kidney TRANSPLANT COLLABORATIVE

# Living Donor Program Enhancement Framework

*Transplant Center-Based Engagement Model*

## Executive Summary

Nearly 100,000 Americans are currently waiting for a kidney transplant, and 12 to 17 individuals die each day on that waitlist. In 2025, deceased kidney donations declined in isolation for the first time this century, taking total kidney transplants down with them. The deceased donor pipeline can no longer be counted on to close the gap. Meaningfully expanding living donation is now more clinically and fiscally imperative than ever. Living kidney donation provides the best opportunity for the recipient to receive a pre-emptive kidney transplant, that is receiving a kidney transplant prior to the need for dialysis. This is the best possible outcome.

The path forward is more promising than commonly perceived. Contrary to widespread assumption, public willingness to donate is substantial: a Mayo Clinic survey found that 84% of individuals would consider donating to a friend or family member and 49% to a complete stranger, and 87% indicated they might consider or would definitely consider donating. Despite this, the number of living donor transplants has remained essentially stagnant between 5,200 and 6,600 annually for more than two decades. The gap is not one of willingness. It is that potential donors are rarely asked in a way that breaks through the noise of daily life and presents donation as a concrete, supported opportunity rather than an abstract idea.

Equally important, even when individuals do come forward to volunteer, the vast majority never complete the journey from first screening to surgery. Prospective donors fall out at predictable points: scheduling conflicts, paperwork, health requirements, work disruptions, and emotional uncertainty. These are exactly the kinds of barriers that structured, non-clinical support can solve. Research from the University of Alabama at Birmingham and Johns Hopkins University demonstrates that when transplant centers train and deploy facilitators to support both recipients in identifying donors and donors in navigating evaluation, living

donor screenings increase 9-fold, approved living donors increase 7-fold, and the proportion of recipients who identify a living donor rises from near zero to roughly 50%. Recipients often hesitate to share their situation, but friends, family members, and broader networks are willing to help when given clear guidance and a supportive framework.

## How the Program Works

The program places a dedicated transplant coordinator on-site at the transplant center, operating within a structured "train-the-trainer" model. The coordinator prepares volunteer facilitators to help the patient find a living donor, then prepares them to support that donor through evaluation and surgery. The same coordinator stays with the recipient and the donor across all six phases. The coordinator is employed by the transplant center and has no clinical role when carrying out this engagement work, and the program does not change the responsibilities of the center's existing clinical or non-clinical staff.

Transplant coordinator is not a new job title. Every transplant center already employs transplant coordinators who manage clinical workflow across listing, evaluation, and post-transplant care. What this program proposes is different: hiring an additional, dedicated transplant coordinator whose sole focus is leading this engagement model, extra headcount funded as part of the program rather than carved out of existing capacity. Transplant centers have not historically deployed coordinator resources in this way, but they are uniquely well-positioned to do so. They already have the clinical infrastructure, the relationships with patients and referring nephrologists, and the credibility within their communities to make a coordinator-led engagement program succeed where standalone outreach efforts have not.

Investing in this dedicated coordinator advances all three pillars of the triple aim of medicine: better patient experience, improved population health, and lower costs. The patient experience improves because recipients and donors are surrounded by structured, non-clinical support at every stage of the journey, from first conversation through the transplant process. Population health improves because more successful living donor transplants displace years of dialysis dependence and the cardiovascular and metabolic comorbidities that accompany it. And costs decline as living donor transplants generate meaningful long-term savings to Medicare and other payers. For transplant centers themselves, the practical effect is enhanced utilization of existing capacity and a stronger business case: more transplants performed, more living donor candidates converted to completed donations, and a more financially sustainable program over time.

Rather than managing outreach directly, the transplant coordinator recruits and prepares a small team of volunteers from the patient's own life — friends, family members, faith leaders, coworkers, or community connectors — called volunteer facilitators. The transplant coordinator equips these volunteers with messaging tools, outreach materials, conversation guides, and ongoing coaching so they can spread the word about living donation across their networks. Once a potential donor comes forward, the transplant coordinator and volunteer facilitators provide non-clinical support, such as helping with scheduling, paperwork, logistics, and emotional encouragement, to keep the donor moving through evaluation to surgery.

All medical evaluation, eligibility decisions, surgical care, and follow-up remain exclusively under the transplant center's authority. The transplant coordinator and volunteer facilitators operate in a non-clinical capacity at all times when carrying out this engagement role.

## Program Objectives

The program is designed to:

- Increase donor referrals and completed evaluations
- Improve recipient knowledge and confidence in exploring living donation
- Reduce delays caused by non-clinical barriers in the donor evaluation process
- Normalize living donation conversations within recipient networks and the broader community
- Educate prospective donors on qualification standards and available cost-reimbursement programs
- Strengthen equitable access to living donor transplantation across diverse patient populations
- Drive sustainable, long-term growth in living donor kidney transplant volume at the center level with the best opportunity to increase pre-emptive kidney transplantation.

## The Six-Phase Engagement Model

The program follows six structured phases. Phases 1-3 help the patient find a donor. Phases 4-6 support that donor through the transplant process.

### Finding a donor:

1. *Recipient Initial Education & Intake*
2. *Committee Formation & Messaging Strategy*

3. *Network Outreach & Awareness*

**Supporting the donor through the process:**

4. *Donor Interest Engagement*
5. *Donor Evaluation Navigation Support*
6. *Donor Transplant Milestone Support*

### Governance and Role Boundaries

The transplant coordinator and volunteer facilitators do not interpret medical findings, determine donor eligibility, coordinate clinical testing, provide medical or financial counseling, or replace transplant center personnel in their clinical capacity. All medical evaluation, eligibility decisions, surgical care, and follow-up remain exclusively under the transplant center's authority.

### What Follows

The remainder of this document provides the full operational framework for each of the six phases, followed by appendix materials including intake guides, messaging toolkits, conversation scripts, FAQ resources, and checklists that support implementation at the transplant center level.

## Transplant Center Toolkit Implementation Guide

### Transplant Coordinator Role Overview

#### Role Scope Across the Living Donation Continuum

The transplant coordinator leads a structured, six-phase "train-the-trainer" engagement model that supports recipients, prepares volunteer facilitators, and guides community-based outreach across the living donation continuum.

Across all phases, the preparation of volunteer facilitators is iterative rather than one-time. Initial training is reinforced through ongoing coaching, retraining, and structured check-ins as outreach unfolds and the donor process progresses. This continuous reinforcement keeps facilitators within their non-clinical role boundaries and aligned with current transplant center guidance.

PHASE 1

## Recipient Initial Education & Intake

### Establishing Continuity at Referral

Upon referral from the transplant team, the transplant coordinator may receive relevant contextual information, including:

- Clinical status
- Transplant readiness
- Nephrology involvement
- Timing expectations

→ See here for a list.

### Structured Intake and Outreach Planning with the Recipient

The purpose of this phase is to assess outreach readiness, map support systems, and begin planning for the formation of a volunteer facilitator committee.

This committee consists of a small group of trusted individuals identified by the recipient who are prepared and supported to help share the recipient's story, increase awareness of living donation, and facilitate outreach within their personal and community networks.

The intake conversation covers:

- Understanding the recipient's comfort with outreach
- Identifying trusted individuals to serve as volunteer facilitators
- Mapping personal, professional, and community networks
- Identifying preferred communication channels

The intake should capture contact details for 3-4 trusted individuals who may initiate committee formation, such as:

- Close family members or trusted advocates
- Spouse (if applicable)
- Adult children (if applicable)
- Donor or recipient ambassadors (individuals in the network who have been through donation or transplantation themselves and may be willing to lend their experience)

→ A sample questionnaire can be found here.

PHASE 2

## Recipient Committee Formation & Messaging Strategy

The transplant coordinator works alongside the kidney recipient to establish a donor search committee that functions as a team of volunteer facilitators. Through preparation, messaging tools, and defined guardrails, the transplant coordinator equips the committee to conduct voluntary outreach.

### Developing a Messaging Toolkit

The transplant coordinator drafts the materials for the volunteer facilitator committee's outreach efforts, starting from tools already available in this program and tailoring them to the specific patient. Volunteer facilitators can then adapt the materials for their own networks.

The toolkit may include:

- Outreach flyer designed for prospective donors
- Social media content
- Talking points
- Sample call to action
- General Q&A, including myth-busting content

Effective materials include:

- Engaging photographs
- Minimal text
- Future-oriented framing of the story
- A memorable hook
- Reassurance addressing common misconceptions

### Forming the Donor Search Committee

A committee of up to 8-10 trusted individuals is formed to support outreach on behalf of the recipient.

Committee members may include:

- Family members
- Friends

- Faith leaders
- Community leaders
- Colleagues
- Organizational members
- Social connectors
- Donor or recipient ambassadors

Guidance on inviting someone to join the committee:

- Frame the ask clearly and respectfully
- Here is an example of how to frame an ask

### Committee Responsibilities

As trained volunteer facilitators, committee members commit to engagement in alignment with transplant center guidance.

This includes:

- Sharing approved outreach materials and messaging tools
- Initiating respectful, voluntary conversations within their networks
- Utilizing appropriate communication platforms (e.g., WhatsApp groups, listservs, social media, direct outreach)
- Participating in scheduled planning calls or check-ins with the transplant coordinator
- Expanding awareness by introducing additional individuals into the outreach network
- Reinforcing voluntariness and confidentiality in all interactions
- Directing all medical questions and eligibility inquiries to the transplant center

→ **View Committee Planning Meeting Guide here.**

PHASE 3

## Recipient Network Outreach & Awareness

During this phase, the volunteer facilitator committee implements structured, education-based outreach within defined personal, professional, and community networks. Outreach may include:

- In-person community gatherings

- Social media engagement
- Targeted, relationship-based outreach within defined networks

→ See the Storytelling & Outreach Message Builder.

### Community Event Model

When appropriate, community gatherings follow this format:

- Target ~20-25 attendees per event
- 30-minute structured program
- Educational and emotionally resonant

→ Here is a Community Awareness Event Guide.

### Realistic Success Metrics

The goal of outreach is not immediate donor commitment. Success is measured by awareness, education, and voluntary engagement. Realistically, 80-90% of individuals who attend or are reached will not donate, and that is expected. The aim is to widen the funnel, normalize living donation, and create multiple pathways for follow-up. At a minimum, each participant can commit to providing their resources or sharing the message within their own networks, thus increasing the reach.

→ Recipients and volunteer facilitator committees are equipped with guardrails and prepared using this FAQ to ensure consistent, voluntary and confidential outreach.

PHASE 4

## Donor Interest Engagement

When an individual expresses interest in learning more about living donation, engagement transitions from broad awareness-building to donor engagement. The volunteer facilitator committee leads this engagement under the guidance and oversight of the transplant coordinator.

The volunteer facilitators may support by providing:

- Education about the potential impact of living donation
- Donation education
- Reassurance regarding the voluntary nature of donation

- Information about donor protection and donor benefit programs (NKR, State, NLDAC, others)
- Clarification of the general process and next steps

→ A Donor Conversation Support Checklist is available here.

PHASE 5

## Donor Evaluation Navigation Support

This phase requires coordination with donor transplant center clinical staff, who retain responsibility for all aspects of the medical evaluation process. The transplant coordinator prepares volunteer facilitators to provide non-clinical support in the following areas:

### Orientation

- Explain evaluation safeguards as outlined by the transplant center
- Reinforce confidentiality, the donor's ability to withdraw at any time, and the non-clinical nature of the support role
- Review anticipated next steps as communicated by the transplant team
- Encourage the presence of a support person during evaluation appointments
- Various programs available for out-of-pocket cost support for the donors

### Evaluation Coordination

Evaluation typically occurs in two phases: an initial set of tests that may be performed remotely or at an outside facility, followed by a comprehensive evaluation at the transplant center, preferably completed in a single visit.

Volunteer facilitators may support by:

- Helping the donor understand scheduling options for the initial evaluation visit
- Supporting navigation of the evaluation process when applicable
- Assisting with the organization of documentation during evaluation, when appropriate

→ See here for examples of common components of the living donor evaluation process.

### Health Qualification Support

Volunteer facilitators may support by:

- Encouraging adherence to transplant center health qualification standards

- Supporting donor understanding of recommended health improvements when applicable

If modifiable risk factors exist, the volunteer facilitator may assist the donor in connecting to appropriate external resources, such as:

- Smoking cessation programs
- Weight reduction programs
- Primary care follow-up
- Other medically recommended supports

### Administrative Support

The transplant coordinator prepares volunteer facilitators to assist with awareness of:

- Required documentation
- Evaluation milestone completion
- Insurance coverage understanding (managed by transplant/finance manager)
- Out-of-pocket cost awareness (managed by transplant/finance manager)

### Appointment Logistics

The volunteer facilitator may support by:

- Assisting with sequencing awareness as directed by the transplant center
- Helping reduce logistical disruption to the donor's routine
- Supporting reliable transportation planning
- Assisting with employer communication planning, if requested
- Attending appointments for emotional support when appropriate and permitted

→ Draft talking points can be found here.

PHASE 6

## Donor Transplant Milestone Support

On surgery day, volunteer facilitators may:

- Assist with logistical coordination as directed by the transplant center
- Reinforce preoperative instructions provided by the medical team (e.g., fasting requirements)

- Provide emotional support during the preoperative process (if permitted)
- Support hospital navigation and check-in logistics
- Assist with safeguarding personal belongings (if appropriate)
- Help communicate updates to family members (if permitted)

→ See here for Donor Surgery Preparation Guide.

SUPPORTING MATERIALS

# Appendix

The following appendix materials align directly with the six structured phases of the transplant coordinator engagement model.

# Recipient Initial Education & Intake

## Recipient Referral Snapshot Guide

Before engagement begins, the transplant coordinator should have a clear picture of the recipient's clinical situation so that the recipient and their family do not have to repeat information. The following information helps ensure continuity and allows facilitation to start at the right point in the process.

### Position in the Transplant Process

- Where is the recipient in their transplant journey? (e.g., receiving early education, currently under evaluation, listed and waiting, or actively working to find a donor)
- Has living donor transplantation been explicitly discussed with the patient as an option?
- Has a nephrology referral occurred?

### Current Kidney Function and Disease Trajectory

- What are the most recent lab values, specifically GFR and creatinine?
- How quickly is kidney function expected to decline?
- What is the transplant team's general timeline for when a transplant is needed?

> Note: Most centers begin evaluation around GFR 20-25, though this varies. Rate of decline matters significantly for outreach planning.

### Nephrology and Medical Coordination

- Is the recipient currently under nephrologist care?
- How frequently do nephrology appointments occur?
- Is transplant planning being led through nephrology, primary care, or a combination?

### Dialysis and Education Status

- Is the recipient on dialysis?
- Has the recipient completed a formal kidney disease education program?

### Prior Testing and Known Barriers

- Have any transplant-related workups been initiated?
- Are there any known medical, logistical, or administrative factors that could affect evaluation or listing?

## Recipient Intake Questionnaire

This conversation is a starting point, not a form to fill out. The goal is to understand their life, their community, and how we can build an outreach plan that feels natural and manageable for them.

### Part 1: Getting to Know You

We want to understand your situation and what matters most to you—as a person, not just as a transplant candidate.

- Where are you based, and do you receive your medical care there or elsewhere?
- Are you working with a nephrologist? If so, how often do you see them?
- What does a typical week look like for you — what fills your time or gives you energy?
- When you imagine life after a successful transplant, what does that look like? What would you be doing more of?

### Part 2: Your Community, Relationships, & Outreach Team

Understanding where you belong and who you know helps us figure out where outreach is most likely to connect.

- Which communities feel most central to your identity—faith, culture, profession, social circles, or something else?
- Are you part of a religious congregation or faith-based community? How regularly do you participate, and are you involved in any specific groups or committees within it?
- Do you hold memberships in any organizations—professional associations, civic groups, sports leagues, or social clubs?
- Are there recurring activities or hobbies that bring you into regular contact with the same people?
- Where in your life do people know you by name—a workplace, school, neighborhood, alumni network?
- Who are the five or ten people you're most likely to talk to or see each week?

- Are there communities you've been part of in the past but aren't currently active in—former colleagues, old congregations, previous neighborhoods?
- Do you spend time in more than one geographic area throughout the year?
- Are there chapters of your life you're particularly proud of, or communities that shaped who you are?
- Are there people in your life who tend to step up when something needs to be done—natural organizers or advocates?
- Who do you already trust to speak on your behalf or help rally others around something important to you?
- Who in your network would you describe as a connector—someone who seems to know people across many different circles?
- Is there a faith leader, lay leader, or respected community figure who knows you personally and might be willing to help?
- Do you have meaningful relationships across different age groups—younger adults, peers, and older community members?
- Think across the different areas of your life—work, family, hobbies, school. Are there people from each who know you well but don't necessarily know each other?
- Is there someone from an organization or group you belong to who has the credibility and motivation to mobilize that community?
- Who in your life would be comfortable inviting others to learn more about kidney donation—not to pressure anyone, but to open the door?
- Who would you count on to follow through once they commit to something?
- Are there people who carry real influence or standing in your community, even if their schedules are full?
- If you were to bring people together, who could realistically commit to bringing a group of their own?

### Part 3: How You Communicate

We want to understand how information moves through your world, so outreach can happen through channels that feel natural.

- Do you use social media? Which platforms, and how active are you—do you post regularly, occasionally, or mostly follow along?
- Are you part of any WhatsApp or group chat communities? Roughly how many, and what are they centered around?

- Do you receive newsletters or listserv emails from any organizations—faith communities, alumni groups, civic organizations?
- How do you most naturally stay in touch with people—texts, calls, group chats, or in-person?
- If you needed to get a message to a large number of people quickly, what would be your first move?
- Is there anyone in your life who seems to know everyone, or who people naturally turn to when something needs to be organized?

APPENDIX · PHASE 2

# Recipient Committee Formation & Messaging Strategy

## Committee Messaging Guide

### What You're Here to Do

Your job is straightforward: help accurate, voluntary information about living kidney donation reach more people.

That means you are not here to:

- Ask anyone to donate a kidney
- Evaluate or screen potential donors
- Offer medical guidance or opinions
- Make any determination about who qualifies

### A Simple Framework for Every Conversation or Post

Whether you're talking in person or sharing something online, a strong message covers five things:

| Element | Example |
|---|---|
| **Set the context** | "[Name] is living with kidney disease and working toward a transplant." |
| **Introduce the topic** | "We're helping spread the word about living kidney donation." |
| **Establish that it's a choice** | "There's no obligation — this is entirely voluntary." |
| **Point to the right authority** | "The transplant center handles all medical evaluations." |
| **Give a clear next step** | "Anyone curious can reach out to the transplant center directly." |

### Language That Works

These phrases are accurate, respectful, and appropriate to share:

- "Finding out more doesn't mean committing to anything."

- "Living kidney donation is a voluntary process."
- "All eligibility decisions are made by the transplant center."
- "The evaluation process is confidential."
- "Donor health and safety come first at every step."

> When a question falls outside your role, redirect: "That's a great question for the transplant center—they can walk you through it confidentially."

### What to Avoid

Some language—even when well-intentioned—can create pressure or convey information you're not positioned to confirm:

- Asking directly whether someone would donate
- Suggesting someone seems like "a good fit" or "a likely match"
- Framing the situation as urgent or desperate
- Explaining medical details beyond general awareness
- Making any assurances about outcomes or safety

### Keeping Perspective

Most people who encounter this outreach will not become donors—and that is completely normal. Research consistently shows that 80-90% of those reached through community outreach do not proceed with donation. The value of outreach is not measured by immediate matches. It is measured by how many people learn something accurately, feel respected, and leave the door open.

### Core Commitments

- Communicate with respect and without urgency
- Keep the recipient's personal information private
- Stay within education-based messaging at all times

## Inviting Your Personal Advocates to Join Your Committee

### Opening & Context

> *"There's something I've been wanting to talk to you about — it's personal, and it matters to me."*

(Give them a moment to settle in.)

> *"As you probably know, I'm dealing with kidney disease and will likely need a transplant at some point. I'm putting together a small circle of people I trust to help get the word out about living kidney donation. It's organized and low-pressure—more about spreading awareness than anything else. I'm not asking people to donate. I just don't want to carry the communication piece alone."*

### The Ask

> *"The role would involve sharing some basic information and pointing anyone who has questions toward the transplant center. They handle everything medical—you wouldn't be responsible for any of that. I want to be straightforward: There's no expectation that you would donate, and there's no pressure to say yes to this either. Our relationship means more to me than any role on a committee."*

> *"Would you be willing to be part of this with me?"*

Then wait. Let the silence do its job.

### Response Guidance

> *If they hesitate: "I hear you—and I mean it, there's no pressure. I asked because I trust you, and that's true no matter what you decide."*

> *If they say yes: "That really means a lot. You'll get clear guidance on what to say and what to leave to the transplant center. Nothing medical falls on you."*

### Sample Text Message

> *"Hey—I wanted to reach out about something personal. I'm building a small group to help spread awareness about living kidney donation while I work through the transplant process. This isn't an ask to donate—just to help with outreach in whatever way feels comfortable. Would you be open to a quick conversation? Absolutely no pressure."*

### What to Remind the Recipient Before They Make the Ask

- Say less than you think you need to
- Resist the urge to fill silence
- The answer doesn't change the relationship
- You're looking for willing people, not filling slots
- This is an invitation, not a recruitment

### A Final Thought to Leave With the Recipient

> **You are not asking someone to give something up. You are asking someone to show up.**

## Committee Planning Meeting Guide

*Mock Agenda: Committee Planning Meeting (30 minutes, virtual or in-person)*

### Setting the Stage – 3 minutes

- Brief round of introductions
- Overview of why this group has been brought together and what success looks like
- Clear framing upfront: this committee is about awareness and outreach, not asking anyone to donate

### Getting to Know the Recipient – 5 minutes

- A short, forward-looking introduction to the recipient—who they are and what a transplant makes possible for them
- Establishing the shared goal: widening the circle of people who know about this need and are open to learning more

### The Outreach Plan – 10 minutes

- Walk through the core messaging and how to use it across different channels
- Each member reflects on their own network: who they can realistically reach and through what channels
- Shared expectation: each member works toward bringing approximately 10 people into the awareness universe

### Commitments and Next Steps – 12 minutes

- Each member confirms what they're willing to take on before the next check-in
- Introduction to the shared contact tracker and how outreach will be coordinated across the group
- Open floor for questions, then a close with appreciation for everyone's time and willingness

APPENDIX · PHASE 3

# Recipient Network Outreach & Awareness

## Storytelling & Outreach Message Builder

*Building Your Outreach Message: A Step-by-Step Worksheet*

This tool helps recipients, committee members, and volunteer facilitators craft outreach posts and messages that are personal, community-appropriate, and aligned with transplant center guidelines.

> All medical questions and eligibility inquiries should be directed to the transplant center. Educational materials approved by the transplant coordinator will be made available to guide your outreach.

### Step 1: Lead With Something Real

A message lands best when it starts from a genuine place. Choose a prompt below and write one or two sentences in your own words.

- "Something most people don't know about my life right now is..."
- "When I think about what a transplant would give back to me..."
- "Living with kidney disease has meant..."

**Write your opening here:**

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### Step 2: Add One Clear Educational Statement

Keep it simple. One sentence is enough. Choose from the options below or use your own words.

- "A living kidney donation could offer a path forward that changes everything."
- "This is a voluntary process — no one is ever obligated to donate."
- "The transplant center manages all testing and determines eligibility."

**Write your educational sentence here:**

### Step 3: Close With a Gentle Invitation

End by making it easy for someone to take the next step — or simply pass it along.

- "If you're curious, the transplant center offers confidential information with no pressure."
- "Not sure if this is for you? That's okay — even sharing this post makes a difference."
- "The right person might be one connection away."

**Write your closing here:**

### Optional Enhancements

- Add a photo that shows the recipient in a meaningful moment
- Tag supportive people in your network, with their knowledge and consent
- Include transplant center contact information
- Return to post again with a small update or new angle
- Alternate between personal reflections and educational content over time

### Before You Post: A Quick Self-Check

- Is the tone calm and respectful throughout?
- Is donation clearly framed as a choice, not an expectation?
- Have you avoided making any promises about medical outcomes or compatibility?
- Are medical and eligibility questions directed to the transplant center?
- Is the recipient's privacy protected?

> When in doubt, add this line: "For medical questions or to learn more about donation, please reach out to the transplant center directly."

### The Formula in Plain Terms

> **Something personal + one educational fact + a voluntary invitation + a clear next step = a message that is honest, ethical, and worth sharing.**

## Community Awareness Event Guide

### Opening Remarks – Community or Faith Leader

A trusted voice from within the community opens the program, grounding the conversation in shared values and establishing a tone of warmth, respect, and openness.

### About This Effort – Organizing Team

A brief introduction to the organization leading this work—who they are, what they do, and why supporting living kidney donation matters to them.

### Understanding Living Donation – Educational Segment

A straightforward, accessible overview of what living kidney donation involves—how the process works, what initial screening looks like, and what it means to take a first step like providing a blood sample or swab.

### Reason for Hope – Story or Mission Moment

A short segment designed to connect facts to feeling. This might be a story from someone touched by transplant, a reflection on the organization's impact, or a values-based call to consider what it means to help someone reclaim their future.

### A Word About the Recipient – Family Member or Close Friend

Someone who knows the recipient personally offers a brief, two-to-three-minute reflection—not a medical summary, but a human portrait. Who is this person? What do they love? What does a transplant make possible for them?

### One Donor's Experience – Past Living Donor

A person who has already donated a kidney shares what the experience was like—in their own words, either directly or in a brief interview format.

### Questions and Next Steps – Closing Segment

Time for the audience to ask questions in an open, low-pressure setting. The session closes with clear information about how to learn more, who to contact, and what a first step looks like for anyone who is curious.

## Living Donation FAQ

*Common Questions About Living Kidney Donation*

*A preparation guide for recipients and outreach committee members*

### Do I have to be willing to donate just to attend the event?

Not at all. Attendance carries no obligation of any kind. The event is an opportunity to learn, ask questions, and understand what living kidney donation involves. People come to listen, show support, and leave better informed than when they arrived.

### What is this event actually for?

The purpose is to bring a wide circle of people together (many of whom may not know each other) to learn about living kidney donation in a welcoming, low-pressure setting. Most people who attend are there out of curiosity or care for the recipient, not because they have already decided to donate.

### Do people actually do this? Has anyone from this community donated before?

Yes. Gathering a community around a recipient is one of the most effective ways to find a living donor. People are far more likely to consider donation when they hear about it from someone they already know and trust, rather than through advertising or outreach from a stranger. Part of what makes these events powerful is hearing directly from past donors, ordinary members of communities just like this one who decided to say yes.

### Who will be part of the program?

The event typically features a community or faith leader, someone who knows the recipient personally and can speak to who they are, and often a person who has already donated a kidney and is willing to share their experience.

### What if I know I'm not in a position to donate? Can I still help?

Absolutely. There are meaningful ways to contribute beyond donation:

- Pass along information to people in your own network

- Bring someone with you to the event
- Share the recipient's story through text, email, social media, or group chats
- Simply show up and offer your presence and encouragement

Are there ways to support that don't involve donating? Can I forward this information to someone else?

Yes. Helping normalize the conversation around living donation is itself valuable. Many successful donor matches happen through second or third-degree connections — someone who heard about it from someone who heard about it from you. Passing information along is one of the most useful things you can do. Living donors most often come through trusted personal networks.

### Will I get to learn about the recipient? Will they be there?

You will hear from someone close to the recipient — a family member or friend who can speak to who they are and what a transplant would mean for their life. Depending on the format, the recipient may also speak directly. The goal is for attendees to leave with a genuine sense of the person, not just the medical situation.

### How safe is it to donate a kidney?

Living kidney donation is a well-established medical procedure with decades of research behind it. Every potential donor goes through a thorough evaluation process to confirm that donation is medically appropriate for them. The vast majority of donors return to full, normal lives. Throughout the process, a dedicated volunteer facilitator is available to help with logistics, answer questions, and provide support at every stage — no one moves through this alone. We fully support regular medical care for all living kidney donors to include at a minimum an annual physical exam with a blood pressure determination, blood chemistry testing and a urinalysis.

### What does life look like for a donor afterward?

For most donors, life after donation looks very much like life before it. Working, exercising, having children, traveling, none of these are prevented by donating a kidney. Long-term health outcomes for donors are generally very good. In the rare circumstance that a living kidney donor would develop progressive chronic disease such that there was a possibility that dialysis would be required, they would rise to the top of the waiting list to receive a deceased donor kidney transplant and they would certainly be eligible for this program to identify a living kidney donor.

### Can anyone donate, or are there restrictions?

Medical eligibility varies from person to person, which is exactly why a thorough evaluation exists. The transplant center sets and applies the health and safety standards that every potential donor must meet before proceeding.

### How do I find out if I might be a match? Does testing mean I'm agreeing to donate?

Initial compatibility screening can happen at the event itself, or you can connect with the transplant team afterward to get started. This first step is simple, quick, and carries no commitment. Testing is informational and it simply helps determine whether further evaluation makes sense. It does not create any obligation, and you can stop at any point in the process.

### What happens if the testing suggests I could be compatible?

The transplant center will walk you through what comes next. There is no rush, and no pressure. You will have time, information, and support to decide whether moving forward is right for you.

### How long does the process take, from start to finish?

Hospital stays for donors typically last one to three days. Most donors return to everyday activities within two to six weeks, depending on the physical demands of their work and how their individual recovery progresses.

### Will I have to pay for any of this?

The medical costs associated with donor evaluation, surgery, and hospitalization are generally covered through the recipient's insurance. Costs that fall outside the medical process — such as travel, meals, or time away from work — vary, and the team can help identify available assistance programs.

### Will I have support if I decide to move forward?

Yes, at every step. From the first conversation through recovery and follow-up, donors have access to a volunteer facilitator who can help with logistics, answer questions, and make sure nothing falls through the cracks.

### What if I want to learn more but prefer to keep it private?

After the event, you will have a direct contact — either a volunteer facilitator or a transplant center representative — who can answer your questions confidentially, on your timeline, with no pressure.

APPENDIX · PHASE 4

# Donor Interest Engagement

## Donor Conversation Support Checklist

This checklist is designed to help volunteer facilitators navigate conversations with individuals who have expressed curiosity about living kidney donation. Use it to stay grounded, on-message, and within your role.

### How You Show Up

- Approach every conversation with patience and a calm, unhurried tone
- Make clear that donation is a personal choice—asking questions or learning more creates no obligation
- Keep what you know about the recipient private
- Let the conversation breathe—avoid anything that feels rushed or pressured

### What You Say and Don't Say

- Be consistent: eligibility is determined solely by the transplant center, not by anyone in this process
- Reinforce that the evaluation process is private and confidential
- When medical or financial questions come up, redirect them to the transplant team—those are not yours to answer
- Do not attempt to interpret test results, health history, or medical information of any kind
- Do not offer reassurances you cannot stand behind

> When you are not sure how to respond: "That is really a question for the transplant center—they can walk you through it confidentially and without any pressure."

### Materials and Information

- Use only materials that have been reviewed and provided by the transplant coordinator
- Confirm that anything you share reflects current transplant center guidance
- Do not supplement with outside resources, personal research, or self-developed content

### Closing the Conversation

- Leave the person with clear, accurate contact information for the transplant center
- Encourage them to reach out directly if they want to continue learning—on their own terms and timeline
- Do not schedule, coordinate, or follow up on any medical appointments
- Do not discuss compatibility, testing results, or anything related to clinical evaluation

APPENDIX · PHASE 5

# Donor Evaluation Navigation Support

## Understanding the Donor Evaluation Process

The living kidney donor evaluation process is designed to ensure that donation is safe, ethical, and medically appropriate for each donor. Specific requirements vary by transplant center and donor circumstances, but the evaluation commonly includes the following components:

### 1. Compatibility Screening

- Confirmation of compatible blood type
- Additional tissue compatibility testing (as determined by the transplant center)

### 2. Core Health Qualification Review

- Donors must meet baseline health and safety standards, which may include:
  - Blood pressure
    - History of hypertension must be well controlled
  - Diabetes
    - Donors with diabetes are typically excluded, though some centers may consider Type 2 diabetes if it is well controlled and without end-organ damage
  - Body weight and BMI thresholds
    - Acceptable BMI varies by transplant center
    - If weight reduction is needed, volunteer facilitators may help donors connect with programs or providers that can support an improvement plan.
    - In some cases, medication-assisted weight loss may be discussed with the donor's primary care physician
  - Smoking cessation
    - Active smoking is generally a contraindication until cessation is achieved
  - Substance use screening
    - Substance use disorder is typically disqualifying
    - Alcohol and other substance history may prompt additional evaluation

### 3. Laboratory Testing

- Donors complete required blood and urine testing, including:
  - Basic metabolic and kidney function labs
  - Screening for chronic infections that could be transmitted to the recipient (e.g., hepatitis, HIV)

### 4. Imaging and Radiology

- Common imaging requirements may include:
  - Chest X-ray (CXR)
  - Kidney ultrasound
  - CT scan or MRI when indicated for anatomical planning

### 5. Specialist Consultations

- Depending on age, history, and center protocols, donors may undergo consultations such as:
  - Cardiology
    - Office evaluation
    - Stress testing
    - In some cases, heart catheterization is clinically indicated
  - Gastroenterology
    - Colonoscopy if not completed within the recommended interval (often within the last 5 years for older donors)
  - Psychosocial Evaluation
    - Assessment by a psychologist, psychiatrist, or licensed clinical social worker
    - Confirms donor is proceeding voluntarily, understands risks, and feels supported

### 6. Final Multidisciplinary Review

- Once all testing is complete, the donor is presented to the transplant center's multidisciplinary team for final approval to proceed with donation.

## Donor Conversation Guide for Work & Family

*Frequently Asked Questions*

If you're exploring living kidney donation, it's normal for friends and family to have questions. Below is a simple overview of the process.

→ For general questions about voluntariness, eligibility, and what to expect, see the Living Donation FAQ.

### What does the evaluation include?

Before any approval, the transplant center conducts a comprehensive evaluation, which may include:

- Blood and compatibility testing
- Imaging
- Medical history review
- Psychosocial assessment
- Consultation with an independent donor advocate

If donation is not medically appropriate, the process does not proceed.

### What is recovery like?

The transplant center provides recovery guidance.

Most donors:

- Stay in the hospital briefly
- Resume normal activity gradually
- Follow lifting and activity guidelines for a defined period

The medical team directs all recovery instructions and follow-up care.

### What about long-term health?

The transplant center provides recommendations for long-term monitoring.

Research shows most donors go on to live healthy, normal lives with one kidney. Donors are also prioritized in the transplant system, should they ever need a kidney in the future.

### Are there financial protections?

Some programs may help reduce financial burden, including:

- Travel assistance
- Lost wage support

- Donor assistance programs
- Certain job protections

The transplant center's financial team provides case-specific details.

### What if someone isn't a direct match?

There may be alternative pathways, such as:

- Paired kidney exchange
- Voucher programs
- National registry options

The transplant center determines eligibility and explains these options.

### Final Note

Living kidney donation is a carefully evaluated medical process overseen by transplant professionals. Any individual considering donation should work directly with the transplant center to receive accurate, personalized medical guidance.

APPENDIX · PHASE 6

# Donor Transplant Milestone Support

## Donor Surgery Preparation Guide

As the surgery date approaches, the volunteer facilitator helps the donor feel practically prepared and personally supported. The items below reflect what is typically reviewed during the run-up to transplant day.

### Confirming Medical Readiness

- Verify that the donor has received final clearance from the transplant center's multidisciplinary team
- Check that all outstanding lab work and imaging have been completed and that the transplant team has reviewed results
- Ask whether the donor has experienced any new illness recently — fever, infection, or other acute health changes that should be reported to the transplant center before proceeding

### Getting the Logistics Straight

- Go over the surgery date, the time the donor needs to arrive, and the exact location within the hospital or surgical center
- Review fasting requirements — typically nothing by mouth for approximately 12 hours before surgery, except any medications approved by the medical team
- Make sure the donor knows where to check in, who to ask for, and what the pre-operative process will look like

### Home and Family Preparation

- Confirm who will be with the donor on surgery day and how they will get there
- Make sure someone will be available at home to help during the first few days after discharge
- Think through any caregiving responsibilities that need coverage — children, pets, or others who depend on the donor

### Work and Time-Off Planning

- Confirm that leave from work has been arranged and that the donor's employer is aware of the timing
- Offer talking points for communicating with an employer if the donor finds that conversation difficult
- Walk through what a realistic return-to-work timeline looks like — commonly two to six weeks, depending on the physical demands of the job

### What to Expect After Surgery

- Discuss the typical hospital stay, which is usually one to three days for living kidney donors
- Talk through early mobility expectations: donors are generally encouraged to walk soon after surgery, with lifting restrictions in place for several weeks
- Prepare the donor for common post-operative experiences such as pain, nausea, and the effects of anesthesia wearing off
- Confirm that a follow-up appointment with the transplant center is already scheduled before surgery day arrives

### Financial Awareness and Available Support

- Make sure the donor has a clear understanding of what is covered — evaluation, surgery, and hospital care are typically paid through the recipient's insurance
- Walk through costs that may not be covered, such as transportation, meals, lodging, or income lost during recovery
- Identify any assistance programs, reimbursement options, or donor support resources that may apply to the donor's situation

### Emotional Check-In

- Create space for the donor to share any lingering questions, uncertainties, or concerns before the day arrives
- Remind the donor that they retain the right to pause or stop the process at any point — voluntariness does not end at the hospital door
- Confirm that the donor has people around them — family, friends, or others — who will be present and supportive through the experience

### Planning for Surgery Day Itself

- Confirm the volunteer facilitator's plan to be present with the donor through check-in and the pre-operative process
- Make arrangements to secure the donor's personal belongings — phone, wallet, keys, glasses — while they are in surgery
- Establish a clear communication plan so that the donor's family or support network knows what to expect and who to contact for updates

APPENDIX · SUMMARY

# Illustrative Engagement Activities Across the Living Donation Continuum

## Living Donation Engagement Overview Chart

The table below summarizes how engagement activities are organized within the model.

| Phase | Transplant Coordinator: Strategy, Preparation & Volunteer Facilitator Development | Volunteer Facilitator: Non-Clinical Support (Under Transplant Coordinator Oversight, Medical Direction by Transplant Center) |
|---|---|---|
| 1-2 | Build a tailored outreach strategy informed by the recipient's circumstances and network strengths; equip recipients and volunteer facilitators with education-based talking points | Support recipient in mapping networks and forming the volunteer facilitator committee |
| 3 | Guide planning of community awareness gatherings; develop voluntary, dignified public messaging | Execute structured outreach across personal, professional, and community networks |
| 4 | Develop structured, shareable messaging resources for use with prospective donors | Help prospective donors understand blood typing, crossmatch, and the voluntary evaluation process |
| 5 | Advise on outreach to community organizations; identify opportunities to engage external transplant support | Support donor understanding of evaluation milestones, psychosocial requirements, and lifestyle recommendations |
| 6 | Establish coordination framework with transplant center for surgical logistics | Support donors in practical and logistical readiness leading up to surgery |

## About the Kidney Transplant Collaborative

The Kidney Transplant Collaborative (KTC) is dedicated to increasing kidney transplants and removing financial and logistical barriers for kidney patients, donors, and their families. KTC is uniquely focused on increasing the number of living donor transplants in the United States through policy advocacy, education, and community organizing. For more details, visit www.kidneytransplantcollaborative.com.

## About Dr. Andy Howard

Andy Howard is the Chairman of Kidney Transplant Collaborative. He is a nationally recognized nephrologist with over 30 years of practice. KTC's core mission is to increase living donation and ensure that every donor is treated with dignity, transparency, and long-term care. We urge policymakers to build a system worthy of their sacrifice.