

Searching for a **Living Kidney Donor**

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- All lines are muted
- Ask questions or make comments through the Chat Box
- Written questions will usually be answered at the end of the program
- You will receive the link to the **recording** and **slides** within a week
- Please complete the feedback form at the end of the program



Harvey Mysel

- ▶ Harvey is a 2-time kidney transplant recipient and started Living Kidney Donors Network a non-profit 501(c)3 org. to help those in need have a successful living kidney transplant experience. Harvey has helped hundreds through the transplant process.

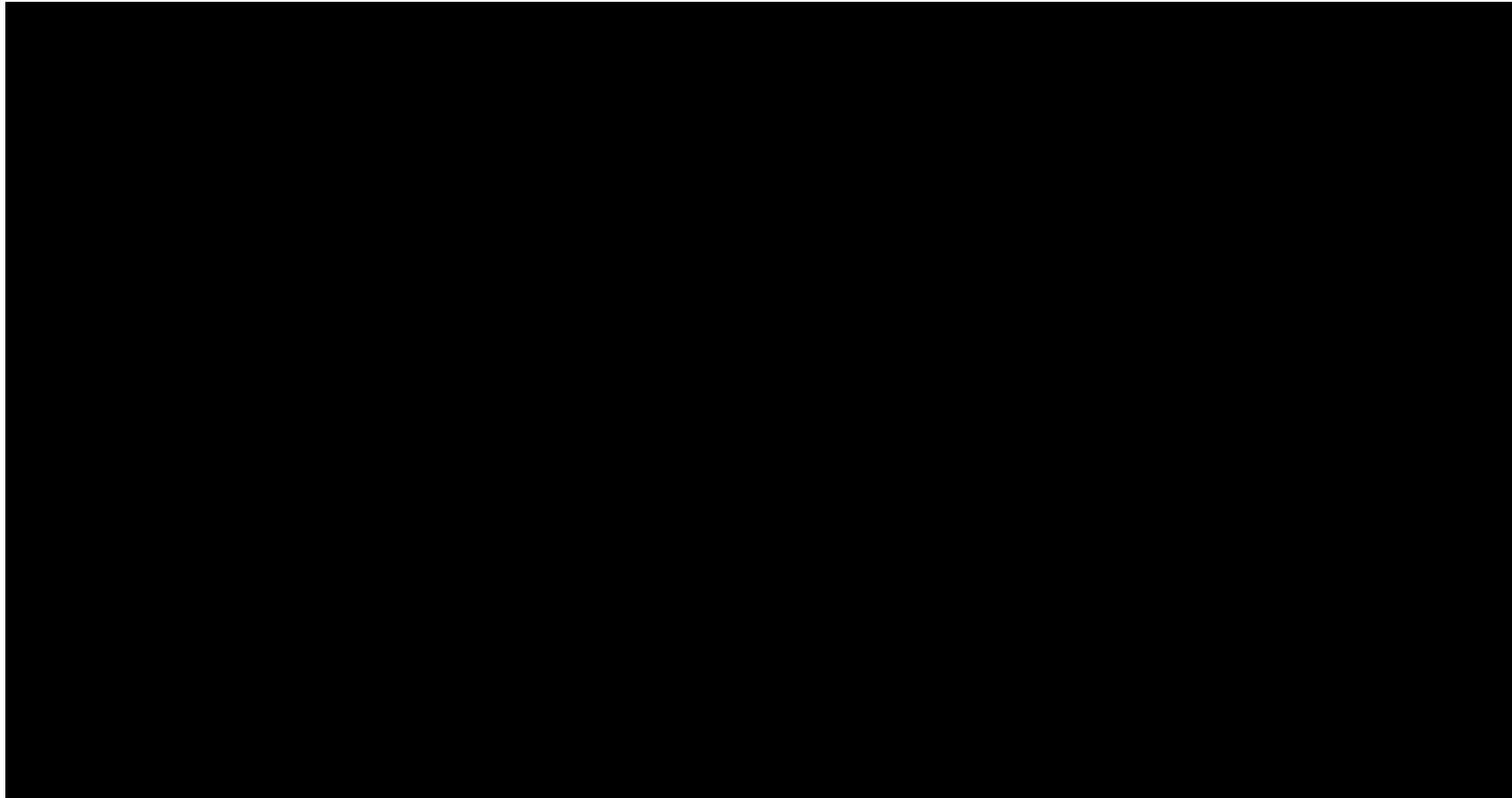


Searching for a Living Kidney Donor



- 1. Letting others Know About YOU!**
- 2. Sharing Your Story**
- 3. Having Advocates**

Having Your **Kidney** Donor Find YOU!
www.havingyourkidneydonorfindyou.org



- **We are hardwired for stories**
- **Donors Connect with Their Recipient**

Communicating Your Need

NOT asking someone to donate

Who Do I Tell...and How Often

Everyone... Everyday

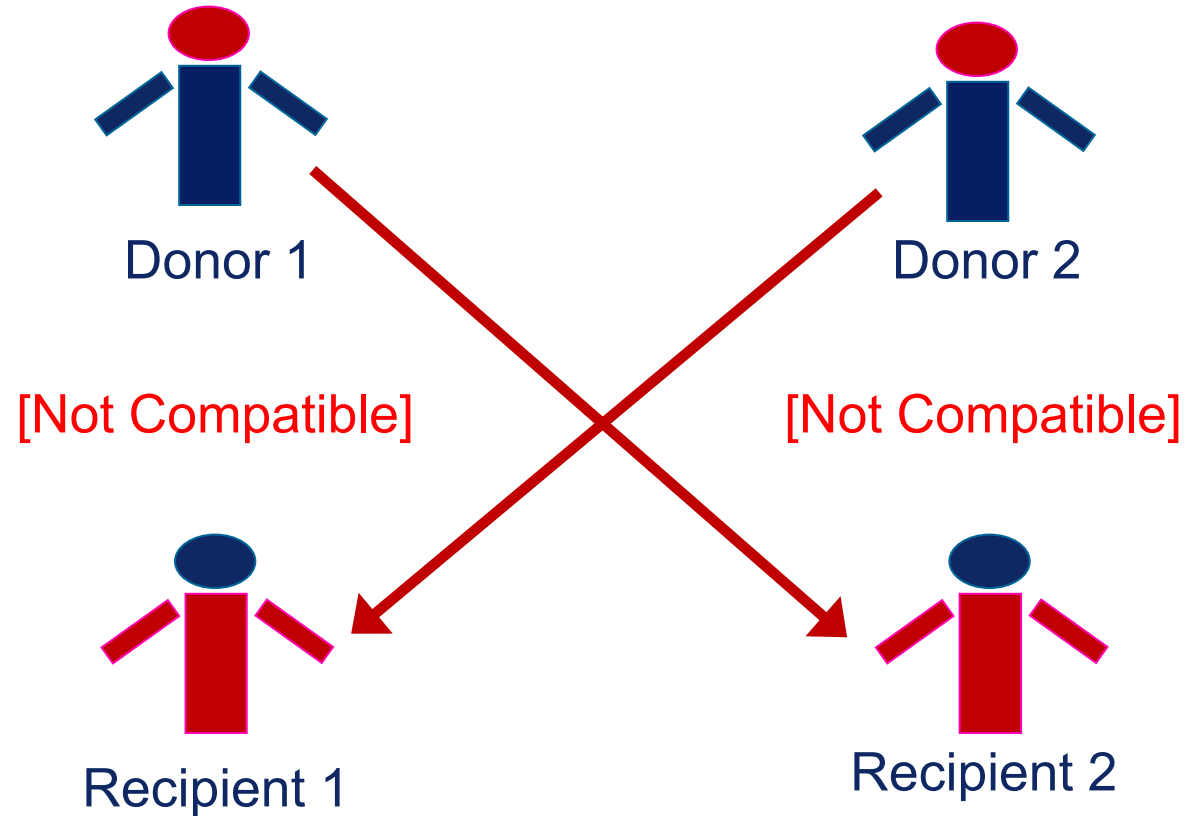
Myths and Misconceptions

- I Have 2 Kidneys because one is a spare
- I need 2 kidneys to have a normal life
- After donating a kidney I can't have children
- Living donors have to take anti rejection drugs
- Someone over 65 years old can't donate a kidney
- Matching is difficult, it's 1 in a Million
- People with tattoos can't be a kidney donor
- Marijuana users are unable to be a kidney donor

No Need To Share Your Blood Type

- Many don't know their blood type
- Others are mistaken about theirs
- Paired Exchanges

Paired Kidney Exchange



I'll keep it short

Harvey is a two-time kidney transplant recipient. After proactively managing an inherited kidney condition, PKD (Polycystic Kidney Disease) for over 20 years he had his first kidney transplant in February 2007. He was fortunate that his wife, Amy, was a compatible donor.

Harvey contracted a virus, (BK Virus,) 2 years after his transplant and in August 2012 had his second kidney transplant. He and his donor, Stephen Liegghio, who was introduced to Harvey by a mutual acquaintance, were involved in a 3-way kidney paired exchange. Following his first transplant, it became clear that the programs in place to increase the number of living kidney transplants were not reaching the people who needed it the most. In 7 of the past 9 years, the number of living kidney transplants has decreased. Something needs to be done to change this trend. Here are some of the programs that Harvey has facilitated since starting the LKDN: Harvey moderates the LKDN Workshops & Webinars, "Having Your Donor Find You." Over 1,500 people have participated in these programs in Illinois, Wisconsin, Texas, Michigan, California, Arizona and Massachusetts. Facilitated patient workshop and trained the transplant alumni at St. Luke's Cooley Transplant Center in Houston so they could facilitate future workshops. Guest speaker for TRIO Leadership Summit 2011 – Presentation, *"Following Your Passion, Making a Difference, One Life at a Time."* Facilitated a training program for Beaumont Hospital's peer mentors, social workers and nurses on how to present the living donation option to patients Since 2007 the National Kidney Foundation of Illinois has invited Harvey to speak about living donation during their "Preparing for Transplantation" seminars. Presented "Making a Difference in Living Kidney Transplantation" to The Society of Transplant Social Workers at their Annual Conference. Those attending received CE credits.

Fresenius and DaVita invited Harvey to present his training program to over 100 social workers. Guest panelist with Dr. John Friedewald & Dr. Joseph Leventhal of Northwestern Memorial Hospital on the WTTW "Chicago Tonight," a PBS station to discuss the recent changes in living kidney transplantation.

A PKD Foundation National Convention invitation since 2008 to be a guest speaker and moderator for their Living Donation Programs.

Wrote the cover story for the January 2010 issue of the AAKP, (American Association of Kidney Patients,) magazine Renalife, "It's About Your Donor Finding You!" UNOS, (United Network for Organ Sharing) invited Harvey to give a presentation to their Transplant Coordinators Committee Meeting on Living Kidney Donation. Contributor for the PKD Foundation "Progress" magazine in the "Ask The Experts" transplant alumni at St. Luke's Cooley Transplant Center in Houston so they could facilitate future workshops. Guest speaker for TRIO Leadership Summit 2011 – Presentation, *"Following Your Passion, Making a Difference, One Life at a Time."* Facilitated a training program for Beaumont Hospital's peer mentors, social workers and nurses on how to present the living donation option to patients Since 2007 the National Kidney Foundation of Illinois has invited Harvey to speak about living donation during their "Preparing for Transplantation" seminars. Presented "Making a Difference in Living Kidney Transplantation" to The Society of Transplant Social Workers at their Annual Conference. Those attending received CE credits.

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Use Bullets Instead of Paragraphs

I Need a Kidney Transplant:

- A kidney from a living donor is my best option
- Wait for a deceased donor is 5-10 years
- Kidney from a living donor lasts twice as long...
- I need to avoid or stop dialysis
- I want to....

- Often make the donor/recipient connection
- See opportunities that others don't
- Help navigate the "system"
- The Best Advocate is...

Who To Tell Your Story To

Different Groups To Reach Out To

- Family Members & Friends
- Email & Social Media
- Meeting People Every Day
- Getting Creative

Who To Tell Your Story To

Different Groups To Reach Out To

- **Family Members & Friends**
 - Write out your story
 - Include contact info for hospital's Donor Advocate
 - Include a photo or video
 - Local Media, Schools, Religious Groups, Reunions
 - www.google.com/alerts

Who To Tell Your Story To

Different Groups To Reach Out To

- **Email & Social Media etc.**
 - Email, Facebook Twitter etc.
 - How Often Should send email or Post?
 - Tuesdays with Harvey
 - Facebook page & website

Who To Tell Your Story To


Different Groups To Reach Out To

- **Meeting People Every Day**
 - Hi Harvey, how are you?
 - It's an Everyday life Experience
 - Short lived opportunity
 - Practice!


Who To Tell Your Story To

Different Groups To Reach Out To

- **Getting Creative**



LivingKidney
DONORS NETWORK
Life Donated...Multiplies Life



Harvey Mysel
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I have kidney disease and in need of a kidney transplant. The wait for a deceased donor kidney can be more than 5 years. I'm actively pursuing a kidney from a living donor. Kidneys from living donors can last twice as long as one from a deceased donor.

Someone in good health, i.e. no uncontrolled hypertension, diabetes etc. is able to donate.

To learn more about my situation contact me or visit the website:
harveyskidneycampaign.com You could also call Jami Hanneman, 312-695-0828 the donor transplant coordinator at Northwestern Memorial Hospital.

Thank you,
Harvey

www.facebook.com/
LivingKidneyDonorsNetwork





Standing on a Busy Corner





Sign in Front of House



Sign in Front of House









Blip Billboard: www.blipbillboards.com/



**PLEASE HELP
MY HUSBAND FIND
A KIDNEY**




LivingKidney
DONORS NETWORK

www.LKDN.org





That's Creative



https://www.youtube.com/watch?v=LQPJyY_IzZw



Who To Tell Your Story To

Being Creative!

Craigslist Ads

Search:

“Craigslist ad I need a kidney transplant”

Similar Experience – Job Hunting

- Reality of your Situation – Develop a Plan
- Research Options
- Learn about those Options
- Write out Your Story (*Write a Resume*)
- Networking (*Rock Star in an Elevator*)
- Tell Your Story (*Like a Job Interview*)

Practicing



Communicating Your Need

... more ideas:

- Imitation is the sincerest form of flattery
- Volunteer!!!! Volunteering will allow you to meet new people. Help others and you will help yourself.
- Fraternal and Religious Organizations
- Meet Ups

“The Harder I Work the Luckier I Get”

Thomas Jefferson and Samuel Goldwyn

Top Three Takeaways:

- Learn as Much as you can about Living Donation
- Find Advocates – Friends and Family Members
- **Tell Everyone About Your Situation!**

There's a kidney out there for you!



Harvey Myself
Living Kidney Donors Network
a Nonprofit 501(c)3 Organization

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312-473-3772

Questions?

Please use the Chat Box



Thank You for Attending Today!

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the Feedback Form**

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session, Goals for Home Dialysis**

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