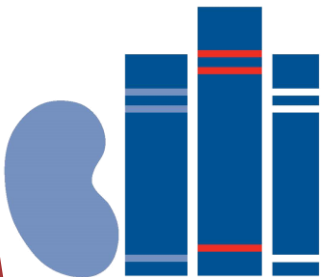


How to be a successful patient advocate

January 25, 2018

Welcome

- All phone lines are muted
- **Mute *6**
- **Unmute: #6**
- Unmute your phone to ask questions at the end of the presentation
- Or, ask questions through the Chat Box
- Recording and slides will be available on web site
- Please provide feedback



Our Speakers for Today's Program



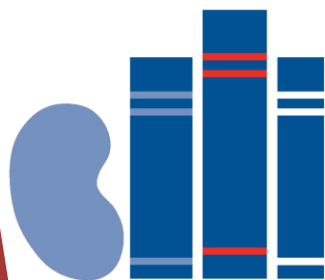
Megan Beveridge

- ▶ Director of Congressional Relations at DPC where she manages and coordinates all efforts between DPC and Members of Congress and their staff



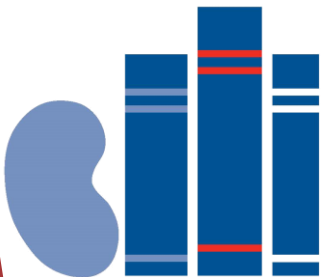
Mike Guffey

- ▶ Kidney transplant recipient who serves as Treasurer and Board Member for Dialysis Patient Citizens.



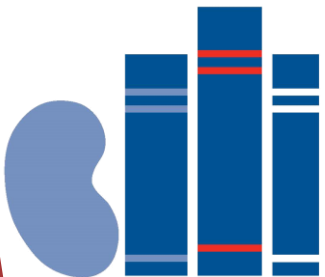
Why Advocate?

- ▶ You are a constituent and voter
- ▶ You have a story to tell
- ▶ You want to make a difference for yourself and others
- ▶ You are an expert on dialysis
- ▶ You don't need to be an expert in public policy
- ▶ If you don't, WHO WILL?



Reaching a Legislator

- ▶ Both House and Senate Members have offices in Washington, D.C. and in their district/state.
 - ▶ To find this information, go to the Members web page
 - ▶ For specific casework, it is normally best to call the district or state office
 - ▶ To voice your policy opinions, it is normally best to call the D.C. office



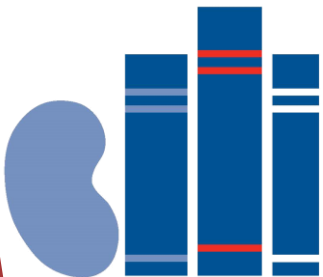
Where to Advocate

In Washington, D.C.

- ▶ Meet with the Member or Legislative staff
- ▶ Make sure to tell them your patient perspective
- ▶ Get their contact information and maintain a relationship - this way when you have legislative priorities, the staff member would be the person to reach out to

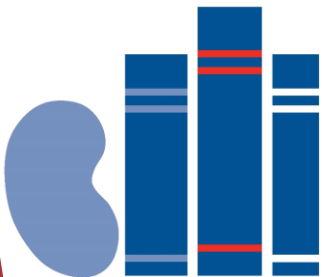
In the State or District Office

- ▶ Contact the state or district office - most Members also allow you to request a meeting through their website
- ▶ Meet with the Legislator or local staff - it is normally the local staff who handle casework issues
- ▶ Become a subject expert for them to reach out to
- ▶ Invite the Member or staff to visit your local dialysis center



Don't Worry - Be Confident

- ▶ Being an advocate takes courage!
- ▶ You are stepping outside your comfort zone, raising your voice for a cause
- ▶ Remember you probably have more experience on this issue than the staff or Member and it's ok if you don't know everything - you can always follow up with additional information



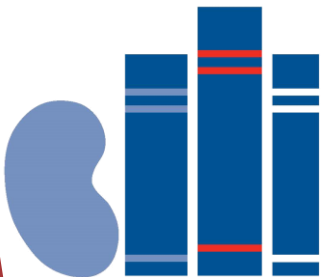
Remember to tell your story!

- ▶ How did you lose kidney function?
- ▶ How long have you been on dialysis?
- ▶ Which modalities have you been on?
- ▶ How has your condition impacted you economically, personally, professionally?
- ▶ Have you been able to access a supplemental plan to help with costs?
- ▶ Why did you want to become an advocate?



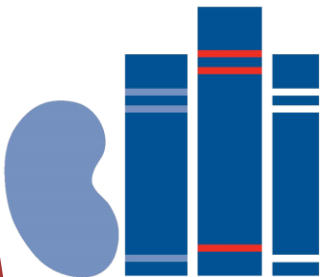
DPC/Kidney Community Priorities

- ▶ H.R. 4143/S. 2065 - The Dialysis PATIENTS Demonstration Act
- ▶ H.R. 3976 - Access to Marketplace Insurance Act
- ▶ H.R. 2644/S. 1890 - The Chronic Kidney Disease Improvement in Research and Treatment Act



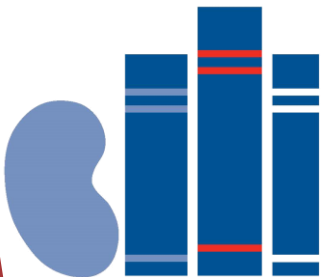
H.R. 4143/S. 2065 - The Dialysis PATIENTS Demonstration Act

- ▶ This bill was introduced by Reps. Smith (R-MO), Blumenauer (D-OR), McMorris Rodgers (R-WA), and Cardenas (D-CA) and Senators Young (R-IN), Nelson (D-FL), Bennet (D-CO), and Heller (R-NV)
- ▶ It has 144 cosponsors in the House and 7 in the Senate
- ▶ This bill would establish a demonstration project to provide more patients with access to care coordination



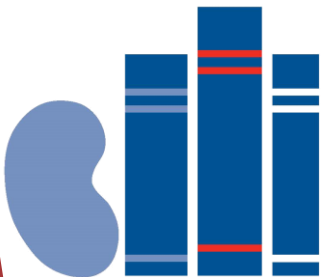
What is Care Coordination?

- ▶ Bridging Gaps in Care
- ▶ Examples for Dialysis Patients
 - ▶ Gap between renal care and diabetes care
 - ▶ Gap between hospital and dialysis clinic
 - ▶ Gap between dialysis treatments
- ▶ One entity, such as a dialysis center, can take responsibility for bridging such gaps
- ▶ Coordinated care means that each health care provider serving a patient shares information with one another in a timely manner
- ▶ This should be a major priority for Medicare - could substantially decrease costs while increasing patient outcomes



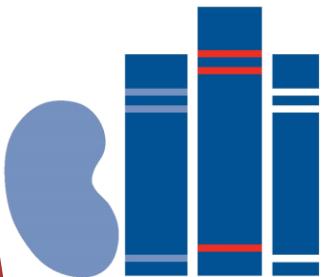
H.R. 4143/S. 2065 - The Dialysis PATIENTS Demonstration Act

- ▶ Care coordination by dialysis organization
- ▶ Medication management
- ▶ Treatment of comorbidities
- ▶ Better communication among providers, such as hospitals
- ▶ Possible additional benefits



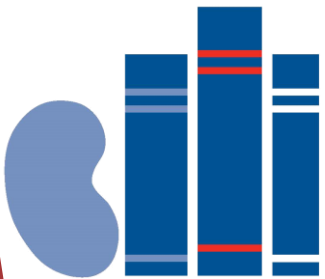
H.R. 3976 - Access to Marketplace Insurance Act

- ▶ This bill was introduced by Rep. Cramer (R-ND) and now has 89 cosponsors
- ▶ This bill would prohibit insurance companies from rejecting a patient's ability to use charitable assistance to purchase private insurance on the individual market.
- ▶ For decades, nonprofit organizations have provided premium and cost sharing assistance for patients who struggle to pay for staggering health care costs.
- ▶ Private insurance companies are increasingly pushing back on a dialysis patient's ability to use charitable assistance to access their plans because they don't want to pay the high costs of treatment.
- ▶ Kidney disease patients, like all other patients, should be able to choose coverage that best meets their needs, whether that be public or private coverage, and through access to charitable assistance they are able to do just that.



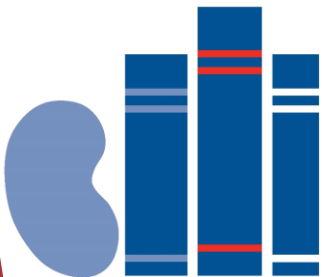
H.R. 2644/S.1890 - The Chronic Kidney Disease Improvement in Research and Treatment Act

- ▶ This bill was introduced by Rep. Marino (R-PA) and Rep. Lewis (D-GA)
- ▶ It would among other things ensure all ESRD Medicare beneficiaries have access to Medigap plans

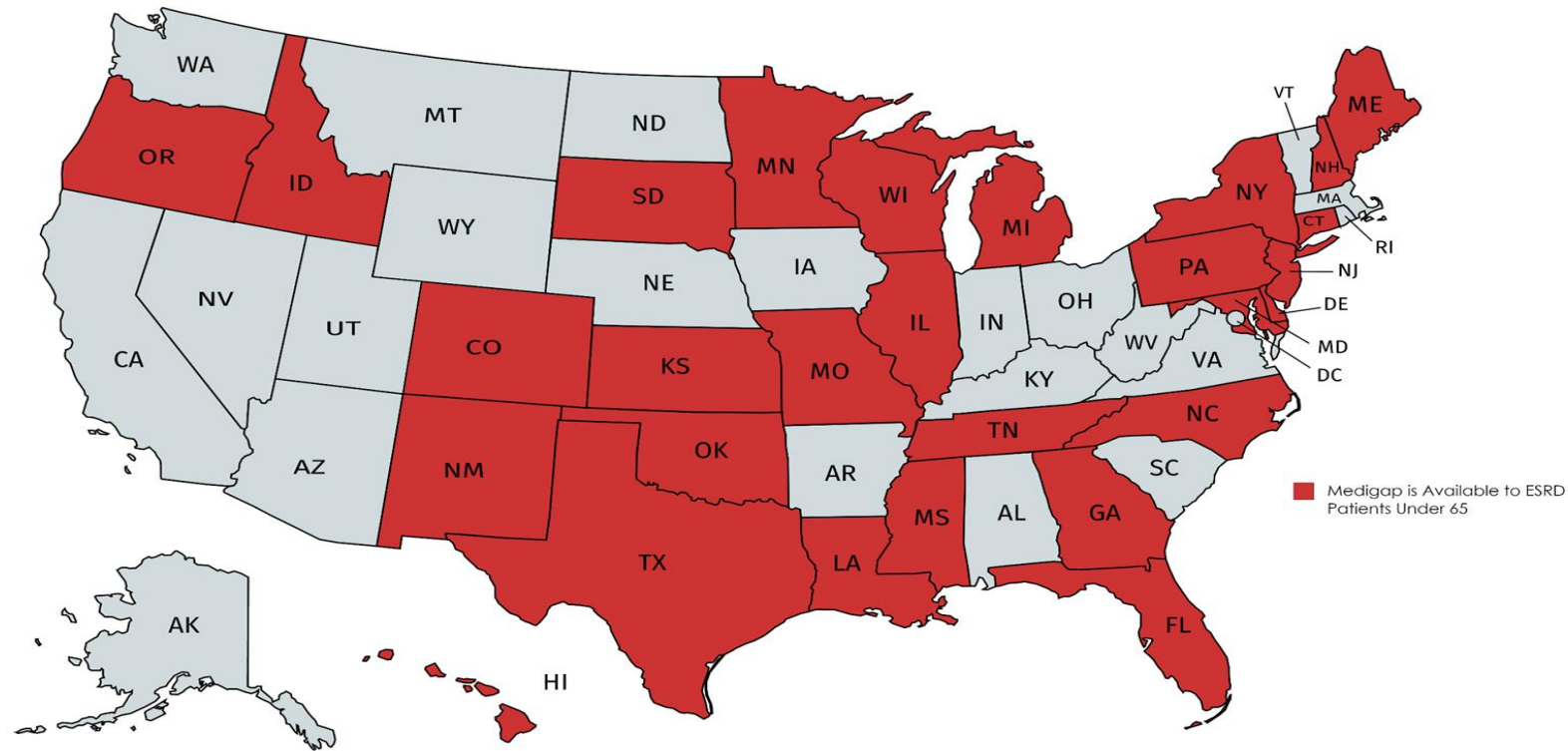


What is Medigap?

- ▶ Medigap policies are standardized, private insurance policies that cover costs not covered by Medicare, such as copayments and deductibles.
- ▶ Under Federal law, Medicare beneficiaries age 65 and older are guaranteed access to Medigap policies, but beneficiaries under age 65, including many with End-Stage Renal Disease (ESRD), do not share this protection.

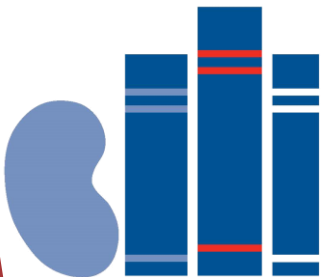


Only the states in red currently allow ESRD patients under 65 access to Medigap



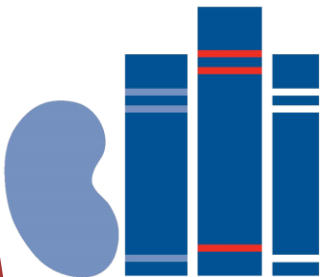
Why do ESRD patients need Medigap?

- ▶ ESRD patients require either dialysis or kidney transplants to survive. Both of these treatments are costly, and without supplemental coverage, Medicare patients bear significant out-of-pocket expenses.
- ▶ ESRD patients face cost-sharing of \$7,225 per year, on average, just for their dialysis treatments. They face additional out-of-pocket costs for physician visits, hospital admissions, and other services they need to stay alive.
- ▶ Access to Medigap could be life saving as most transplant centers require patients to have supplemental coverage as a condition of receiving a kidney transplant.



H.R. 2644/S.1890 - The Chronic Kidney Disease Improvement in Research and Treatment Act

- ▶ H.R. 2644 would also
 - ▶ improve the lives of those suffering with kidney disease by identifying barriers for transplantation and improving donation rates.
 - ▶ promote access to home dialysis treatments
 - ▶ seek to understand the progression of kidney disease and the treatment of kidney failure in minority populations and improve access to kidney disease treatment for those in underserved rural and urban areas.



What to do now?

- ▶ Contact your Member of Congress by phone or email and urge them to support H.R. 4143/S.2065, H.R. 3976, and H.R. 2644/S.1890
- ▶ Request a meeting with the Representative or staff member to discuss these issues
- ▶ Keep in touch with staff - become their resource on dialysis issues
- ▶ Continue to be an advocate - if not you, then who??

