

# Trailblazing Towards Transplant: A Transplant Patient Peer Program Guide

## What Is A Transplant Patient Peer Program?

A Transplant Patient Peer Program is a program that connects kidney transplant recipients with dialysis patients to support their journey towards transplantation. A *transplant* patient, known as a Transplant Trailblazer, is paired one-on-one with local (e.g., same or sister dialysis facility or home program, same transplant center, same healthcare system) a *dialysis patient*, also called a Dialysis Peer. The Transplant Patient Peer Program is goal-focused, can include family and caregiver interaction, and includes multiple ways for Transplant Trailblazers and Dialysis Peers to connect.

## Who Is Involved?

- ESRD Networks: Promote the program to dialysis facilities and transplant centers and share program resources with facilities and centers.
- Dialysis Centers: Promote the program to people receiving dialysis and welcome Transplant Trailblazers into the facility's activities and space.
- Transplant Centers: Identify potential transplant recipients to be Trailblazers for Dialysis Peers who are journeying towards receiving a transplant.
- Transplant Trailblazers: Provide emotional support and practical tips from their own transplant experience to guide their Dialysis Peer to getting on the waitlist, being active on the waitlist, and ultimately receiving a transplant.
- Dialysis Peers: Engage with their Transplant Trailblazer and receive guidance and support on their journey to transplant.

## What's Included in This Guide?

- Introduction
- ESRD Network Role
- Dialysis Facility Role
- Transplant Center Role
- The Transplant Trailblazer Role
- The Dialysis Peer Role
- Multiple Ways to Connect



## Program Goals

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Share transplant journey experiences to inspire people on dialysis to seek transplant as their preferred treatment choice

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Enhance patient awareness of kidney transplant options, including high-Kidney Donor Profile Index (KDPI) and increased-risk kidneys

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Activate patient motivation to pursue a kidney transplant by preparing them to get on the waitlist, remaining active on the waitlist, and ultimately receiving a transplant

# *We're Better Together*

Share | Inspire | Activate

## **Who Are Transplant Trailblazers and What Can They Do?**

A Transplant Trailblazer is a kidney transplant recipient who provides guidance and emotional support by sharing their transplant experience, including preparing for the waitlist, staying active on the waitlist, being ready for transplant, and post-transplant expectations. Transplant Trailblazers are paired one-on-one with people receiving dialysis treatments. Transplant Trailblazers do not offer medical advice but are encouraged to share their firsthand experience receiving a transplant with their Dialysis Peer.

## **Should I be a Transplant Trailblazer?**

As a transplant recipient, you know better than anyone else what it is like to go through treatment for kidney failure, how to deal with dialysis side effects, and how to manage all the emotions—the highs and the lows—that come with waiting for and getting a transplant. Share your experience and expertise by volunteering as a Transplant Trailblazer with someone who is currently receiving dialysis, is waitlisted and looking to remain active on the waitlist, or is considering a transplant as their preferred treatment option.

## **Would a Transplant Trailblazer Benefit Me?**

As a person on dialysis, understanding how to cope with kidney disease can be overwhelming. There are many people who have been in your shoes. Connecting with someone who's received a transplant to learn about how the choice to pursue transplant impacted their life can be a positive life-changing experience. A Transplant Trailblazer can also support you by answering your questions, connecting you with resources, and even providing emotional support on tough days.



# Who Would Be a Great Transplant Trailblazer or Dialysis Peer?

## Suggested Criteria for a Transplant Trailblazer

- A kidney transplant recipient
- Proud of one's transplant journey and eager to share their story to inspire Dialysis Peers to choose transplant as their preferred treatment
- Familiar with the terms, or received a high-KDPI or increased-risk kidney
- Well-adapted to the challenges faced by Dialysis Peers
- Effective communicator with empathy skills
- A desire to support Dialysis Peers in their transplant journey
- Schedule flexibility to be available for their Dialysis Peer by telephone or other virtual ways, or in-person if program participants are located near each other
- A trusted confidant for their Dialysis Peer

## Suggested Criteria for a Dialysis Peer

- A person who is receiving dialysis either at a dialysis facility or at home
- Someone who is interested in learning about how to get on a transplant waitlist, or a person who is already on the transplant waitlist and is interested in meeting their goal of remaining active on the list and receiving a transplant
- An individual who is interested in learning about their options of being on multiple waitlists or understanding how they might receive an offer sooner by consenting to a high-KDPI kidney, or increased-risk kidney
- Someone who is engaged in their dialysis plan of care and participates in patient activities at their facility , such as education, lobby days, etc.



***I do just about everything I can for the ESRD community. People came together to support me when I had my transplant. Now I'm doing my best to pay that gift forward.***

**TRANSPLANT RECIPIENT  
LITTLE ROCK, ARKANSAS**

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# ESRD Network Role

## How to Contribute

The role of the ESRD Network is to promote the Transplant Patient Peer Program with dialysis facilities and transplant centers within the Network and be a champion of spreading program success stories. The Network should expect to coordinate with participating dialysis facilities and transplant centers to introduce the program, track program success, and provide support when needed.

## How It Works

- 1 Introduce the program to dialysis facilities and transplant centers in their service area
- 2 Recruit dialysis facilities and transplant centers to participate in the program
- 3 Partner with dialysis facilities and transplant centers to host a program kick-off event and invite staff to attend
- 4 Provide support when needed, share success stories in the Network provider and patient newsletter
- 5 Celebrate Transplant Patient Peer Program Accomplishments
- 6 Be a champion by promoting the program within your Patient Advisory Council and throughout your service area

## Implementation Recommendations

- Prepare an introductory program flyer to share with dialysis facilities and transplant centers
- Collaborate with dialysis facilities and transplant centers to recruit Transplant Trailblazers and Dialysis Peers
- Identify a dialysis facility and transplant center staff member to lead the program and connect Transplant Trailblazers with Dialysis Peers
- Recommend that dialysis facilities and transplant centers coordinate the pairing of Dialysis Peers and Transplant Trailblazers
- Share kick-off materials to educate both Transplant Trailblazers and Dialysis Peers on their roles and program expectations
- Provide support by scheduling regular check-ins with dialysis facilities and transplant centers
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

### How will your Network benefit?

- + **Enhances patient outcomes** by increasing patient motivation to seek transplant and awareness of transplant options, like high-KDPI kidneys
- + **Improves patient engagement** by empowering patients to be advocates for their treatment plan

- + **Boosts mental health for patients** by connecting patients and establishing a community of emotional and social support
- + **Supports a culture of patient-centered care** by prioritizing a higher quality of life and long-term outcomes for patients

# Dialysis Facility Role

## *How to Contribute*

Support the Transplant Patient Peer Program by implementing the program at your dialysis facility, identifying people on dialysis who are interested in learning about kidney transplantation, hosting Transplant Trailblazers at your site for education, and celebrating program accomplishments. Dialysis Peers at your center will gain valuable knowledge about the road to transplant from someone who's experienced both dialysis and transplant.

## *How It Works*

- 1 Be introduced to the program and gain an understanding of your facility's involvement
- 2 Partner with local transplant centers to identify, match, and connect the Transplant Trailblazers to one of your patients receiving dialysis
- 3 Host a kick-off event virtually or at your facility to educate Dialysis Peers on their roles and program expectations
- 4 Welcome Transplant Trailblazers and Dialysis Peers to meet at your facility and provide support when needed
- 5 Celebrate Transplant Patient Peer Program accomplishments
- 6 Sustain the program by being a program champion and promoting the program success at your facility

## *Implementation Recommendations*

- Utilize introductory materials to announce the program and create awareness
- Identify a dialysis facility staff member to lead the program and connect Transplant Trailblazers with Dialysis Peers
- Share kick-off materials to educate Dialysis Peers on their roles and the program expectations
- Introduce Transplant Trailblazers to your Dialysis Peers as a knowledge resource and support system
- Establish a way for Transplant Trailblazers and Dialysis Peers to meet virtually or in-person
- Provide the opportunity for Transplant Trailblazers and Dialysis Peers to share their program experience during lobby days
- Offer support by scheduling regular check-ins with Dialysis Peers engaged in the program and inform your ESRD Network of program successes
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

### **How will your facility benefit?**

- + **Increases patient accountability** by encouraging patients to maintain and be engaged in their treatment plan
- + **Improves the patient experience** by helping patients feel supported emotionally and socially

- + **Creates a community** by supporting the development of relationships amongst your past and present patients
- + **Promotes patient engagement** by urging patients who have good experiences to suggest the program to others looking to learn more about transplantation

# Transplant Center Role

## How to Contribute

Support the Transplant Patient Peer Program by introducing the program at your transplant center, identifying people who are interested in being a Transplant Trailblazer, hosting program meetings at your site, and celebrating program accomplishments. Collaborate with dialysis centers and your ESRD Network to promote the program beyond your organization.

## How It Works

- 1 Share information about how to become a Transplant Trailblazer at your center and notify your Network that you have done so
- 2 Work closely with local dialysis centers to connect your Transplant Trailblazers with a Dialysis Peer
- 3 Host an orientation kick-off to teach Transplant Trailblazers about their role and program expectations
- 4 Support the program by collaborating with local dialysis facilities and your ESRD Network
- 5 Provide basic resources about the benefits of transplantation for your Transplant Trailblazer to share with their Dialysis Peer
- 6 Celebrate the program success with your local Network, dialysis facilities, Trailblazers, and Dialysis Peers

## Implementation Recommendations

- Use introductory materials to announce the program and create awareness.
- Identify a transplant program staff member to lead the program and connect Transplant Trailblazers with Dialysis Peers
- Share kick-off materials to educate Transplant Trailblazers on their role and program expectations
- Provide the opportunity for Transplant Trailblazers and Dialysis Peers to share their program experience during transplant center new patient orientation
- Establish a way for Transplant Trailblazers and Dialysis Peers to meet in-person or virtually at their dialysis facility or local transplant center
- Offer support by scheduling regular check-ins with Transplant Trailblazers engaged in the program
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

### How will your center benefit?

- + **Increases patient accountability** by encouraging patients to maintain and be engaged in their post-transplant treatment plan
- + **Improves the patient** experience by helping patients feel supported emotionally and socially after receiving their transplant

- + **Creates a community** by supporting the development of relationships amongst your past and present patients
- + **Promotes transplantation** as the preferred treatment option for Dialysis Peers

# Transplant Trailblazer Role

## How to Contribute

As someone who's been on dialysis and the transplant waitlist, you are familiar with the ups and downs of kidney disease. Now that you have received a transplant, you can use this experience to share your transplant story and guide a Dialysis Peer along a familiar journey.

## How It Works

- 1 Sign up to be a Transplant Trailblazer through your transplant center
- 2 Work closely with your ESRD Network to connect with a dialysis center and a Dialysis Peer
- 3 Attend a kick-off meeting to learn about your role and program expectations
- 4 Support your Dialysis Peer partner through activities that interest you both and fit your schedules
- 5 Provide motivation and encouragement to your Dialysis Peer by sharing your transplant experience
- 6 Celebrate your accomplishments and successes

## How to Be a Trusted Partner

### How you can help your Dialysis Peer:

- Share insights from your personal experience with receiving a transplant
- Refer your Dialysis Peer to their care team when asked medical questions
- Maintain patient confidentiality
- Provide reassurance and be an empathetic listener
- Encourage Dialysis Peers to remain engaged in their plan of care, maintain doctor appointments, and stay active on the transplant waitlist
- Offer encouragement after a discouraging day and help them to thrive in their circumstances
- Meet at a time and place that is convenient for both people

### What you should **not** do for your Dialysis Peer:

- Give any medical advice, including diet options
- Handle their grievances or challenges, always refer them to their social worker or facility administrator
- Borrow or loan money
- Invade their privacy, personal space, or breach their confidentiality

## How will the Transplant Trailblazer benefit?

- + **Remain motivated in your own treatment** by staying engaged in your plan of care and up-to-date on the best treatment opportunities and practices
- + **Expand your leadership skills** by guiding your Dialysis Peer through their treatment journey and times of uncertainty

- + **Improve your problem-solving and communication skills** by clearly sharing your own treatment experiences and assist your Dialysis Peer in setting goals to achieve their transplant goals
- + **Contribute to something larger than yourself** by supporting the overall quality of life for people with kidney disease

# Dialysis Peer Role

## How to Contribute

Meet with your care team to find out how to connect with a Transplant Trailblazer and learn how their journey to receive the gift of life improved their quality of life and can help you. Kidney transplantation can be overwhelming, but there are many people who have been in your shoes and are willing to be your support peer. Your Transplant Trailblazer can also offer support by answering your questions, connecting you with resources, and even providing emotional support on tough days.

## How It Works

**1** Talk with your care team about the program and sign up to be a Dialysis Peer to learn more about kidney transplant

**2** Your facility will help you get matched and connected with a Transplant Trailblazer

**3** Attend a program kick-off to learn about ways in which a Transplant Trailblazer can support you

**4** Seek guidance from your Transplant Trailblazer, listen to their story, and learn from their experiences

**5** Commit to a positive treatment journey by remaining compliant to your dialysis treatment and engaged in the program

**6** Celebrate accomplishments in achieving your treatment goals and share your success story

## How a Transplant Trailblazer Can Help You

### Your Transplant Trailblazer can:

- Share knowledge and insights from their personal experience with receiving a transplant
- Be a strong source of support by listening to your concerns
- Refer you to members of your care team related to medical questions
- Provide encouragement and guidance

### What your Transplant Trailblazer should **not** do for you:

- Give medical advice, like changing your diet or medication
- Invade privacy and personal boundaries or breach your confidentiality
- Handle grievances or complaints
- Borrow or loan money

### Sample activities that you can do together:

- Visit your local library for social and educational events to remain active
- Team-up and share your experience at your facility lobby day
- Connect by phone to share times of joy or challenging days

## How will the Dialysis Peer benefit?

- + **Increases your knowledge of kidney failure treatment options and benefits** as your Transplant Trailblazer shares insights from their own experience receiving a transplant
- + **Encourages you to be an advocate for your own health** and empowers you to become aware of the steps required to reach transplant

+ **Reduces communication gaps with dialysis staff** by connecting you to the appropriate resources and experts when there are questions or concerns

+ **Provides emotional and social support** and encourages you to share your feelings and introduces you to a support system within your facility

# Multiple Ways For Transplant Trailblazers and Dialysis Peers to Connect

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*Here are some tips for how to connect virtually and in-person. Each method offers unique features, pick which one works best for you!*

## Telephone & Text Messages

Exchange phone numbers! The telephone is a great way for Transplant Trailblazers and Dialysis Peers to connect with each other. Agree upon a time to talk with each other, decide who will call who, be sure to put a reminder on your calendar, and connect with each other at the scheduled appointment time.

## Google Hangouts

The [Google Hangouts](#) app, available for both iOS and Android smartphones and mobile devices, is easy to install and use for free voice and video calling and video conferencing. It's available for Windows and Mac desktop and laptop computers as well, so it synchronizes across all your devices. You can even use Hangouts for texting.

## Messenger Apps

Use instant messaging! Apps like [WhatsApp](#) or [Facebook Messenger](#) are mobile messaging apps used for instant messaging, sharing photos, videos, audio recordings and for group chats. The apps are usually free to download, can be used to communicate on your phone, but can also sync to your computer or tablet.

## Google Duo

[Google Duo](#) is a free video chat mobile app that enables one-to-one video and voice calls across both iOS and Android devices. Simply download the Duo app and get started using video calling regardless of what kind of smart phone you have. It's also available via Google's chrome web browser on desktop and laptop computers.

## FaceTime

[FaceTime](#) is perfect for seeing and hearing people over the phone. FaceTime is exclusive to Apple, so the Transplant Trailblazer will both need an iPhone, iPad, iPod touch, or Mac to use this service. The good thing about FaceTime is that you can use WiFi when calling, saving minutes on your cellular data plan.

## In-Person

Talk with your dialysis facility and transplant center about when Transplant Trailblazers and Dialysis Peers can meet at the dialysis facility or even at the transplant center if the partners are both near the transplant center. Trailblazers and Dialysis Peers may also choose to meet at their local church, favorite kidney diet-friendly eatery, local community center, or a mutually agreed upon location.

## Email

Exchange email addresses! Email is another way to stay in touch with each other, especially if you would like to share information and resources that can be found on the internet. Email is also a good way to connect with each other before or after your agreed upon time to meet.





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FL-ESRD NCC-7N52TB-12012020-02