



Brief Overview of Your Organization or Program

[Explore Transplant & Explore Living Donation](#) (ET/ELD) is a comprehensive health education program built to reach people with kidney disease, those who want to learn about becoming a living kidney donor, as well as healthcare professionals in medicine and dialysis. Using web content, video, print, and interactive storytelling experiences, ET/ELD blends evidence-based best practices in health literacy and health education with creative flair and a scientific evaluation approach.

For nearly a decade, Health Literacy Media (HLM) has provided the creative energy behind ET/ELD. HLM is an award-winning, interdisciplinary team of creative professionals, with expertise in areas such as health literacy, behavioral science, public health, health and healthcare policy, clinical research, plain language medical writing, communication, web development and accessibility, animation, and graphic design.

Health Literacy in Action Case Study – Health Literacy Media

The Explore Transplant & Explore Living Donation family of programs

Empowering people with kidney disease and their communities with education that's built on the science of health literacy

HLM's goal is to help people understand, access, and use health care, health insurance, and scientific information in ways that help them make important health-related decisions and take action to promote their own health and that of their communities.

The Challenge We Are Addressing

Chronic kidney disease (CKD) is one of the leading causes of preventable illness and death in the U.S. Educating the public around prevention, management, and treatment is key in addressing what's been called a "[silent killer](#)".

Kidney disease prevalence in the U.S.:

- About 35.5 million people have kidney disease
- About 815,000 people are living with kidney failure
- Nearly 555,000 people are on dialysis

Kidney disease is growing at an alarming rate:

- Affects more than 1 in 7 (or 14%) of U.S. adults, with people of color at greater risk for kidney failure
- 131,000 U.S. adults were newly diagnosed with kidney failure in 2022
- 9 out of 10 people with kidney disease are unaware they have it
- 1 in 3 people with severely reduced kidney function (but not yet on dialysis) are unaware they have kidney disease



Why don't more people get transplants?

Even with transplant widely recognized as a standard of care, the reality for too many patients is that personal and systemic barriers stand between them and a transplant.

There aren't enough donor kidneys in the U.S.:

- More than 260,000 people are living with a kidney transplant
- More than 90,000 people are on the kidney transplant waiting list
- In 2024, just 28,492 - or about 1 in 4 - were able to get a kidney (6,418 of those were from living donors)
- There were 6,418 living donor transplants performed in the U.S. last year



Kidney donation and transplant: a life-giving option

The vast majority (97%) of people who develop kidney failure are treated with dialysis. But people who get transplants live longer and have better health outcomes compared to those who stay on dialysis.

And there's an urgency: getting a transplant less than 2 years after starting dialysis is linked to better transplant outcomes and overall health.

Getting a kidney from a living donor is a further advantage for patients. Compared to deceased donor transplants, patients with living donor transplants have better physical functioning social life.

Many facets of patients' lives present barriers:

- A person's English literacy skills, health-related vocabulary, and knowledge of health topics will influence their ability to read, understand and act on information about transplant. These factors may also influence their ability to ask questions and say when they don't understand something.
- Health care situations can be uncertain and stressful and make it difficult for patients to hear and understand all the information that providers or health educators are sharing. Mistrust of the health care system can affect what information a patient takes away from an interaction, or even if they go for care in the first place.
- Cost is a major barrier for seeking health care, especially pursuit of transplant. This can impact a patient's ability to follow through with instructions, such as getting needed medicines. Unexpected out-of-pocket costs or a lack of paid time off can also present economic barriers. Moreover, poverty itself is stressful and impacts health.
- People may not have the social supports that we know increase the chance of pursuing transplant and navigating transplant surgery and recovery.

Healthcare professionals may unwittingly present barriers:

- Providers often use medical jargon or technical terms that patients may not understand, and act as a barrier to a patient's understanding.
- Providers also may give vague or unclear instructions that leave a patient confused or with the wrong take-home message.
- It's impossible to be an expert on every culture, and differences can be a barrier to building a strong client-provider relationship, especially if the provider has negative preconceived notions or a disrespectful attitude.
- Providers themselves may have low knowledge of transplant or living donation, particularly for newer approaches such as [non-directed donation](#) and [donation chains](#).

The health care system can fail patients:

- The U.S. health care system is complex, and getting a transplant means getting a lot of health care. Patients need to know about the various types of health professionals they need to see, how and where to access care and how to use public or private health insurance.
- The built environment can also present barriers to transplant, since patients must not only get to a facility, but also find their way around it.

These barriers can compound upon each other, setting up what can feel to patients like an insurmountable obstacle between them and transplant.



The Solution We Implemented

Education Matters

A study by [Amy Waterman, PhD](#) found that education makes a measurable difference to patients in pursuit of kidney transplants and those seeking to become living donors. For example, Dr. Waterman found that kidney transplant recipients who were successful in completing transplant evaluation within a year of starting the process were more likely to have prior transplant education. These recipients also had increased knowledge about transplants.

But, the type of education makes a difference. Traditional education often does not integrate health literacy best practices. In contrast, ET/ELD includes information that:

- Is written following plain language guidelines
- Focuses on what patients need to know to make decisions, while deemphasizing background information that is interesting but does not directly support behavior, such as kidney disease prevalence
- Clearly describes behaviors, provides tools to do those behaviors, and explains the benefit of the behavior
- Uses health-literate graphic design tactics—such as color, imagery, chunking, and whitespace—to make information attractive, memorable, easy to navigate, and to highlight behavioral action steps

Our kidney transplant education program applies theory to education and meets patients where they are in making specific health behavior decisions. Using the stages of change theory, our information is tailored to the patient's individual level of readiness to change. Patients who are only just beginning to think about transplant need very different information than those who have already taken action and are ready for next steps.

Outcomes and Impact

Explore Transplant and Explore Living Donation are considered the gold standard, backed by [HRSA](#). Our education can be easily repeated and shared, and has reached:

- Healthcare providers (~7500 providers training in 200+ provider trainings)
- Patients (10,000+ educated since 2009) and those that help patients make important health decisions



exploretransplant.org

Lessons Learned and Plans For Sustainability

Through the cycle of developing, evaluating, iterating, and improving ET/ELD, some distinct lessons stand out:

- **Give patients a voice:** by integrating [patient stories](#), ET/ELD has been able to build an authentic perspective into its work. Beyond audience testing and other formative evaluation methods, ET/ELD literally gives patients a voice through the [Living Donation Storytelling Project](#), allowing audiences to easily find real stories from people whose identities and experiences resonate with them.
- **Many seats at the table:** Having a truly interdisciplinary team working together from the very beginning allows health educators to approach communication challenges from a wide variety of perspectives, and to strategically unite those perspectives into a cohesive, audience-centric approach.
- **Bake in health literacy:** Health literacy goes beyond simply telling patients what they need to do. It explains to them clearly why it matters, and gives them the tools to do it, while packaging education into easy-to-understand and use formats that patients want to share with their loved ones.

We continue to iterate on and improve ET/ELD, and to promote its integration into clinical practice nationwide. The Explore Transplant family of programs has been studied in many research projects and clinical trials over the past two decades. Currently, there are several active studies underway utilizing the ET/ELD components in new and innovative ways.

A Call To Action

Regardless of health topic, a collaborative, multidisciplinary approach that centers audiences through health literacy and reaches them in ways stick and resonate holds promise for education, activation, and positive health impact. While education cannot solve for every structural barrier that patients face, it can—when done well—empower them to recognize and act on what is in their control and feel confident in doing so.



Primary Author

Senior Advisor of Transplant Partnerships and Education

Christina Goalby MSW, LMSW

As the Senior Advisor of Transplant Partnerships and Education, Christina dedicates her work to the kidney transplant and living donation community, including patients, providers, and research collaborators to promote informed treatment decisions.

Having spent years as a nephrology social worker, Christina has experience working with ESRD patients, their loved ones, and providers who serve them. She has extensive experience developing and delivering transplant and living donation education using health literacy techniques and principles. Starting her career over 25 years ago as a dialysis social worker, where she served as the Divisional Lead for DaVita, co-chair of the CNSW Chapter, Christina went on to work at Washington University School of Medicine where she became the co-creator of the Explore Transplant Dialysis Provider Training. To date, Christina has educated over 7500 dialysis providers serving over 26,000 ESRD patients. She continues to work tirelessly on new and innovative ways to help patients pursue treatment plans that are right for them.

Christina holds a Masters of Social Work (MSW) degree from the Brown School at Washington University in St. Louis and her Bachelors of Sciences from the University of Missouri – Columbia



Secondary Author

Assistant Director of Health Communication

Christopher Casey, MPH

As Assistant Director of Health Communication, Casey provides creative leadership and expertise in materials and media development to support HLM's health literacy, health communication, and training programs.

Casey's education and experience combine art and science in the service of bringing reach, clarity, and impact to health communication and promotion. Casey has led or contributed to the development of a wide variety of creative media, including websites, interactive data dashboards, social media content, videos, illustrated storybooks, a wide variety of print materials, and more. Casey is interested in helping our partners build health literacy into both their communication media and their organizations' processes and culture.

Prior to coming to HLM, Casey led graphic and information design services for research programs that developed and evaluated communication-based strategies to improve the public's health. Between a 15-year career in research and starting at HLM, Casey served as managing editor for an alumni magazine with a circulation of more than 10,000.

Casey holds a Master of Public Health (MPH) degree in Behavioral Science and Health Education from Saint Louis University and a Bachelor of Fine Arts degree from the University of Missouri – Columbia