

Through Brian's Eyes

by Leslie Coefield

On February 18, 1993, my husband Keith was already at work, and as usual I dropped my two sons, Colin and Brian, first and second graders, off at school on my way to the office. It was a day like any other until late that afternoon when a series of events took place that would change my life forever.

At 4:00 p.m. I was looking forward to picking up the boys from a friend's house; they had gone to sell candy for the Cub Scouts and then play until I arrived at 5:15. My secretary tells me I have an emergency telephone call; I am told that Brian has been in an accident and is on his way to the emergency room in an ambulance. My thoughts are racing, but I'm sure it is something minor, perhaps a broken arm. "Ambulance" does not register.

I arrive and am advised that Brian has sustained a severe head injury; he is in very critical condition. I feel faint and sick, and suddenly everything is surreal. I am in a movie, watching from a distance. Everything has slowed down and I am in a thick fog. Family is arriving and I try to understand what is happening around me. My son, my baby, is dying and there is nothing I can do. The doctors keep telling me I can see him any minute. Time passes slowly, and I am crying, begging to see my son. I am his Mom: I should be making the decisions, but continue to be sequestered in a small confined room.

The doctor eventually appears and is sorry to inform me that Brian has been gone "about three minutes." I simply tell him, "He can't be dead, he has a swimming lesson tonight." I am led down an endless hall and ushered into the room where Brian lies, looking like he is asleep. I implore him to breathe, knowing that will happen at any moment. I touch him and he is cold; I am insistent that he needs a blanket.

More sounds, voices, people talking, asking questions - and finally I am told that it is time for me to "go home." Go home without Brian - how can anyone even suggest such a thing! I stop as I reach the door and ask, "What about donation?" A form is placed before me to sign and then I go. Later that night I receive a call from the coordinator at the tissue bank who is kind, compassionate and incredibly understanding.

I soon became acutely aware that Brian was to help restore someone's sight. Not just

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Brian gave the gift of sight



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anyone, but two young people who had lost their eyesight through an accident and disease. How do you put a value on that? A gift, simple and complete, a precious, priceless gift.

To try to measure the impact that this decision has had on me is hard to put into words; they do not seem adequate. I miss my son deeply; I will always miss him and forever wish that this tragedy had never occurred. Unfortunately accidents and untimely deaths are most often out of our control, nothing we can prepare for. I had no way of knowing that when I dropped Brian off at school that day that I would never see him alive again, that the last decision I could make for him, as his Mom, was that he would give the gift of sight as an eye donor. I was fortunate to have had the opportunity to make that choice; it has given me great comfort to know that something good could result from my personal tragedy. To be denied the opportunity to make that choice would have only compounded the calamity. The decision to donate is personal and families need to be able to decide what is best for their loved one. By giving them the choice, their shock and sadness will not be compounded; it will empower the family to feel they can help others through their unselfish decision.

Over the years I have had the great fortune to talk to many civic groups, schools, and medical professionals about my personal experience. The message never changes - I am very grateful for my decision, and it has helped my healing process immensely. One talk in particular has always left a lasting impression. I was sharing my story with my older son Colin's Cub Scout group, and at the end I asked if there were any questions. Colin raised his hand and with total innocence and sincerity, asked if the person that received Brian's eyes would see the world as he did. I hold that thought near and dear. Intellectually I know that this is not how transplantation works, but in my heart I know that those who see the world through Brian's eyes see a truly awesome place.

FOCUS GROUPS PROVIDE LEARNING OPPORTUNITIES

This spring Pacific Northwest Transplant Bank held two focus groups to provide staff from our service area's largest hospitals with a chance to learn from each other. Discussion in both groups focused on educational and cultural challenges hospitals have run into, best practices for what has worked well, and discussion about donation after cardiac death (DCD). Key topics of conversation included:

- Many hospitals identified physician education and leadership as challenging areas.
- Most hospitals have found that having hospital staff who are dedicated to improving donation and who work proactively to change hospital culture to be pro-donation, is key to improving donation outcomes.
- The hospitals located outside the Portland metro area, where hospital staff are responsible for requesting for organ donation, identified a need for greater support from PNTB toward improving the requesting process.
- Many hospitals have found experienced speakers invaluable in creating a DCD policy and in training their staff. If you would like to invite someone with DCD experience to speak to a group at your hospital about donation after cardiac death, please ask your hospital services coordinator.

PNTB is planning to host more focus groups in the future. To participate or to suggest topics for discussion, please contact your hospital services coordinator.



THE LIONS EYE BANK OF OREGON CELEBRATES 30 YEARS OF VISION

Each year in the United States more than 40,000 individuals receive corneal transplants. At one time not that many years ago, those in need of a cornea transplant waited through many months of darkness for their transplant. Today, the long waiting list is gone. This is a testament to the generosity of families in the Pacific Northwest and to the humanitarian efforts of the hospital staff who present the option of donation to grieving families.

In 1975 the Lions of Oregon recognized the need in Oregon and Clark County, Washington, for an eye bank to provide tissue for transplants, research and medical education. Since its inception 30 years ago, more than 13,000 people have received the gift of sight from tissue procured and screened by the Lions Eye Bank of Oregon. In addition, the Lions Eye Bank of Oregon is the largest distributor of disease-specific research tissue in the nation, according to the National Disease Research Interchange (NDRI), the government entity authorized to distribute research tissue.

As the only eye bank in the state of Oregon, the Lions Eye Bank of Oregon provided 382 corneal transplants in 2004 to residents of the state. Another 639 transplants were provided to residents in other states and to citizens of other countries where blinding diseases are prevalent. Equally important, 1184 ocular tissues were sent to important research programs in Oregon and elsewhere for the study of such diseases as glaucoma and macular degeneration.

On July 30, 2005, the Lions Eye Bank of Oregon will celebrate 30 years of vision with a fundraising black-tie gala celebration, honoring the eye bank's volunteer medical directors over the past 30 years. Devers Eye Institute and Casey Eye Institute have come together to sponsor this special event that will benefit the Oregon Lions Sight and Hearing Foundation and the Lions Vision Research Laboratory. For more information on this event, please contact Corrina Patzer at (503) 413-8376.

THREE AREA HOSPITALS RECEIVE HRSA MEDAL OF HONOR

The U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) has awarded the first Organ Donation Medals of Honor to hospitals achieving organ donation rates of 75 percent or higher in a 12-month period. Three hospitals in our area received the award: Southwest Washington Medical Center in Vancouver, Legacy Emanuel Hospital & Health Center in Portland, and St. Alphonsus Regional Medical Center in Boise.

To be eligible for the Medal of Honor, hospitals must have had at least eight eligible donors in a single, continuous 12-month period occurring between September 2003 and March 2005. To win the award, hospitals and organ procurement organizations (OPOs) must have successfully collaborated to convert at least 75 percent of these eligible donors to actual donors. Approximately 160 (30 percent) of the 542 qualifying hospitals nationwide merited the inaugural Organ Donation Medals of Honor.

Medal of Honor winners were recognized on May 19, 2005 at a formal dinner at the first annual Organ Donation Breakthrough Collaborative National Learning Congress in Pittsburgh, Pennsylvania. Award-winning hospitals are also planning their own recognition ceremonies.

In just these time periods, these three hospitals helped 117 recipients have another chance at life, and provided 11 organs for valuable medical research. On behalf of those recipients and their families, we thank and recognize these hospitals for their outstanding collaboration and success.

DONATED TRACHEAS LEAD TO RESEARCH BREAKTHROUGHS

After 20 years of effort, OHSU researchers are the first in the world to grow human airway parasympathetic nerve cells in culture, thanks to donated human trachea tissue from deceased donors. This project, and others, is possible thanks to the generosity of donor families in consenting to donate tissue for research.

Dr. David Jacoby, chief of Pulmonary and Critical Care, and Dr. Allison Fryer of the Department of Physiology and Pharmacology, both at OHSU, persisted in their long quest to grow cultures of human airway nerve cells because these cells play a crucial role in asthma. Understanding how the asthmatic reaction occurs in the airway is key to understanding and better controlling the disease.

The parasympathetic nerve cells of the human airway produce a protein, eotaxin, which attracts white blood cells called eosinophils. Autopsies of patients who have died of an asthma attack have shown great quantities of these eosinophils lining the nerve cells. It is believed that eosinophils stimulate the nerves, causing the muscles of the airway to constrict, creating the asthmatic symptoms. By growing the nerve cells, Dr. Jacoby and Dr. Fryer will be able to characterize the cells and these reactions carefully to further our understanding of asthma and its triggers. They are also working with pharmaceutical companies to identify compounds that may reduce the impact of eotaxin, potentially leading to new methods of controlling asthma.

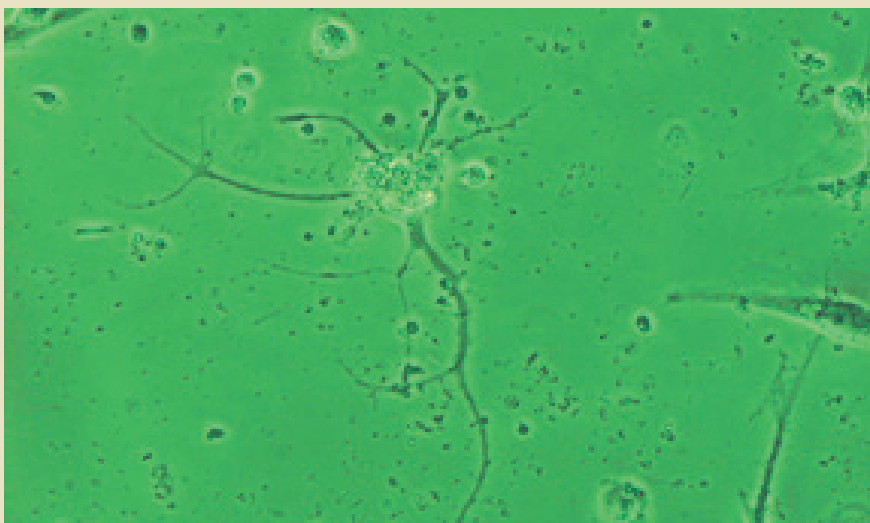
Due to asthma, in 2002 Americans missed

- 14.7 million school days
- 11.8 million work days

(National Health Interview Survey, National Center for Health Statistics, CDC)

Dr. Bruce Magun, chairman of OHSU's Department of Cell and Developmental Biology, is using the donated tracheal tissue to examine the impact of the potential bioterrorism agent ricin on human lungs. Upon inhalation, the first cells ricin would contact are the epithelial cells of the airway, so Dr. Magun's group is looking at the impact the toxin will have on those cells.

Dr. Grover Bagby and other researchers at the Oregon Cancer Institute are using the donated tissue to research the role of cigarette smoke in causing airway cell chromosomal changes. Such changes may be the first step in causing lung cancer.



The first human airway parasympathetic nerve cells ever grown in culture.

As with all research that relies on donated organs or tissues, these breakthroughs would not happen without the donor families and hospital staff members who support donation. While an organ donated for transplant has an immediate impact on the recipient's life, research projects like these will eventually help the 20 million Americans with asthma better control their disease, will help reduce the number of people diagnosed with lung cancer each year and will be invaluable in the country's attempts to prepare for a ricin attack.

POWERFUL WORDS IMPACT DONATION PART 1: TALKING ABOUT DONATION

From the Donor Family Council of the Association of Organ Procurement Organizations

Words have the power to hurt and heal; to encourage or create despair; to promote understanding or contribute to misconception. That has never been truer than in dealing with the sensitive subject of organ, eye and tissue donation.

Certain words have been in the donation and transplantation lexicon for years without much regard for the effect they have on potential donors and donor families.

Last May, the Donor Family Council of the Association of Organ Procurement Organizations (AOPO) approved the use of new terminology about donation. They reasoned that avoiding words and phrases that cause concern among donor families and the general public will not only increase understanding, but acceptance of the donation process.

Although the word "harvest" has been widely used in the medical community for years, "recover" is a better word that doesn't conjure up visions of crops, crows and combines. "Surgical recovery of organs" is better than "harvesting of organs."

In the past, there was no need to be specific in the use of the word "donor." But as more and more people choose to be living donors, use of the word "cadaver" or the phrase "cadaveric donation" tends to depersonalize the gift of donation. The Donor Family Council suggests that the use of "deceased donor" and "deceased donation" provide a more positive message to donor families and the general public.

Another sensitive area is the use of the words "life support" when referring to someone on "mechanical or ventilated support." There are two ways of determining death: when the heart stops functioning and when the brain stops functioning. Most organ donors suffer brain death before donation, and are on "mechanical support" when they die. During that time, the donor's organs are perfused with oxygen for several hours, using "mechanical or ventilated support." When death occurs, there is no support that can make the individual live again, and using that terminology can confuse donor families.

Words mean everything when a donor family is dealing with the shock and grief over the death of a loved one, and words may make the critical difference when someone is trying to decide whether or not to become an organ, eye and tissue donor.

In our next issue: the importance of language in the requesting process.

OREGON DONOR PROGRAM CALENDAR OF EVENTS

Sisters Quilt Show
Benefiting ODP Threads of Life quilts
July 9
Sisters, OR

ODP Golf Tournament
August 23
Pumpkin Ridge Golf Course
North Plains, OR

Summer Garden Party
Benefiting ODP
July 10
Vancouver, WA

ODP booth at Oregon State Fair
August 26 - Sept. 5
Salem, OR
Columbia Hall

National Minority Donor Awareness Day
August 1

American Red Cross "O" Blood Drive & Organ and
Tissue Awareness Event
October 1
Portland, OR

Bovine & Wine Dinner
Benefiting ODP
August 6
Ridgefield, WA

Contact 503.494.7888 or 1.800.452.1369 for details on all events



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