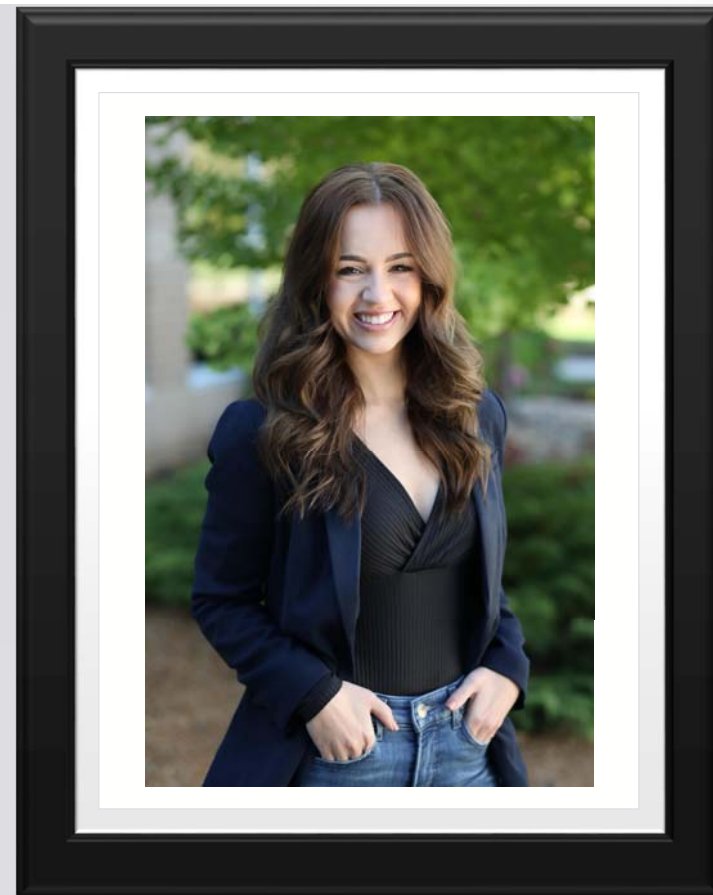




My Journey to Kidney Donation

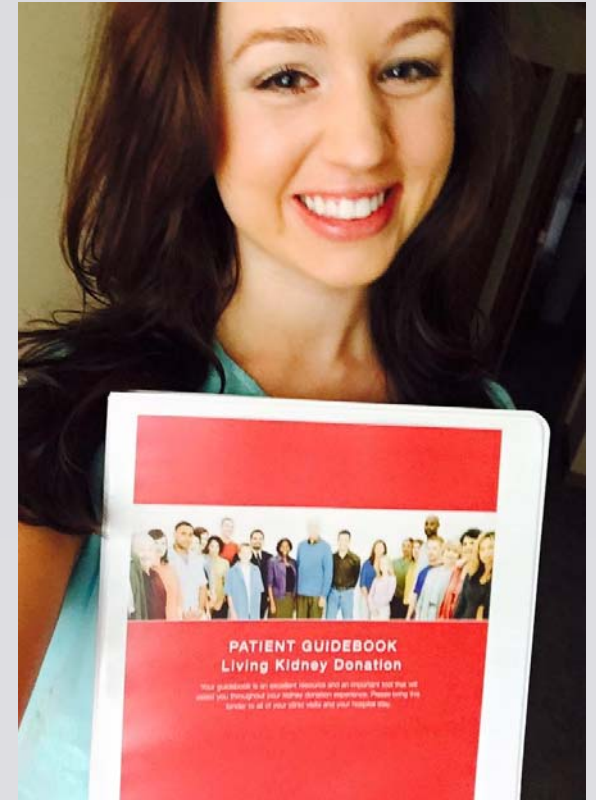
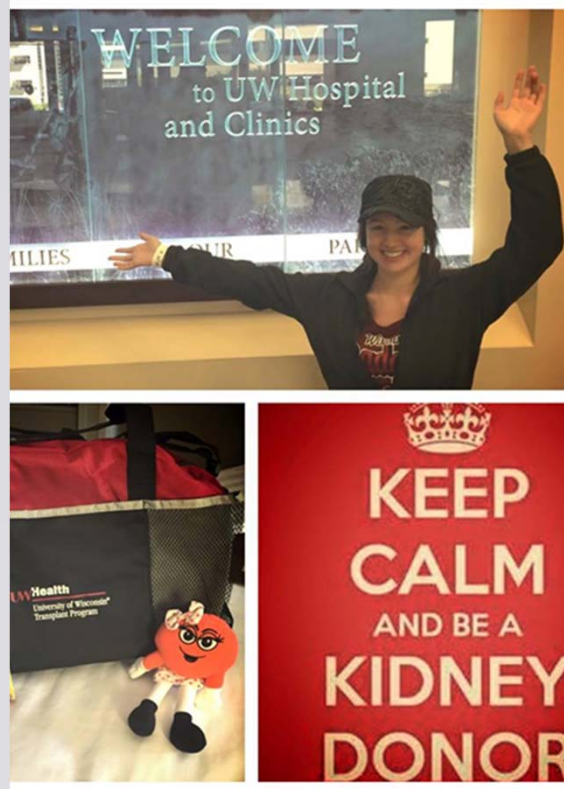
Devyn Prielipp



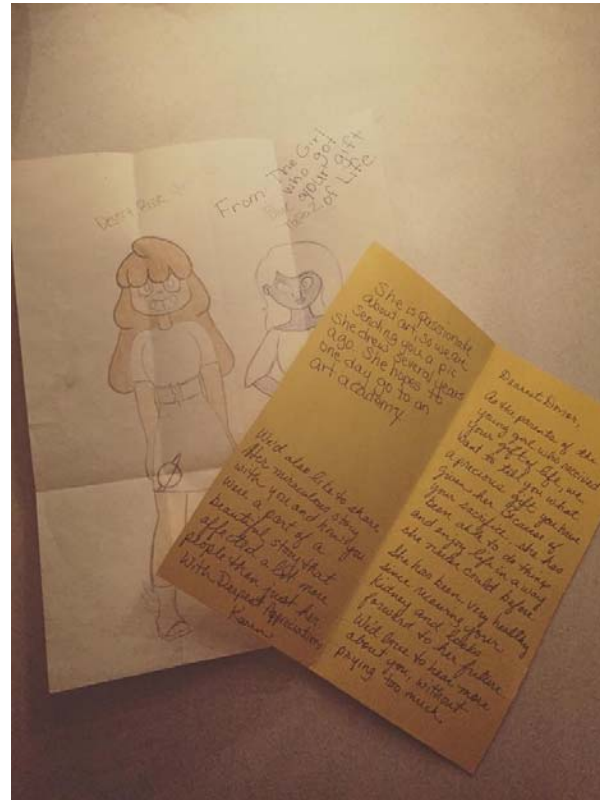




July 22nd, 2009







Dear Dad,

From The Girl who got a lot of love



She is passionate about art so we are sending you a pic a go. She hopes to one day go to an art academy

With love and appreciation
From
Kiana

Dear Dad,

As the parent of the young girl who received your letter, we are so happy to hear that you are so proud of her. It is because of her that we are so happy and proud of her. She has been very healthy since leaving your house and is doing better than ever. We love to hear more about you, without paying too much.



*Your hardest times
often lead to the
greatest moments
of your life.*

HONOR THE GIFT CAMPAIGN

Mary Baliker – Patient Advocate

www.honorthegift.org



THE HONOR THE GIFT CAMPAIGN



Mary Baliker – Patient Advocate



Honor the Gift is a national patient-centered campaign, promoted by a coalition of kidney and transplant organizations, focused on extending Medicare coverage of immunosuppressive medication for kidney transplant recipients beyond the current three-year cap.

www.honorthegift.org



CONGRESSIONAL CHAMPIONS

SENATE SPONSORS



Sen. Bill Cassidy (R-LA)

- Rob Butura (Health Policy Advisor)
- Led the efforts to get technical assistance and CBO score.
- Last heard on Oct 3, he is getting frustrated by HHS' delayed response to the technical assistance request



Sen. Dick Durbin (D-IL)

- Jessica McNeice (Health Policy Director)
- Was involved in briefing Sen. Durbin before his visit to University of Illinois transplant clinic on Oct. 2
- Sen. Durbin offered to contact Sec. Azar urging action on technical assistance

HOUSE SPONSORS



Rep. Ron Kind (D-WI)

- Alex Eveland (Legislative Director)
- Alex visited U Wisconsin in August.
- He remains involved and is included on regular communications from Rob B.



Rep. Michael Burgess (R-TX)

- Elizabeth Allen (Senior Health Policy Advisor)
- She remains involved and is included on regular communications from Rob B.



- The U.S. Department of Health and Human Services' **Secretary Alex Azar** has expressed continued and strong support for the policy change.
- On July 10, during the President Trump's signing of the *Advancing American Kidney Health* Executive Order, Azar stated, "the Trump administration is supporting legislation that would extend [Medicare's coverage of immunosuppressive medications] beyond 36 months in Congress."
- **Nick Uehlecke**, Advisor, HHS' Immediate Office of the Secretary



HONOR THE GIFT WEBSITE & ADVOCACY HUB



[ABOUT](#)

[COALITION](#)

[POLICY](#)

[NEWS](#)

[TAKE ACTION](#)

A hero image showing a diverse group of four people (two women and two men) sitting at a table, smiling and talking. The image is overlaid with a semi-transparent red filter.

Reject Coverage Limits on Kidney Transplant Care

Medicare's 3-year coverage limit on immunosuppressive medications costs transplant patients their lives and Medicare millions. Help us honor the gift of life by protecting kidney transplants.

[SIGN THE PETITION](#)

HONORTHEGIFT.ORG



OTHER INFORMATIVE COMMUNICATIONS

POLICY-ISH

Lawmakers, Advocates Push To Extend Medicare's Coverage Of Kidney Transplant Drugs

July 17, 2019 · 5:01 AM ET

JONEL ALECCIA

FROM **KHN**



<https://www.npr.org/sections/health-shots/2019/07/17/742349066/lawmakers-advocates-push-to-extend-medicares-coverage-of-kidney-transplant-drugs>



THE GIFTED LIFE PODCAST

<https://www.thegiftedlife.org/>



Release Date: 6/07/2019

Show Notes: A crucial aspect of kidney transplantation is aftercare by way of immunosuppressive medications. We talk with kidney recipient, Monica Fox, and transplant surgeon, Dr. Matthew Cooper, to learn about a campaign called **Honor the Gift**. They are hoping to engage Congress and solve problems with Medicare coverage limits. Sara Blakemore talks to us about traumatic grief. Monica Fox rejoins us to share the story of her hero, Milton Powell, and we answer your question, all here on episode 110 of The Gifted Life Podcast.



WHAT CAN YOU DO TO BE A PART OF THE CAMPAIGN?

- **Prior to Introduction**
 - Visit www.honorthegift.org and sign the pledge for email updates
 - Share your story
 - Follow Honor The Gift on Facebook, Twitter, and LinkedIn
 - Share social content
- **Upon legislation introduction**
 - Revisit the website and use the activation tool to contact your legislators
 - Engage with you legislators, encourage them to become cosponsors
- Keep engaged! It's been a long road & we may continue to have many hurdles...
- Keep positive!!!

THANK YOU



Advocacy Update

November 2019

NKFW Advocate

Sara Hicklin

Transplant Recipient



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

- Overview

- Bills were introduced in both chambers of Congress on 2/14/19
 - House bill is assigned to the following committees:
 - Education and Labor (Glenn Grothman, R-6)
 - Energy and Commerce (subcommittee on Health)
 - Financial Services (Bryan Steil, R-1)
 - House Administration
 - Oversight and Reform (Glenn Grothman, R-6)
 - Senate bill is assigned to the Health, Education, Labor and Pensions Committee
 - Tammy Baldwin is a member of this committee
- Protects living donors from discrimination related to life insurance, disability insurance, or long-term care insurance regarding denial or limits on coverage, charging higher premiums or canceling coverage based solely on the applicants status as a living organ donor
- Clarifies FMLA to include living organ donation as a serious health condition

- 116th Congress (2019 – 2020)
 - All bills currently introduced remain active until either acted on or the current Congress ends at the end of 2020
 - House bill is currently co-sponsored by the three Democratic representative in the House (Mark Pocan – D2, Ron Kind – D3, and Gwen Moore – D4)
 - Senate bill isn't co-sponsored by either Wisconsin Senator
 - Committees need to release the bill to be put on the chamber calendar for vote, debate or amendment
 - If passed by both chambers, a conference committee resolves and differences between the two versions of the bill
 - Both chambers vote and, if passed, the President has 10 days to sign or veto the legislation

How can you help?

- Contact your Representatives and Senators about co-sponsoring the Living Donor Protection Act (S. 511 and H.R. 1224)
 - November and December can be good times to connect with the local office.
 - Week of 11/25 through 11/29 neither chamber is in session
 - Both sessions are adjourned for 2019 in mid-December
 - Write letters or email
 - Connect on social media – you will be notified of local meetings
 - Call their offices both locally and in Washington DC and ask for support of the appropriate bill (H.R. 1224 or S. 511)
 - Attend local listening sessions
 - Ask for sponsorship and tell your story

Some reasons to ask for support of LDPA (real reasons submitted by fellow Wisconsinites)

- My employer refuses both life and short/long term disability insurance for employees who donate a kidney. The first question asked on the applications is “Have you ever donated a kidney?”
- When I was going through the process to donate, many expressed their reluctance to donate because of the potential future costs to them
- My sister donated a kidney to me. Taking the necessary time off for recovery was difficult for her.
- Please help the people who are trying to help others
- My son-in-law lost \$3,000 in wages for the recovery time after donating a kidney to me