



# Coalition for Life Quarterly

“yes”  
Idaho!

Beginning July 1<sup>st</sup>, the new Idaho Donor Registry, “YES Idaho!,” will enable Idahoans to make an informed and binding decision to be organ and tissue donors.

In the past, Idaho residents who chose to be organ and tissue donors could make their decision known only by marking it on their driver’s license, by carrying a donor card or by telling their family. Because these methods were not considered informed consent, the decision was not binding. At the time of death, the family was asked to consent to donation, and the family’s decision was followed, even if it differed from that of the deceased.

The Idaho Anatomical Gift Act has been strengthened. The act now requires that detailed information about donation be provided to each individual who indicates a desire to become an organ or tissue donor upon death. This detailed information, primarily provided by the Idaho Department of Transportation during driver’s license application or renewal, has been meticulously prepared to meet national standards for informed consent.

At the time of death of a person on the Registry, the designated requestor will no longer ask the family for consent. Instead, he/she will inform the family of their loved one’s decision to be a donor and will provide information about donation and answer any questions the family has.

“We have found that families are often pleased to learn that their loved one had documented their decision to be a donor,” explains Jay Lugo of the Idaho Lions Eye Bank. “That knowledge helps families see the donation process as a way of fulfilling their loved ones’ last wishes and provides a comforting sense of closure. The Idaho Donor Registry is an even stronger way to make this possible.”

## HOW TO JOIN THE IDAHO DONOR REGISTRY

Log onto the Yes Idaho Registry Web site and follow the instructions:

**[www.YesIdaho.org](http://www.YesIdaho.org)**

or call:

**866-937-4324**

to have registration information mailed to you.

## THE REQUEST FOR DONATION: A MOTHER'S POINT OF VIEW

By RACHEL MACKKEY

Nathan, age 24, died of a posterior fossa intracranial hemorrhage in December 2002 at Legacy Emanuel Hospital. His family made the decision to donate his organs, and he became the first patient in Oregon to be a Donation After Cardiac Death donor. His mother, Rachel, agreed to share with us her experience with the requesting process, in the hopes that it will help *Coalition for Life Quarterly* readers understand the process from the family's perspective.

CLQ: *How were you approached about donation? How did it feel to you?*

Within about 36 to 48 hours, we realized Nate was not going to survive. The doctor had been clear with us about Nate's condition: Nate was not brain dead, but was not going to recover. We told the nursing staff we would like to talk to someone about organ donation, and they contacted PNTB [Pacific Northwest Transplant Bank].

When we first raised the issue of organ donation, the nursing staff told us that Nate's drivers licences (both Kansas and Oregon) indicated his wishes to be an organ donor. He had discussed this with family and friends, so it was as we expected. I do remember feeling that the possibility of Nate being an organ donor was a small bright spot in a tragic circumstance.

CLQ: *Did you have questions for the donation team who worked with you? How were they answered?*

The donation team provided us with very clear and detailed information about donation. Whenever I did have any questions, they were answered promptly and with care and compassion. I felt that every individual involved took great care to keep us informed and to provide support. Again, I had feelings that despite my sadness, this would provide something positive. I knew Nate would be pleased.

While there were times when everything seemed so completely out of control, there was a calming and comforting sense of purpose coming from the donation team and the ICU staff at the hospital. It was sort of a grounded feeling that something special and meaningful was happening. All of the contact with the team was very good.



Nate, with his mother,  
Rachel.

One particular memory I have is of one of my first conversations with Curt [Kandra, a PNTB coordinator]. We were in the ICU waiting room talking, and he told me that he needed more information about Nate. I immediately launched into telling him all about Nate – what kind of person he was, what he had been doing with his life, what his loves and idiosyncracies were – things like that. I realized later that Curt was probably trying to initiate arrangements for taking the medical/social history, and that all of the information I gave him was not the kind of information he needed. Curt sat and listened attentively and patiently to all of my descriptions and stories about my son. He allowed me to do exactly what I needed to do at that time. I am appreciative of that kindness.

Everyone was so kind and supportive throughout the entire process. Even the team members with whom I only had a little eye contact in the operating room helped me immensely. I knew Nate was in loving and caring hands.

CLQ: *Was going through the medical/social history and consent form a difficult process for you?*

For me, this was not really a difficult process. Again, it was an opportunity to remember things about Nate and his life, and to talk about him. Again, Curt was patient and wonderful during this process. I recall thinking he must find us all a bit odd, but he handled it all really well. We sat over by the closed coffee counter to do this and it seemed peaceful and quiet. I recall Curt asking if Nate ever had any broken bones, and all of us being amazed that the answer was no. He was a daring, hyperactive kid and we all held our breath a lot at his childhood sense of indestructiveness. When he was about five or six, he used to put on capes made of scarves and tell us he was “nigh invulnerable.” How he managed to escape without at least one broken bone was amazing.

Nate's friends were included in the social history, and I think it made them feel they were a part of the process. His friends from Portland had stayed close by all week, and three of his best friends had come from Kansas. I believe they needed to be a part of this, and the involvement and inclusion of their information in the social history was good. There was some well-needed comic relief in that part of the process.

CLQ: *Do you have any suggestions for future requesting teams, either something this team did exceptionally well, or something that could have been better for you?*

Everything this team did was done exceptionally well. I have not had any complaints or concerns about how things were handled. In fact, there was an underlying peacefulness to this for me.

One of the most important and well done aspects is one that is hard to describe. As a mother experiencing the death of her son, there were many times when I needed to separate myself from the process (sometimes physically and sometimes emotionally), and times when I needed to be immersed in the process. There was not a single time when my need to separate was intruded upon by any of the donation team or hospital staff. When I needed to be left alone, that seemed to happen without my asking. When I needed to be involved, or needed support, that also seemed to happen without my asking. I remain grateful for the kindness I received. Thanks to everyone who was involved.



*Back row, l-r: Cyndy O'Brien, Paige DaSaro.  
Front row, l-r: Julia Corson, Craig Van De Walker*

## NEW ROLES, NEW FACES AT PNTB

As part of its organizational restructuring, PNTB has created several new positions.

### **WAYNE DUNLAP, PROCUREMENT MANAGER**

Wayne Dunlap, formerly an organ procurement coordinator, has been promoted to the newly created position of procurement manager. His responsibilities include management of the clinical aspects of donation and supervision of the organ procurement coordinators. Wayne has been with PNTB for more than three years, and was a critical care nurse at St. Alphonsus Regional Medical Center in Boise before joining PNTB. Wayne also represents Region 6 on the United Network for Organ Sharing (UNOS) Transplant Coordinators Committee.

### **CURT KANDRA, CONTINUOUS QUALITY IMPROVEMENT**

Curt is responsible for ensuring and tracking the organization's high quality service in all aspects of donation. Before taking this new position, Curt was an organ procurement coordinator for PNTB for six years.

### **DEBORAH HOERNER, DATA COORDINATOR**

Deborah's responsibilities include submitting organ placement and death record review data to UNOS; tracking data for hospital development purposes; coordinating PNTB's proprietary referral and donor database; and managing the designated requestor training program. Deborah was previously in higher education administration.

PNTB has also hired several new organ procurement coordinators to meet the growing need for organ procurement services.

### **CYNDY O'BRIEN**

Cyndy is a registered respiratory therapist. She has several years experience in critical care, most recently for 13 years at OHSU.

### **PAIGE DAsARO**

Paige was previously a pediatric critical care nurse, specializing in cardio-thoracic surgery and ECMO. She worked at several institutions, including OHSU, Children's Mercy in Kansas City, Missouri, and the University of Kansas, Kansas City, Kansas.

### **JULIA CORSON**

Julia worked for seven years at University of Rochester on the blood and marrow transplant unit. She also worked for a year and a half at Planned Parenthood of the Columbia-Willamette before joining PNTB.

### **CRAIG VAN DE WALKER**

Craig is a respiratory therapist and was previously a Manager of Respiratory Therapy at Providence St. Vincent Medical Center. Craig is currently serving a term as the Management Chair of the Oregon State Society of Respiratory Care (OSRC).

## THE IMPORTANCE OF THE MEDICAL / SOCIAL HISTORY INTERVIEW

Many of you have donated blood. Prior to donation, a battery of questions must be answered in order to assess risk of the donor transmitting a disease to the recipient. A similar set of questions is required in order to determine eligibility for eye, tissue and organ donation.

The questions in the interview are designed to elicit a broad range of information including general medical history, travel history and sensitive high-risk information related to drug abuse and sexual behaviors. Expecting families to answer questions about their loved one's history is difficult when uppermost in their mind is the loss they have suffered. Donation coordinators recognize this and work very hard to present these questions compassionately.

The average length of the interview is 15-40 minutes. The length varies not only because medical history is so variable among the donor population, but because each family has unique needs. We try to address these needs throughout the interview, which often results in a positive experience for the family. Having the opportunity to speak directly to the donation agency helps families feel comfortable with those who will be handling their loved one's donation.

There are a few things you, as donor family advocates, can do to assist the family at this time. Make sure that the family member to be interviewed is fully informed about the length and scope of the interview. Also, make sure they are in a quiet, private place that is appropriate for this conversation.

Although our time constraints are critical, we can wait up to several hours after death to go through these questions. Some families need this additional time, while some need to "be done with it." The caregiver's assessment of the family's needs is critical to the positive outcome of the donation process. Those needs must be communicated to the donor agency so that we are prepared to adequately comfort the family.

The importance of the medical and social information is highlighted by the fact that we deferred 31 consented potential donors in 2003 as a result of information gathered during the medical/social history interview. Most often we had to decline to accept the donation because of high-risk behaviors for hepatitis and HIV, a remote history of hepatitis that had not been reported in the current medical record, or neurological conditions that are contraindications to donation. Had we procured these tissues before conducting the medical / social interview, we would have been unable to utilize the gifts. This would have been very disappointing to families who had already given consent for donation.

With an increasingly complex landscape of diseases that pose risk to recipients, these questions are more important than ever. SARS, new variant Creutzfeld-Jakob disease (the human version of mad cow disease), small pox vaccination viremia and West Nile virus are all emerging infectious diseases that pose threats to recipients.

Our experience has been that a properly prepared family member is determined to do whatever is necessary to ensure a safe outcome for the recipient of the generous act of donation. With your help preparing the family for the medical / social history interview, we can make sure that safe tissue, eye and organ donation is possible.

### RECIPIENT STATISTICS:

So far in 2004, the donation agencies in our service area have helped 9,305 people through transplantation.

#### JAN-MAY 2004 RECIPIENT STATISTICS:

##### ORGAN RECIPIENTS

**144** total  
72 kidney (R, L, or enbloc\*)  
6 kidney-pancreas  
15 heart  
36 liver  
14 lung (R, L, or enbloc)  
1 intestine

##### TISSUE

**8,717** grafts were distributed in our service area.  
(Although these may not have all been transplanted yet, we have included them in the total number of people helped above.)

##### EYE RECIPIENTS

**444** total  
19 sclera  
425 cornea

*\*Enbloc kidney or lung refers to both kidneys or lungs being recovered and transplanted together.*

## FREQUENTLY ASKED QUESTIONS FROM HOSPITAL STAFF

### 1. WHY CAN'T I CALL THE LOCAL DONATION AGENCIES DIRECTLY WITH A REFERRAL?

The donor referral line (1-800-344-8916) is in place to ensure compliance with the Center for Medicare/Medicaid Services (CMS) Conditions of Participation for Hospitals. Every death or impending death must be reported to the donor referral line as part of the regulation. Without proper notification to the donor referral line, compliance cannot be verified.

### 2. AM I A DESIGNATED REQUESTOR?

If you have attended a training course or completed the online recertification course within the last 12 months, you are a designated requestor. If you attended the organ donation portion of the training, you are a designated requestor for organs, tissue and eyes. If you left before the organ portion (because you are in a metropolitan area and PNTB requests organs at your hospital), you are a designated requestor for tissue and eyes only. If you are not a current requestor and cannot locate a designated requestor on your unit, please call the donor referral line (1-800-344-8916). The coordinators at the local donation agencies are designated requestors and can make the request over the telephone.

### 3. CAN I TAKE THE ONLINE TRAINING FOR DESIGNATED REQUESTORS?

The online training for designated requestors is for recertification only. Once you have attended an in-person training course for new designated requestors, you are eligible to recertify using the online training program found at [www.pntb.org](http://www.pntb.org). If your last training, either in-person or online, was more than 12 months ago, you will need to attend another in-person training to update your knowledge and skills.

**IF YOU HAVE ANY QUESTIONS REGARDING YOUR DESIGNATED REQUESTOR STATUS, PLEASE CONTACT YOUR PNTB HOSPITAL SERVICES COORDINATOR OR DEBORAH HOERNER AT (503) 494-5560.**



A Donate Life Organization

## UPCOMING DESIGNATED REQUESTOR TRAININGS

### Bend

St. Charles Medical Center  
Aug. 5, 9:00 a.m. – 4:00 p.m.

### Salem

Salem Hospital Auditorium  
Aug. 20, 9:00 a.m. – 4:00 p.m.

### Eugene

Eugene Hilton  
Sept. 7, 9:00 a.m. – 4:00 p.m.

### Portland

PNTB offices  
Sept. 13, 9:00 a.m. – 4:00 p.m. (FULL)  
Sept. 14, 9:00 a.m. – 4:00 p.m. (FULL)  
Sept. 16, 9:00 a.m. – 4:00 p.m. (FULL)

*To register for a designated requestor training, contact your designated hospital services coordinator (find your hospital's liaison at [www.pntb.org](http://www.pntb.org)) or contact Deborah Hoerner, 503-494-5560.*

## CTS AND LEBO CONTINUE TO IMPROVE THE DONATION PROCESS

BY AARON J. MADSEN

Community Tissue Services (CTS) and Lions Eye Bank of Oregon (LEBO) have implemented a change in their coordinators' roles to further improve their service to hospitals. CTS and LEBO coordinators are now designated either to screen referral calls or to procure gifts from the donors. The separation of these roles, which were previously both handled by the coordinators on call, has made it easier for the screening coordinators to spend more time talking with nursing staff and families. This additional time for customer service has already resulted in an increase in the number of families giving consent for donation.

Following on the heels of CTS and LEBO's switch to a centralized call center, this change is another way that your donation agencies are making donation easier for hospitals.

## EVENTS CALENDAR – JULY TO SEPTEMBER

**Bethany Vineyard Bovine & Wine, Ridgefield, WA**  
Benefit for Oregon Donor Program  
Aug 7, 6:00 – 9:00 p.m.

**Jason Giani Memorial Golf Tournament, Aurora, OR**  
Langdon Farms Golf Course  
Benefit for Oregon Donor Program  
Aug. 9, 1:45 p.m.

**Threads of Life Quilt Display, Florence, OR**  
Florence Quilt Show  
Aug. 14-15

**Benefit Golf Tournament, West Linn, OR**  
The Oregon Golf Club  
Benefit for Oregon Donor Program  
Aug. 23, Noon

**Five Points of Life Bike Ride (Oregon Stops)**  
Coast-to-coast Organ and Tissue Awareness Raiser  
Aug. 27 (morning) – Downtown Portland  
Aug. 27 (afternoon) – Capitol Building, Salem  
Aug. 28 – Sisters/Bend

**Taste of Vancouver, Vancouver, WA**  
Benefit for Oregon Donor Program  
Sept. 3-6

*For more information about any of the awareness or fundraising events, please contact  
Oregon Donor Program at 503-494-7888*

## Coalition for Life Quarterly

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