



The ICD Support Group of Manitoba

Volume 19

October 2017

SUPPORT GROUP MEETINGS

The last group meeting was held on May 27, 2017. Our guest speaker was Emily Hyde RN, BSN, BMSc from St. Boniface Hospital, Cardiac Sciences Program. Emily is the Continuing Education Instructor for 5A Cardiac Medicine, Post Recovery and the Pacemaker/Defibrillator Clinic. Her presentation was entitled “Who is at the Helm of your Health?” Healthcare has historically been paternalistic – we did what the doctors said and didn’t ask many questions. However, these days there is way more access to information particularly on the internet. While we can now ask more informed questions to better understand our health situation we can’t overlook the fact that information found on the internet may not always be accurate. We must also remember that doctors have many years of medical training and experience leading to their decisions. This has led to a more team approach to our health care. We ask questions and come to a decision together with healthcare providers. This increased access to information has led to a shift in what defines a patient. The patient used to be the person with the healthcare issue being addressed. The patient now includes spouse, children, other relatives, close friends or anyone the patient deems important in their lives. This has in turn led to *Patient and Family Centered Care* at St. Boniface Hospital. It encourages the principles of collaboration, dignity, respect, sharing of information and encouraging participation in patient care. Clinical decisions are made based on individual patient values. Many patients today want to be actively involved with their healthcare but in some cases it can be overwhelming.

.....continued on Page 2

NEXT MEETING - SATURDAY, DECEMBER 2, 2017

RECEPTION: 1:00 p.m.

GUEST SPEAKER: 2:00 p.m.-3:00 p.m.

ST. BONIFACE HOSPITAL ALBRECHTSEN RESEARCH CENTRE

351 TACHE AVENUE

SAMUEL N. COHEN AUDITORIUM, MAIN FLOOR

The closest parking lot is at the south end of the Hospital near Emergency. The Albrechtsen Research Centre is at the southwest end of the Hospital.

Our guest speaker will be Estrellita Estrella-Holder. Estrellita works as a Nurse Practitioner in the Cardiac Sciences Program’s Heart Failure Clinic. You will learn what heart failure is, the high level of care provided to patients and much more.

Please join us for refreshments, fellowship and information about heart failure and the Heart Failure Clinic at St. Boniface Hospital. We encourage you to bring along a family member(s) and/or guest(s) as this provides a great opportunity to chat informally with others who live with a defibrillator.

THERE IS NO NEED TO CONFIRM YOUR ATTENDANCE.

Inside this issue:

<i>Did you know...??</i>	2
<i>Did you know.....??</i>	3
<i>Contact Information</i>	4
<i>Web sites of Interest</i>	4
<i>Clinic changes</i>	4
<i>Feedback</i>	4

VOLUNTEER BOARD OF DIRECTORS

- Larry Sherman, President
- Greg Smith, Director
- Dianne Brown, Director
- Bob Mawson, Director

**.....CONTINUED FROM PAGE 1**

Patients and family centered care is a fundamental part of care throughout St. Boniface Hospital because it leads to better patient outcomes and greater patient satisfaction along with decreased errors and lower costs. St. Boniface Hospital has implemented two specific initiatives to ensure that patient and family voices are heard: 1) the Patient and Family Advisory Council. Members of the Patient and Family Advisory Council are volunteers who have been patients or are family members of patients. They bring the patient's voice to matters of importance, informing new ideas or projects to continuously improve the patient experience and enhance the services provided at St. Boniface Hospital. The value of input from those using the health care system is enormous. They ensure many strategies being developed are vetted by patients and family who can then provide perspectives and ideas that staff may not have considered. Feedback from the Council is reported annually to Hospital Executive. 2) the Patient Relations office. The Patient Relations office can answer questions or concerns about patients' treatment or care at St. Boniface Hospital. They are available for patients and family members. More information on both initiatives can be found on the St. Boniface Hospital website. (www.sbgh.mb.ca)

DID YOU KNOW.....??**HiRO**

HiRO stands for the Hearts in Rhythm Organization. It is a network of Canadian inherited heart rhythm specialists, including Dr. Colette Seifer and Dr. Clarence Khoo from St. Boniface Hospital. The organization works together with health care professionals and patients to improve care for patients and families affected by inherited heart rhythm conditions. The second annual HiRO Symposium was held in Winnipeg this past June. Attendees included heart rhythm specialists from across Canada and England; the heads of both the Canadian and American Sudden Arrhythmia Death Syndrome foundations, patients and family members. Larry Sherman from the support group provided an overview of The ICD Support Group of Manitoba. HiRO's website can be found on page 4 of this newsletter.

KNOWING YOUR DEVICE

Do you know the correct name of your implanted device? Do you know what the settings are for when the device will deliver a shock? We often use many different terms to describe the type of device we have in our chests. Many of them are incorrect. Common ones are "I have a pacemaker" or "I have a pacemaker/defibrillator". The correct names are Implantable Cardioverter Defibrillator (ICD) which has either one or two leads or a Cardiac Resynchronization Therapy-Defibrillator (CRT-D) which has three leads. It is important to refer to your device by its correct name when talking with medical people. A cardiac nurse recently explained that if the device is not accurately described to her it can cause confusion. She said if someone tells her they have a pacemaker her initial thought is they have slow atrial fibrillation, a heart block, have had an myocardial infarction (MI or heart attack). If she hears ICD she thinks the person has survived a cardiac arrest or are at risk of one. If she hears CRT-D she knows they probably have heart failure. Treatment of each type of device is different and the questions she needs to ask about the device are also different. While this may not be an issue if you are speaking to a doctor or nurse in the Pacemaker/Defibrillator Clinic since they have immediate access to your device information, it could be an issue if you are seeking medical assistance elsewhere.

REMOTE MONITORS

The Pacemaker/Defibrillator Clinic at St. Boniface Hospital implants ICD's (Implantable Cardioverter Defibrillator) and CRT-D's (Cardiac Resynchronization Therapy – Defibrillator) from five different manufacturers: Medtronic, Abbott (formerly St. Jude), Boston Scientific, LivaNova (formerly Sorin Group) and Biotronik. Each company offers a remote monitor that can be used with their implanted arrhythmia device.

.....continued on page 3



DID YOU KNOW.....??

REMOTE MONITORS.....continued from page 2

What are the benefits of a remote monitor?

Remote monitors play a significant role in relaying information from an ICD / CRT-D to the Pacemaker/Defibrillator Clinic in a timely fashion allowing for quicker investigation. They can reduce hospitalizations, ER visits and the frequency of in clinic visits. They can also have a positive impact on Quality of Life and provide patients and family members with a sense of security and peace of mind.

What does a remote monitor do?

An implanted ICD / CRT-D device constantly records and stores data internally. This information would be the same as if you were having an in clinic appointment and would include: any therapies delivered, battery or lead issues, problems with the implanted device and more. On a regular basis (usually every 24 hours) and provided the remote monitor is within range of the ICD / CRT-D, the remote monitor communicates wirelessly with the ICD / CRT-D device to capture what has transpired since the last communication. The information is then forwarded to the Clinic via a secure website for review during regular Clinic hours by a nurse. Remote monitors can also be used by the patient to transmit data either upon request from the Clinic or on their own initiative. If a patient decides to send in a transmission on their own (not at a regularly scheduled time or upon request from the Clinic) the patient should contact the Clinic to let them know when and why they sent the transmission.

What does a remote monitor NOT do?

A remote monitor is not a substitute for appropriate medical attention in the event of an emergency. The monitor cannot call 911 for you. It will not function unless properly connected to the appropriate telecom service, which could be cellular, land line, or internet depending on the requirements for your specific remote monitor.

Should you take your remote monitor with you when travelling?

Usually it is not necessary to take the remote monitor with you on short trips. The rule of thumb should always be that if you feel unwell – seek immediate medical assistance – don't delay by waiting to get the results of a transmission you sent in. If you know you will be away when a regularly scheduled remote transmission is due you should contact the clinic for instructions before leaving. Similarly, if you are going to be away for an extended period of time i.e. spending several weeks at the cottage or leaving the country you should discuss this with the Clinic ahead of time.

What should you expect after a regularly scheduled remote transmission?

If there is anything that requires investigation the Clinic will contact you shortly after they receive the information.

General information

Some of the manufacturers provide the ability for the patient to obtain additional information about their implanted device and monitor. For example, Medtronic's MyCareLinkConnect.com website provides detailed information about the implanted ICD / CRT-D and remote monitor. It can also provide confirmation to the patient when a transmission has been successfully received; provide reminders of upcoming scheduled transmissions and much more.

Any questions about remote monitor set up and troubleshooting should be directed to the respective manufacturer.

The majority of ICD / CRT-D patients now have a remote monitor. If you do not presently have one or have any questions or concerns about your implanted device and/or remote monitor do not hesitate to ask the nurse during your next scheduled in clinic appointment or call the Pacemaker/Defibrillator Clinic at (204) 237-2431.



**THE ICD SUPPORT GROUP
OF MANITOBA**

www.icdsupportgroupofmanitoba.com

MAILING ADDRESS

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

CLINIC PHONE #:

204-237-2431

BOARD MEMBERS - CONTACT LIST

Larry Sherman

- 204-889-4029 (Winnipeg)
- larrysh@mts.net

Greg Smith

- 204-894-4393 (Winnipeg)
- gwasmith1960@gmail.com

Bob Mawson

- 204-729-8788 (Brandon)
- LBVILLAGE@mts.net

Dianne Brown

- 204-888-3677 (Winnipeg)
- diannecb@mymts.net

WEB SITES OF INTEREST:

- Hearts in Rhythm Organization. This website has information and resources on inherited heart rhythm conditions for the public, patients, families, health care professionals and research staff.
 - www.heartsys.org
- Manitoba Institute for Patient Safety. This organization promotes patient safety to patients, families, the public and healthcare providers. The “It’s Safe to Ask” section contains information that patients and families should ask regarding their healthcare. The “Resources & Tips” section provides information on medication safety, a sample medication card for recording your medication, Emergency Response Information Kit (E.R.I.K.) as well as details on how to advocate for yourself and others. The advocacy section includes lots of information, videos and forms including a Patient Advocate Agreement.
 - www.mips.ca

**STAFF CHANGES IN THE PACEMAKER /
DEFIBRILLATOR CLINIC**

Welcome to both Wendy Dziadyk and Cathy Seri-Bangert. Wendy is moving from the implant room to join the Clinic nursing staff and Cathy is at the front desk coming to us from another department just down the hall.

VOLUNTEER OPPORTUNITIES

We are always on the lookout for new additions to the board of directors. New thoughts and ideas are always welcome. We generally hold 3 or 4 board meeting per year. If you would like more information please contact Larry Sherman.

FEEDBACK

Do you have any questions, suggestions or comments regarding this newsletter and future support group meetings or activities? If so please contact Larry Sherman.