



PKD FOUNDATION
**ADVOCACY CHAMPIONS
NETWORK**

Kickoff Webinar

November 29, 2022



PKD FOUNDATION
Polycystic Kidney Disease

Who Are We?



PKDF Advocacy Champions

Advocates committed to sharing their personal stories with federal legislators to further PKDF initiatives



PKD Foundation

A trusted leader in funding and advocacy in PKD who sets legislative goals and priorities

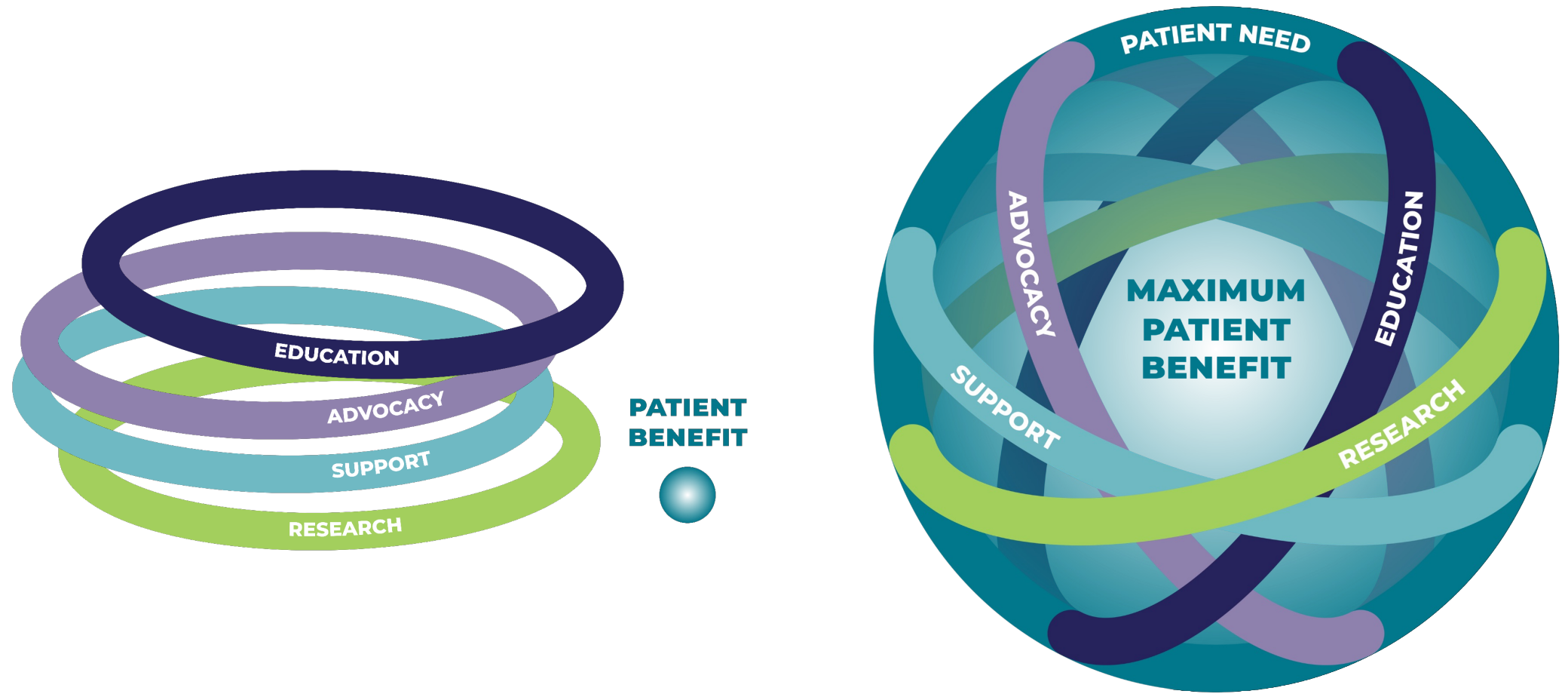


CURA Strategies

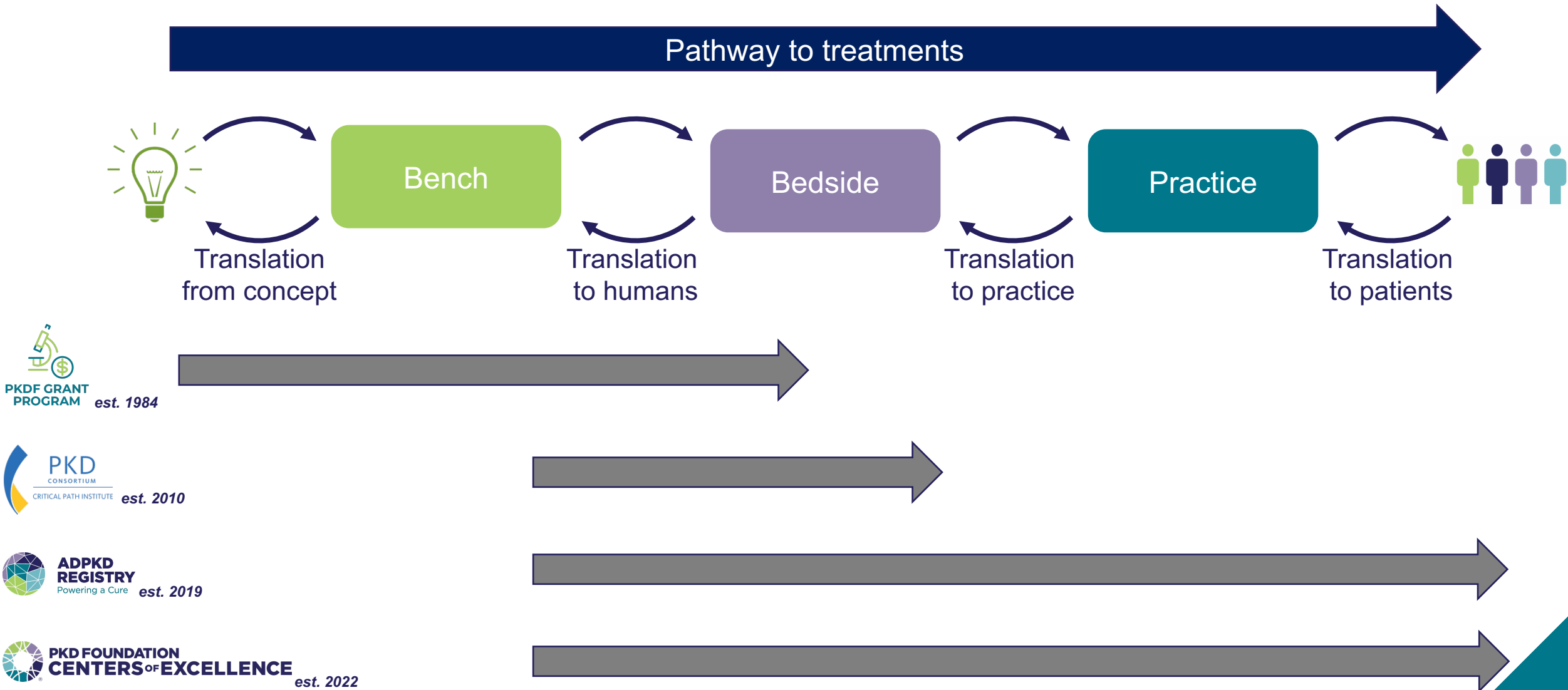
PKDF's partner in federal advocacy and providing the expertise and training to maximize PKDF's legislative efforts



Supporting patients along your full journey



Advancing research from concept to patients



*Modified from NIH Roadmap for Medical Research



Our grants program is successfully providing seed funding to drive PKD research



\$3.2M

in funding to 22
PKD Investigators



~\$10.6M

in grant funding to 66
investigators since
2017



\$180M+

in federal funding to
PKD since 2017



HISTORY OF PKDF ADVOCACY



PKDF Advocacy History

1990

Advocacy efforts begin at the Foundation, with an initial focus on NIH funding for PKD research



2015

Began partnering with American Society of Nephrology & National Kidney Foundation for our annual hill day



1998

Began hosting **United on the Hill Day** to meet with members of Congress and advocate for both PKD-specific issues, as well as broader kidney and health related issues



Advocacy Accomplishments

1998

NIH Established PKD
Core Research
Centers



2007

Clinical Trial
Endpoints workshop
put on by FDA and
PKDF



2012

PKDOC meeting to
discuss total kidney
volume



First U.S. Senate
National PKD
Awareness Week
Resolution

2006



Genetic Information
Nondiscrimination Act
(GINA)

2008



Partnered with the
Honor the Gift
coalition to pass the
Immuno Bill into law

2020



Success in Advocacy 2021-22



Advocated for federal protections for living organ donors by encouraging Congressional support for the Living Donor Protection Act (H.R. 1255/S. 377)



Ensured PKD's inclusion as a covered disease area under the DoD's Peer Review Medical Research Program (PRMRP) in FY22, and advocated for continued inclusion in FY23



Held the Foundation's first-ever Virtual Advocacy Day on April 27, 2022, where nearly 100 advocates participated in over 110 Congressional meetings to advocate for the Foundation's priorities



PKDF Virtual Advocacy Day 2022

On April 27, 2022, PKD Advocates from across the country united for the first-ever PKD Foundation Virtual Advocacy Day!

- Nearly **100** advocates registered
- Over **110** meetings with Congressional offices
- **8** Meetings with Members of Congress
- Opportunities for PKDF Advocacy Champions to serve the community by volunteering as State Leaders

ACN Champions will continue to serve as State Leaders in future PKDF Virtual Advocacy Days



Advocacy Priorities 2022-23

1

Maintain and maximize federal investment in polycystic kidney disease research under the Congressionally Directed Medical Research Program (CDRMP)

2

Advocate for legislation that directly impacts and encourages kidney donations among the PKD community, including the Living Donor Protection Act (LDPA)

3

Elevate and address the consequences of racial disparities in kidney disease diagnosis, treatment, and access to transplantation (particularly for PKD)

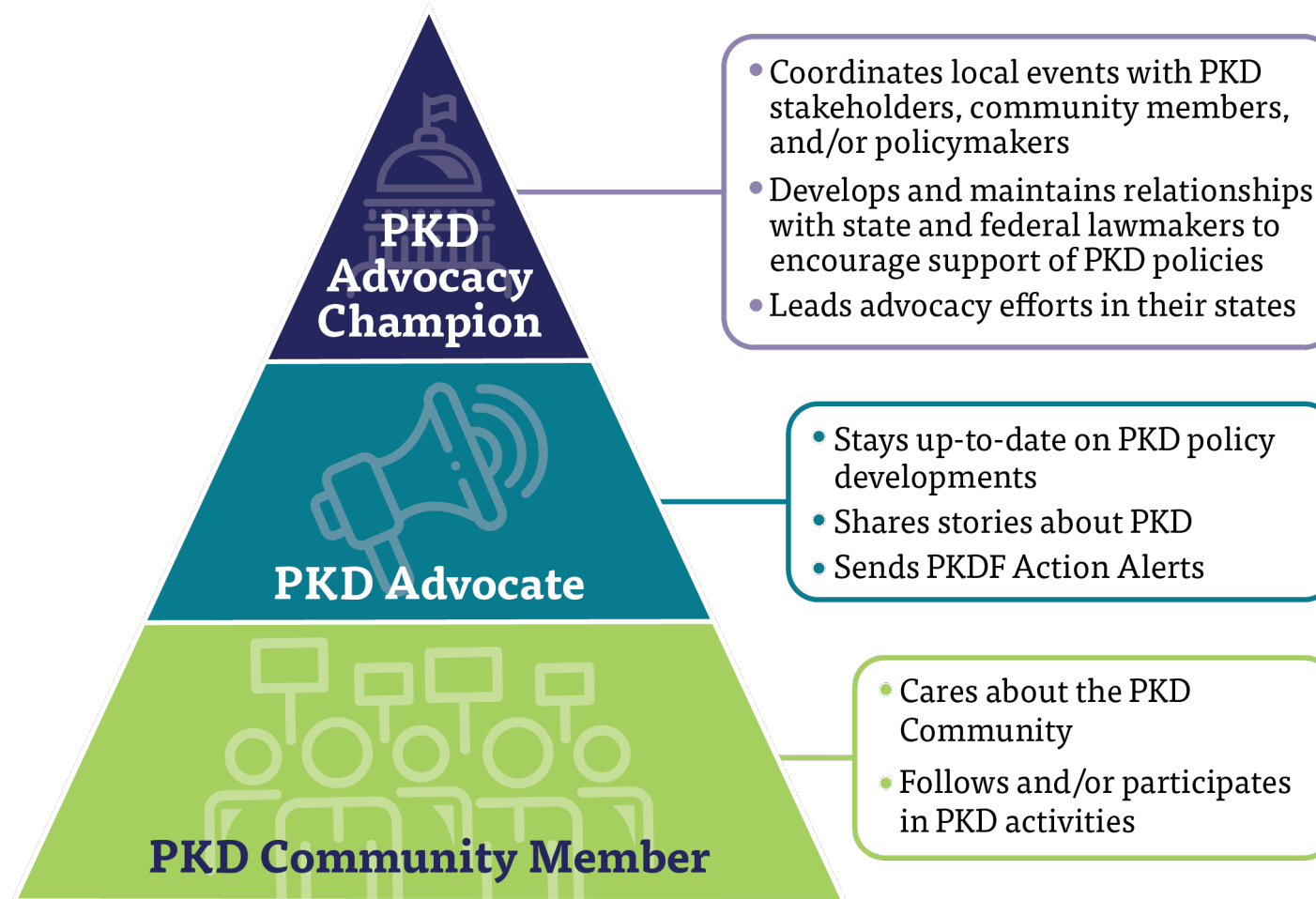


WHY THE ADVOCACY CHAMPIONS NETWORK?

Connecting PKD patient stories and advocacy



PKD Advocacy Engagement





PKD FOUNDATION **ADVOCACY CHAMPIONS NETWORK**

Grassroots, handpicked advocates to drive federal PKDF initiatives

What

- A powerful, unified voice to advance advocacy goals
- Great engagement opportunity for our most key stakeholders
- Year-round advocacy programming

Who

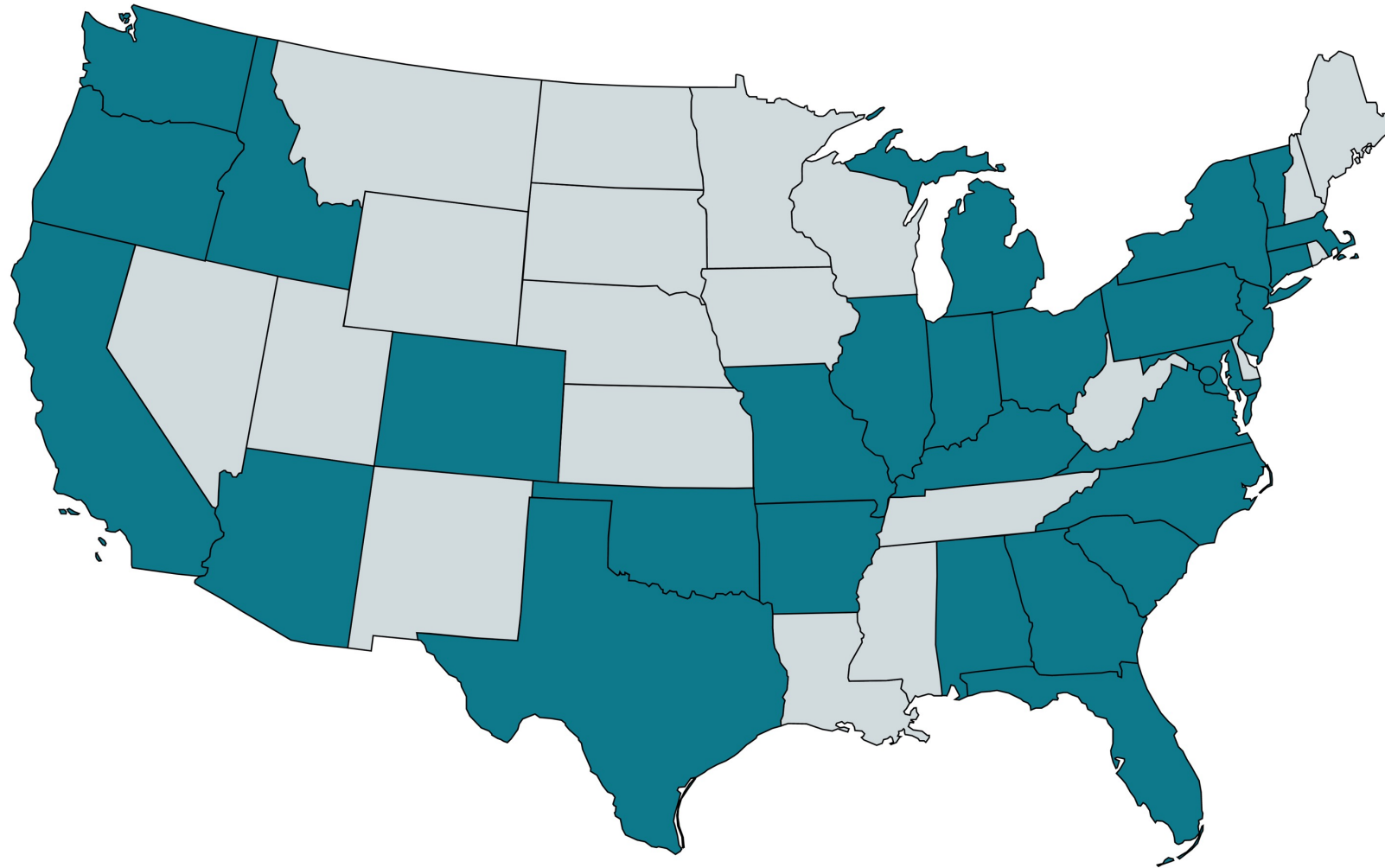
- **YOU! 58+** dedicated volunteers in 2022-23
- Willing to provide about 10 hrs/mo to support PKDF advocacy mission
- Willing to be advocacy leaders within the PKD community

How

- Participate in bi-monthly education and training
- Create closed, dedicated communication channels
- Organize for legislative action

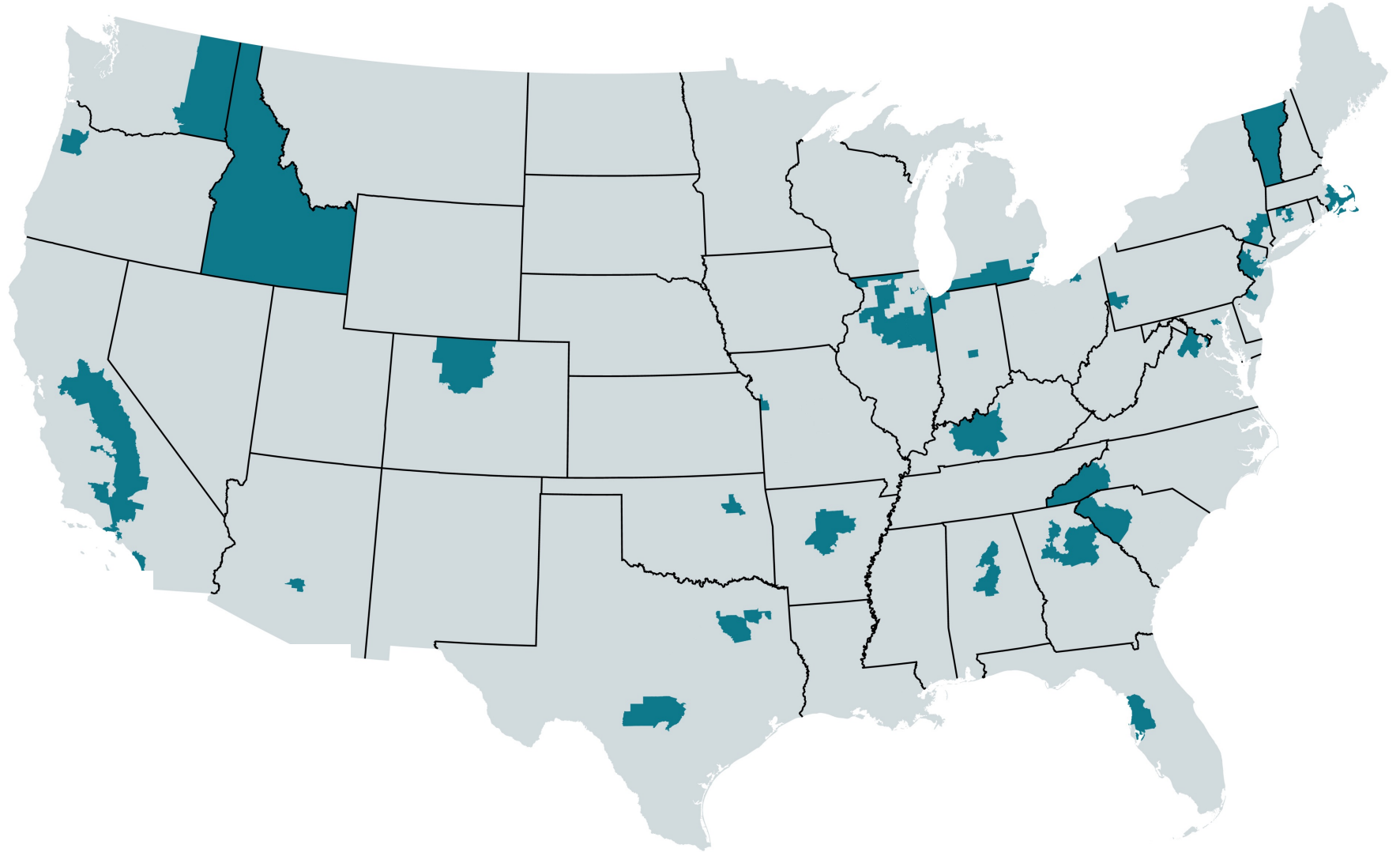


Advocates Across America



Our 58+ Advocacy Champions hail from 29 different states...

Advocates Across America



...and 51 different congressional districts!

Build an Advocacy Community

ACN members have membership in an exclusive, private Facebook group as a place for group discussion among advocates

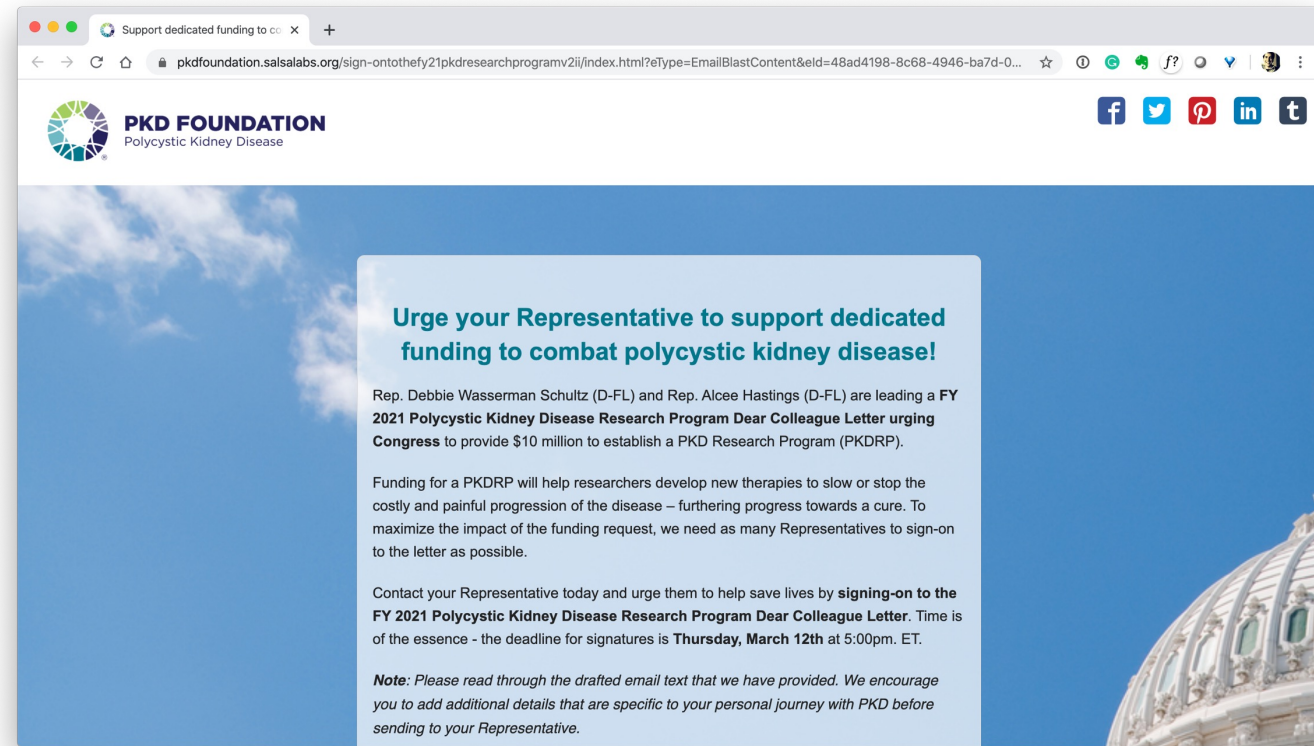
This closed Facebook group will allow you to:

- Share your PKD story
- Ask questions
- Share tips and tricks for outreach
- Engage with other advocates in the PKD community



Take Action As A Team

- ACN Champions will use action alerts to engage the PKD community and build on the Foundation's advocacy contact list
- Action alerts allow for a community's voice to be heard by legislators on Capitol Hill
- Champions will help spread the word in your communities and reach new advocates



Take Action Now!



Meet with Congress

Advocacy Champions participate in trainings about Congress and how to formally request meetings with federal representatives.

- ▶ ACN Champions have met with their Members of Congress in standalone meetings, as well as during our 2022 Virtual Advocacy Day
 - ▶ Champions have participated in 65+ Congressional meetings so far in 2022
 - ▶ **15 Senators** and **14 Representatives** have cosponsored the Living Donor Protection Act after meeting with Champions!
- ▶ Champions have scheduled in-district, in-person meetings with their Members of Congress



Share Your Story

- ACN members are encouraged to share their PKD stories in local media outlets
- PKDF amplifies this coverage and ensures that champion stories are properly broadcast online
- Local articles will spread awareness in your community and may even be flagged for your Congressional members



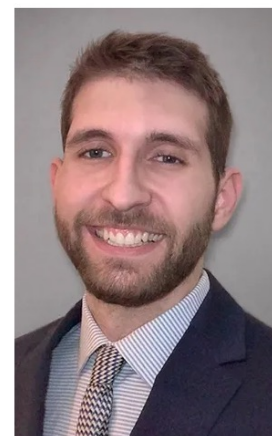
ASHEVILLE CITIZEN-TIMES

Opinion: Bipartisan bill for Living Donor Protection Act would provide key protections

Devan Woody OPINION COLUMNIST
Published 5:00 a.m. ET Sept. 4, 2022

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Thirty seven million Americans or more than one in seven adults [are estimated to have chronic kidney disease \(CKD\)](#). Nearly 786,000 have progressed to [end-stage renal disease \(ESRD\)](#), requiring either dialysis or a kidney transplant to live. Unfortunately, dialysis is not a perfect treatment, and from my experience working as a hemodialysis technician, I have seen the toll it can have on someone's quality of life. Organ transplantation can provide a much higher quality of life, but organs are limited, and barriers to living donation currently exist. Several conditions can cause ESRD, with diabetes and high blood pressure being the two most common. Another cause affecting roughly 600,000 Americans, including myself, is [Polycystic Kidney Disease \(PKD\)](#).



Devan Woody Submitted

Clovis woman backs law to protect organ donors from job losses, higher insurance rates

BY LAINIE ESQUIVEL

UPDATED SEPTEMBER 26, 2022 10:38 AM



Clara Salinas, of Sanger, and Adrian Pizano, of Fresno, recover from a recent three-way kidney transplantation swap involving six people. It was undertaken at Sutter's California Pacific Medical Center in San Francisco. Salinas acted as donor to another person; Pizano was a recipient from another donor. In March the donors and recipients gathered in a virtual meeting. JOHN WALKER Fresno Bee file





"WE IN AMERICA DO
NOT HAVE
GOVERNMENT BY THE
MAJORITY. WE HAVE
GOVERNMENT BY THE
MAJORITY WHO
PARTICIPATE."

- THOMAS JEFFERSON



QUESTIONS?



Contact Us



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