

Brandon

ADVANCES IN LUNG TRANSPLANTATION THE BRANDON GIBSON STORY

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.

"I Have Cystic Fibrosis; It Doesn't Have Me": Brandon's Journey
Image and Description of the Lungs
Over To You...

- a) Research/Interview
- b) Experiment and Stream of Consciousness Writing
- c) Website Investigation
- d) Emotional Analysis and Exploration
- e) Express Intellectual Insights Through Various Media

I talk to my disease. I tell it that I'm not going to let it beat me.

I Have Cystic Fibrosis; It Doesn't Have Me: Brandon's Journey.

I am 14 years old and I have a fatal disease called cystic fibrosis.

If you breathe through a straw for 60 seconds, you have just felt what it is like to have cystic fibrosis. I asked a friend to do it, and it was really hard for him to breathe. That is one of the ways I get my friends to be in my shoes for a minute or so. Try it, and you will have a sense of how I manage each day.

"I am waiting for a double lung transplant because the lungs I have right now are not doing anything for me; basically they are making me sick.

There are some days when I ask if this disease is God's fault, or my mom's fault. My mom tells me that God gave me this disease for a reason. On a really tough day, I think that there can't be a good enough reason to make someone sick.

I get admitted to the Hospital for Sick Children in downtown Toronto every six to eight weeks. Music really helps me get through the hard times in the hospital. I sing for my family - for my sisters. I would definitely rather be at home with my family than come to the hospital. Cystic fibrosis is a life- shortening disease.

To try and give you a feeling of what it is like to live with cystic fibrosis, you have to imagine that you can't breathe as well as you should be able to breathe. Secretions are a lot thicker than they should be, and you can't clear the mucus. It feels as though something is stuck inside of you. I get short of breath. I cough up stuff when I am doing exercise, so it really limits what you can do.

In the morning, when I wake up, the first thing I do is take my pills. By the end of the day, I have probably taken 45 to 50 pills. Then I put on a mask that has a drug in it that helps me breathe. That takes about 20 minutes. The mucus is loosened, and I can cough it up, that takes me about another 40 minutes, 20 to

actually cough it up and another 20 to actually control my coughing.

After that, I visit with a physiotherapist. She helps me break up more phlegm. It is the phlegm, or mucus, that causes all the infections, so it is important to get as much out of my lungs as possible. All in all, it takes about three hours a day.

Whenever I am down, my family totally understands. My mom is always available and my dad is always there for me. Music also really helps me on my down days. Sometimes, when nothing is going right, I come home and play some music. No one is in my room. It is just my music and me. It puts me in a zone where nothing can touch me, nothing can take me down. Cystic fibrosis will never beat me. I have CF; it doesn't have me.

Sometimes, I feel hurt and lost in the disease. I just have to walk toward it, face the path I am on because it is not going away. Right now, I have the use of one and a half lungs. The half lung that's missing was surgically removed because it didn't work and was just full of pus and infection.

I am waiting now for a double lung transplant. The doctors have used so many antibiotics there is not much left in the drug arsenal to fight off infections. Even though I desperately need new lungs, it is kind of sad that someone has to die for me to get them. It is sad to even have to think about it.

When you are placed on the transplant list, you are given a pager. The hospital calls you as soon as they know that there may be suitable lungs. You always wonder, "Will the pager go off before it's too late?"

Mostly, I wake up and think, 'Today is a good day for the pager to go off.' Finally, it did.

We went to the hospital, and called our relatives in Montreal. They started to get ready to come down and see me after the surgery. Eight hours later, the surgeons came and said that the lungs weren't good enough. There was some kind of infection in them. If they put the lungs in, they wouldn't work and I would be just as sick as I was before, if not sicker. The doctors need lungs that match mine in size and they also need a match of my blood type. That is hard to find. I have been waiting for a year and a month; it has been quite a long time, and it feels even longer.

The doctors try to keep me in the best possible condition while I am waiting. I do some basketball. I do some stretching, some biking on a treadmill to put me in shape for the transplant. I have to be as healthy as possible.

If people would register their wishes and tell their families their wishes, then you wouldn't have so many people dying. You would give more people a chance to live a normal life. I have never experienced what it is like to be normal, to run with all my friends, to play hockey. I stopped playing hockey because my lungs just couldn't take it anymore. At the end of a game, I would be tired and I would be coughing. Sometimes, I even had to go to the hospital in an ambulance.

I talk to my disease. I tell it that I'm not going to let it beat me. There's no way I am going to let cystic fibrosis beat me. I'm gunning for it."

Brandon was right. Nothing did stop him. The lungs arrived, just in time. For two weeks after his double lung transplant, everything was just a big blur. Then he started to recover.

And, today - at sixteen - he is on the ice again and back to playing street hockey.

"In the fall, I am going to start playing ice hockey again. I have pretty much made it. I really hope people will register their wishes, you never know - it can save a life. It saved mine."

Dr. Shaf Keshavjee, the Director of Toronto General Hospital's Lung Transplant Program and the Director of Thoracic Surgery Research, is the surgeon who performed the double lung transplant on Brandon Gibson. He has developed a new strategy to preserve lungs and he is utilizing gene therapy to repair donor lungs. The gene he uses is IL-10, the gene that plays a role in the regulation of immune responses; it promotes the development of immunologic tolerance. In lay person's language, that means that the body does not move to reject the transplanted lungs - critical for the person who has just received a new gift of life and breath. Long term, one of the key goals is to prevent the body with little or no medication from rejecting a new organ. Currently, all transplant recipients have to take immunosuppressive drugs every day for the rest of their lives. Dr. Keshavjee is passionate about his research, to benefit other patients like Brandon. "Previously, a patient would be facing certain death if he or she needed two new lungs. Now, we can get people back to a normal life; we don't even have to set an age limit." Keshavjee is very clear about the two critical problems we face in the area of transplantation: "Your parts wear out. You have to replace them, and Canadians just don't donate enough organs. Everything else is secondary; people need to know how urgent the problem is, and they have to respond."

No one seems to disagree with Dr. Keshavjee's analysis. In June 2006, from the 2000 Canadians asked about organ donation, 93% were in favour of organ donation, 79% were willing to become donors and 60% have already spoken with their families about their desire to become a donor. Good statistics. Great theoretical support. Now, all we need is ACTION on our collective altruistic intentions.

The Lungs

Human beings can live without food or water for days, sometimes even weeks. There are dozens of survival stories that document the human capacity for extreme weather conditions. People manage to live with almost no food rations, and with very limited water supplies. What humans can't live without is air. Within minutes, people suffer irreversible brain damage or death without oxygen - the body's fuel for all living cells.

Your respiratory system brings oxygen into your body and takes out carbon dioxide. Your body cells use the oxygen you inhale to release the energy you need to perform all the tasks of daily living. Carbon dioxide is removed as you exhale. This process is critical; too much carbon dioxide can poison your body's central nervous

system. Every day, 20,000 times a day, you inhale and exhale. The body needs a constant supply of oxygen because it cannot store fresh air.

We almost never think about breathing. We just do it. It is only when we are suffering from allergies, asthma, bronchial infections, pneumonia or emphysema that we become conscious of our breathing. Not being able to breathe easily creates a feeling of panic in most people. Having damage to your lungs – through smoking or illness – makes getting oxygen into your bloodstream a very difficult process.

In healthy people, about four and a half litres of air pass into and out of your lungs each minute. Obviously, this amount increases if you are exercising – by walking fast, running, dancing or playing sports. Then you need to inhale air more quickly and you have to breathe more deeply because your muscles need extra oxygen. As you breathe in, the air contains about 20% oxygen, some nitrogen and other gases, and very little carbon dioxide. When you exhale, the oxygen level drops to about 16% and the level of carbon dioxide increases to about 4%.

When you breathe, fresh air passes through your nose or mouth, past the throat (pharynx) and windpipe (trachea). At the base, the airway splits into two bronchi, or tubes, entering the lungs. You have two lungs; the left one is smaller because it is positioned close to the heart and needs to share space in your chest. The right lung is larger. Both lungs expand to bring in the air, and then they shrink to allow for exhalation. Deep in the lungs are clusters of sacs (alveoli), which allow oxygen to move into the bloodstream as carbon dioxide moves out. Between the two lungs, there are about 300 million air sacs, providing a large surface for the exchange of oxygen and carbon dioxide.

Breathing problems often arise at high elevations where oxygen is limited, and under water when a too-rapid ascent to the surface of an ocean or lake can cause “the bends,” an illness caused by nitrogen bubbles in the blood. Very few of us are mountain climbers or deep-sea divers, so altitude sickness and collapsed lungs from water pressure are not likely to affect our breathing.

By the time you reach the age of 75, you will have taken more than a half billion breaths – about 12 each minute. That’s a lot of breathing.

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

Over to You...

Research/Interview

You have just read a very brief description of lungs and how they operate. Certainly there is much more to know about these organs. For a research paper, choose two or three well-illustrated books that explore the workings and problems associated with healthy and diseased lungs.

You can contact The Lung Association in your community. They will be more than pleased to provide you with additional information about the people they serve and

the supports they provide. There are several offices across Ontario – in London, Brantford, Belleville, Mississauga, Simcoe, Kingston, Hamilton, Stratford and Windsor. You can visit the website at www.lung.ca or call their toll-free phone number: 1- 888-LUNG {5869}.

When you have completed your research, write a 1,000-word paper in which you demonstrate your understanding of how the human respiratory system works in a healthy person, and outline the problems that can interfere with the breath of life.

You may know someone who uses oxygen at home and/or carries an oxygen tank with him or her everywhere. Before you start to write, you may want to include an interview with a person who has limited lung capacity, in order to provide another dimension to your theoretical research. Terrible diseases can affect the lungs; long-term smokers often develop malignant tumours. You or a friend may know someone who has struggled with smoker's cough. It enhances your writing to have first-person accounts of people's personal experience.

Experiment and Stream of Consciousness Writing

Warning: If you have asthma or other breathing difficulties, please do not attempt this activity.

Brandon has cystic fibrosis. His illness is physical, emotional and spiritual. You can have a tiny feeling of the physical and emotional challenges of limited breathing by taking a straw, pinching your nose and trying to breathe exclusively through a straw for three or four minutes. Don't give up; Brandon cannot switch from a straw to a healthy set of lungs just because he is getting tired or frustrated. See how long you can continue breathing through the straw without becoming totally exhausted. When you really feel the strain, start breathing normally again. Now, you have an idea of the struggle that Brandon endures every hour of every day.

When you have finished breathing through the straw, jot down how you felt – at the beginning of your experiment when you were breathing naturally through your nose, at the point where you wanted to give up, and at the end of your three- or four-minute experience.

Keep yourself in contact with the feelings you had at the end of four minutes. How was your body feeling? What were you thinking? Project yourself forward to a week-long restriction of breathing only through a straw. After seven days, how many different emotions would you feel?

Write down all of your responses on a single piece of paper. You may use single words, phrases, whole sentences or even rants. Read your response to the class. Do not worry about punctuation. You are trying to create – in language – the emotions associated with having seriously damaged lungs. Using the blackboard or a large flip chart, each person should jot down two or three emotions on the board or paper. When all the words are collected, number them – 1 to 30 (or however many students there are in the class). Collectively, start to read the words aloud. Speak in unison. Repeat the list a second time as though you were reading a chant.

Do you have a greater appreciation of Brandon's respiratory prison now?

C Website Investigation

Brandon waited a long time for his new lungs. He was scared that he might die before any became available. There are many people in Ontario who are on the waiting list because they need a life-saving transplant. Tragically, there are not enough donors to provide the organs that are needed.

Visit the Trillium Gift of Life Network website at www.giftoflife.on.ca and research statistics on the ten-year history of:

- Number of people on the waiting list
- Number of organ donors
- Number of organ transplants

Use these statistics to create a persuasive message to convince people that we must all help to resolve the critical shortage of organs. Your message could be presented on a poster, in a PowerPoint presentation or in a pamphlet.

D Emotional Analysis and Exploration

Not surprisingly, Brandon had many days that were difficult and hard to bear. Music became an oasis for him, a place where nothing could touch him, nothing could take him down. His choice of artists included Nickelback and Green Day.

Reread Brandon's story and examine the various times where you imagine he would be feeling disheartened, discouraged and afraid. Find and select three songs that could move you from feeling down to feeling up. Copy the lyrics and record which emotions you are feeling on your lyrics sheet to show when and how your mood changes. Prepare copies of lyrics sheets for some of your classmates and bring the CDs to school.

Distribute your lyrics sheets and play your songs for a group of classmates. Ask them to jot down on the sheets how they are feeling before you start the mini-concert, shifts (if any) in their mood as they are listening, and how they feel at the end of the third song. Compare your notes on your emotional shifts to the ones your classmates describe.

It might be interesting to do a tableau to illustrate the emotional paths you and your classmates feel in response to the songs you have chosen.

Society does not place very much emphasis on ways we can assist ourselves emotionally – without smoking, drinking or doing drugs. In some instances, but certainly NOT in Brandon's situation, decisions are made and actions are taken by teens and adults that harm organs, and place a person in danger of needing a transplant. These actions may include taking excessive legal medications, illegal substances or excessive alcohol. Since donated organs are in such short supply, and require lifelong drug regimens to avoid organ rejection, it is useful to explore ways in which we can remain healthy, and still have pleasure in our lives.

For My Sister by Maureen Riley.

The painting depicts the artist's sister Michele, while waiting for a liver transplant, with her daughter. Michele, infected with hepatitis C from a transfusion during her daughter's birth, spent almost 13 months on the waiting list before her transplant.

"Together as angels, there's a strong spiritual bond between mother and daughter. They are bonded at wings, hair, hearts and hands, showing their complete love for life and one another. The hands together say 'I love you' in sign language. The symbolic hieroglyphics on the feet represent longevity and good health. The roses are a personal sign to Michele of hope and answers to prayers. The blue bird of hope carrying the donor ribbon is a symbol of faith and hope in people and in life. They smile at each other, enjoying the blessings they have already received."

Over to You...

E Express Intellectual Insights Through Various Media

In Canadian culture, language is given a very high priority as a way of presenting information and exploring ideas. Along with language, artistic expression is another equally powerful way in which people can make their position known on matters that are important to them. If you are someone who has musical ability or a passion for painting, sculpture, dance, public speaking, ideography or photography, then you are keenly aware that artistic expression is a powerful vehicle for conveying emotions and ideas.

Reread Brandon's story. Look at the four images. Choose one image that you think illustrates Brandon's emotions at a particular point in his recounting of his medical journey. Explain the reasons for your decision to a small group of classmates.

Using an art form of your choice, create your own image to communicate what you feel Brandon was going through during a particular point in his journey.

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

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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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One Life...Many Gifts