



# Resolved: I Will Speak Up and Advocate for Transplantation in 2020

- How to advocate
- Updates on pending legislation

# Guide to New Year's Resolutions

- ▶ How to succeed?
  - ▶ Choose specific, measureable goals
  - ▶ Have a detailed, written plan
  - ▶ Start with small steps
  - ▶ Remember change is a process
  - ▶ Get support from friends and family
  - ▶ Renew your motivation

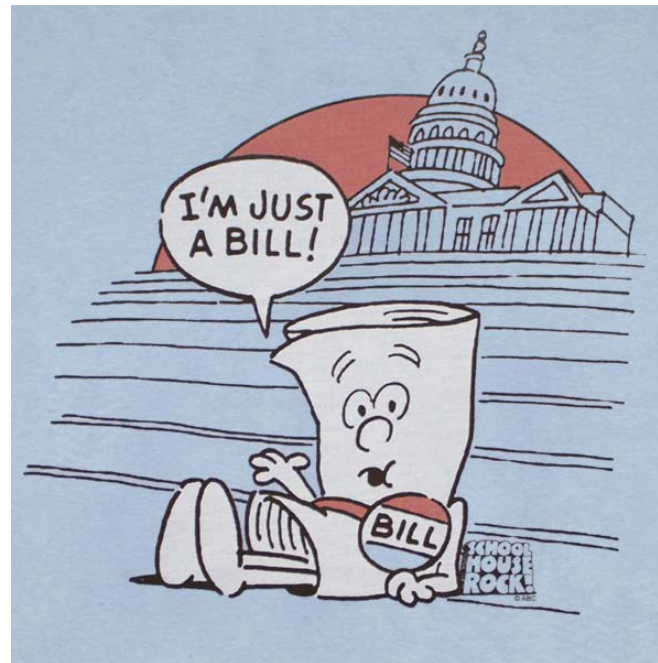


# How do you become an advocate?

- ▶ An advocate is a person who publicly supports or recommends a particular cause or policy
- ▶ Find your passion
- ▶ Turn your passion into action
- ▶ Tell your story as a patient, living donor, deceased donor family member or medical professional
- ▶ Use your experience and expertise to inform public policy makers of related legislation, policies, research, programs, and education

## How does a bill become a law?

1. A bill is introduced in either the House, Senate or both by the primary sponsors. The President can also introduce legislation, but this is rare.
2. The bill is assigned to the appropriate committee in either chamber.
3. The bill may be discussed and debated in committee, and there can be hearings held with expert witnesses.
4. If the committee votes favorably, the bill goes to the House or Senate floor for the whole chamber to vote on the bill.
5. If passed in just one chamber, the bill goes to the other chamber and goes through steps 2-4. Once passed in both chambers, a conference committee resolves any differences between the two bills and both chambers vote again.
6. Once both chambers have approved the combined bill, it goes to the President who can either sign it into law or veto the bill.

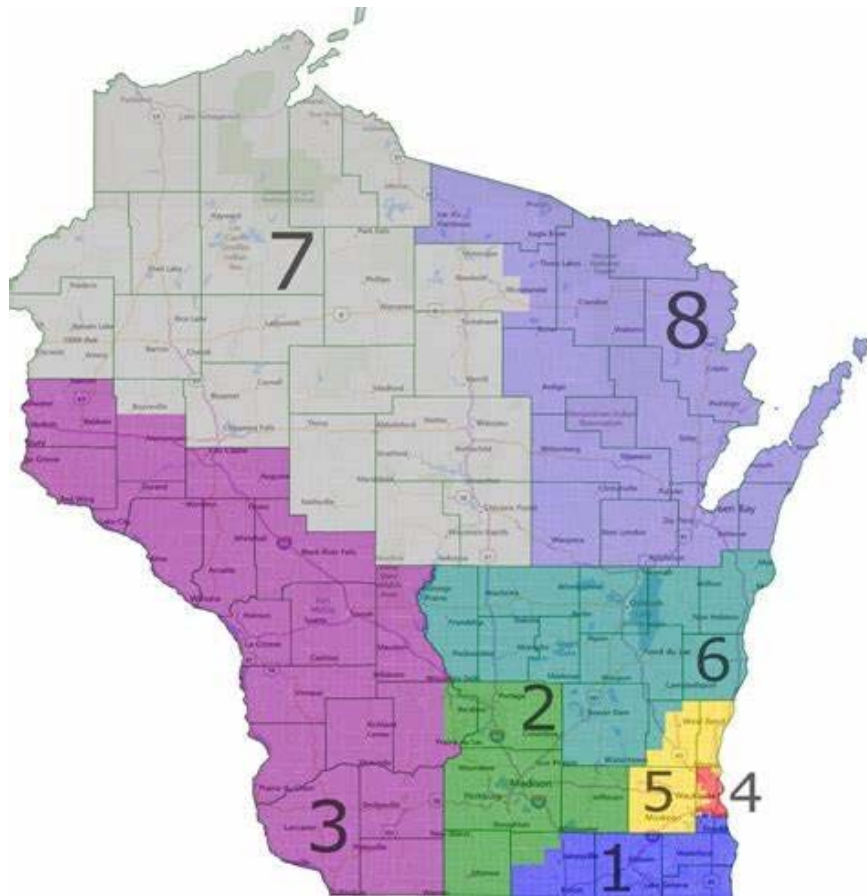


## What happens in Committee?

- Bills in committee are usually assigned to a subcommittee for review but can also be held for the full committee. If held for the full committee, it usually means that the bill is either
  - Fast-tracked or
  - Pigeonholed (no action will be taken)
- Hearings can be held at either the subcommittee or full committee level to discuss the merits of the bill
  - Expert witnesses are called
  - Affected government agencies can testify
- After hearings are held, the bill goes into markup where amendments can be made and the bill is either accepted or rejected.
- Bills that are accepted in committee go to the floor for a full chamber vote



# Find Your District



# Wisconsin legislators and committee assignments

## House of Representatives

- ▶ District 1 - Bryan Steil (R)
  - ▶ Financial Services
- ▶ District 2 - Mark Pocan (D)
  - ▶ Appropriations
- ▶ District 3 - Ron Kind (D)
  - ▶ Ways and Means
- ▶ District 4 - Gwen Moore (D)
  - ▶ Ways and Means
- ▶ District 5 - Jim Sensenbrenner (R)
  - ▶ Judiciary
  - ▶ Foreign Affairs
- ▶ District 6 - Glenn Grothman (R)
  - ▶ Oversight and Reform
  - ▶ Education and Labor
- ▶ District 7 - Vacant
- ▶ District 8 - Mike Gallagher (R)
  - ▶ Transportation and Infrastructure
  - ▶ Armed Services

## Senate

- ▶ Tammy Baldwin (D)
  - ▶ Appropriations
  - ▶ Health, Education, Labor and Pensions
  - ▶ Commerce, Science and Transportation
- ▶ Ron Johnson (R)
  - ▶ Homeland Security and Governmental Affairs
  - ▶ Foreign Relations
  - ▶ Budget

# Does your voice really matter?

- Bills are introduced by their primary sponsors
- Other legislators that want to show their support of the bill can sign on as co-sponsors at any time after the bill is introduced
- Generally, if the number of co-sponsors is more than half of the total number of legislators in the chamber, it should be brought to the floor for a vote. (Senate = 51, House = 218)
- Public opinion does influence whether a legislator will co-sponsor a bill
  - Staffers keep track of the number of phone calls, emails, letters, and social media posts in favor of or against a particular issue
  - Many legislators monitor their own social media accounts, so tagging them on Twitter, Facebook or Instagram can be very effective
  - Contact from constituents who live in the district has more meaning than contact from someone who doesn't live in the district



# Advocacy Resolution for 2020

- ▶ Choose specific, measureable goals
  - ▶ Contact your legislators on a regular basis
  - ▶ Monitor the status of the bills you are passionate about
  - ▶ Start following your legislators on Facebook, Twitter and/or Instagram
- ▶ Have a detailed, written plan
  - ▶ Use a calendar to plan your contacts - at least monthly
  - ▶ Decide which methods of contact you will use (social media, email, letters, phone calls) and how often you will use each method
  - ▶ Schedule in-person meetings with your legislator's local office
  - ▶ Use websites such as govtrack.us to get emailed updates on the bills you are following
- ▶ Start with small steps
  - ▶ Read about advocacy on [kidney.org/advocacy](https://www.kidney.org/advocacy)
  - ▶ Decide what you are passionate about
  - ▶ Attend a town hall meeting hosted by your legislators to understand their priorities
- ▶ Remember change is a process
  - ▶ If you miss a reminder for a contact, just make the contact as soon as you remember
  - ▶ If you're getting too many emails, see if you can change the settings to get weekly or monthly updates
- ▶ Get support from friends and family
  - ▶ Ask for their help in making contacts - especially if they live in a different district or even a different state than you
- ▶ Renew your motivation
  - ▶ Remember who you're fighting for and why this is important to you

## H.R. 5534 - Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2019

- ▶ Kidney transplant patients under age 65 can enroll in Medicare Part A and Part B coverage at the time of transplant.
- ▶ Part B includes coverage of immunosuppressant drugs that are vital to avoid rejection of the kidney
- ▶ Coverage currently begins the first of the month in which the transplant is received, and lasts for 36 months
- ▶ The bill would eliminate the 36-month restriction for patients who don't have other coverage for the medications (employer coverage, individual coverage, Medicaid, Tricare, etc.)



# Living Donor Protection Act H.R. 1224 and S. 511

- ▶ Living donors are not currently covered under FMLA because they are having elective surgery and do not have a serious illness.
- ▶ FMLA doesn't apply to employers with less than 50 employees.
- ▶ Wisconsin does not have legislation protecting living donors as twelve other states have done, but individual employers (such as the State of Wisconsin) may have policies protecting living donors
- ▶ Living donors can be subject to discrimination when applying for or renewing life insurance, health insurance, and long-term care insurance. This could be anything from higher premiums, non-coverage for pre-existing conditions or denial of coverage



# Current Co-Sponsors of LDPA

## House of Representatives

- ▶ Mark Pocan, WI-2 (D)
- ▶ Ron Kind, WI-3 (D)
- ▶ Gwen Moore, WI-4 (D)

## ▶ Senate



## Resolved!

Please choose 2-3 actions items to begin your 2020 Advocacy efforts

- ▶ Write down your story and have a 5-minute talk and an “elevator” talk
- ▶ Decide how to best contact your legislators (you can choose more than one)
  - ▶ Mail
  - ▶ Email
  - ▶ Phone
  - ▶ Social Media
- ▶ Decide how often you will make contacts
- ▶ Ask friends and family to help you advocate
- ▶ Research Advocacy resources on kidney.org
- ▶ Choose kidney events to attend in 2020
- ▶ Volunteer at events in an advocate capacity
- ▶ Watch Schoolhouse Rock “I’m Just a Bill”
- ▶ Use #mykidneysmylife on Facebook, Twitter and Instagram when posting about transplant and donor issues