accept that I was having a heart attack at 49 years of age, but I knew something was seriously wrong, and that immediate action was necessary. Believing it would take too much time for the volunteer ambulance to get to the golf course I made the choice to have my golfing buddy drive me to the closest hospital in Erickson. After a couple hours there the decision was made to transfer me by ambulance to Minnedosa Hospital. They gave me a thrombolytic (clot busting) drug and very shortly after that I went into cardiac arrest three times over a twenty minute period. Fortunately I was in good hands and the medical professionals were able to bring me back. Unfortu-



nately, my wife Darlene and my friend were in the room watching all the excitement. I can only imagine what that must have been like for them. The next day I was transferred by ambulance to St. Boniface Hospital for an angiogram. When they discovered a 99% blockage in my left anterior descending artery, a stent was put in. Two days later I was at home, starting down the road to recovery. In October, Darlene and I entered into the 4 month Cardiac Rehab program at The Rehfit Centre which was extremely beneficial for both of us. During subsequent medical tests it was determined that as a result of the significant damage done to my heart muscle I might be a candidate for an ICD. At the time I had no idea what an ICD was or how it might help me. I was referred to Dr. Wolfe at the Defibrillator Clinic who put me at ease by answering all my questions and explaining the benefits I could expect from an ICD if and when needed. In July of 2003 I become the proud owner of my first ICD. I had my second device implanted in December 2010. My only "shock" to date was a minor one late last year to deal with short run of tachycardia. The ICD did exactly what it should and I did not even realize I had the therapy until my next regular check up a couple months later. I refer to my ICD as my own personal paramedic as I know it is sitting there monitoring every heartbeat and waiting to do its job if called upon. I don't regret for a minute having the implant as it allows me to continue doing things that I enjoy with confidence. I still golf regularly (not very well but that's another story) and Darlene and I enjoy family gatherings, yard work and travelling.

About two years after my heart attack the opportunity for an early retirement from Royal Bank presented itself and in January 2005 after some 34 years I retired at the age of 52. Having some extra time on my hands allowed me to become involved with The ICD Support Group of Manitoba which I have done since the inception of the group. I have certainly learned a lot more about heart disease and ICD's plus I've had the wonderful opportunity to speak with many people (and their family members) who either have an ICD or are about to receive one. I work closely with several of the staff in the defibrillator clinic and I am very impressed with the care and compassion they have for their patients. They are truly a dedicated group of professionals who really care about people.

I am also the author of this newsletter, so if you have any comments or suggestions please let me or any of the board members know. We'd love to hear from you.



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DID YOU KNOW??

Support Group feedback

At the June meeting we asked for suggestions on future presentations from those in attendance . Here is a recap of the feedback:

- Some suggestions for future meetings include:
 - more individual stories from ICD patients and/or family members
 - more technical information on ICD's
 - a simple description of heart anatomy and how the heart works
 - more presentations by experts including cardiologists
 - information on Automated External Defibrillators
 - more information on driving restrictions as a result of an appropriate therapy.
 - some people indicated difficulty in hearing all the presenters. We will do our best to improve on this.

We have asked Dr. Khoo to include some of these topics in his presentation at our October meeting.

Why should I carry my interrogation report with me?

Your printouts are given to you each time you have your ICD interrogated. During office hours the settings are available if you require urgent care. During off hours the chart must be pulled and the information interpreted and provided by medical records technologists. This may lead to a delay in your receiving optimal care in an emergency. By having the printout readily available you are helping your physician help you.

New implanted defibrillator works well without touching the heart

According to research in the American Heart Association journal a new type of defibrillator implanted under the skin can detect dangerously abnormal heart rhythms and deliver shocks to restore a normal heartbeat without wires touching the heart. The subcutaneous implantable defibrillator (S-ICD) includes a lead placed under the skin along the left side of the breast bone. Traditional ICD's include electrical conducting wires inserted into blood vessels that touch the heart. The S-ICD has been available in Europe and New Zealand since 2009 and received FDA approval in the United States in 2012. These new devices are not a replacement for all other ICD's. In Manitoba each patient's situation will be evaluated on a case by case basis. (this information was obtained from: sciencedaily.com/releases/2013/08/130826182631.htm)

Electro surgery / Cautery and ICD's

Definition: Cauterization (i.e. burning) by means of a wire, heated by electricity that is either direct or alternating current. The use of electrocautery is sometimes necessary during surgical or non-surgical procedures. When used there is a potential to produce Electromagnetic Interference or EMI. Some types of EMI can decrease the ability of the ICD's filter to identify the heart rhythm and interpret it as increased heart rate. This can cause the device to deliver therapy that is inappropriate and unnecessary. If the EMI is excessive it could damage the devices circuitry.

POINTS TO REMEMBER (for you and/or your Doctor)

- Bipolar cautery should be used whenever possible as it uses a more defined & shorter current path which reduces the risk of interference.
- If unipolar cautery is used then the electrosurgical site and the ground plate should not cross the ICD lead system.
- Short bursts of cautery are preferable to prolonged application.
- Battery powered cautery will not interfere with the ICD because it does not produce strong enough EMI.
- PLEASE CALL THE CLINIC IF YOU OR YOUR DOCTOR HAVE ANY QUESTIONS OR CONCERNS.



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WEB SITES OF INTEREST:

- The MedicineNet site contains slideshows on various illnesses including heart disease.
 - www.medicinenet.com (At the top of the page click on "slideshow pictures" then go into "all slide shows". From there select heart disease.)
- For entertaining clothing apparel and merchandise for ICD patients.
 - www.medtees.com
- The Manitoba Institute For Patient Safety is a local organization which developed a program called "It's Safe to Ask". This program encourages patients and families to request the information they need from health professionals in order to become active participants in their medical care. This website also contains a "medication card" which can be used to record all your meds. It is wise to carry such a list with you at all times.
 - www.safetoask.ca

DID YOU KNOW?continued

Why does an ICD recipient have to avoid an MRI?

The MRI or Magnetic Resonance Imaging test has the potential to disable the sensing circuit of your ICD. Therefore it is not advisable to have this test done. It is one of the screening questions on the requisition submitted by your physician.

SUPPORT GROUP VOLUNTEERS

We'd like to welcome Jerry Samels from Portage La Prairie who is our newest board member.

Our sincere thanks to Lori Trapp for her contribution to the board of directors over the past several years. She and husband Ron were volunteers when our group started. They continue to travel as much as possible and spend quality time with their grandchildren and great grandchildren.