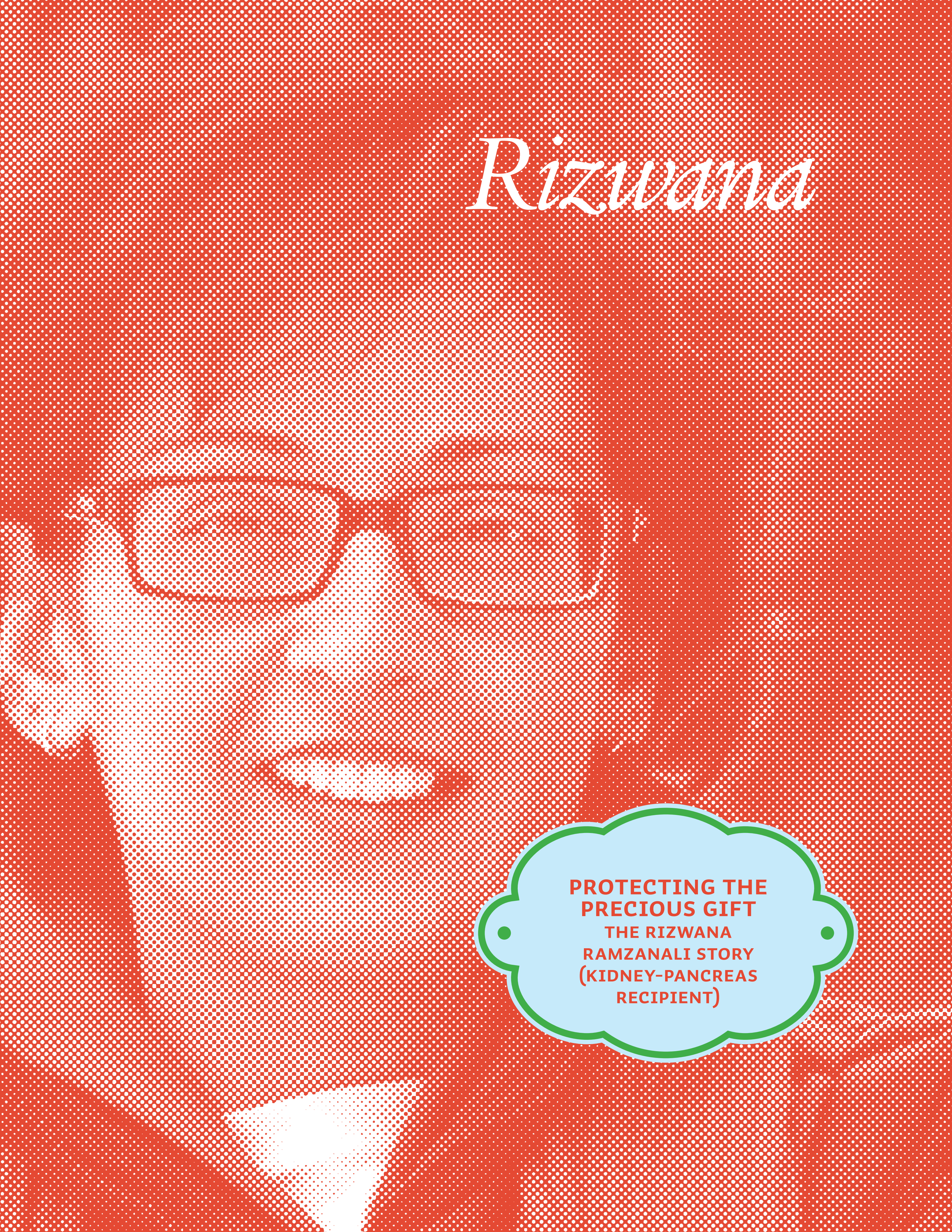
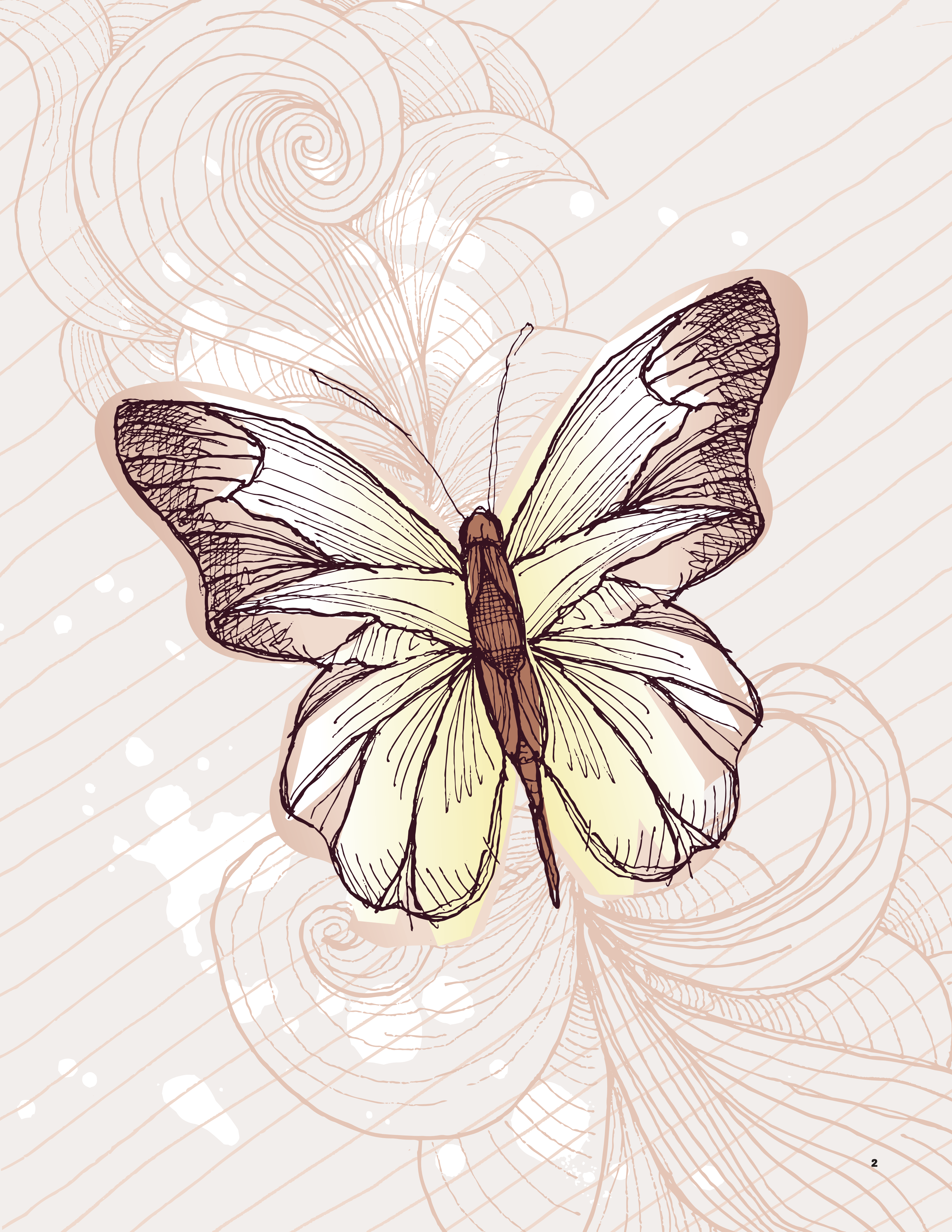


Rizwana

PROTECTING THE PRECIOUS GIFT

THE RIZWANA RAMZANALI STORY (KIDNEY-PANCREAS RECIPIENT)

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.



protecting the precious gift

Rizwana Ramzanali

I WAS BORN IN NAIROBI, KENYA. I was nine years old when I was diagnosed with diabetes. I lost weight. I was thirsty all the time. My skin was looking very yellow, so the doctors thought I might have jaundice. After they did a series of tests, including a whole battery of investigations that were looking at my blood, it was clear that my glucose levels were very high. I dropped to 50 pounds over a six-week period; that was a loss of more than 30 pounds. I had to go to the washroom all the time. It was very embarrassing because I had to pee every 15 minutes. It certainly raised a lot of questions in my class at school. I hated my illness because it meant that I didn't feel like everyone else.

Here, in Canada, it would not be unusual to find a child with Type 1 diabetes, the kind that means your pancreas cannot create any insulin. In Africa, there are a lot of diseases that are even more life-threatening – typhoid, cholera, tuberculosis. After my diagnosis, I had to start taking insulin immediately. Even though diabetes was prevalent on my father's side of the family, I was the only insulin-dependent diabetic. No one had heard of a nine-year-old child with this disease. The needles themselves did not bother me. What upset me is that I was the only one in a large family who had to be very careful about what I ate. We ate lots of rice and potato dishes in spicy curries. If the curry had rice, I had to watch how much rice I ate. If the meal included potatoes, I could choose between pita bread and potatoes. Having both was out of the question. The biggest food loss was ice cream; I really missed ice cream.

I adjusted to everything else in my diabetic program – the needles morning and night. The insulin. I even learned how to do without some of my favourite foods. What I wanted to be, and what I really missed, was the feeling of being normal.

In my early twenties, I developed retinopathy, an eye disease that causes blindness. It is very common among diabetics whose glucose levels are not well managed. For four years, I had laser treatments in an attempt to save the vision in my eyes. It was very frightening. The lasers, which were not very well developed at that time, felt like needles poking into my eyes. My mind was filled with thoughts, thoughts that were all filled with fear: "What will happen if the laser treatments are not successful?" "What if I go blind, and cannot see anything?"

My worries were not totally unfounded. I did lose all of the vision I had on the periphery of my eyes. I had no vision on either side; it was all gone. I could look straight ahead but, if I wanted to see on the side, I had to turn my head. Otherwise, everything was in darkness. That was certainly scary.

I didn't go to movie theatres. I didn't go anywhere that I didn't know well, even during the day. I made a fool of myself a couple of times. I walked into a lamppost because I didn't see it. I walked into doors that I didn't see. I bumped into people. Eventually, I gave up driving because I didn't feel safe for myself or for the people travelling with me. I had always been a very independent person. Now, I was limited, but I didn't give up.

I finished my education and became a Montessori teacher. Gradually, I took on more responsibility, avoided too much paperwork because of my sight, and restricted myself to places in and around the school where I felt comfortable.

I thought my life was now going to be trouble-free. I was wrong.

After my marriage, I became pregnant and spent most of the next few months in bed or in the hospital. My doctor told me I might have an early delivery and he also told me the sex of our baby – a boy. When my son was born at seven months, he was very, very tiny – only one kilogram. I knew he was going to be small, and I knew he was going to be a boy. What I didn't count on was the hair. I was shocked to see so much hair on his head. Junayd, my son, is now 11. If you look at him, you cannot believe he started out about the same size as a small bag of sugar or two pounds of butter.

By the time Junayd was 14 months old, the doctors discovered he had inherited my diabetes; at the same time, I learned that my kidneys were starting to fail. As you know, you cannot live without kidneys because they

> I thought my life was going to be trouble-free. I was wrong.

do so much work in the body. I was struggling with severe migraine headaches. I had a sour taste in my mouth all the time. I was tired and my feet were continually swollen. There is no way to reverse a kidney condition so I learned that I would need dialysis within a relatively short period of time.

I was overwhelmed. Everything was happening at the same time. My husband was closing down one business, starting another, and he was going to be travelling a lot. Initially, the doctors told me that I might have a year to a year and a half before I would have to start dialysis. Three months after that conversation, my kidneys completely failed. I was hospitalized. I had shooting pains in my arm. My chest was hurting. The kidney specialist told me that if I didn't have dialysis within a few hours, I would die. I was very, very sick. I thought I was going to die. At that time, my son was 17 months old. This could be the end. How could I just be starting my life, and leaving it at the same time?

I didn't know anything about kidney failure, but I soon learned. I had to restrict fluid very severely. I underwent dialysis sessions three times a week. In between sessions, I could only have two litres of fluid. That's everything – water, tea and all other beverages – anything that was in liquid form. Two litres. It sounds like a lot, but measure out that much fluid. A litre is nothing. I struggled with that restriction for seven years. It was extremely hard.

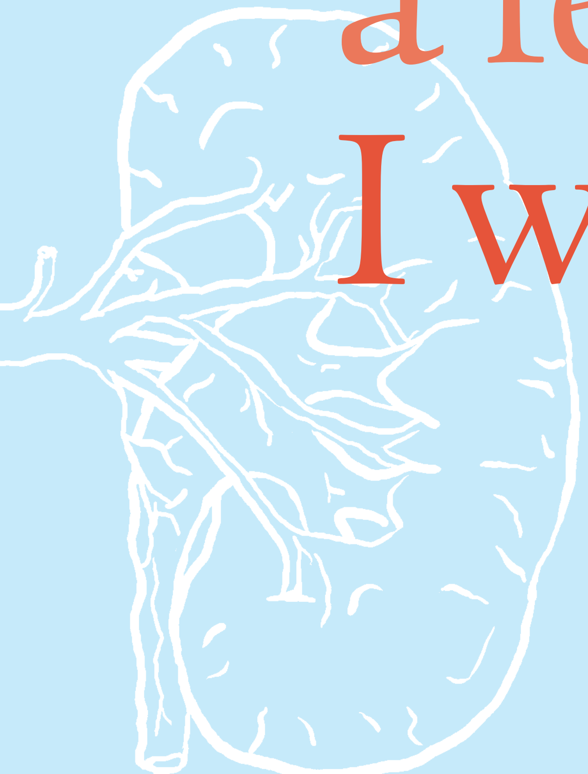
I am of East Indian origin. We eat lots of curries, dishes that are cooked in tomatoes or coconut. These fruits are very high in potassium. Without kidney function, the body cannot rid itself of potassium and that can lead to heart failure. Most of the food I ate was very bland. Everything I liked and enjoyed was spicy. Now, it tasted like nothing, well, nothing that I wanted to eat.

I was on dialysis for almost seven years. My mom decided to be assessed as a donor because, as you know, you can have a kidney from a living donor. Unfortunately, although my mom volunteered to donate a kidney, the doctors decided it would impair her health in the future. It was disappointing for both of us, more for her than for me.

My condition was deteriorating very quickly. I developed hypoglycemic unawareness. When my glucose levels dropped, I didn't feel them. Before, I was able to treat a sugar low quickly by drinking apple juice or eating something sweet. Now, I felt nothing.

Luckily for me, London introduced a kidney and pancreas transplant program. I was selected as a candidate for both a kidney and a pancreas. The transplant team wanted to have one donor for both organs because they thought the match would be better if the two organs came from one person. When you are chosen, you are given a beeper and you are told to keep it with you 24 hours a day. You could be notified at any time, during the day or all through the night.

The kidney specialist told me that if I didn't have dialysis within a few hours I would die.



My aches were gone.

I can remember – to the day, to the minute, when the transplant recipient coordinator called me. It was a Monday, August 10, 2004, at 4.30 in the afternoon. You never forget the date or the time. She called, and told me not to get my hopes up too much because they had to run final tests to confirm the match for blood and tissue type. She promised me that one of the surgeons would call back within an hour. I had been waiting for that moment. When it came, there were a million thoughts going through my mind.

It is hard to believe, but my first thoughts were about my husband and son. I wanted to leave the house organized. I wanted everything to be easy for them to find. I had a bag packed, but I emptied it and repacked it again. Then, I thought about getting groceries. My life was just about to change, and I was trying to figure out what foods we needed in the fridge.

As soon as I arrived at the transplant unit, my family joined me for a short time. After they left, the reality of what was going to happen started to sink in. I was going to be transplanted. My life was going to change. I felt sad for the family who had lost their loved one. Despite their loss, they had chosen to give me the gift of life. I had a million questions about the donor family. I couldn't imagine their grief. To be honest, I also felt guilty. The only reason I was going to have a new life is because they had lost someone who was so important to them.

My operation took five hours. I was taken to the operating room at midnight, and I was in the recovery room the next morning at seven. As I started to come out of the anaesthetic, the energy I felt was very powerful. I felt it all through my body. My aches were gone. I didn't feel that my body was worn out because of the dialysis. That evening I was up, and wobbling all over the transplant unit. I had the nurse walk with me because I was, obviously, very weak and still drugged with the anaesthetic.

I stayed in the hospital for 11 days. They were the best eleven days I have ever spent in hospital. I was really looking forward to going home and having a normal life. And I did just that. But I also found that since my transplant I have become stronger in body and mind.

Every day, I take three kinds of anti-rejection drugs. The only thing I can't do is carry heavy things. I still have my old kidneys and my old pancreas, so the surgeons had to put my new pancreas on the right side of my body, and the kidney on the lower left. I have gained a little weight, so I tell everyone that the reason I am carrying a few more pounds is because I have two extra organs.

You are not allowed to know who donated organs and you cannot be in touch directly with the donor family. But the organ recipient coordinator in London takes the letters and cards I write, and passes them on to the family. My hope is that my correspondence makes it a little bit easier for the donor family. My feeling is that they are heroes. Their decision to donate the organs of their loved one changed my life, and the life of my entire family. For me, there are no more needles, no more insulin and no more dialysis. *I am free.*

While Rizwana is at home, packing her bag and making sure that everything in her home is tidy for her husband and son, the surgeon – Dr. Patrick Luke – is working with his medical team to make sure everything is in order, and ready for Rizwana's arrival at the London Health Sciences Centre, University Hospital.

After Rizwana is registered at Hospital Admitting, she is taken to the transplant floor. A full team of nurses, surgeons and an anaesthesiologist assess her. "We need to make sure that she is healthy enough and fit enough to survive the lengthy operation," cautions Dr. Luke. "It takes between four and six hours to transplant both a pancreas and a kidney."

In the operating room, there is a surgical team, two nurses and an anaesthesiologist. There is always total cooperation between the transplant surgeons: "Sometimes Dr. Vivian McAlister works with me and we operate together. Every attempt is made to coordinate our efforts for maximum efficiency."

The surgeon places the two new organs (kidney and pancreas) in the right and left lower abdomen and connects the blood vessels of the pelvis to the blood vessels of the organs. Rizwana's own kidneys, which are not functioning, and her own pancreas remain inside her because there is no need to remove them: "There's a good feeling from everyone in the operating room once the organs are sewn in, and they begin to work. We can usually tell that the organs are working well by the time the surgery is finished."

In the recovery room, the pulse, blood pressure and respiratory rate are monitored. Rizwana's urine output is measured because that gives the staff an indication of how well the new kidney is functioning. They also monitor the blood sugar level, which indicates the immediate production of insulin by the transplanted pancreas. Most patients are transferred to the multi-organ transplant unit one or two hours after surgery. There are twelve private rooms in the unit, with three patients under the care of one nurse. With its intensive monitoring, it is definitely not like a regular ward in the hospital.

Cardiovascular and respiratory stability are closely watched around the clock. Kidney function is closely monitored. Blood pressure readings are taken several times a day. The team needs to make sure the patient is eating, drinking and free of infection. A pharmacist visits to introduce new immunosuppressive drugs and other medications that will be part of Rizwana's daily routine. Usually, a patient who receives both a kidney and pancreas will stay for ten days in the hospital until he or she is ready to go home.

Dr. Luke says that it is typical to watch patients transition from being nervous about going home, to being excited about leaving the hospital. Having been diabetic most of her life Rizwana is euphoric that she is free of insulin shots. She no longer has diabetes because of her new pancreas. Also, with her new kidney, she no longer has to face dialysis several times a week. The change in her life has been sudden and dramatic.

Throughout the entire process, the patient receives a lot of coaching from the transplant staff. Surgeons and other specialists check on the recipients. Social workers visit to see how well the patient and family are adjusting. The nurses, physiotherapist and pharmacist give individual teaching sessions about all aspects of the patient's new life, and then provide information to take home.

After discharge, each patient is seen twice a week initially, and then once a week until the medical team feels that organ function is stable. Transplant drugs can have side

Photo by K.Stuart. London Health Sciences Centre.

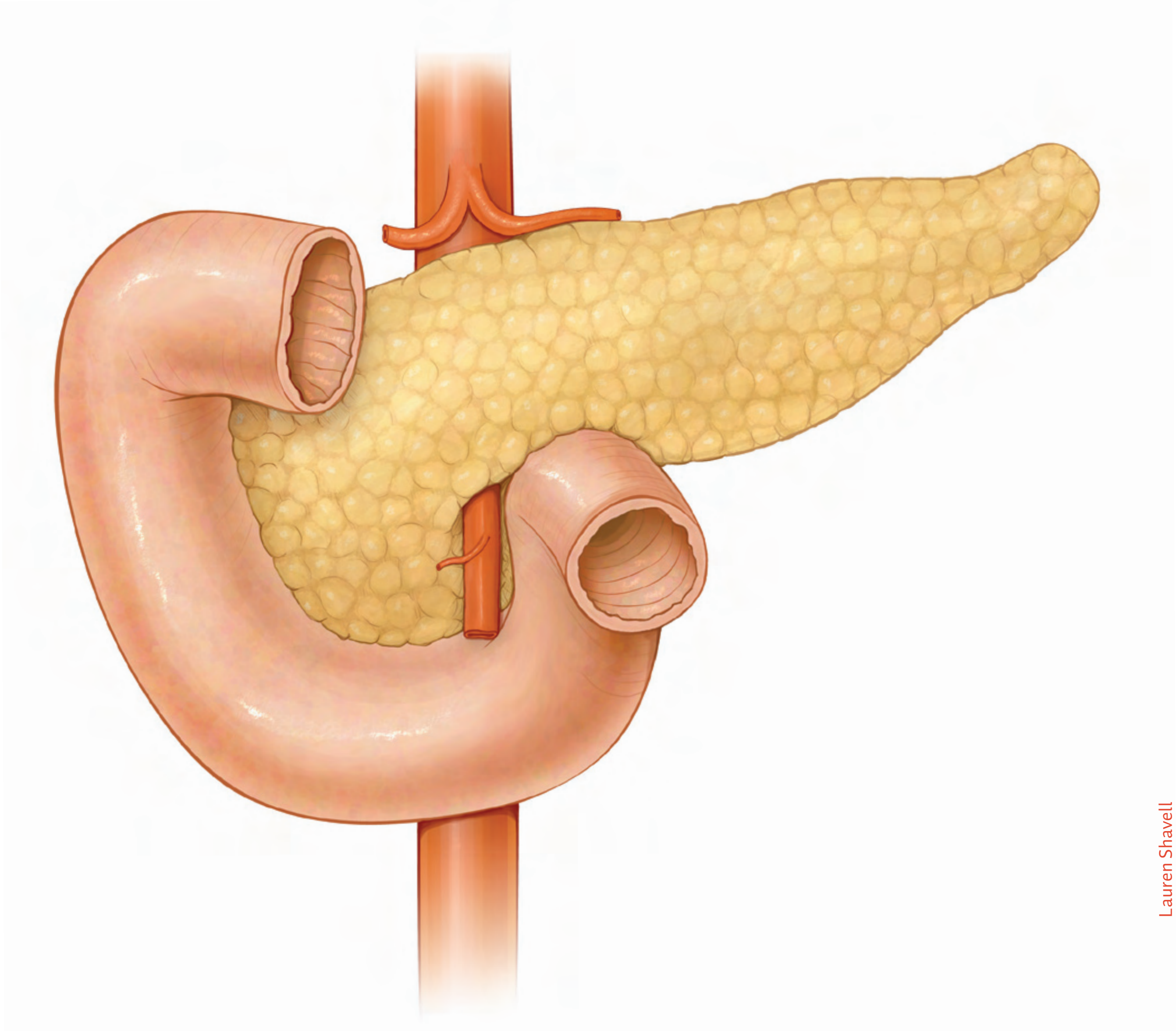
effects, and doses may need to be adjusted. On the one hand, if the immunosuppressive drug doses are too high, the patient may face increased side effects and risk of infection. Alternatively, if the drug doses are too low, the transplanted organs may be rejected by the patients. There can be other issues; sometimes a wound is slow to heal, or the blood pressure may be too high.

A combined kidney and pancreas transplant will last an average of 12 to 15 years. If the patient loses the function of one of the organs, the organ may be transplanted a second or even a third time. As anti-rejection drugs get better, doctors are predicting a time when organ transplants will remain viable for the patient's lifetime. We already know that well-matched kidney transplants can last for more than 25 years.

Dr. Luke is justifiably proud of the work of the multi-organ transplant team at London Health Sciences Centre. They change people's lives every day. Dr. Luke says the various professionals all work together – the surgeons, nephrologists, physiotherapists, nurses, pharmacists and social workers. "Patients are enormously grateful to have a second chance at life. But we make it very clear that they must take care of themselves and maintain their health to prolong the life of their new organs. That includes giving up cigarettes, eating a healthy diet, and getting the right amount of exercise." Dr. Luke does not pass judgment, but he does want people to remember that a new organ is a precious gift, one that must be valued because of the enormous time, effort, skill and level of resources given to each recipient. Given the privilege we have in Canada of a universal health-care system, Dr. Luke's request is very simple, and completely reasonable.

When Rizwana was discharged from hospital, she referred to herself as FREE. "For me, there are no more needles, no more insulin and no more dialysis. I am free." It is very easy to understand why Rizwana experiences herself as free. She no longer has to check her blood sugars two to four times a day. She no longer has to have insulin injections – two, sometimes four times a day. Her own body can clean the toxins she generates; dialysis is no longer required to remove the impurities from her blood. Even with dialysis, the procedure is not a perfect replacement for a healthy kidney. Almost immediately after a dialysis session, toxins build up again, so often patients do not feel entirely well. Fatigue is also an issue. It is impossible for any mechanical process to provide a perfect solution for organs that are not working well. The body meets its own requirements best, as long as we are healthy. So, for Rizwana, the concept of personal freedom is very powerful indeed. She is released from the daily discipline of testing, injecting and blood cleansing. It does not take much imagination to share her joy.

Rizwana had done nothing to cause her Type 1 diabetes, yet she was in a medical prison cell, with the bars firmly locked, until a donor gave her a new kidney and a new pancreas. Then she could open the cell door, and travel back to a wonderfully ordinary life. Dr. Patrick Luke could be confident that Rizwana, with her new-found freedom, would protect the gift.



Lauren Shavell

the pancreas

The pancreas is located behind the stomach. It has two major functions: it produces enzymes that are released into the intestine to digest food, and it produces hormones – insulin and glucagon – that are released into the bloodstream to regulate blood sugar. Insulin lowers blood glucose levels and glucagon raises them. Between them, they create a stable level of blood glucose, giving all the cells of the body a constant supply of fuel.

The specialized cells of the pancreas that produce insulin are called islet cells – they are dispersed throughout the pancreas in clusters, or "islands," hence the term islet. There are about one million islet clusters in a human pancreas. When the islet cells stop producing insulin, the blood sugar rises uncontrollably and the patient develops Type 1 diabetes.

Type 1 diabetes typically affects younger individuals during childhood or early adulthood They have to take insulin by injection (pen or pump) throughout the day and eat specific amounts of carbohydrates to balance their blood sugar. It can be very tricky for patients to keep their sugars in good balance. Over time, diabetes can cause blindness, kidney disease, heart attacks and gangrene of the feet, resulting in amputation. It is a serious illness that produces life-threatening complications.

Type 2 diabetes appears in adults, and it is caused by the failure of insulin receptors on the surface of the cells to respond to insulin's signal to take up glucose from the blood – insulin resistance. The blood sugar levels go too high, and the cells cannot utilize the energy source. Initially, pills can be taken to stimulate the pancreas so that it produces more insulin, but eventually the islet cells often don't respond and the patient then needs to take insulin injections.

People who are excessively overweight from too much food intake and too little exercise are at much greater risk for developing Type 2 diabetes. The prevalence of obesity in the general population is why leading health-care professionals, public health advocates and organizations such as the Canadian Diabetes Association refer to diabetes as an epidemic in many communities. A healthy diet, exercise and maintenance of ideal body weight can help prevent Type 2 diabetes and, if a person has it, can limit its progression and the risk of complications.

Information about the pancreas can be found in several sources, including Human Body: A Visual Guide *and* online human body. *Both books are included in the annotated bibliography.*

OVER TO YOU...

A. Personal Reflection/ Philosophical Inquiry

When Rizwana Ramzanali is discharged from hospital, she refers to herself as FREE:

> ***"For me, there are no more needles, no more insulin and no more dialysis. I am free."***

For Rizwana, the concept of personal freedom is very powerful indeed. She no longer has to check her blood sugars two to four times a day. She no longer has to have insulin injections – two, sometimes four times a day. Her own body can clean the toxins she generates; dialysis is no longer required to remove the impurities from her blood. She is released from the daily discipline of testing, injecting and blood cleansing.

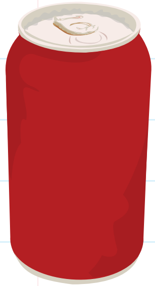
For Rizwana, her freedom is *freedom from*...hospitals, procedures and needles. It does not take much imagination to share her joy. In a broader sense, what do we mean by the word **free**? Do you think of yourself as free or as confined in some way?

There is one area in which you will not be free – depending on luck, genetics, accidents and how you choose to protect your health. You are not free when you are sick. Illness confines. Illness limits. Illness debilitates. Illness holds you in a mighty grip.

Working with a partner, list the ways in which you think of yourselves as free, and the areas in which you feel constrained. Will any of those freedoms and constraints change with age? With more money available? With a career? With a family you create with a partner later in life? Why, or why not?

B. Research, Planning and Action

Dr. Jackie James, an endocrinologist at Mount Sinai Hospital and Principal of the Undergraduate Program for the University Health Network, is frustrated. Although she works tirelessly with patients who have diabetes, James finds that many people do not want to change their lifestyles; they do not want to give up fast foods, fried foods and drinks loaded with sodium and sugar. Despite the presence of Canada's Food Guide in every school and nutritional charts in every restaurant, there is no shortage of people eating hot dogs, fries, burgers and pizza, and drinking litres of soft drinks.



Dr. James acknowledges the media attempts to highlight the current and expanding diabetes epidemic. Yet in Canada, despite the fact that everyone has access to quality health care, our numbers are exploding – both in terms of obesity and diabetes. James doesn't pull any punches:

> ***"Despite the overwhelming evidence that you will lose your eyesight, possibly your kidneys, and maybe even your legs, I find it very difficult to convince patients that they have to buy fresh fruits and vegetables, and take the time to prepare nutritious meals. Everyone claims that they are too busy, too stressed or just too tired to prepare good food."***

OVER TO YOU...

Many activities become a first priority; shopping and cooking are way down the line. There is nothing more precious than the gift of good health. You may never need an organ transplant. But, if you do, you have to be in the kind of physical shape that would allow you to receive an organ, and keep it healthy after you become an organ recipient.

It is important to remember that in the case of people like Rizwana, who have Type 1 diabetes, nothing in their personal lifestyle or nutritional choices caused their disease. However, for many people, lack of exercise and too much fast food may lead to the development of Type 2 diabetes and other health problems.

Research foods and beverages that keep our various organs functioning properly. Make a list of these foods. Consult the notes you have created every day, and make sure you are eating and drinking nutritious foods and beverages.

Over the period of one week, add one healthy food item each day to the lunch or dinner you eat. In a notebook, quickly jot down the additions you make to your daily menu.

At the end of the week, share the list of your new foods with a partner. Pass the lists around the classroom until all of the notes on healthy foods and drinks are collected. Try to extend your brief experiment into your life on an ongoing basis. You will have more energy, a stronger immune system and a sense of greater well-being.

C. Research and Presentation ✽ ◎ ▲

If you are interested in scientific activities, you may want to work with a partner to research the Canadian discovery of insulin by Sir Frederick Banting and the structure and function of the pancreas. Present Sir Banting's story to your classmates. One partner can be Banting and the other partner can present what is currently known about the structure and function of the pancreas. One resource you may wish to use is *The Discovery of Insulin*, by Michael Bliss (University of Toronto Press, 1982). The story of Banting's work was dramatized in the film *Glory Enough for All.*

⌘ THE ARTS ✿ CANADIAN & WORLD STUDIES ✽ ENGLISH 🟧 GUIDANCE & CAREER EDUCATION
◎ HEALTH & PHYSICAL EDUCATION ▲ SCIENCE ✪ SOCIAL SCIENCES & HUMANITIES

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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The Steering Committee gratefully acknowledges and thanks the many individuals who contributed to the success of this project. Donor families, recipients, health-care professionals, educators and community members were all very generous with their time and expertise. *One Life...Many Gifts* is richer because of their participation.

Ontario
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Réseau Trillium pour
le don de vie

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