



Recipient and donor family members greeted Cayse Ruiter as he arrived at the Sydney Ferry Terminal on July 26. Pictured from left to right are Mark Sberlock, Georgina MacDonald, Cayse Ruiter, Jean Marie MacDonald and Kyle Hickey.

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Cross Canada Cyclist Promotes Organ Donation

Cayse Ruiter, a 26-year old from Ottawa, undertook an 8000 km solo bike trip across Canada this summer to raise awareness of organ and tissue donation after his good friend passed away while on the organ transplant wait list.

Cayse left Tofino, British Columbia, on June 3rd and arrived in St. John's, Newfoundland, on August 3rd

As he journeyed across Canada, Cayse recorded his experiences in his blog, including this entry from July 26th:

“Exhausted from a long and hilly day of biking, I arrived at the Sydney Ferry Terminal only to be greeted by a bagpiper and nearly twenty green-clad, banner waving, smiling faces! The group was comprised of donor recipients, individuals awaiting transplants, their families, and a number of others; all of whom showed up to offer their support and thank me for championing the cause of organ and tissue donation. I still cannot stop smiling about the kind-heartedness and generosity of this gesture. The beauty of Cape Breton seems only to be surpassed by the beauty of its people.”

Legacy of Life NS Organ and Tissue Donation Program was implemented in 2006 to help improve the organ and tissue donation process in the province.

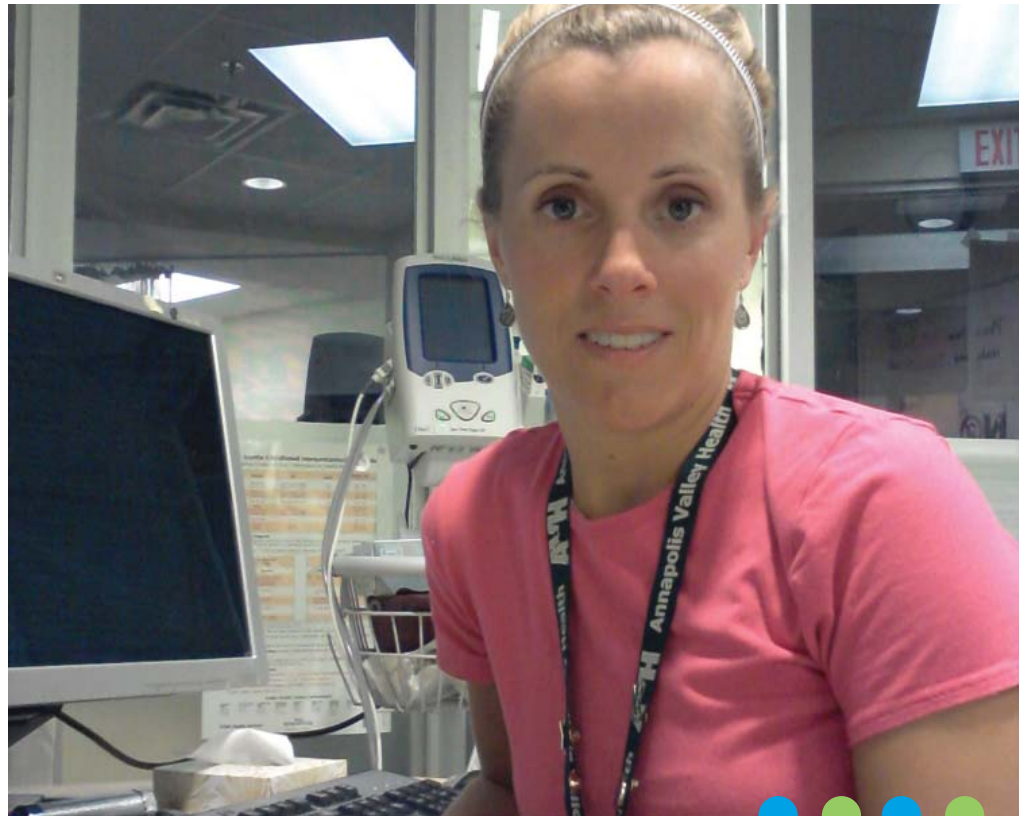
The program has been in existence for over seven years, and has completed its third strategic plan. The work of the donor family working group was part of the original plan.

Donor families are considered a key component in the system. The donor family working group's focus is the impact of the legislation on donation, review of the donor experience survey results, and monitoring the recommendations implementation from a report submitted to the advisory council in 2009.

The working group will explore what components would need to be in place to facilitate more organ donor and recipient interaction.

New District Resource Nurse

We're pleased to advise that Amanda Amero-Hubbard has taken on the duties of the District Resource Nurse position at South West Nova District Health Authority. We all welcome Amanda to the role! ■



Robin Stacey, District Resource Nurse, AVDHA

Robin Stacey has been a District Resource Nurse for organ and tissue donation for the Annapolis Valley District Health Authority since November 2012. Robin's interest in organ and tissue donation developed when she became a Critical Care nurse float and worked in the Intensive Care and Emergency Departments at Valley Regional Hospital. Robin has been an advocate for organ and tissue donation in both the community and clinical settings. She completed numerous

presentations for community groups and is an active support for staff to promote quality end of life care. She is looking forward to supporting the roll-out of the new legislation when it is proclaimed.

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INNOVATIVE IDEAS

Danielle Byrne-Surette, former district resource nurse from South West Health, has initiated a writing group to identify topics that Legacy of Life could develop further for publication. The members of the group will go through a process

to find suitable topics that are of interest to a variety of learners. In addition to Danielle, members of the writing group include Jane Franklin, Corinne Corning, and Janet Evans. ■

Professional EDUCATION HIGHLIGHTS

Yarmouth Nursing Students 2013

Dalhousie University Nursing Students – Yarmouth Site created awareness on campus of the importance of organ and tissue donation not only for themselves and their families but for the patients they care for. The topic of organ and tissue donation appears in various courses from palliative care to ethics.



Cape Breton Clinical Day 2013

The fourth annual Organ and Tissue Donation Conference was held for over 100 frontline professionals on April 25, 2013 at the Quality Inn, Sydney.

Participant evaluations were extremely positive and the topics covered included personal stories from donor and recipient families, the donation conversation, forensic examination,

palliative care, grief recovery, and offering donation at the time of an unexpected sudden death of a loved one.

There was also a Living Green Ribbon photo shoot where people become part of a living tableau – a giant green ribbon. This formation followed an emotional presentation from the donor family of Hannah Carmichael.



Participants of the 2013 Organ and Tissue Donation Clinical Day shared their experiences and expertise on April 25th at the Quality Inn in Sydney, Cape Breton.

WORKING GROUP UPDATES

Human Organ and Tissue Donation Act (HOTDA)

A new working group has been formed to provide advice on the proclamation

date and roll-out of the HOTDA that was passed in December 2010. Since then preparations have been ongoing and include the development of a provincial policy and screening tool, an education plan and E-Learning module, and communications strategies. One component that is currently being reviewed is whether to change the information provided in the registration system for the MSI Donor Registry. Nova

Scotians register their donation wishes on their MSI health card every four years. The Registry can be accessed by critical care and tissue bank donation staff to help with the conversation with families regarding donation. Currently when someone registers, a brochure is provided as well as the sign up form, phone numbers for more information, and the Legacy of Life website address. ■



David Lawrence Morse

Prior to the development of the Living Donor Paired Exchange (LDPE) Registry by Canadian Blood Services, living kidney donation programs evolved to meet the needs of patients, independently. At the time, programs were developed to meet local or regional needs because provinces and territories were not sharing kidneys.

Today there are twenty-seven (27) living donation programs across Canada, including seventeen (17) major centres that perform the transplant surgeries. The remaining ten (10) programs perform intakes and assessments and then arrange to send patients to the larger centres for surgery. Because of this, there is no standard agreement between programs on how to assess a living kidney donor, in absence of Canadian Guidelines.

In some cases, donation chains proposed by the LDPE Registry have broken down or taken much longer than expected to complete. Also, as donors are traveling to other centres to donate, it is important that all programs adhere to a common protocol for assessment and acceptance. It is particularly important if programs wish to resume shipping kidneys, instead of donors, that they are in compliance with Health Canada Cells, Tissue, and Organs (CTO) Regulations.



The Living Donation Advisory Committee (LDAC) has been struck by Canadian Blood Services to meet this objective. As the LDPE Registry has increased the number of living kidney transplants across the country, the LDAC is working towards establishing a Living Kidney Donor Assessment and Acceptance Protocol (LKDAAP), to which all programs will adhere, in order to assure patient safety and an efficient process across the country. ■

Tissue Donation Provides Hope and Healing

At the end of a perfect ski vacation on the last run of the day my 41-year old husband, David, had an accident on the hill. Our story was far from typical as it was filled with things that no family should have to survive. Like many families I cling to the memory that I was by his side telling him he was going to be ok, and I would help make things better. That wasn't the case and hours later I found out from a stranger that he had died in the ambulance on his way to the hospital.

Even though I have worked as a nurse with the provincial organ and tissue donor program, teaching and providing education across Nova Scotia, and as a kidney donor myself, I never thought I would be faced with making a decision for my own family.

On January 12, 2012, my entire life changed, and I asked for something that most families don't even think of in my circumstance.

We were hundreds of miles from home yet my first call was to a tissue specialist

at the QEII. Because of this profound tragedy, my boys, 11 and 14, lost their father, their coach, and their mentor. I knew what I needed to do to give them hope and healing. I knew the benefits of tissue donation. I knew it might not make a difference that night but in whatever capacity their father's tissues could be used, he would continue to be a hero to my boys in death as he had been in life. I felt I needed to make that happen. The tissue specialist and the New England organ bank team worked hard to make our family's end of life wishes come true. David became a donor, and a hero to my boys.

My husband was a kind, gentle giant who loved sports, golf, the woods, and nothing more than his family. He died as he lived, helping others. We celebrate his memory with Donate Life wrist bands provided by New England organ bank and are happy to be champions for organ and tissue donation to honour such a beautiful life.

Dana, Keighan, Rhylan Morse in memory of David Lawrence Morse ■

Dr. Stephen Beed, Legacy of Life's Clinical Advisor, was recently appointed Chair of the Deceased Donation Advisory Committee (DDAC), a national-level committee comprised of physician leaders from across the country. Reporting to the Organ Donation and Transplantation Expert Advisory Committee of Canadian Blood Services, this physician-focused committee provides expert advice on

issues relating to the donation of organs and tissues from deceased donors. Dr. Beed and the DDAC will work closely with the Organ Procurement Organizations working group to collectively address strategies to further develop leading practices, processes to improve family support, professional education, and a donation physician's network. ■

The Moncton Branch of the Canadian Transplant Association is pleased to announce that the 7th CANADIAN TRANSPLANT GAMES will be hosted in Moncton, New Brunswick July 7th to 12th, 2014.

Since 2000, the Canadian Transplant Games have been a showcase for transplant recipient athletes from across the country to enjoy the competition and camaraderie, while celebrating a second chance at life as well as to showcase the return to a healthy lifestyle post-transplant.

The Games, held every two years, is a family oriented event. In addition to the competition for recipients, there are activities designed for family members and supporters. Donors and their families are recognized throughout the week, especially at the organ donor luncheon. The games include an Opening Ceremony, special events throughout the week, closing ceremonies followed by a Gala Dinner/Kitchen Party. Children and adults of all ages and of all levels of athletic ability will compete in aquatics, bowling, golf, tennis, racquetball/squash, badminton, cycling, lawn bowling, table tennis, track and field.

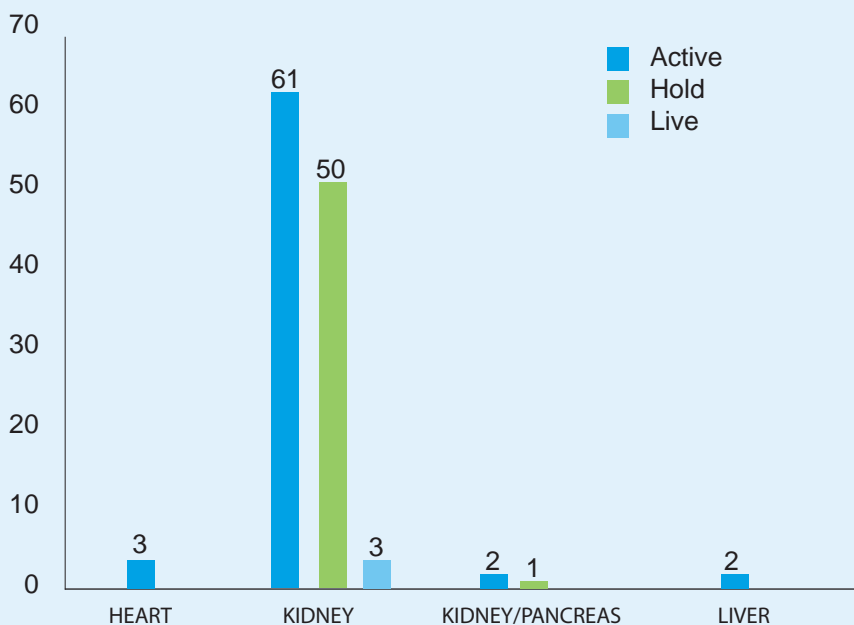
Events will be held in the greater Moncton area including the Moncton Stadium and l'Université de Moncton. Contact 2014 Canadian Transplant Games co-chair Monique McTiernan-Black at mctblack@hotmail.com for more information. Registration forms will be available online at the Canadian Transplant Association's website: www.organ-donation-works.org ■

STATS

Multi-Organ Transplant Program Waitlist

From January 1 to September 1, 2013 the Multi-Organ Transplant Program (MOTP) completed 86 transplants; 45 were performed for Nova Scotians. There are a total of 122 Nova Scotians waiting to receive a transplant. The graph below depicts the MOTP waitlist numbers for solid organ transplant by organ. Criteria exist for each organ that potential recipients must satisfy in order to get on a waitlist. The waiting period varies from months to years, depending on several factors including general health, blood type, immune system, and organ availability. Patients requiring kidney transplants are encouraged to discuss live donation. This involves receiving a healthy kidney from someone who is willing to donate and is an appropriate match. The transplant community is grateful to the individuals and families who make the decision to donate organs. If you require more information, please visit the MOTP website: www.motphalifax.net.

Current kidney organ transplant waitlist numbers as of September 01, 2013



PARTNER UPDATES

The IWK Health Centre has an established Centre-wide committee to focus on organ and tissue donation and to ensure families are offered the opportunity to consider donation. The committee has worked on ways to improve referral rates throughout the entire Health Centre in a variety of ways. The committee is comprised of IWK representatives from critical care areas, palliative care and quality, as well as representatives from the Legacy of Life program. They guide the process and highlight the importance of donation for families. As chair of the committee, Grace MacConnell is also on the Legacy of Life Advisory Committee, thus strengthening the link between the IWK

and other donation programs throughout the province.

The committee identifies ways to heighten clinician awareness of organ and tissue donation by improving the clarity of the policies related to end-of-life care, endorsing awareness campaigns, and linking with clinicians who are most likely to be involved in discussions related to donation.

Educational opportunities on end of life care and organ and tissue donation are held regularly within the IWK, and webinars are available for interested parties to view at any time. Initiatives such as increased visibility of the GIVE

and CALL posters have also been part of the strategy to increase awareness of donation.

Due to the low numbers of eligible donors from the IWK, it is extremely important to insure clinicians offer the option to donate in discussion with patient and/or family. The Pediatric Palliative Care Service is the lead on all end-of-life policies within the IWK. Along with the Organ and Tissue Donation Committee, it works to heighten the awareness of organ and tissue donation throughout the Health Centre with the goal of insuring all eligible donors are offered the option of donation. ■

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