

FACT SHEET: OBAMA ADMINISTRATION ANNOUNCES KEY ACTIONS TO REDUCE THE ORGAN WAITING LIST

“America’s progress in science and technology has countless revolutionary discoveries within our reach... New breakthroughs in treating cancer and ending the wait for organ transplants... That’s some of what America can do.”

President Obama, May 19, 2016

Every 10 minutes, someone is added to the waiting list for a life-saving organ transplant in the United States. And every day, 22 people die while waiting. Today, the Obama Administration, as well as dozens of companies, foundations, universities, hospitals, and patient advocacy organizations are taking steps to change that by announcing a new set of actions that will build on the Administration’s efforts to improve outcomes for individuals waiting for organ transplants and support for living donors. The announced actions aim to increase the number of people who register to become organ donors, increase the number of transplants and improve outcomes for patients, and change what might be possible for future patients by facilitating breakthrough research and development.

NEW ACTIONS ANNOUNCED TODAY

- [Facilitating breakthrough research and development with almost \\$200 million in investments](#). For example, the Department of Defense (DOD) is announcing more than \$160 million in public-private investment in a new Advanced Tissue Biofabrication Manufacturing Innovation Institute to research and develop next-generation manufacturing techniques that can be used to repair and replace cells and tissues and that may one day lead to organ replacement.
- [Closing the gap between the 95 percent of Americans who support organ donation and the roughly 50 percent who are registered organ donors](#). For example, more than 20 organizations including Facebook, Google, ORGANIZE, and Twitter are developing new tools and public advocacy campaigns to increase the options and ease of registering to be an organ donor.
- [Investing in clinical research and innovation that could potentially increase the number of transplants by almost 2,000 each year and improve outcomes for patients](#). For example, more than 30 transplant centers are today announcing a collaboration to share data and best practices for kidney transplants for hard-to-match patients, which has the potential to help almost 1,000 more people a year access transplant. Also, Johns Hopkins University is working with the National Institute of Allergy and Infectious Disease to launch a multicenter study of HIV-positive to HIV-positive organ transplants; as protocols are

developed to use the HIV-positive donor pool, this could lead to as many as 1,000 more transplants per year.

REDUCING THE ORGAN WAITING LIST

Revolutionary medical breakthroughs in the 20th century—such as advances in organ transplantation, tissue typing, and the development of immunosuppressant drugs—have led to hundreds of thousands of life-saving organ transplants and a longer survival rate for recipients. Transplants of kidneys, livers, hearts, pancreata, intestines, and lungs are now considered achievable medical successes.

Advances in medicine and technology and increased awareness of the need for organ donation and transplantation have increased national rates of these interventions. Last year there were more than 30,000 transplants in the United States—representing the most annual transplants ever and the largest year-over-year percentage increase in transplants since 2004. Despite this progress, there are still more than 120,000 people on the waiting list for an organ in the United States.

The vast majority—almost 100,000—of the people on the organ waiting list are waiting for a kidney transplant. In addition to the tremendous human cost, the kidney waiting list carries a huge cost to the public purse: Medicare pays more than [\\$34 billion per year](#) to care for patients with end-stage kidney failure. According to the [2013 Economic Report of the President](#), on average, the Government would save \$60,000 a year for every patient who receives a kidney transplant rather than continuing to receive dialysis. Those patients also would see appreciable gains in life expectancy. For example, the life expectancy of a living donor kidney recipient increases by 10–15 years after a transplant, relative to dialysis treatment.

Today's announcements represent an essential step toward increasing access to organ transplants and reducing the organ waiting list. But there is more to be done. The Administration is committing to providing an update in the next 180 days, which will outline common-sense steps to reduce the organ transplant waiting list and improve outcomes for patients and will report on continued progress on public and private actions like those announced today. This update will be a roadmap for more opportunities in the three areas described in this Fact Sheet, including narrowing the gap between the 95 percent of Americans who support organ donation and the roughly 50 percent who are registered organ donors; new clinical research and innovations that can increase the number of transplants and improve outcomes for patients; and facilitating breakthrough research and development.

FACILITATING BREAKTHROUGH RESEARCH AND DEVELOPMENT

Just a few generations ago, living without kidneys was unimaginable. But that diagnosis changed thanks to Dr. Willem Kolff, a Dutch immigrant who brought his invention of the dialysis machine to the United States after World War II. New breakthroughs in bioengineering,

transplantation, and organ preservation can further increase the number of organ transplants and improve outcomes. Researchers have the potential to repair or replace tissues and organs, reduce waiting list for organ transplants, and potentially reduce health care cost for treatments—but we must continue to invest in breakthrough research and development. For example, consider that most organs can only be stored for 3 to 12 hours, which means that many viable transplant organs are discarded. If even half of all unused donated hearts and lungs could reach transplant patients in time, experts estimate that the waiting list for hearts and lungs could end in 2 to 3 years.

New Federal Investments and Actions

- **The Department of Defense (DOD) is committing to a series of actions to advance what is possible in tissue and organ repair and organ preservation**, including:
 - DOD is announcing more than \$160 million in public-private investment in a new Advanced Tissue Biofabrication Manufacturing Innovation Institute, which will bring together industry leaders, preeminent universities, and non-profits to research and develop next-generation manufacturing techniques that can be used to repair and replace cells and tissues that may one day lead to organ replacement. In addition, the Institute will provide education and workforce training on how to use these techniques to bio-fabricate tissues. The Institute will solve cross-sector manufacturing challenges that stand in the way of producing new synthetic tissues and organs—such as improving the availability, reproducibility, accessibility, and standardization of manufacturing materials, technologies, and processes to create tissue and organ products. The Institute will integrate bioprinting and automation technologies with the pharmaceutical industry to speed up and standardize organ-based drug screening assays. These assays will screen thousands of drug candidates to focus development on best candidates—significantly shortening drug development cycles, reducing costs, and exponentially accelerating innovation. The Institute will also link supply chain and process design specialists with biofabrication and biomanufacturing specialists to shorten design-build-test cycles for tissues and organs, resulting in improved and validated tissue and organ products faster.
 - Recognizing that many transplants are limited by the time required to transport donor tissue to the recipient, DOD is announcing \$7 million in awards to small businesses working to advance the science and technology of organ and tissue preservation. DOD also is announcing six new Small Business Innovation Research topics with up to \$7.8 million to be awarded to expand the availability of donated organs and to improve the treatment of catastrophic injuries by developing novel strategies for preserving organs for transplantation, and tissues for reconstruction.
 - Further recognizing that arm and facial transplantation may offer solutions for wounded service members, DOD will release a fourth call for proposals for the Reconstructive Transplantation Research Program by November 2016 to identify

strategies for expanding access to the procedures, for a total investment of \$57 million since inception of the awards in 2012.

- **The Health Resources and Services Administration (HRSA)** and the **White House Office of Science and Technology Policy** will invite experts in fall 2016 to share individual insights and expertise, with the goal to inform a framework that supports innovation in clinical research in organ transplantation and improve outcomes in transplantation and reducing the organ transplant waiting list.
- The **Kidney Health Initiative**, a public-private partnership established by the **U.S. Food and Drug Administration** and the **American Society of Nephrology** and composed of more than 75 member organizations, will initiate the development of a roadmap that will describe scientific, technical, and regulatory milestones needed to achieve the goal of creating a bioartificial or bioengineered alternative to dialysis as renal replacement therapy. The roadmap will also consider challenges, provide "state of the art" expectations for entrepreneurs and other technology developers, and spur innovation in producing functioning kidney replacements by engaging stakeholders, identifying research priorities to alleviate critical knowledge gaps, and advancing the science of alternatives to dialysis.
- The **National Aeronautics and Space Administration (NASA)**, in partnership with the **New Organ Alliance** and the **Methuselah Foundation** is announcing a prize competition to advance the field of bioengineering with applications that will benefit human disease research and tissue engineering, as well as NASA's journey to Mars. In addition, the **Center for the Advancement of Science in Space (CASIS)**, which manages the International Space Station U.S. National Laboratory, will announce a follow-on prize competition in partnership with the New Organ Alliance and the Methuselah Foundation that will provide researchers the opportunity to conduct research in microgravity conditions. The flight opportunity will help develop a capability to understand tissue level effects of the microgravity environment and may provide a technology to help test countermeasures for radiation effects on human tissues, critical for deep space exploration. These efforts include:
 - NASA, the New Organ Alliance, and the Methuselah Foundation are announcing the Vascular Tissue Challenge competition, with a \$500,000 total prize purse that will be divided among the first three teams that can successfully create thick, metabolically functional human vascularized organ tissue *in vitro* in a controlled Earth environment. NASA's Centennial Challenges Program is funding the prize purse, and the New Organ Alliance is administering the competition on NASA's behalf to help advance research on human physiology, fundamental space biology, and medicine. The intended outcome of the challenge is to enable the growth of new tissues that one day could help the development of organ analogs for research and therapeutic applications on Earth and on long duration deep space missions.

- CASIS, the New Organ Alliance, and the Methuselah Foundation will announce an opportunity for one team to launch an experiment to the International Space Station (ISS) National Laboratory to research the effect of microgravity on vascularized thick-tissue growth. CASIS will provide the team up to \$200,000 in flight integration support costs, along with transportation to the ISS National Laboratory, support on station, and return of experimental samples to Earth.
- **The National Institutes of Health** recently funded the (Re)Building a Kidney consortium to develop ways to isolate, expand, and generate all adult kidney cell types and to understand how to construct the structures of the kidney and replicate human kidney function. This consortium also has a Partnership Project Program that includes efforts to create a molecular atlas of kidney cells from normal and diseased human kidneys. Applications to the Partnership Program will be accepted through July 1, 2016. Up to \$1 million in awards will be announced in early October 2016.
- The **National Institute of Standards and Technology** is developing new standards and technology for accurate and efficient transplant matching, and is supporting research and standards development to underpin the United States' leadership in the emerging cell-based medical technologies that researchers may one day use to regenerate organs.
 - The National Cell Manufacturing Consortium, led by the Georgia Research Alliance and the Georgia Institute of Technology and supported by Nexight Group, is unveiling a 10-year national roadmap representing consensus amongst experts from industry, academia, and government on current industry barriers and a critical pathway of research and development needed to implement next-generation cell manufacturing technologies in the United States.
 - The National Institute of Standards and Technology and Stanford University, through the Joint Initiative for Metrology in Biology, are announcing the launch of a collaborative effort using genomic methods to develop more efficient and accurate human leukocyte antigen (HLA) matching for organ transplants. Since mismatched HLAs are a major cause of organ transplant rejections, this effort could greatly improve the organ-matching process moving forward.

New Private Sector Actions

- The **American Society of Nephrology (ASN)** commits the first \$7 million toward the design, launch, and execution of a potential Kidney Disease XPRIZE, in partnership with the **XPRIZE Foundation**. The Kidney Disease XPRIZE will incentivize the development of a wearable or implantable innovation that replaces kidney function and improves patient quality of life.

- **The American Society of Transplantation (AST)** will fund \$1.2 million in grants in 2016 aiming to double long-term graft survival by supporting innovative transplantation research.
- The **AST** and the **American Society of Transplant Surgeons (ASTS)** are announcing a partnership to create the Transplant Therapeutics Consortium. The consortium will facilitate a 3-5 year research effort for development of more effective innovations and new therapies. Through collaboration with the FDA, academia, and industry, the consortium will aim to improve outcomes in transplant recipients, increase graft survival, and reduce the need for retransplantation.
- Today, **CASIS** announces the winners of the \$1 million 3-D Microphysiological Systems for Organs-On-Chips Research Challenge. These research teams have advanced the field of bioengineering by developing new platform technologies that will be used to study human skeletal muscle cell growth, spaceflight-induced muscle atrophy, and musculoskeletal disorders like osteoporosis, arthritis, and back pain in the microgravity environment of the International Space Station.
- The **Cystic Fibrosis Foundation (CFF)** announces a commitment over the next 5 years to develop a consortium of academic medical centers and laboratories dedicated to improving outcomes after lung transplantation. Supported by \$15 million of CFF funding, the consortium and laboratories will focus on projects which improve delivery of lung transplant clinical care, increase understanding of chronic graft dysfunction, and develop new therapies for lung transplantation through clinical trials.
- The **Kidney Research Institute**, a collaboration of Northwest Kidney Centers (NKC) and the **University of Washington**, will launch its new Center for Dialysis Innovation with the mission of keeping individuals on dialysis healthier and better candidates for transplant. With an investment of \$1.2 million from NKC, the Institute's Center will launch "Blue Sky" projects to revolutionize dialysis technology using biomaterials and bioengineering.
- The **Laura and John Arnold Foundation (LJAF)** is announcing a 3-year, \$4.2 million grant to launch the Donor Management Research Institute—a collaboration between researchers at the **Oregon Health and Sciences University**, the **University of California-San Francisco**, the **United Network for Organ Sharing**, and several organ procurement organizations around the country. The Institute will seek to produce new evidence-based standards of care by expanding a national, web-based donor management portal and conducting rigorous randomized controlled trials to test donor interventions that maximize the quantity and quality of life-saving organs that each donor is able to give.

- As part of their University 3D Bioprinter Program, **Methuselah Foundation** and **Organovo** are announcing more than \$200,000 in grant and bioprinter support to the **University of California-San Francisco** for research into the creation of new human bone organoids, which may ultimately be used to replace or repair damaged skeletal structures and to treat a variety of bone conditions with real living functionally bioidentical skeletal tissues. The research under this partnership will address diseases ranging from osteoarthritis to rare bone disorders that have no cure such as fibrodysplasia ossificans progressiva.
- The **Organ Preservation Alliance** is organizing and hosting the Summit on Organ Banking through Converging Technologies, to be held in August 2017 at the Martin Conference Center at Harvard Medical School, in partnership with **University of North Carolina at Charlotte** and the **Center for Engineering in Medicine at Massachusetts General Hospital**. The **Organ Preservation Alliance** also will host a Breakthrough Ideas in Organ Banking Hackathon to bring together teams of young scientists, engineers and technology entrepreneurs to propose innovative solutions for the most pressing problems in organ and tissue banking, with the winning team receiving a \$10,000 prize. With support from the **Thiel Foundation, Association of Organ Procurement Organizations, American Society of Mechanical Engineers, Society for Cryobiology, and New Organ Alliance**, the **Organ Preservation Alliance** also commits to developing a Roadmap to Organ Banking to identify challenges and milestones for advancing organ and tissue preservation technologies.
- **Virginia Commonwealth University (VCU)** will launch the \$1.7 million VCU Organ Reanimation Laboratory to help end the shortage of organs for transplantation by translating proven research principles of reanimation or reconditioning of human organs into innovations that are transplant-ready. This first-of-its-kind facility and operations will serve as a pilot program for 140 similar facilities across the country.

CLOSING THE GAP BETWEEN AMERICANS WHO SUPPORT ORGAN DONATION AND WHO ARE REGISTERED DONORS

The donor registration system was first built in 1968 and has been run almost exclusively through states' Departments of Motor Vehicles. Despite data showing 95 percent of Americans support organ donation, only approximately half are registered as organ donors. Today, with new technologies available, there is an opportunity to re-imagine the donor registration system in more seamless and effective ways, with the goals of increasing registrations and life-saving transplants.

New Private Sector Actions

Today, more than 20 entities—from organ procurement organizations (OPOs) to patient advocacy organizations to major technology companies—have committed to help reduce the

agonizing wait for an organ transplant. By tying advocacy campaigns to easy donor registration technologies, these efforts can help improve the current reality, in which 22 people in the United States die every day waiting for a life-saving transplant.

- **Amy Poehler’s Smart Girls** will create content and use its social channels to promote organ donation and registration throughout summer and autumn of 2016.
- **Carnegie Mellon University (CMU) and New Jersey Organ and Tissue Sharing Network (NJSN)** will conduct a pilot to understand the effects of sharing a video highlighting family donation decisions with legal next-of-kin. CMU and NJSN analysis suggests that increased consent by legal next-of-kin could lead to 3,000 additional life-saving transplants per year. Results of the 1-year pilot will be published next year and shared with all 58 OPOs, organizations that work to increase donor registration and also coordinate the donation process when actual donations become available.
- The **Cystic Fibrosis Foundation** announces its commitment to a multiple-year partnership of up to \$1 million with **ORGANIZE** to promote organ donation for lung transplantations. This campaign will focus on strategic partnerships with organ procurement organizations and social media strategies to increase the number of registered organ donors and decrease lung transplantation waiting time.
- **Donate Life America (DLA)**, a national 501(c)(3) non-profit alliance focused on increasing organ, eye, and tissue donation in the United States, in partnership with advertising agency **Leo Burnett**, will launch a social media campaign in the summer of 2016 to target populations that have typically been less likely to register as organ donors. In June 2016, DLA, working with **Ogilvy & Mather** and **Instagram**, will launch an update to its "Give Me a Heart" social media donor registration campaign. Through this campaign, DLA will try to drive online registrations throughout the year by adding new stories of patients who have received transplants and others who are waiting for transplant.
- **Google** will develop ways people can easily locate information on organ donation and how to register online.
- In order to increase awareness of organ donation, the **MedStar Georgetown Transplant Institute** is developing a free smartphone and tablet app that will allow individuals to designate their healthcare preferences. This app will allow for an individual’s organ donation preferences to reside on a smart phone or tablet, and be shared with family and friends. When users opt-in to organ donation, the app sends the donor data in real-time to the relevant donor registry. MedStar Georgetown Transplant Institute is partnering with **Donate Life America** and **ORGANIZE** to launch this effort by the end of 2016.
- **ORGANIZE**, a nonprofit dedicated to ending the wait for organ transplants, commits to working with partners to launch a national “social media declaration” campaign to

achieve 1 million new registrations and social declarations by the autumn of 2016. A “social media declaration” is when people communicate their organ donation wishes on social media by using statements such as #organdonor or #organdonation. These social media declarations will be captured within “53”, a registry freely available to all OPOs in order to assist next-of-kin in decision-making. The following organizations are helping to reach the 1 million goal:

- [DoSomething.org](#) is committing to make organ donor registration its featured campaign in August 2016, ensuring that organ donation registration messages reach its 5 million active users.
 - [DMV.org](#) will make organ donor registration the prominent call to action for the hundreds of thousands of visitors it receives on a daily basis.
 - [Edelman](#) will provide creative and media support to distribute messages about the importance of social declarations across all online platforms.
 - [Facebook](#) will promote opportunities to register as an organ donor as part of the campaign to help ORGANIZE reach its 1 million goal.
 - [Funny or Die](#) is launching a national organ donor awareness campaign that will be distributed to its 35 million social media followers. The campaign will encourage Millennials to speak to their parents about the need for organ donation since donors aged 50 to 75 have the lowest donation rates of any demographic.
 - [GOOD](#) will promote organ donation in 2016, including both content creation and distribution.
 - OPOs such as [Indiana Donor Network](#), [Life Alliance Organ Recovery Agency](#), [LiveOnNY](#), and [Nevada Donor Network](#) will use social declarations via the registry “53”, as part of their standard operating procedure, and will commit to sharing best practices to inform new industry standards on the role of social media in next-of-kin conversations.
 - [Tinder](#) will launch a donor registration campaign in which users will be presented with organ donation content and will be encouraged to “swipe right” to begin the donor registration process. This will be presented to Tinder’s millions of users beginning in September 2016, with the goal of increasing donation rates among Millennials. A similar campaign was run in the United Kingdom with the National Health Service.
 - [Twitter](#) will enable organ donation registration campaigns by facilitating a way for anyone to register as an organ donor when they use an organ donation-specific hashtag on Twitter.
- **North American Transplant Coordinators Organization (NATCO)**, the largest professional organization for transplant coordinators, is committing to offering continuing education training beginning in summer of 2016 to share best practices for the use of social declarations to inform next-of-kin conversations.
 - Members of the **Social and Behavioral Sciences Team** at the **U.S. General Services Administration** will collaborate with experts at **Duke University**, **ORGANIZE**, and the **Wharton School of the University of Pennsylvania** to produce a best practices report

on organ donation messaging. With the advent of new digital registration pathways there is an opportunity to conduct behavioral science research that has the potential to significantly increase registration rates across the country. This research will commence in summer of 2016 with a target publication date of 2017.

- **Walgreens** and **Donate Life America** will use targeted communications to Walgreens pharmacy customers throughout 2016 to encourage organ donation registration via the online Donate Life Registry.

INCREASING THE NUMBER OF TRANSPLANTS AND IMPROVING TRANSPLANTATION OUTCOMES FOR PATIENTS

New Federal Investments and Actions

Federal agencies are taking new actions to improve outcomes in transplantation. Actions include greater support for veterans—who experience kidney failure at a higher rate than the general public—and helping more Americans access life-saving transplants through kidney paired donation, which pools living donors and recipients to increase the likelihood of matches.

- The **U.S. Department of Veterans Affairs (VA)** and the **American Society of Nephrology** are joining forces to launch the Kidney Innovation Initiative that will challenge scientists and technologists around the globe and the public to develop tools that improve quality of life and outcomes for people with kidney disease and/or facing a kidney transplant. The first public prize will launch later in 2016 and be focused on improving technological resources for individuals with kidney disease through a smartphone app. The outcome of this challenge will be a resource that is available not only for veterans, but also the public.
- The **Health Resources and Services Administration (HRSA)**, an agency of the U.S. Department of Health and Human Services (HHS), commits to help support living donors and ensure appropriate metrics are in place to help more patients receive deceased-donor transplants.
 - Support for living donors. In collaboration with the **American Society of Transplantation (AST)** and the **American Society of Transplant Surgeons (ASTS)**, HRSA announces a coalition to support living donors. The coalition will include patient organizations and other stakeholders within the transplant community, and seeks to help address three key areas: providing education and resources for potential living donors to make an informed decision about donation, addressing financial and other barriers to donation, and ensuring that living donors have long-term medical follow-up and access to care. This summer, HRSA will release findings from the Scientific Registry of

Transplant Recipients (SRTR) on the feasibility of establishing a national living donor registry to obtain information about long-term health and socioeconomic outcomes of living organ donation.

- Ensure appropriate metrics are in place to help more patients receive deceased donor transplants. In fall 2016, HRSA will release the findings of two studies performed by the **Organ Procurement and Transplantation Network (OPTN)**, one on the feasibility of collecting new information and another for modifying existing performance monitoring, to increase understanding of good practice in organ procurement and transplantation. One study relates to the feasibility of collecting patient-level data on in-hospital deaths to evaluate organ procurement organization (OPO) effectiveness. HRSA will evaluate the results of this study to determine next steps in ensuring that appropriate data are collected to measure OPO performance. The second study will develop a new model, the Collaborative Innovation and Improvement Network (COIIN), for monitoring transplant center outcomes that could potentially be used to support greater national use of moderate- to higher-risk deceased-donor kidneys. This model is intended to identify and disseminate successful transplant center practices together with real-time data and other technical assistance to help centers adopt these practices.
- **Walter Reed National Military Medical Center (Walter Reed Bethesda)** today announces a pilot to pioneer kidney paired donation chains started via the military share program—in which families of active duty military service members donate one of their kidneys to patients listed for transplant at Walter Reed Bethesda—to help those who are hard to match to receive kidney transplants. Military men and women around the country can help some of the hardest-to-match veterans and their dependents receive transplants using kidneys from the military share program, while at the same time facilitating life-saving kidney paired donation chains for civilian patients. Walter Reed Bethesda also commits to help military retirees and their dependents increase access to kidney transplants by offering them transplant services at Walter Reed Bethesda, including covering travel and housing for eligible donors.
- The **White House Office of Science and Technology Policy**, in collaboration with **HRSA**, will bring together researchers from diverse fields for an Organ Datapalooza this year to explore new ways of linking OPTN transplant data with data from other databases to use more organs effectively for transplantation.

New Private Sector Actions

Better resources and tools are critical to ensuring access to life-saving transplantation opportunities. This is particularly important on health equity grounds, as communities of color are simultaneously over-represented in end-stage renal disease (ESRD) while receiving transplants at a lower rate than non-Hispanic white patients.

- Building on recent breakthroughs in incompatible kidney transplants, more than 30 organ transplant centers are announcing a collaborative study to identify best practices for the one-third of kidney patients who are difficult to transplant because they have a highly sensitized immune system that would attack the transplanted kidney. This study will provide new insights into treatment options for this population through what is known as “desensitization” so that transplants are not rejected. Successful treatment of sensitized patients could yield up to an additional 950 transplants per year.
- The **American Society of Transplant Surgeons**, the **American Society of Transplantation**, and the **Laura and John Arnold Foundation** will partner to award research grants that will study transplant centers’ performance, beginning in July 2016. The initiative aims to increase the number of organ transplants by reducing undue risk aversion and incentivizing innovation transplantation, while maintaining patient safety and care. The results of these studies will be featured in a conference designed to draw key findings from each analysis into a formal proposal.
- The **American Society of Transplant Surgeons**, **Baylor University Medical Center**, **Cleveland Clinic**, **Fahrenheit 212**, **Mount Sinai Health System**, **ORGANIZE**, and the **University of Chicago Medicine** are launching a collaborative to explore the design and development of an Anonymous, Non-designated Living Donor Database. While only one donor is required for any particular transplant patient, for many transplant recipients, multiple potential donors are identified; this project will help centers direct these additional willing donors fairly and ethically to other donation opportunities, including to start living donor chains.
- **Beth Israel Deaconess Medical Center**, **Duke University School of Medicine**, **Emory University**, **Mount Sinai Hospital**, **Northwestern University**, **Temple University**, and the **University of California Los Angeles** have created a Blue Ribbon Advisory Panel committed to establishing a national clearinghouse of educational resources about transplant and living donation for patients, living donors, and the interested public. Their goals are to ensure informed transplant and living donation decision-making and equity in access to quality information to combat barriers that research suggests limits access to transplants. Resources will be made publicly available by the end of the summer of 2017.
- The **Cystic Fibrosis Foundation (CFF)** announces a commitment to develop new programs to support individuals with cystic fibrosis and their families as they enter the lung transplantation process. A mentoring program, being piloted in 2016, will connect individuals who are preparing to undergo transplantation with others who have experienced the transplantation process.

- The **Global Liver Institute**, in collaboration with the **Johns Hopkins University School of Medicine**, **Sibley Innovation Hub**, and **Astellas Pharma**, is committed to developing a model Patient-Centered Medical Home and Survivorship Program for Transplant Recipients that improves the long-term outcomes for solid organ transplant recipients by reducing the number of retransplantations through care coordination and shared decision making tools informed by predictive analytics and human-centered design principles. A pilot will begin in August 2016 with information publicly available by the following spring.
- **Johns Hopkins University** is working with the **National Institute of Allergy and Infectious Disease** in a cooperative agreement to design and launch a multicenter study of HIV-positive to HIV-positive organ transplants in the coming year. This grant award builds on the first U.S. HIV-positive-to-HIV-positive kidney and liver transplants that were performed there in March 2016 as a result of the HOPE Act signed into law by President Obama in November 2013. Results of the study will be public, and as protocols are developed to use the HIV-positive donor pool, this could lead to as many as 1,000 more transplants per year.
- **Johns Hopkins University**, working with the **National Kidney Foundation** and **Novartis**, will disseminate a comprehensive set of educational resources to more than 50 leading transplant centers to expand the Live Donor Champion Program. This program will help centers teach patients how to leverage their personal connections and social networks to raise awareness about the need for organ donors and to help identify potential live donor candidates. Participation in the program is associated with an over five-fold increase in identification of potential live donor candidates. Given that Hispanic patients are disproportionately affected by kidney disease and are less likely to pursue live donor transplantation, **Northwestern University** will tailor a Live Donor Champion model for this community. Novartis will also launch a lecture series to educate 20 transplant centers about culturally competent ways to engage Hispanic families in discussions about transplant and living donation, in particular. As African-Americans also face a significantly higher incidence of end stage renal disease and disproportionately low rates of live donor transplantation, the **University of Alabama at Birmingham** will tailor a Live Donor Champion model for African-American patients. These tailored models will be publicly available by the end of 2016.
- **Johns Hopkins University** and **ORGANIZE** are launching a second version of a living donor app, Donor, to help patients find life-saving kidney or liver transplants using social media. Donor helps patients create and post their personal story directly to **Facebook**. In the initial pilot study, patients who used Donor had a six-fold increase in finding a living donor compared with patients who did not. Facebook, which provided the initial funding for Donor, will continue to explore ways to support the app and Johns Hopkins and ORGANIZE's efforts. The next round of testing will

take place in June with Johns Hopkins University, **Northwestern**, the **University of Alabama at Birmingham**, and **Walter Reed Bethesda**, with expanded roll-out to at least ten transplant centers by the end of 2016.

- The **National Kidney Foundation (NKF)** will launch a nationwide campaign called The Big Ask/The Big Give to promote awareness of living kidney donation for recipients who have trouble asking someone to consider kidney donation and potential donors. The Big Ask/The Big Give will roll out in the fall of 2016 in transplant centers, dialysis centers, and nephrology practices, providing education to remove misconceptions and confusion from what can be a complex process for patients and donors. NKF will also host a Consensus Conference on Kidney Discards in early 2017 to explore approaches to reduce the number of kidneys that are discarded—currently 3,000 every year.
- The **National Kidney Registry (NKR)**, the largest kidney paired exchange network in the United States, announces a reimbursement program to pay for out-of-state physician fees associated with organ removal from non-Medicaid beneficiaries when the organ transplant recipients are Medicaid beneficiaries. While states can pay for out-of-state providers if they deliver a service to a Medicaid beneficiary, physician fees associated with organ removal from a donor who is not a Medicaid beneficiary generally are not reimbursable by a state Medicaid program. This new NKR program will reimburse a standard rate for the donor surgeon and anesthesiology fees which are required to facilitate the removal of the living donor's kidney, providing transplant opportunities for the underserved Medicaid population and reducing health care inequality. Although medical complications related to kidney donation are rare, NKR and its Member Centers are committed to covering such costs so that they are not borne by donors, and is therefore today announcing the creation of a \$1 million Donor Protection Program.
- **The Nonprofit Kidney Care Alliance (NKCA)**, through its member companies, pledges to launch new programs to increase access to transplant for more than 4,000 chronic kidney disease (CKD) and end-stage renal disease (ESRD) patients.
 - **Dialysis Clinic, Inc. (DCI)** will increase access to pre-emptive transplant by expanding the REACH Kidney Care program to 27 communities in 17 states, offering this service to 2,500 patients with less than 30 percent kidney function. DCI's goal is that by next year, 11 percent of its patients who need a transplant will receive one preemptively—quadruple the current national number.
 - **Northwest Kidney Centers (NKC)** is investing \$250,000 to launch its new CKD Patient Navigation Service to help patients move toward transplant through individualized assistance from a registered nurse. Also NKC will expand access for patients in rural areas via K View, a new \$400,000 teleconferencing system to be fully operational in summer 2016 to increase education and awareness about access to information on transplantation.

Through this investment, NKC commits to a 5-year goal to increase the transplantation rate among its dialysis patients by one third, bringing the annual rate of its dialysis patients who get a transplant to 10 percent, which is twice the current national average.

- The Rogosin Institute will launch a program this summer with 100 community volunteers to promote kidney transplantation through culturally-specific grassroots education and mobilization in high disease-burden areas of Brooklyn, New York. Rogosin's Center for Health Action and Policy will also convene a national roundtable in fall 2016 to generate pilot projects to expand access to transplant that will be tested in each of Rogosin's eight centers and in the communities of national partners. Results from both programs will be disseminated nationally. Rogosin's goal is a 30 percent increase in patient transplants over the next 12 months and the creation of a replicable model that advances transplantation and reduces disparities.
- The **University of Pittsburgh Medical Center (UPMC)** and the **Children's Hospital of Pittsburgh of UPMC**, the Nation's first pediatric transplant program, commits with **Donate Life America** to pioneer innovative outreach via social media to increase the availability of living donor organs with the goal of minimizing transplant wait list mortality for all patients with an emphasis on eradicating pediatric wait list mortality. This effort will be launched in 2016 to patients and their families, integrating social media experiences to educate families of patients waiting for a donation about living donation. Tools will be shared with the broader transplant community via social media, Donate Life America communications, national webinars and meetings.
- The **United Network for Organ Sharing (UNOS)**, the Nation's Organ Procurement and Transplant Network, commits to provide new technology and data tools to increase the number of transplants done in the United States. By the end of 2016, UNOS will increase efficiencies in the organ procurement and transplant system as well as the potential number of transplants by building on TransNet software initially developed through an HHS Innovation project in conjunction with HRSA that uses barcode scanning technology to accurately label and track organs shipped for transplantation; with a new transplant center pilot project designed to speed organ check-in; implementing electronic data exchange capabilities to expedite delivery of critical and time sensitive information between stakeholders to reduce delays and complications caused by manual entry of information; and establishing donor profile capability within this online database system to allow transplant centers to specify additional criteria for organ selection for their patients, thus reducing delays caused by unwanted organ offers. UNOS will also start publishing annual, national hospital benchmark reports as well as making de-identified information on every organ offered, accepted, and rejected publicly available to inform better decision-making. UNOS will also create a technology platform that will allow transplant and behavioral

science researchers to work together to test new ways of improving the organ offer system.

BUILDING ON A RECORD OF SUPPORTING PATIENTS AND INCREASING ACCESS TO ORGAN TRANSPLANTATION

Today's commitments build on earlier Administration actions to improve outcomes for individuals waiting for organ transplants and support living donors.

- Each year, approximately 6,000 Americans make the selfless decision to become a living organ donor, facilitating life-saving kidney and liver transplants. Thanks to the [Affordable Care Act](#), individuals who have donated organs have access to health insurance without worrying whether their donation will be considered a pre-existing condition.
- [The Hope Act](#) signed by President Obama in 2013 legalized the use of organs from HIV-positive donors for use in HIV-positive recipients, in the setting of clinical research. Earlier this year, surgeons at Johns Hopkins University performed the first-in-the-United-States HIV-positive to HIV-positive liver and kidney transplants. As this research continues, we will understand more about the success of these transplant procedures, and the potential for the use of organs from HIV-positive donors to increase access to all patients on the waiting list.
- HHS launched a nationwide kidney paired donation program in 2010 to build on the transformative innovation of pooling living donors and recipients to increase the likelihood of matches.
- Drawing on the spirit of innovation that President Obama spoke about in this year's [State of the Union address](#), seven government agencies have invested nearly [\\$3 billion over a 3-year period](#) in the future of bioengineering to advance our understanding of wound repair and organ and tissue regeneration and preservation.

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