

Living Donors Together

September 15, 2020

Program will begin in a few moments.

Living Donors Who Gave Through a Paired Exchange

September 15, 2020

Agenda

- Welcome – Cindy
- Introduction of Michelle Schuerman and Jill Dillon
- Real Stories | Real People
- Open Mic Q&A
- Closing



Welcome

Cindy Huber, CEO
National Kidney Foundation of Wisconsin



Living Donors Together Co-Chairs



Michelle Schuerman
Living kidney donor



Jill Dillon
Living kidney donor



Ami Blattner
Living Kidney Donor Coordinator
Froedtert Hospital

NKFW Advocate

Sara Hicklin
Transplant Recipient



Real People | Real Stories



September 15, 2020





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together
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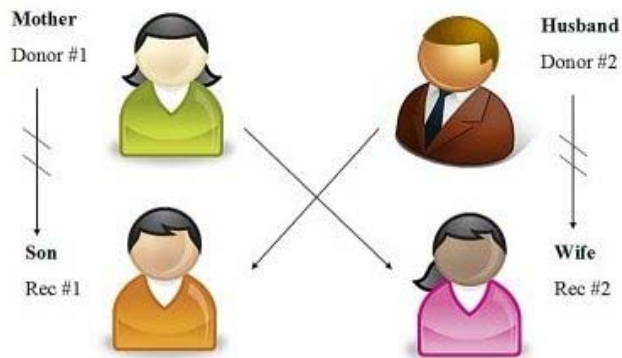
Options for Living Kidney Donation

- Altruistic
- Directed
 - Related
 - Emotionally-related
- Blood Group Incompatible
- Positive Cross-match
- Non-directed in Paired Exchange
 - Local
 - National

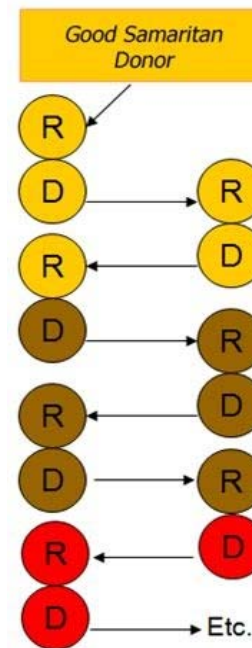


Paired Exchange

Swap



Chain



Live Donor Coverage

- Donor testing, surgery, hospitalization, post-op visit and complications are billed to the recipient's insurance through the transplant center

Donor's insurance should NOT be billed

- Some private health insurance policies may pay for travel/lodging for the donor. Please refer to the individual benefits policy

Donor Expenses

- Expenses related to other health conditions identified during the donor evaluation and regular health maintenance (preventative care measures ex: mammogram)
- Travel, lodging and food – Reimbursement programs are available based on income
- Lost or reduced wages while hospitalized and recovering
- NKR and Alliance Paired Exchange Programs now have lost wage & travel/lodging reimbursement programs IF the donor donates through their paired exchange program. Reimbursement occurs only after the donation has taken place

Open Mic Q&A



Program Evaluation Survey

Watch for our **Living Donors Together** – **Wisconsin** survey in your email to share your opinion.



Living Donors Together – Wisconsin

- Created BY living donors FOR living donors
- Keep current on trends in living donation through awareness, networking opportunities, and education
- Dedicated to inspire and to save lives in Wisconsin and throughout the country

www.facebook.com/groups/livingdonorstgether



Follow on Facebook

- Stay connected with Living Donors Together:
www.facebook.com/groups/livingdonorstgether
- Private Facebook Group
- Get details on
 - *Living Donors Together* meetings
 - Fundraising activities
 - Educational programs for LD or recipients
 - Advocacy



Tonight's Presentation

- Find a recording or copy of tonight's PowerPoint slides:
www.kidneywi.org/living-donors-together-wisconsin



Annual Kidney Patient Summit

The Kidney Patient Summit, led by the National Kidney Foundation, brings together advocates from across the country representing several kidney patient groups, to meet with lawmakers on Capitol Hill to push for early detection, living organ donation, and more funding to fight kidney disease.

Advocates share their stories and urge Members of Congress to support public policy priorities which advance CKD prevention, early detection, treatment, research, and access to transplants, including living organ donation.

Congressional Meeting Talking Points

- Appropriations Funding Request – *Are You the 33%?* campaign seeking a \$10 million appropriation to support NKF work in reaching at-risk Americans
- The Living Donor Protection Act (S. 511/H.R. 1224)
- The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (S. 3353/H.R. 5534)

Advocacy – Status of a Bill

The image displays two overlapping screenshots of the GovTrack website. The left screenshot shows the page for **S. 511: Living Donor Protection Act of 2019**. The right screenshot shows the page for **H.R. 1224: Living Donor Protection Act of 2019**. Both pages include navigation menus, search bars, and sections for 'Overview', 'Summary', 'Details', 'Text', and 'Study Guide'. The 'Sponsor and status' section on both pages identifies the sponsor as **Kirsten Gillibrand**, Junior Senator for New York, Democrat, and notes the bill was introduced on Feb 14, 2019, in the 116th Congress (2019-2021). A large URL is overlaid on the screenshots: [govtrack.us/congress/bills/116/s511](https://www.govtrack.us/congress/bills/116/s511), [govtrack.us/congress/bills/116/hr1224](https://www.govtrack.us/congress/bills/116/hr1224)

Advocacy

- Tell your member of Congress to support the **Living Donor Protection Act (S. 511 / H.R. 1224)**.
- Do this NOW.
- Go to house.gov/representatives/find-your-representative and write an email.

Advocacy

- Find and contact your U.S. Senator:
 - Visit the Senate website (www.senate.gov).
 - Search using the **Find Your Senators** pull-down menu in the upper left corner (select your state and click Go).
- To find and contact your U.S. Representative:
 - Visit the House of Representatives website (www.house.gov).
 - Search using the **FIND YOUR REPRESENTATIVE** zip code search box in the upper right corner (enter your zip code and click **LOOK UP**).
 - On the results page is a photo of your Representative(s), links to the Representative's personal website and online contact form, and a local map.



kidney.org

ADVOCACY PRIORITIES AND PROGRAMS



TOP 3 FEDERAL LEGISLATIVE PRIORITIES

Living Donor Protection Act (H.R. 1224/S.511)

Support legislation that would prohibit discrimination in the pricing or long-term availability of life, disability or long-term care insurance for living donors. The bill also adds living donation to the Family and Medical Leave Act (FMLA).

Extending Medicare Coverage for Immunosuppressive Medication

Transplant recipients need these drugs to maintain their kidney and lower risk of rejection. Medicare covers immunosuppressants for only 36 months post-transplant, leaving many recipients struggling to find affordable coverage. Extending Medicare coverage for immunosuppressive medications indefinitely ensures patients have access to these lifesaving medications.

Appropriations

Increase funding in Fiscal Year 2020 for: CDC's Division of Diabetes Translation's (DOT) CKD Surveillance Project; the Health Resources and Services Administration's (HRSA) Division of Transplantation and Bureau of Primary Care; the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); and Kidney X, the Kidney Innovation Accelerator.

NKF'S ADVOCACY EFFORTS

Kidney Advocacy Committee (KAC)

Consists of more than 200 patient liaisons who use their personal experience to advance NKF's advocacy efforts. The committee comprises those with early stages of CKD, dialysis patients, transplant recipients, living donors, family members, and caregivers. KAC liaisons also represent the NKF through local and national media outreach and on various local committees and advisory boards relating to kidney disease.

kidney.org/advocacy/kidney-advocacy-committee

Kidney Outreach Team (KO Team)

An advocacy organization for practitioners and other select advocates to engage in changing kidney disease public policy through building and strengthening relationships with, and educating, their legislators.

Contact: Andrew.Fullerton@kidney.org

Advocacy in Action blog

Outlines important legislative updates and documents our current advocacy efforts.

nkfadvocacy.wordpress.com

Annual Kidney Patient Summit

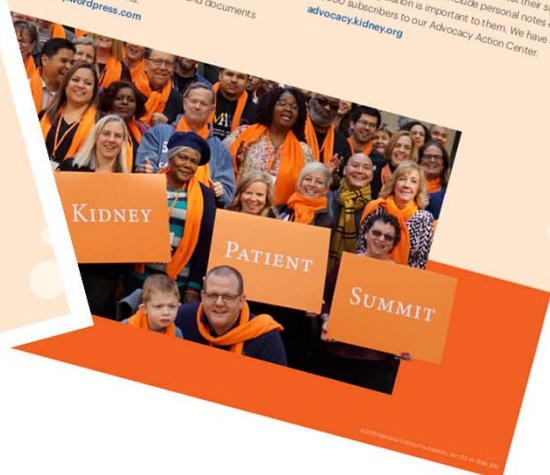
Kick starts National Kidney Month (March) by bringing patient advocates throughout the country to our nation's capital to raise awareness of CKD. Advocates learn about current legislation and tips for sharing their personal connection to kidney disease. They meet with their legislators to influence legislation to improve the lives of kidney patients.

advocacy.kidney.org/6th-annual-kidney-patient-advocacy-summit/

Advocacy Action Center

Allows for easy contact with Congress. Subscribers receive email alerts when their help is needed on legislation and guidance to email their legislators to request their support. They also have the option to include personal notes explaining why the legislation is important to them. We have over 113,000 subscribers to our Advocacy Action Center.

advocacy.kidney.org



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Did you know that **amazon** will make a donation to the **National Kidney Foundation of Wisconsin** every time you shop with AmazonSmile?

Visit **smile.amazon.com** and select the NATIONAL KIDNEY FOUNDATION OF WISCONSIN as “your charity” of choice.



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DONATE TO HELP A KIDNEY PATIENT

1-800-488-CARS (2277)

kidneycars.org

**CONTACTLESS
Pick-up**

KIDNEY
CARS

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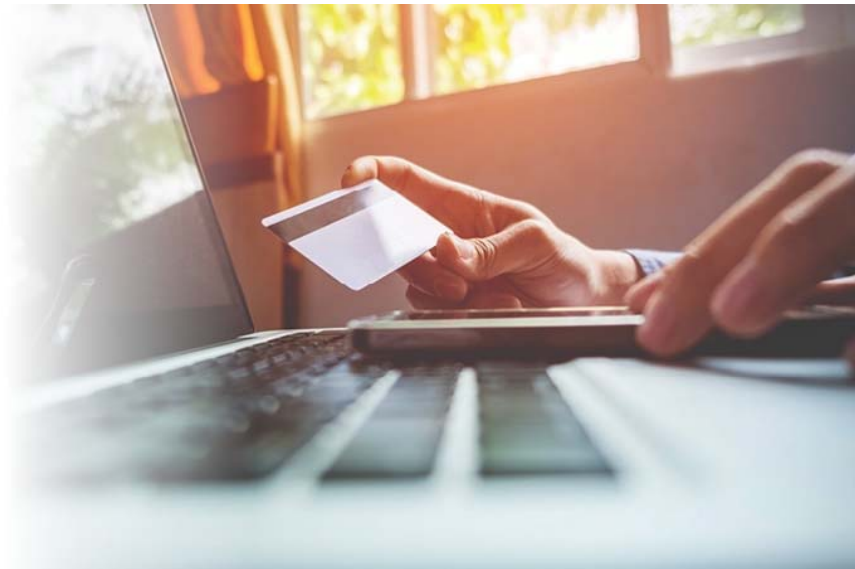
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SHOP
amazonsmile

Did you know that **amazon** will make a donation to the **National Kidney Foundation of Wisconsin** every time you shop with AmazonSmile?

Visit smile.amazon.com and select the NATIONAL KIDNEY FOUNDATION OF WISCONSIN as "your charity" of choice.



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Upcoming Program – Living Donors Together

Tuesday, October 20

watch kidneywi.org for information

Tuesday, November 17

watch kidneywi.org for information



Upcoming Programs – Living Well Before & After Transplantation

Tuesday, October 13

Time, Space, People, Place: Navigating the Holidays during COVID

Allison Stephans, Abdominal Transplant Social Worker

Samantha Hamilton, Post-transplant Coordinator

Froedtert & the Medical College of Wisconsin

Froedtert Hospital

Tuesday, November 10

A Taste of Something New for the Holidays

Closing Remarks

Living Donors Together

September 15, 2020

Thank you for being a part of the program!