



THE CONNECTION

A YEAR IN REVIEW

Arizona

WE MAKE THE MOST OF LIFE

JUNE 2018 - MAY 2019

Cover: Shovels in the ground March 5, 2019, kicked off the construction of DNA's new home in Tempe.

Below: Reggie shows his organ and tissue donation pride at the 2018 Celebration of Life back in October.

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GREETINGS

FROM TIM BROWN, *PRESIDENT AND CEO*

While we look back on the past year of organ and tissue donation in Arizona, we're also looking ahead to our future. If you haven't heard, our path now leads us from Phoenix to Tempe where, after much research and problem solving, the new headquarters for the gift of life in Arizona is finally sprouting from a pile of dirt.

However, before construction crews started their part, we got a humbling reminder why listening to the people touched by donation is important. At our groundbreaking ceremony March 5, 2019, Jennifer Loredo shared how the work Donor Network of Arizona (DNA) does truly is an invitation for donor families to grieve, to heal and to be certain no one will forget their loved ones who went on to save and heal others, like her brother Jacob Daily. He is a donor who saved three people and healed countless others. He is a true hero.

Arizona witnessed an amazing year in donation. From June 2018 to May 2019, an unprecedented 298 donors saved the lives of 812 people through organ donation. Tissue donation has and will provide restored sight and mobility to thousands thanks to the 1,593 tissue donors. And 662 cornea donors will restore sight for people who are visually impaired.

We are grateful to those who have helped DNA get this far, to all Arizonans who have said yes to donation, and we're looking forward to moving into our new home in 2020 with a clear vision of always realizing Arizona's potential to save and improve lives.



After breaking ground, President and CEO Tim Brown poses near construction equipment at the sight of DNA's future home in Tempe.

*"We make the most of
life through the gift
of organ and tissue
donation."*

XAYNE PINEDA

FOREVER OUR VALVENTINE

At only 4 months old, Xayne Pineda didn't wake up one morning in the spring of 2018. His parents scrambled to call 911, and they started CPR hoping they too would wake up—that it was just a nightmare.

Medics rushed Xayne to Banner Thunderbird Medical Center (BTMC). The doctors got a pulse back, but it was too late to save his life. The lack of oxygen to his brain resulted in doctors declaring him brain dead. His mother, Shianne Pineda, says it was the result of bed sharing, also known as co-sleeping.

"It's been really hard on us," says Shianne. "We've just been trying to get by. We just keep ourselves really busy."

The March of Dimes says bed sharing is the most common cause of death in babies younger than 3 months old. The organization advises against co-sleeping and suggests, if parents want to sleep close to their young children, the best place for a baby is in a bassinet or crib placed close to their parents' bed, a practice defined as room sharing.

Samuel Pineda, Xayne's father, saw a glimmer of light in the darkness of such a sudden loss. The family authorized tissue donation, and they say it has provided a small sense of peace for them.

"It was actually my husband's idea," says Shianne. "Xayne wasn't going to

be able to recover. So, we had a conversation [about how] we didn't want any other parents to go through what we were going through."

Xayne's family wants to keep his legacy alive for his brother Xander by sharing his story as a lifesaver. In his honor, Samuel and Shianne hosted a pillow pet drive for Xander's birthday, and they collected 300 teddy bears to donate to BTMC.

What marked the end of Xayne's presence on earth is a new beginning for two recipients. He donated two heart valves, one of which already saved the life of a 4-month-old girl in Florida. His second donated valve saved the life of a 6-month old boy who needed conduit revision, which is the retubing of part of the heart to correct the blood flow.

Heart valve donations save the lives of pediatric patients 76% of the time. For his lifesaving gifts, Donor Network of Arizona honored him Feb. 14, 2019—National Donor Day, also coined Valventine's Day.

"It makes me very glad my husband had convinced me to agree to donation," Shianne says, hoping to one day learn more about Xayne's recipients and maybe meet them. "For the first year, we checked the mail daily to see if there had been any updates."

**“... We didn’t
want any
other parents
to go through
what we were
going through.”**

SHIANNE PINEDA, XAYNE’S MOTHER



DIRECTING DONATION IN ARIZONA

U.S.—The Opt-In System for Donation Registration

The opt-in donation system asks people in the U.S.—even immigrants with permanent residency or foreigners who visit regularly—to record their choice to donate their organs, tissue and corneas. In Arizona, more than 3.5 million people have joined the DonateLifeAZ registry.

With the current opt-in system, the U.S. has one of the highest organ donation rates in the world, with data showing the U.S. in the top five in the world in donors per million population.

This system differs from the opt-out system in some countries, such as Spain. Opt-out is the legal authority to recover organs from a deceased donor unless the person previously registered a refusal. It otherwise assumes a person agrees to organ and tissue donation.

For the U.S., the opt-in system works best and often outpaces countries with an opt-out system. The top 12 organ procurement organizations (OPOs) in the country combined have more donors per million than all of Spain. Also, Spain's high donation rate itself was only realized 10 years after the adoption of the opt-out system because it based many of its hospital strategies on the U.S.'s already established systems.

While countries with an opt-out system seem to have less obstacles by not requiring their people to register, they do not act on an individual's donor status as authorization for donation. These nations still require family consent

in addition to opt-out authorization. Spain's system is better understood as a "presumed intent" system, but not authorization.

For context, cases in which Donor Network of Arizona (DNA) required next-of-kin authorization for donation to occur with donors who did not previously register, families declined donation almost 54% of the time. So, donation would decrease in Arizona if it were to rely heavily on family consent rather than a donor's legally binding decision to register as a donor.

In the U.S., the decision to register as a donor cannot be legally overridden. It is considered an end-of-life decision, much like a will. Also, under the current system, DNA can contact the family for consent and see if being a generous donor matches their loved one's values if they were not already registered. In Spain, documentation of refusal means legal next-of-kin cannot be approached. Therefore, zero potential for donation exists in such a case.

The opt-in system is based on the Uniform Anatomical Gift Act (UAGA), which every state has adopted. This system is founded on known American values of individual rights, autonomy and choice.

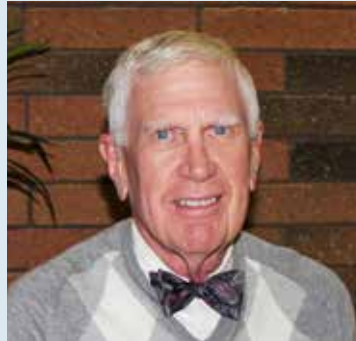
DNA's BOARD OF DIRECTORS



Gregory Pivrotto

Board Chairman

Retired President and CEO,
University Medical Center
Corporation



**Lawrence James
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Immediate Past Chairman

Retired Transplant and
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Eye Bank



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OASIS Hospital



John R. Peters

Interim Leader,
B.E. Smith



Laurie Wilshusen

Administrator, Patient
Experience Research
Mayo Clinic



**Joseph M. Zabramski,
MD, FAANS, FACS**

Neurosurgeon, Barrow
Neurological Institute

MAKING CONNECTIONS TO MAKE AN IMPACT



COMMUNITY OUTREACH



291k ARIZONANS REGISTERED
*as organ, cornea and tissue donors
for the first time.*

1,746 VOLUNTEER HOURS
*dedicated to educating others on the
lifesaving message of donation.*

152 EVENTS
*across the state reached
thousands of people.*

104 MEDIA STORIES
*shared the lifesaving message
of donation.*



June 2018 -
May 2019



THE GIFT OF DONATION

298 **ORGAN DONORS**
*gave a second chance to those
waiting for a lifesaving transplant.*

662 **CORNEA DONORS**
restored sight to others.

1,593 **TISSUE DONORS**
gave the gift of healing.

262 **HEART VALVE DONORS**
saved lives.



SHARING HOPE

812 **LIVES SAVED**
*thanks to the generosity of donors
and their families.*

29,037 **LETTERS MAILED**
*to provide comfort and
correspondence.*

154 **ORGAN DONORS**
*who registered their wishes
gave the gift of life.*

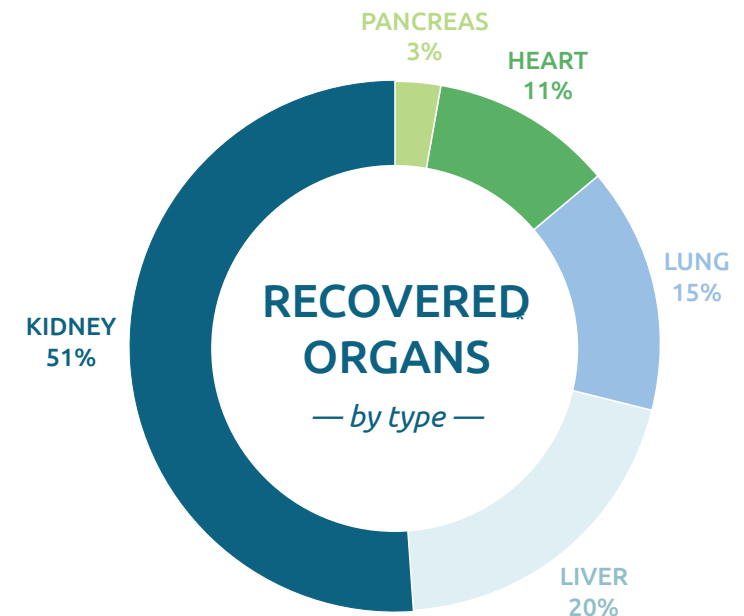
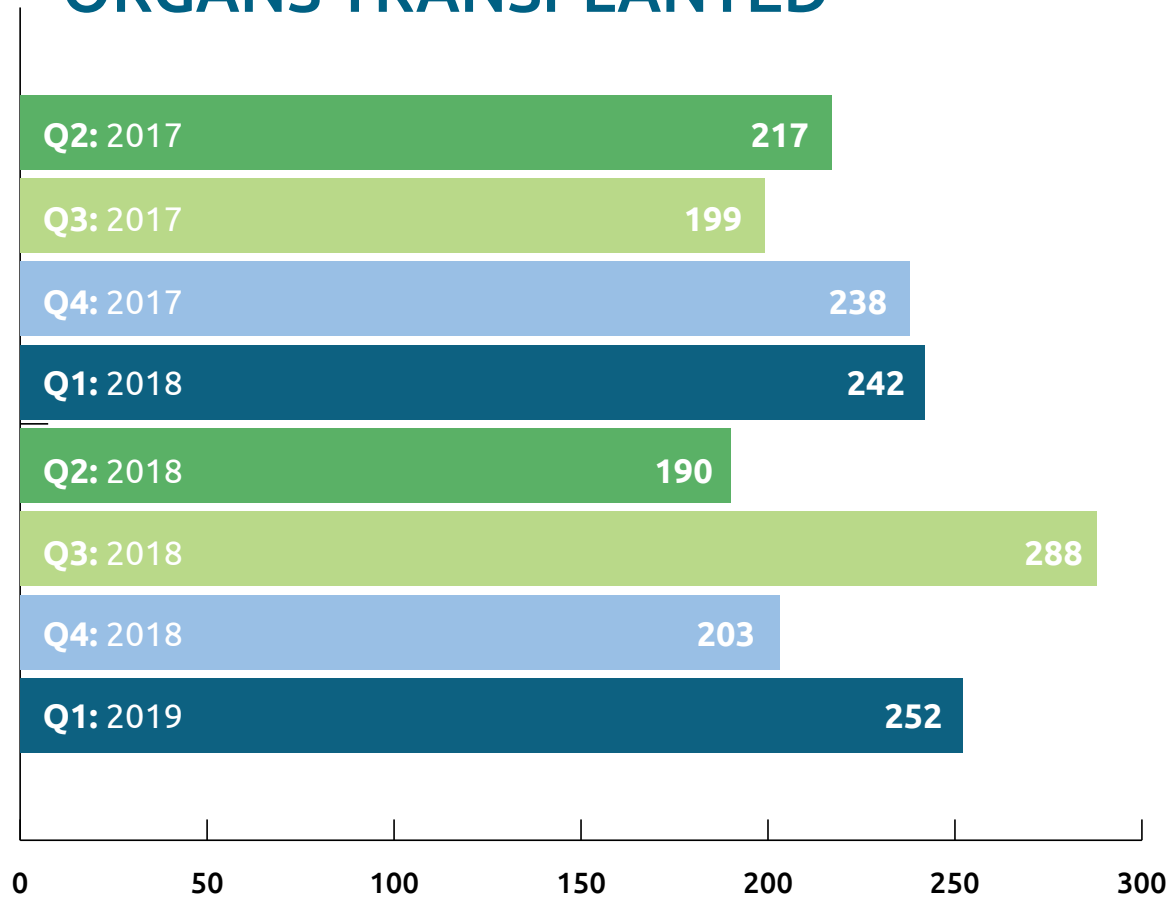
36 **BIRTH TISSUE DONORS**
*provided healing to others after
giving birth.*



DONATION BY THE NUMBERS

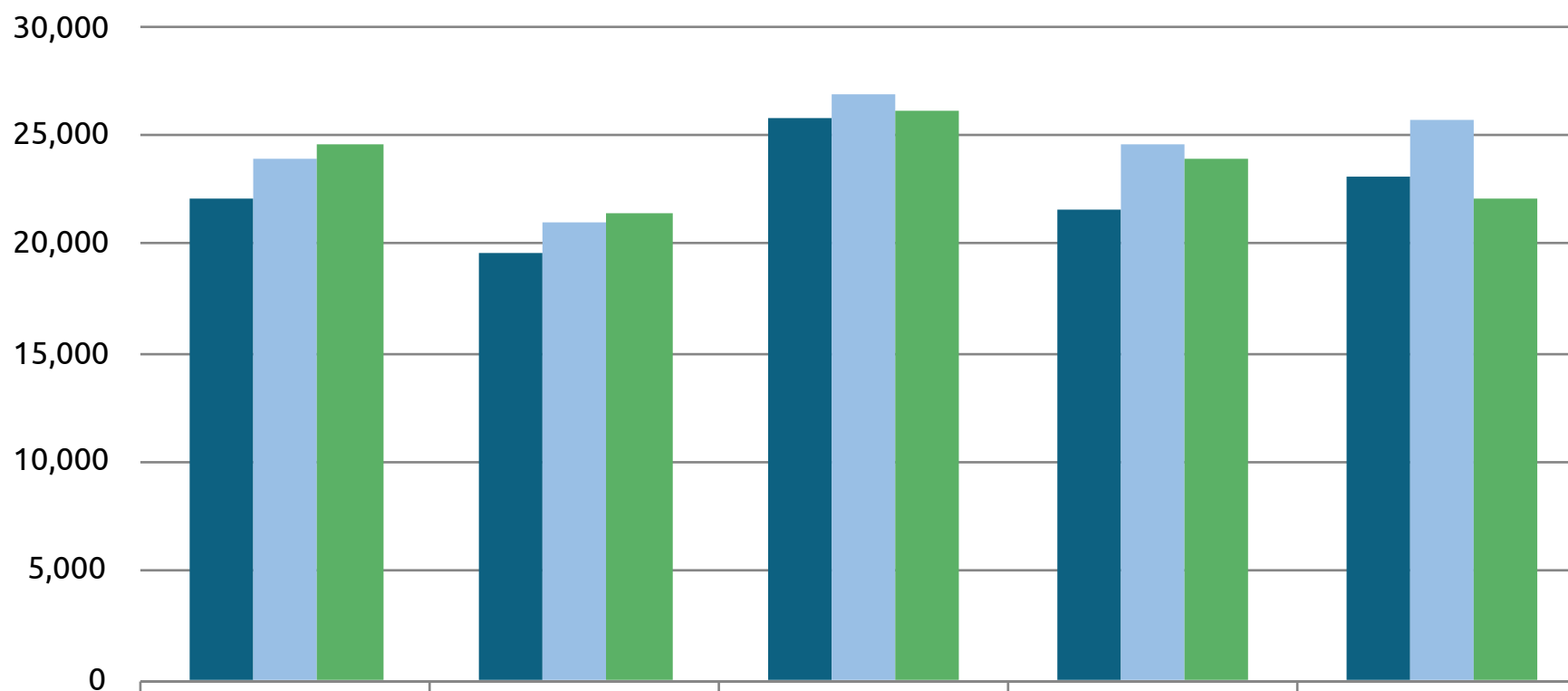
**Reflects data from June 2018 to May 2019*

ORGANS TRANSPLANTED



62% OF ORGANS RECOVERED IN ARIZONA WERE TRANSPLANTED IN ARIZONA*

REGISTRATION COMPARISON



	JANUARY	FEBRUARY	MARCH	APRIL	MAY
2017 REGISTRATIONS	21,733	19,251	25,617	21,569	22,926
2018 REGISTRATIONS	23,877	20,927	26,696	24,352	25,532
2019 REGISTRATIONS	24,484	21,108	25,975	23,731	21,951

SAVING MORE LIVES THROUGH INNOVATION

OPTIONS FOR EVERYONE TO HELP

Imagine a world in which anyone, with any illnesses, could donate to save and heal lives.

While it's true that there is no age limit or health requirement to register as an organ and tissue donor, certain conditions or diseases can impact someone's donation potential at their time of death. But the possibilities for everyone to donate are growing.

MORE OPTIONS THAN EVER

Donor Network of Arizona (DNA) works tirelessly to fulfill the wish of any willing donor to give the gift of life. Through medical advancements, organ donation is now possible from HIV-positive donors as well as from people with Hepatitis C.

Because of the 2015 HIV Organ Policy Equity (HOPE) Act, HIV-positive donors can donate organs to HIV-positive patients. Most regions across the country have successfully performed such transplantations, and in 2019, we even saw the first HIV-positive living donor in the United States give her kidney to save someone's life.

With Hepatitis C donations, the virus is curable. So, a recipient can choose to accept an infected liver donation, for example. This person would later go

through Hepatitis C treatment to rid the body of the virus.

In all cases, DNA evaluates the donors and shares such information with transplant centers to determine suitability of the organ for their candidates.

SAVE LIVES AND SUPPORT RESEARCH

End-of-life decisions sometimes include whole-body donation for research and education. And, yes, a donor can participate in both donation for transplantation and whole-body donation.

DNA works directly with American Association of Tissue Banks (AATB) accredited organizations, such as Science Care and United Tissue Network. However, organ and tissue recovery teams will coordinate with any whole-body research agency a donor or family may choose.

Through such partnerships, in the event organ recovery is not a viable option, a person's end-of-life wish may still be fulfilled by helping advance medicine and educating the next generation of medical professionals in a way only donors can do.



Jeff Lamotte and his wife, Lexy Lamotte, during their on-field recognition for Donate Life Day at the Diamondbacks April 14, 2019, about a year after Jeff's transplant. A Hepatitis-C-positive liver donation saved his life.



OSSIUM PARTNERSHIP

More than 170,000 people are diagnosed with blood cancers such as leukemia, lymphoma or myeloma every year in the United States.

More than 20,000 of these patients can be treated through a bone marrow transplant. But finding a match can take months, and typically one living donor can only donate to one patient.

In 2018, Donor Network of Arizona (DNA) started expanding the reach of such a donation by partnering with Ossium Health, an agency that makes therapy products that cure leukemia and other blood cancers, to help save more lives with building the world's first bone marrow bank.

Through this partnership, DNA works with Ossium Health to utilize bone marrow from deceased donors to help treat blood cancer for up to five different patients per donor. DNA recovers a section of the spine, with donor family authorization, and provides it to Ossium Health. The biotechnology company will recover bone marrow from the spinal section, which will "treat blood cancers, improve organ transplantation,

and repair damage from radiation," according to its website.

DNA is one of 24 organ procurement organizations in the U.S. to join this effort so far and has recovered 12 such donations since the partnership began.

"Deceased bone marrow recovery is picking up momentum," says Rhiannon Knueven, DNA Tissue Services manager. "I would anticipate the recovery being pretty consistent with around five donors per month."

DNA is confident that, through this innovative and hope-restoring collaboration, the gift of life can be extended even further to save and heal more lives. As the program grows, the DNA team is excited to touch the lives of people in a whole new way through the Ossium Health partnership.

Photos: DNA has a new partnership with Ossium Health, an agency that creates therapy products to cure leukemia and other blood cancers. Pictured here are Ossium Health cellular therapy associates and laboratory assistants preparing donor bone tissue for long-term storage. They partner with 24 tissue recovery organizations across the country, including DNA, to help save lives by building the world's first bone marrow bank.

BREAKING GROUND AND BUILDING HOPE

The sun rose over a barren dirt lot in Tempe March 5, 2019, casting light onto the new headquarters of Donor Network of Arizona (DNA) and the future of organ and tissue donation in the state.

Approaching the site, you could see construction equipment, hard hats and shovels. What couldn't be seen in that empty lot, but rather felt, was hope for the 114,000 people on the national organ waiting list.

"We are a very caring and compassionate community," says Mark Mitchell, mayor of Tempe, as he welcomed the lifesaving mission to its new host city. "We are so honored to have DNA move its headquarters to Tempe."

Greg Pivrotto, DNA board chairman, kicked off the digging by saying, "today we are going to dig for the future." With each scoop of dirt, a new era for the gift of life began.

Because of national and statewide increases in donation volume, DNA's current campus does not have the capacity to continue coordinating organ and tissue recovery efficiently.

The new building will have 70,000 square feet. Clinical space will use more than 25%, at 18,000 square feet. That will include two ORs for tissue and ocular recovery, space for tissue and ocular preparation, as well as a human leukocyte antigen (HLA) lab for histocompatibility testing. The HLA lab is currently in a leased facility in Phoenix where clinical staff performs testing to match organs with recipients.

A new building also means new opportunities to honor and thank donors and their families. Jennifer Loreda, donor sister, tearfully shared what this new location means to her family.

"Going to the current office and seeing my brother's picture up in the building is really heartwarming," she says, "and I know that's what this is going to be for so many other families like mine."

Opposite Page, Top: Tempe Mayor Mark Mitchell (c) joined by (l to r) DNA Board Chairman Greg Pivrotto; Vice President of Clinical Services PJ Geraghty; Senior Vice President and CFO Kathy Mills; President and CEO Tim Brown; Vice President of Development and Referral Services Sara Pace Jones; Senior Director of Human Resources Maureen Hanson.

Opposite Page, Bottom: Dozens of people joined in on the digging fun after the formal groundbreaking ceremony March 5, 2019.





OFFERING HOPE IN NEW WAYS

A FULL CIRCLE OF GENEROSITY

Donor Network of Arizona (DNA) works to support charitable opportunities in its communities. In 2018, its mission extended beyond organ and tissue donation with DNA's Community Involvement Committee's focus on helping children, veterans, the homeless and the environment.

COLLECTING FOR A CAUSE

For example, the committee placed pop tab collection jars in DNA's break room. They have already donated several gallon-sized bags of the recyclable aluminum to help fund Ronald McDonald House Charities, a nonprofit supporting children in need of health care, in Phoenix. Then, they upped the ante.

DNA's most successful drive came from the competitive spirit among employees during Donate Life Blue and Green week in April 2019. Team Blue and Team Green competed to donate the most cases of water. By the end of the week, DNA donated more than 6,000 bottles to Phoenix Rescue Mission, a faith-based homeless, substance addiction and trauma services organization.

The committee and employees also supplied 65 backpacks with school supplies for Pappas School, a nonprofit that assists children of low-income and homeless families. And staff filled two car trunks with snacks for Childhelp, which helps victims of child abuse.

THE COMFORTS OF HOME

DNA also teamed up with Ronald McDonald House to cook five meals for the families, and the committee helped remodel a room at the Roanoke House.

"Being able to volunteer for the Ronald McDonald House meals program has been very humbling, and you see that the families are really grateful," says Nataley Hernandez, the administrative assistant for Donor Program Development at DNA. "We're able to provide a hot, home-cooked meal to help make their day a little less stressful, even if just for a moment."

DNA employees vow to continue helping others make the most of life, particularly through difficult times.



Left: DNA staff collected more than 6,000 water bottles to donate to Phoenix Rescue Mission ahead of the hot Arizona summer months.

Right: Team members from all departments got together to cook a hot meal for Ronald McDonald House families.



DNA'S BIRTH TISSUE PROGRAM

When Ja'Leisa White-Newhouse gave birth to her daughter Da'Kota Washington, she also gave someone else the chance to heal.

Donor Network of Arizona (DNA) debuted its birth tissue program late last summer when White-Newhouse signed up to heal and save lives and donated her placenta.

White-Newhouse considered donation after her OB-GYN suggested it, since her cesarean section was already scheduled. To White-Newhouse, it was an easy decision to make after learning the healing that birth tissue donation brings.

"My great-grandmother passed away at 96 years old after she fell and had a wound that was not able to heal," White-Newhouse says, adding she donated so other people could have more time with their grandparents. "Donation was something very touching to me and I wanted to help people."

After a child is born through a scheduled cesarean section, transplant teams acquire birth tissue that doctors can use to stimulate the healing mechanism of a recipient in need.

As of today, DNA's birth tissue program has completed 36 acquisitions from six hospitals: Banner Gateway, Banner Estrella and Banner Del E Webb medical centers, as well as Carondelet St. Joseph's Hospital, HonorHeath Scottsdale Shea Medical Center and Abrazo Arrowhead Hospital. Banner Thunderbird Medical Center was the first with White-Newhouse's donation.

Rhiannon Knueven, DNA's Tissue Services manager, says she feels hopeful the program will continue to grow and bring forth a second chance at life to those who are in need.

"The program is slowly picking up speed and everyone has been very supportive of the program," says Knueven. "The ability to provide this tissue to our partners and continue to improve lives is why we do this work every day."



Photos: Ja'Leisa White-Newhouse, the first donor through DNA's birth tissue program, holding her 3-month-old daughter Da'Kota Washington.

HEATHER JAUREGUI

THE DIFFERENCE A VALVE CAN MAKE

"My heart was racing!" Heather Jauregui said shortly after throwing the first pitch at a Diamondbacks game April 14, 2019. But she's grateful her heart can beat properly.

Absent pulmonary valve syndrome (APVS), a congenital heart defect, changed the course of Jauregui's health care before birth. Her mother was four months pregnant when doctors determined something didn't function properly with the now-14-year-old's heart.

She was safe in the womb because her mother's oxygen supply compensated for any defects. Someone with APVS has an underdeveloped or missing pulmonary valve, which is supposed to supply blood to the lungs for oxygen.

"My heart was very loud because some of the blood was flowing back," she says, describing what her family went through in her first months. You could also sometimes see the effects of her illness. She had periodic cyanosis—a blue or purple discoloration of the skin because of the low oxygen levels in her blood. She was always tired, and she had difficulty with necessities such as bottle feeding.

After close observation and approval from her cardiologist, doctors performed Jauregui's first of two open-heart surgeries at Phoenix Children's Hospital when she was only 4 months old.

Jauregui is here today because tissue donation saved her life, and she feels lucky to have only gotten the one diagnosis. Most often, APVS comes with other heart defects that can further complicate a patient's health. Her first procedure extended her life for eight years before that valve started to leak. Doctors would have to intervene once again.

Imagine a 9-year-old girl going in for her second open-heart surgery. While facing a serious health condition, she had other priorities on her mind.

"I remember I was more concerned with the surgery landing on my birthday than the actual surgery itself," she says.

Three hours later she had a new heart valve. Jauregui says it still works perfectly, and she credits her cardiologist as well as the surgeon who performed both operations.

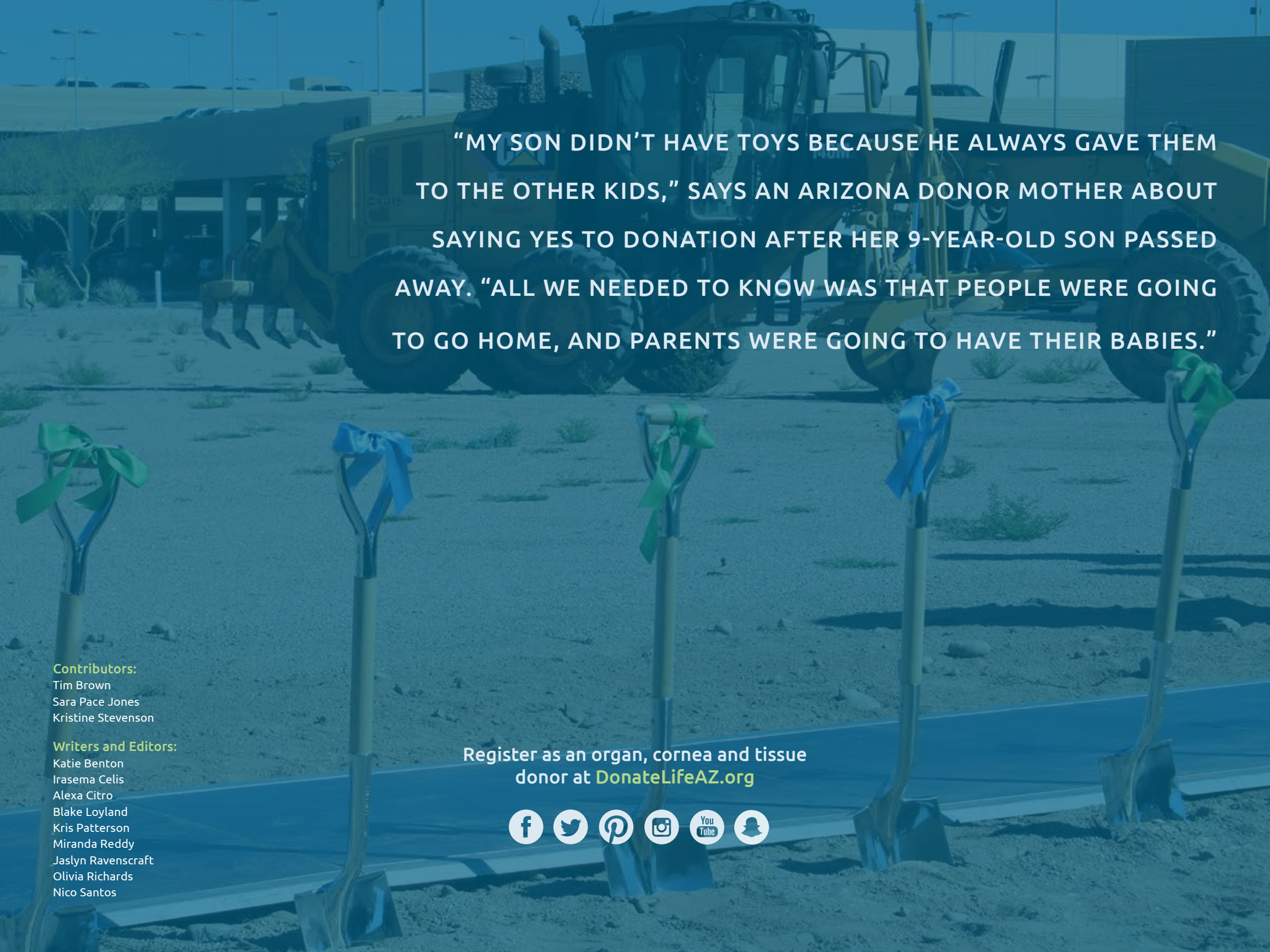
"I'm very thankful to the organ donor who gave me my heart valve and to their family who must have been so sad but still so giving."

This poised young teen says her journey has influenced her career path. She plans to go into nursing or cardiology to help other people with heart concerns like hers.

**“I’m very
thankful to the
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but still so giving.”**

HEATHER JAUREGUI, HEART VALVE RECIPIENT





“MY SON DIDN’T HAVE TOYS BECAUSE HE ALWAYS GAVE THEM TO THE OTHER KIDS,” SAYS AN ARIZONA DONOR MOTHER ABOUT SAYING YES TO DONATION AFTER HER 9-YEAR-OLD SON PASSED AWAY. “ALL WE NEEDED TO KNOW WAS THAT PEOPLE WERE GOING TO GO HOME, AND PARENTS WERE GOING TO HAVE THEIR BABIES.”

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Register as an organ, cornea and tissue donor at DonateLifeAZ.org

