

# A Walk in Their Shoes: Referral to the Transplant Waitlist

Journey of a patient seeking kidney or pancreas transplant at Hackensack University Medical Center

Presented by Jenna Lowe  
Transplant Outreach Coordinator

# Selection Criteria for Kidney Transplant Listing

## INDICATIONS

- End Stage Renal Disease
- Documented creatinine clearance less than or equal to 20 ml/minute
- Documentation of initiation of dialysis
- Documented diagnosis of ESRD ( $\text{GFR} \leq 20 \text{ mL/min}$ )
- Pediatric patients (age < 18 years): medically indicated based on Pediatric Nephrologist recommendations



# Who qualifies for Pancreas Transplant?

- Patients with Type 1 Diabetes
- Patients with Type 2 Diabetes:
  - Body Mass Index less than 30
  - Low insulin requirement
- Completion of testing
- Transplant team approval



# Requirements & Absolute Contraindications

## REQUIREMENTS

- Completion of multidisciplinary evaluation

## ABSOLUTE CONTRAINDICATIONS - (to be assessed and determined by transplant team)

- Severe heart disease
- Severe blood vessel disease
- Severe lung disease
- Untreated cancer
- Sickle Cell Disease
- Advanced liver disease
- Active non-compliance
- Active drug abuse
- Unstable psychiatric illness



# Relative Contraindications

**RELATIVE CONTRAINDICATIONS** - (to be determined on a case-by-case basis)

- Age  $\geq$  80 years
- History of melanoma
- Body mass index (BMI)  $>$  40



# Referral Phase

- Direct call to HackensackUMC Organ Transplant center
  - 551-996-2608
- Fax referral form
  - 551-996-0826
- Physician referral
- Online referral portal
- <https://www.hackensackumc.org/services/organ-transplants/organ-transplant-refer-a-patient/>
- Outreach efforts
  - Jenna Lowe 551-996-3203
  - [Jenna.Lowe@hmhn.org](mailto:Jenna.Lowe@hmhn.org)

# Referral Phase

- Brief Medical Intake & Insurance Authorization
- Scheduled for Evaluation
- Patient is contacted by our front desk team or outreach coordinator up to 3 times
- After 3 unsuccessful attempts we contact the dialysis center social worker to relay the message to the patient



# Purpose of Transplant Evaluation

- Patients learn about the process and various risks and benefits
- The transplant team determines if a patient is suitable and healthy for transplant surgery and will be able to take anti-rejection medications safely
- The patient determines if we are the right transplant team for them





# Evaluation Phase

- Evaluations are held weekly on Tuesday & Wednesday at 8am
- Comprehensive Evaluation by Multidisciplinary Team

SPECIALTY	ROLE
Surgeon	Performs transplant surgery and provides medical care
Nephrologist	Provides medical care before and after transplant
Nurse Coordinator	<u>Coordinates</u> testing, requirements for listing, and waitlist activity
Social Worker	Addresses psychosocial needs (e.g., social support)
Dietician	Addresses dietary needs/adherence
Pharmacist	Addresses medication adherence and requirements
Financial Coordinator	Addresses financial and insurance issues

- Based on existing comorbidities a patient evaluation can be discontinued following the evaluation appointment

# Required Testing

Day of Evaluation patient will have:

- Chest X-Ray
- EKG
- Blood Work

Then:

- CT Scan of Abdomen/Pelvis
- Echocardiogram, Nuclear Stress Test
- Cancer Screenings: Colonoscopy, Prostate Specific Antigen (PSA), Mammogram, Pap Smear
- Consults based on current or past conditions

Testing **MUST** be complete within 90 days of evaluation



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# Additional Testing as Needed

- Carotid Duplex
- Vascular testing
- Pulmonary function testing
- Bariatrics
- Geriatrics
- Psychiatry

# Evaluation is Complete

- When the evaluation is complete and results are received, the multidisciplinary selection committee discuss the patient to determine if he/she can be placed on the transplant waitlist
- Patients are notified when they are being presented at selection committee
- Nurse coordinator will contact the patient by phone and letter will be sent out to the patient, referring Nephrologist and dialysis center
- Patients have the option to be listed at other centers outside of New Jersey
- Any potential living donors can begin their screening process at this time by contacting our living donor team and register at [hmh.donorscreen.org](https://hmh.donorscreen.org)
- Patients have the option to refuse transplantation at any time

# Waitlist

- UNOS - United Network for Organ Sharing is the organization that manages the nation's organ transplant system
- Manages the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year.
- Maintains the database that contains all organ transplant data for every transplant event that occurs in the U.S.
- Wait time clock begins when the patient is listed or dates back to dialysis start time
- Most recent dialysis start date is used for patients who were transplanted
- Wait time varies per region
- Average wait time for kidney in NJ is approximately 4-5 years.

**Average wait time for kidney at Hackensack Organ Transplant is 1-3 years**

# Waitlist

- Written notification of listing status
- Monthly sample to Sharing Network
  - 10ml red top tube
  - Label: Patient's first, last name, DOB, last 4 digits of social security number must be included
- Mail before the 10<sup>th</sup> of every month
- Monthly updates are sent to dialysis centers on patients' statuses
  - Evaluation In Process
  - Waitlist Active/Inactive
  - Waitlist Removed/Evaluation Discontinued
- Monthly samples only needed for ACTIVE waitlist patients
- If additional supplies are needed, please call 551-996-2608 to notify our team

# After Being Listed..

- **Maintain contact** with the transplant team and comply with requests for follow-up visits
- Be sure to inform the transplant team of any changes in **contact** information
- Be sure to inform the transplant team of any changes in **insurance** information/**dialysis center**
- Be sure to inform us of any **significant** changes in **health status**

Otherwise, the patient might miss an opportunity to get transplanted



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# Microsites

- The goal of the microsite is to create a free website that patients can share via social media, email, etc. in order to get the message that they need a donor to a larger audience and subsequently find a kidney donor
- This program is directly connected to the center and can aid in avoiding the uncomfortableness of verbally asking someone to donate
- Outreach coordinator will assist patients with creating their site



# How it works

## Invitation to Create a Website to Help Find a Kidney Donor



No Reply <noreply@donorscreen.org>

To [REDACTED]

Dear [REDACTED]

Your transplant center has invited you to create a free website to help you find a kidney donor. To accept this invitation, [click here](#).

If you have any questions, please contact your transplant coordinator.

MSG ID: 595293


To begin, your transplant center will invite you to create a site through an email like this one.



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# Starter Site

 NATIONAL KIDNEY REGISTRY  
FACILITATING LIVING DONOR TRANSPLANTS

Tanya ThomasLearn about living donationRegister to donate for Tanya

**Tanya**  
Age 44

**My Story** Hello! My name is Tanya Thomas and I need a kidney transplant. Please consider being tested to determine if you are healthy enough to donate on my behalf. To see if you are medically able to donate, click the 'Register to donate for Tanya' button or, to learn more about living donation, click the 'Learn About Living Donation' button. Thank you for viewing my web site.

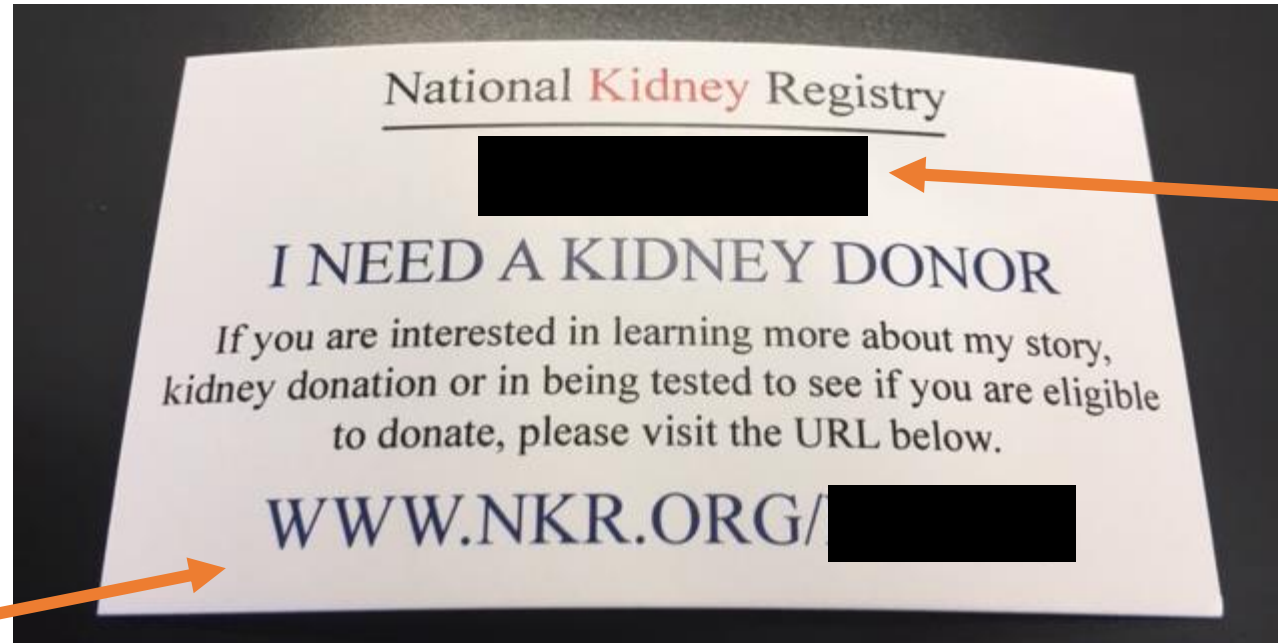


**Can you help Tanya by donating a kidney?**

Becoming a live kidney donor could give Tanya the gift of a normal life. Click the buttons below to learn more about becoming a living kidney donor or to start the screening process.

Learn about living donationRegister to donate for Tanya

# Business Cards




Your name  
here

Your  
Microsite's  
unique web  
address/url  
here




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# Custom Microsite

[You are currently previewing this microsite.]


Mark EisenLearn about living donationRegister to donate for Mark



**Mark**  
Age 63

**My Story** I have lived an amazing life. I was lucky enough to grow up in the Bronx and then I was honored to be able to serve my country for almost seven years in the U.S. Navy as a Cook, Gunner and on the Helicopter Crash Team. I have been a volunteer Fire Fighter for almost 29 years as well as being a member of the Park Ridge NJ Elks and Park Ridge NJ American legion. My mother has always taught us it is important to give back as that is what makes a community and family. I have a great family, a wife, two sons, daughter in-laws, grand kids, nieces, nephews, cousins. My amazing family in the fire department as well as the Elks and American legion. I work with for the best company with the best co-workers who are not only great at their jobs, but care so much about the dental industry and how our products better peoples lives. I have been lucky enough to live in the best community where I also serve on the board of governors for the Tri-boro Ambulance Corps. I truly like serving the community and hope to continue living as long as possible with my family and friends.

**Why I Need a kidney** I was diagnosed with stage four kidney failure earlier this year. I have had diabetes for many years and it has taken a toll on my kidneys. I have lost a serious amount of weight in the past few months as I feel if someone is giving me their kidney I will need to take care of it. I have changed my eating habits and life style around. I will have to start Dialysis sometime in 2021 and am hoping it is in the later part. I am hoping to get a kidney donated before I have to start the dreaded Dialysis. It is effected my family as they are worried for me and I don't want them to have to worry as they have enough on their plates. I feel life is short and I would like to live as long as possible as I have a lot to live for.



**Can you help Mark by donating a kidney?**

Becoming a live kidney donor could give Mark the gift of a normal life. Click the buttons below to learn more about becoming a living kidney donor or to start the screening process.

Learn about living donationRegister to donate for Mark

# Microsite Writing Tips

1. Tell your story, including what your life is like and what efforts you have made to find a donor
2. If you choose, mention your friends and family, try to also explain why they can't donate
3. Share your hopes and dreams, including what you will do after you receive a transplant
4. Do not offer any payment or compensation to potential kidney donors
5. Check spelling and grammar before submitting to the site



# Tying it all together: Patient Experience Story

## George Perez

- On dialysis for 4 ½ years
- Received a deceased donor transplant 10/29/20



*Save the Date*

# 2021 Transplant Designee Symposium

Friday, April 23<sup>rd</sup> • 8:00 a.m. – 3:30 p.m.

Virtual Platform: Zoom

Hackensack University Medical Center

*Registration will open soon*



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Questions?

Thank you for joining today!  
Please reach out to me directly  
with any questions or concerns

Jenna Lowe  
Transplant Outreach Coordinator  
551-996-3203 | C: 908-675-4373  
[Jenna.Lowe@hmn.org](mailto:Jenna.Lowe@hmn.org)



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