



The ICD Support Group of Manitoba

THE ICD SUPPORT GROUP OF MANITOBA

Volume 16 - October 2015

SUPPORT GROUP MEETINGS

At our May 2015 meeting we were joined by two guest speakers. Kristin Millar provided us with an overview of her journey leading up to and beyond her heart transplant. Barry Guttormson shared his insight into the often confusing world of travel insurance.

Kristin Millar is a delightful, funny and energetic young lady. To meet her you would never guess that she was near death on several occasions and is alive today only due to her heart transplant in 2012. In her own words Kristin lived a normal healthy life up until her late teens. There was no family history of cardiac disease in her immediate family. She was active in art and the theatre. At 18 years of age she fainted while at the gym which led to a number of medical tests. Some three months later she found herself in a cardiologist's office learning that she had Hypertrophic Cardiomyopathy. It was difficult to comprehend what this really meant especially since she had no symptoms other than the original fainting episode. So when the cardiologist told her that sudden death was a potential outcome the seriousness of her condition really hit home. She went through a huge range of emotions and threw herself into things she loved like school, and acting, all the time trying not to think about her heart condition. After her initial diagnosis she sought a second opinion in Toronto that resulted in the implantation of an ICD. In late 2009 Kristin thought she had the flu. She made many trips to the hospital and each time was told she had the flu. She knew it was more than that and told her dad, "I think it's my heart". Turns out she was right. Shortly after Christmas after undergoing an unrelated fairly routine medical procedure her heart stopped. Fortunately her ICD did its job and got her heart beating again.

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FALL MEETING

Unfortunately we are not able to hold a support group meeting this fall. Due to some medical issues for the editor the newsletter was late getting into production. Plus there are no suitable dates available at our usual venue before December. As winter driving at that time of year is unpredictable the decision was made to defer until the Spring meeting.

TEST YOUR KNOWLEDGE

How many of these cardiac related acronyms can you get correct? (see page 3 for answers)

CHF	_____	VT	_____
EF	_____	VF	_____
EPS	_____	MRI	_____
HCM	_____	BPM	_____
MI	_____	CPR	_____
ICD	_____	PVC	_____

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Kristin Millar cont'd

But her heart was in real bad shape and she was in heart failure. Her organs were failing and she had no measurable blood pressure. Her ejection fraction (EF) was less than 6% (EF is a measurement of how much blood the left ventricle pumps out with each contraction. A normal heart is in the 55% to 70% range). She underwent surgery to have a LVAD (left ventricular assist device) implanted. An LVAD is kind of a mechanical heart. It helps the heart pump oxygen rich blood throughout the body. A control unit and battery pack are worn outside the body and are connected through a port in the skin. The surgery had some serious challenges as all her veins had collapsed and it was not possible for the doctors to insert a line to get the readings they needed and to administer drugs. Rather than being sedated she was wide awake and communicating with her surgeon throughout the surgery. Although the LVAD implant worked fine, a large blood clot had formed in her heart. A brain scan revealed 7 strokes. The neurologist said she would be blind, unable to speak, partially paralyzed and ineligible for a heart transplant. Kristin would not give up and with help she taught herself to walk, talk, swallow and more. Several weeks later she left the hospital and was placed on the heart transplant list in Ottawa. Living with an LVAD has its challenges and restrictions but she was so grateful to have the device. She went back to school and went to the gym every day. After a year or so with the LVAD the phone rang - there was a heart waiting for her in Ottawa. While still in the air ambulance on the way to Ottawa the pilot was told the heart was "not good" and they would have to return to Winnipeg. Disappointing for sure but she still had the LVAD to keep her alive. In January 2012 she received a similar phone call - there is a heart waiting for you in Ottawa. This time the heart was a match. Much to the amusement of the doctors and nurses, while on her way into the operating room Kristin sang the song "Achy Breaky Heart". After the transplant the new heart did not need to be "shocked" to start pumping - it just started to beat on its own. When she woke up she felt warm for the first time in years as her blood was now circulating properly throughout her body. It's been over 3 years since the transplant and Kristin has not had any hospital stays or side effects from the anti rejection medications.

Kristin doesn't look at illness as a weakness nor does she feel being sick is your fault. She told us that she found great comfort in talking to others who were in a similar situation to her. She said it felt so good to be able to talk to someone who truly understands and can relate to what she was going through.

For information on organ and tissue donation visit: www.signupforlife.ca.

Hotwinters.ca

Barry Guttormson is the President of Hotwinters.ca which offers travel insurance. They specialize in plans medically approved prior to travel. Barry has been in the financial field for 20+ years. Prior to that he spent another 20 years as a critical care paramedic both as an instructor and manager. Everyone has heard horror stories about travel insurance. Approximately 95% of claims in the industry are paid with the remaining 5% being declined for one reason or another, often because the application form contains an "innocent" error. The application process is critical in that all information must be 100% accurate and honest. Don't overlook something you think is routine or under control. Some examples could be: sleep apnea that is treated with a CPAP machine, previous fainting spells, polyps that have been removed, diabetes that is under control, prostate issues, gout, diverticulitis, esophageal reflux, etc. Make sure you are eligible for the policy you are applying for. If you do not understand a question or what is being asked consult with your doctor. Consider having your doctor review the application with you. If you have to submit a claim it must match your medical records which the insurance company will review in detail. Keep a list on hand of medications (drug name, dosage, frequency, condition treated, date first prescribed, date last changed and how dosage changed). (Visit Hotwinters.ca for a sample medical history summary). Pay close attention to the stability clause in the policy. Any change to your health (worse, new, change in medication etc.) could have an impact on the stability clause as could an outstanding referral to a specialist. In some policies a change from a brand name medication to a generic brand could affect your stability. Make sure you fully understand how the policy calculates the number of days you need to be stable prior to your travel date. As an example lets say you had surgery on June 1, were discharged on June 5 and had a follow up with the doctor/surgeon on August 15. In all likelihood the stability period calculation would start on August 15. If you purchase a multi trip plan remember that all of this information comes in to play each time you travel. The financial cost of a policy should not necessarily be the overriding decision to buy. The wording in the policy needs to fit your individual situation and needs. Finally once you select and purchase a travel insurance policy if there are any changes to your situation between the time you bought the policy and when you travel you must contact your seller in case the policy no longer meets your needs.



DID YOU KNOW.....??

PERSONAL HEALTH INFORMATION ACT (PHIA)

To ensure The ICD Support Group of Manitoba is in compliance with PHIA guidelines as outlined by the Province of Manitoba we are required to obtain written consent from every ICD patient who wishes to be contacted from time to time by us. In particular, if you wish to continue receiving our regular newsletter or receive any other information regarding our group you MUST SIGN a new consent form during an upcoming visit to the ICD Clinic at St. Boniface Hospital. Even if you previously provided the support group with your permission to be included in an email or regular mailing list you are still required to sign the new consent form. Without the new form on file at the hospital we will no longer be able to send you any information on our services including the newsletters, meetings, special events etc. Consent can be withdrawn at any time by contacting the support group.

REMOTE MONITORING UPDATE

The rollout of remote monitoring machines is almost complete for all Medtronic, St. Jude, Boston Scientific and Sorin ICD's. Patients will generally be seen in the Clinic annually with a remote transmission done at the six month interval. Remember that remote transmissions provide the same information as an in clinic visit and they are followed up with a phone call to the patient from a nurse. For more information on the use of these devices you can refer to our Volume 15 newsletter. Questions should be directed to the Clinic.

HELPING THE HEART FIX ITSELF

If you're a heart attack survivor, you know things just don't return to normal right away. The trauma can damage and weaken your heart, leaving you vulnerable to disease and premature death. But what if it was possible to reverse the damage? What if the heart could actually fix itself. That's the goal of Heart & Stroke Foundation funded research by Dr. Duncan Stewart, who's conducting the world's first clinical trial to repair the heart using patient's own genetically enhanced cells. Here's how it works: Stem cells are taken from the patient's blood. They're then infused with a gene known for stimulating blood vessel growth and tissue healing. The enhanced cells are then injected back into the patient's heart. This groundbreaking research has enormous potential to change the lives of the 500,000 Canadians living with heart failure. (article taken from Heart & Stroke Foundation 2015 mid-year accomplishment report)

SUBCUTANEOUS IMPLANTABLE DEFIBRILLATOR (S-ICD)

In our October 2013 newsletter we mentioned this new ICD is able to deliver a shock to restore a normal heartbeat without wires actually touching the heart. The lead (wire) is placed under the skin near the breast bone versus inside the heart. They are not a replacement for all other ICD's and each patient's situation will be evaluated on an individual basis. To date the Pacemaker/Defibrillator Clinic at St. Boniface Hospital has implanted a S-ICD in four patients. Each implant went well and there have been no issues to date.

TEST YOUR KNOWLEDGE - ANSWERS FOR PAGE 1 QUIZ

CHF	Congestive Heart Failure
EF	Ejection Fraction
EPS	Electrophysiology Study
HCM	Hypertrophic Cardiomyopathy
MI	Myocardial Infarction
ICD	Implantable Cardioverter Defibrillator
VT	Ventricular Tachycardia
VF	Ventricular Fibrillation
MRI	Magnetic Resonance Imaging
BPM	Beats per minute
CPR	Cardiopulmonary Resuscitation
PVC	Premature Ventricular Contraction



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)
- defib1960@gmail.com

Bob Mawson

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

WEB SITES OF INTEREST:

- The Canadian Genetic Heart Rhythm Network offers insight into inherited heart rhythm disorders for the public, patients and health care professionals.
 - www.heartrhythmresearch.ca
- Mended Hearts is an American national non profit heart patient support group.
 - www.mendedhearts.org
- ICD Support Group (not ours - a different one) has a very active “message board” where people living with ICD’s post questions, thoughts opinions etc. Just keep in mind that these posts are made by individuals and not medical professionals.
 - www.icdsupportgroup.org (then click on “message board”)
- Myheartsisters.org is about women and heart disease from the perspective of Carolyn Thomas, a Mayo Clinic trained women’s health advocate, heart attack survivor, blogger and speaker.
 - www.myheartsisters.org

IN APPRECIATION

- Jake Suderman, one of our founding board members has resigned from the board for personal reasons. We would like to acknowledge Jake’s contribution to the group over the years and wish him all the best in the future.
- A big thank you goes out to Medtronic and St. Jude for their ongoing financial support of our group.

CHANGES IN THE CLINIC

A very warm welcome to Randi Sommerfeld who joined the front desk staff in the clinic.