2018 Annual Report

ALLIANCE FOR PAIRED KIDNEY DONATION

Serving kidney patients through technology, education and generosity.

Table of Contents

Our Mission

To save lives by securing a living donor kidney transplant for every patient who needs one.

Our Core Values

As we seek to fulfill this mission, we are guided by the following core values:

Academic Excellence & Engagement: Adhering to the highest standards of academic integrity, with a commitment to sharing insights, experience and knowledge with the broader academic community

Altruism: Promoting altruism in the transplant community with respect

Commitment to Innovation: Being an innovative organization for discovering new medical approaches

Integrity: Holding to the highest standards, worthy of patient trust, seeking to do the right thing

Leadership in Transplant & Bioethics: Leading the way in ethical standards and scientific advances

Patient-Focused: Dedicated to the well-being of all patients

Sustainability: Fiscally prudent and solvent, generating funds to invest in innovations

Transparency: Operating in an open and accountable fashion

Celebrating Ten Years of Success

It is really amazing what the Alliance for Paired Kidney Donation has accomplished in its first decade of innovative work to advance living kidney donation. We literally set out to change the world—and in many ways we have done just that!

In 1999, kidney exchange didn't exist. In that year if you walked into your doctor's office and you wanted to help somebody that you loved by donating a kidney to them, but you didn't match, the doctor would look downcast and tell you he was sorry. He would point to the door and tell you that you would have to wait to receive a donation from someone who died--that you would have to wait 3 to 5 years. Many patients don't survive a 3 to 5-year wait.

No one knew then that we were about to change that. Swapping kidneys is a pretty simple concept, but it turns out it's really complicated to figure out who matches who and how to do the matching in order to help the most people and to achieve the best quality of kidney transplants.[1] Our team was the first to build software that allowed transplant centers to work together over the Internet.[2] That software is now in use in six countries around the world!

Kidney paired donation essentially allowed us to make use of a valuable resource that was right in front of us—but we couldn't see it. Who would've imagined that a kidney inside of a family member that didn't match the person that they love could still be used to save not only the life of their loved one, but also a complete stranger? And here we see the real value of the Alliance for Paired Kidney Donation—it starts with a blank piece of paper and it creates for us new knowledge, which it then deploys, to produce to life-saving solutions.

Our Second big accomplishment came as a result of our good fortune to work with brilliant economists like Alvin Roth, Utku Unver, and Itai Ashlagi. Once we had people willing to give complete strangers kidneys, the Alliance for Paired Kidney Donation showed that we could do more, by taking that precious gift and turning it into not just one kidney transplant, but many. The New England Journal of Medicine chose this concept for publication in 2009 and now our pay-it-forward concept has been duplicated by many others around the world producing about three fourths of all the kidney paired donation transplants performed globally.[3] While we can celebrate in this annual report that the Alliance for Paired Kidney Donation has facilitated more than 500 kidney transplants over the last decade, the ideas to which we have given birth have led to more than *five thousand* kidney transplants over the last decade.

The Third major achievement of the Alliance for Paired Kidney Donation solved this problem: many paired donation transplants did not move forward because of barriers related to how we pay for healthcare in the United States.[4] With all the different healthcare payers we have, it was very complicated when you had to pay hospitals to take out kidneys, doctors to do the surgeries, anesthesiologists for putting patients to sleep, Airlines to fly kidneys and taxi companies to move kidneys from hospitals to airports. It was very complicated to negotiate the payment for each one of these

services associated with every paired exchange transplant.[5] Prior to 2012, this single challenge prevented many KPD transplants from taking place. Through a federal grant entrusted to the Alliance for Paired Kidney Donation, we created a process to simplify these transactions, passing them through a central clearinghouse that has now become a standard mechanism to pay for paired exchanges in the United States.

These three breakthroughs: Internet-based kidney exchange matching, pay-it-forward chains of transplants and a transparent financial ecosystem, have revolutionized how kidney exchange is done today. But we believe that our biggest contributions are yet to come.

Believe it or not, when we first suggested the concept of pay-it-forward chains most of our transplant colleagues thought it was a bad idea. They thought it wasn't fair to give a kidney to somebody who wasn't at the top of the waiting list—even if it could help more people. We lived through criticism and push back so that today, you won't find anyone in the United States who thinks that the kidney from someone who is willing to save the life of a stranger should go to the person at the top of the waiting list. Instead almost all of these kidneys produce pay-it-forward chains of transplants.

We are currently working on two big new ideas and we would love to have your to help support us financially, to support us with your time and energy, and maybe for some of you, to literally save lives with your kidney. Not just lives in our own community, but lives around the world.

In 2012, The Alliance for Paired Kidney Donation began work on a project that aimed to use the mechanism of kidney exchange to help save the lives of people who can't afford kidney transplants. After three years of work to build international relationships and work out the legal aspects of the concept with Duke Law Professor, Kim Krawiec, The Alliance for Paired Kidney Donation completed its first Global Kidney Exchange transplant in 2015.[6] In 2018, we started the seventh and eighth Global Kidney Exchange transplants, competed the second chain, and began working with Rejuvenate Healthcare to sign our first US healthcare payer to participate in project.[7,8] To date, The Alliance for Paired Kidney Donation has utilized the process of Global Kidney Exchange to save the lives of eight patients outside of the United States, and as a result, 26 American patients were transplanted through the resulting chains.

In 2015, The Alliance for Paired Kidney Donation began working with the White House and the US Military through our collaborators Walter Reed Military Hospital, Jason Hawksworth and Eric Elster, to show that we can make better use of some kidneys from people who have died. We are calling this concept deceased donor-initiated chains: a concept to start pay it forward chains with a deceased donor's kidney, allow each kidney treated in this way to save more than just one life.[9]

If we are going to do this it's not going to be easy. Change never is. With your support we are ready for the next 10 years of work, innovation and progress!

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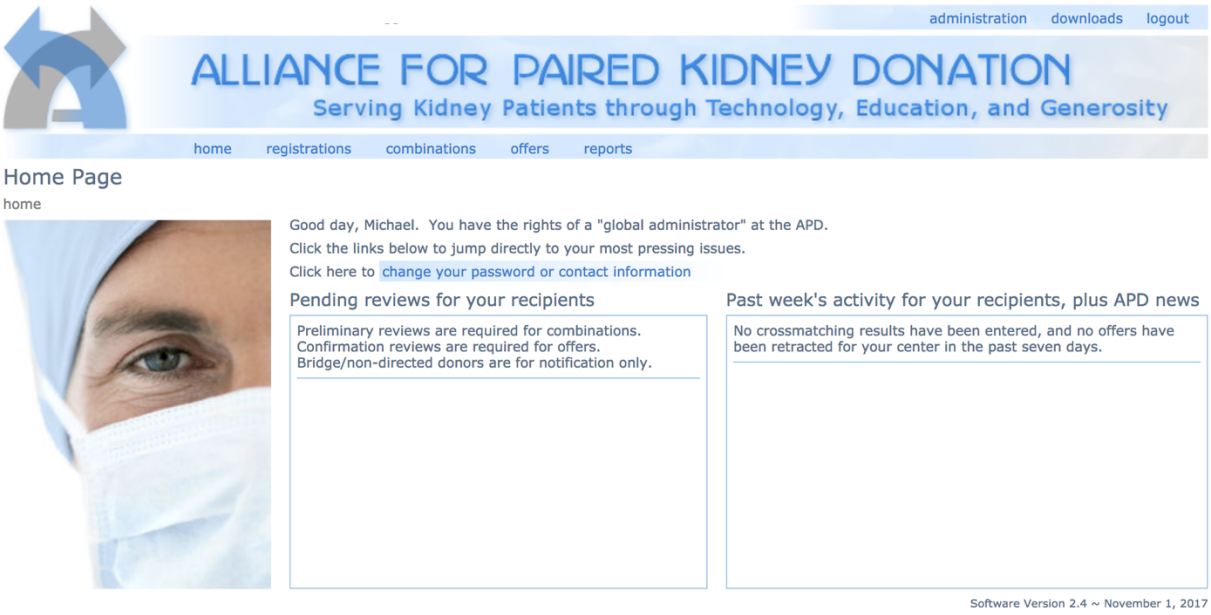
Kidney Exchange

In 2018, the Alliance for Paired Kidney Donation was actively engaged in arranging kidney exchange transplants for patients in the following countries: US, Mexico, Denmark, Philippines, Saudi Arabia and India. Overall, more than 120 transplants were facilitated using APKD kidney exchange matching software.

In the United States, 51 kidney transplants were facilitated for patients at 16 transplant centers while 30 transplant centers enrolled pairs into the APKD matching. The University of Michigan was the leading transplant center for the APKD, performing 11 transplants, while Scripps Hospital performed 6 transplants; Vanderbilt University, The University of Toledo Medical Center and Jewish Hospital Transplant Center in Louisville performed 4-5 transplants each. Our one-year patient and graft survival averaged over the last five year is 99% and 98%, respectively.



Standard Acquisition Charge Model

In 2018, the Alliance for Paired Kidney Donation successfully completed its $2 million grant through the Agency for Healthcare Research and Quality (AHRQ) to redesign reimbursement and provide a mechanism to reduce the administrative burden of negotiating payment and legal agreements between providers for the costs associated with KPD. It has also provided cost certainty for participating transplant centers and payers. Perhaps the best way to explain the benefit that has taken place as a result of this project is to consider the transplant program participants who now join routine pre-KPD transplant conference calls. Prior to the development of the KPD SAC mechanism, all conference calls required the attendance of transplant center financial staff. Negotiations used to require up to seven separate negotiated financial agreements (a facility fee, surgeon fees, anesthesia fees, taxi fees to and from an airport, airline fees, logistics fees, preservation and packaging fees) for one transplant center to perform one KPD transplant. For the last two years of the Demonstration Project, no financial staff member from any transplant center has joined one of these pre-KPD transplant conference calls. KPD conference calls have been about logistics and clinical decision-making—no different than similar decisions that are made routinely for deceased donor organ offers.

ANNOUNCING

a

$2 Million Grant

to Develop a National KPD SAC

Global Kidney Exchange

Kidney failure is a terrible burden for both patients and society, yet its treatment represents one of the few areas in medicine where the best quality care is also the least expensive. While a patient can live on long-term dialysis, kidney transplantation provides at least an additional ten years of life for recipients as compared with dialysis—not to mention the improved quality of life. Further, the per person per year cost of dialysis is at least three times more expensive over time than the cost of kidney transplantation. Because dialysis in most high income countries is at least three times the cost of kidney transplantation when considering time frames of three to five years, healthcare payers in high income countries could pay for two transplants, if paying the cost of the first transplant for a patient from a low to middle income country created a kidney exchange that eliminated the need for dialysis for a one of the payer's insureds with kidney failure who had a willing, but immunologically incompatible living donor. We refer to this new concept as Global Kidney Exchange. In so doing, the pool of patient-donor participants that can be matched through kidney exchange can be significantly expanded to include "financially incompatible" pairs from low- and middle-income countries, thus increasing the likelihood of finding a match for patients participating in the exchange. In short, Global Kidney Exchange creates more kidneys for transplantation and avoids expensive months of dialysis, thus reducing the cost of care for high income countries like the United States, while increasing access and quality of care for both rich and poor.

Deceased Donor-Initiated Chains

In a 2016 American Journal of Transplantation article, we proposed that some deceased donor kidneys be allocated to initiate non-simultaneous extended altruistic donor chains of living donor kidney transplants to address, in part, the huge disparity between patients on the waitlist and available donors. We argued that the use of some deceased donor kidneys for this purpose would benefit waitlisted candidates in that most patients enrolled in kidney paired donation systems are also on the waitlist. Thus, receiving a kidney through kidney exchange would help reduce the wait for many patients. In addition, a living donor kidney usually provides survival potential equal or superior to that of deceased donor kidneys. As such, if kidney paired donation chains are initiated by a deceased donor kidney, but end by giving a living donor kidney to a candidate on the waitlist, the quality of the kidney allocated to a waitlisted patient is likely to be improved. After this article was published, representatives from the White House Office of Science and Technology called to recommend that we work with the US Military to pilot such a program through something called the Military Share Program. Three years later, we believe that 2018 has set the stage for us to begin utilizing some deceased donor kidneys offered to the US Military to instead start pay-it-forward chains of transplants that will end with a civilian living donor giving a kidney to a member of the US Armed Forces with kidney disease.

2018 Income and Expenses