

# C3 Glomerulopathy

*Getting ready to transplant*

20<sup>th</sup> C3G Family Conference  
Iowa City, Oct 4, 2025

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# Objectives

- Considerations for the donor: understanding the surgical risks, emotional readiness, legal and financial planning, lifestyle adjustments, long-term follow-up
- Considerations for the recipient: choosing a center, mental health preparation, physical health optimization, medication education
- What changes are coming to UNOS and how do they impact transplant decisions and the hospital you choose
- What types of donations are possible: daisy-chain; LRD; DD
- How do you make that ask? Sensitive topics and how to broach them
- NKF's The Big Ask, The Big Give

# CONSIDERATIONS FOR THE DONOR

# Information for living donors

- About 6000 living donors per year in the US (25-35% of all kidney transplants)
- Donors can be related (parent, child, sibling) or unrelated (spouse, friend, stranger)
- Donation can be directly to someone you know or to someone unknown - locally or elsewhere (kidney exchange)
- Donors can remain anonymous to the recipient

## Benefits from a living kidney donor transplant:

- Surgery can be electively scheduled.
- Kidney usually works immediately and lasts longer than from a deceased donor

**Among the most selfless and altruistic acts by one person for another**

# Living donation comes with risks

## Potential Medical/Surgical risks

- i. Typical of any surgical procedure – bleeding, DVT, scars, hernia, wound infection, pain, post-op pneumonia
- ii. Psychological – post surgery depression, emotional distress
- iii. Increased risk of preeclampsia (high BP during pregnancy)
- iii. Increased risk of kidney failure (about 5-fold higher)
- iv. Increased risk of death (about 1 in 10,000)

# Potential financial impact

i. Personal expenses of travel, housing, child-care, and lost wages related to donation might not be reimbursed;

Iowa Anatomical Gift Fund: covers travel for a donor to Iowa resident recipient

NLDAC: covers lost wages, travel for donor to non-Iowa residents (income based)

NKR: covers lost wages and travel for any donors through NKR

Iowa Law: 30 days paid vacation to state employees

ii. All medical evaluation, surgery and post surgical care is covered by recipient's insurance

iii. Need for life-long follow up at the donor's expense

iv. Possible loss of employment or income

iv. Future health problems experienced by living donors following donation may not be covered by the recipient's insurance

Considerations for the recipient

# Choosing a hospital for listing

- Proximity to home
- Transplant center with experience/expertise with C3G
- Active living donor program including paired kidney exchange
- High transplant rates, excellent post transplant care and outcomes
- Consider listing at multiple transplant centers (> 100 miles apart)

Areas with longer wait times are expected to see it gradually shorten and vice versa.



# Steps in preparing for a transplant - I

Discuss with your nephrologist as early as possible

- Know the eGFR threshold for waitlisting = 20
- Schedule a visit to a transplant center
- Take your support person (caregiver) with you
- Be prepared for a long visit (1-2 days to complete)

At the transplant center:

Meet with surgeon, nephrologist, social worker, nurse coordinator, dietician, pharmacist, financial counselor, blood tests, X-rays

Sometimes specialists, clinical psychologist, CT scan, stress test

# Steps in preparing for a transplant -II

- Counseling about dialysis versus transplant for C3G
- Complete any additional visits, tests required (specialists, vaccinations)
- Ask about treatment options for disease recurrence
- Get placed on the transplant waitlist
- Maintain your hemoglobin around 9.5-10 gm/dl (avoid transfusion if possible)
- Encourage your living donors to contact transplant center
- Keep your contact information up to date with the transplant center
- Let the transplant center know if you get pregnant, fall sick or need surgery or will be unavailable for an extended period of time

# Changes to UNOS

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- UNOS operates the Organ Procurement and Transplantation Network (OPTN) - contract with the Fed Government.
- Organs are procured from deceased donors by an Organ Procurement Organization (OPO)
- In the past organs were preferentially allocated to patients within their donor service area (DSA)

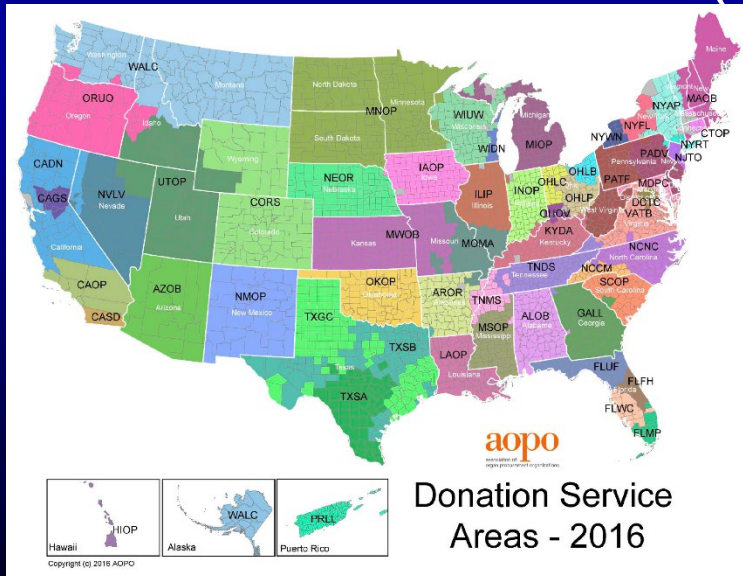
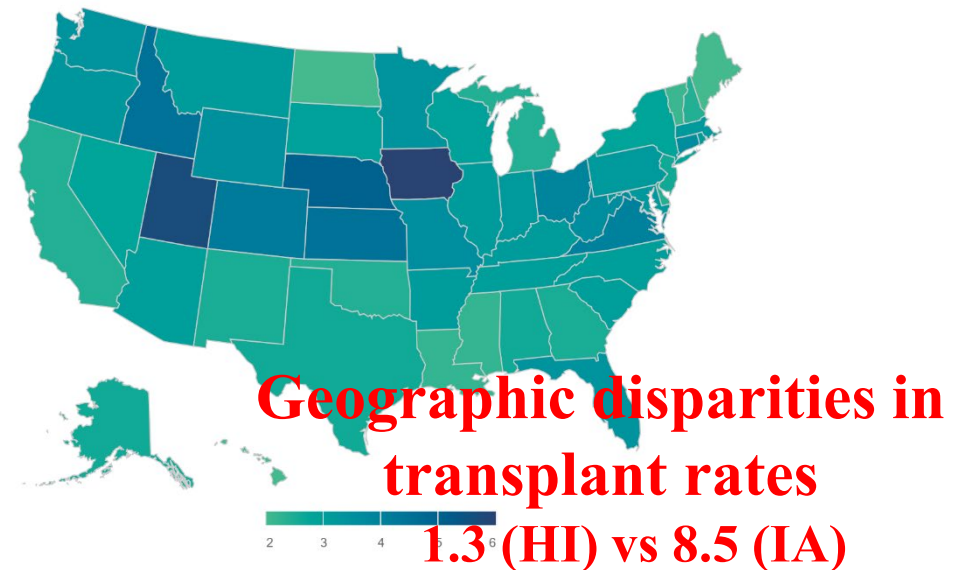


Figure 7.11 Rate (per 100 patient-years) of kidney transplants in patients undergoing dialysis, by state, 2020

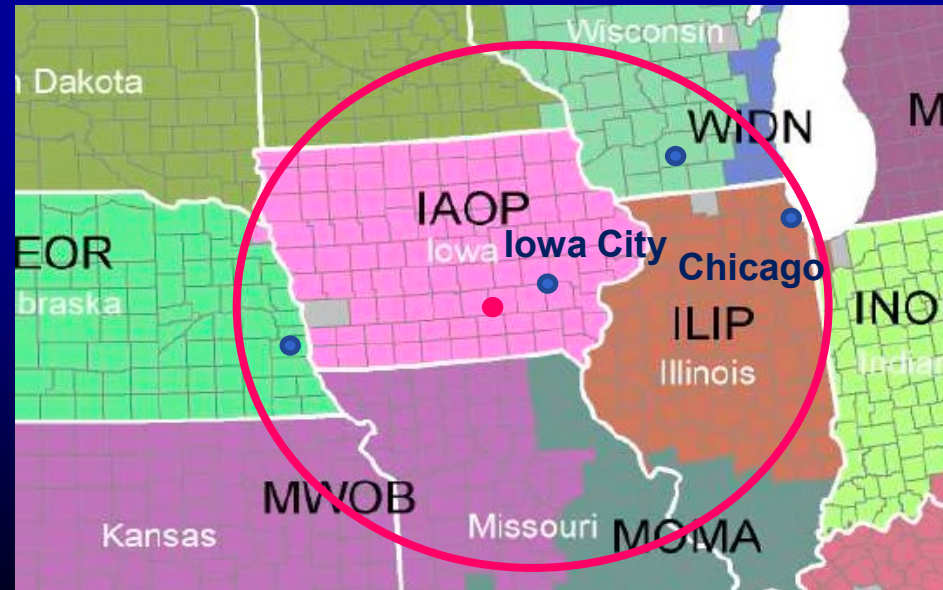
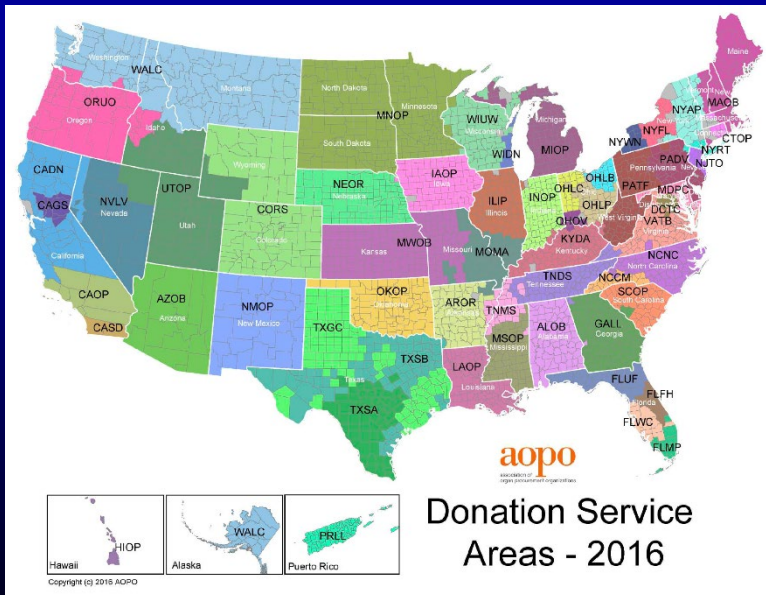


Data Source: 2022 United States Renal Data System Annual Data Report

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# Changes to UNOS

- Organs are still procured from deceased donors by an Organ Procurement Organization (OPO)
- They are preferentially allocated to patients within a 250-mile circle from the donor hospital
- Eventually there will be a continuous distribution model
- Intent to reduce penalties for people listed in certain population areas



# What types of living donation is possible

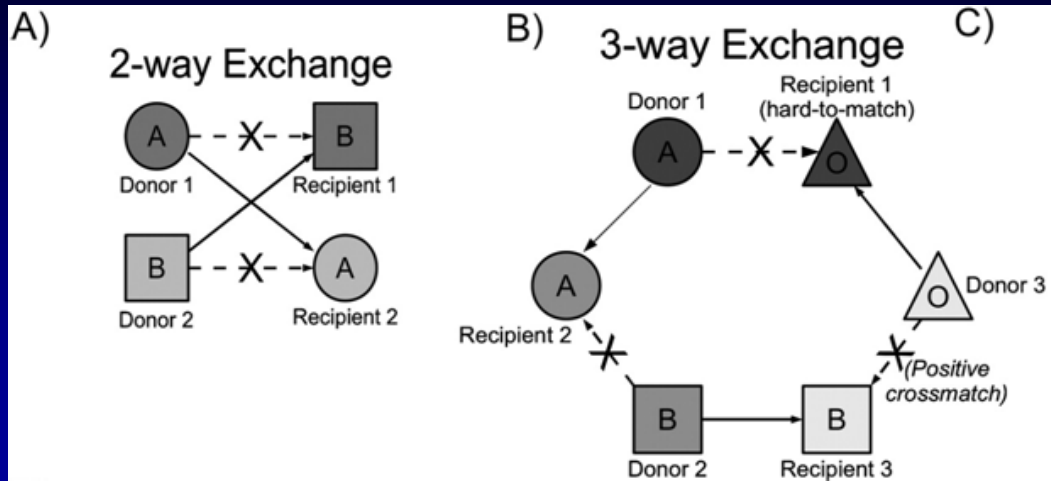
Direct donation

Or

Kidney paired donation (KPD)



# Kidney Paired Donation (KPD)



- Conventional
- Simultaneous
- Closed loop

## Another option – chain donation

- Requires a non-directed donor (no intended recipient) to start a chain
- At the end of the chain, donor 3 is available to start another chain
- Non-simultaneous, extended, altruistic donor chain (NEAD) or daisy chain
- Open



# How does donor kidney get to recipient in KPD?

Options when matched donor and recipient are at different centers

1. Recipient travels to donor center

taxing for the recipient

2. Donor travels to recipient center

inconvenience for donor

has to be away from intended recipient

3. Donor kidney removed and shipped to recipient center

requires coordination of transportation – **preferred method**



# Finding a living donor

- Learn about living donation
- Talk to living donor recipients and to former living donors
- Share your story
- Resources:
  - National kidney Foundation – Kidney Learning Center/finding a living donor  
[Kidney Learning Center](#)
  - UNOS – About donation/living donation/how to find a living donor  
[Patients – OPTN](#)
  - National Kidney Registry – Links in 'For Patients'  
[National Kidney Registry | Facilitating Living Kidney Donation](#)

[The Big Ask: The Big Give](#)



# Questions

# When should patients with C3G be transplanted?

- Ideally when the disease appears inactive
  - patient not requiring immunosuppressive therapy
  - Urine testing shows no red cells (blood) or casts
  - Signs of complement activation have resolved
    - Normal C3
    - undetectable C3 nephritic factor (if previously abnormal)
    - MORL assays: Normal CH50, Normal APFA, Normal hemolytic assay
- Adults with monoclonal Ig (MGRS) should first be treated for the plasma cell disease