Gift of Life: Empowering Living Kidney Donation



Kidney Donor Conversations www.MyKDC.org

Sessions

- Advancements and Challenges in Kidney Transplant: Empowering Patients and Professionals
- Pathway to Giving: Understanding the Living Kidney Donor
 Process
- Giving Life, Exploring Impact: Benefits and Considerations for Living Kidney Donors
- Finding a Lifesaving Match: Strategies for Finding a Living
 Kidney Donor



Continuing Education

- To complete the course, the learner must:
 - Watch the 60-minute webinar
 - Complete evaluation & post-test questions
- Social Worker CEs approved by ASWB.
- Glenna Frey speaker for this webinar, is on the speaker's bureau for American Nephrology Nurses' Association. All relevant financial relationships listed were mitigated.





Learning Outcomes

- After this course, the learner will:
 - Recognize the limitations of transplant centers and organ procurement organizations (OPOs) on finding a living donor to improve communication with patients and families.
 - Explore strategies for effectively communicate the need for a kidney donor to the public.
 - Discuss the American Society of Transplantation guidelines for public solicitation.









Where do you get the best treatment?













The best treatment for kidney failure for most patients is a living donor transplant.



But who provides this treatment?

Who Supplies the Living Donor Kidneys?



Surgeon?

Organ Procurement Organizations (OPOs)?

Dialysis Units?

Patient/Family?



Transplant Centers?

Registries?

Nephrologist?





U.S. Adults & Healthy People



https://www.census.gov/quickfacts/fact/table/US/IPE120218 retrieved 12/23/2019

Joana Araújo, Jianwen Cai, June Stevens. Prevalence of Optimal Metabolic Health in American Adults: National Health and Nutrition Examination Survey 2009–2016. Metabolic Syndrome and Related Disorders, 2018; DOI:

- 10.1089/met.2018.0105
- https://www.cdc.gov/chronicdisease/about/index.htm retrieved 12/23/2019
- https://www.statista.com/statistics/398384/total-number-of-us-organ-donors/ retrieved 12/23/2019
- https://www.organdonor.gov/statistics-stories/statistics.html#glance retreived 12/23/2019





Joana Araújo, Jianwen Cai, June Stevens. Prevalence of Optimal Metabolic Health in American Adults: National Health and Nutrition Examination Survey 2009–2016. Metabolic Syndrome and Related Disorders, 2018; DOI: 10.1089/met.2018.0105

https://www.statista.com/statistics/398384/total-number-of-us-organ-donors/retrieved 12/23/2019

https://www.organdonor.gov/statistics-stories/statistics.html#glance retreived 12/23/2019

21,167 Kidney Transplants (HHS, 2018)









Living Kidney Donor Transplants



Anonymous Kidney Donors (HHS, 2018)







MARK WAS DIAGNOSED WITH VASCULITIS. AN AUTO-IMMUNE DISEASE. IN 2009 WHICH DAMAGED HIS KIDNEYS. IN AUGUST. 2012. HE HAD A TRANSPLANT WITH A KIDNEY DONATED FROM HIS WIFE. THE TIME HAS COME THAT HE IS IN NEED OF ANOTHER REPLACMENT.

MARK BEGAN HIS EMPLOMENT AT SAUDER IN 2015 AND IS CUR-RENTLY WORKING AS A CRAFTSMAN IN PDS. ALONG WITH WORKING FULL TIME HE MAINTAINS DIALYSIS 3 DAYS A WEEK. HE IS VERY THANKFUL TO GOD FOR HIS ABILITY TO REMAIN ON THE JOB.



PLEASE CONSIDER GIVING THE GIFT OF LIFE THIS SEASON

FOR MORE INFORMATION TAKE A CARD



HELPHOPPER MARK IS VERY APPRECIATIVE TO TOM SALSBURY. SHERRY GOLDSMITH. MARK MILEER. MYRL SAUDER FOR THEIR CARING AND SUPPORT AS WELL AS HIS " ADOPTED" BROTHERS AND SISTERS AT NPD





UNOS, AST, & ASTS Guidelines for Public Solicitation

American Journal of Transplantation 2007; 7: 1047–1054 Blackwell Munksgaard © 2007 The Authors Journal compilation © 2007 The American Society of Transplantation and the American Society of Transplant Surgeons

doi: 10.1111/j.1600-6143.2007.01751.x

Meeting Report

Guidelines for the Psychosocial Evaluation of Living Unrelated Kidney Donors in the United States

M. A. Dew^{a,*}, C. L. Jacobs^b, S. G. Jowsey^c, R. Hanto^d, C. Miller^e and F.L. Delmonico^f

^aDepartments of Psychiatry, Psychology and Epidemiology, University of Pittsburgh School of Medicine and Medical Center, Pittsburgh, PA ^bSocial Work Department, University of Minnesota Medical Center, Minneapolis, MN ^cDepartments of Psychiatry and Psychology, Mayo Clinic, Rochester, MN ^dNew England Organ Bank and New England Program for Kidney Exchange, Newton, MA ^eLiver Transplant Program, The Cleveland Clinic Foundation, Cleveland, OH [†]Massachusetts General Hospital, Harvard Medical School, Boston, MA, and the United Network for Organ Sharing, Richmond, VA * Corresponding author: Mary Amanda Dew, dewma@upmc.edu

Received 10 October 2006, revised 2 January 2007 and accepted for publication 16 January 2007

Introduction

On May 25, 2006, over 70 representatives of the North American transplant community gathered in Washington, DC, to develop guidelines for the psychosocial evaluation of prospective living kidney donors who have neither a biologic nor a longstanding emotional relationship with the transplant candidate. This conference was convened by the United Network for Organ Sharing (UNOS), in collaboration with the American Society of Transplant Surgeons and the American Society of Transplantation. The participants comprised experts in the field of living organ donation and included transplant surgeons and physicians, nurses, social workers, psychologists, psychiatrists, ethi-



- Living kidney donation is cost-saving to the health-care system.
- Living donors do incur nonmedical expenses.
- Buying, selling or any trade in organs is illegal in the United. States.
- Living donation in the United States is not limited to donor-recipient pairs in which individuals have long-standing emotional relationships or biological linkages.
- Public solicitation of living donor organs cannot be regulated or restricted in the United States, as long as no felonious or illegal activity is involved (i.e. no party knowingly acquires, receives or otherwise transfers any human organ for valuable consideration for use in human transplantation). In other words, the ways in which relationships are developed in society with respect to living donation cannot be regulated or restricted.





QUIET THINKING

Stories

EXPLORING KIDNEY DONATION







Advocacy The act of pleading or arguing in favor of something, such as a cause, policy, or interests of active support of an idea or c



Coach





















Circle













Car



SHARE YOUR SPARE



MARK WAS DIAGNOSED WITH VASCULITIS. AN AUTO-IMMUNE DISEASE. IN 2009 WHICH DAMAGED HIS KIDNEYS. IN AUGUST. 2012. HE HAD A TRANSPLANT WITH A KIDNEY DONATED FROM HIS WIFE. THE TIME HAS COME THAT HE IS IN NEED OF ANOTHER REPLACMENT.

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PLEASE CONSIDER GIVING THE GIFT OF LIFE THIS SEASON

FOR MORE INFORMATION TAKE A CARD











Resources to find a

Living Kidney Donor

NATIONAL KIDNEY FOUNDATION



FREE WEBINAR **FIRST STEPS TO TRANSPLANT & FINDING A LIVING DONOR**

Sunday, March 21st

-First Steps to Transplant -Chat with Medical Professionals -Finding a Living Donor

Join us for one or all three sessions!



www.kidney.org/transplantation/livingdonors





TRANSPLANT**STRONG** BE PROACTIVE STAY ENGAGED STRIVE THRIVE DONOR-SEEKER® PROGRAM Y THRIVING POST TRANSPLANT Y BOOKS | STORY VIDEOS Y PATH 2 TRANSPLANT Y HOME TALKING-UP YOUR KIDNEY DONOR SEARCH

www.transplantstrong.com









Videos LESSON 1 INTRODUCTION & OVERVIEW











AVAILABLE FOR FREE DOWNLOAD ON ANDROID & APPLE DEVICES



Mobile App





Contact List

Worksheet

		NG-UP YOUR	KIDNEY DO				
NAME	EMAIL ADRESS	PHONE NUMBER	IST - WORKSHEE BEST CONTACT	WILL SHARE STORY?	CONSIDERING	COMMENTS	
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		
				YES NO	YES NO		









Book (Amazon)





IN PURSUIT of LIFE

The Ultimate Guide For Finding Living Kidney Donors





The Ultimate Guide for Finding Living Kidney Donors

SAMPLE

A FRIEND FAMILY 8 FAMILY 8 CLIENT LE SOCIAL N POTENTIA

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Life Donated...Multiplies Life

Having Your Donor Find YOU Video Series

www.kdc.havingyourdonorfindyou.org

Introduction and Overview
Episode #1 – Advocates
Episode #2 - Developing Your Story
Episode #3 – Knowledge Builds Confidence
Episode #4 – Telling Your Story - In person
Episode #5 – Telling Your Story - Using Email
Episode #6 – Telling Your Story - Social Media
Episode #7– Telling Your Story - Getting Creative
Episode #8 – Donor/Recipient Compatibility

- Episode #9 Paired Exchanges
- Summary







Microsite = Website

www.findakidney.org



FINDA KIDNEY.ORG®



Transplant centers that participate in the National Kidney Registry's microsite program can help you set up your own personal microsite, where you can tell you story, spread the word about your donor search and give potential donors an easy way to get tested on your behalf. There ar currently 51 centers participating in the microsite program. To find a center that offer microsites, see the map of microsite participant centers.

View Map

Currently Active Microsites





Load More...

×



Jay Brill



Bruce McLaughlin



AJ Tantala



Matthew Albino



Manu Harris

Share my story and help me find a kidney

> Hello, family and friends! My name is Manu Harris. I was born in Tonga, raised in California, and now a resident of Utah for over 30 years. I am happily married with two beautiful children. Since I was diagnosed with kidney failure in Jan 2022, I have been greatly limited in what I can do with my life. However, I have been earnestly searching for a kidney donor. If I were to receive a new kidney, my dream is to serve a fulltime church mission with my husband anywhere in the world! Maybe serve several Read more...

Why I Need a Kidney

Because of years of unmonitored hypertension (high blood pressure) both my kidneys failed After being diagnosed

 \sim

By sharing my story to your group of family and friends, you help to increase the number



See if you're qualified to donate

How You Can Help



A microsite gives kidney patients looking for living donors a free unique web address with all your relevant information in one place to help you share your story. Here is an example.

Having Your Kidney Donor Find You is a free education video series about transplantation and how to campaign for a living donor.

Fill out the form below to create your microsite. Include your address and select up to five t-shirt sizes and they will automatically be shipped to you free of charge. If you want more than five shirts for an additional cost, please contact the generous folks at Design A Shirt and they will help you out.

www.thegreatsocialexperiment.net





FREE MICROSITE & FREE T-SHIRTS

(Yes, both are free, no strings attached) 🙂



Want Your Microsite Taken Down?

Email

Remove

Is it because you were transplanted? Please let us know!

The Essential Search Package



www.kidneysearchfoundation.org

Profile page on our website . The purpose of the profile page is to provide you with more exposure so that potential donors who visit our website can learn more about you. Visit the "client profiles" page on our website to see what your profile will look like.

In addition to the profile page, we will create (2) out of the (3) items below for you:

- A. (2) car window decals
- B. (2) personalized t -shirts

C. a set of **personalized search cards** (business card size) that you can hand out to promote your search.

Once your items are printed and ready to go, they will be shipped to you directly for FREE.



Focus on a Specific Groups

Help patients and their families navigate the complex process of kidney transplant, from finding a donor to arranging the transplant and beyond.

www.renewal.org

ARenewal

Renewal Transplant Services

Renewal National

Since its inception in 2022, Renewal National has developed relationships with multiple transplant centers across the United States. This enables patients across the country to utilize the services that Renewal offers at their local transplant center.



Support

Renewal accompanies the donor and recipient throughout the entire transplant. Renewal strives to make the experience as smooth and comfortable as possible. This includes reimbursement for the donor for any expenses associated with donation, including loss of wages, transportation, and convalescence. Renewal has guides and helpful information for donors and recipients, to help take the guesswork out of transplant.



Outreach

Renewal provides kidney patients the tools and information they need to find a living donor, from tailormade seminars and advice on how to search for a donor, to personalized donor flyers. We screen and swab potential donors and are a resource for their questions and concerns.



Although there are many good medical referral agencies, they do not put a particular emphasis on the specialties of nephrology and transplant surgeons. Renewal offers guidance through the maze of experts in these fields.



Cutting Edge Genetic Matching

Renewal's new virtual lab, under the guidance of the world-renowned immunologist, Dr. Massimo Mangiola represents an exciting future. With our state-of-the-art high resolution swebbing, and large detabase of potential donors to swap with, we are now able to match based on Eplet matching. This reduces the probability of rejection, enables patients to safely reduce immunosuppressive medication, and increases the longevity of the transplanted kidney.



Dialysis Education

The world of dialysis can be overwhelming. Peritoneal and hemodialysis, best centers, as well as nutrition; there is a lot to unpack. While not replacing medical guidance, Renewal's experts will help explain and demystify the process.



Focus on a Specific Groups D Έ

KIDNEY DONATION FOR VETERANS

Support to any eligible Veteran who is actively listed for a kidney transplant at any US Transplant Center in creating an outreach campaign within their networks and community.

www.dovetransplant.org





ଦ୍ୱାଧି ÷ Info for Kidney Info for Veteran Transplant Donors Candidates





Focus on a Specific Groups



Help those in search of a kidney reach into their community organizations and ask for help.

www.kidneysforcommunities.org








Kidneys for Communities Put your kidney where your heart is.







Recipient

Resource Why is Living Kidney Donor Transplant Best?

Why is Living Kidney Donor Transplant Best?

Problem 1 4 1

- The average lifespan on dialysis is 5 -10 years. Most people will die before getting a kidney transplant. The longer people are on dialysis, their lifespan shortens.

 There are enough people that want to be organ donors at death. But not enough can donate due to poor health, dying in the wrong way, and it being the family's decision.

Transplant is Better than Dialysis

- The time it takes to get a deceased (dead) donor kidney transplant is about 5 years on average. Only about 1 in 5 people on the waiting list get a kidney because there aren't enough donors. The kidney lasts about 8-12 years

- Dialysis costs \$90,000 and kidney transplant costs \$30,000 each year on average.

Living Kidney is Best

It can take about 1 year or less for you & your living kidney donor to get approved and schedule surgery. The kidney lasts about 12 - 20 years.

Types of Living Kidney Donors

Directed Donor is someone you know giving you a kidney.

Paired Exchange is when someone you know wants to give you a kidney, but you are not a match. You are matched with another donor. Your person donates a kidney to someone else. Don't worry about your blood type when looking for a donor, just find someone who wants to donate.

Non-Directed Donor is a stranger giving you a kidney.

- The risk surgery wi about 3 da - Risk for the normal a kidney. Y - There is could be co

> - Websit - Family share your The Big Gi - Use car

Your circle of friends, family, and people where you live may want to help you. Ideas for sharing your story: church, work, post in grocery stores, restaurants, etc.
Make t-shirts, post on social media & billboards.

Other:

"The Kidney Donor's Journey" book by Ari Sytner Renal Support Network at <u>www.rsnhope.org</u> Call a Transplant Center!

Risk for a Living Donor

- The risk of surgery problems is less than 3%. Most donors have a minor surgery with small punctures in the belly area (laparoscopic). Hospital stay is about 3 days & recover 6 weeks before going back to work.

 Risk for donors needing dialysis or transplant in the future is lower than the normal public. Living donors go to the top of the waiting list if they need a kidney. You can live a healthy, normal life with one kidney.

- There is no cost for testing needed to be approved or for surgery. There could be costs for travel or time off work.

Finding a Living Kidney Donor



- Tell your kidney story to people you know.

- Websites: www.LKDN.org & www.TransplantStrong.com

- Family or friends can be your coach to help tell your story. Have them share your story with others. National Kidney Foundation "The Big Ask The Big Give" can help you & your coach.

- Use cars to tell your story. Make or buy a window message, sign or bumper sticker about your need for a donor.



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2023

Resource onor



Why Become a Living Kidney Donor?

Problem

- The average lifespan on dialysis is 5 -10 years. The average wait time for a deceased donor kidney is 5 years. Most people will die before getting a kidney transplant.

- There are enough people that want to be organ donors at death. But less than 1% can donate due to poor health, dying in the wrong way, and it being the family's decision.

Transplant is Better than Dialysis

- The time it takes to get a deceased (dead) donor kidney transplant is about 5 years on average. Only about 1 in 5 people on the waiting list get a kidney because there aren't enough donors. The kidney lasts about 8-12 years

- Kidney transplant costs \$30,000 each year on average, while dialysis costs \$90,000 a year. That means dialysis costs tax payors 3 times as much.

Living Kidney is Best

- A living donor kidney lasts about 12 - 20 years. A deceased donor kidney lasts about 8-12 years.

- A living kidney donor transplant surgery can usually be approved and schedule in a year or less. (Deceased transplant wait time is about 5 years.)



work.

Risk for a Living Donor

- The risk of surgery problems is less than 3%. Most donors have a minor surgery with small punctures in the belly area (laparoscopic). Hospital stay is about 3 days & recover 6 weeks before going back to

- Risk for donors needing dialysis or transplant in the future is lower than the normal public. Living donors go to the top of the waiting list if they need a kidney. You can live a healthy, normal life with one kidney. - There is no cost for testing needed to be approved or for surgery. There could be costs for travel or time off work.

Ways to Donate

Directed Donation is donating to someone you know.

Paired Exchange is when you want to donate to someone you know (friend or family), but you are not a match. You are matched with someone else instead. Your friend or family receives a kidney from another donor. Don't worry about blood type. As long as you are willing to donate, your friend or family will be able to find a match.

Non-Directed Donation is donating to someone you do not know. Advanced Donation is doing a non-directed donation now. You can then give a coupon to a family member (spouse, child, etc.) or friend who might need a kidney in the future. When they need a kidney, they can turn in the coupon and be matched with a donor.

Interested in Living Kidney Donation?

- Take an easy private online health survey to see if you might qualify. Go to www.MyKDC.org

 On the home page click "See if you can be a kidney donor" Contact a transplant center.

- Get the book "The Kidney Donor's Journey" by Ari Sytner Questions? Email us at info@MyKDC.org



Book









Network 5

www.qualityinsights.org/qirn5

ABOUT 🗸 ONGOING PROJECTS 🗸 HEALTH EQUITY 🗸 EMERGENCY PREP DATA 🗸 DIALYSIS PROVIDERS 🗸 PATIENTS & FAMILIES 🛩 CONTACT US 🗸

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PECIAL INITIATIVES

ORGANIZATIONAL STRUCTURE

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WEBINARS

WELCOME WE ARE QUALITY INSIGHTS RENAL NETWORK 5

Serving the District of Columbia, Maryland, Virginia, and West Virginia.

QUALITY INSIGHTS RENAL NETWORK 5

One of 18 Medicare-funded organizations in the U.S. responsible for improving the quality of care delivered to patients with End-Stage Renal Disease (ESRD).

We are a nonprofit corporation serving the District of Columbia, Maryland, Virginia, and West Virginia.







Gift of Life Sessions & Resources



OUR LATEST OFFERINGS

Finding a Lifesaving Match: Strategies for Finding a Living Kidney Donor

January 10, 2024

- · Recording (coming soon)
- Slide Deck (coming soon)

Giving Life, Exploring Impact: Benefits and Considerations for Living Kidney Donors

December 6, 2023

- Recording
- Slide Deck
- Assistance Programs for Living Donors Handout

Pathway to Giving: Understanding the Living Kidney Donor Process

November 1, 2023

- Recording
- Slide Deck
- Transplant Center Registry Enrollment Guide

Advancements and Challenges in Kidney Transplant: Empowering Patients and Professionals

October 4, 2023

- Recording
- Slide Deck
- A Charles the Constraint of The The section of the sec















Care Conference











What have you been told about living

kidney donation:

- ? How to tell your story
- ? People who may be able to help find

living donors

- Ways to discover living donors?
- ? Organizations that may be able to help

find living donors



When to start the transplant discussion in dialysis?



As soon as possible, based on their readiness to learn.

- Anxious?
- General health?
- Independent?
- Family/support?
- Basic understanding of: kidney disease, dialysis, transplant (deceased and living)
- Misconceptions?
- Goals? (short term, long term related to family, quality of life, travel, pain, medications, hobbies, etc.)





Transplant is **not** a once-a-year discussion by one person

It takes a team.

It takes small, supportive steps.

Goals may change as understanding changes. Goals may change as health changes (better or worse).

What if you had resources for finding living donors? What if you had resources to help living donors?



This is an ongoing conversation...



Consider referring all patients for transplant

Would it be best for the patient if:

- Dialysis staff did not decide who is a good candidate for transplant.
- Patients were referred to the transplant team within the **first 2 months** of starting dialysis.
- Transplant centers communicated why they are not a good candidate and what it would take to help them be a good candidate.
- Goals were set based on changes needed to become a good transplant candidate.
- Goals were re evaluated monthly. When appropriate, refer back to the transplant team.

or transplant. Te **first 2 months**



Develop a Plan to Discuss the Best Treatment



Education Ideas

Introduce the idea that a living donor transplant is the best treatment for most people with kidney failure; benefits of transplant over dialysis. Acknowledge resistance. The goal is to help them fully

understand all the implications before making any decisions.

- Benefits of a living donor over a deceased donor kidney. •
- Ways kidneys can be donated. Kidney donor risk and benefits.
- Resources to help a living donor find them.
- Family meeting to discuss transplant.









FREE WEBINAR **FIRST STEPS TO TRANSPLANT & FINDING A LIVING DONOR**







Presentation? Website? Video Education? **T-Shirt? Car Decal?** Cards? **Jewish Faith?** Read a book? Veteran?

Involved in their community?

Kidneys for Communities

Put your kidney where your heart is.



FINDA KIDNEY.ORG®











LIVING KIDNEY DONATION FOR VETERANS





Thank you!



Kidney Donor Conversations www.MyKDC.org

Mission: To provide education and support for living kidney donation 501(c)(3) nonprofit

Glenna Frey, MSN, APRN-CNS

Executive Director

Glenna@MyKDC.org



What are the **barriers** to providing education about living kidney donor transplants to your patients and families?

Place answer in CHAT









What are Your Concerns?

Adrenal Glands and Fatigue Right or Left Nephrectomy?



"...the adrenal vein is usually transected during left-sided donor nephrectomy—which is not necessary on the right side—we hypothesized that venous congestion could lead to an impairment of adrenal function."

"In conclusion, left-sided living kidney donation entails a transiently reduced adrenocortical responsiveness, which returns to baseline after 28 days."

Burn, F, Schirpenbach, C, Bidlingmaier, M, Reincke, M, Vetter, D, Weishaupt, D, Brockmann, JG, Müller, MK, Weber, M, Dahm, F & Nocito, A. Left-Sided Living Kidney Donation Leads to Transiently Reduced Adrenocortical Responsiveness. Am J Transplant 2017; 17:1879–1884



Elizabeth Nuschke, RD Quality Improvement Specialist – Network 5 804-320-0004 ext. 2710 enuschke@qualityinsights.org



Evaluation and Post-Knowledge Check

- Link to the evaluation
 - https://www.surveymonkey.com/r/5Q75 YN9
 - Social Worker CEs approved from ASWB



QR Code

Activate the camera on your smart phone and scan this QR code to link to the evaluation



Kidney Donor Low eGFR or Albuminuria

Results

- 8.6 years
- 47 of 590 donors (8.0%) developed sustained low eGFR or moderate-severe albuminuria
- median time 2.9 years
- higher risk if pre-donation hypertension or post-donation diabetes

https://www.kidneymedicinejournal.org/article/S2590-0595(23)00185-1/fulltext?dgcid=raven jbs aip email#%20