



January 2018 | A periodic e-bulletin to share results of organ donation and transplantation projects funded by the Division of Transplantation.

## Education Empowers Patients, Reduces Fear of Kidney Transplant

*This is the first in a two-part series featuring the results of Division of Transplantation grant projects focused on living kidney donation education.*

### Grant projects resulted in new approach to educating providers and patients with end-stage renal disease



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Several grant projects funded by the Division of Transplantation shifted how providers educate patients with end-stage renal disease (ESRD) about living donor kidney transplant (LDKT). The projects found that providing LDKT education in dialysis centers and tailoring it to patients' readiness to pursue living and deceased donation can result in more knowledgeable patients who are more willing to take steps toward transplantation.

#### Strategies that work:

- Educate patients in dialysis centers, before they present for a transplant evaluation
- Target education to each patient's level of readiness to pursue transplantation
- Train and support dialysis providers



A decade ago, many patients undergoing dialysis lacked knowledge of the benefits of living donation and were unmotivated to pursue a transplant evaluation. Additionally, many providers recommended LDKT to patients without mentioning alternatives or considering how ready patients were to consider transplantation. This approach left patients feeling pressured, overwhelmed, and uninformed.

From 2005 to 2008, faculty and staff at **Washington University School of Medicine** in St. Louis, Missouri, developed the Explore Transplant curriculum, an LDKT education program designed to reach patients before they present at transplant centers. This allows educators to tailor the information to each patient's level of readiness to pursue transplantation. "To really help someone make an informed decision, you have to support them in moving along a continuum of readiness," says Explore Transplant creator and principal investigator Amy Waterman, Ph.D.

The curriculum was presented to **patients at 10 dialysis centers** in St. Louis. Patients spent four, 75-minute sessions with a health educator. They reviewed brochures, fact sheets, and videos sharing patient and donor stories and compared a variety of treatment options, including LDKT, deceased donor kidney transplant, and continuing dialysis, and strategies to increase their knowledge and consideration of living donation.

**One month after the sessions, patients in the Explore Transplant group were more knowledgeable, less fearful, and more likely to present for transplant evaluation** than those in a control group. And **98% of patients** said they **would recommend Explore Transplant to a friend with kidney disease**. **One year later, more patients in Explore Transplant dialysis centers were starting or reactivating transplant evaluations.**

### ***Educating the educators***

In 2009, **Heartland Kidney Network** partnered with Washington University School of Medicine and Waterman on a DoT-funded grant project to provide one-day Explore Transplant sessions to 185 dialysis providers from four states.

Before the sessions, only 36% of providers felt confident in their ability to educate patients about transplantation; **58% of providers felt confident after the sessions**. And 88% said they planned to educate at least five of their patients using Explore Transplant. However, after eight months, only one-third of providers had followed through with this plan. Still, 42% of providers sent patients home with Explore Transplant materials and DVDs and 38% made these materials available in their dialysis center waiting rooms.

Ultimately, the project was a learning opportunity for the researchers. “We learned that dialysis providers did want more education because they fundamentally want what’s best for their patients,” Waterman says. “We also learned that we need to offer dialysis providers ongoing support and build an education pipeline where staff within community nephrologists’ offices, dialysis centers, and transplant centers can all work together to repeat education multiple times for patients and potential living donors.”

### ***Beyond the studies***

Explore Transplant has been made available to more than half of the country’s 6,000 dialysis centers and has educated more than 4,000 nephrology and dialysis providers. Since 2009, more than 120 training seminars have been conducted in partnership with transplant centers, foundations, ESRD Networks, and OPOs, including the **Gift of Life Donor Program**, **Gift of Hope Organ & Tissue Donor Network**, the **Center for Organ Recovery & Education**, **OneLegacy**, and **LiveOnNY**.

Learn more about these projects using the resources below.



### **Want to know more?**

#### **Increasing Dialysis Patients’ Interest in Living Donation Using Health Education: A Group Randomized Controlled Trial**

Principal Investigator: Amy Waterman, Washington University School of Medicine, [awaterman@mednet.ucla.edu](mailto:awaterman@mednet.ucla.edu), 424-372-7278

Waterman AD, Robbins ML, Pavia AL, Hyland SS. Kidney Patients’ Intention to Receive Deceased Donor Transplant: Development of Stage of Change, Decisional Balance, and Self-Efficacy Measures. *Journal of Health Psychology*. 2010. Vol. 15, No. 3: 436-445.

Waterman AD, Hyland SS, Stanley S, Barrett A, Millinger R. Abstract: Improving Education Increases Dialysis Patients’ Pursuit of Transplant: Explore Transplant RCT Findings. *American Journal of Transplantation*. 2009. Vol. 9, No. 2: 360.

#### **Training Dialysis Providers to Promote Living Donation: A Four-State Explore Transplant Intervention**

Principal Investigator: Amy Waterman, Washington University School of Medicine, [awaterman@mednet.ucla.edu](mailto:awaterman@mednet.ucla.edu), 424-372-7278

Waterman AD, Goalby C, Hyland SS, McCabe M, Dinkel KM. Transplant Education Practices and Attitudes in Dialysis Centers: Dialysis Leadership Weighs In. *Journal of Nephrology & Therapeutics*. 2012. Vol. 2, No. S4 (007).

Waterman AD, Hyland SS, Goalby C, Robbins M, Dinkel K. Improving Transplant Education in the Dialysis Setting: The “Explore Transplant” Initiative. *Dialysis and Transplantation*. Vol. 39, No. 6: 236-241.

Waterman AD, Peipert JD, Goalby CJ, Dinkel KM, Xiao H, et al. Assessing Transplant Education Practices in Dialysis Centers: Comparing Educator Reported and Medicare Data. *Clinical Journal of the American Society of Nephrology*. 2015. Vol. 10, No. 9: 1617-1625.

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