



Living Kidney
DONORS NETWORK
Life Donated... Multiplies Life

Living Kidney Donors Network Webinar
Having Your Donor Find You! &
Developing Your Kidney Campaign
November 3rd & 4th 2014



Our Goals for Today


- Introduce you to the Living Kidney Donors Network.
- Provide you with an Overview of Living Donation
- Help you develop a Kidney Campaign to communicate your need.



Living Kidney Donors Network



Disclaimer

The information provided by the Living Kidney Donors Network 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 of their accuracy, content or views.



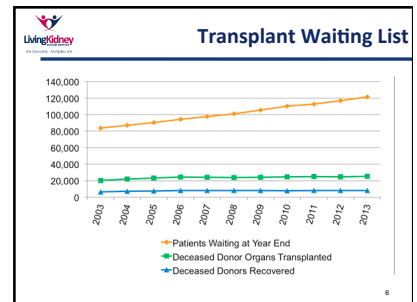

Section 1: Knowing the Basics

Knowledge Builds Confidence

Transplant Waiting List


- ALL Organs - 124,00 people
- Kidneys – 102,000 people
- Kidney Dialysis Patients – 400,000+
- Not All Waiting Lists are Equal
– <http://www.srtr.org/sr/current/Centers/TransplantCenters.aspx?organcode=K>

Know the Statistics

Statistical Info: www.unos.org www.srtr.org

- Kidney Survival Rates
- Most People Starting Dialysis are Good Candidates for a Kidney Transplant
- 15 People from the Kidney Waiting List Die Every Day
- In 2014 there were 16,895 kidney transplants




Statistics

Kidney Transplants 2013 – 16,895

Statistical Info:

- Deceased Donor Transplant - 11,163
- Living Donor Transplants – 5,732

Deceased Kidney Transplants lower in 4 of last 9 Years
Living Donations lower in 7 of last 9 Years



Benefits:
Living vs. Deceased Donation

- Short & Long Term Survival Rates
- Know Your Donor & Their Health History
- New Kidney Functions Immediately
- Avoid Being on Dialysis...Pre-emptive Transplant
- Cost Savings for Medicare and Private Insurance

Donor/Recipient Evaluation

- Age Requirement
- No National Health Standard
- How Many Donors at One Time
- How Long Does the Evaluation Take?
- How are Out of Towners Evaluated

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Donor Evaluation and Potential Risks

- First Do No Harm
- Anticipated and Unanticipated Surgical Complications
- Patient Pain, Fatigue, or Discomfort
- Long Term Risks - High blood pressure, loss of kidney function and unforeseen complications
- Donor Follow Up

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Donor Insurance etc.

- Many hospitals require insurance for donor
- You can purchase a catastrophic policy
American Foundation for Donation & Transplantation
- Donors Future for Health Insurance & Life Insurance

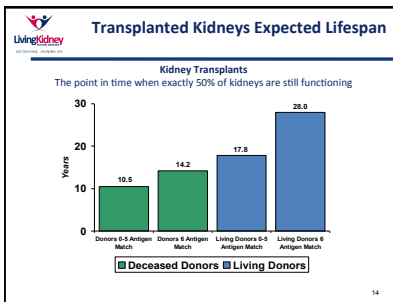
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What about Matching?

Isn't it difficult to find a Match?

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

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Blood Type Compatibility

Donor Blood Type	Can Donate to	Recipient Blood Type
O (45%)	→	A, B, AB, O
A (40%)	→	A or AB (O)
B (11%)	→	B or AB
AB (4%)	→	AB

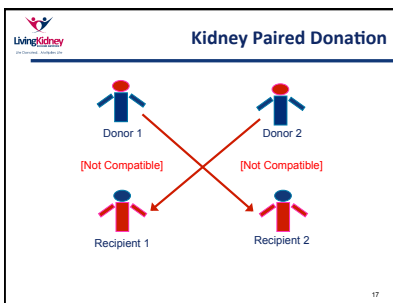
Blood Type O is the Universal Donor
Blood Type AB is the Universal Recipient
+ & - Are Not a Factor

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Living Donor Transplant Options

- Related (2002 – 77% vs. 2012 – 53%)
- Non Related
- **Kidney Paired Donation (Swaps or Chains)**

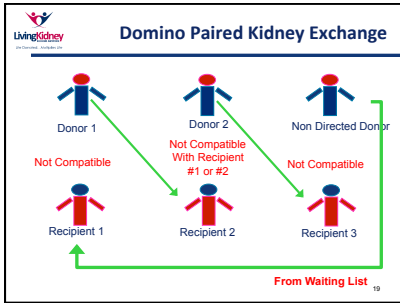
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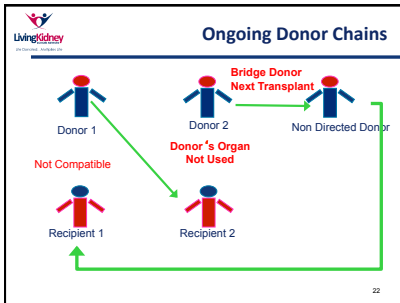
Living Donor Transplant Options

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- Non Directed Donor
- **Domino Paired Kidney Exchange**

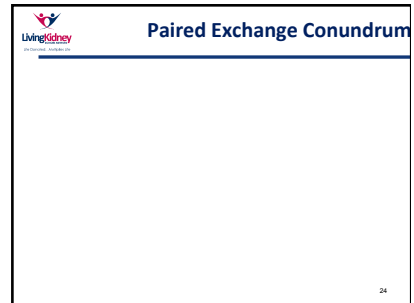
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 - Non Related
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 - Non Directed Donor (NDD)
 - Domino Paired Kidney Exchange
 - Ongoing, Chains, Never Ending KPD's



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 - Compatible Paired Exchanges



- ### Paired Exchange Conundrum
- National Kidney Registry
 - UNOS
 - Alliance for Paired Donation

- ### More Info
- I Have a Donor!
 - Changes in the Deceased Donor List
 - Donor & Medical Advocates
 - Dental Health
 - Paying Donors to Donate?
 - Reimbursing Donors

- ### National Foundation for Transplants
- Financial Assistance Through Fundraising and Grants
 - Fundraising Training and Guidance
 - Receive a Personal Page on the NFT Website
 - www.transplants.org or (800) 489-3863

Alphabet Soup


Don't be Intimidated by Doctors and Nurses

- ABO – Your Blood Type
- SCD – Standard Criteria Donors
- ECD – Extended Criteria Donors
- DCD – Donation After Cardiac Death
- HLA – Human Leukocyte Antigens
- PRA – Panel Reactive Antibodies
- DJN – **Don't Just Nod**

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Section 2

Power and Importance of Communication



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Developing Your Kidney Campaign

We'll Review:

- Concerns.....Overcoming Them.
- How to tell "Your Story" ...Preparation
- How Advocates can tell Your Story
- "Elevator Speeches"
- Social Media, Networking, Meeting New People

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Your Kidney Campaign

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Your Kidney Campaign

How Do I Ask Someone to Donate?

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Your Kidney Campaign

Developing a Strategy:

- Not asking anyone to Donate: **"Tell Your Story"**
- Learn about Living Donation and Your Condition
- Send out regular updates to Friends and Family
- Similar to Looking for a job

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Handout/Flyer/Business Cards

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Your Advocate(s)

Advocate: *Supporter that appeals on your behalf.*

- Educate your advocate(s). Share material.
- Some can be more direct with people.
- Keep them up to date on your progress, medical, personal, monthly emails with info and articles, etc.
- The Best Advocate is...

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NDD CAMPAIGN

LKDN & NDD Campaign

- Educating the Public about Living & NDD
- Fraternal Organizations - Rotary, Kiwanis, Chambers of Commerce etc.
- Religious Organizations

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Your Kidney Kampaign

How to Educate Others

People want to help – share *your story* and be visible. Consider:

- Newspapers, TV and radio stations (List online)
- Schools, Churches, Reunions
- When Someone Asks....What Could I Do To Help...
- Letters to the Editor
- Facebook, email, blogs, Twitter....etc.

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Your Kidney Kampaign

- Facebook and other Social Media Sites
- Web Page

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Your Kidney Kampaign

Be Creative:

- Write out your Story
- www.Google.com/alerts
- www.LKDN.org/attachments.html
- CraigsList, Matchingdonors.com Konnectology.com
- T-Shirts, Flyers, Signs, Billboards, Penny Saver
- Get Creative...

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Your Kidney Kampaign

Talking Points:

- I have a kidney disease that....
- I've been on dialysis....or I want to avoid....
- The wait for a deceased donor is....
- My best option is a transplant from a living donor, on average they last twice as long...
- Most healthy people can donate...
- You are not “asking” someone to donate!

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Sample Scenario

You are at a party in a friends house and you see someone you know - but have not spoken to recently and is probably unaware of your situation.

How would you let this person know about your need for a transplant?


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Your Kidney Kampaign

What would you say in this situation.

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Practice



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Being Lucky!

“Luck Happens When Preparation Meets Opportunity”

Seneca, a Roman philosopher


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Creating Your “Elevator Speech”




- You have 1 - 2 minutes to convey your message
- **Preparation**
- If they want more information, go further

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 **Supporting Documents**

- www.LKDN.org/webinar
- Evaluation Form
- Links are at the bottom of page
 - Copy of this Presentation
 - Articles of Interest
 - Other Documents Referenced
- LKDN FB, Newsletter, Tuesdays with... updates
- LKDN "Get-Togethers"


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 **Review**

Top Five Take Aways:


- Learn as Much as you can about Living Donation
- The Waiting List is NOT the only Option
- Donor Matching has Changed - Its become easier
- Kidney Paired Donations – Incompatible Donors
- Social Media Letting People Know about Your Condition

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 **Keys to Success**

- Staying Motivated
- Building Knowledge
- Continue to Reach Out


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 **Closing**

- Q & A?
- Let us know how we can help you

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