

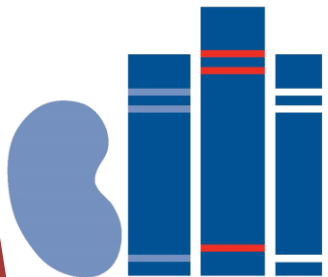
# Having Your Donor Find YOU!

This webinar will start shortly. The slides and the webinar recording will be available at [www.dpcedcenter.org](http://www.dpcedcenter.org)

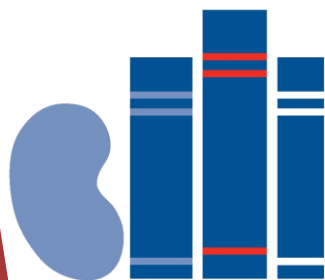
Next webinar: March 19th

# Reminders

- All phone lines are muted
- **Unmute: #6** to ask questions
- **Mute: \*6** after your question
- Or, ask questions through the Chat Box
- You will receive the link to the **recording** and **slides** by email
- Please complete the feedback form at the end of the program

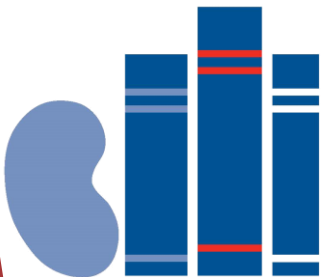


# Today's Presenter



# Section I: Knowing the Basics

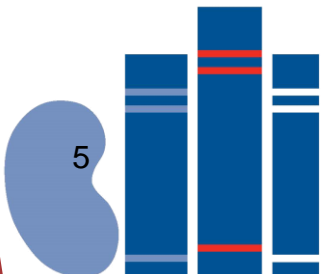
## Knowledge Builds Confidence



# Living Kidney Donors Network

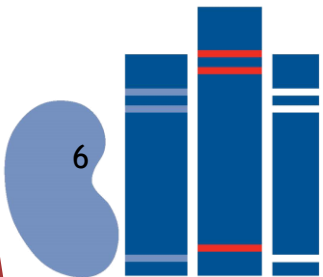
## Disclaimer

The information provided during this presentation should be used as a resource only and is not intended to be used as medical advice. Although every reasonable effort is made to present current and accurate information no guarantees of any kind to its accuracy is made. Any links to Web sites are provided as a courtesy. They should not be construed as an endorsement by the Living Kidney Donors Network or Donor to Donor of their accuracy, content or views.



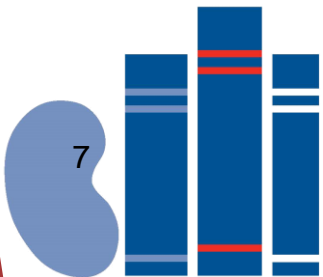
# Myths and Misconceptions

- I Have 2 Kidneys because one is a spare
- I need 2 kidneys to have a normal life
- Someone over 65 years old can't donate a kidney
- Matching is difficult, it's 1 in a Million

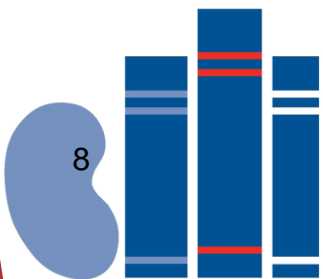
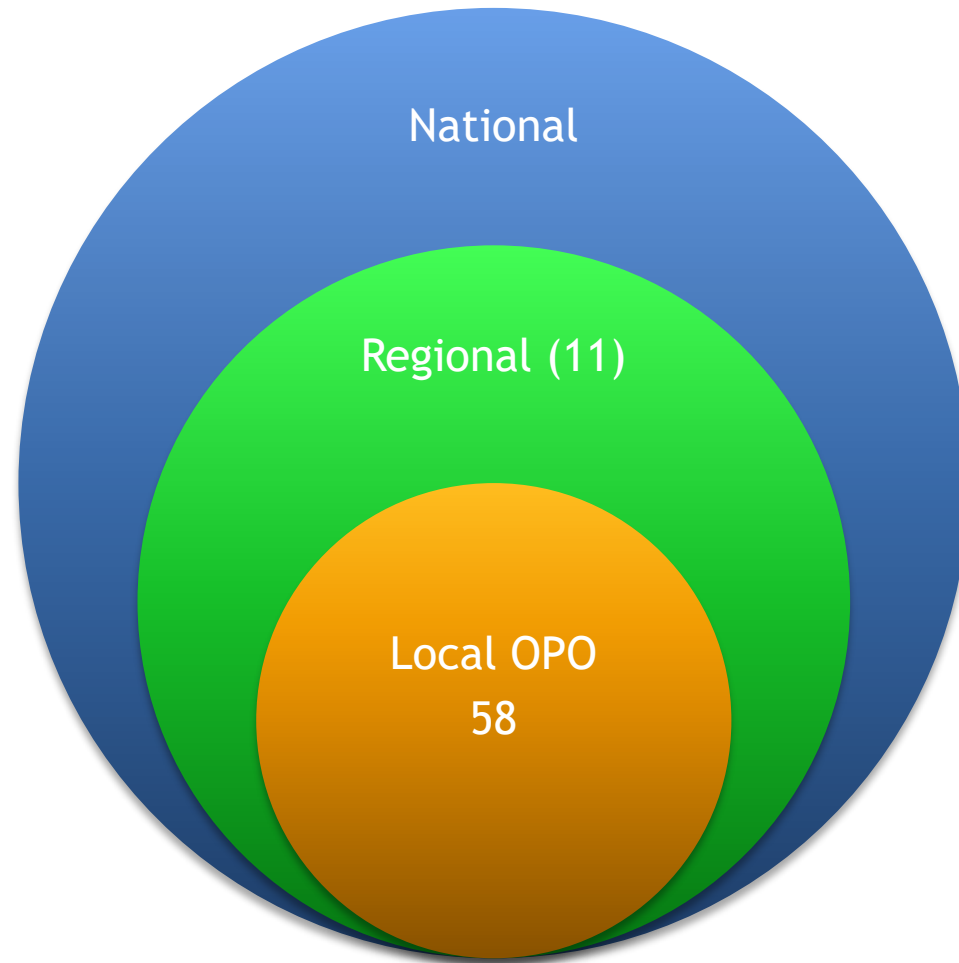


# Transplant Waiting List

- ▶ ALL Organs - 110,000 people
- ▶ Kidneys – 95,000 people
- ▶ Number of Dialysis Patients – 500,000+-
- ▶ Not All Waiting Lists Are The Same



# Distribution of Deceased Donors



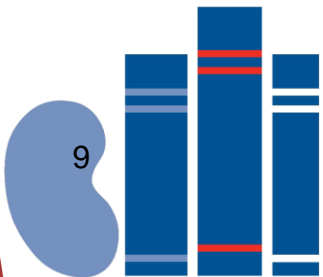


# Kidney Transplant Statistics

23,401 Kidney Transplants in 2019

16,534 Deceased Donors Transplants

6,867 Living Donor Transplants

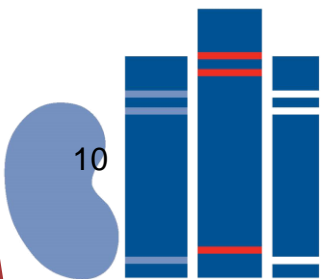


# National Deceased Donor Statistics

Recently there have been MORE Deceased Donor  
Kidney Transplants

70,000 drug overdose deaths  
Double the number from 10 years ago

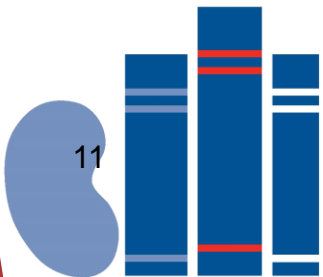
Hepatitis C infected organs  
Recently have more than tripled to  
1,500 a year



# National Living Kidney Donor Statistics

Recently there have been **MORE** Living  
Donor Kidney Transplants

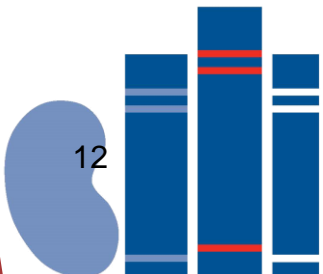
Mostly from Paired Exchanges



# What about Matching?

Is it difficult to find a Match?

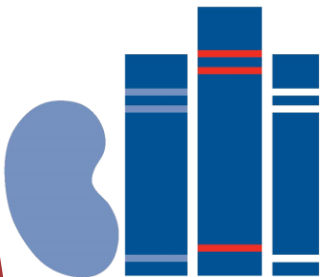
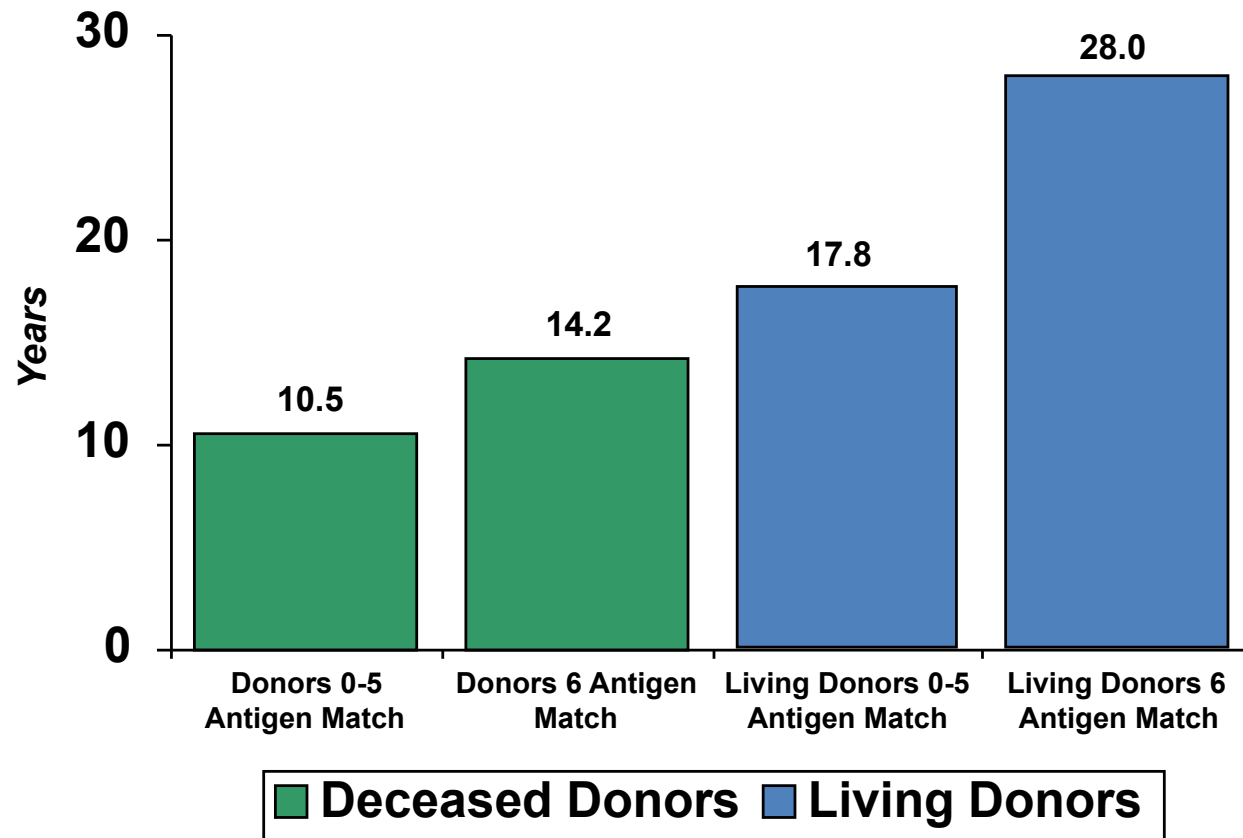
- ▶ Suitable and Compatible
- ▶ PRA: Panel Reactive Antibodies
- ▶ Cross Match
- ▶ HLA - Human Leukocyte Antigen / Tissue Typing (Traditionally Known as Matching)



# Transplanted Kidneys Expected Lifespan

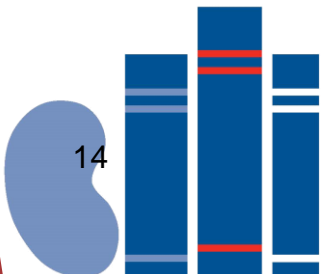
## Kidney Transplants

The point in time when exactly 50% of kidneys are still functioning

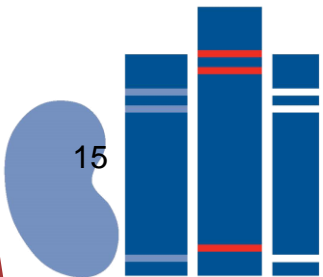
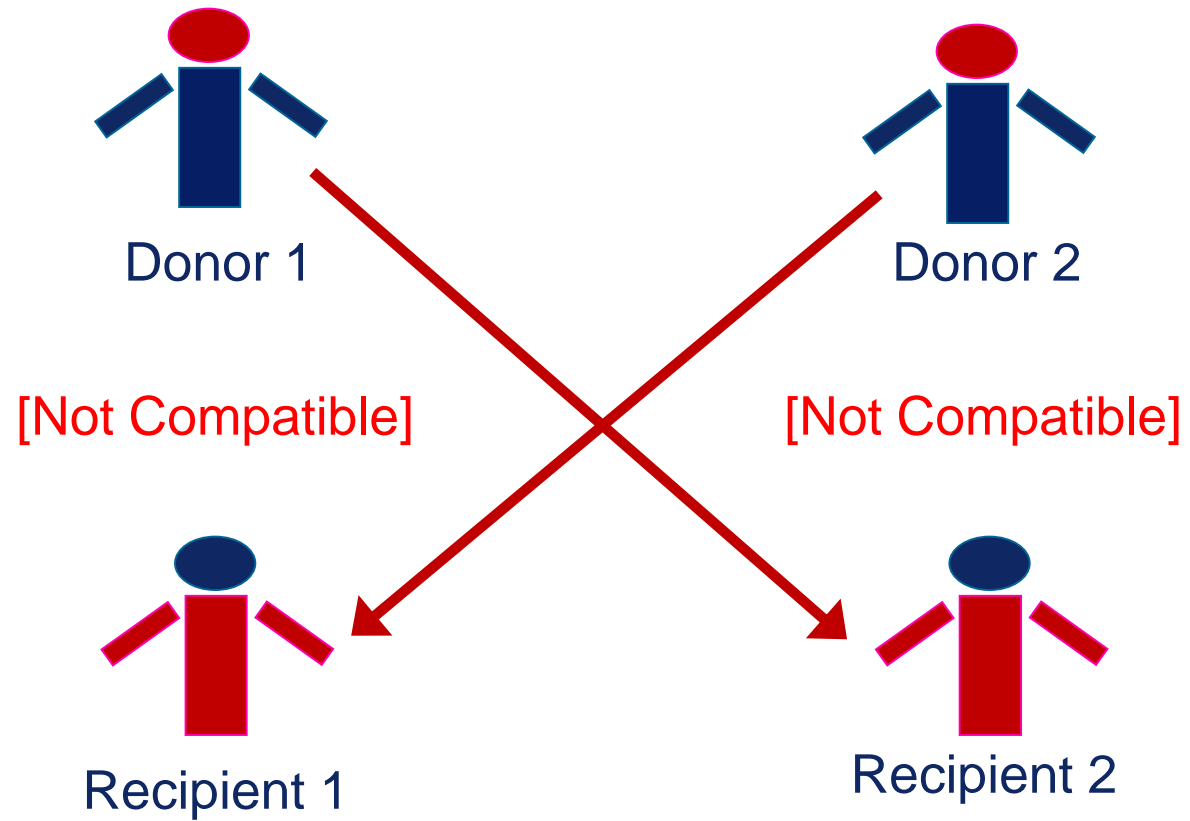


# Living Donor Transplant Options

- ▶ Related
- ▶ Non Related
- ▶ Non Directed Donor (Altruistic)
- ▶ Paired Exchanges (Swaps)

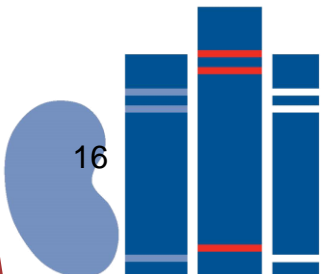


# Paired Kidney Exchange



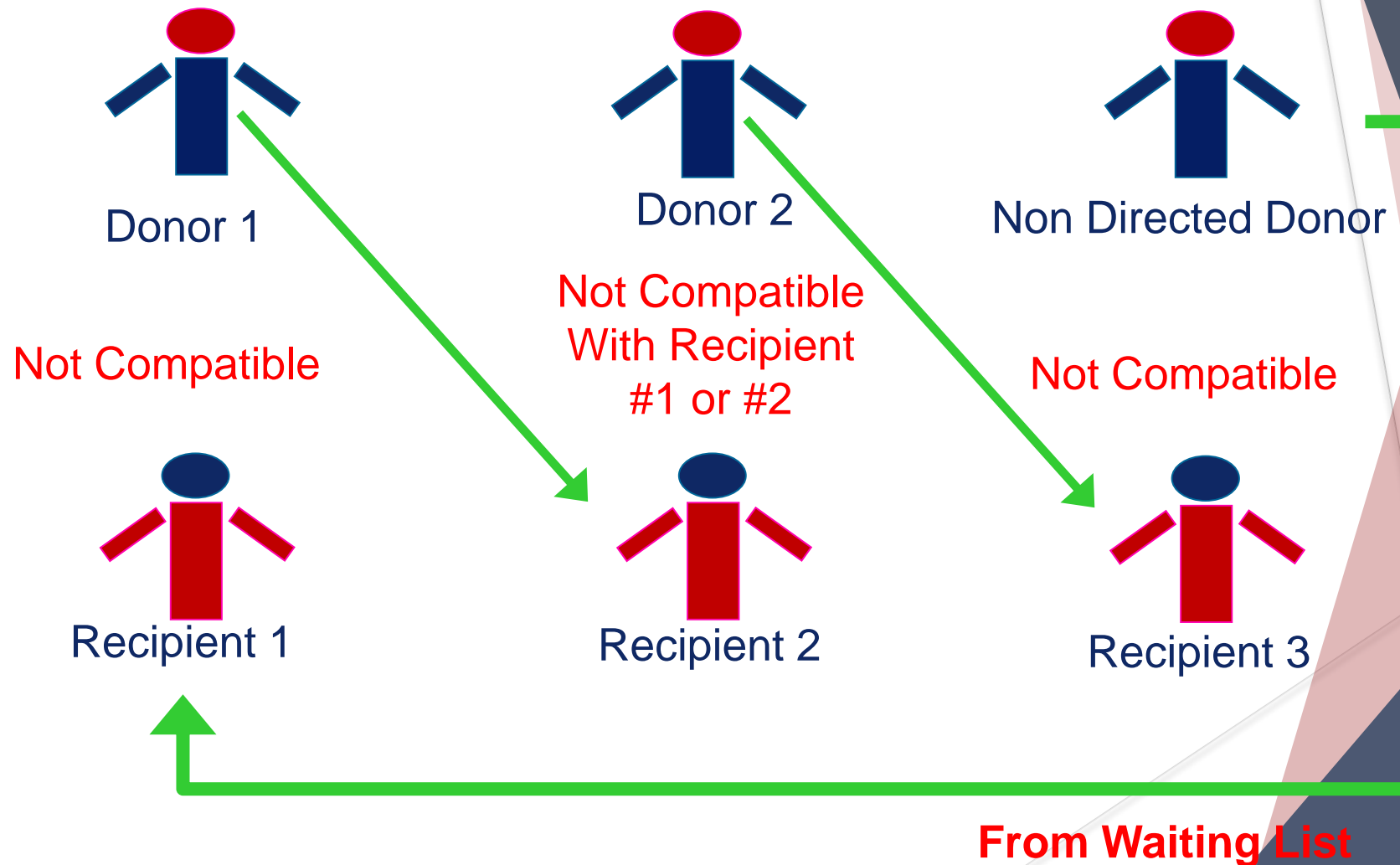
# Living Donor Transplant Options

- ▶ Related
- ▶ Non Related
- ▶ Non Directed Donor (Altruistic)
- ▶ Paired Exchanges (Swaps)
- ▶ **Domino Paired Kidney Exchange (Closed)**



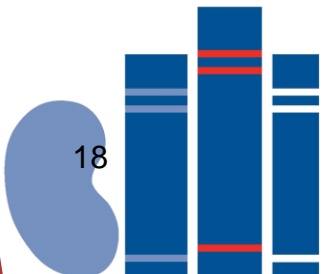


# Domino Paired Exchange

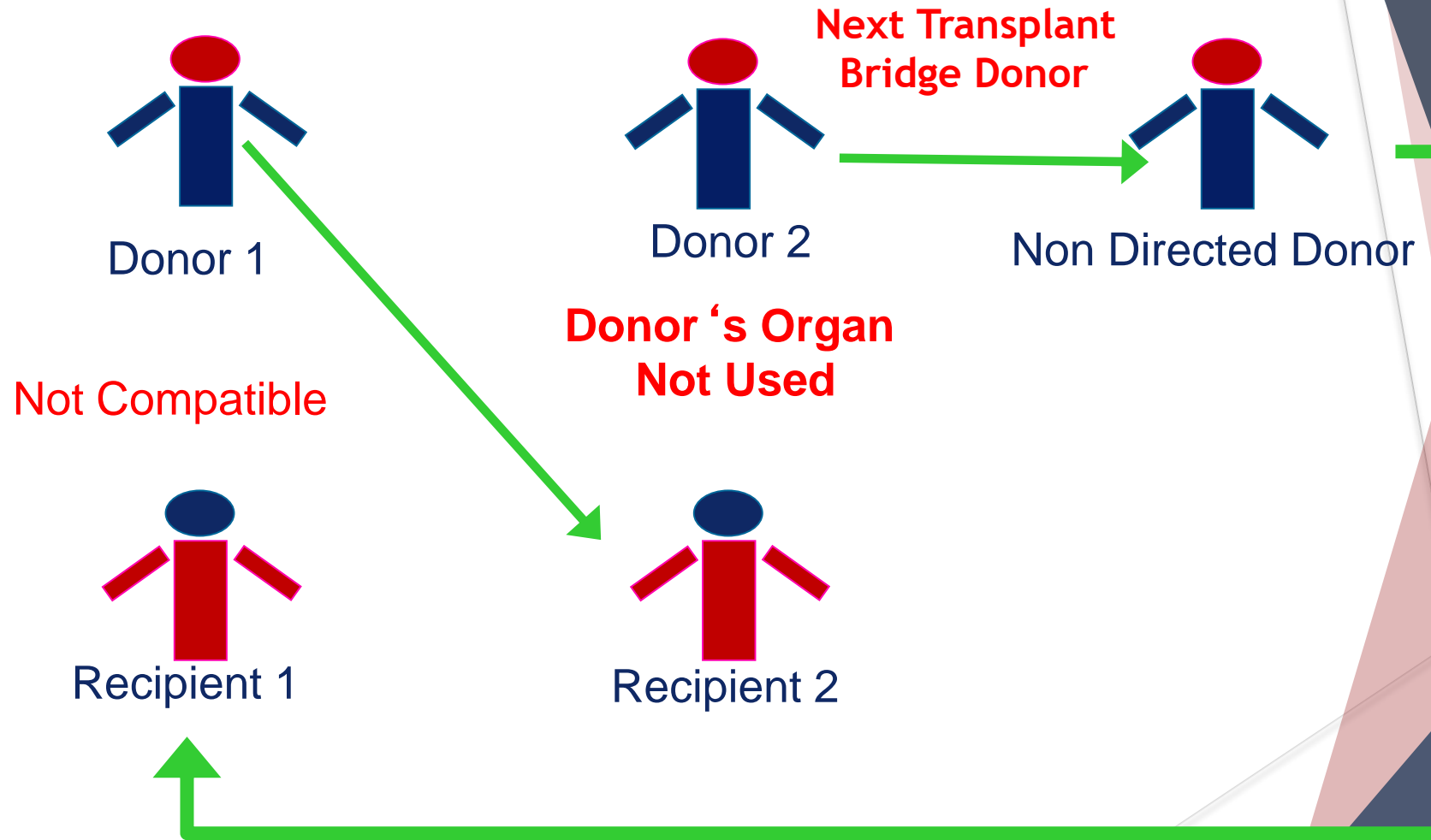


# Living Donor Transplant Options

- ▶ Related
- ▶ Non Related
- ▶ Non Directed Donor (Altruistic)
- ▶ Kidney Paired Donation (Swaps)
- ▶ Domino Paired Kidney Exchange (Closed)
- ▶ Ongoing Paired Exchange (Chains)

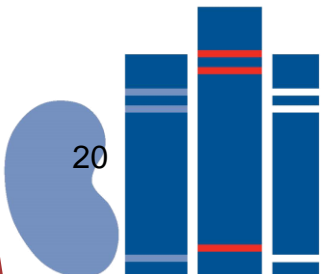


# Never Ending Donor Chains



# Living Donor Transplant Options

- ▶ Related
- ▶ Non Related
- ▶ Non Directed Donor (Altruistic)
- ▶ Kidney Paired Donation (Swaps or Chains)
- ▶ Domino Paired Kidney Exchange
- ▶ Ongoing Paired Exchange
  - ▶ **Paired Exchange Conundrum**
    - ▶ [http://lkdn.org/Paired\\_Exchange\\_Conundrum/index.pdf](http://lkdn.org/Paired_Exchange_Conundrum/index.pdf)



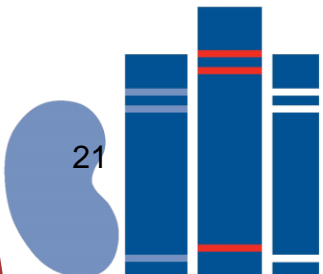
# National Kidney Registry

Affiliated centers:

<https://www.kidneytransplantcenters.org/>

Leader in protections for donors, i.e. family voucher program, reimbursement lost wages:

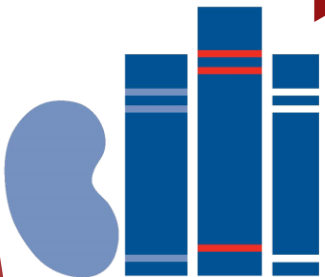
<https://www.donorcarenet.org/donor-shield/>



# Financial Support

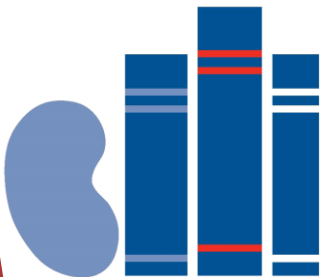
If You Can Provide Financial Support Include That in Your Story (You could fundraise)

- ▶ Go Fund Me [www.gofundme.com](http://www.gofundme.com)
- ▶ Sources of Financial Support
  - ▶ NLDAC (National Living Donor Assistance Center)
    - ▶ [www.livingdonorassistance.org](http://www.livingdonorassistance.org)
- ▶ Listing of Additional Financial Resources
  - ▶ <http://www.lkdn.org/financial-assistance/index.html>



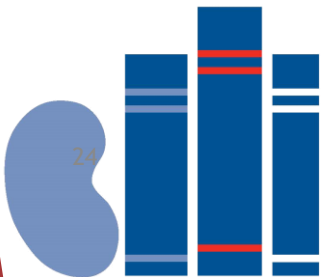
## Section II

# Power and Importance of Communication



# Story Telling

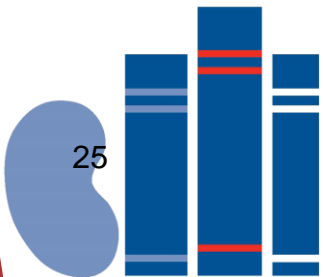
We are hardwired for stories





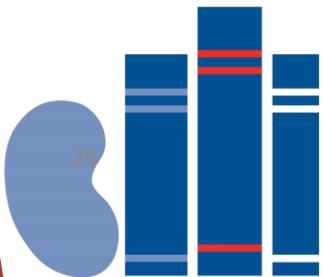
# Communicating Your Need

**NOT asking someone to donate**



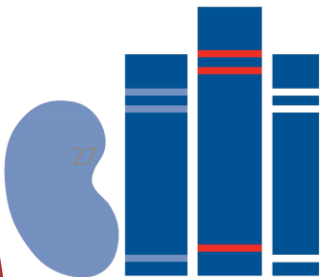
# Who Do I Tell...and How Often

**Everyone... Everyday**



# My Story

I'll keep it short



# My Story

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.

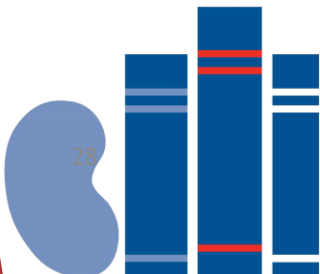
A PKD Foundation National Convention invitation since 2008 to be a guest speaker and moderator for their Living Donation Programs.

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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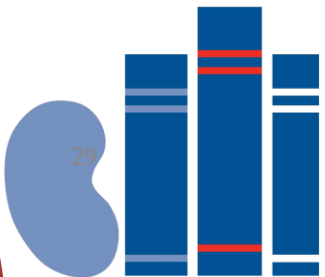


# For Your Story

## Use Bullets Instead of Paragraphs

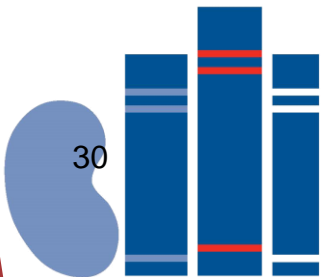
### I Need a Kidney Transplant:

- ▶ 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....



# Advocates

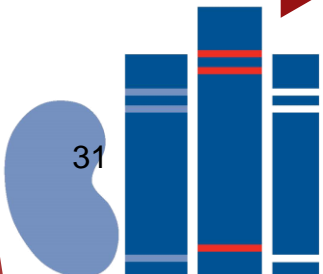
- ▶ Often make the donor/recipient connection
- ▶ See opportunities that others don't
- ▶ The Best Advocate is...



# Who To Tell Your Story To

## Different Groups To Reach Out To

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

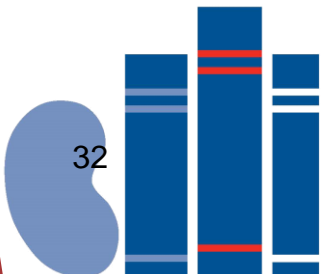


# Who To Tell Your Story To

## 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](http://www.google.com/alerts)

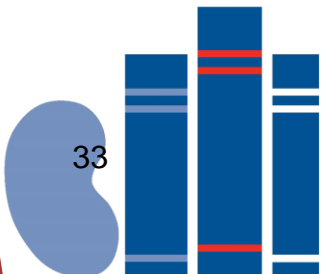




# Who To Tell Your Story To

## Different Groups To Reach Out To

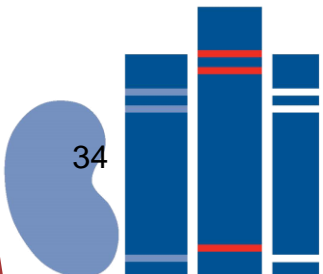
- ▶ **Email & Social Media etc.**
  - ▶ Email, Facebook Twitter etc.
  - ▶ How Often Should send email or Post?
  - ▶ Tuesdays with...update
  - ▶ Facebook page & website



# Who To Tell Your Story To

## Different Groups To Reach Out To

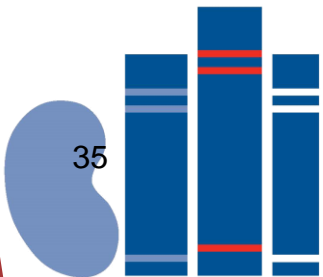
- ▶ **Meeting People Every Day**
  - ▶ Hi Harvey, how are you?
  - ▶ It's an Everyday life Experience
  - ▶ Short lived opportunity
  - ▶ Practice!



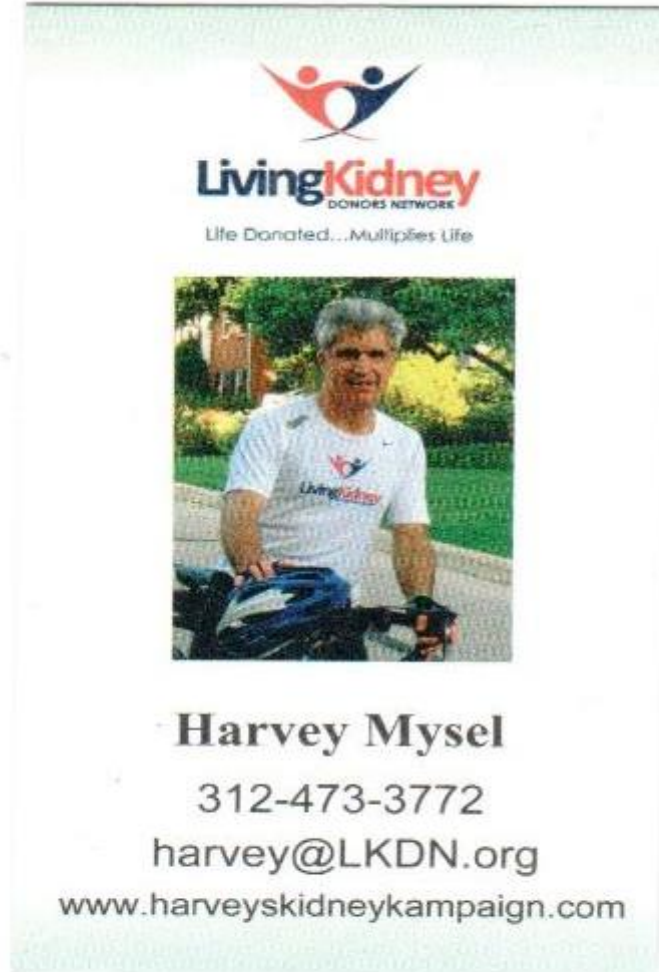
# Who To Tell Your Story To

## Different Groups To Reach Out To

### ► Getting Creative



# Business Card



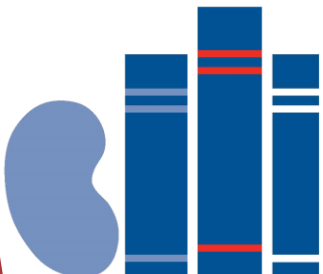
I have kidney disease and in need of a kidney transplant. The wait for a deceased donor kidney can be more than 5 years. I'm actively pursuing a kidney from a living donor. Kidneys from living donors can last twice as long as one from a deceased donor.

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.

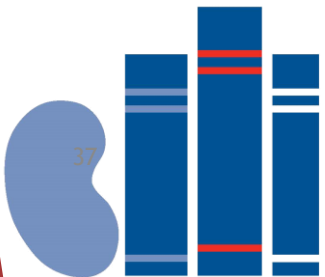
Thank you,  
**Harvey**

[www.facebook.com/  
LivingKidneyDonorsNetwork](http://www.facebook.com/LivingKidneyDonorsNetwork)



# Other Ideas

- ▶ Car sign
- ▶ Holding a sign on a busy corner
- ▶ Sandwich board
- ▶ Sign in front of house
- ▶ T-shirt
- ▶ Billboard sign



## Next Door





# That's Creative



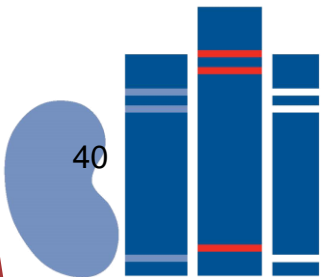
# Who To Tell Your Story To

Being Creative!

**Craigslist Ads**

**Search:**

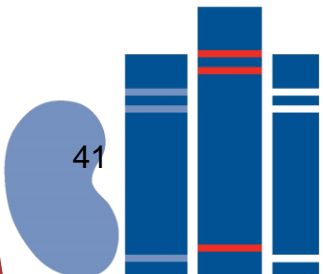
***“Craigslist ad I need a kidney transplant”***





# 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*)



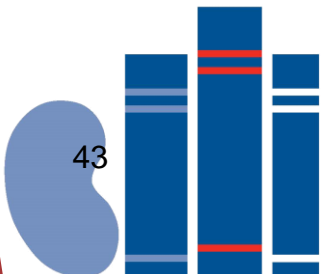
# Practicing



# Communicating Your Need

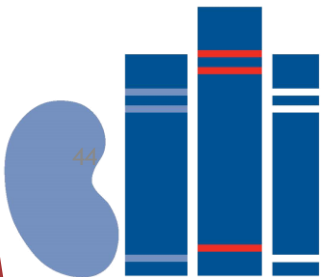
... more ideas:

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



# No Need To Share Your Blood Type

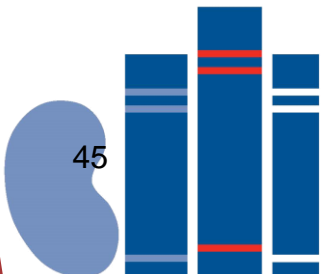
- ▶ Many don't know their blood type
- ▶ Others are mistaken about theirs
- ▶ Paired Exchanges
- ▶ Blood type incompatible
- ▶ Plasmapheresis



# YOU CAN DO IT!!!



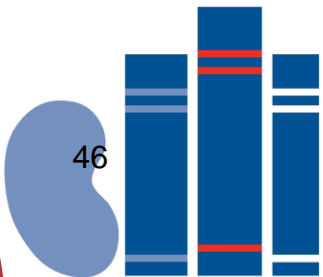
There are 18 Living Kidney Transplants EVERY  
DAY!!



# Being Lucky!

## **“The Harder I Work the Luckier I Get”**

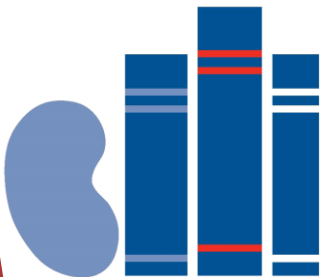
*Thomas Jefferson and Samuel Goldwyn*



# Review

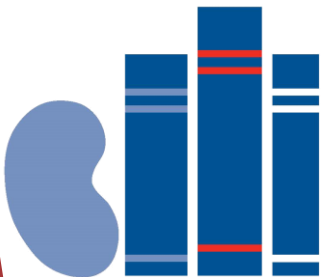
## Top Three Takeaways:

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



# Closing

**There's a kidney out there for you!**





# Questions?

Chat box or unmute phone line #6

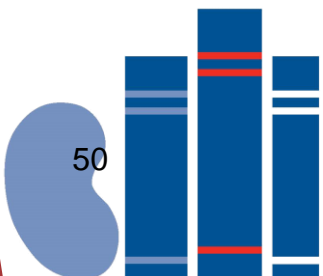




Life Donated...Multiplies Life

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

[www.LKDN.org](http://www.LKDN.org)  
[harvey@LKDN.org](mailto:harvey@LKDN.org)  
312-473-3772



# Thank You for Attending Today!

Please complete the  
Feedback Form



Join us on **March 19<sup>th</sup>** for our  
next webinar!

