



Better healthcare,  
realized.

# A Team Approach: Navigating the Journey to Kidney Transplant

May 17, 2018

# MEET OUR PANELISTS

A graphic of several hands in various shades of blue and purple, overlapping and reaching towards the center, set against a dark blue background. The hands are rendered in a simple, outline style with some color fill.

# BARBARA BRECKENRIDGE

*Patient Advocate/SME, PAC Chair, Buffalo  
Director of Patient Services and Community  
Outreach, Kidney Foundation of Western NY*

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*PAC Chair, Bronx*

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Bronx Dialysis Center*

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*Administrative Director, Kidney Transplant,  
SUNY Downstate Medical Center*

# ELLIOT GRODSTEIN, MD

*Transplant Surgeon,  
Assistant Professor, Donald and Barbara  
Zucker School of Medicine at  
Hofstra/Northwell Health*

The background features a large, faint, light blue graphic of two hands reaching towards each other, symbolizing support and care. The overall color palette is a gradient of blues and purples.

# **KIDNEY TRANSPLANT JOURNEY**





# STEP 1

*Patient Suitability for Transplant*

- **Addressing perceived patient risks or apprehensions**
- **Strategies on successfully addressing barriers**

**LET'S  
TALK!**

**Maria and  
Carrie**

# STEP 2

*Patient Interest in Transplant*



**LET'S  
TALK!**

**Ken and  
Barbara**

- **Overcoming patient fears in the community, misconceptions**
- **Education on multiple waitlists or living donation**

# STEP 3

*Referral Call to Transplant Center*

- **Support navigating the process complexities**
- **Provide resources with process coordination, participation in pair exchange programs**

**LET'S  
TALK!**

**Maria and  
Ken**

# STEP 4

*First Visit To Transplant Center*



**LET'S  
TALK!**  
**Barbara  
and Maria**

- **Provide resources to help patients overcome financial burdens, social support issues, lifestyle barriers**



# STEP 5

*Transplant Center Work-up*

- **Approaches to streamlining the transplant process**
- **Transitions of care between dialysis facilities and transplant centers**

**LET'S  
TALK!**

**Dr. Grodstein  
and Carrie**

# STEP 6

*Successful Transplant Candidate*



**LET'S  
TALK!**

**Carrie and  
Dr. Grodstein**

- **Overcoming challenges to transplant waitlist**
- **Ethical concerns with organ procurement**

# STEP 7

*Patient on Waiting List OR  
Evaluating Potential Living Donor*

- **Supporting patients with adjusting to post-transplant care**
- **Accepting potential post-transplant health issues such as cancer and cardiovascular diseases**



**LET'S  
TALK!**

**Ken and  
Dr. Grodstein**



# AVAILABLE RESOURCES



## Transplant Resource Toolkit

**End-Stage Renal Disease Network Program**

## New York State Transplant Center Referral Guide

A kidney transplant is a possible treatment option for people on dialysis. However, not everyone who wants a transplant can be considered eligible to receive one. Only transplant center professionals can determine if a patient is a good candidate for a transplant.

Each transplant center uses its own set of standards for deciding if a patient is a good candidate for a kidney transplant.

In some cases, a patient can be turned down by one transplant center, but found to be eligible at another transplant center.

On the following page is a contact

### New York State Renal Transplant Centers



- ALBANY MEDICAL CENTER**  
47 New Scotland Avenue MC-61-GE, Albany, NY 12208 • Phone: (518) 262-5614 • Fax: (518) 262-5571  
[www.amc.edu/PatientServices/Surgery/transplant\\_surgery](http://www.amc.edu/PatientServices/Surgery/transplant_surgery)
- DOWNSTATE MED CENTER - SUNY**  
450 Clarkson Ave., Transplant Unit, Brooklyn, NY 11203 • Phone: (718) 270-3168 • Fax: (718) 270-3762  
[www.downstate.edu/transplant/kidney\\_transplant.html](http://www.downstate.edu/transplant/kidney_transplant.html)
- ERIE COUNTY MEDICAL CENTER**  
462 Grider Street, Renal Transplant Unit - 10th Floor, Room 1032, Buffalo, NY 14215 • (716) 898-5001  
[www.ecmc.edu/medicalservices/kidneytransplant.asp](http://www.ecmc.edu/medicalservices/kidneytransplant.asp)
- MONTEFIORE HOSPITAL & MEDICAL CENTER**  
111 East 210th Street, Renal Transplant Unit - Rosenthal 2, Bronx, NY 10467 • (718) 920-6757  
[www.montefiore.org/surgery-services-professional-training-programs-transplant-kidney](http://www.montefiore.org/surgery-services-professional-training-programs-transplant-kidney)
- MT. SINAI MEDICAL CENTER**  
Transplant Center, 5 East 98th Street, 12th Floor, New York, NY 10029 • (212) 659-8086  
[www.mountsinai.org/patient-care/service-areas/organ-transplants/programs-and-services/kidney-pancreas](http://www.mountsinai.org/patient-care/service-areas/organ-transplants/programs-and-services/kidney-pancreas)
- NY-PRESBYTERIAN HOSPITAL/COLUMBIA**  
622 West 168th Street, Transplant Ctr., 12th Floor, New York, NY 10032  
(212) 305-6469 • New Patient Referral (877) NY1-KIDNEY  
<http://columbiasurgery.org/patient-services/renal-transplant.html>
- NY PRESBYTERIAN HOSPITAL/WEILL CORNELL**  
525 East 68th Street, Box 98, Kidney Transplant Program, New York, NY 10065 • (212) 746-3099  
<http://cornellhospital.org/transplant>
- NEW YORK UNIVERSITY HOSPITAL**  
403 East 34th Street, 3rd Floor, New York, NY 10016 • (212) 263-8371  
<http://surgery.med.nyu.edu/transplant/kidney/patients>
- NORTH SHORE UNIVERSITY HOSPITAL MANHASSET**  
1554 Northern Blvd., Transplant Center, Manhasset, NY 11030 • (516) 472-5800  
[www.northwell.edu/find-care/locations/transplant-center](http://www.northwell.edu/find-care/locations/transplant-center)
- STRONG MEMORIAL HOSPITAL UNIVERSITY OF ROCHESTER**  
601 Elmwood Avenue, Transplant Unit, Box 675, Rochester, NY 14642 • (585) 275-7753  
[www.strongmemorial.com/urology/transplant-procedures/kidney-transplant.aspx](http://www.strongmemorial.com/urology/transplant-procedures/kidney-transplant.aspx)



To file a grievance, please  
**IPRO** End-Stage Renal Disease  
1979 Marcus Avenue, Lake Success, NY 11042-1072  
Patient Toll-Free: (800) 238-3773  
Fax: (516) 326-8929 • E-mail: [esrd@ipro.org](mailto:esrd@ipro.org)  
Developed by IPRO ESRD Network of New York

## Is a kidney transplant right for me?

















### Your guide to the transplant process

### Cambiando Negativos a Positivos

Abordando las preocupaciones y los miedos comunes de los pacientes

#### Razones por las cuales un trasplante es una buena idea

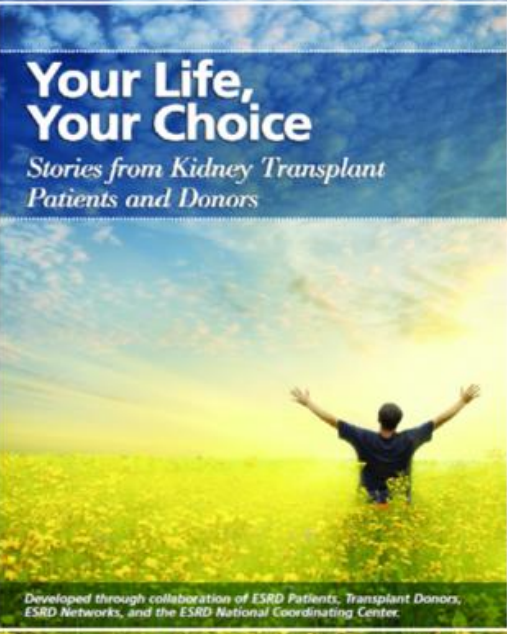
-  "Por qué debo ir a una consulta para un trasplante?" Se a lo que me enfrento cuando se trata de recibir diálisis.
-  "No creo que sea candidato para un trasplante".
-  "Con frecuencia me siento cansado".
-  "No puedo controlar mi presión arterial".
-  "No tengo apetito; la comida no sabe bien".
-  "Tengo problemas con mi fígado y con la inserción de agujas en mi brazo".
-  "Siempre dependo de mi familia para que me lleven y me recojan en el centro de diálisis".
-  "Nunca recuerdo tomarme el aglutinante de fosfato con las comidas".
-  No hay cura para el fallo renal; cada modalidad tiene sus efectos a largo plazo. El trasplante es la mejor modalidad - le provee un riñón activo y funcional y reduce muchos de los efectos a largo plazo que puede provocar el tratamiento de diálisis.
-  El primer paso para consultar si usted es un candidato es llamando al centro de trasplante y hacer una cita. No hay nada malo en hacer la llamada para obtener la información. Muchos centros están ofreciendo trasplante a pacientes que usualmente no recibirían un trasplante.
-  Un trasplante ayuda a filtrar los desechos de su sangre y produce células rojas que le proveen oxígeno a su cuerpo. Este procedimiento puede ayudarle a sentirse menos cansado.
-  Después de un trasplante, su sangre es filtrada las 24 horas al día por su nuevo riñón. Esto renueva el fluido que causa alta presión arterial cuando está en diálisis. Debido a que el fluido es filtrado por su riñón todo el tiempo usted no tendrá las mismas preocupaciones de tensión por la presión arterial baja durante sus tratamientos de diálisis. En lugar de estar desanimado por tener que ingerir muchos líquidos, se animará!
-  Con una sangre más limpia y con químicos normales en su sistema, la comida sabrá mejor. Una vez usted reciba un trasplante, usted se animará a comer todos los alimentos y los líquidos que tuvo que restringir de su dieta mientras estaba en diálisis.
-  Con un trasplante, las únicas agujas requeridas son las de pruebas en sangre para monitorear la función de su riñón.
-  Después de un trasplante, usted aún necesitará apoyo de sus familiares para regresar de la clínica, pero después de que su riñón esté estable (alrededor de tres meses después del trasplante), usted tendrá su independencia de vuelta.
-  Un trasplante ayuda a su cuerpo a eliminar el exceso de fósforo, por lo que usted no tendrá que tomar fosfato o limitar los alimentos altos en fósforo de su dieta.

Para presentar una queja, comuníquese con:  
IPRO End-Stage Renal Disease Network of New York  
1979 Marcus Avenue, Lake Success, NY 11042-1072  
Línea directa para el paciente: 1 (800) 238-ESRD (3773)  
Main: (516) 209-5578 • Fax: (516) 326-8929  
Correo electrónico: [info@nw2.esrd.net](mailto:info@nw2.esrd.net) • Web: [esrd.ipro.org](http://esrd.ipro.org)

Desarrollado por la Red de Paciente de ESRD de IPRO en Nueva York bajo contrato con los Centros de Servicio de Medicina Médica. Contrato número HHSM-500-2016-0002C.

## Your Life, Your Choice

### Stories from Kidney Transplant Patients and Donors




Developed through collaboration of ESRD Patients, Transplant Donors, ESRD Networks, and the ESRD National Coordinating Center.

### Types of Kidney Donors

- Living Donor**
- A living related donor kidney comes from a blood relative, such as a parent, brother, sister, or an adult child, and is the best transplant option.
  - A living unrelated donor kidney comes from someone who is not related to the person receiving the kidney.
  - The donor is evaluated by the transplant center to make sure he/she is healthy enough to donate and is offering higher kidney willingness without pressure from anyone.
- Non-Living Donor**
- A non-living donor is someone who has recently died and has donated a healthy kidney.
  - Patients who do not have a living donor can be placed on the national organ transplant waiting list to receive a deceased donor kidney.
- Kidney Donor Exchange**
- If your kidney donor is approved for a living donation but is not a match with you, you and the donor may be able to join a living donor exchange program.

### For more information

 End-Stage Renal Disease Network of New York

For more information, or to file a grievance, please contact us:  
IPRO End-Stage Renal Disease Network of New York  
1979 Marcus Avenue  
Lake Success, NY 11042-1072  
Patient Toll-Free: (800) 238-3773  
Main: (516) 209-5578  
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Web: [esrd.ipro.org](http://esrd.ipro.org)

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### Get the Facts: Kidney Transplantation



Learn the facts about getting a kidney transplant and how it might affect you before you make decisions about your treatment.

 End-Stage Renal Disease Network of New York

- What are the advantages of a kidney transplant?**
- Your overall health and quality of life will likely improve.
  - You may be less tired and have more energy.
  - You have more freedom because you no longer need dialysis.
  - If you have not been able to work, you may be able to return to work.
- What are the disadvantages of a kidney transplant?**
- You may have to take anti-rejection medications daily after a kidney transplant.
  - You may have side effects from the medications, including weight gain and changes in body image.
  - There is a small risk of losing kidney function in the first year or having complications following the surgery. The kidney could be rejected by your body.

the surgery. You must also be able to take the medications which help your body accept the new kidney.

- Donor kidneys come from living donors and non-living donors. A non-living donor is a person who

Part of the cost of anti-rejection medicines may not be covered afterwards. These may be expensive.



# Facility “Education Stations”

- **Colorful bulletin board**
- **Bright posters in waiting area**
- **Resource “booth” on the floor**
- **Mobile cart of tools**
- **Dedicated peer mentor counseling area**
- **Monthly feature of newsletter patient stories**
- **Multiple tables - information on different stages in process**
- **Video streamed on education “station”**



**Bronx Dialysis Center and  
Eastchester Road Dialysis (Bronx, NY)**

# OPEN FORUM: Questions/Comments?



# Thank You!



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1979 Marcus Avenue, Suite 105  
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<http://network2.esrd.ipro.org/>

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