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WEEKEND POSTBULLETIN

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THE UPS AND DOWNS OF AUTUMN



Traci Westcott / Post Bulletin

Kids from Rainbow School Christian Preschool play in the leaves Thursday. Mother Nature's colorful show is starting to wane, but that only means there are more leaves on the ground. With this weekend's temperatures predicted to be in the 60s, raking could be on top of many to-do lists.

Welcome to Rochester

Catholic Charities prepares to help resettle up to 16 Afghan families

BY JOHN MOLSEED
Post Bulletin

When Abas Iqbali and his wife Ghira Sohrabi arrived at the Rochester International Airport in mid-October, no one was there to meet them.

The couple was, nonetheless, relieved to be there, considering they almost never got off the ground in Afghanistan in the first place.

In Kabul, the two narrowly escaped a bomb that killed at least 170 Afghan civilians along with 13 members of the U.S. military on Aug. 26.

After spending two days at the Hamid Karzai International Airport in hopes of leaving the country before flights from there ended under Taliban rule, they were airborne about 3:30 p.m. local time.

The bomb, which exploded near the waiting area where they had spent the past nearly 48 hours, detonated less than two hours after they took off. They learned of the attack only after landing in Bahrain.

"We had been in that same waiting area," Sohrabi said through an interpreter this week.

"We saw the crowds of people trying to get to safety," she added. "These were people like us who had passports and visas."

The 10-minute wait at the airport in Rochester wasn't the worst part of their journey. But, arriving in Minnesota after a month-long stay at the U.S. Marines base in Quantico, Virginia, speaking little English, and finding no one there to meet them made them a bit nervous, they said.

Iqbali worked for the U.S.-



John Molseed / Post Bulletin

Kristina Hammell, left, a case worker with Catholic Charities of Southern Minnesota, sets up an infant carrier and carseat while John Meyers, Catholic Charities director of refugee resettlement, loads luggage onto a cart for a family of arrivals from Afghanistan at the Rochester International Airport on Nov. 2.

backed government that fell to the Taliban in August. He served on presidential security details there — a job that made him a target for the Taliban. When the Taliban took over, he and his wife didn't go out in public for more than two weeks. Eventually, he realized the window to leave the country was closing.

Once here, the identity badges they each wore around their necks prompted Rochester Airport staff to call Catholic Charities of Southern Minnesota, the local resettlement agency tasked with helping Afghan refugees.

Kristina Hammell, a case manager at Catholic Charities, scrambled to the airport to meet the couple.

"That's not how it's supposed to go," said John Meyers, Catholic Charities' director of refugee resettlement.

Catholic Charities staff were expecting a couple. However, they never heard from the

State Department's Bureau of Population, Refugees, and Migration (PRM), the federal agency coordinating relocation of Afghanis, as to when the couple would be arriving. About a week later, another family, with children, arrived at the airport with no notice.

When a third Afghan family arrived Tuesday night on a flight from Chicago, Meyers was already there to greet them in person.

"This is more traditional," he said.

Meyers intends to be at the gate to greet each of the Afghan arrivals in person. Meyers speaks Dari, a version of the Persian language widely used in Afghanistan. He spent about nine years in Afghanistan working for non-governmental organizations doing relief and development work from 2005 to 2014.

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ORGAN FAILURE

Transplant system's performance may be costing lives

BY NORA ECKERT
Post Bulletin

The most important decisions made in Minnesota's organ transplant system may not be determined in a hospital or surgeon's room, but in a sleek office building on Minneapolis' north side.

The \$18-million structure bearing the name "LifeSource" holds Minnesota's organ procurement organization, one of 57 such organizations federally designated to oversee the delivery of organs from the deceased to those in need.

The typically behind-the-scenes organization has recently found itself in an unfamiliar position: under scrutiny.

LifeSource has twice been classified as underperforming by a federal agency, and it is one of 11 organ procurement organizations Congress is investigating for lagging performance and potential conflicts of interest.

The work organ procurement organization staff do is grueling.

LifeSource employees have to make requests of grieving families, recover organs under strict time constraints and deliver them to patients who need a transplant to survive.

The staff who fill LifeSource's halls often have personal connections to the transplant world. Many have received "the gift of life," as they call it, or had a loved one donate organs after their death.

But for too long, these employees have operated within an inefficient system, transplant surgeons, organization leaders and researchers say.

"What we need to understand is this system is operating at nothing like full potential," said Jennifer Erickson, who focused on reducing the more than 100,000 person-long waitlist for transplants while working in the White House Office of Science and Technology Policy under President Barack Obama. "Whenever it's not operating at full potential, Americans are dying unnecessarily."

In the first of a three-part series, building off of more than 60 hours of interviews with patients,

LifeSource at a glance:

- LifeSource is a non-profit organ procurement organization founded in 1989 and headquartered in Minneapolis.

- LifeSource is under contract with the federal government to facilitate transplants across its 226,487-square-mile service area, serving 7.5 million people in Minnesota, North Dakota, South Dakota and western Wisconsin.

- Since its inception, LifeSource said it has facilitated 17,000 organ transplants and reached 1 million tissue and corneal transplant recipients.

COMING TUESDAY: The congressional investigation and finances of organ procurement organizations.

COMING NOV. 13: Racial disparities in the nation's organ transplant system.

transplant surgeons, organ procurement organization employees, researchers and patient advocates, the Post Bulletin explores the complicated role OPOs play in the transplant field. We'll examine how LifeSource lobbied against the newly-approved metrics that ranked its performance as lacking, and review the plan the organization has set to nearly double the number of transplants it facilitates in the next six years.

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WEEKEND



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Organs

From page A1

THE LIFECYCLE OF AN ORGAN

When someone dies, it takes a lot more than having a sticker on his license to determine if he becomes an organ donor. Less than 10% of people who die have the potential to donate an organ, according to federal data.

For example, a 55-year-old man suffers a stroke in Rochester. He is admitted to a nearby hospital, and staff begin efforts to save him.

If the patient fits the conditions needed to be a potential donor, the hospital contacts LifeSource to give its team the best chance at recovering organs in the needed time frame. Then, LifeSource works with the hospital team to review the patient's available medical information and determine whether his organs may be viable for transplant.

Most deceased organ donors experience brain death. After hospital staff exhaust all possible means to save the patient, and he is declared brain dead, a LifeSource team member is often at the hospital to work with the decedent's family and educate them about the potential for donation. This is an emotionally taxing process in which organ procurement organization professionals have to navigate difficult conversations with grieving families. If the patient isn't listed as a donor, the goal is to earn the family's trust and secure a "yes" to donation.

"My team might be there for 10, 12, 14 hours of a given day, just simply intersecting and trying to support that family in whatever way they need," said Laura Svoboda, who leads LifeSource's team of family support coordinators. In some rare cases, she said, staff stand in for the family in the hospital, adding personal touches such as playing the deceased donor's favorite song at the family's request.

If the family agrees to donation, LifeSource takes over as leader of the decedent's care. LifeSource staff conduct tests to determine the status of the patient's organs and take steps to ensure they're kept as healthy as possible.

Next, the patient is brought to the operating room.

Surgeons recover all viable organs, and organs are typically flown to a transplant center so a patient in need may receive them. Airline logistics are especially important for LifeSource, as it serves a 226,487-square-mile region covering Minnesota, the Dakotas and a sliver of Wisconsin. It is the second largest area of any OPO in the country.

Even if someone dies in a way that may allow for donation, he can be lost because of a misstep from the hospital, OPO or transplant center.

If a hospital nurse fails to call in a potential patient, or if the OPO doesn't accurately assess a patient's potential for organ donation, a donor can be lost. If an OPO representative can't secure a family's consent to donate a loved one's organs, the donor is lost. If an OPO staff member doesn't appropriately manage the patient before the organs are removed, a donor can be lost. An organ can also be spoiled if it is improperly stored or lost in transit, a problem that ruined nearly 170 organs between 2014 and



Photos by Joe Ahlquist / Post Bulletin

Susan Gunderson, CEO of LifeSource, an organ procurement organization on Sept. 14 at their office in Minneapolis.



The Minneapolis skyline can be seen out of the second story at LifeSource, an organ procurement organization in Minneapolis.

2019, an investigation from Kaiser Health News found. Finally, if a transplant center deems an organ not healthy enough to use, the donation cannot go through.

Teresa Shafer, who served as the chief operating officer for Texas OPO LifeGift for 26 years before becoming a consultant in the field, said that the transplant system is a joint effort between donor hospitals, OPOs and transplant centers. She hopes that changing regulations will propel growth among all these groups.

Still, the pressure is rightfully on organ procurement organizations, she said.

"Nobody else can do donation but an OPO," said Shafer. "That responsibility, that accountability, has to be huge."

Many OPOs appear to be falling short of that mandate.

The most damning reports say the U.S. is only capturing one-fifth of the current potential — missing 30,000 donors a year.

Another found that the system can recover up to 28,000 more organs annually. According to a federal analysis, even modest increases in procurement efficiency could allow for 7,000 more transplants each year, enough to wipe clean the Minnesota waiting list almost three times over.

Some OPO executives say their hands are tied. They argue that an OPO is at the mercy of the population it serves, and if people don't want to donate, it's hard to change their minds.

Yet, recent examples

prove otherwise. Organ procurement organizations in Indiana, Ohio, Texas and California dramatically improved donation rates after a change in leadership, a boost in staffing, or a redesign of how to better reach potential donors.

'THE FOX GUARDING THE HENHOUSE'

The government agency that funnels billions of taxpayer dollars into reimbursing organ procurement organization costs released a report in late 2019 charging that the system lacked objective metrics, transparency, accountability and incentives for improvement.

The Centers for Medicare and Medicaid Services, or CMS, exposed what insiders say has been the industry's core problem: for decades, the dedicated workers who aim to save lives have done so without objective guideposts. This has sometimes prevented them from seeing when and where they are failing.

The result has been widespread variability in organ procurement organization performance. A 2019 report found that there was a 400% difference between the top-performing organ procurement organizations and the bottom. However, no procurement group has ever lost its federal contract.

The new CMS rule attempted to address this by replacing what was previously a self-reported figure with an objective one.

Organ procurement organizations are evaluated by the percentage of potential donors they reach in their area, a fraction by which total donors is the numerator and potential donors is the denominator. While OPOs previously self-reported the number of eligible donors in their service area, that number will now be calculated based on public data from death certificates.

Many within the industry say the change is overdue.

"If you're going to put a regulatory framework in place, having the people that are being regulated determine the numerator and denominator of the metric they are being regulated by is probably not a good setup," said Dr. Seth Karp, surgeon-in-chief at Vanderbilt University Medical Center. "We have to decide as a society if we want the fox guarding the henhouse."

Under the new metric, organ procurement organizations are measured relative to one another and placed in three tiers. The top are secure in their appointments, the middle are at risk of losing their territory and the bottom, if they fail to improve, will be replaced.

For LifeSource, the first report card carried bad news.

The Minnesota OPO ranked 38th out of 58 for its ability to reach potential donors and facilitate transplants. LifeSource fell at the bottom of the Tier 2 "underperforming" group, in the last slot

before the "failing" OPOs. The rankings were based on 2018 data, and included a total of 58 organizations, before a merger in early 2021 reduced that number to 57.

CMS measures OPO performance in two ways: the donation rate — which is defined as "the number of donors as a percentage of the donor potential" — and organs transplanted.

Updated rankings based on 2019 data show improvement. For donation rate, where LifeSource initially needed to reach 12 additional donors to be classified as Tier 1, it now needs zero. Where LifeSource once needed an additional 71 organs transplanted to be Tier 1, it now needs 20.

Still, the OPO sits in the "underperforming" tier.

LIFESOURCE'S OPPOSITION

A startling forecast blared on LifeSource's website in the months before the CMS metrics were approved: "The new regulations as proposed would result in significant damage to organ donation and tremendous loss of life." The same site also hosted misleading and, in some cases, inaccurate information about the rule change and its supporting research, along with calls to action for supporters to write to their members of Congress.

The Post Bulletin asked about the website's content in an interview, and followed up in detail through email, but LifeSource did not address these questions.

How do I confirm I'm an organ donor?

- You can register to be an organ donor with the national Donate Life registry or your local state registry. Both should be checked to confirm if you are a registered donor, and you can register in both.

- According to Donate Life America's website, "Any adult age 18 or older can register to be an organ, eye and tissue donor — regardless of age or medical history. 15-17 year olds can register their intent to be organ, eye and tissue donors in the National Donate Life Registry. However, until they are 18 years old, a parent or legal guardian makes the final donation decision."

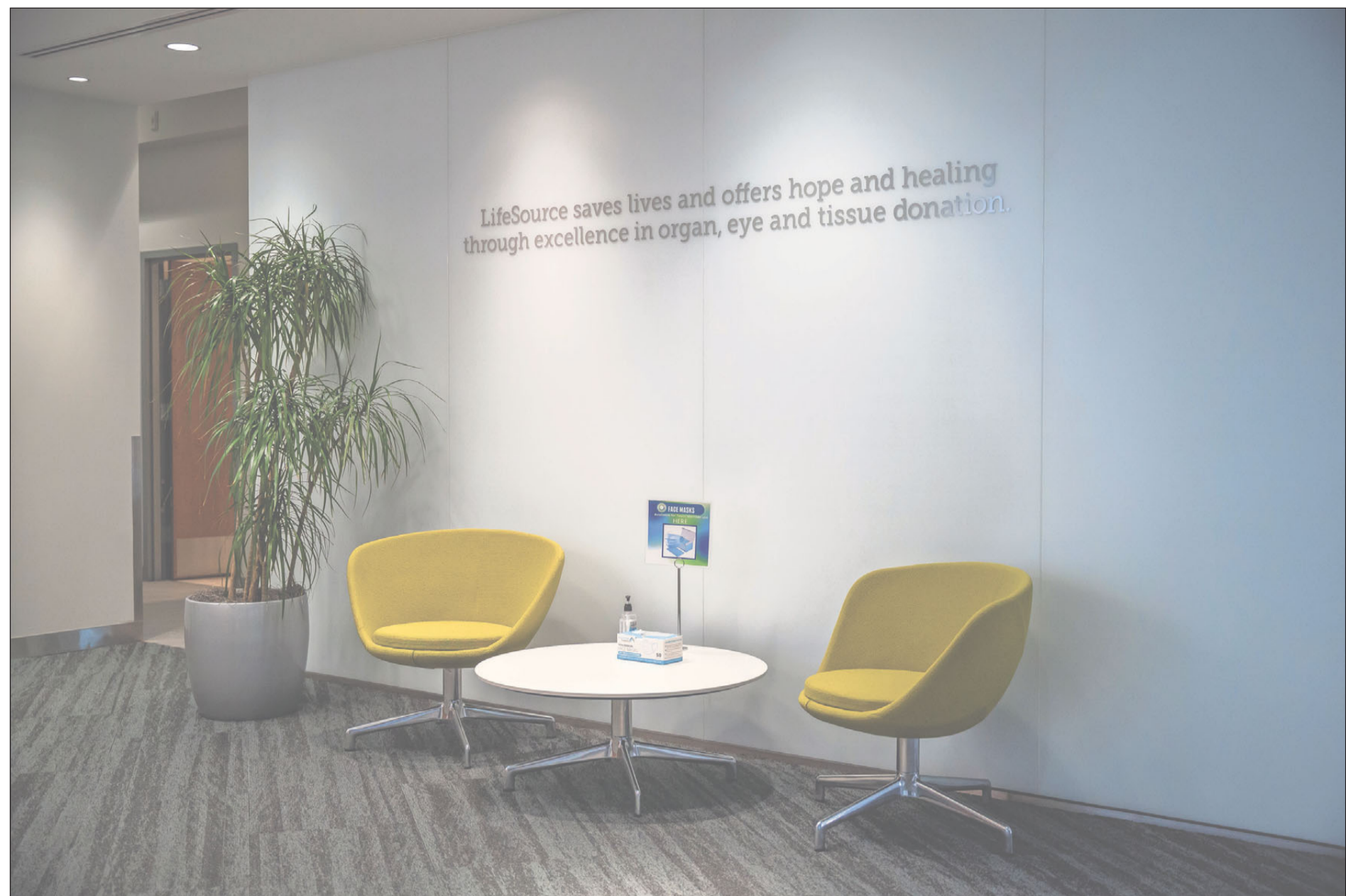
- For Minnesota residents, you can register here: <https://www.lifesourcedonorregistry.org/>.

- To register on the national registry, visit this link: <https://registerme.org/>. Contact customerservice@donatelife.net with any questions.

Some of LifeSource's cited concerns were echoed by other leaders in the field, particularly about the reliability of the death certificate data used to calculate potential deaths, and how ranking OPOs in relation to each other would stifle collaboration in the field. However, CMS responded to these concerns with evidence of the reliability of death certificate data, and broke down its methodology for ranking OPOs in comparison to each other.

When the Post Bulletin presented this information to the organization, LifeSource issued the following statement:

"When the new metric was introduced, we believed there were issues with it and that it was our responsibility to express our concerns based on our experience. Now that the new metric is in place, we are embracing it and will work to ensure it yields positive benefits to donor families and recipients, who are the heart and soul of LifeSource and our entire system."



Photos by Joe Ahlquist / Post Bulletin

The reception area at LifeSource, an organ procurement organization in Minneapolis.

Failure

From page A5

Even some OPO leaders whose organizations have taken a hit under the new regulations supported them from the start.

“I’m scared, like everybody else, to be decertified. I’m scared to be Tier 2. But that doesn’t change the fact that I have to be better,” said Kelly Ranum, CEO of Louisiana Organ Procurement Agency. The Louisiana agency was listed as “underperforming” when CMS data was first released.

Across the swath of OPOs, there’s been a 500% increase in lobbying expenditures since 2017, according to an investigation from the Project on Government Oversight. LifeSource ranked seventh out of the 34 OPOs with available financial disclosures in percent of functional expenses dedicated to lobbying, according to a Post Bulletin analysis. While 18 of these organizations dedicated no money to lobbying efforts, LifeSource spent \$53,000.

“LifeSource is the only entity advocating for donation in three states’ legislatures (MN, ND and SD). We also advocate with the Congressional delegations in those states. Expenditures for advocacy account for 0.08% of our total budget,” wrote LifeSource CEO Susan Gunderson in response.

The lobbying efforts against the rule, especially those bolstered by false information, unsettled Karp, the Vanderbilt surgeon.

“It’s not an argument. What I hear would just be blatant lies and untruths. That’s hard to take because we at least (need to) start off by saying OK, we’re all going to be honest about it. In my experiences, that’s not been true,” said Karp.

Citing concerns over financial conflicts of interest between



The “healing garden” at LifeSource, an organ procurement organization in Minneapolis.

procurement groups and other parts of the health care system, Congress has begun its own review of the organ donation pipeline.

In December 2020, LifeSource was named one of 11 organ procurement organizations under investigation by the Committee on Oversight and Reform’s Subcommittee on Economic and Consumer Policy. A spokeswoman for the committee informed the Post Bulletin that LifeSource is under investigation because it “is a low performing OPO and has potential conflicts of interest.”

“I’m not sure what these allegations are,” Gunderson said of the reasons given by the congressional staffer, “and there is nothing in our practices that would not stand up to being clearly in the field of best practice.”

A BLUEPRINT FOR IMPROVED PERFORMANCE

In the time since

the CMS rule was proposed, LifeSource has committed to expanding its staff in order to facilitate 1,000 transplants by 2027, nearly doubling its 2020 performance.

“It’s involving a redesign of how we deliver our frontline care for organ donation and being more visible earlier in the hospitals on referrals. Being integrated more as part of a consultant in the care team and not coming in and being viewed as a separate person,” said Gunderson. She has led the OPO for 32 years and will retire in 2022.

The strategy Gunderson identified has been best practice in the field for decades, according to Shafer, the former OPO leader who also served as co-chair of the Organ Donation Breakthrough Collaborative. The collaborative was started by the Health Resources and Services Administration in 2003 to encourage best practices in donation

across the country. “When it works right, the hospital staff, OPO staff, they are part of that health care team. It should be hand in glove,” said Shafer.

Gunderson said LifeSource has added at least 20 people to its team of 174 this year, and plans to recruit more in 2022. Leaders from some of the nation’s top organ procurement organizations say bolstering staffing in key areas is a trusted way to improve performance and save more lives, especially for an OPO like LifeSource that has such a large service area.

At Life Connection of Ohio, CEO Matthew Wadsworth tripled his staff after taking the position in January 2020. Since then, the organization has increased its number of donors by 90%.

Patti Niles, CEO of the Southwest Transplant Alliance in Texas, also has added to her team’s manpower

in order to drive its performance.

“You’re limiting what you can do by the number of people you have,” Niles said. “When you have to go in front of a family and ask them for a donation, knowing that you’ve been up for 24 hours already working, and if the family says yes, you have to be up for another 24 hours, it’s hard as a human being to really work hard to get that,” Niles said.

The cumulative effect of underperforming procurement groups is significant across the system. If all OPOs in the nation had performed during the last decade as well as the top 25% had, 10,170 more donors would have been secured. That is according to internal industry research obtained by the Post Bulletin. The analysis uses the new CMS definition of potential donors as the point of reference.

If LifeSource had performed as well as the top 25% of OPOs

since 2010, it would have secured 137 more donors, the analysis found.

The 2,500 Minnesotans awaiting a transplant upend their lives and freedoms to improve their chances of receiving a life-saving organ. They spend 15 hours a week hooked up to dialysis machines, start social media campaigns to recruit potential donors and advertise their need on cars and front lawns.

It’s vital for OPOs to be held to high standards in an effort to reach every potential donor, so those waiting have a better chance at survival, said Shafer.

“Every organ, every time,” said Shafer. “When you do that for any organ ... you change history. Because you don’t know what people who would have died had they not received an organ, you don’t know what they’re going to do with their life.”

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