



**Living Kidney Donors Network
Workshop
July 21, 2010**



Our Goals for Today

- Introduce you to the Living Kidney Donors Network.
- Provide you with an Overview of Living Donation
- Help you communicate your need to Family Members and Friends.
- Learn why you are attending and hear your Goals.

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Introductions

What do you hope to get from today's program?

1. Where are you in the process?
2. What is your biggest hurdle?
3. What is your favorite movie?

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Program Outline

Section 1

- Provide an Overview of Living Donation

Section 2

- Help you - and your Advocates - communicate your need to Family Members and Friends.

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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.

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Section I: Knowing the Basics

Knowledge Builds Confidence



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Being Lucky!

“Luck Happens When Preparation Meets Opportunity”

Seneca, a Roman philosopher

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Brief History of Kidney Transplants

- **1954** – 1st Successful Transplant, 23 yr old identical twins
- **1960's** – Only **Living Donations** were performed. Immunosuppressive drugs became available.
- **1983** Cyclosporine Approved for Transplants
- **1984** - Congress passed the National Organ Transplant Act (NOTA).
- **1995** –Laparoscope Procedure for Living Donors
- **2007** – Paired Kidney Exchanges legally allowed.

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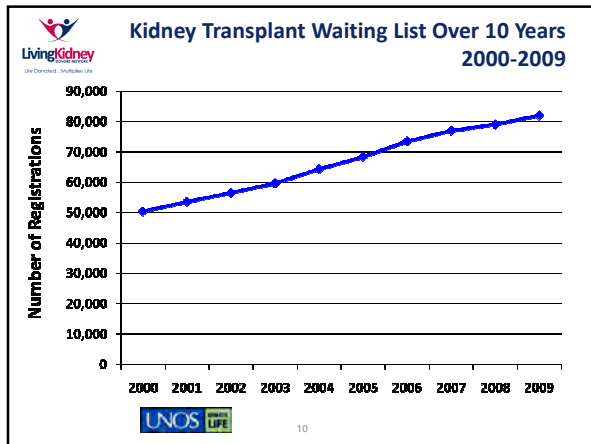


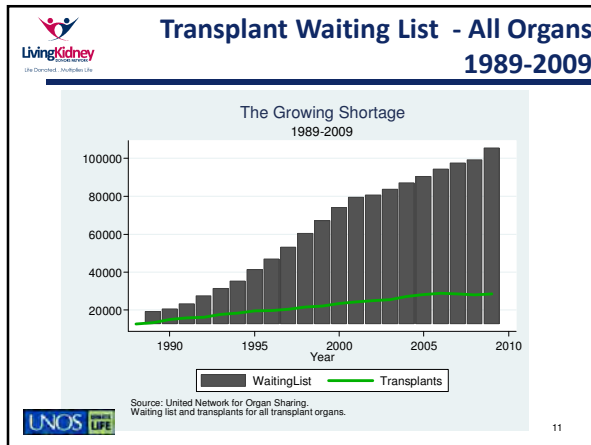
Know the Statistics

Statistical Info (Source: UNOS) www.unos.org

- Kidney 5 yr. Survival Rates
 - Living Donor 89%
 - Deceased Donor 67%
- Most People Starting Dialysis are Good Candidates for a Living Donor Transplant
- Yearly Waiting List Additions
 - 2009 – 35,122
 - 1999 – 20,166

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- Benefits:**
Living vs. Deceased Donation
- Short & Long Term Survival Rates
 - Know Your Donor & Their Health History
 - New Kidney Functions Immediately
 - Shortens the Waiting Time for Others
 - Avoid Being on Dialysis...Pre-emptive Transplant
 - Being on Dialysis for more than 1 year effects long term success rates
- UNOS OPTN LIFELINE



Possible Donor Risks

- Anticipated and Unanticipated Surgical Complications
- Patient Pain, Fatigue, or Discomfort
- Long Term Risks - High blood pressure, loss of kidney function and other complications currently unforeseen

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What about Matching?

Isn't it difficult to find a Match?

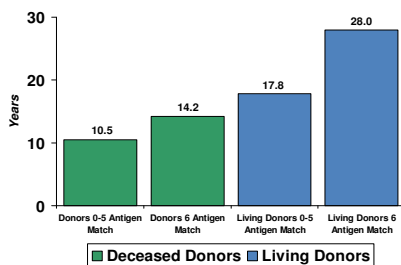
- Suitable and Compatible
- PRA: Panel Reactive Antibodies
- Cross Matching
- HLA - Human Leukocyte Antigen / Tissue Typing (Traditionally Known as Matching)

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Outcomes - Living/Deceased Transplants

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



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Blood Type Compatibility- Donors

Donor Blood Type	Can Donate to	Recipient Blood Type
O	→	A,B, AB, O
A	→	A or AB (O)
B	→	B or AB
AB	→	AB

Blood Type O is the Universal Donor

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Blood Type Compatibility - Recipient

Recipient Blood Type	Can Receive From	Donor Blood Type
O	→	O (A)
A	→	A or O
B	→	B or O
AB	→	A, B, AB or O

Blood Type AB is the Universal Recipient

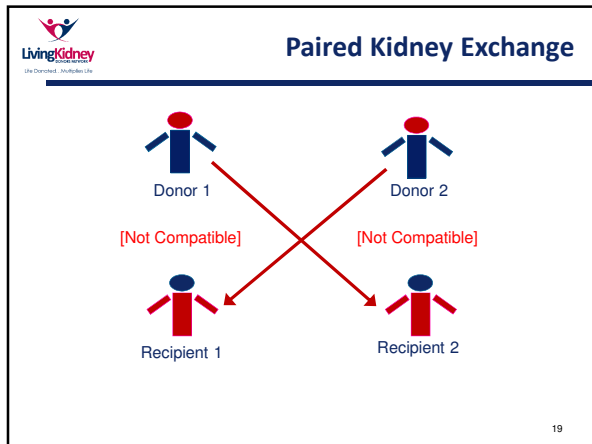
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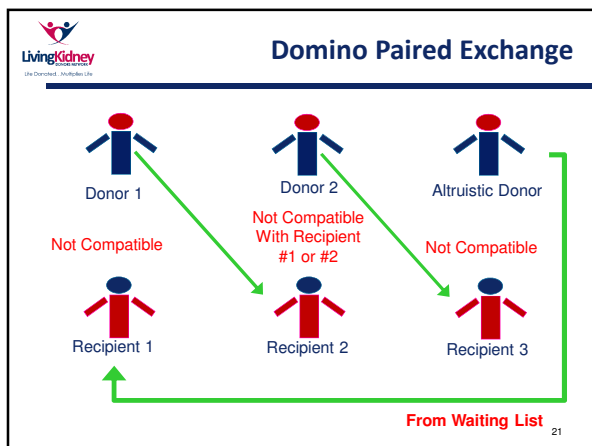
Living Donor Transplant Options

- Related (1999 – 78% vs. 2009 – 58%)
- Non Related
- Non Directed – Altruistic
- **Paired Kidney Exchange**

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- Living Donor Transplant Options**
- Related (1999 – 78% vs. 2009 – 58%)
 - Non Related
 - Non Directed – Altruistic
 - Paired Kidney Exchange
 - Domino Paired Kidney Exchange
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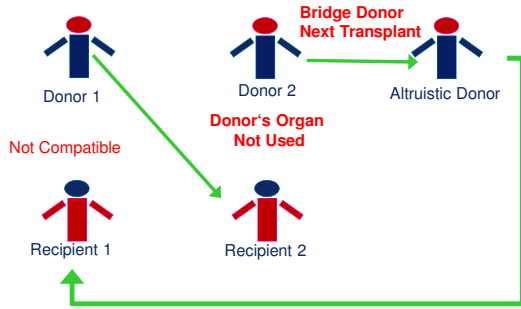


8 Way Domino Paired Exchange



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Ongoing Donor Chains



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Living Donor Transplant Options

- Related (1999 – 78% vs. 2009 – 58%)
- Non Related
- Non Directed – Altruistic
- **Paired Kidney Exchange**
- **Domino Paired Kidney Exchange**
- Blood Type Incompatible (*Plasmapheresis*)

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Things You Should Know

- Getting Listed at a Hospital(s)
- Medical Advocates
- The Surgical Procedures
- Speak to Recipients and Donors
- Donor Evaluation

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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 II

Power and Importance of Communication





Communicating Your Need

We'll Review:

- Your Concerns.....Overcoming Them.
- How to tell "your story"...Preparation
- How Advocates can tell Your Story
- "Elevator Speeches"
- Expand your Network & Meet New People

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Communicating Your Need

What concerns do you have about speaking to other people?

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Communicating Your Need

Developing a Strategy:

- You are not asking people to donate
- Learn about Living Donation and your Condition
- What do you want to Say to People
- How will you let others Know
- Interviewing for a Job – Other Life Experience

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Life Experience – Loss of a Job

- Reality of your Situation
- Research Options
- Learn about those Options
- Write a Resume
- Write a Cover Letter
- Networking
- Job Interview-Tell Your Story

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Networking for a: Job Search or a Transplant

- | | |
|------------------------------|-----------------------------|
| • Reality of your Situation | • Reality of your Situation |
| • Research Options | • Research Options |
| • Learn about those Options | • Learn about those Options |
| • Write a Resume | • Write Your Story |
| • Write a Cover Letter | • Write a Letter |
| • Networking | • Networking |
| • Interviews-Tell Your Story | • Tell Your Story |

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Communicating Your Need

Who to Talk To – Everyone!!

- Family Members
- Friends
- Co-workers
- Other People you Know
- New Acquaintances
- The General Public

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Communicating Your Need

How to Educate Others

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

- You and your Advocates personal contacts
- Newspapers, TV and radio stations
- Schools, Churches, Reunions
- Volunteer!!!! Volunteering will allow you to meet new people. Help others and you will help yourself.
- Email and the Internet, is it for You?

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Communicating Your Need

Talking Points:

- I have a kidney disease that....
- I've been on dialysis for.....
- The wait for a deceased donor is.....
- My best option is a transplant from a living donor.
- Most healthy people can donate
- You are not "asking" someone to donate

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Networking

- ***Individuals do not plan to fail, they fail to plan!***
- Develop a list of everyone you know (Prioritize: A,B,C's)
- How Can You Help Others?
- How Can Others Help You?
- Unanswered Questions...follow up.

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Communicating Your Need

Email and the Internet etc.

- Write out your Story
 - www.lkdn.org/attachments.html
 - www.google.com/alerts
- Web sites, Facebook, Blogs, Twitter etc.
 - www.matchingdonors.com
 - www.livingdonorsonline.org
- Craigs List - www.floodsisters.org
- Signs???

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Your Advocate(s)

Advocate: *A supporter, someone that appeals on your behalf.*

- Educate your advocate(s). Share material.
- Some can be more direct with people than you
- Keep them up to date on your progress, medical, personal etc.

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Improving Communication Skills

- Being Too Subtle.....or Overpowering
- Speak from the Heart – Tell Your Story
- Be Brief...make it personal...be Positive
- Speak Slowly and maintain eye contact
- Be a Good Listener
- You're not "asking" someone to donate

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Sample Scenario

You are at a party in a friend's 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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Communicating Your Need

Discuss what others would say in this situation.

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Practicing



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Creating Your “Elevator Speech”



- Less than 1 minute to convey your message
- Make 2 to 3 quick points
- If they want more information, go further

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Support and Using This Network

- You’ve built friendships in this program.
- Take advantage of this new network of people with a common interest and goal.
- Support one another – value your bond and look to help each other.
- This is a “Safe” starting point.
- Getting Started - Practice

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Getting Started

Select One Idea!!!

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Help me Help Others

- Evaluation Form (Downloads are at the bottom of the page.)
 - www.lkdn.org/evaluation
 - Copy of this Presentation
 - LKDN Resource Guide
 - Articles of Interest
 - Getting Started
- Sign up for LKDN updates, Blogs, Twitter
- LKDN “Get-Togethers”

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Review

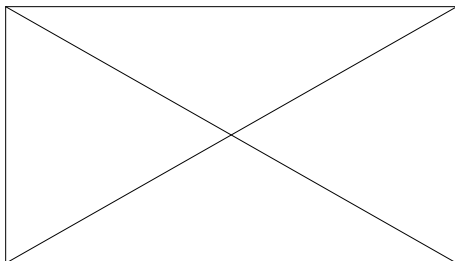
Top Five Take Aways:

- Learn as Much as you can about Living Donation
- The Waiting List is **NOT** the only Option.
- Donor Matching has Changed-It’s become easier
- Your Communications and Network are Powerful!
- Many Ways to Let People Know about Your Condition

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Video



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Inspiration

There is no greater joy nor greater reward than to make a fundamental difference in someone's life.

- Sister Mary Rose McGeady

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URL of Video

<http://www.youtube.com/watch?v=EZHmKkoag8g&feature=related>

In You Tube, search for Joel Barker, Star Thrower

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Closing

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



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 LivingKidney
DONORS NETWORK
Life Donated...Multiplies Life


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