Gift of Life

Empowering Living Kidney Donation



Continuing Education

- To complete the course, the learner must:
 - Watch the 60-minute webinar (live or recorded)
 - Complete evaluation & post-test questions
- Social Worker CEs approved by ASWB.

 Glenna Frey speaker for this webinar, is on the speaker's bureau for American Nephrology Nurses' Association. All relevant financial relationships listed were mitigated.





Learning Outcomes

- After this course, the learner will:
 - Discuss the emotional and psychological rewards of being a living kidney donor
 - Describe strategies for addressing the challenges donors might face including time off from work, travel expenses, and childcare
 - Explain donor insurance and protections in place to safeguard living kidney donors



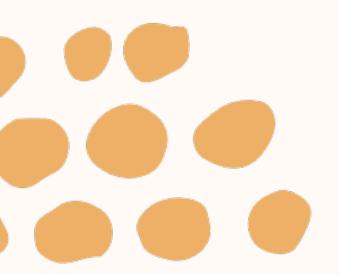
Sessions

- Advancements and Challenges in Kidney Transplant: Empowering Patients and Professionals
- Pathway to Giving: Understanding the Living Kidney Donor Process
- Giving Life, Exploring Impact: Benefits and Considerations for Living Kidney Donors
- Finding a Lifesaving Match: Strategies for Finding a Living Kidney Donor

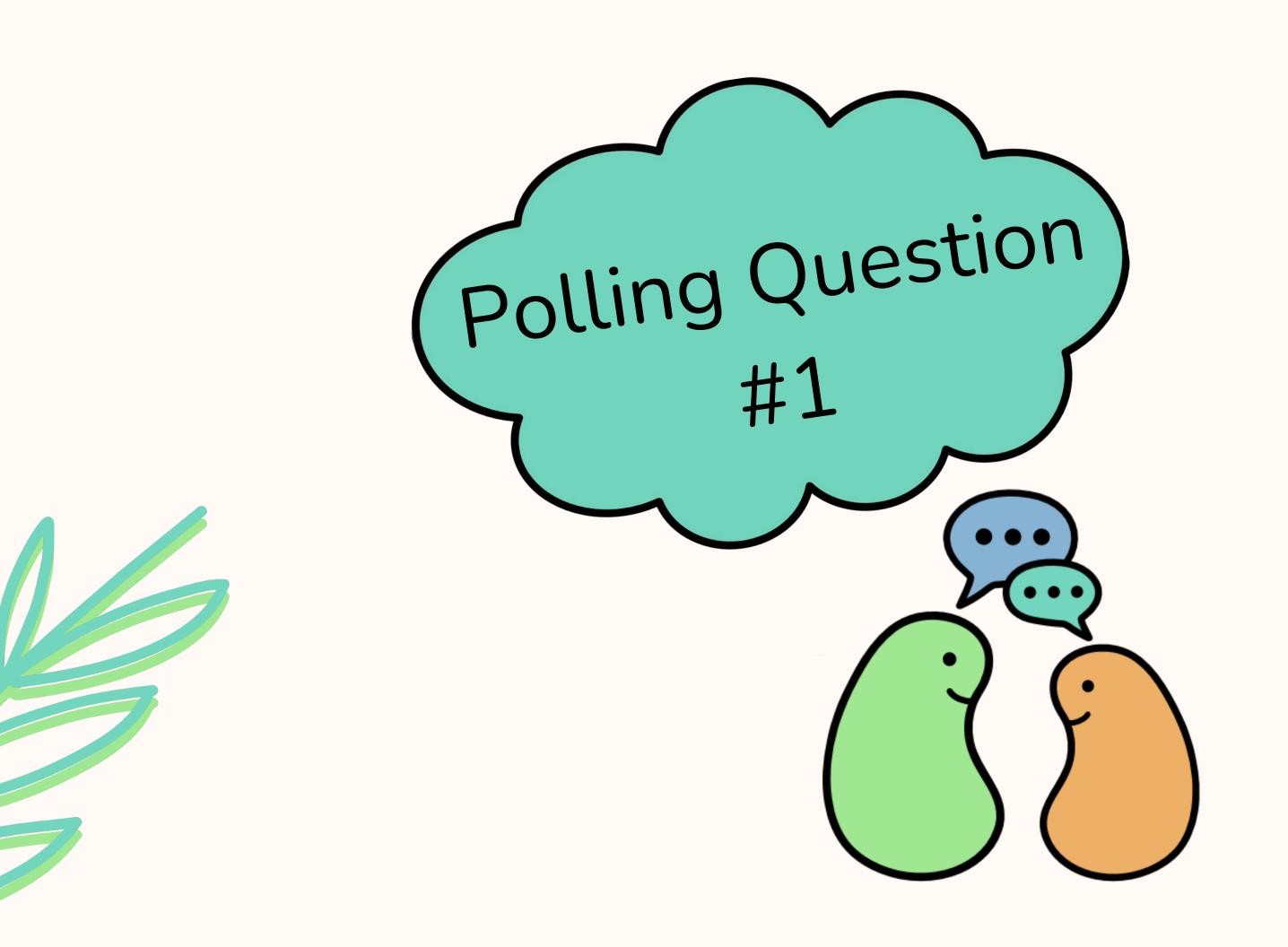


Session 3

Giving Life, Exploring Impact: Benefits and Considerations for Living Kidney Donors









You can lead a healthy life with one kidney!







How can a kidney have the longest life in a recipient?

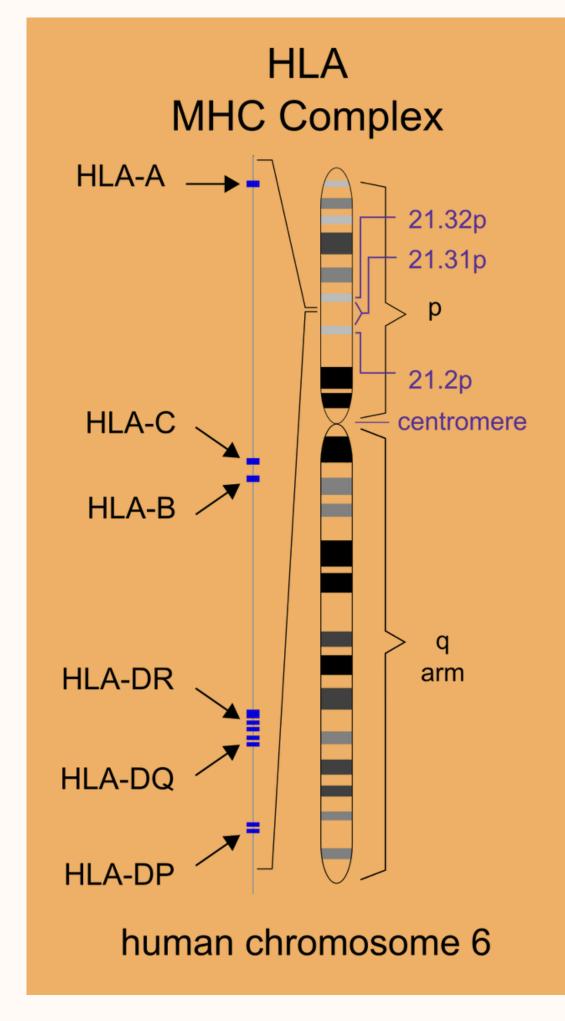


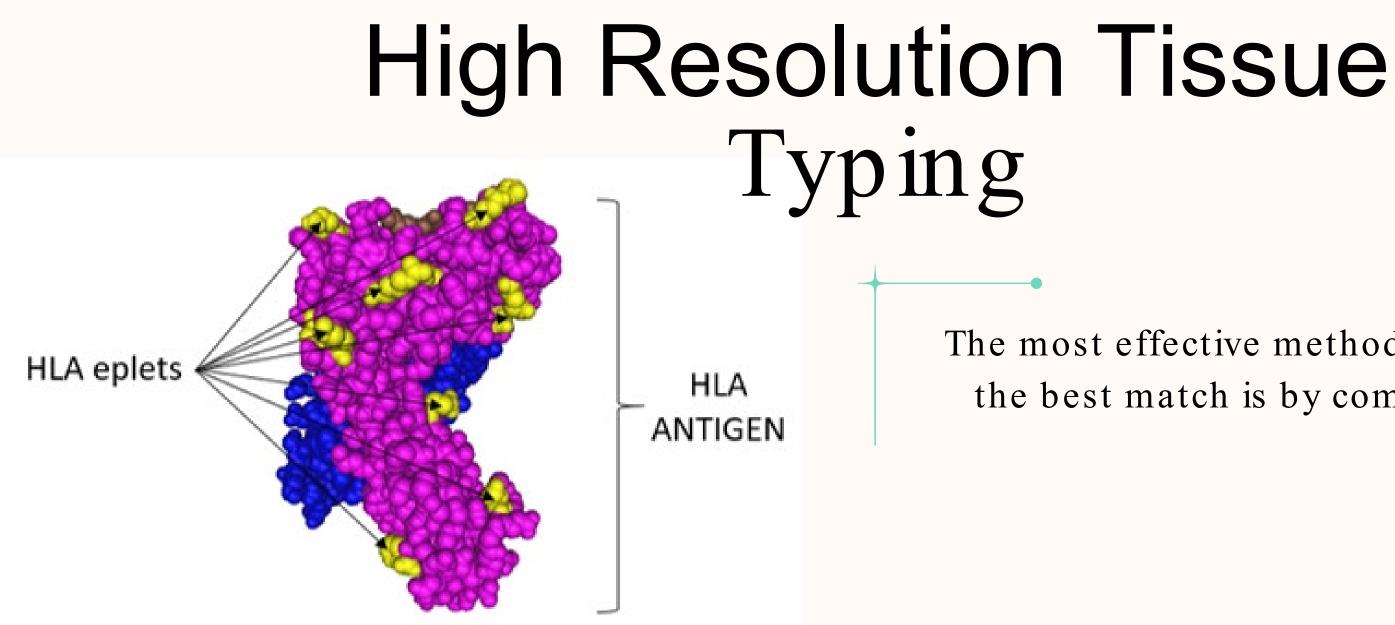


Typical HLA Tissue Typing



By HLA.jpg: Original uploader was Pdeitiker at en.wikipediaderivative work: Faigl.ladislav (talk) - HLA.jpg, Public Domain, https://commons.wikimedia.org/w/index.php?curid=8194240





Higher Eplet Mismatch (~ >10%; best to check with HLA lab) = More Donor Specific Antigens = More Rejection

Mohammadhasanzadeh H., Oualkacha K., Zhang W. On path to informing hierarchy of eplet-mismatches as determinants of kidney transplant loss. Kidney Int Rep. 2021;6:1567-1579.

The most effective method of determining the best match is by comparing eplets.





Benefits of Eplet Matching

Reduced Risk Of De Novo Antibodies

Lower Risk Of Rejection



Opportunity For Safely Reducing Immunosuppression



KIDNEY FOR LIFE[®] BETTER MATCHES = BETTER OUTCOMES



Less Risk Of Graft Failure

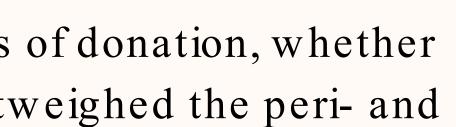
Fewer Side Effects From Immunosuppressive Medication

https://www.kidneyforlife.org

What are the benefits of donating a kidney?

- Boost in self-esteem
- Increased sense of well-being
- Improved relationship with recipient
- Almost every donor says they would do it again if they could

All participants acknowledged that the benefits of donation, whether experienced by themselves or the recipient, outweighed the peri- and postoperative risks as they understood them.



Van Pilsum Rasmussen SE, Robin M, Saha A, Eno A, Lifshitz R, Waldram MM, Getsin SN, Chu NM, Al Ammary F, Segev DL, Henderson ML. The Tangible Benefits of Living Donation: Results

What is the risk of donating a kidney?

- Risk of death in surgery is 0.03%
 - Same as for childbirth
 - Gall bladder is higher at 0.18%
- Slightly higher risk of high blood pressure in pregnancy (preeclampsia)
- Donors live as long, or even longer than, the general population

• because they are healthier

Lentine et al. Clin J Am Soc Nephrol. 2019;14: 597-608.

Ibrahim et al. N Engl J Med. 2009;360:459-69.

Gaston et al. J Am Soc Nephrol. 2015; 26: 1017–1019.

Dew et al. Adv Chronic Kidney Dis. 2012; 19(4): 237–243. 5. Purnell et al. Adv Chronic Kidney Dis. 2012; 19(4): 244–251





What is the risk of donating a kidney?

- Risk of ESKD after 15 yrs. on average 0.27%;
 - Risk Index Calculator at <u>www.transplantmodels.com/esrdrisk</u>
 - Points on the deceased kidney transplant list if need a kidney 0 after donating
 - Some non-directed donors can get living kidney transplant 0 through some registries

Lentine et al. Clin J Am Soc Nephrol. 2019;14: 597-608. Ibrahim et al. N Engl J Med. 2009;360:459-69. Gaston et al. J Am Soc Nephrol. 2015; 26: 1017–1019. Dew et al. Adv Chronic Kidney Dis. 2012; 19(4): 237–243. 5. Purnell et al. Adv Chronic Kidney Dis. 2012; 19(4): 244–251







Living Donor Collective



- Performance of transplant programs
- Registry of donors and potential donors • Assess long term outcomes
- Living Donor Advisory Committee

www.livingdonorcollective.org



What is the cost of donating a kidney?

Donor and Support Person

- Transportation (car, air, parking, etc.)
- Hotel, food
- Time off work
- Dependent Care (child, parent, pet)
- Workup, Pre-Op Visit, Surgery, Recovery, Follow-up

- Costs exceeded: • \$1000 for nearly 75% of donors • \$5500 for 25% of donors

- \$10,000 for 13% of donors

Przech S, Garg AX, Arnold JB, Barnieh L, Cuerden MS, Dipchand C, Feldman L, Gill JS, Karpinski M, Knoll G, Lok C, Miller M, Monroy M, Nguan C, Prasad GVR, Sarma S, Sontrop JM, Storsley L, Klarenbach S; Donor Nephrectomy Outcomes Research (DONOR) Network. Financial Costs Incurred by Living Kidney Donors: A Prospective Cohort Study. J Am Soc Nephrol. 2018 Dec;29(12):2847-2857.



Financial Assistance for Living Donors



Recipient

Reimbursement to people being evaluated for and/or undergoing living organ donation of:

- travel and subsistence expenses
- lost wages
- dependent care expenses



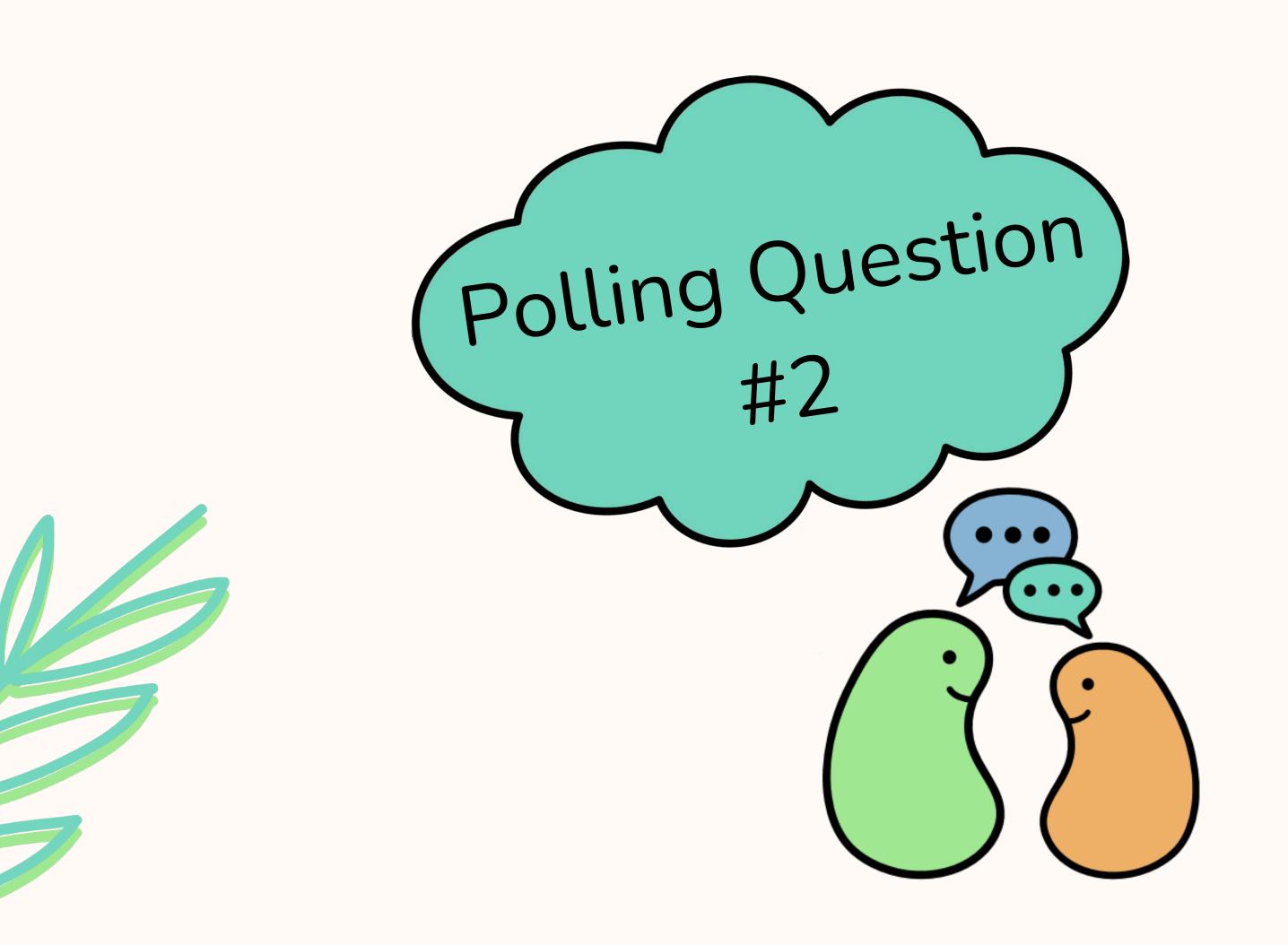
Family, Friends, Community Fundraising





National Living Donor Assistance Center









NLDAC National Living Donor Assistance Center

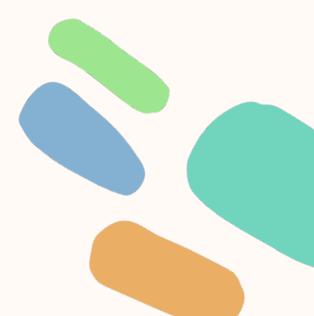
Reduce the financial disincentives to living organ donation. Priority is given to those who could not otherwise afford to donate.

Based on the recipient's income.

- Not be more than 350% of the current HHS Poverty Guidelines (family of two \$70,000)
- Start when the workup starts; must be submitted before surgery

Non-directed donors can apply

www.livingdonorassistance.org







National Living Donor Assistance Center Celebrating

Home

submit a financial hardship waiver worksheet.

Recipient Financial Hardship Waiver Worksheet

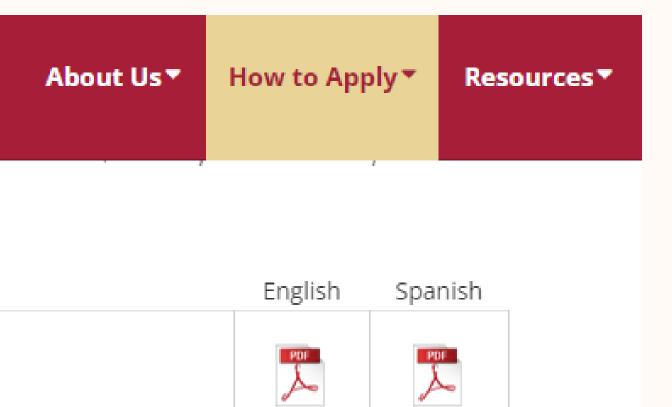


Give these documents to your transplant coordinator, social worker or other transplant professional.

The transplant professional will file the NLDAC application the donor's behalf. Do not send completed worksheets to NLDAC. We do not accept applications from patients.

NLDAC cannot reimburse expenses that have already occurred. We recommend completed applications be submitted as early as 6-8 weeks before travel or surgical procedure.

www.livingdonorassistance.org





HOLD Act

- HR 6020 Honor Our Living Donors Act 2023
 - Help more donors qualify for reimbursement
 - Change NLDAC guidelines that is based on the income of the 0 intended recipient.
 - Use donors income to determine eligibility

HOLD Act

CONGRESS.GOV

Legislation

V

Examples: hr5, sres9, "health care"

Home > Legislation > 98th Congress > S.2048

S.2048 - National Organ Transplant Act

98th Congress (1983-1984)

NOTA

Title III: Prohibition of Organ Purchase - Prohibits the purchase or sale of human organs if such transfer affects interstate commerce. Establishes criminal penalties for such violations.





Living Organ Donor Tax Credit Act

- HR 6171 Living Organ Donor Tax Credit Act 2023
- Provide up to a \$5,000 one-time refundable tax credit to living organ donors.

Living Organ Donor Tax Credit Act

Refundable tax credit means you receive the amount regardless of how much income tax you pay.



ct 2023 le tax credit to living



HEROS Act

- Helping End the Renal Organ Shortage (not yet introduced)
 - All living donors of kidneys will receive \$100,000 in the form of a refundable federal tax credit.
 - Uniformly applied over a period of 10 years in the amount of \$10,000 per year.

HEROS Act



Living Donor Insurance & Protections

- Employer Benefits
- Transplant Center Benefits
- State Benefits
- Registry Benefits

Living Donor Circle of Excellence

Learn about the **AST Living Donor Circle of** Excellence



If your company is interested in joining the Circle of Excellence, request more information or apply todayl

Thanks NKP for providing a link to hare about the Circle

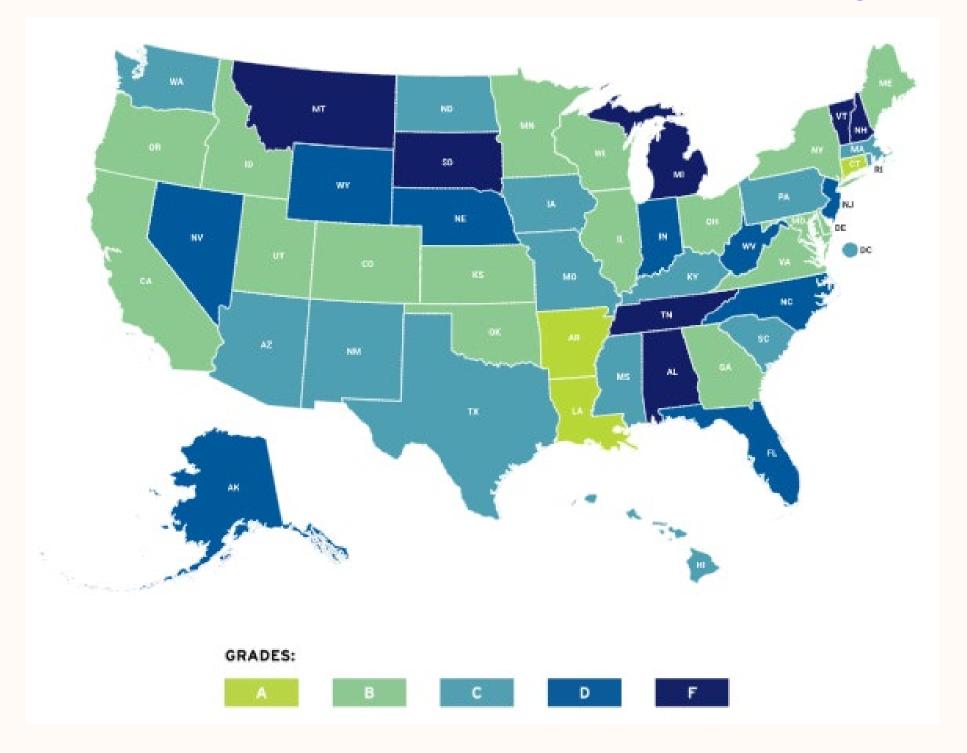
www.livingdonorcircle.com

- Policies should include salary support for a minimum of 4 weeks
- Minimum proportion of wage support is 80%; companies may elect to support more
- Annual confirmation of support and report to

Corporate Recognition Program

the American Society of Transplantation







State benefits

Tax Credit Job Protections Reimbursement **FMLA** Insurance





DonorProtect Program

www.paireddonation.org

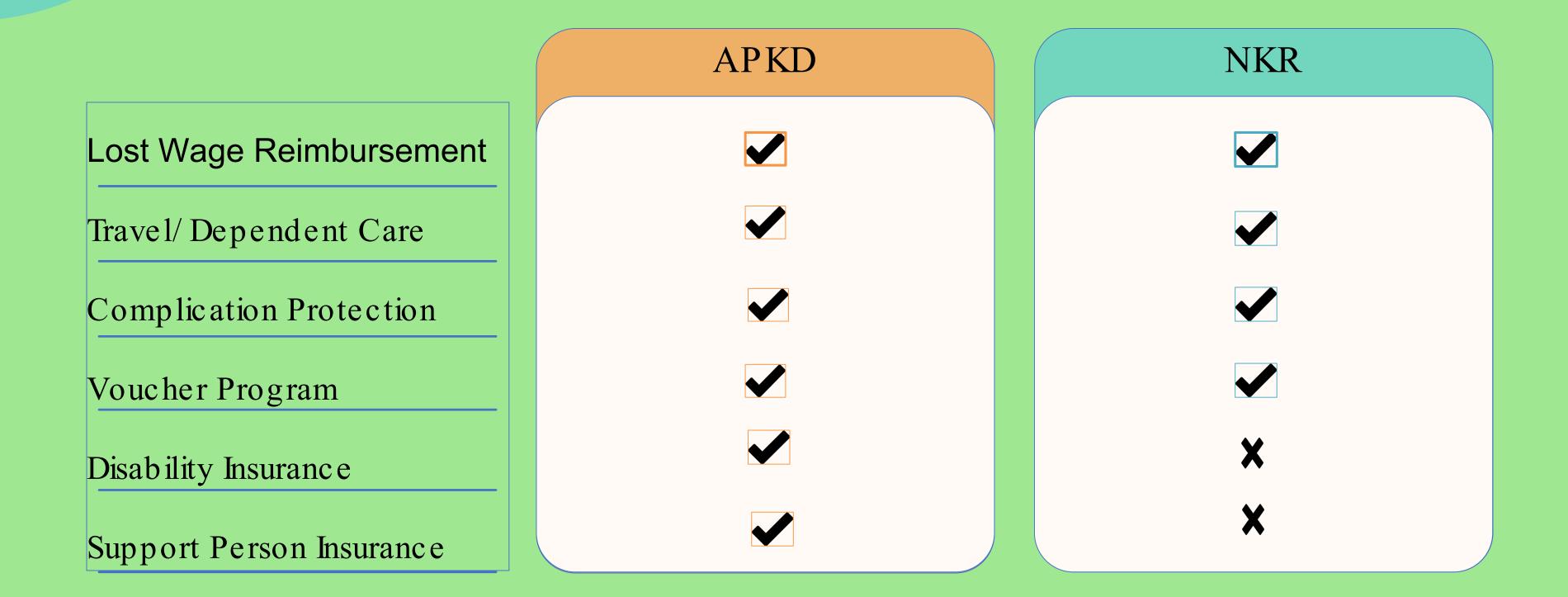


NATIONAL KIDNEY REGISTRY FACILITATING LIVING DONOR TRANSPLANTS

Donor Shield

www.kidneyregistry.org

Donor Protections Comparison



Donor Protections Comparison

Remote Donation

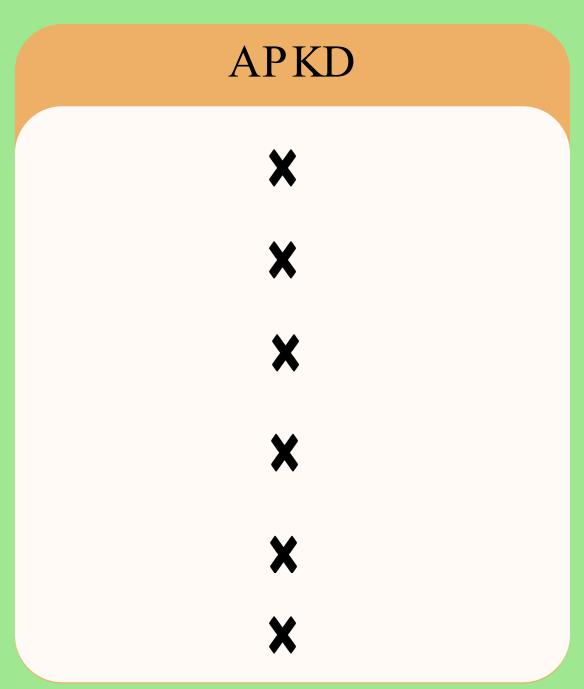
Best Match

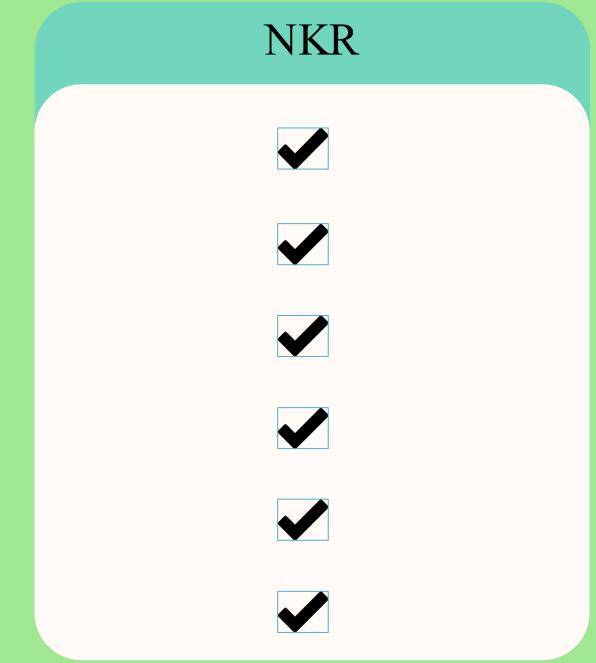
Legal Support

Home Blood Draws

Living Donor Support Person

Living Kidney Prioritization







FREE access to top of the line weight loss and smoking cessation resources



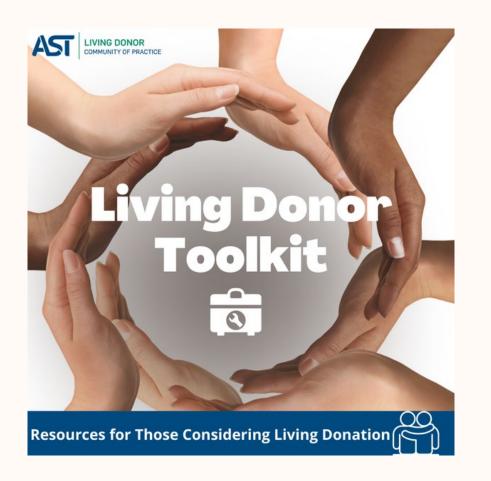












Financial Tool Kit

- Work
- Insurance
- **Estimation Worksheet**)
- Medical Tool Kit
 - Evaluation
 - Experience

www.livingdonortoolkit.com

Finances (Living Organ Donor Cost





Informs, Assists, Supports, and Advocates for Multicultural Living Donors and Families of Deceased Donors.

www.mmdfoundation.org



Living Kidney Donor Peer Support



NATIONAL KIDNEY REGISTRY FACILITATING LIVING DONOR TRANSPLANTS



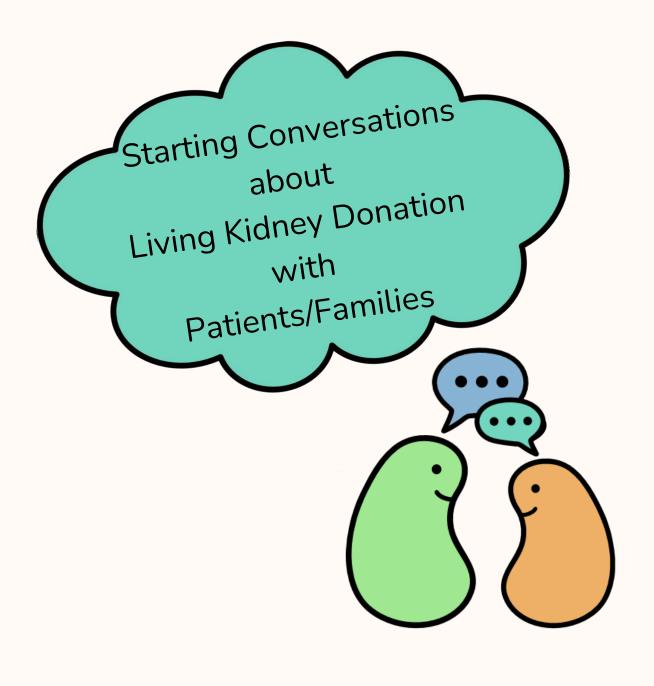






National Kidney Donation Organization



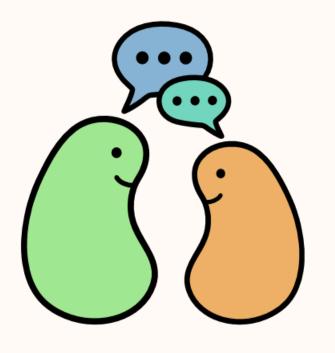


What have you been told about living kidney donor:

- **Benefits**
- **?**Cost
- ? Financial Resources/Protections
 - employer, state, registries, fundraisers
- ? Support Resources organizations
- ? High Resolution Tissue Typing



Thank you!



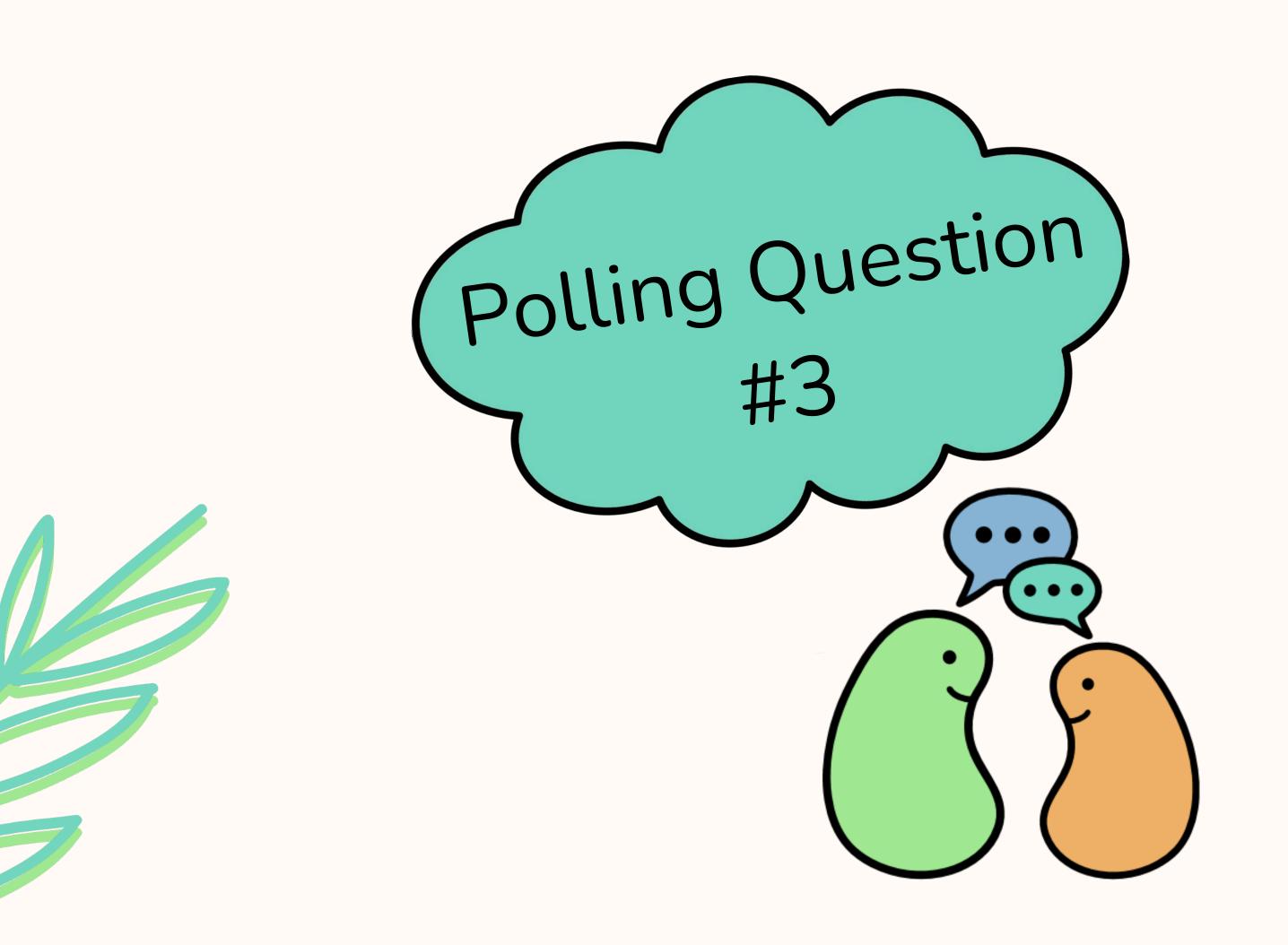
Kidney Donor Conversations

www.MyKDC.org

Mission: To provide education and support for living kidney donation 501(c)(3) nonprofit

Glenna Frey, MSN, APRN-CNS **Executive Director** Glenna@MyKDC.org















What are Your Concerns?

Next Month ...

Evaluation and Post-Knowledge Check

- Link to the evaluation
 - <u>https://www.surveymonkey.com/r/KX52BXP</u>
 - Social Worker CEs approved from ASWB



QR Code

Activate the camera on your smart phone and scan this QR code to link to the evaluation





Session 4

Finding a Lifesaving Match: Strategies for Finding a Living Kidney Donor

