



Becoming a Donation Champion



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Kidney Transplant Program Roadmap



Referral

Patients are contacted by a team member within 2 days of referral receipt. Pre-dialysis patients are scheduled within 2 weeks.

Requirements to refer

- Age < 85
- BMI ≤ 45
- GFR ≤ 25 ml/min
- Diagnosis of CKD 4/5

How to refer

1. EPIC (EMR)
2. Fax: 617-726-0882
3. Physician Gateway
4. Secure e-form



Scan for e-Form



Evaluation

Initial assessment of a patient's medical and psychosocial history, including minimal lab tests*, to determine program candidacy.

* Additional required tests are completed at Readiness.

Multidisciplinary team

- Transplant nephrologist
- Transplant surgeon
- Transplant registered nurse coordinator
- Transplant nutritionist
- Social worker
- Financial coordinator

Available resources

- Dedicated care team
- Kidney recipient education
- Guide to living donation
- Access to National Kidney Registry's paired-exchange program
- Rapidly growing robot-assisted surgery program
- Health and nutrition coaching
- Virtual group visits
- Genetic testing
- Guide to finding supplemental financial resources

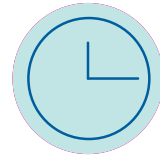


Selection

Based on a careful review and Mass General's selection criteria, the multidisciplinary team determines the patient's eligibility for transplant.

Potential committee decisions

1. Accept
 - » Active
 - » Inactive
2. Defer
3. Decline



Waitlisting

The patient is listed on the United Network for Organ Sharing (UNOS) waitlist within a week of acceptance.

Accepted patients will accrue time on the waitlist regardless of status. Only active patients can move on to Readiness.



Readiness

Through care coordination and communication, we ensure that every patient is ready to receive an organ offer as soon as possible.

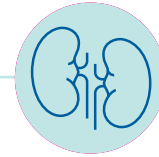
To prepare for kidney transplant

- Be in good health
- Maintain healthy habits and weight
- Be up to date on required vaccinations, health screenings and lab/imaging tests

Patients near the top of the waitlist are cleared for an organ offer once s/he has completed evaluation and tests.

Determinants of an organ offer

- Position on waitlist
- Blood type
- Level of sensitization
- Acceptance of "opportunity" kidney



Transplant

Location of procedure

The transplant surgery takes place at 55 Fruit St, Boston, MA 02114—Mass General Hospital, main campus.



After Transplant

During the three-day stay in the hospital, the patient recovers under the care of our skilled inpatient team.

Before discharge

Our team customizes and reviews the patient's medication regimen and care action plan.

Graft maintenance

Our post-transplant care team provides ongoing care throughout the life of the patient's new kidney, making necessary changes to the care plan to extend the transplanted kidney's survival.

Kidney Living Donor Program Roadmap



Intake

The potential donor (PD) completes a questionnaire that is assessed by the donor team for kidney donation suitability. Information shared is kept confidential.



Scan for Questionnaire

After applying, a member of the team contacts the PD for intake. The PD receives a welcome packet, completes consent forms and shares requested medical records.

Once consents and initial review are complete, the PD will be contacted by the independent living donor advocate (ILDA). Screening labs (blood, urine, and other as needed) will be ordered by the coordinator to evaluate kidney function.



Review & Initial Testing

If the screening labs are favorable the PD is invited to attend a multidisciplinary clinic (MDC) evaluation.

Multidisciplinary team

- Transplant nephrologist
- Transplant surgeon
- Transplant registered nurse coordinator
- Social worker
- Independent Living Donor Advocate (ILDA)
- Transplant psychiatrist
- Living donor dietitian

Available resources

- Option for virtual evaluation
- Independent Living Donor Advocate
- Guide to living donation
- Access to remote or advanced donation through paired-exchange
- Guide to finding supplemental financial resources
- Robot-assisted surgery program
- Post-donation follow-up care



Evaluation MDC 1

Includes:

- Education session with a nurse coordinator
- Visits with a nephrologist, a social worker, and additional specialists, if needed



Evaluation MDC 2

After MDC 1, if suitable, the PD comes to MGH to complete the work-up:

- Abdominal CT scan
- Chest X-ray
- Cardiac testing
- A second ABO blood typing
- Human leukocyte antigen (HLA) testing
- Visits with a transplant surgeon, ILDA, and other specialists, including psychiatry, if needed



Selection

The Multidisciplinary Selection Committee reviews the PD candidacy and determines suitability for donation.

Potential committee decisions

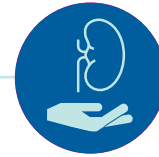
1. Approve
2. Decline
3. Defer

The candidate is kept informed throughout the process.



Before Donation

Once the PD is approved and the intended recipient is ready for the transplant, a surgery date is scheduled. Two weeks ahead of this date, the PD will come to MGH for education, additional lab tests, screenings, and to sign consent forms.



Donation

Location of procedure

The nephrectomy, removal of donor kidney, takes place at the Mass General Hospital main campus.

Before discharge

The donor stays in the hospital for two days in addition to the surgery. The nurse coordinator, social worker, and ILDA visit with the donor.



After Donation

The donor completes an online follow-up questionnaire, lab testing, and returns for follow-up (virtual or in person), 10 days, 6 months, 1 year, and 2 years after donation.

The donor is welcome to receive additional follow-up care at Mass General Hospital Transplant Center, as needed.

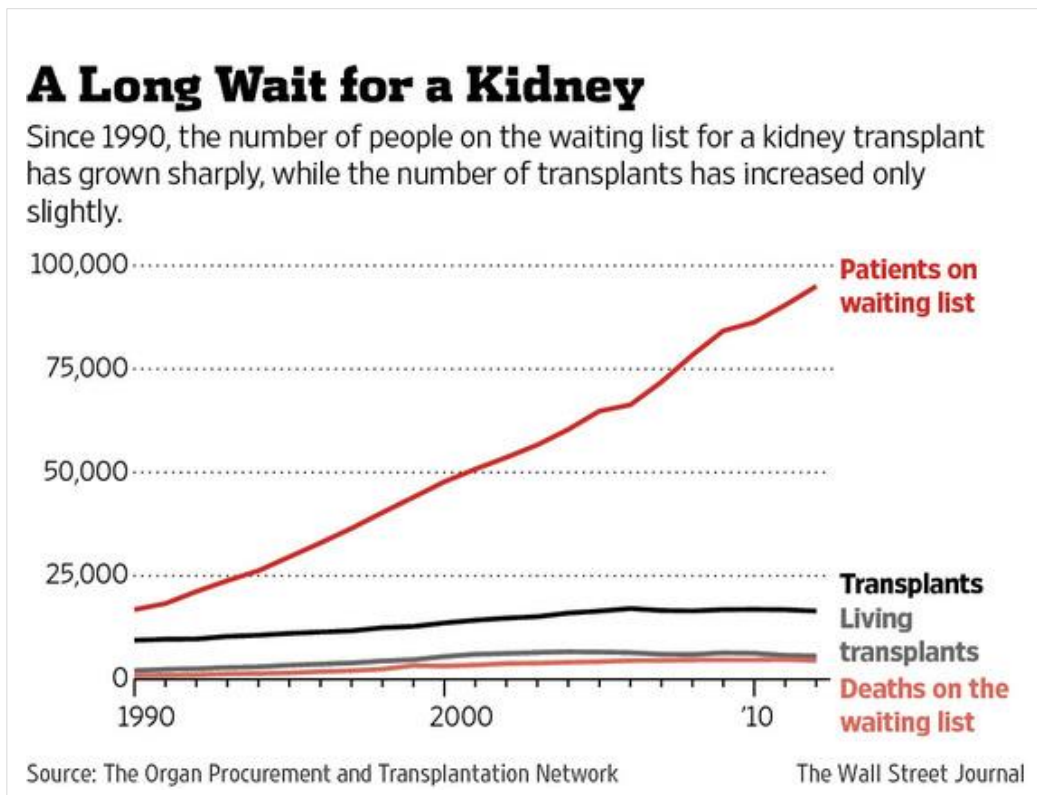
Advantages of Living Donor Kidney Transplantation

There are approximately 100,000 patients on the UNOS waitlist with about 20,000 kidneys made available per year. The demand for kidneys is five times higher than the available supply, which leads to longer wait times. The longer a recipient waits on dialysis for a kidney transplant, the less benefit they get from the graft, or transplanted organ.

Some advantages of Living Donor Kidney Transplantation include:

- Little to no wait time
- Avoid dialysis (preemptive kidney transplant)
- High rates of immediate function of the transplanted kidney
- Longer graft lifespan
- Elective surgery scheduled when recipient's health is optimal
- Allows for paired exchange for incompatible pairs (Swaps)
- Better patient and graft survival on the long run

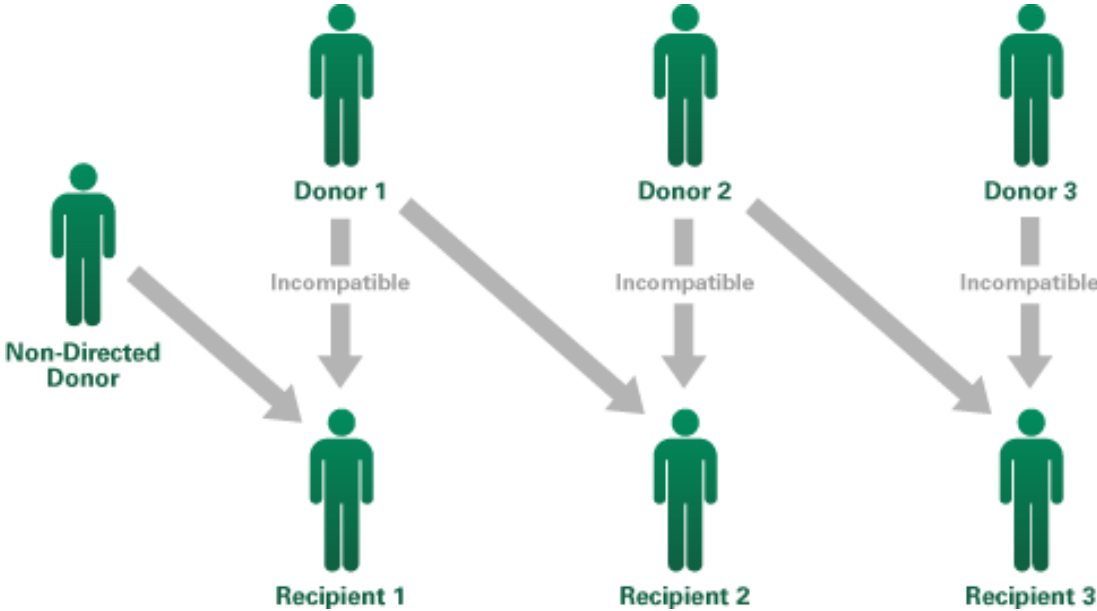
Anyone healthy and willing can be a donor!



Paired Exchange

- Blood type mismatch
- “Matching” (tissue typing/sensitization)
- Difference in age between donor and recipient
- Distance between donor’s home and Mass General
- Donor/recipient supports

Can utilize the paired exchange if the donor and recipient are not compatible for any of these reasons!



Your Social Network

Who Do I Reach Out To?

- People in your social network
 - Immediate family or close friends
 - Distant family, friends of friends, acquaintances
 - Co-workers
 - Members of community groups
 - Donation champions are a strong part of your team in reaching out to these networks

A donor does not have to be a close contact, in fact donors are often connected in distant ways but have an emotional or indirect relationship to you

Who Is in My Network?

- Who do I turn to when I have a bad day?
- Who do I ask if I need a ride?
- Who do I ask if I need financial help?
- Do I belong to a religious group?
- Do I volunteer?
- What are my hobbies and who am I connected to through this?
- Am I connected to an alumni group?

Can you think of any other questions?

How Do I Reach Out?

- Letters
- Phone
- Social gatherings
- Family newsletters
- Social media

Bulletins:

Living Kidney Donor Needed! Our friend *John* recently learned that they need a kidney transplant, and that a kidney from a living donor is their best chance of survival. If you are healthy, over age 18 and willing to donate a kidney, please complete the form at MGHLivingDonors.org. If you wish to learn more about living donation, go to massgeneral.org/transplant/about/living-donor-program. If you wish to speak to (champion's name), *John's* living donation champion, please call (champion's number) or email (champion's email).

Religious groups:

Prayers for (Recipient), who is in need of a kidney transplant. If you are willing to give the gift of life, please visit www.MGHLivingDonors.org or contact (his/her) Living Donation Champion at (insert phone and/or email address).

Alumni groups:

Our classmate (Recipient, class of 'XX) is in need of a kidney transplant. If you are interested in learning more about donation to our fellow classmate or how to help please visit www.MGHLivingDonors.org or contact (his/her) Living Donation Champion at (insert phone and/or email address).

What Do I Say?

- Explain what End Stage Renal Disease is and how it is impacting your life
- Talk about how your life has changed
- What are your hopes for donation?
- Share information about donation
- You don't have to focus on an ask, just tell you story and share information
- If someone is not able to donate, invite them to become a Champion

Share the donor center contact information. We screen and assist donors through the process so that you don't have to. All of your written information should direct potential donors to our website: mghlivingdonors.org

Examples

Letter from Recipient:

Dear Friends,

Some of you may know that I have kidney disease. Over time, my kidney disease has gotten worse causing my kidneys not to work well enough to keep me alive. This is what I am facing now, and my treatment options are limited to dialysis treatments or a kidney transplant.

- *Getting regular dialysis treatments, usually three times a week for four hours at a time, will help my kidneys do their job and keep me alive, but a transplant would offer me more freedom and the ability to live a longer, healthier, more normal life. A transplant would also give me more time to do the fun things I enjoy most, like spending time with my family and friends.*
- *However, finding a kidney for a transplant is not easy. Just ask the 100,000+ people on the waiting list for a deceased donor kidney like me. Time is not on our side. Some wait for years; many die while waiting. The average wait time is five years or more for a kidney from a deceased donor. However, there is another option: receiving a kidney from a living donor.*

Asking a family member or a friend to consider donating a kidney to me is difficult, but it greatly improves my chances of getting a transplant. A living kidney donation typically lasts longer and has better function.

You might not know a lot about living donation - I know I didn't before kidney disease affected my life. Understandably, some people are afraid about the surgery and what living with one kidney will mean for them. Here's some basic information about kidney donation:

- *You only need one kidney to live a healthy, long life.*
- *Most donor surgery is done laparoscopically, meaning through tiny incisions.*
- *The recuperation period is usually quick, generally 2-6 weeks.*
- *The cost of your evaluation and surgery will be covered by my insurance. The hospital can give you extensive information on this.*
- *You will have a separate team of healthcare professionals to evaluate you as a living donor. Their job is to help you understand the risks and benefits and look out for YOUR best interests.*

You can also learn more about living donation on the National Kidney Foundation (NKF) website: www.kidney.org/livingdonation or by contacting the NKF's free, confidential helpline at [855.NKF.CARES \(855.653.2273\)](tel:855.NKF.CARES) or nkfcare@kidney.org. If you want to talk to someone who's already donated a kidney, NKF can also help.

Thank you for taking the time to read my story. If donating a kidney to me is something you would like to consider, I would be happy to tell you more about my story and explore the process of determining if you are a match for me. You can fill out the Mass General donor questionnaire at www.MGHLivingDonors.org.

However, I know living donation may not be right for everyone — but you can still help! Consider being an organ donor after death and also, help me by sharing my story with everyone you know. At the very least I want to bring awareness to kidney disease and living donation. I am hopeful my efforts will help me receive a kidney sooner and encourage others to consider helping the many people on the wait list.

Thank you,

Letter from Donation Champion of recipient:

Dear [insert name here],

I am writing to you about my (e.g., friend, brother, husband), (Recipient), to let you know about (his/her) current health challenge and how you can help. This is not an easy letter for me to write, but I know that without sending this, someone who might be interested in helping won't have that opportunity.

(Recipient) is a wonderful person. (Talk about the recipient's work, family, volunteer work, involvement with the community and anything that could connect with other people.)

(Recipient) has end-stage kidney disease/kidney failure and has three options for treatment: dialysis, a kidney transplant from a deceased donor or a kidney transplant from a living donor. Dialysis is only a temporary solution. While (Recipient) can remain on dialysis for many years, it is not a cure for kidney disease. It is also physically exhausting and time consuming, with treatment schedules as frequent as three times each week for four hours each session.

Since I care so much for (Recipient), I'm doing everything I can to help find him/her a living kidney donor. (Give a brief history of Recipient's health challenges, whether on dialysis, had a previous transplant, how long waiting, how many other people have tried to help, etc. Potentially include a picture. If Recipient has made many positive lifestyle changes, mention them. If you are unable to donate, explain why. If Recipient isn't on dialysis, talk about how difficult it is to have a normal life while being on kidney dialysis. If on dialysis, describe the routine.)

(Recipient) needs a new kidney, and we hope you will consider being tested to be a donor. I know this is a big request. But I make it on behalf of someone who devotes every day of his/her life to making a difference to his/her family and friends. If you can help, please do. If you know anyone who might, please forward this on. Forwarding this to your family, friends, work, school, congregation, or any other communities you belong to would be most gratefully appreciated.

If you would like to learn more about living kidney donation, please feel free to call me at (insert phone number). I want to be as helpful as possible. You can also visit massgeneral.org/transplant/about/living-donor-program to get answers to any questions.

Thank you so much!

Contact Information and Resources

- **Mass General Living Donor links:**
 - www.massgeneral.org/transplant/about/living-donor-program
 - www.MGHLivingDonors.org (donor screening questionnaire)
- Mass General Hospital Transplant: Stacy Jean-Claude – Outreach Program Manager
sjean-claude@mgh.harvard.edu
- National Kidney Foundation’s “The Big Ask, The Big Give” initiative:
 - kidney.org/livingdonation
 - 844-BIGASK (844-224-4275)
 - bigask@kidney.org
- American Transplant Foundation
 - americantransplantfoundation.org and click “Living Donors”
 - Free 1+1=Life mentorship program available for recipients and living donors
- American Society of Transplantation (AST)
 - <http://www.myast.org/patient-information/>