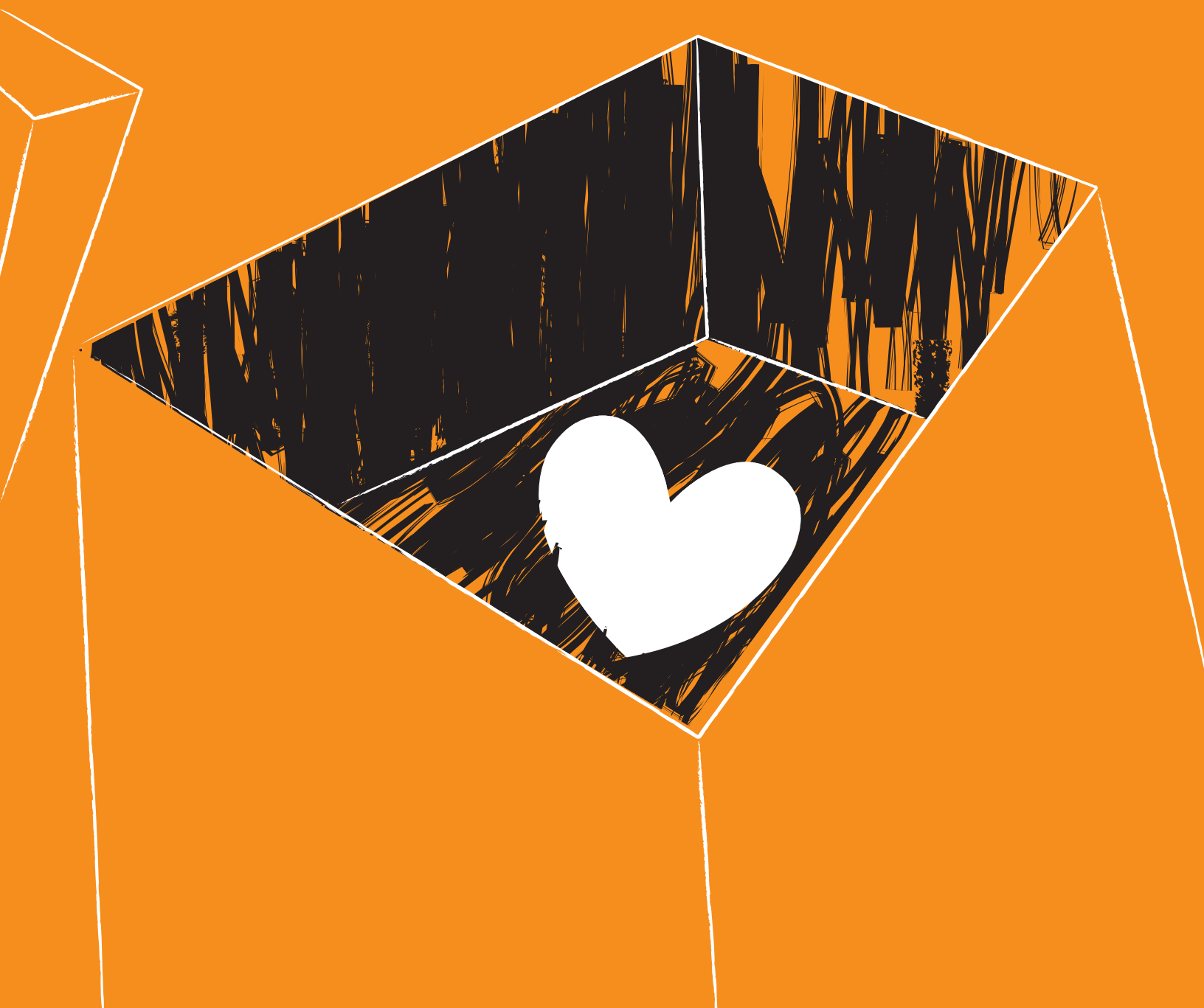
# CHANGE OF HEART

## THE EDDIE SABAT STORY

Eddie

*One Life…Many Gifts* is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.



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# I have an idea now of how it feels to be ‘normal’ again:

## Eddie Sabat’s story.

Even the diagnosis is
hard to pronounce:
hypertrophic
cardiomyopathy.
If all those polysyllables
sound like a description
of a strange illness in a
science fiction fantasy,
living with the disease
is an incredible challenge
in a very real,
earthbound world.

Hyper-'trō-fik 'kärd-ē-ō-(ı)mī-'äp-ə-thē is a medical condition. If you have it, the muscle of your heart thickens; the inner cavity becomes smaller, and the heart doesn't pump as much blood as your body needs to function properly. When you have cardiomyopathy, you are exhausted every day, all day, and all night too. If that weren't enough to accept, there is also a very real risk of sudden death. As the heart muscle thickens, the ability of electrical pulses to travel to the pumping chamber – the left ventricle – is impaired. Sometimes, the pulses cannot travel at all, and you die. **End of story.**

Eddie Sabat had **hypertrophic cardiomyopathy**, but his story has a much happier ending. It is an oft-repeated cliché that *you just never know.* For Eddie, that overused phrase describes his life. He had a pain in his appendix, was rushed to the hospital by his dad, wheeled into an operating room and had his appendix removed. So far, so good. In the recovery room, doctors noticed a heart murmur and referred him to a cardiologist. Eddie wasn't the least bit worried; doctors told him that it could be nothing to worry about, just a minor detail that wouldn't affect him in any meaningful way. Life continued. Eddie continued his senior year in high school, and kept playing his favourite sports – soccer and hockey. He wasn't experiencing any significant symptoms although, in retrospect, Eddie realizes his body was trying to adjust to his decreased cardio capacity.

For most people, the condition is congenital but – in Eddie's case – there was no clear reason for his heart problem.

At his annual checkup, Eddie's doctor prescribed heart medication. Like many teenagers, Eddie felt invincible, and wasn't very diligent about taking his pills. The following year, the cardiologist suggested a heart biopsy. Eddie's illness was a bit of a mystery. He had no history of heart disease. There was a theory that a virus might have affected his heart early in his teenage years. For most people, the condition is congenital but, in Eddie's case, there was no clear reason for his heart problem. Blood work was inconclusive. His physical exam revealed no secrets. A heart **biopsy** was the next logical step.

The procedure is done while the patient is awake. A local anaesthetic is applied to the neck area. A catheter snakes its way through a main artery and down into the heart. Tiny pieces of heart muscle are retrieved with a tiny clip, and brought back through the body for examination. For Eddie, there was no pain, although he was certainly aware of something travelling through his body: "What you feel is a kind of flushing, but you can't tell exactly where the catheter is inside of you. Most of the pain is in the needle and the initial puncturing. Once your neck is frozen, it is more of a pressure than a pain."

Finally, the proverbial penny dropped. The heart biopsy confirmed their suspicions from previous tests, including an ultrasound. Doctors now knew that there could be a serious problem with his heart. Eddie started to look on the Internet to find out exactly what was happening to his body. Both of Eddie's parents were frustrated and afraid, but they realized it was silly to sit in intellectual darkness, and speculate about Eddie's condition – with the Internet as a primary source of information. The family went to a cardiologist at Women's College Hospital; Eddie's dad asked where the heart doctor would send his own son. Answer: Mount Sinai first for pre-treatment care, with a transfer to the Toronto General for any necessary heart surgery; the two hospitals share medical staff. The family couldn't have been more pleased: "As soon as we met the doctors at Mount Sinai, they inspired total confidence in us. We had the utmost faith in the medical team; we knew we were in good hands."

Two years had passed since Eddie started on his medical mystery tour. He was diagnosed at 19 and referred for a biopsy when he was 21. The final step was an electrical physiology study – a test that would show how well electricity was travelling through his heart. Immediately following the test, Eddie

was admitted to hospital for emergency surgery. He wasn't allowed to go home; they wouldn't let him leave until a pacemaker was implanted. A solution seemed to be hours away.

What was supposed to be the happy ending quickly morphed into a potentially tragic outcome. Eddie's heart stopped during the implantation of the pacemaker. Eddie remembers waking up momentarily in the operating room. He saw a doctor on top of him, pumping his heart. Then he passed out again. "I remember it all happening, and not remembering it at the same time. I was sedated, so it is kind of a blur."

Temporarily, the pacemaker helped. He shifted from playing the game he loved so much – hockey – to coaching hockey. Because Eddie had gained a significant amount of weight, his doctor at Mount Sinai Hospital referred him to a cardiac rehabilitation program. It helped a bit. Initially, the exercise strengthened him, and motivated him to lose some weight. But the situation started to deteriorate again. Eddie couldn't finish his exercise prescription from the rehab centre. His doctor ordered another round of tests. The medications Eddie had been taking were not working. Walking became a real challenge. "I was always short of breath." The hospital decided to try a new kind of bi-ventricular pacemaker. Eddie knew from the beginning that the **pacemaker** was going to be a bridge, a temporary solution to help him feel better. Ultimately, he was going to have to return to the hospital, and get a new heart. In the short term, Eddie was grateful for a chance to breathe easier and to walk without difficulty. He agreed to the 45-minute operation.

What started out as a procedure that should have been completed in less than an hour became a four-hour marathon. The surgeons couldn't get the pacemaker into the left side of Eddie's heart because of the way his body was structured. His surgeon was very upset. His doctor remained calm: "Eddie, I told you it would only be an interim measure. We have to look at the heart transplant option a little sooner."

Eddie subjected himself to more tests at the Toronto General and met with the transplant coordinator, a cardiac surgeon, a social worker and a psychologist; they all wanted to make sure Eddie knew what was happening. Eddie was placed on a waiting list for a new heart on January 21, 2003. From that moment, he was *on call*. He had to stay within the Toronto city limits at all times, and he had to be able to get to the hospital within two hours after his pager signalled a heart was available. People usually wait four to six months for a call, sometimes longer. Eddie's new heart became available in less than two weeks after he was placed on the list.

The phone rang at 11.30 p.m. Eddie assumed it was his girlfriend, and waved the call away: "I was always tired, so I was always sleeping. I didn't want to talk to anyone." But this call wasn't just *any* telephone message; it was the heart transplant coordinator, telling him to get downtown immediately. Eddie freaked: "Are you kidding? I'm not ready. What if I miss my one and only chance?" Knowing time was precious, Eddie moved into ultra-rush mode. He woke up his mom, his brothers and his dad. His girlfriend arrived. His brother's girlfriend raced over to the house. The cavalcade drove down to the hospital.

# Eddie's heart stopped during the implantation of the pacemaker.

Eddie was whisked into the Cardiac Vascular Intensive Care Unit and prepped for surgery. Then everyone had to wait. His new heart was on its way from another city in Ontario, landing at the Toronto Island airport.

Surgery took five and a half hours; then the surgeons felt ready to manually jump-start the new heart and hope it worked. It did! In what can only be understood as a complete understatement, Eddie says, "That was a huge moment right there." As a precaution, Eddie was placed on an external pacemaker although his new heart was working very well all by itself. He was heavily sedated. Medications were pumped into him through an IV; counting all the various drips, he had six poles, with three or four medications on each one. Eddie doesn't remember much, even from the second day. Then the nurse arrived. She wanted Eddie out of bed. He didn't want to get up, and he definitely did **not** want to walk around his hospital room. The nurse persisted, even suggesting that he might want to walk around the entire floor of the hospital. Eddie knew that the walking was crucial for his recovery. Eddie got up. He walked.

Free of sedatives and more fully conscious of the hospital surroundings, Eddie realized that he was alive, and that his donated heart was working. *Amazing*. Eddie barely had time to be happy when he realized that his stomach was swelling up. Nothing would make it go down. Doctors discovered that Eddie had adhesions in his small bowel; he had to have six inches of his small bowel removed immediately.

All the other transplant patients went home. Eddie stayed, giving his body time to recover from his second surgery.

Two weeks after the transplant, Eddie started to feel better. Then the doctors checked his lungs, just part of a routine physical. Oh, oh. There were bacteria in his right lung; there was also fluid in his lungs. Immediately, Eddie was wheeled back into the operating room. When he woke up, "I had chest tubes galore. At one point, I had four chest tubes to help drain the fluid. The chest tubes caused excruciating pain. I had terrible problems trying to get comfortable enough to rest. Basically, sleeping wasn't on the agenda."

Over the next couple of weeks, doctors withdrew one tube after another until there weren't any tubes left. "Then I started to feel good. I thought, 'This feels great.'" Most patients are discharged after nine or ten days. Eddie's stay in the Cardiac Vascular Intensive Care Unit, over to the transplant floor, and down to a regular cardiac floor took one and a half months, from February 5th to March 15th. Finally, he was allowed to go home. His doctor was there to say good-bye: "You're fired as my patient. On an ongoing basis, you're going to be looked after by Dr. Heather Ross and her team."

Eddie's *good-bye* to the physician with whom he started the journey was short-lived. New infections started in his body. For an ordinary person, winter is a time of flu bugs and fevers. For a transplant patient,

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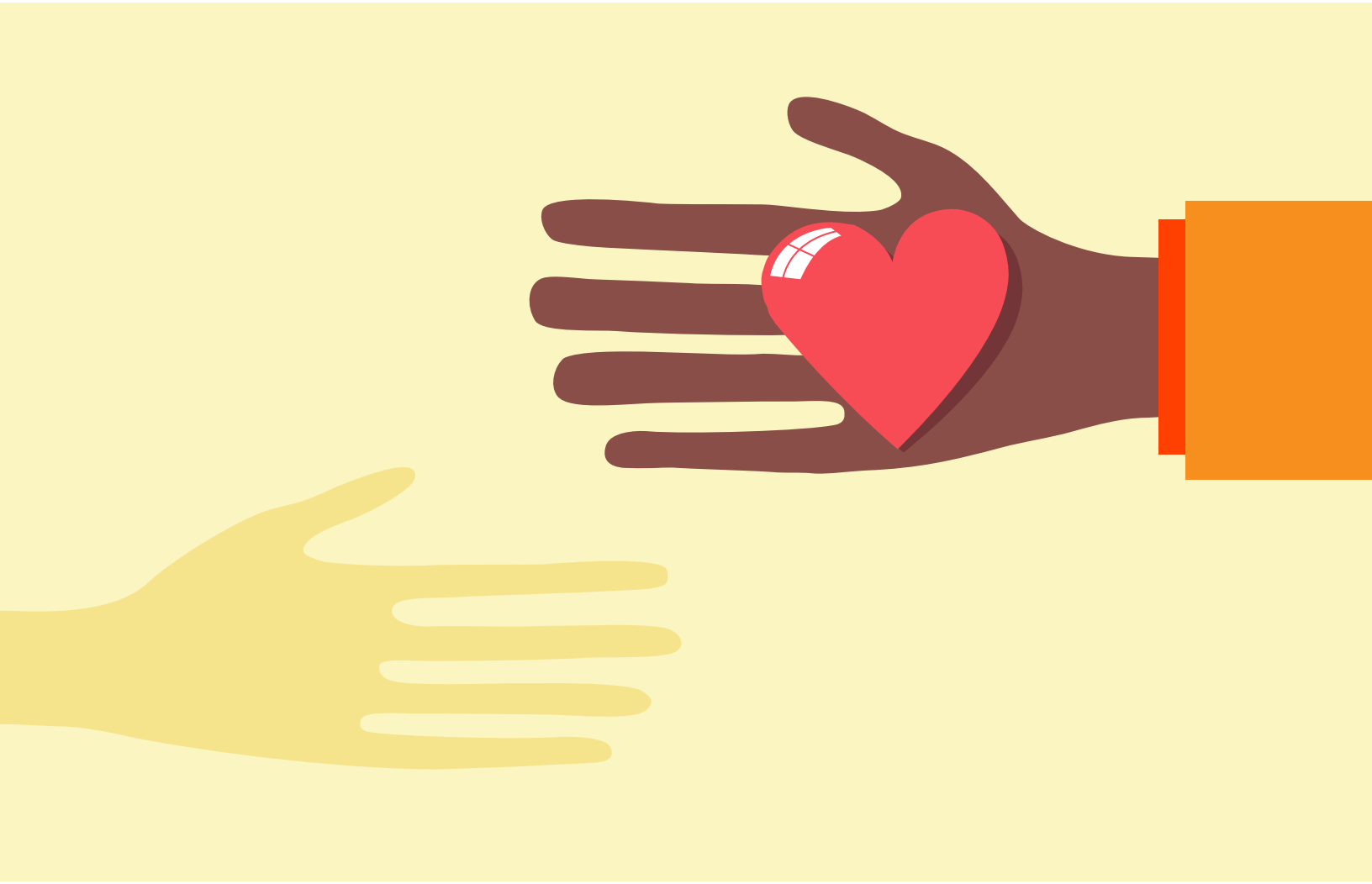


infection is a life-threatening complication. Transplant patients have to take **immunosuppressive** drugs to make sure their bodies don't reject the donated organ. That's the *up* side. The *down* side is that the necessary suppression drugs compromise a patient's immune system. Just to complicate an already traumatic circumstance, Toronto was hit by **SARS**. Eddie's hospital room was sealed off. No visitors were allowed. The whole floor remained in isolation for weeks. Before SARS, Eddie had family and friends coming to visit constantly; one of his friends even started a social calendar. Right after his transplant surgery, Eddie had had visitors all day and all night. Now he was alone, completely. The only people who entered his room were medical personnel – all wrapped up, with hats on their heads, masks on their faces and boots on their feet. Even their hands were covered with gloves.

Eddie broke down: "I was extremely scared of what would happen. I worried that my heart would stop working. I was afraid that it would start rejecting, and I would die." After SARS, a psychologist visited and assured Eddie that he could call her at any time. The transplant nurses also visited, and answered all of Eddie's questions. They also helped to allay his fears: "It makes a difference, just to know that you're not by yourself. The hospital also gave me a mentor, a person who has had the same operation. That's helpful; at least you can speak with a person who has survived. My mentor, a young woman who also had a heart transplant, was able to help with the fears I had, but she couldn't completely eliminate them. No one could. The heart is the most important organ. If it fails, you die."

Before his heart transplant and before his stomach surgery, Eddie was really scared. Still, "I felt things were going my way. So, just as I was being wheeled down the hall for my second surgery, I said to Nancy, my girlfriend, 'When I come through this, I want to get married.'" Afterwards, Nancy wondered if he was joking. He wasn't. Eddie went out, got a ring and proposed. He was married in 2004, and now has a baby girl, Gabriella.

Dr. Heather Ross and Dale Shippam in Antarctica

Yanick Rose

Eddie isn't naïve. He knows that someone who has to take up to 60 pills a day isn't the same as everyone else. Some days, he forgets that he is a heart transplant recipient. The first action he took after his hospital discharge was to think about writing a thank you to the donor family. It took him six months to find the right words: "How do you say thank you to people who have lost their loved one? I tried to find the right language for my letter. I hope the donor family found some peace in knowing that their loss allowed me to live. They might also find comfort in knowing I am trying to make the most of this wonderful gift."

Today, Eddie participates in the World Transplant Games, an occasion when transplant recipients get together and do Olympic-style events. Eddie's personal goal was to participate in a run. He did it, all 5K, and he completed it. Now, he works out five days a week, and eats well – all to protect his gift of health. He also works full time; the heart transplant freed him from worrying about his personal mortality. As a financial adviser, he helps other people address their monetary fears. As is always the case, health is the most important gift – as Eddie well knows.

Eddie's cardiologist Dr. Heather Ross has discovered that a vast majority of heart transplant patients recover from surgery, and embrace life more intensely than they have ever done before: "They just put it all out there." Dr. Ross works hard to dispel the myth that heart transplant patients can't have rewarding and active lives after their surgeries. She encourages her patients like Eddie to pursue their goals and live life to its fullest.

On December 18, 2006, she personally demonstrated her outlook when she and one of her heart transplant patients, Dale Shippam, joined four others to climb the 4,892-metre Mt. Vinson Massif in Antarctica.

Not all stories have a happy ending. Sometimes a person gets a new heart, and then dies. There is no question that the clock is always ticking; that is why Toronto General Hospital created a support group called *Heart Links*. It connects heart transplant patients and staff with each other, for information and mutual support. In the background of each meeting, there is always the unspoken question: "What might be coming in the future?" That inquiry is not unique to heart transplant patients. It is a question mark we all face. What her professional life has done for Ross is to remind her that "life is short, life is precious and you just never know." That is why Ross packs up her patients, gets them into gear and jets off to Antarctica and other exotic destinations.

Eddie has final words for the people who are reading his story: "Register your consent to donate. And talk to your family. Let them know what you want because they can override your wishes. You could save someone's life, just as mine was saved. Now, my life is normal, just as it was when I was a child. You wake up and you can breathe, play, work, love, have a family – ordinary take-it-for-granted activities for many people – but not for me. My life is a gift. I have had two gifts, one when I was born and another when a donor family decided I could have a second chance to live. I don't forget that, ever. And I don't forget the docs who pulled me through and made my life possible."

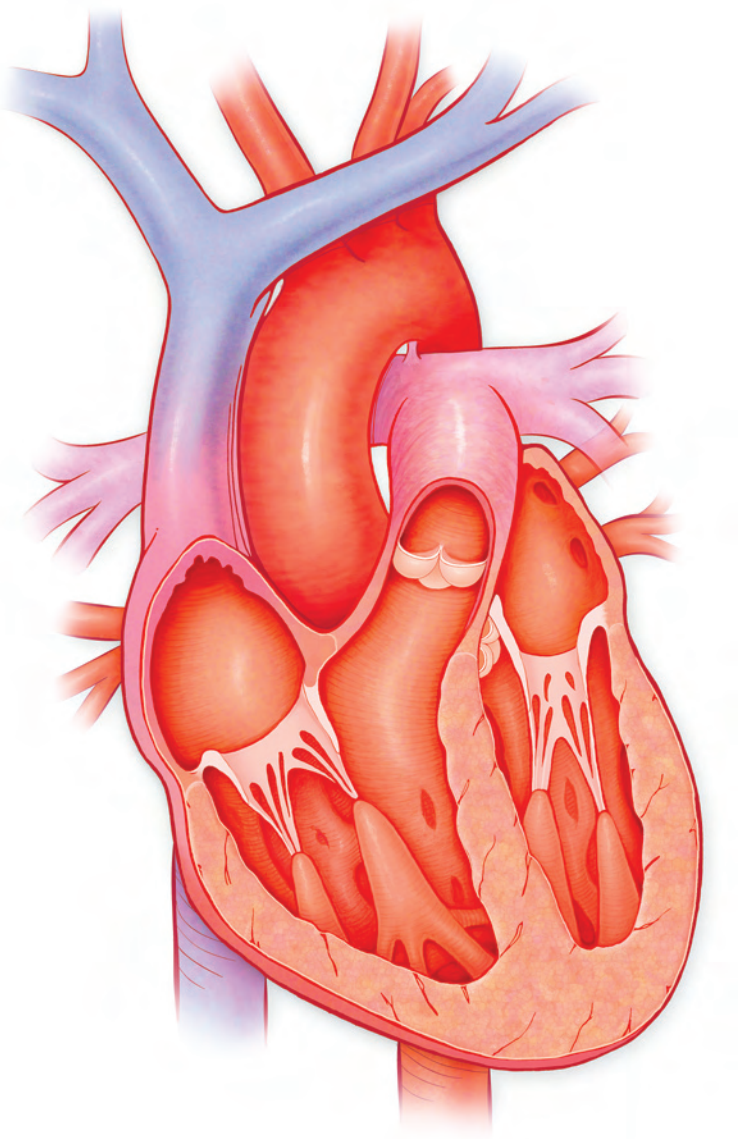
# The Heart: Your Lifelong Partner

The heart is, first and foremost, a muscle and a pump about the size of a closed fist. It weighs between 200 to 425 grams, 7 to 10 ounces. When your heart beats, the muscular walls of the heart contract to pump blood. Your blood circulates around the body, carrying oxygen from the lungs, nutrients from food and hormones to your cells.

The heart is divided into two halves and four chambers – the right and left atrium and the right and left ventricle. The right side receives oxygen-poor blood from the tissues and pumps it into the lungs to collect oxygen. The left atrium receives oxygen-rich blood from the lungs, and the left ventricle pumps the oxygen and sugar-rich blood from the heart to all parts of the body through a network of arteries, arterioles and capillaries. A wall of muscle, the septum, separates the left and right atria and the left and right ventricles. The left ventricle is the largest and strongest chamber in the heart.

When the heart is resting, it beats approximately 70 times every 60 seconds. The number of times a heart beats each minute determines a person's heart rate. Of course, when we exercise, the heart beats faster to supply muscles with more oxygen and sugar – the fuel that muscles require to work more strenuously. Within a 24-hour period, 7,200 litres of blood travel around the body. Over a lifetime, your heart will beat more than 2.5 billion times.

If you were to unravel all of your blood vessels, they would reach around the earth four times, a total of 100,000 miles or 160,000 kilometres.



Lauren Shavell

*(Information about the heart has been obtained from the books:* Human Body: A Visual Guide and Body, An Amazing Tour of Human Anatomy *and from the* Heart and Stroke Foundation of Canada. *Both books are included in the annotated bibliography.)*

# Over to you...

## A. DISCOVER NEW TERMS

There are five medical terms included in Eddie Sabat's story that are presented to the reader in bold. Use the glossary included within the resource materials to discover each of their meanings. Jot down the descriptions of the words, and remember their definitions. You may already know a few of the words; the rest will be new to you, and you will probably meet them again in newspaper and magazine articles. Heart transplants are no longer revolutionary; in the Province of Ontario, there are more than 75 heart transplants performed each year.

## B. RESEARCH

You have probably heard someone say, "He pulls my heartstrings." We actually have fibrous cords called heartstrings. In medical terms, they are called the "chordae tendineae." Investigate where they are and what they do. Prepare a brief presentation to explain in simple terms what heartstrings do in our bodies. You can write a short report, create a poster or draw a labelled illustration.

## C. CREATE AN ARTISTIC REPRESENTATION

Although there are now six different organs that can be transplanted from living or deceased donors into the bodies of people who have failing organs, none has more emotional resonance than the heart. Throughout human history, the heart has occupied a special place in the human imagination.

There are hundreds of songs, poems, paintings, sculptures and photographs that celebrate the heart and its place in our psyche. We even dedicate one day each year to sending notes, cards and tokens of love to the people who occupy a special place in our heart – Valentine's Day.

The heart is also part of our daily vocabulary: we say that a friend is *heartsick* after a bad breakup; we even hear reports that someone died of a *broken heart*. On occasions when we hear a particularly moving speech, we say that it was *heartfelt*. If people are behaving badly, we immediately claim that the calculating, cold person under discussion has a *heart of stone*, or no heart at all.

You have probably had many different emotional experiences you connect with the heart – with special vocal artists or with a special love. Not all heart connections are good ones; we have had our feelings hurt, and our hearts battered or broken.

Create a three-dimensional heart, with all of its chambers. You can use a combination of digital photographs, clip art, Internet or magazine images, computer animation or downloads from websites. Add your own materials – beads, buttons, marker graffiti, sound loops from your MP3 player and/or synthesized music.

Write notes on your heart, using old Valentine cards or phrases from a song or poem. Any scientific or artistic expression is valid. Your task is to utilize a myriad of images, sounds and words to make a personal statement about the heart. Include a persuasive statement on the importance of heart transplants as lifesavers and how people can make their donation wishes known and honoured.

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When you have finished, working either by yourself or with a partner, create a classroom and/or library display of the various *heartfelt* creations.

Share the thinking that informed your choice of images, words and sounds, leading you through the process of creating your heart.

Prepare an artist's statement about your work. Limit yourself to two or three paragraphs. Place the statement under the sculpture so that viewers can read your artistic intention.

**Optional:**
Ask two or three videographers in the class to record the collective comments of class members; make sure all of the sculptures are photographed or recorded on video.

Working in small groups of three or four, prepare a short video for a public space – the library or the community centre – in which all of the *heartworks* can be displayed.

## D. RESEARCH PAPER

A good heart is a work of extraordinary beauty and efficiency. Research and write a 1,000-word essay on the ways in which heart transplantation developed in the twentieth century. Do not limit yourself to the present; investigate emerging research that will refine current practices and extend the life of a transplanted heart.

## E. CREATE A TOP TEN LIST

In the medical world, there are a number of factors that are considered indicators of good outcomes: the initial health of the patient before surgery, his or her age at the time of surgery, and a patient's willingness to be compliant with doctors' directions – give up smoking if you are a smoker; take the various medications that will assist the health of the heart, particularly the immunosuppressive drugs because they help the patient accept the new organ; exercise regularly and eat healthily. All of those requests make sense. There are, however, a plethora of subjective factors that also play a large part in a patient's recovery and continued health.

First, make a list of the body/mind connections that you think would influence a person's recovery and continued good health. Work alone or with a partner.

Second, read chapters you find interesting in any one of the following books: *Healing the Planet One Patient at a Time; Eating Well for Optimum Health;* and *The Food Connection. (See bibliography in the Resource Guide for complete descriptions.)*

There are dozens of excellent books in libraries and bookstores that explore the very direct connections between mood and food and emotional and physical health and food.

Third, compare your ideas with the investigations done by scientists and physicians. Did your research present any surprises? If so, share the insights you gleaned from your reading with other members of the class.

Fourth, make a list of the top ten behaviours that will really make a difference to the health of your heart. You can check out the website of the Heart and Stroke Foundation at *www.heartandstroke.com* for some hints.

For Eddie, it is all about undertaking a challenge, meeting it and moving on:

# "I did it."

Over to you...

## F. CREATE A SLOGAN

When you read Eddie Sabat's story, you can completely understand why he is so dedicated to his exercise program. You can also appreciate his desire to participate in the World Transplant Games, even though his heart function does not allow him to be a first- or second-place winner. For Eddie, it is all about undertaking a challenge, meeting it and moving on: "I did it."

Sit in a circle with three or four classmates. Discuss the reasons why – with so much information and opportunities available – many people fail to live a healthy lifestyle. So many people get less sleep than they need, exercise less than they should and make junk food a regular part of their diet. Once you have discussed and identified some of the motivations that lead to these behaviours, choose **one** good habit people could follow to protect their heart health, and prepare a slogan that could enter everyone's mind and become a guide for daily living.

For example, Nike shoes was very successful with its swish mark, inviting everyone to *Just Do It*. Mazda has entered our collective consciousness with its *Zoom, Zoom* car campaign. Even the Milk Marketing Board has captured our attention with its moustache of milk ads. Kleenex is now synonymous with tissues; the object and the brand are interchangeable in our minds. How can you connect a behaviour that is helpful for the heart to a slogan that would immediately capture our attention, recognition and action?

## G. CREATE A PLAN

After his transplant operation, Eddie Sabat is justifiably worried. We can live without an arm, a leg, a spleen or a gall bladder. We can manage without an appendix or tonsils; even one kidney can disappear without causing a serious problem. But we definitely cannot live without a heart.

Become Eddie Sabat in your mind's eye. In addition to the fears he articulates, what additional anxieties would you experience as a heart transplant recipient? Choose a partner. Together, make a list of the worries you would have in Eddie's situation.

Invite two other partners to join you. As a foursome, decide how you could relieve Eddie's ongoing anxiety. What would you need to say or do in order to help him feel comfortable on a day-to-day basis as he returns to work and supports his family? Develop a list of ways you would help Eddie if you were his friends.

It is worth noting, before you begin, that Eddie himself is a real optimist and a fighter. He isn't plagued by feelings of negativity. However, he is also a human being and there are very few medical conditions that can create as much fear as the potential loss of an organ you must have functioning in order to live.

## H. MONOLOGUE

Suppose you are a healthy heart that has been transplanted into a less healthy body than you were in before. Become this heart, imaginatively.

Write a three-paragraph monologue, a first-person narrative to offer advice to the body you now inhabit. When you have finished, join others who have done this activity; form a circle and have each person read his or her monologue.

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*One Life…Many Gifts* is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

Funding for this project has been provided by the provincial Ministry of Education and the Ministry of Health and Long-Term Care. This project would not have been possible without their support or the generosity of an anonymous Ontario resident whose contribution ensures that students in the province understand the life-saving promise of organ and tissue donation and transplantation. The Steering Committee sincerely thanks all of our supporters.

The development of this curriculum has been co-sponsored and coordinated by the Trillium Gift of Life Network, the Multi-Organ Transplant Program at London Health Sciences Centre and The Kidney Foundation of Canada.

Educating secondary school students and their families about the need for organ and tissue donation and the success of transplantation was originally initiated in the London region in 2000. With funding received from The Kidney Foundation of Canada, the Multi-Organ Transplant Program at London Health Sciences Centre had the vision to develop a unit of study, *One Life…Many Gifts*, working with both the Thames Valley District School Board and the London Catholic District School Board. The original program was used in Healthy Active Living Education, Grade 11, Open (PPL30) in Ontario's curriculum. The curriculum resource before you builds on the vision and foundation provided by this original program and the Steering Committee gratefully acknowledges the dedication and pioneering effort of all those involved in the original program.

This curriculum is dedicated to the many Ontarians who have given the gift of life through the donation of organs and tissue and to the many others who will in the future.

For more information on the *One Life…Many Gifts* curriculum program please contact the Director of Communications, Trillium Gift of Life Network at 1-800-263-2833 or visit: www.onelifemanygifts.ca



Medical health-care professionals from the field of organ and tissue donation and transplantation and educational advisors were involved in the development and implementation of the *One Life…Many Gifts* project.

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Trillium Gift of Life Network
Réseau Trillium pour le don de vie

London Health Sciences Centre

The Kidney Foundation of Canada
*The foundation of kidney care.*

# ONE LIFE... MANY GIFTS