

Living Donation

A boy named Lucas and a stranger

Lucas

One Life...Many Gifts is a curriculum 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.

Lucas Belisario/Tom Mildenberger Story

Image and Description of the Kidney

Over To You...

- a) Personal Reflection/Journal Entry
- b) Create a Profile of Heroism
- c) Public Service Announcement
- d) Role Play
- e) Online Research and Key Message Writing
- f) Debate and Perspective Taking
- g) Critical Analysis
- h) Scientific Presentation

May 2, 2004:

First Holy Communion

"He's a wonderful, wonderful boy."

- Lori Belisario comments on her son, Lucas.

Lucas announces himself:

My name is Lucas Charles Lawrence Belisario. My middle names come from my grandfathers. One is named Charles, the other is Lawrence. I am always called Lucas, never Luke. My medical problems started when I was five, just three days before my 6th birthday.

August 20, 2001: At Turkey Point (Lake Erie)

All children get a touch of the flu and most kids are lethargic sometimes. It is nothing to worry about - or so Lori Belisario thought. When Lucas was feeling weak for a few days, a quick check with his paediatrician was set up - just to be on the safe side. The doctor suggested taking Lucas to McMaster Hospital immediately because he had concerns and wanted further advice.

After eight hours of waiting, some blood work was done, and then Lori was bombarded by questions: "Has Lucas visited a farm recently?" "Has he had any hamburgers in the last few days?" Lori had no idea why the questions were being asked. She was scared. Lucas just wanted to go home.

For Lucas, home was going to be a hospital for a very long time. Lucas's kidneys were failing. He was diagnosed with an uncommon syndrome: Hemolytic Uremic Syndrome

(HUS), a condition that is nearly always caused by E. coli bacteria. It develops after eating undercooked meat or contaminated dairy products, or drinking water contaminated from manure spread on farms. This is why the doctors were questioning Mrs. Belisario about hamburgers and farms. A small percentage of cases follow a viral illness. Lucas had no known exposure and he tested negative for infection, so the doctors labelled him 'atypical' HUS.

Lucas stayed in hospital for more than 50 days. The doctors kept hoping that his kidneys would start functioning again on their own. That happens to many individuals with HUS.

The kidneys recover their function in a few weeks. Lucas was placed on temporary peritoneal dialysis, a treatment to clean his blood and remove excess waste and water from his body. Ordinarily, those cleansing functions are the daily tasks of healthy kidneys. For Lucas, peritoneal dialysis became a substitute for his inefficient kidneys. He was not allowed out of bed in case the tube in his abdomen shifted or moved. It was imperative that the tube stay safely in place for the dialysis to work.

Lucas was only five, but he was in bed 24 hours a day. Think of a young child confined to bed, with no opportunities to run, play or even walk. Because Lucas was so weak, he didn't even have the energy to complain about his confinement, or to want to be out of his hospital room. He received dozens of Then Lucas coded. His mom says she can use the word easily because she was in the hospital around the clock and became very used to "Code Blue" (cardiac arrest) and "Code Red" (fire). The code calls are never good. They always mean that there is a life-threatening situation. In Lucas's case, his heart had stopped. He was revived, and sent immediately to CCU (Cardiac Care Unit). From there, he was given an MRI, a magnetic resonance imaging scan that can reveal brain damage.

Lori's life revolved around abbreviations - CCU, MRI. Luckily, there were no problems with Lucas's brain.

Physicians speculated that Lucas must have had a seizure, even though there was no evidence of one. Despite their investigations, the doctors remained stumped. Lucas was not getting better.

Lori started to ask, "What the heck is going on here?" Lucas had blood in his urine, and the output of urine was almost nothing. Lori kept thinking - tomorrow, tomorrow, but it just never happened. "I kept waiting, as they asked me to do, for the situation to clear itself. I kept thinking the situation was going to get better, but it never did. The worst part was the not knowing."

The doctors had to put Lucas on permanent peritoneal dialysis to remove the toxins and fluids that were accumulating. His kidneys were not going to recover. Lucas stayed in bed, watched movies, constructed puzzles and played board games. He never complained.

If there could be a blessing in this horrendous circumstance, it surfaced in the person of Dr. Brian Steele, a paediatric nephrologist. According to Lori, "He was there every day, seven days a week. When he was scheduled to go on vacation, he phoned in every day to check on Lucas. I can't say enough about him. He went above

and beyond. As a family, we were very, very fortunate. I trust him totally.”

She has strong opinions about physicians. From Lori’s point of view, the best ones are old school; they go on experience, on what they have seen, what they have dealt with. Lori also values commitment: “Lucas got pneumonia because he was immune-suppressed. Dr. Steele called me from his home on a Sunday. He kept our family going the eight long weeks Lucas was in hospital. The nurses did too; they were like our family.”

Still, Lucas remained ill. Dr. Steele proceeded like a detective. Lucas’s mom and dad took turns, taking shifts at his bedside so that Lucas always had a parent nearby. When Lucas was released from hospital, he was still on dialysis. It was done at home, 11 hours every single night, with a second treatment in the afternoon. It meant that the parents never went out together in the evening. “We wanted to be there. He was our responsibility. We have no regrets, none at all.”

Lucas lost all of his muscle mass, lying in bed. He came out of the hospital in the middle of the summer. He was very thin and couldn’t walk up the stairs because he had spent such a long time in hospital without walking. Lucas was weak, but he was finally back in his own bed. Home.

He had diet restrictions. Dialysis cannot remove phosphate efficiently so Lucas had to stay away from all dairy products – milk, cheese, yogurt, ice cream and chocolate. Also, he had to follow a very low sodium diet. He was placed on a growth hormone, which meant he had an injection in his leg every day. Blood was taken from him very often to monitor his waste levels. If those interruptions in his day were not enough, he also had to take numerous medications, including blood pressure pills and appetite enhancers.

Summer passed, and Lucas went back to school in September 2002. He was withdrawn and cried every day at school. He didn’t play with other children and spent most of his outdoor time sitting in the shade, alone.

Seven months later, in the spring of 2003, Lucas underwent several tests to see if he would be a suitable candidate for a kidney transplant. The Renal Transplant Nurse warned the family that the waiting list was long. Nevertheless, on June 24, 2003, Lucas was placed on the active transplant waiting list. The family was given a pager and told that the wait for a suitable donor could take a year, or even longer. Neither Lucas nor his parents were very encouraged. Unfortunately, Lucas’s parents were unable to be living donors for medical reasons.

Then, suddenly – literally out of nowhere – a stranger appeared and offered one of his kidneys to Lucas. Amazingly, Lucas and the donor had the same blood type. This was the first small ray of hope. Further tissue typing tests had to be done to ensure their tissue matched – the better the match, the greater the likelihood of a successful transplant. If it were confirmed that this Good Samaritan really could be a donor, then Lucas would not have to remain for months or years on the waiting list.

It was definitely a case of hope, mixed with large doses of fear and uncertainty.

Lucas's waste levels continued to climb, and he had less and less energy. Then, in late October 2003, it was determined that the transplant could go ahead because the mysterious benefactor was a complete match. The transplant was booked for January 13, 2004. Lucas's life was going to be changed by a gift from a stranger.

The morning before his operation, Lucas left his house at six in the morning, grabbing some Cheerios for the long car ride to Toronto. He was pleased to have his own room at the hospital and, although he was a little uncertain about the details, he was very happy that there was someone who had shown up "to give me a good kidney."

The operation was completed in the proverbial nick of time. Lucas's creatinine levels were around 1400 just before the transplant. (A creatinine level is the measure of a waste substance produced when muscles are used; creatinine levels rise when kidney function decreases.) Normal is 60-115. After the surgery, there was a dramatic drop in his waste level; it dropped down to 400. Not perfect, but moving in the right direction.

Lucas stayed in hospital for almost three weeks, followed by a stay at Ronald McDonald House for another few weeks. Several trips a week were undertaken to Toronto for blood work and checkups. Described by his mother as a sick little guy before the transplant, he is now playing ice hockey. He is outgoing, and no longer shy. He is growing well, and is happy and healthy. The many medications, taken twice a day, are just part of a regular routine. The rest is history - Lucas's history of health, not sickness.

Lucas has eight scars, some of them "pretty big." But he feels really energetic: "I can do everything." He has to drink two bottles of water a day, and three milks. At night, he is allowed a pop. All the liquid is meant to keep his kidney going. In the morning, Lucas has three pills and at night he takes six or eight more: "They're fine. They're easy."

On the anniversary of his transplant, Lucas and his parents travel to share a meal with the kidney donor. For the first few years, both families met at a restaurant, and had dinner together. Last year, everyone met at the donor's home, and they had supper together. Lucas and his donor showed each other their scars. "I am completely normal now," Lucas reminds everyone. The donor has remained a very private person in the community, not expecting any particular thanks. It was something he felt called to do, giving Lucas a chance to live a normal life. So he did it.

Lucas's life has a new addition - a little cat named Chicklet who showed up unexpectedly at Lucas's house one day. Chicklet is a total love connection. She travels from one person's lap to another when company comes to the Belisario house. At bedtime, as soon as Lucas's bedroom door is open, Chicklet is there. She jumps onto Lucas's bed every single night, and lies by his head. "Chicklet chose him, that's for sure," says his mom.

Chicklet's presence and her love for Lucas are as much of a mystery as the arrival of the donor who heard the story of Lucas, the little boy who needed a kidney.

So, who is this mysterious man, this father of three sons who arrived at exactly the right time, and persisted with his desire to assist Lucas all through the various tests he had to undergo? In most cases, a stranger is never a suitable candidate to donate. It is more usual to find blood relatives who provide a match. A potential donor would have to undergo surgery, and accept that he or she was now in a position of having only one functional kidney himself or herself. That kidney could fail, and then the donor would be forced onto dialysis and a similar journey that Lucas had faced – waiting for a transplant. This noble donor is Tom Mildenberger.

He would not call himself brave, altruistic, compassionate or a saver of lives. All of those qualities are accurate descriptions of this husband and father, but he is much more modest about the gift he gave: “My wife, Theresa, is a secretary at the school Lucas attends. Over dinner, she mentioned that a little boy was very ill, and getting worse. I heard he was on dialysis and deteriorating rapidly. Coincidentally, weeks earlier, I read an article about an unrelated person donating a kidney to a young boy. I thought, ‘I could do something to help this child.’ I was out walking our dog in a field one night, and I just suddenly felt – I could save his life. And that was it. My wife was surprised because I had never met the boy or his family.

After I volunteered, I had to go to Toronto. I had to meet with a psychiatrist to discuss the reasons why I wanted to donate a kidney to an unrelated person. They felt they needed to determine why I wanted to be a donor for a stranger, and they also wanted to ensure that I was fully aware of the risks involved.

After the interview, they took a blood sample to see if my blood and Lucas’s blood would react. They needed to know if his body would reject my kidney. That is why a match was done. Ordinarily, relatives offer the best chance as possible donors but, in Lucas’s case, there was some concern that his medical issues were genetic, so the doctors did not want to take a chance of passing a medical problem along to him. I had two kidneys. I thought, ‘I can live fine with one kidney if it means saving a life.’ Of course, at some points, I did get nervous. But I am a Catholic and I didn’t want to think of my faith as one that was based on words, not actions. I committed myself, and I wanted to follow through with my promise. My children and my wife were fine with my decision. I had to ask myself, ‘If I didn’t contribute my kidney, and then heard about him dying, what kind of person would I be if I chickened out?’

Tom was taken into an operating room. Lucas was in a separate room. The surgeons took his kidney out, and put him in a room to recuperate. Then Lucas’s surgery was done. For Tom, the first few days were really painful: “It really hurt.” Tom was kept in hospital for five days, given painkillers, and then stayed off work for four weeks. His employers were phenomenal: “They were totally shocked– and happy. They told me to take all the time I needed to get better.”

The Kidney – Cleaning our Blood, Regulating our Hormones, Getting Rid of Wastes.

Each day, your body dumps waste substances into your blood, waste that would poison

you if it was allowed to build up. The good news is that, minute to minute, the kidneys are working to process your blood, extracting wastes and surplus water. During an ordinary day, nearly 2,000 litres of blood pass through your kidneys.

Everyone has two kidneys, unless one or both are lost through disease or given as a donation to another person. In terms of size, each kidney is about the size of a clenched fist, containing about one million tiny nephrons. Each nephron has a very small filter, a glomerulus. It cleans the blood by filtering out excess water and waste products. What is left is urine, which is then excreted by the body.

(Information about the kidney has been obtained from the books *Human Body: A Visual Guide* and *Body, An Amazing Tour of Human Anatomy* and from the website www.kidney.on.ca supported by the Ontario branch of the Kidney Foundation of Canada. Both books are included in the annotated bibliography.)

Healthy kidneys have three essential functions.

1. They remove wastes from the blood and
2. they regulate the levels of water and minerals the body needs to remain healthy.
3. They also regulate hormones that control other body functions.

Basically the kidneys work like chemists in the body.

Over to you...

Initially, Tom Mildenberger heard about the story of Lucas Belisario from his wife, who works as a school secretary. Lucas's story was floating around the school, with everyone agreeing that the little boy's health was deteriorating. From that small anecdote, and with no personal connection to the child, Mildenberger showed up, and offered a kidney.

A. PERSONAL REFLECTION/JOURNAL ENTRY

If you heard a story about a person who needed a kidney or part of your liver, would you step up and find out if you could be a match? Why, or why not? Do you agree with Tom that people are often reluctant to make time for others? Is it "me, me, me"? Write a paragraph or journal entry describing your perspective on these questions.

B. CREATE A PROFILE OF HEROISM

i) Creating a List

Working with four classmates, make a list of the kinds of actions you would want to see

in order for you to consider that person's behaviour worthy of your respect and admiration. What kind of person would you consider to be virtuous, noble, courageous, loyal, compassionate, brave or heroic? Do not restrict yourself to our sample list of adjectives; you may add other attributes of a person's character that deserve our attention and praise.

For example, many people feel that organ donation is an act of courage, requiring the donor and the donor's family to accept the finality of death and – despite intense personal suffering – to move beyond their own grief to provide the possibility of hope and life for complete strangers. There are no fireworks shooting into the sky when one person saves another person's life through organ donation.

The gift is a quiet one, barely noticed beyond the recipient's immediate family. But it changes the world, for all the patients who are given a second chance to regain their health, and for everyone with whom they come into contact for the rest of their lives.

Share your list with the members of your group, and then travel to a second, third and fourth group, until you have heard all the outstanding actions people have listed.

ii) Investigating Opinions

You may wish to investigate the opinions of others. In the media, we often hear of people's selfishness. In a healthy society, it is helpful to focus on positive accounts of people's generosity and altruism. We are living in an age when few people in the public eye escape the plague of tabloids or television scandal programs. When you go home, ask the people who live with you if they can think of a person or a group who deserves their respect and admiration. When you go back to school, compare your list of worthy people with the list mentioned at home.

C. PUBLIC SERVICE ANNOUNCEMENT

There are people who live in the world that our society embraces as modern-day heroes. Gandhi is one, Martin Luther King another and the Dalai Lama a third; Mother Teresa, the Canadian astronaut Julie Payette and everyone who has won the Nobel Peace Prize or a major environmental award are others. Google the word hero. Find one person in the scientific or medical world whom you would choose as being worthy of heroic status. Do you think of transplant surgeons as heroic? Do you see donor families as heroes? You have read the story of Lucas. Would you consider his parents (and other long-term caregivers) as heroes? Jot down the name of one person you think is heroic. Beside the name, make notes on the reasons for your choice.

You do not need to limit yourself to famous people in your search for heroes. There are a number of otherwise ordinary citizens, like Tom Mildemberger, who keep their day jobs and go about the business of daily living as a parent and spouse. However, when special circumstances arise, they stand up and stand out.

When you are comfortable with your list of heroes, prepare one-minute scripts for televised public service announcements. Read your text out loud to the class or prepare an audiotape, which may or may not feature your voice. The title of your script is Stepping Up in a Complex World.

D. ROLE PLAY

We have read about Tom's decision to give one of his kidneys to Lucas, the very ill child. That would be fine if Tom lived alone and could make the decision by himself. But Tom is not a bachelor; he has three sons and a wife.

Divide the members of the class into groups of three. One of you is Tom Mildenerger. The second person is Tom's wife, Theresa. The final member of the group is one of Tom's teenage sons. At the time of the kidney donation, the boys were 15, 14 and 10. In real life, everyone in Tom's family supported his decision; they were very proud of his courage and compassion. However, there is always a risk with surgery and, if Tom were to be involved in an accident or found himself in a situation where his one remaining kidney was damaged, he would have no spare kidney. He would have to move onto dialysis for the rest of his life. As a minimum, that would mean going to a hospital to have his blood cleansed for several hours, three times a week, sometimes more. The dedication of that amount of time would present a serious intrusion on Tom's life, not for a few weeks or months, but for a lifetime. It would have an impact on both his home and work life.

Working in a group of three, choose to assume the role of Tom, one of his sons or his wife. Would you argue for or against Tom's decision to be a donor? Make notes to defend your position. For the student who undertakes the role of Tom, jot down the ideas that led you to make the life-saving decision to be a kidney donor for Lucas.

Each fictional family household should present their cases to the other groups in the class. Did you find that you reached a consensus about the wisdom of being a donor, or did you remain divided in your opinions?

E. ONLINE RESEARCH AND KEY MESSAGE WRITING

Lucas had Hemolytic Uremic Syndrome, commonly known as hamburger disease because it often appears in warmer weather when families are using an outdoor grill to prepare supper. Hamburgers and hot dogs are party favourites; it is very easy to serve burgers and hot dogs before they are completely cooked. That can mean disaster.

Animals carry E. coli bacteria in their intestines; the bacteria are present in the animal's feces. During the slaughtering process, E. coli can be transferred into the meat. The E. coli bacteria produce toxins, toxins that can cause fever, vomiting, abdominal cramps and even bloody diarrhea.

When E. coli contaminates water supplies after manure has been spread on fields, an entire town can become ill. That happened in Walkerton, Ontario, when hundreds of townspeople were infected because E. coli entered the town's water supply. People died from E. coli infection. In Lucas's case, the E. coli source was never identified, but he, like 10% of children who have E. coli gastroenteritis, developed Hemolytic Uremic Syndrome. It is a very serious disease; it can cause permanent kidney damage and at least 50% of the children who develop HUS require dialysis.

Go to The Kidney Foundation of Canada, Ontario website (www.kidney.on.ca). There is an article that discusses Hemolytic Uremic Syndrome and other information on additional risk factors for kidney disease and kidney failure. Working with a partner, take the quiz on the website called "Am I at Risk?" Discuss your quiz results and read about ways to prevent kidney failure and disease. In your own words, write the key messages you feel people should understand about how to take

care of their kidneys and avoid the “risks.”

F. DEBATE AND PERSPECTIVE TAKING

You now know that Lucas did receive his kidney. Think back to the time that he was still on the list for a kidney transplant. Even though he is young, he has had to face the possibility that time might have run out before a suitable donor appeared. Then he would die, even before he became eligible to drive a car.

We know how desperately Lucas wanted to live. He was fighting the fight, and was committed to not letting go. But there was only so much he could do.

Lucas did not live alone. He has parents, adults who also wanted to preserve the life of their son.

In Canada, it is illegal to turn organs into commodities, objects that we can put into the marketplace and sell to the highest bidder. Do you agree or disagree with our country’s law? Jot down your answer, with point-form notes on why you have made your decision.

Divide into pairs and assume the roles of Lucas’s parents.

Now, step into your role as one of Lucas’s parents. The doctors have been candid with you. Your son is dying.

Would you change your mind about buying an organ if your own child needed one? In this case, Lucas is in that situation: he will die if you cannot find or purchase a life-saving kidney.

When the theoretical question about the ethics of buying and selling organs concerns an actual person, do you change your original philosophical position? This is a situation in which strong beliefs meet an even harder reality.

Take a poll within the class. This is the question: Are you prepared to do anything to make sure your son receives a life-saving kidney?

Read the articles on the buying and selling of organs included in the Religious and Ethical Perspectives section. After your reading, you are free to share your final decision with the class. Buying a kidney: yes or no?

G. CRITICAL ANALYSIS

An organization called matchingdonors.com has been in existence for several years. Individuals in need of a transplant and donors who are interested in being a living donor (for a kidney or part of a liver) are invited to tell their individual stories over the Internet. The process encourages a potential donor to select a particular recipient to receive his or her organ. Is it appropriate that patients with kidney failure compete against one another by telling their most compelling stories on the Internet? Matchingdonors.com has been criticized because it is hard to know the true motives of the donor; some people may genuinely want to help a person in need, or others could be seeking personal gain for example, publicity, self-fulfilment or financial remuneration. What do you think about the website?

Should it be continued or not? Write your opinion in a paragraph and share your viewpoint with a partner.

H. SCIENTIFIC PRESENTATION

Using PowerPoint, drawings, printed materials, etc., prepare and deliver a 15-minute presentation that describes:

- the anatomy of the kidney
- the kidney's role in maintaining major functions of the body
- the common diseases that destroy the function of the kidney, leading to the need for artificial kidney dialysis

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

© Queen's Printer for Ontario, revised 2009.

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.

Steering Committee:

Frank Markel, President and CEO, Trillium Gift of Life Network

Dr. William Wall, Transplant Surgeon, Multi-Organ Transplant Program, London Health Sciences Centre

Jim O'Brien, Executive Director, The Kidney Foundation of Canada, Ontario Branch

Project Support Team:

Cailey Crawford, Education Project Manager, Trillium Gift of Life Network

Cate Abbott, Information & Resources, Multi-Organ Transplant Program, London Health Sciences Centre

Mahms Richard-Mohamed, Transplant Donor Coordinator, Multi-Organ Transplant Program, London Health Sciences Centre

Wendy Kudeba, Director of Marketing and Communications, Pam Logan, Communications Manager, The Kidney Foundation of Canada, Ontario Branch

Writer:

Linda Rainsberry

Educational Consultant and Program Advisor:

Joan Green

Design:

Niki Fleming

Vince Rozas, design assistant and line art illustration

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.

One Life...Many Gifts