



U. S. Department of Health and Human Services
Health Resources and Services Administration
Health Systems Bureau
Division of Transplantation



GRANTnews

NOVEMBER 2024 | A periodic e-bulletin to share results of organ donation and transplantation projects funded by the Division of Transplantation.

Pairing is caring: Empowering patients with early, consistent kidney paired donation (KPD) education

A new animated curriculum on kidney paired donation and transplant prioritizes approachability and consistency.

As of April 2024, more than 89,000 people on the National Transplant Waiting List need kidney transplants. Dialysis is a common treatment for kidney failure, but according to the National Kidney Foundation, “Research shows that a preemptive or early transplant, with little or no time spent on dialysis, can lead to better long-term health. It may also allow you to keep working and have a better quality of life.”¹

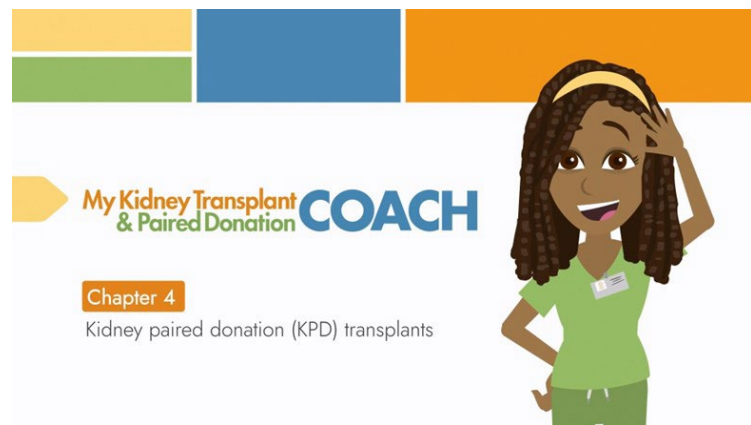


Image from My Kidney Transplant & Paired Donation Coach, available on HRSA's YouTube channel.

Many people who would benefit from an organ transplant know a potential living donor who is not a compatible match. This is where kidney paired donation (KPD) comes in. In KPD, a prospective recipient and their incompatible living donor are matched with one or more incompatible recipient-donor pairs to create kidney transplant chains where all patients receive a matching living donor kidney.

¹ <https://www.kidney.org/atoz/content/kidney-transplant> (last accessed May 3, 2024). See also: https://www.kidney.org/sites/default/files/11-10-0352_choosing_treatment_kidney_failure.pdf

KPD can save the lives of more patients who would otherwise face dialysis or the uncertainty of waiting for kidney transplants from deceased donors. However, current KPD education has gaps and inconsistencies, according to recent research funded by the Health Resources and Services Administration (HRSA).

“Patients and donors may not be getting all the information they need,” said lead researcher Dr. Amy Waterman of Houston Methodist Hospital. “There is inconsistency in when KPD education is offered, whether only the living donor is given the information or both the donor and kidney patient, and what content is shared. For these reasons, we cannot be assured that all potential donors and recipients are truly making informed decisions about KPD.”

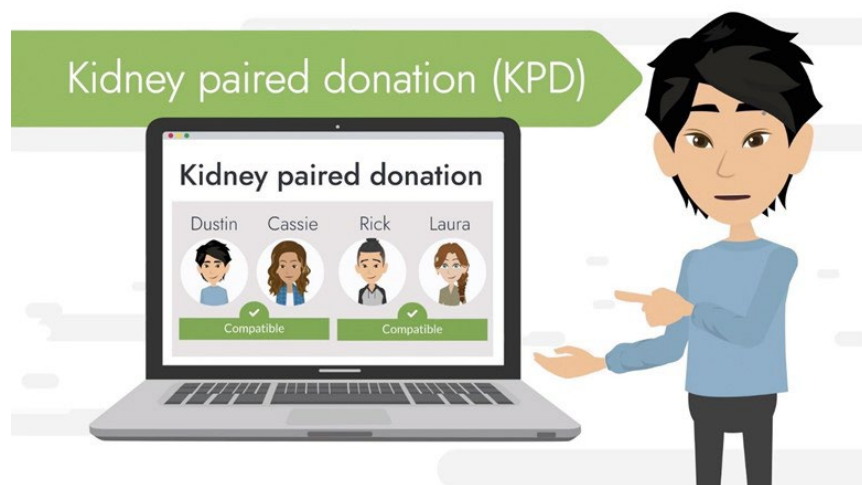


Image from My Kidney Transplant & Paired Donation Coach, available on HRSA's YouTube channel.

In partnership with Health Literacy Media (HLM), Dr. Waterman set out to design a new interactive curriculum to improve and standardize KPD education.

With support from the National Kidney Registry (NKR) and J.C. Walter Jr. Transplant Center at Houston Methodist Hospital, Dr. Waterman conducted research to assess existing gaps in

the education available to prospective KPD participants. Through surveys of 90 transplant coordinators from 68 transplant centers and interviews with 43 KPD participants (25 living donors and 18 recipients), Dr. Waterman gathered data about KPD educational practices, content, and barriers.

In surveys, transplant coordinators recommended more:

- Comprehensive training about how to share the option of KPD with patients successfully and
- Multi-language standardized content.

In interviews, KPD recipients:

- Reported receiving less information than donors,
- Requested more information about financial protections or assistance for donors related to KPD and
- Wanted psychological education and support during and after KPD.

Dr. Waterman added that existing KPD education modules generally tend to overstate benefits without adequately addressing risks and often use complex medical terminology that requires viewers to be more health-literate.

To address these concerns, Dr. Waterman and her team developed a comprehensive animated video series designed to provide education about kidney disease, the risks and benefits of living and deceased donor transplants, and KPD.

It was challenging to develop a curriculum that accommodates the variety of ways different centers participate in KPD. “We spent a lot of time creating neutrality so that the information in the curriculum is generally true for all programs,” said Dr. Waterman. “The videos then encourage people to contact their transplant center for additional information about the opportunity of KPD in their area.”

Another challenge was designing the videos so viewers with diverse levels of health literacy could easily understand and act on the content. To connect with viewers, Dr. Waterman and HLM developed characters with diverse ethnic and racial backgrounds and varied personal histories, including stories of patients and potential donors who were family members, friends, and members of religious congregations.

“Our education and video production teams are diverse by design,” added Catina O’Leary, PhD, President and CEO of HLM. “This helps us create characters and stories that connect with our viewers and meet people where they are.”

“To help with the curriculum’s accessibility, we presented an approachable, gentle tone, used diverse, animated characters to represent people moving through their KPD journey, and provided health-literate medical content to ensure key facts were understood,” said Dr. Waterman. We also provided storylines that modeled seeking out peer mentors,” she added.

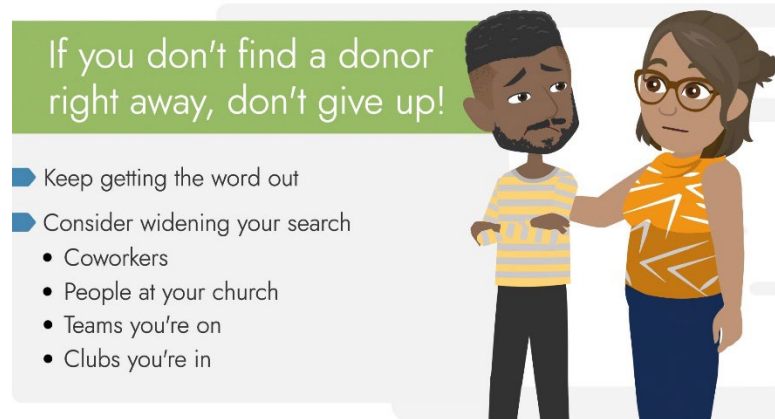


Image from My Kidney Transplant & Paired Donation Coach, available on HRSA's YouTube channel.

To further refine the videos, 16 people with a personal connection to kidney disease provided feedback through four focus groups. Participants described the content as informative and empowering, as well as inclusive and easy to read for those who are visually impaired.

Dr. Waterman is currently evaluating the curriculum’s effectiveness. Recipients and potential donors undergoing evaluation at Houston Methodist Hospital were invited to participate in a randomized controlled trial (RCT). The trial compares the revised curriculum with Houston Methodist Hospital’s standard educational curriculum for KPD participants. Analysis of the RCT data is underway.

Dr. Waterman emphasized that the animation curriculum ends without the characters coming to a final decision about KPD. “The curriculum follows the stories of the

characters moving through the decision process. We chose to leave the stories open-ended to underscore that there is no one right treatment option. Our goal is to help people make an informed decision, not pressure them to make a certain choice.”

Watch and share Dr. Waterman’s 10-part KPD curriculum, [My Kidney Transplant and Paired Donation Coach](#), on HRSA’s YouTube channel.



Strategies that work:

- **Make content relatable.** Use diverse stories and characters in videos to help viewers relate and imagine themselves in the characters’ place.
- **Use animation.** Animation can make videos about complex health topics easier to understand and less scary.
- **Keep it neutral.** Rather than pressure patients to make a certain choice, empower them to make an informed decision about what option is best for them.



Image from My Kidney Transplant & Paired Donation Coach, available on HRSA’s YouTube channel.

This publication was produced for the U.S. Department of Health and Human Services, Health Resources and Services Administration, under contract number GS00F162CA.

This publication lists non-federal resources in order to provide additional information to consumers. The views and content in these resources have not been formally approved by the U.S. Department of Health and Human Services (HHS) or the Health Resources and Services Administration (HRSA). Listing these resources is not an endorsement by HHS or HRSA.

Grant News is not copyrighted. Readers are free to duplicate and use all or part of the information contained in this publication; however, permission may be required to reproduce the photographs and images.

Pursuant to 42 U.S.C. § 1320b-10, this publication may not be reproduced, reprinted, or redistributed for a fee without specific written authorization from HHS.

Suggested Citation: U.S. Department of Health and Human Services, Health Resources and Services Administration, Grant News. Rockville, Maryland: U.S. Department of Health and Human Services, November, 2024.

This communication was printed, published, or produced and disseminated at U.S. taxpayer expense.