



WELCOME



**Erase the Wait
Training
Will Begin Soon**





Erase the Wait Mentorship Program

Patient Mentee Training





Technology Tips

- Muting and unmuting
- Chat box
- Getting disconnected





Erase the Wait Overview

- 1. Get the Facts**
- 2. Build Your Support System**
- 3. Create Your Story**
- 4. Spread the Word**
- 5. Learn from Others**
- 6. Make a Plan**





Today's Session

Get the Facts

- Introductions
- Learn about living kidney donation
- Understand mentorship program
- Brainstorm questions for panelists

Build Your Support System

- Brainstorm “Circles of Support”
- Identify different ways people can support you





Guidelines

- Be respectful of each other and time
- Be open and honest
- Be willing to learn from and share with others
- Be willing to participate
- Any to add?





Parking Lot

- Questions
- Comments
- Ideas/suggestions
- Info requests





Overview

What is Donate Life Northwest?

- Nonprofit
- Oregon and SW Washington
- Education & awareness for organ, eye, and tissue donation



Origins of Erase the Wait

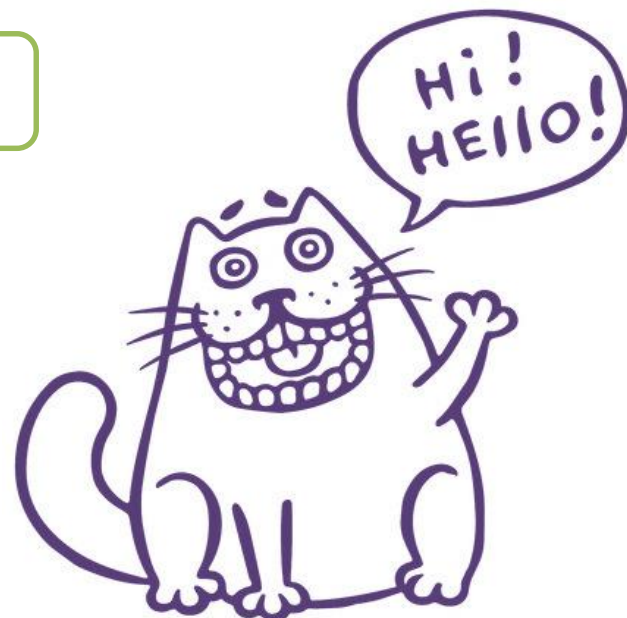
- Support for people waiting
- Current program:
 - Patient support
 - Public education
 - Policy





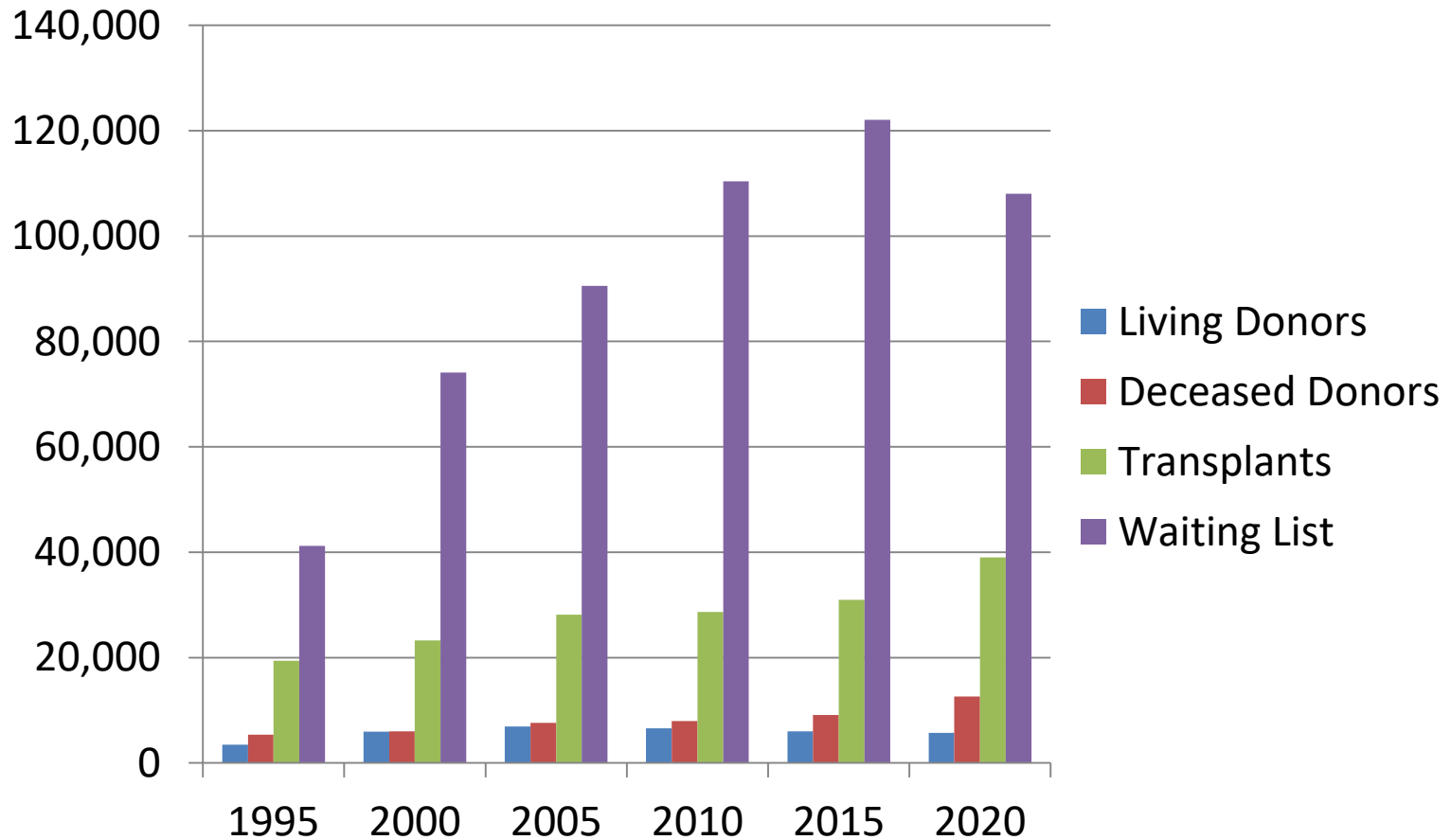
Introduce Yourself to the Group!

- What is your name? Where do you live?
- Share one struggle and one source of support with kidney disease.
- What do you hope to learn today?
- What are your concerns?





The Donor Gap

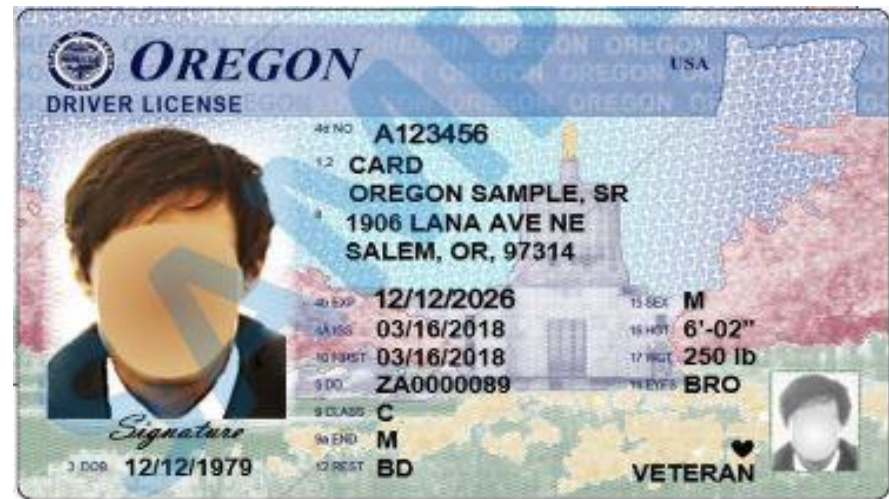


Source: US Department of Health and Human Services; Organ Procurement and Transplantation Network
organdonor.gov



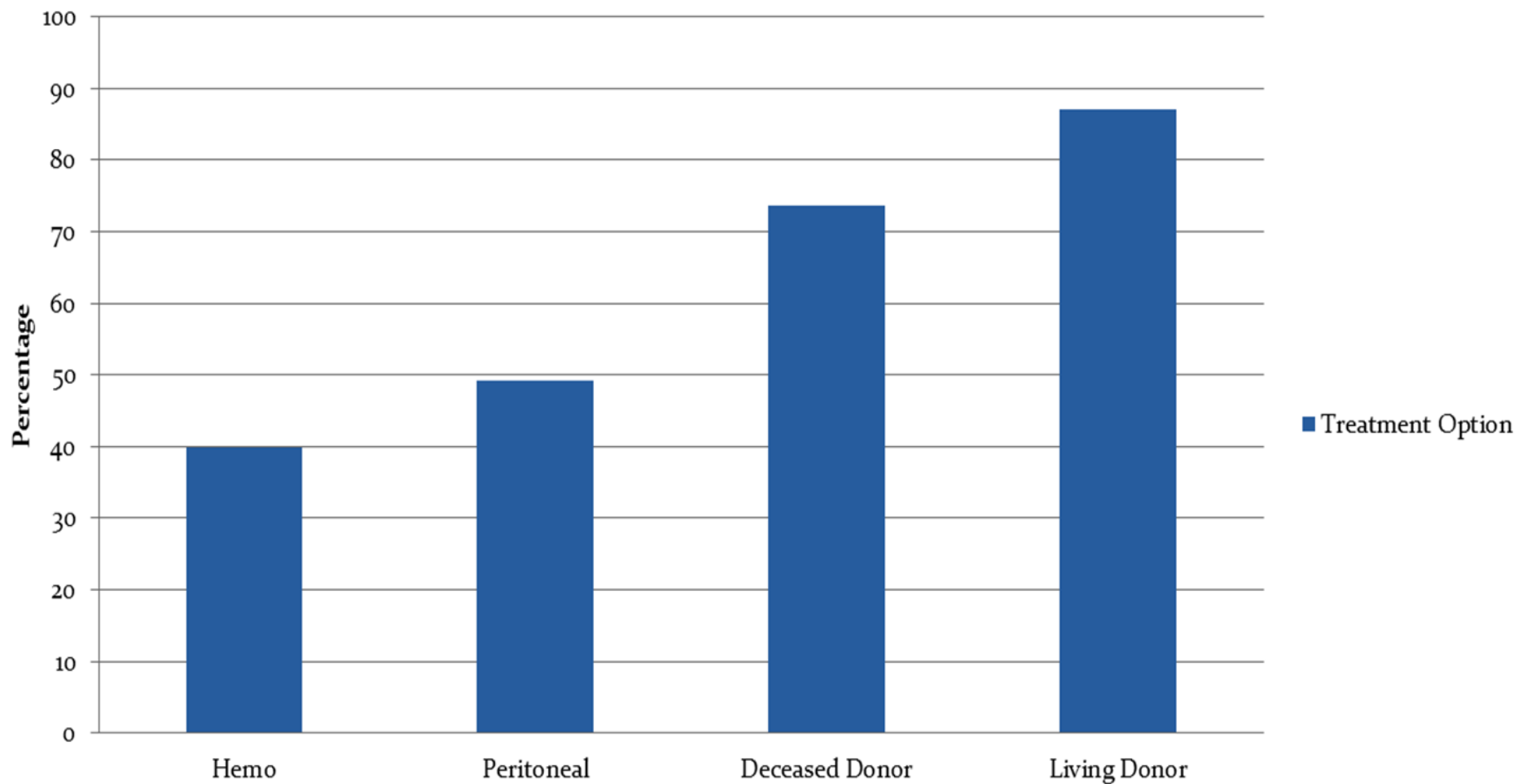
The Waiting List and Deceased Donation

- The Waiting List is not a “list” as much as it is a pool of candidates
- Deceased organ donation is very rare
 - Less than 1% of people die in a manner suitable to organ donation
 - Then, of those people, they either need to be registered or their families must agree to the donation process





ESRD 5-Year Survival Rate



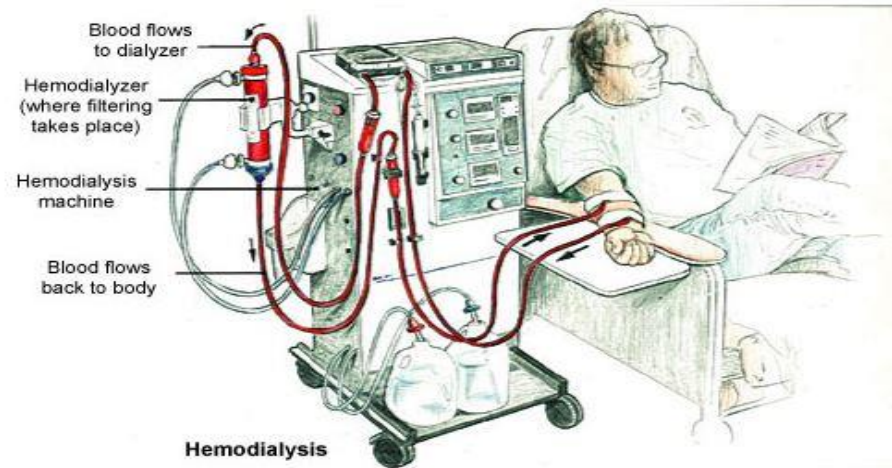
Source: USRDS, 2014



Types of Dialysis

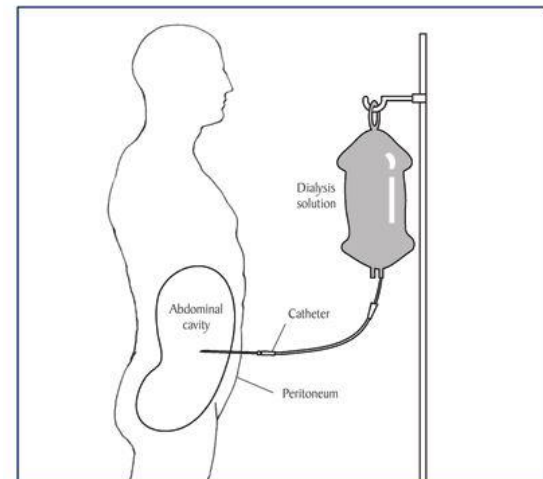
Hemodialysis

- In-center
- Home



Peritoneal Dialysis

- Continuous Ambulatory
- Automated



Continuous Ambulatory Peritoneal Dialysis (CAPD)



What Are the Advantages to Living Kidney Donation?



Shorter wait time
(Months, not years!)



Great kidney
(Best match!)



Scheduled surgery
(Recovery is easier!)

Kidney lasts
2x
as long

Longer success



Shortens waitlist
(Removes person from list!)

Source: University of Wisconsin—Madison, School of Medicine and Public Health



Don't Be Afraid to Accept an Offer!

Living kidney donation is a safe, common surgery which will greatly improve your quality of life

By accepting a donation you:

- **Allow someone to help you**
- **Take another person off the waitlist**
- **Give someone the opportunity to be more present and active in your life**





Living Kidney Donors

Basic Health Requirements

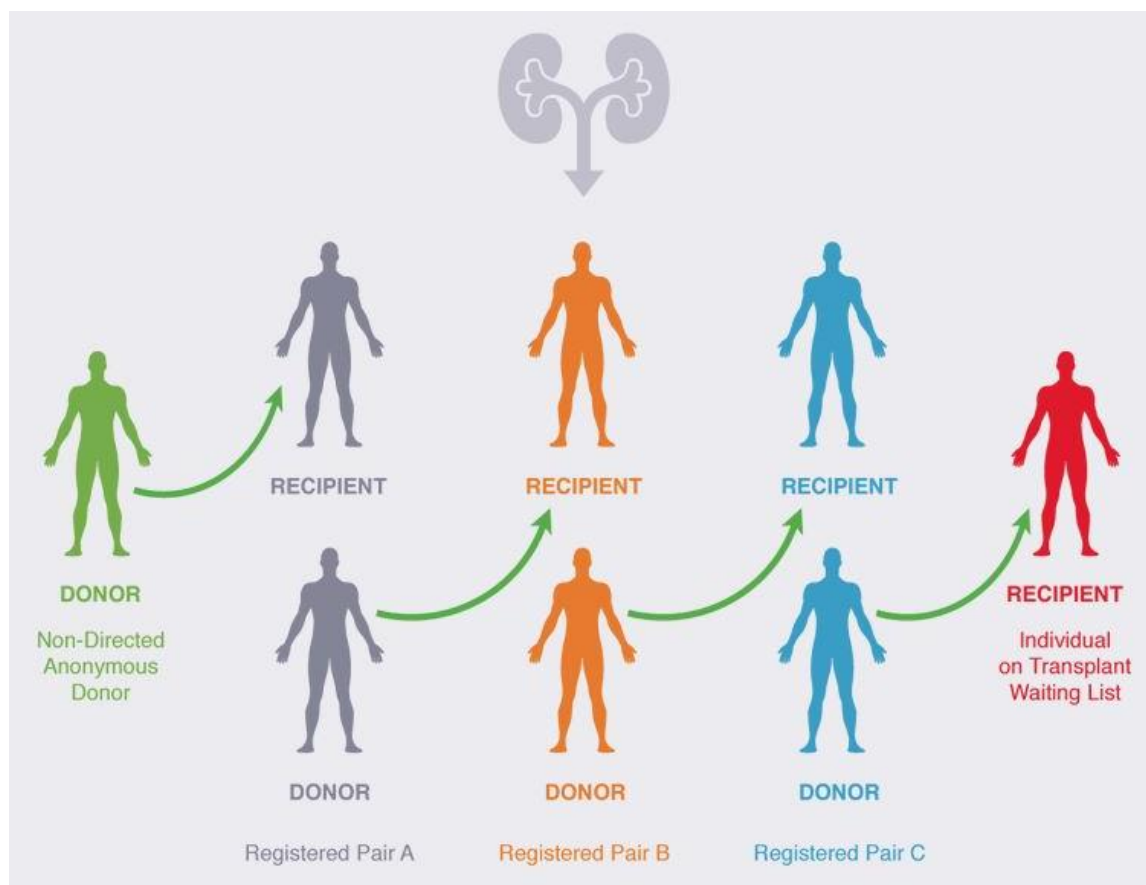
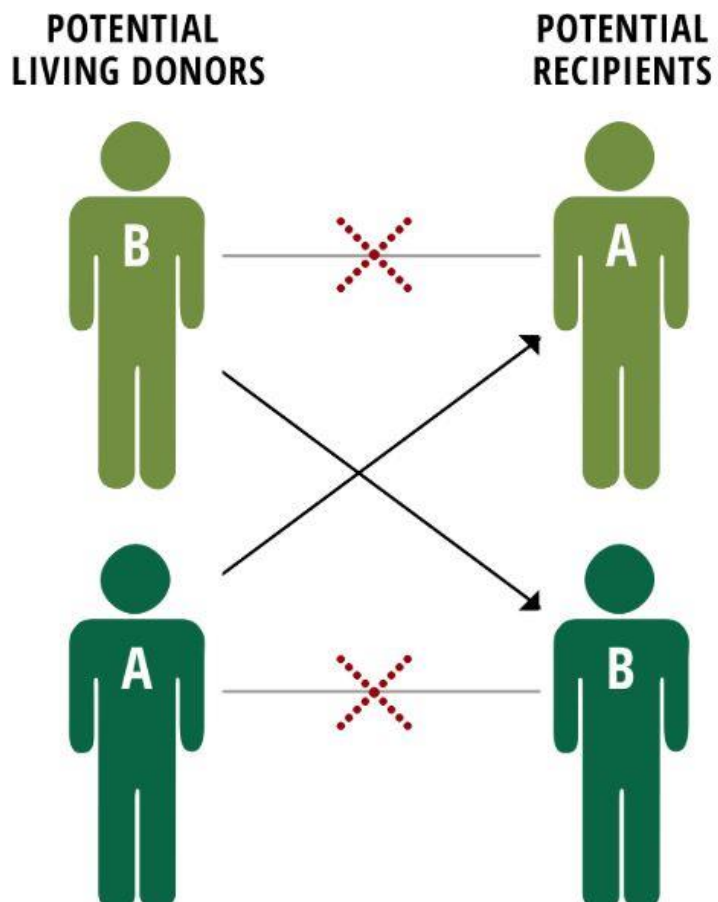
Testing Process

Compatibility





Paired and Chained Donation





Terms and Acronyms to Know



Glomerular Filtration Rate (GFR): Test to measure percentage of kidney function

Blood Urea Nitrogen (BUN): Test of kidney injury or disease

Chronic Kidney Disease (CKD): Divided into five stages

End Stage Renal Disease (ESRD): Final stage of CKD

Creatinine (Cr): Waste product from normal breakdown of muscle tissue, estimates kidney function



Be Your Own Best Advocate

To stay active on the transplant list:

- **Micromanage your own health**
 - **Manage stress, exercise, healthy kidney diet, sleep**
- **Have a proactive relationship with transplant team**

To receive a living kidney transplant:

- **Let people know you need help / tell your story**
- **Educate your community**

To take care of your kidney post-transplant:

- **Maintain your health daily**
- **Adhere to medication regime**



Gathering Support



Your Kidney Partner

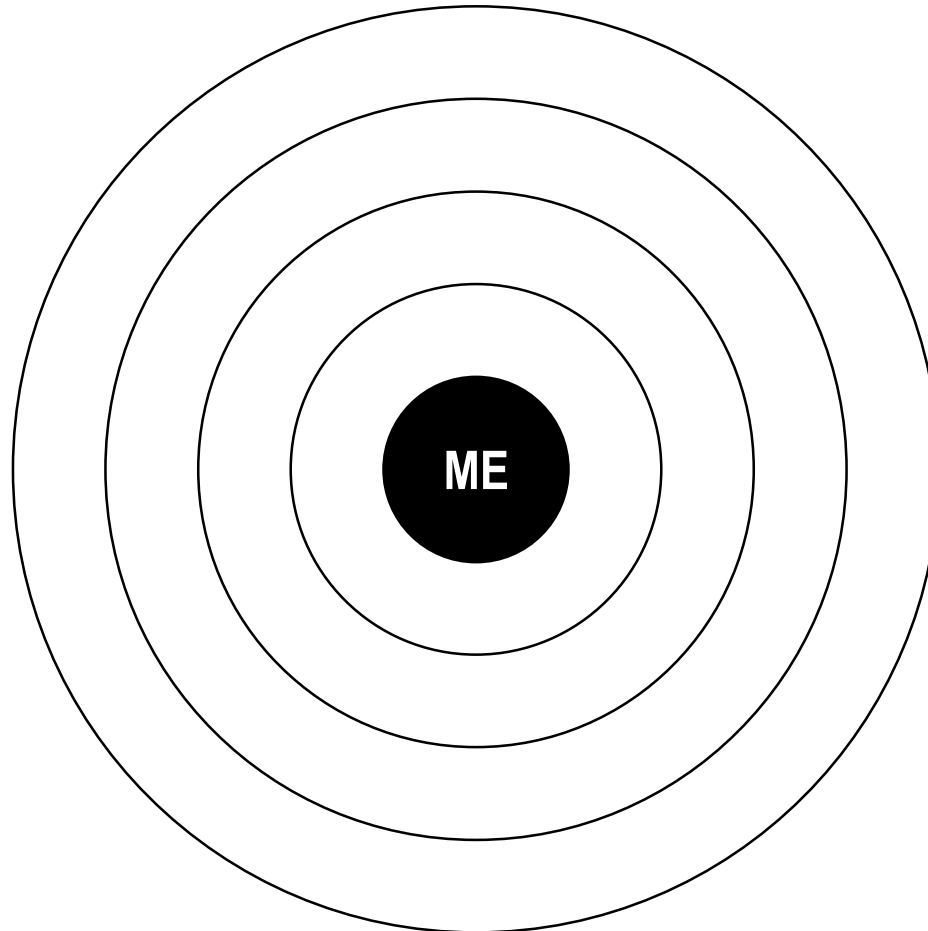
- You will **NEED** someone who is not your living donor to accompany you to every appointment
- This person will also take care of you after surgery

Cultivate a Strong Support System

- Even if someone cannot be a donor, there are many ways they can support you

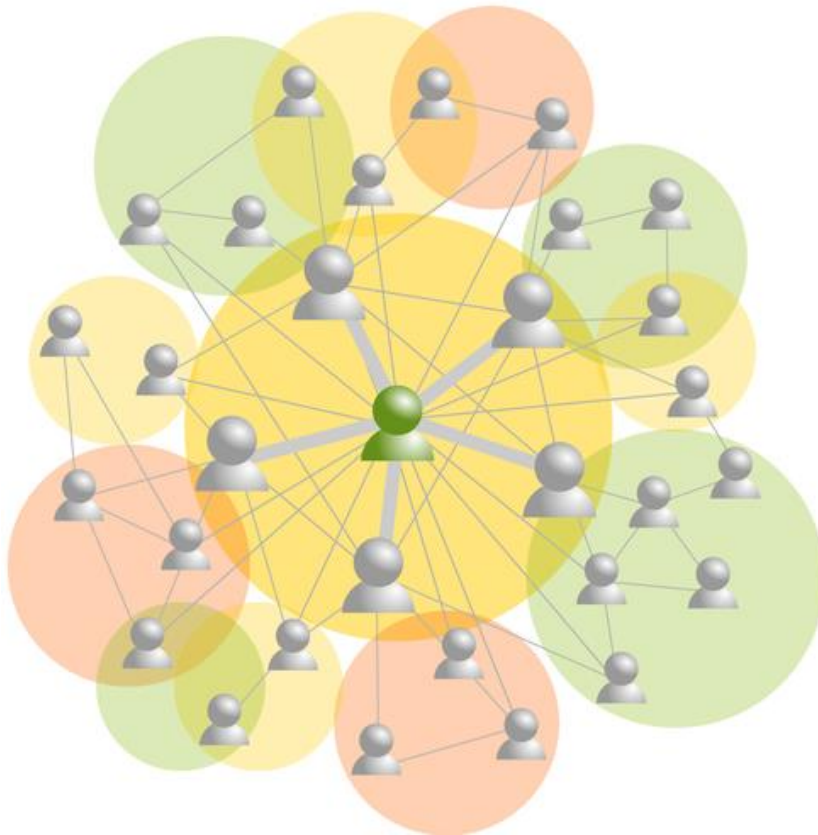


Circles of Support





Strength in Loose Connections



Hairdresser

Dentist

Child's Teacher

Dialysis Nurse

Retail Customer

Barista's Husband

School Acquaintance

Child's Athletic Coach



Expectations from ETW and Your Mentor

- What do you expect?



- What is the program?
- What is it not?
- What is the role of your mentor?
- What is not a good role for your mentor?



Mentorship Expectations

People remember 20% of what they hear, 40% of what they hear and see, and **80% of what they discover for themselves**

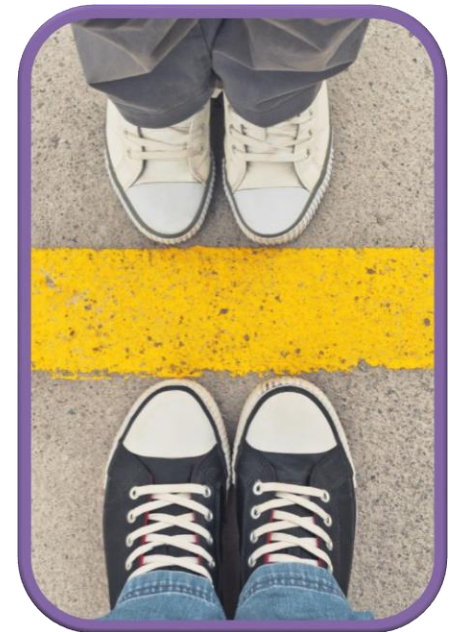
Mentors Help:

- Guide discoveries about LKD
- Explore networking and sharing your story
- Give hope and support



Mentorship Boundaries

- Respect each other's time
- Beware of self-disclosure / oversharing
- Respond to inappropriate advances
- Not a therapist or counselor





SMART Goal Setting

- Set a self-care or outreach goal to work on
- Goal setting is helpful to keep going
- Set small goals as steps to a larger goal
- Ensure the goals are SMART:
 - Specific
 - Measurable
 - Achievable
 - Relevant
 - Time-Limited





Questions for Panelists

- What are people's biggest concerns about finding a donor and receiving a living kidney transplant?
- What are people's obstacles to getting a living kidney transplant?
- How does receiving a living kidney transplant impact people's lives?
- Why do people donate their kidney?
- What are possible complications / difficulties with donating a kidney?
- What are the benefits of donating a kidney?



Homework Due Next Session

- 1 Complete survey/evaluation for today's session
- 2 Complete "Worksheet for Sharing Your Story"
- 3 Work on your "What Kind of Support Do I Need?" handout based on your "Circles of Support"
- 4 Watch Brené Brown video (link on homework handout)
- 5 Work on your SMART goal
- 6 Watch/read donor stories



Be this guy



Not this guy



What to Expect for the Next Sessions

SESSION 2

WHEN & WHERE

Sunday, Oct 23rd
10:00am-2:30pm
Zoom

TOPICS OF FOCUS

- Create Your Story
- Build Your Support System
- Spread the Word: Learn Outreach Ideas
- Learn from Others: Discussion Panel

SESSION 3

WHEN & WHERE

Sunday, Nov 6th
*10:00am-2:30pm
Zoom

TOPICS OF FOCUS

- Learn from Others: Your Mentor
- Spread the Word: Practice Outreach
- Make a Plan



Questions?



Contact:

Marissa Markintire
markma@ohsu.edu

Hallie Johnson
johnhall@ohsu.edu