

Update

September–October 2002

First Person Consent

OPOs across the country are adapting to the change

By Karen Sokohl

Whether you call it “first person consent” or “donor designation,” it means the same thing—the donor’s decision is paramount and should be respected at all costs. Exploring new ways to combat the ever-increasing waiting list, more states are legislating some form of donor designation.

Although the legislation is a hot topic these days, organ procurement organizations (OPOs) in Pennsylvania have dealt with the issue since passage of its comprehensive organ donation legislation in 1994. Pennsylvania Act 102 has three major components, each of which has had a dramatic effect on donation rates in that state:

- mandating the routine referral of all deaths to the OPO (levying a fine if hospitals miss a referral);
- setting up a donation registry through the Division of Motor Vehicles (DMV), allowing licensed drivers to indicate their consent for donation on their license; and
- strengthening the language to make the donor’s wish paramount.

“We’re convinced that this was effective in increasing donation rates,” said Howard Nathan, executive director of the Gift of Life OPO in Philadelphia. “And we’re convinced that partnership with DMV is the way to go.”

Pennsylvania’s donor registry is affiliated with the DMV, and OPO coordinators have 24-hour, seven-day-a-week phone access to the database. Delaware

(also part of Gift of Life’s service area) has a similar registry, although it can be accessed online. DMV updates the information every 24 hours.

“You don’t just pass a law,” Nathan continued. “We’ve always had a grass roots style. We’re present in the hospitals, and our primary focus is on physicians and administrators. We want to be their partner—we don’t just want to tell them they have to follow a law.”

Their OPO also changed its request process. OPO coordinators now reaffirm the donor’s designation with the family or make a request if no donor designation is present, rather than donor hospital staff acting on their own.

Adapting to change

Having the legislation on the books is one thing—implementing a new approach is another. Moving away from the traditional model of approaching families for their consent took some getting used to.

“It was difficult for the staff at first,” said Brian Broznick, executive director of CORE, the OPO serving the western part of Pennsylvania and much of West Virginia. “In fact, it was much harder for them than for the hospital employees. Hospital folks assumed that we were already operating this way. But the feeling among some of our staff was that we simply couldn’t go against a family’s wish, even if the person had indicated the wish to be a donor on his or her driver’s license.”

continued on page 3

CONTENTS

From the Board _____	4
National Donor Memorial Update _____	6
Committee Chairs, Vice Chairs _____	8
News from Members _____	10
African American Campaign _____	15
A Judeo-Biblical Perspective _____	19
Recent Transplant Research _____	20
Book Review _____	22
Life Goes On _____	23
Career Moves _____	24

Executive Director
Walter Graham

Director of External Affairs
Elisabeth J. Gabrynowicz

Assistant Director, Communications
Joel D. Newman

Editor
Diana G Westbrook

Graphic Designer
Andrew T. Swartz

UNOS Update (ISSN 1077-8268) is a bimonthly publication of the United Network for Organ Sharing, 1100 Boulders Parkway, Suite 500, P.O. Box 13770, Richmond, VA 23225-8770; News (804) 330-8562; Advertising (804) 323-4300; fax (804) 330-8507. Copyright © 2001 United Network for Organ Sharing.

Visit the UNOS Web site at www.unos.org

continued from page 1

Throughout the seven years the legislation has been in effect, CORE has proceeded with three donation cases when the family expressed opposition.

“This was difficult for us,” said Broznick. “We wanted to honor the wishes of the donor, but the families were against it and became angry. They didn’t want anything to do with us. We didn’t stop trying, though, and eventually they returned our phone calls and became more involved with our organization. Some of them now speak at our educational events. In fact, they told us later that they were glad we pushed them, because if we hadn’t, they wouldn’t have been able to fulfill their loved one’s final wish.”

Having ventured into uncharted waters, CORE staff were understandably anxious.

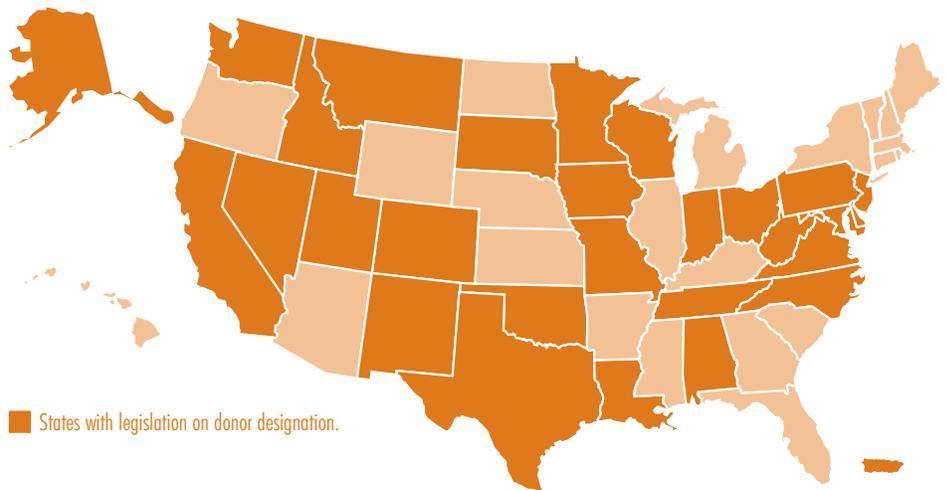
“We were nervous after the first case. We were prepared for families to take their story to the media. We were prepared for bad press and even prepared to be sued. We had our crisis plan in place, but we never had to use it.”

Virginia’s experience

LifeNet, the Virginia OPO serving the eastern, central and southwestern part of the state, also had some difficulties making the 180-degree change in its process. Since July 2000, the state’s newly modified organ donation law reads as follows:

The donor designation on the driver’s license or a signed donor document is sufficient legal authority for the procurement of organs and tissues following death, and without additional authority from the donor, his family or estate and that no family member, guardian, or agent shall refuse to honor the donor designation in any way.

This change was an outcome of a Virginia Joint Commission on Health Care study; at the time of the study, none of the OPOs serving Virginia were willing to go above a family’s wishes, even though the original language of the [federal] Uniform Anatomical Gift Act made it legal to do so. But the new language left nothing to interpretation.



For updates or corrections to this graphic, please contact Karen Sokohl at sokohlka@unos.org.

“We weren’t ready,” said Helen Leslie, LifeNet’s executive director. “You can’t automatically switch to something like that. It was a complete philosophical change.”

They began extensive preparation. Over a six-month period they worked with their board, committees and members of their local coalition.

“We had lots of staff discussions at first,” said Leslie. “It was absolutely essential that we had 100% buy-in of this concept. That took some gut-wrenching, lay-everything-on-the-table discussions. Some of the staff initially had problems, and they would say to me, ‘How can you do this to the families?’”

“The point is, our focus has always been taking care of families, and that hasn’t changed. We’re simply taking care of the donor as well, and the two don’t have to be mutually exclusive.” Eventually everyone came on board. The Richmond paper even wrote an editorial supporting the decision.

Virginia’s law also made it clear that there is no need to sign a consent form. A photocopy of a driver’s license or a will or donor card is sufficient. This is also true in Pennsylvania.

Spanning the country

First-person consent legislation is now affecting additional states, and the issue crosses state lines. Maria Sanders, community services director for New

Mexico Donor Services, commented that they received a phone call from a hospital in Colorado.

“Colorado has first person consent laws, but the person who died was from New Mexico and they wanted us to check the donor designation on their driver’s license. The person in Colorado was unsure what this meant legally and was calling to get confirmation from us. People are always asking us which states have donor designation. Nothing is standardized.”

In an effort to help OPOs deal with their first person consent issues and learning curves, Helen Leslie has traveled across the country and shared her experiences with at least a dozen different organizations.

“I think people want to hear that if they implement a registry that their numbers will magically increase and it will solve a lot of our problems,” she said. “That’s not going to happen.”

“But when the day comes when you can go into Ohio or Alaska or Missouri and a signed donor card or driver’s license means the same thing in every place—well, that’s when we’ve really accomplished something.”

This is the first of a three-part series on first person consent legislation and donor registries. Watch for a follow-up article about the development and growth of donor registries in the Nov.–Dec. issue of the UNOS Update.

Karen Sokohl is the member communications specialist at UNOS and a contributing writer.

The Nuts and Bolts of Developing Donor Registries

States across the country have varied experiences

By Karen Sokohl

As more and more states adopt first-person consent legislation, we are seeing a proliferation of donor registries across the country. Everyone from Virginia to Utah and beyond is jumping on the bandwagon. Some of these registries are affiliated with local motor vehicle departments, while others are independent or OPO-based. Here are profiles of just a few of them.

Utah

On April 16, 2002, Utah Governor Mike Leavitt and his wife, Jacalyn, celebrated the launch of their state's first online donor registry. In front of 100 supporters, they added their names to Utah's Internet registry of organ donors. The successful launch was a long time coming.

"We first began looking at the idea of a registry about three years ago," said Alex McDonald, chairperson for the Utah Coalition on Organ, Eye and Tissue Donation. "At that point, we weren't convinced that registries were necessarily the way to go." After nearly 16 months of careful planning and support from the strong local coalition, however, the result was www.yesutah.org, allowing all Utahns to register online as a donor.

If they prefer, they have the option of mailing in a registration form, made widely available at Utah's Driver License Division (DLD) offices. Once their registration is received through the mail or through the Internet, Intermountain Donor Services (IDS—Utah's OPO) sends them a confirmation card containing an identification number, which registrants can use to access their information online.

Prior to the development of the registry, Utah had no easy way to check the donor designation status on an individual's driver's license record. Existing administrative laws restricted the distribution of driver's record information to anyone unless they had the driver's license in hand. The local coalition worked to amend the legislation,

which then allowed the DLD to release to the OPO more than a million names of individuals who had agreed to donation when applying for their license.

When they first imported DLD's existing donor database, IDS sent out 580,000 letters to all the households of organ donors on that list. The letter informed them that because they had said yes to becoming an organ donor on their driver's license, their information was being transferred to an updated donor registry. For those not agreeing with that assessment or wanting to change their decision, they could either fill out the form that was enclosed and send it back, or simply go online and edit their existing information.

"Once a no designation is in place, a family is very reluctant to go against it..."

Notably, of all the letters sent, only 180 so far have been returned with the request to be removed from the registry. Those requests weren't necessarily anti-donation. Some included notes such as, "I still want to be an organ donor, but I want my family to be able to make that final decision." In addition to the roughly 180 forms requesting changes, 15,000 forms were returned indicating no objections or changes at all, with a handful containing limitations on specific organs or tissues that could be donated. Many people simply returned the form, sometimes adding notes that praised the development of the Utah donor registry or reiterating their support of organ donation.

Since the coalition does not have the technical expertise to develop and maintain a registry in-house, they contracted with a well-respected, local Internet services provider and allocated a specific portion of the coalition's yearly budget to the creation and maintenance of the registry.

In addition, they already have spent close to \$80,000 on an advertising campaign, including billboards and television ads.

IDS has also found the registry to be a highly effective tool when communicating with health-care professionals as well.

"We have always stressed to hospital personnel that they need to call us first when they have a donor referral," said McDonald. "The registry gives us yet another reason to encourage that, since we can tell them straight away whether this individual is a donor. It really helps them when approaching the families, if they can walk in knowing that the person wanted to be a donor."

New Mexico

Because of an antiquated record-keeping system at New Mexico's DMV, which consisted of photo copies stored on microfilm, for years the only way the New Mexico Donor Services (the state's OPO) could check on potential donors was to wait for the DMV to send them the actual microfiche. They could then view the record through a special machine.

Five years ago, however, the DMV converted all its records to an Internet-based system, making the information much more easily accessible. After signing a confidentiality agreement stating that the OPO would not use the driver's license information for any purpose other than donor identification, procurement coordinators were allowed instant access to the donor registry information. The registry was now a functional resource, and their already positive relationship with the DMV continued to flourish.

The new system also meshed perfectly with New Mexico's first-person consent legislation, which took effect last May. New Mexico has long had an indication of donation on its driver's licenses. In fact, it was one of the first states to imprint a heart logo on the front of the card. For first-person consent purposes, though, the heart logo was considered a statement of intent only and not sufficient legal documentation.

All new and renewal license applicants now follow a new procedure. When they apply for their license, they are asked

whether they want to donate their organs. If the answer is yes, they sign a digital pad with a line under their signature stating they are an organ donor. If the answer is no, they sign a blank pad. These digital signatures are later transferred onto the license, and the license becomes a legal indication of donation.

The DMV driver's license forms are being changed to comply with the new first-person consent legislation. For people issued a license before the first-person consent legislation passed, they can request a sticker for the back of their card, making their license a valid legal donation document.

Brochures and posters are widely distributed through the motor vehicle departments, and because of an effective working relationship, the New Mexico Donor Services (NMDS) is confident DMV asks the question in the right way. The donation question is actually a mandate for motor vehicle department clerks, and NMDP has access to the DMV director, managers, supervisors and clerks if any problem is identified or reported by the public.

"It's interesting to note," said Maria Sanders, community services director for NMDS, "that 47 percent of New Mexicans who have a driver's license, identification card or commercial license have registered to be organ donors."

Virginia

Since the passage of its first-person consent legislation in July 2000, LifeNet, one of two Virginia OPOs, has had its biggest battle with the development of the registry itself.

For years, Virginia's DMV has warehoused the records of individual decisions to be an organ donor. LifeNet has struggled with inconsistencies in this system. It seemed as if a disproportionate number of "no" answers had been popping up on the database, and this has had a negative impact on donation.

"In one month alone," said Helen Leslie, LifeNet's executive director, "out of 17 potential organ donors, 12 had a no on the registry. Noes are coming up on a three-to-one ratio."

One explanation for this could be the process the DMV uses to record donation decisions. In addition to yes, DMV also allows the following opt-out options: no, undecided, refused and no answer. The problem is that these multiple options allow for operator error, much more so than if there were a yes option only. "Once a no designation is in place, a family is very reluctant to go against it," said Leslie.

Plans for a donor registry to be housed by the Virginia Department of Health (VDH) have long been under way. Recent state budget cuts, however, have forced the VDH to work creatively with the Virginia Transplant Council to keep the registry alive. An abbreviated version of the registry is very close to launch.

"It was very important to us to have our registry up and running when our first-person consent legislation took effect."

Once activated, DMV will transfer all "yes" responses into this registry and will update the information every evening. Most important, all Virginia OPOs, tissue banks and eye banks will have 24-hour access to that information. Ultimately, Virginians who want to designate themselves to be a donor will be able to register online. LifeNet has moved ahead with plans to launch a full-scale media campaign to promote the new registry.

"Even with the new registry in place," said Leslie, "we will continue to encourage the DMV to change to a fully opt-in system. This has been a difficult process, yet I'm inspired with the collaboration and dedication I've seen."

Iowa

Iowans are logging on to the new Internet-based donor registry in record numbers. Iowa Donor Network (IDN) has tracked approximately 1,300 new registrants a month since the launch of its registry in March of this year.

"We've had a tremendous response to our advertising campaign," said Paul

Sodders, public information manager for IDN. "We've actually had to hire additional part-time staff to assist with registry logistics. Many people in our state were outraged when they discovered that prior to first-person consent legislation, their families could actually override their decision to donate. They were extremely grateful to hear about the registry and the new law."

IDN moved ahead to create an independent registry once discovering it would be too expensive and time-consuming to work with the DMV in accessing its database.

"DMV's database wasn't set up to easily isolate organ donor information fields, and it could have taken years to access that information," said Sodders. "It was very important to us to have our registry up and running when our first-person consent legislation took effect."

Iowans can add their name to the registry in one of three ways. They can go to www.iowadonorregistry.org and do it themselves. They can call and register by phone. Or they can mail in a brochure found in DMV branches, hospitals or local libraries.

Regardless of the method used, all registrants are first sent a signature postcard when their request is processed. The signed postcard must be returned and scanned into the system before the registry entry is considered legal documentation under first-person consent law. Most important, the registry can be accessed 24 hours a day from anywhere coordinators have access to the Internet.

"That's probably the most important element for anybody to consider when they are creating a registry," said Sodders. "That and making sure it's an opt-in only system. It will save you a lot of heartache in the end." ■

This is the second in a three-part series on first person consent and donor registries. The third and final article will look at lessons learned while developing donor registries.

Karen Sokohl is the member communications specialist at UNOS and a contributing writer.

How We Did It

Four OPOs talk about what worked in developing their donor registries

BY KAREN SOKOHL

The idea behind first-person consent legislation and donor registries is a radical departure from the message that has been communicated for the past 10 years. Focusing on the donor's decision instead of the family's consent has basically turned the process upside down. As organ procurement organizations (OPOs) adapt to the change and prepare to revamp their processes, they are finding that it is impossible to plan or communicate too much.

Arizona: Starting from scratch

Arizona is unique. There is nothing on Arizona's driver's license to indicate that a person is an organ donor, and the information isn't recorded in a database when individuals first apply for or renew their license. In addition, Arizona doesn't require renewal for many years.

"My license doesn't expire until 2026," laughed Sara Pace Jones, donor program development director for Arizona Donor Network. "But what if, when I had registered for my license, I chose not to be a donor, and then five years later changed my mind. Odds are I'm not going to go to the trouble of making the change on my license just to reflect the organ donation indication—especially if I'm not scheduled to renew it for many years."

The result? While other states have been able to initially transfer thousands of names into a new donor registry based on data from the Division of Motor Vehicles (DMV), Arizona is forced to create an independent registry from scratch.

"It's going to be a challenge," Jones said. "But we have a comprehensive plan in place, and we're very excited about it."

Although the language in Arizona's anatomical gift act had allowed for first-person consent for years, procurement coordinators never relied on signed donor cards as a legal means of consent. They have relied instead on permission from the family. Arizona's new donor registry, however, will satisfactorily meet the OPO's requirements for informed consent and a registry entry alone will now be sufficient.

A number of donation and health-care-related organizations in Arizona with shared goals first began work on a state registry in December 2001. They received a grant from St. Luke's Health Initiatives Technical Assistance Program, which provided an auspicious launch for their efforts. Developed for groups seeking to collaborate, the grant provided a professional facilitator.

"Using a facilitator to bring the groups together and put everyone on the same page was a huge help," Jones said. "I attribute much of our initial success to that."

“Research tells us that Americans are overwhelmingly in support of donation,” Jones said. “Most of our messages tell people that donation is a good thing, when what they may want to know is how to become a donor. One researcher told us that in many donation Web sites you had to go three pages deep just to find out how to be a donor. After hearing this, she said, “I immediately changed our Web site to bring that information front and center.”

Washington: The challenge of multiple regions

Another situation entirely is faced by LifeCenter Northwest, which has the challenge of serving multiple regions across state lines. Enforcing first-person consent legislation and creating donor registries for one state is a challenge, but doing so for more than one can be daunting. At the onset, LifeCenter created a “first-person consent team” with a representative from every OPO department to prepare the organization for a fundamental shift in operations.

“We developed the team mainly for Washington, but we have duplicate legislation creating a registry going through in Montana. We hope to use this system as a template for all the states in our service area,” said Jill Steinhaus, public relations manager for LifeCenter Northwest. “We’ll work closely with the other states to help them to create a system that matches this one,” she added.

LifeCenter also had relied on the advice of others when first getting started.

“I have to give a lot of credit to Colorado,” Steinhaus said. “It was wonderful to have feedback from people who had just gone through exactly what we were dealing with. I can’t begin to estimate how many hours Cindy Harms, director of donor education, spent on the phone with me.” LifeCenter studied organizations across the country but looked most closely at Virginia, Iowa, Utah and Colorado. “All those organizations were wonderful in sharing what they had gone through and helping us figure out what we needed to do.”

Steinhaus is confident that the donor registry legislation currently being considered will work. A public perception survey conducted last March told LifeCenter that 74 percent of respondents in the region believed that a registry was already in place. Another 11 percent weren’t sure.

“That percentage bodes well for what we’re doing,” said Steinhaus.

LifeCenter’s ultimate goal is to have one database that will register donors from Washington, Montana and Alaska. Interestingly, neighbor Oregon has been following Washington’s progress closely and is considering replicating LifeCenter’s system exactly.

Ohio: Keeping it simple

Unlike Arizona and Washington, whose registries are still in the development stage, Ohio has had an operational registry since last July. Although initially funded through the Ohio Department of Health, the Bureau of Motor Vehicles (BMV) maintains the registry. As a result, the four OPOs that cover the state of Ohio have developed close working relationships with both state entities.

“The recovery agencies don’t own the registry,” said Marilyn Pongonis, communications manager at Lifeline of Ohio in Columbus, “so it’s very important for us to have a good relationship with the state agencies involved in the

A public perception survey conducted last March told LifeCenter that 74 percent of respondents in the region believed that a registry was already in place. Another 11 percent

process. Our IT manager was very involved with the BMV in establishing the registry database and access protocol. He also established a list-serve forum connecting all the recovery agencies in the state with the BMV, so that issues could be raised and information shared in a very efficient manner. Just something as simple as duplicating the donor registry form into our publications and brochures involved a lot of coordination. We had to conform with the BMV on size and format and be consistent every time we used it.”

While implementing first-person consent legislation and developing a donor registry, members of the statewide OPOs also have had a good relationship with one another.

“The public relations folks did a lot of sharing in the beginning,” Pongonis said. “And we continue to stay in contact.” Public relations representatives from the four OPOs each developed talking points and shared them among themselves to ensure consistency with the media throughout the state.

“In the months leading up to the launch all of us were laying the groundwork for the change in the law. In the beginning, some reporters approached the subject as if we were cutting out the family by not involving them in the decision. With a little education they came to understand that

the law's intent is to empower and encourage individuals to make their own end-of-life decisions.

"When reporters showed up at the press conference launching the registry, most were extremely well educated about the subject—and it showed. The media coverage was very positive in central Ohio. The *Columbus Dispatch* even ran a front-page story and a follow-up editorial," said Pongonis.

Ohioans can register their wishes to become a donor when renewing or receiving their driver's license or state ID at the BMV. Additionally, potential registrants can access the registry at www.ohiobmv.com, print the donor registry form and mail it to the BMV offices. Based on data from the first four months, 600,000 Ohioans have added their names to the list—almost half of all people getting a driver's license.

"We're focused on keeping it simple," Pongonis said. "We want the registry to be our call to action."

Informal data show that interest in the registry is growing. Lifeline of Ohio put the donor registry form on church bulletin inserts for National Donor Sabbath. Soon after, BMV employees noticed such a dramatic increase in this particular mail-in form that they called the OPO to see if it had done a special promotion.

Minnesota: Careful, steady planning

The passage of two donation-related statutes in 2002 required that LifeSource, Minnesota's OPO, move quickly to begin reversing its long-practiced approach of obtaining family consent for donation. The Darlene Luther Anatomical Gift Act strengthened the original anatomical gift language of by making driver's licenses, state-issued identification cards and advance directives sufficient legal documentation to proceed with donation. The state also passed legislation increasing the state's mandate to provide education on donation through the Department of Public Safety. South Dakota (also part of the Minnesota OPO's service area) had already made information about donation an integral part of applying for a driver's license.

This new legislation passed in April. Since then, LifeSource, which also serves North Dakota, South Dakota, and portions of western Wisconsin has carefully and steadily planned and prepared a new approach in obtaining consent. Now, in early 2003, LifeSource is testing a new procedure in which qualified personnel can obtain donor designation information 24 hours a day, 7 days a week in both Minnesota and South Dakota. The new process is done in collaboration with the DMV since LifeSource doesn't maintain an independent database. LifeSource also is currently working with the DMV in North Dakota and South Dakota to develop a similar system.

"We took a careful approach from the very beginning," said Susan Mau Larson, public relations manager for LifeSource. "We developed a thorough briefing and included input from stakeholders in all areas—hospital staff, medical ethicists, donor families, transplant patients. We also invited Helen Leslie from LifeNet to present to our staff at one of our board meetings so she could share with us Virginia's experience with the first-person consent situation. This was very helpful.

"Throughout the entire process our board of directors was quite receptive. They saw that we had covered all our bases and that we had solicited input from all the important groups. Plus, we have never lost focus that the concern of the family is still a major focus of our attention—we are simply shifting our approach from asking the family to helping the family understand and support their loved one's wishes."

Ultimately, Larson says, donor designation and the new consent approach was warmly received by stakeholders in Minnesota.

"To be successful," she added, "the entire process absolutely has to be paired with education." 

Karen Sokohl is the member communications specialist at UNOS and a contributing writer.

Advice from Registry Veterans

- Focus on how to become a donor through the registry or through first-person consent legislation.
- Keep the marketing message simple.
- Fully inform constituents and the media every step of the way.