



The ICD Support Group of Manitoba

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Volume 9 - May 2012

SUPPORT GROUP MEETINGS

Dr. Omar Sultan was the keynote speaker at our June 2011 meeting. He provided us with great background information on ICD's as well as what can be expected in the future. We appreciated his candid answers to the questions asked by the audience. We also heard from Garry Frankel, an ICD patient and Sudden Cardiac Arrest survivor. Garry shared his life and death experience with us and emphasized the importance of CPR training. If you are interested in starting a Sudden Cardiac Arrest survivors association in Manitoba contact Garry at "garryfrankel@hotmail.com". Our thanks to Mary Wilson RN from the Defibrillator Clinic for joining us as well.

Due to circumstances beyond our control we were unable to have a meeting in the second half of 2011. We look forward to seeing many of you at our upcoming meeting. In the interim please do not hesitate to contact members of the support group or Clinic staff with any questions, concerns, comments etc.

SPRING MEETING - SATURDAY MAY 26, 2012

Please join us for a presentation and discussion with Dr. Alex Tischenko from the Defibrillator Clinic. We will also hear from the Wiens family whose story appears on page 2 of this newsletter.

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).

Changes at the Pacemaker/Defibrillator Clinic

Dr. Omar Sultan has moved on to the Electrophysiology department at Regina General Hospital. Welcome back to Lisa Kalic who recently returned from maternity leave. Dianne Brown RN retired at the end of January. Dianne devoted her nursing career to helping folks with pacemakers and defibrillators. She was very good at what she did and her skills and compassion for people will be missed. However, the Clinic's loss is our gain. We are delighted to report that Dianne has joined the board of your support group. Her experience and enthusiasm will be invaluable to the group. Here are a few words from Dianne.

Greetings: I have recently retired after 34 years in the Pacemaker/Defibrillator Clinic. It has been a privilege and a pleasure taking part in your care. The patients who I have met have all taught me so much, whether you had a single lead device; biventricular ICD, 2 different devices, an LVAD or were 1 month old or 101 years old . I even had the fun of following 2 dogs with pacemakers, after hours of course.

I will miss the challenges of learning new devices and advancing technology, sharing stories, hearing about all your successes and your families, drying your tears & enjoying your laughter. I now look forward to the opportunity of helping with your support group, so I won't lose touch with you.

Retirement is a whole new chapter which I know I will enjoy. Best regards Dianne Brown

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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



The Wiens family story - by Shannon Wiens

The morning of September 10, 2003 was filled with nerves and excitement as my children get ready for school. Shane, 15 is nervous, he's in high school now, grade 10. Sheridan is 10, in grade 6 and thrilled that his brother is no longer in the same school. Kaileigh is 6 and in grade 1, she's thrilled she can now go to school full days and play outside at recess. As a mom, I'm excited to have routine back.

I am enjoying the peace and quiet after the kids are gone when I receive a call from the local RCMP. Shane has collapsed in gym class and been taken to the hospital. He is later pronounced dead of an undiagnosed heart condition, Hypertrophic Cardiomyopathy. An ICD could have saved his life. Within six weeks we are at the Variety Children's Heart Centre. It appears Sheridan and Kaileigh have the same heart condition. We must wait six months to have them retested.

April 2004 we are back at Variety. My fears are confirmed, they both have this horrible condition and will need to go to Edmonton to have ICD's implanted. The next few weeks are filled with questions I can not answer. Will I still be able to play football? Can I still ride my bike? Run? Jump on the trampoline? Will it hurt when the ICD shocks me? Will I wake up from surgery?

May 28, 2004, we are in Edmonton. Sheridan and Kaileigh have their ICD's implanted, their surgeries are two hours apart. Their lives as ICD patients begin. Sheridan is 11, Kaileigh will be seven in a few days. I'm relieved to know my children will now be protected and as soon as they've healed our lives can return to normal. Whatever that may be.

They have had their share of complications. Internal bleeding, chest tube, badly placed lead, rejection of the ICD which required removal and replacement, pocket infection requiring hospitalization. These were Kaileigh's complications that took place during the first four months after implant.

Sheridan experienced emergency replacement surgery in August 2008 because his battery died unexpectedly. Kaileigh's was replaced as well to be on the safe side. In December 2010 Sheridan had replacement surgery again, this time the lead was faulty.

They have both experienced several shocks, all of which were true. Sheridan's first shock we were unaware of. He told me he had fallen while running to school and felt a little funny. At the next defibrillator appointment we found out he had been shocked. They have experienced shocks at school, at home, the grocery store, while running, walking and sleeping. They tend to faint before therapy is delivered, which protects them from feeling the pain of the shock. Kaileigh, however did not faint once and experienced the painful shock while fully conscious.

Sheridan and Kaileigh have taken very different approaches to life with an ICD. Sheridan was determined to keep doing what he was doing and has remained very active. Kaileigh was afraid to do anything for fear of being shocked. This fear has intensified after her first shock, it happened in gym class and resulted in her first ambulance ride. This brought back memories of Shane's passing.

I am very proud of my children, now 19 and 14. They've been amazing through all of this. They have had their fears and frustrations but for the most part have remained positive. In a way they are lucky, they have each other to share these experiences with. As a Mom I've had my share of fears and frustrations, anxiety and sleepless nights. I've shed more than my share of tears. It's been a long hard road but has been worth it, without their ICD's my children would not be with me. It's amazing how much peace of mind this little metal machine has given me. In September 2007 I too was diagnosed with Hypertrophic Cardiomyopathy and had an ICD implanted. I've been lucky, there have been no shocks or complications.

Update on "A Shocking Experience" by Kerry Liebrect, Nursing Coordinator

Since the last support group newsletter in May 2011, I am pleased to report that I have been contacted by the educators for the Health Authorities requesting further information and help in developing policies and procedures and magnet use. Many have developed policies and procedures and have bought magnets to have available. We continue to hand out the "fact sheet" to each person implanted who lives in a rural area and I would encourage those patients to periodically have this discussion with your physician to keep this matter at the forefront of everyone's mind. If you require additional fact sheets please ask at your next appointment or call the Clinic at (204) 237-2431 and we would be happy to mail it out to you.



DID YOU KNOW.....??

Implant Room nurses role, by Deborah Shaski RN

The cardiac device implant nurses are highly specialized. They have both ICU and OR training. One will “meet and greet” you in the pre-op holding area. She/he will review your history, allergies, reason for device implant, check blood work and make sure you are NPO (nothing by mouth). Basically, she/he will ensure you are ready and fit for your procedure. You will then be taken into the OR where two nurses will be present with you at all times. One will monitor your vital signs, administer medication and test your ICD wire(s) once the doctor places them in your heart. The other nurse will be “scrubbed” and will assist the doctor with your procedure. Once the procedure is complete, a nurse will take you back to the pre-op holding area and hand your care over to another nurse for you to recover.

What happens with your device during non cardiac surgery/procedures, by Esther McGimpsey RN

The Pacemaker / Defibrillator Clinic has adopted a new policy in regards to surgery and turning off therapies for a procedure. With the increase in our ICD population we have been unable to fulfill requests made for one of the nurses to be present during surgery. In researching what other centers in Canada do in this regard, we have found that the clinics instruct the responsible physician as to what to do and look out for. They do not go to the center to physically turn off therapies. The policy we have adopted is as follows: Any procedure that does not involve the chest, large head and neck surgeries or breast surgeries on the side of the device, staff will not be present. For any other procedure instructions are sent to the facility performing said procedure. The basic guidelines being that the patient is cardiac monitored and a donut magnet placed over the device. The device may deliver a tone with the magnet application depending on the device. With the magnet in place all therapies are off, no shocks will be delivered and the pacemaker functions as normal. Should an arrhythmia occur the magnet can be removed to allow detection of the arrhythmia or an external defibrillator can be used to deliver a shock. Once the procedure is complete the magnet is removed, the device returns to the permanently programmed parameters.

Organ and Tissue Donation

For the few weeks it has been possible to register online to be an Organ and Tissue donor at www.SignUpForLife.ca. You must be 18 years of age or older and have a valid Manitoba Personal Health Information Number (PHIN). When you register your intent to donate organs and tissue, your donation decision is recorded in a Manitoba Health Database. You should register even if you signed a donor card. A signed donor card is not recorded in the Manitoba Health database and may not be available when needed. According to Arlene Wilgosh, president and CEO of the Winnipeg Regional Health Authority 30 to 40 Manitobans give the gift of life most years. More than 50 are beneficiaries of an organ donation annually. Please consider supporting this worthwhile cause.

ICD Support Group expands its service

In April, volunteers from the ICD Support Group met with 10 people on the “pending ICD implant” list. These face to face discussions usually included one or more family members as well. Early indications are that the patients and their families appreciated the opportunity to talk with someone who is living with an ICD.

of ICD patients

The Pacemaker/Defibrillator Clinic at St. Boniface Hospital follows approximately 1,060 ICD patients throughout Manitoba, NW Ontario and Nunavut. A significant increase from about 400 in late 2006.



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CONTACT INFORMATION

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WEB SITES OF INTEREST:

- The Winnipeg Free Press ran an article written by Ron Pradinuk about travel insurance in their April 21, 2012 edition. It contained a link to a CBC Marketplace documentary on this very important subject.
 - www.cbc.ca/marketplace/2012/trippedup
- The following are links regarding travel information on the Air Canada Website
 - www.aircanada.com/en/travelinfo/onboard/healthtips.html
 - www.aircanada.com/en/travelinfo/before/specialneeds.html
- Canadian Air Transport Security Authority. This site deals with security screening for air travel.
 - www.catsa-acsta.gc.ca/

IN APPRECIATION

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

SUPPORT GROUP UPDATE

We are pleased to announce two new individuals have joined The ICD Support Group Board of Directors. Dianne Brown recently retired from the Defibrillator Clinic and brings a wealth of related knowledge to our group. Ruthe Penner, an ICD patient with extensive volunteer board experience also joins us. A big welcome to Dianne & Ruthe. We are always looking for new people so if you are interested please contact one of the current board members.