

Legacy of Life

Nova Scotia Organ and Tissue
Donation Program



Don de vie

Programme de don d'organes
et de tissus de la Nouvelle-Écosse



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Legacy of Life Program Aims High To Achieve Goals

Surveys shows that an overwhelming majority of Nova Scotians support organ and tissue donation, yet only about half get around to signing the donor form on their Health Card application. Even when the card is signed, some potential donations are missed. The result is that hundreds of Nova Scotians continue to wait for life-saving and life-enhancing organs that could have been available.

The Legacy of Life program seeks to close that gap. Our vision is that every Nova Scotian will know about organ and tissue donation, and will choose to donate. To achieve that goal, the Legacy of Life program, created by the Nova Scotia Department of Health in 2006, focuses on

improving legislation, engaging health professionals, and creating more public awareness.

Organ and Tissue District Resource Nurses in each health district develop and help implement guidelines and policies. They also monitor charts to ensure that patients and their families are offered the opportunity to donate, and to identify any missed donation opportunities. These reviews have provided district health authorities with a wealth of data to help improve donation rates.

An Advisory Council guides the Legacy of Life program. For more information on program activities visit www.legacyoflife.ns.ca

PROFESSIONAL EDUCATION HIGHLIGHTS

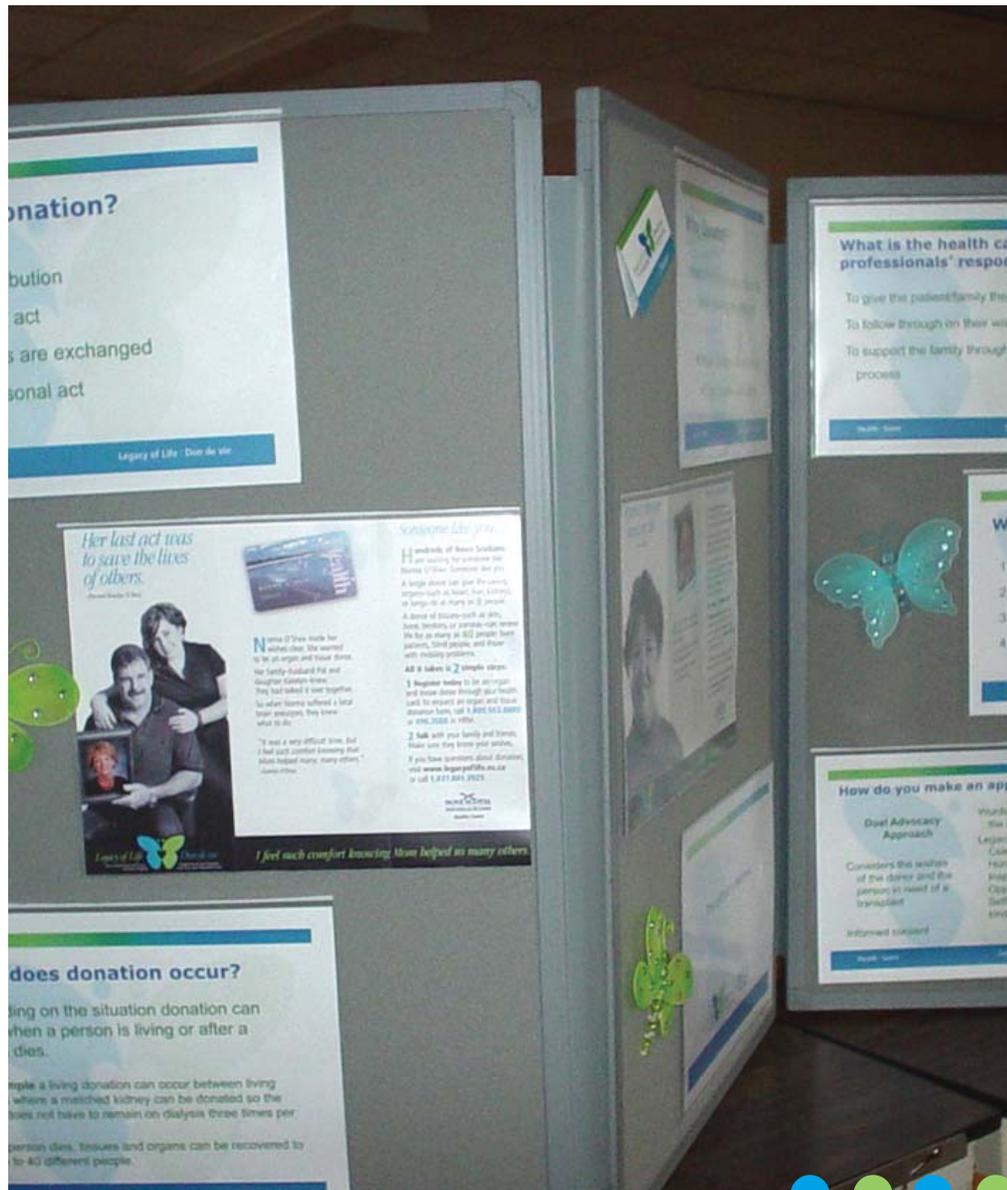
GETTING TO KNOW YOU

The Professional Education Working Group Has Completed Two Complex Tasks

In 2009 Legacy of Life released a document entitled, *Organ and Tissue Donation Process: What Health Professionals Need to Know*. The document explains how to identify and refer organ and tissue donors, how to approach the conversation with families, and how to provide follow-up support for donor families. It also includes information about regulations that govern organ and tissue donation. You can download this document from the Legacy of Life website: www.legacyoffile.org. Copies have also been placed in key hospital areas such as ICU and Emergency Departments.

In March, 2009, the Professional Education Working Group also piloted a workshop in Sydney called, "Offering a Legacy of Life: Meaningful Donation Experiences." The workshop is now ready for use in other districts. The working group has planned a workshop schedule for the coming year.

For more information on the workshop or the document, please contact your local District Resource Nurse. ■



District Resource Nurses

Since 2006, every District Health Authority has had an Organ and Tissue Donation District Resource Nurse position. Most of these nurses work one day a week, but in Cape Breton, the position is full time.

District Nurses work with the Critical Care Donation program in Halifax, where Organ Donor Coordinators and Tissue Bank Specialists are on call 24 hours a day to help with referrals of organ and tissue donors throughout the province. The District Resource Nurses help implement guidelines and standards, educate health professionals, and monitor compliance.

A key part of their role is to ensure that all health providers know how to access available staff. The "District News" section of this newsletter includes more information about local activities.

Using tools developed by the Legacy of Life Program, Organ and Tissue Donation Resource Nurses have put together eye catching poster presentations for conferences, to help spread the word about organ and tissue donation. This poster was displayed at the Provincial Palliative Care Conference in May 2009, which drew about 175 participants from around Nova Scotia. ■

Cape Breton Team Raises Awareness About Organ And Tissue Donation



From left to right: Johnny Bernard, Native Liaison; Elaine Evely, VP New Waterford and Glace Bay Hospitals; Sandra Morrison, Pastoral Care; Janet Evans, Resource Nurse; Anne MacIntyre, Quality Control; Deanna Steiger, Respiratory Therapist; Kerri MacDonald, ICU RN; Murdeena Moore, ER Clinical Nurse Lead; Cathy Schella, Social work. *Missing from photo:* Debbie Conrad, ICU Clinical Nurse Lead; Debbie Lieve, ER Manager Inverness Hospital; Dr. Rick Bedard, Cardiologist; Dr. Dave Brake, Intensivist; Dr. Art Coakley, ER Physician.

A multidisciplinary Cape Breton Team is raising awareness within their work environments by taking part in an Atlantic Organ Donor Collaborative organized by Canadian Blood Services. The team is comprised of clinical nurse leaders, social work, respiratory therapy, pastoral care, native liaison representative, quality control nurse, physicians, and the Organ and Tissue Donation Resource Nurse.

Their goal over the next year is to improve the quality of life and end of life care by implementing a Best Practice Model for

Organ and Tissue Donation that results in a 100% identification and referral of all potential organ donors and a 100% increase in referrals for tissue donation in the CBDHA by June 2010.

The first step in raising awareness about organ and tissue donation is to create an organ and tissue donation organizational presence in the district. The team plans to conduct several change concepts such as to identify and educate clinical champions in their work areas. To utilize provincial guidelines and create the expectation that

all deaths and impending deaths should be screened for potential tissue donation. Several workshops will be facilitated by the team on how to approach potential donor families, in the upcoming fall season. In addition, the team will organize a winter clinical day for frontline staff presenting several different topics surrounding organ and tissue donation.

Team CB moto is “Just make the call”.

The next year promises to bring many exciting changes to CBDHA. ■

WORKING GROUP UPDATES

Since the Legacy of Life Program began in 2006, four groups have been working on activities to help achieve the vision that everyone in Nova Scotia will know about organ and tissue donation, and will choose to donate.

The Legislative Working Group has completed much of the background work required to update the Human Tissue Gift Act legislation, which has not been revised since 1991.

The Communications Working Group has revised the organ and tissue brochure that accompanies health card renewal forms. This pamphlet is given to everyone who signs up for, or renews, a health card in Nova Scotia. It provides a critical opportunity to get Nova Scotians to sign their card. The new, simpler brochure focuses on two actions: sign your card, and talk with your family. Both steps are key to increasing donation rates. The communications group also developed our website, www.legacyoflife.ns.ca, and

implemented a public awareness campaign to raise the profile of organ and tissue donation in Nova Scotia.

The Donor Family Working Group produced recommendations to ensure that donor families receive appropriate information and respectful treatment throughout the donation process.

The activities of the Professional Education Working Group are detailed in the Professional Education Highlights in this Newsletter. ■

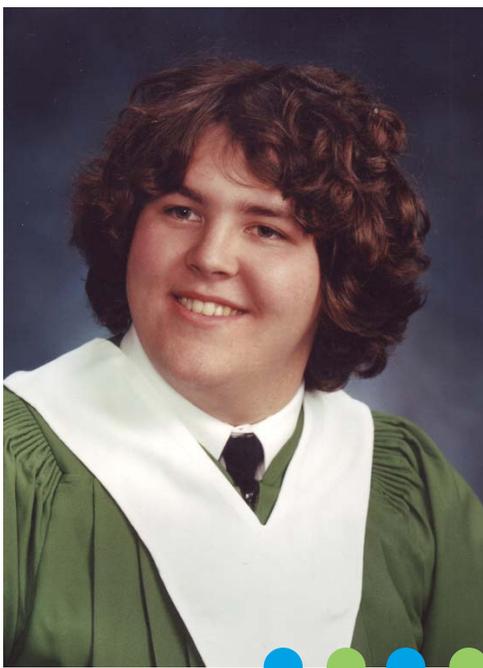
NATIONAL PERSPECTIVE

The Canadian Council for Donation and Transplantation, begun in 2003, has now become part of the of Canadian Blood Services — Organs and Tissues Division. Approved in 2008, this transition represents a major step to improve organ and tissue donation and transplantation within Canada. Over the next several years, after consulting with stakeholders across the country, CBS will pilot test registries and collaborate on the design of a renewed organ and tissue donation system to better meet the needs of Canadians. ■

KUDOS CORNER

Over the last year, the Cape Breton Regional Hospital has made great strides in referrals for organ and tissue donation. In past years, referrals from the hospital had lagged. The appointment of a full-time organ and tissue donation resource nurse has led to new education programs and the development of new policies and procedures. The result is a dramatic improvement. There were no organ donor referrals from CBDHA in 2006; one in 2007, none in 2008, and already seven referrals in 2009, with three actual donors. Tissue referrals have increased as well with two referrals in 2006, five in 2007, eighteen in 2008 and 21 to date in 2009. This indicates that more staff are thinking about organ and tissue donation, and making referrals that give families the opportunity to donate. ■

DONOR FAMILY RECOGNITION



Simon's Gift

Our story began in September, 2004, when we received a call that our youngest son Simon had collapsed with a ruptured brain aneurysm. This is every family's worst nightmare, and so it was for us.

From the time he could walk, Simon was always a helper. He dropped in daily to visit his grandparents, see what chores needed doing, fill the wood box, and raid the cookies. He loved to play guitar, fish, tie flies, cook, and take part in 18th century re-enactment. He loved seeing his cousins at big family parties. At 6 feet, 4 inches, he was known as the friendly giant. Simon had just started a community college course and was living in the city.

After racing to Halifax, we learned that our son would not survive. At this point, we asked about organ and tissue donation. We kept thinking, "Please do not let all these

healthy organs and tissues go to waste. Let some good come from this nightmare."

Thankfully, Simon met the medical and legal criteria for organ and tissue donation. The Critical Care Donation Coordinator and physician explained the procedures and answered our questions. Because our family had taken the time to discuss donation, the decision to donate our son's organ and tissues was clear. Both our boys had told us they would want to be donors in the event that nothing more could be done for them. Simon had also signed his health card.

Our large extended families supported our decision. We have been amazed and comforted to learn that our son changed the lives of five organ recipients, a cornea recipient, a burn patient, and more than 30 other tissue recipients. Some of these people may have been on a waiting list for years, but now they are able to live full and productive lives due to our son's generosity.

I often think about Simon's impact on so many lives! As a result of his gift, we continue to educate friends, neighbors, and family about the importance of taking the time to sit down with your loved ones, make decisions, and sign the organ donor consent on the health card application. Even as we went through the terrible loss of our son, we have been fortunate to know that he lives on in so many other people. That is truly a special legacy of his life.

Pat deMolitor, Donor Mom. ■

DID You Know?

Each year, several organizations join forces to recognize organ and tissue donors and families. The annual “Gift of Life” ceremony is organized by Capital Health’s Critical Care Donation program, with the support of the Regional Tissue Bank, the Legacy of Life Program, and the Multi-Organ Transplant Program. It offers a day to reflect upon the generosity that donors have shown to people in need of life-saving and life-enhancing transplants.

Guest speakers describe some of the feelings and benefits that have come from organ donation. This is not an easy task. Many people find it hard to express in words what this wondrous gift has meant to them and their families. Each family at the ceremony receives a beautiful medallion to recognize this outstanding contribution to society. The day is somber, yet inspirational. ■



Fran Calnan, Legacy of Life administrative support

INNOVATIVE IDEAS

A simple acronym, developed in New Brunswick and adapted for use on fingertip cards in Nova Scotia, is helping clinical caregivers keep organ and tissue donation top of mind. The G.I.V.E. acronym identifies four clinical triggers that remind healthcare providers in emergency and intensive care units when someone may be a potential organ donor.

G stands for Glasgow Coma Scale less than 5. GCS is a standard tool for assessing neurological state, in particular, consciousness.

I stands for intubated. For a person to be a potential organ donor, they need to be intubated and ventilated.

V stands for ventilated.

E stands for end of life discussion.

Whenever someone has a severe head injury, a devastating stroke, or an anoxic brain injury, they should be evaluated for their potential as an organ donor. In high-pressure, emergency medical situations, this sometimes gets overlooked. By wearing GIVE fingertip card on their name badges, health care staff are constantly reminded of the clinical triggers, and more likely to bring up the topic of organ donation in appropriate situations. ■

STATS

There is a big gap between the number of organ and tissue donors, and the number of people waiting for life-saving or life-enhancing transplants. About 130 Nova Scotians are awaiting organ transplants, and thousands of tissue donations are needed annually. The Nova Scotia Legacy

of Life program seeks to improve the identification and referral of organ and tissue donors.

The following table provides statistics for Nova Scotia for the past three years:

	2006	2007	2008
Number of organ donor referrals	41	40	44
Number of actual organ donors	19	15	16
Number of tissue donation referrals	181	158	189
Number of actual tissue donors	112	96	98

PARTNER UPDATES



Sean Margueratt
RTB Manager

The Regional Tissue Bank is one of Canada's premier tissue banks. We offer the Maritime Provinces comprehensive tissue banking services and distribute safe, high quality tissue allografts to every province in Canada.

Maritime generosity and strong belief in

sharing the gift of donation to improve and save the lives of others makes our service possible. Together, we provide a gift that goes beyond our own mortality.

We are honored to serve our communities. ■

The District Health Authorities are key partners with the Legacy of Life Program. The districts provide service directly to patients in their care, and understand the importance of meeting the health needs of their citizens. All districts have patients awaiting organ transplantation as well as many patients who benefit from tissue transplants. As a provincial program of the Nova Scotia Department of Health Legacy of Life promotes standards, recommends service delivery models, provides professional education and monitors standards implementation. Through a Memorandum of Understanding, districts 1- 8 and the program work together to ensure that all potential organ and tissue donors are referred. The work of the other

districts to identify and refer potential donors supports and enhances the work of Capital Health's programs including the Critical Care Donation Program, the Regional Tissue Bank and the Multi-Organ Transplant Program. With staff on call 24/7 to respond to organ and tissue referrals, Capital Health is a key stakeholder and partner.

The District Resource Nurses represent the Legacy of Life Program at the district level and are employees of their DHAs. They play a critical role in ensuring that the goals and objectives of the provincial program are met. ■

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