



The ICD Support Group of Manitoba

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Volume 10 - October 2012

SUPPORT GROUP MEETINGS

Dr. Alex Tischenko was the keynote speaker at our May 2012 meeting. He provided an update on the world of ICD's as well as what can be expected in the future. We appreciated his candid answers to the questions asked by the audience. Shannon Wiens, accompanied by her daughter, Kaileigh shared their very personal story with us. If you missed their presentation you can read about it in our Volume 9 newsletter.

FALL MEETING - SATURDAY OCTOBER 27, 2012

Please join us for a discussion with Dr. Kevin Wolfe from the Defibrillator Clinic. Dr. Wolfe has been with us previously and he always provides us with current information about ICD's and candid answers to our questions.

We will also have a presentation on travel insurance from Barry Guttormson, President of Hotwinters.ca. This company has 35 years experience in the medical and financial fields which helps them to match plans that are suitable to your unique medical history.

**RECEPTION: 1:15 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).

At our last meeting we set up more tables and chairs so it was easier to sit and chat with other patients/family members over a beverage and dainties prior to the formal part of the session. For the upcoming meeting we will be setting up even more tables and chairs so come early and meet other folks who have ICD's.

BRAIN TEASER

The more you know about your heart and physical health, the better you can care for it.

Fill in the blank with the most appropriate answer.

Sleep is like _____

- A. Money, because you can never have too much
- B. Seatbelts, because it helps your body come to a stop
- C. Your boss, because its most agreeable when it's uninterrupted
- D. Church, because it is quiet and peaceful

See answer on page 2

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VOLUNTEER BOARD OF DIRECTORS

- Larry Sherman, President
- Bob Mondy, Treasurer
- Greg Smith, Volunteer Coordinator & Director
- Lori Trapp, Director
- Jake Suderman, Director
- Ruthe Penner, Director
- Dianne Brown, Director



Meet Ruthe Penner - ICD patient and Support Group Board Member

"If you can laugh at it you can survive it"

What in heaven's name is an ICD? I certainly knew what a pacemaker was because my father had one. But in June 2006, at age 54, when I learnt that I too required a pacemaker due to a 100% heart block between the upper and lower chamber I was very surprised. If I expected things to go smoothly I was very wrong and instead of an uncomplicated one surgery procedure, it took three surgeries and 12 days in ICU restricted to complete bed rest before the pacemaker was functioning fully and firmly in place. After that ordeal was over I counted on returning to a normal life and expected at least 15 uneventful years before my next hospital visit for a battery update!



Well I was wrong. I enjoyed 3 1/2 carefree, satisfying and busy years before everything changed in an instant. On Saturday, Jan 9th, 2010, something went drastically wrong when I lay down for a nap. My world went black unlike anything I had ever experienced before. But that feeling before I passed out was so familiar to me and all I could think about was that my pacemaker must be malfunctioning. But this time was also very different because I saw my life flashing before me with my own deceased father guiding me along the way. When I arrived at the hospital I tried to explain what had happened to me in great detail. All my questions about whether perhaps my pacemaker wasn't working or could this be another heart episode were dismissed with a smile and instead the doctor's began treating me for a "Grand mal" seizure disorder. This was a very frightening and frustrating time.

Six months later, after 50+ doctor appointments and a battery of tests I finally had my first heart test. The results of my Echo were very shocking. Heart disease was evident showing an enlarged heart functioning at only 30% capacity with an ejection fraction between 18 and 20%. Interestingly enough my first Echo test of February 2006 also showed an enlarged heart with an ejection fraction of 35%. Now officially diagnosed with Cardiomyopathy things began to move in an entirely different direction. Finally the suspicion that my seizure might be linked to my heart was now being fully investigated.

I had so many questions about what had happened but it really doesn't matter because the end result was that on December 24, 2010, I received the most amazing Christmas present ever! Dr Alex Tischenko performed my surgery and successfully implanted an ICD with no complications. The surgery was not without its challenges though - my pacemaker unexpectedly stopped during the procedure and against all odds Dr. Tischenko was able to use an already full artery loaded with leads from my 3 previous pacemaker surgeries to add the additional thicker defibrillator wire required for the ICD functionality.

We are very fortunate to live in a time where astounding new discoveries, improved surgical techniques and incredible medical advancements are being made every day helping people with heart disease enjoy a better and longer quality of life. Because of my ICD, I can live each and every day with a thankful spirit and a sense of confidence knowing that if my heart ever decides to do something funny again I will at least be able to make it to the hospital and get the help required instead of becoming another statistic of an unexplained heart death. Keeping my spirits up are not always easy but with the help and support of my loving husband, family and friends and my strong faith in God, I am learning to accept my limitations and love each and every day celebrating the gift it is.

Lastly a big thank you to the Directors of the ICD Support Group who welcomed me onto the board this year. Your ICD Support Group is here trying to support you with helpful educational information and planned meetings and social gatherings. Please feel free to contact us with your input as we plan events and publish your newsletters.

Answer to Brain Teaser from page 1

C. The more uninterrupted your sleep, the better, because you get more patterns of rapid eye movement and slow-wave sleep patterns, which help restore normal bodily functions. Like recharging the batteries of an electric car, it does not matter when recharging is done, provided it happens with some regularity, otherwise, performance becomes progressively slow and unreliable

(Courtesy of Boston Scientific LifeBeat 2012 OnLine publication)



DID YOU KNOW.....??

Important decisions at later stages in life, by Kerry Liebrecht RN

The goal of an implantable defibrillator is to provide lifesaving treatment should your heart develop an abnormally fast and ineffective rhythm. Despite all the treatments and technologies available, all patients will reach the end of their lives either due to their underlying heart condition or the development of another terminal illness. In the last weeks of the patient's life there is an increased risk of receiving shocks which are painful, lead to a decrease in quality of life and contribute to the distress of both the patient and their family.

It is important to have communication between yourself, your family and the physicians and nurses caring for you about what your wishes are. The decision to turn off the therapies provided by your ICD should occur when the therapies delivered, or the increased risk of therapies occurring have become a burden and are not consistent with your health care wishes. Turning off the therapies may improve quality of life for some by eliminating the threat of pain and the emotional distress associated with the delivery of shocks.

In the situation where your heart is being supported by the pacing therapy provided by the device it is important to know that these are not altered and therefore turning off shock therapies is unlikely to result in immediate death unless you are experiencing continuous or increasingly frequent fast heart rhythms.

Discussions about turning off device therapies must not be misunderstood as "giving up". The physicians and nurses involved in your care will continue to work to provide you with physical and emotional care and treatment.

In certain circumstances the clinic staff may initiate a discussion with you regarding whether the device should be replaced when it has reached that point. Replacement of the device carries with it the risk of complications and the physicians and nurses want to proceed with your best interests as our primary concern.

If you live outside of Winnipeg and are unable to travel at the time the device therapies should be turned off a magnet may be used. You or your families are advised to discuss this alternative with your family physician.

It is advisable that everyone have a health care directive in place to ensure your wishes are carried out.

EDITOR'S NOTE: Our volume 8 newsletter (May 2011) contained an article on Health Care Directives. For more information go to: www.gov.mb.ca/health/livingwill.html.

Potential Income Tax benefit re travel insurance premiums

In the summer edition of CSA News (Canadian Snowbird Association) the editor outlined how one of the largest Canada Revenue Agency offices in Canada had decided that, if any part of a travel medical insurance policy contained benefits that were not of a medical nature, then a tax deduction would be denied for the entire policy premium. An update on this topic in their Fall 2012 issue states that "purchasers of travel medical insurance remain eligible for the medical expense tax credit". They go on to say "because most travel plans are primarily medical, the Canada Revenue Agency has agreed to simply accept all travel insurance medical travel plans as 100% eligible". If you purchased travel medical insurance you may want to check with your tax preparer or the Canada Revenue Agency to determine if your premium may be claimed on your tax return.

ICD Support Group expands its service

In our last newsletter we mentioned that in April volunteers from the ICD Support Group met with 10 people on the "pending ICD implant" list. Since then we have met in person with many more new patients and their family members. We share information about the support group and answer all "non-medical" questions that we can. We also provide copies of recent newsletters and other related information. Several people have told us that being able to talk with someone who already lives with an ICD was very beneficial. We will continue these discussions and although we are not able to meet with 100% of new patients, by working closely with the Clinic we expect to meet with the majority. If you have been through one of these meetings we would appreciate any feedback or suggestions you have.



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WEB SITES OF INTEREST:

(some of these were provided in the past but due to the continual increase in ICD patients we thought it timely to include these web sites again.)

- Hotwinters.ca is an independent Canadian travel medical insurance broker.
 - www.Hotwinters.ca
- Manitoba Institute for Patient Safety. This local organization was created by the provincial government. It developed a program called "It's Safe to Ask", which 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 sample "medication card". Whether you choose to complete this card or use something similar we should all carry this type of information with us at all times.
 - www.safetoask.ca
- Canadian Heart Rhythm Society. This site contains lots of good information about ICD's and heart rhythm issues.
 - www.chrsonline.ca

IN APPRECIATION

- We would like to thank the following ICD manufacturers for their ongoing financial support.
 - Medtronic
 - St. Jude Medical
 - Boston Scientific

SUPPORT GROUP VOLUNTEERS NEEDED

We are planning on creating an on-line website for the support group. We see this as a quick and efficient way to supplement how we currently communicate with you. As this would only affect those who use a computer we would still continue to produce this newsletter in hard copy for those who want it. If you have the experience and technology skills to help get this project off the ground please contact one of the board members shown above.

We are always looking for new people to join our volunteer board of directors. Let us know if you can help.