



PKD FOUNDATION
**ADVOCACY CHAMPIONS
NETWORK**

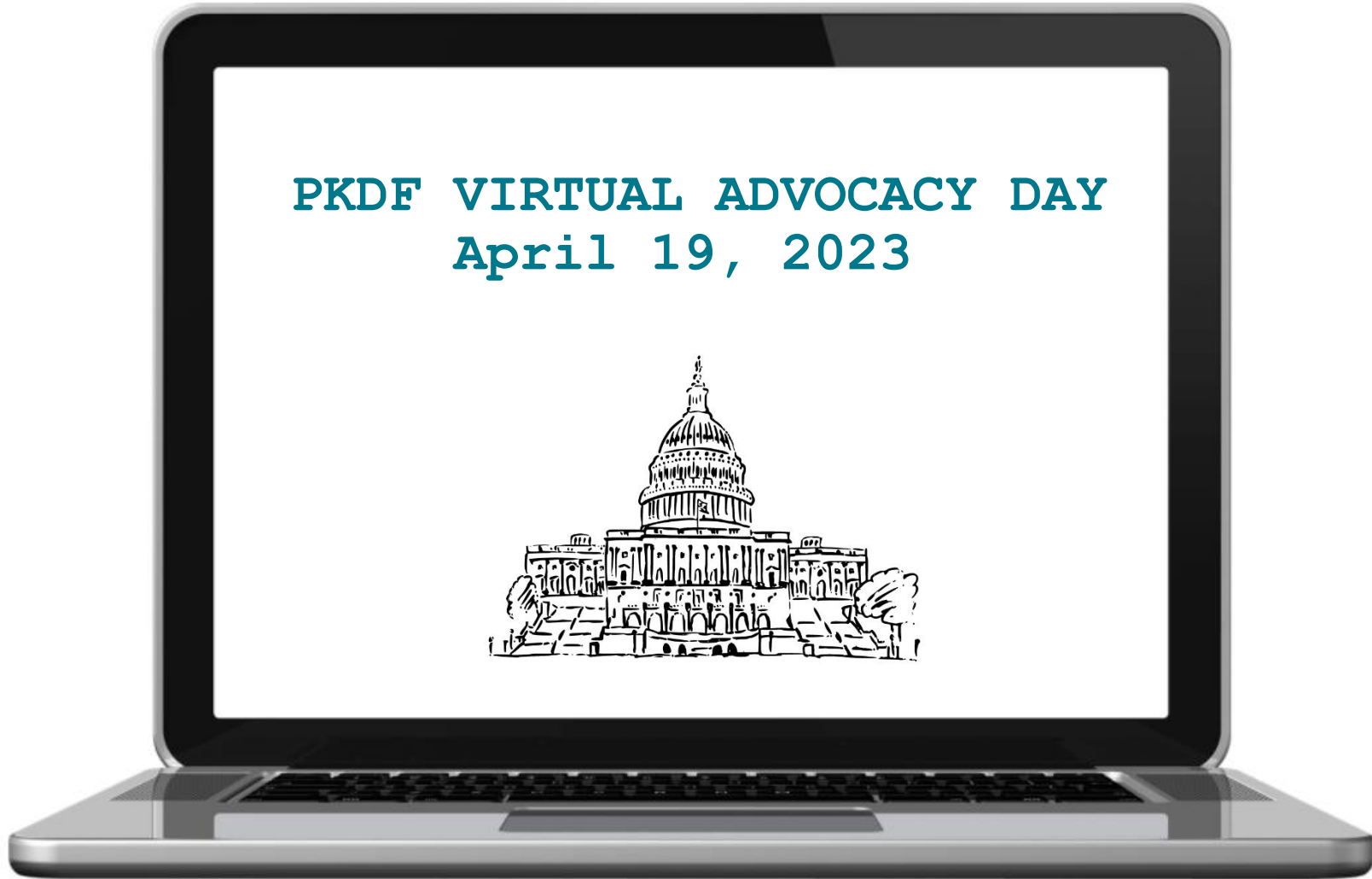
**Virtual Advocacy Day 2023 & Serving as a
State Leader**

March 14, 2023



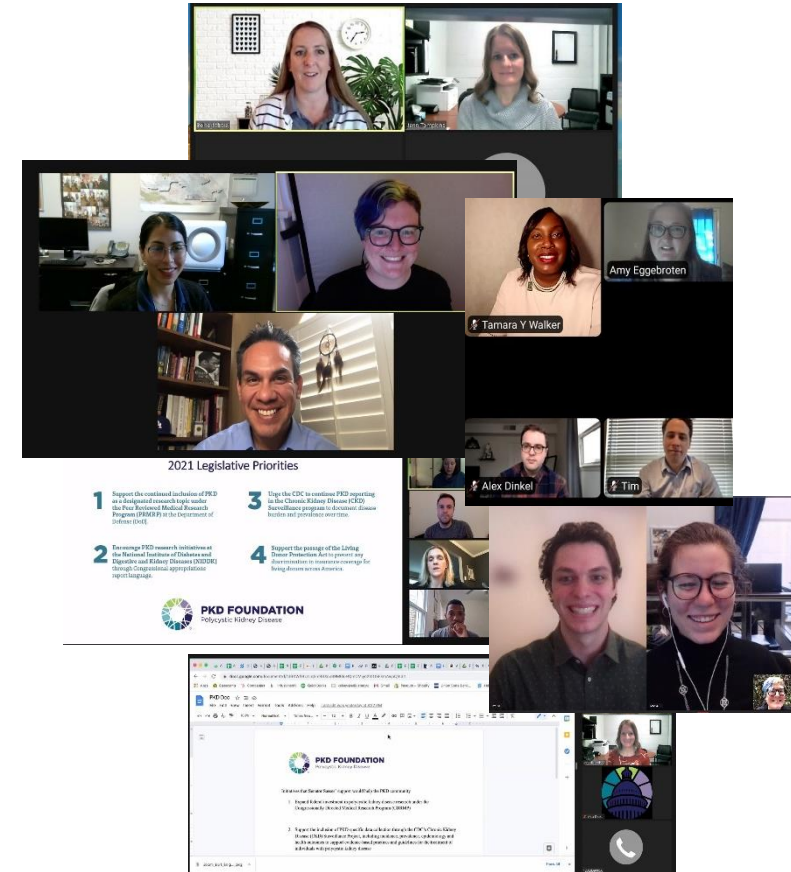
PKD FOUNDATION
Polycystic Kidney Disease

PKDF VIRTUAL ADVOCACY DAY
April 19, 2023



ABOUT VIRTUAL ADVOCACY DAY

- **All** PKD patients, family members, caregivers, researchers and supporters are invited to participate
 - **Goal: 100 – 150 Participants**
- Advocates will learn about issues affecting the PKD patients and how to engage Congress to garner support for kidney care policies and appropriations funding for PKD research
- PKDF will schedule all meetings and provide preparatory materials including talking points, bill one pagers, and other useful resources
- **DATE: 9am-5pm ET on Wednesday April 19, 2023**



ADVOCACY PRIORITIES 2023-24

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)



VIRTUAL ADVOCACY DAY POLICY PRIORITIES

Appropriations Funding

Continued inclusion of polycystic kidney disease (PKD) as a topic area in the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP) through its Peer-Reviewed Medical Research Program (PRMRP) for Fiscal Year (FY) 2024

****Our #1 ask!***

The Living Donor Protection Act

Prohibits discrimination against living donors obtaining life, disability, and long-term care insurance, and clarifies that donors are eligible for unpaid time off from work via the Family Medical Leave Act to complete their donation and recovery.

**Subject to change based on language used upon introduction in the 118th Congress*



VIRTUAL ADVOCACY DAY POLICY PRIORITIES

Organ Transplantation Transparency, Accountability, and Reform

PKDF is working alongside other kidney care stakeholder organizations to get new legislation introduced that will address racial disparities and supports in kidney transplantation.

Fast Facts

- Black patients are less likely to be identified as kidney transplant candidates, be referred for transplant evaluation, complete the evaluation, and be placed on the transplant waiting list than white patients.
 - A study cited in the Clinical Journal of the American Society of Nephrology found that Black/African American individuals were **25% less likely to be waitlisted**, even after adjusting for medical factors and social determinants of health.

The median wait time for Non-White patients is **five years**, compared with **3.4 for White patients**—resulting in **nearly 50% longer wait times** for racial and ethnic minorities.



VIRTUAL ADVOCACY DAY POLICY PRIORITIES

Organ Transplantation Transparency, Accountability, and Reform

Bill Core Components

- Increasing access to transplantation in health disparity populations
- Transplant Navigator Program
- Medicare provisions for preemptive transplant and reporting
- Improving data collection and transparency
- Benchmarking for quality improvement

We anticipate that this legislation will be introduced in Q2 or Q3 of 2023.



**Rep. Gwen Moore (D-WI-4)
Lead Sponsor**



YOUR ROLE AS A CHAMPION



SERVE AS A STATE LEADER



PROMOTE THE VIRTUAL ADVOCACY DAY



ENCOURAGE OTHER ADVOCATES TO SIGN UP TO RECEIVE PKDF ACTION ALERTS AND NEWS UPDATES*

**Will continue to be a post-Virtual Advocacy Day ACN Activity*



WHAT IS A STATE LEADER?

Trusted, reliable voice in the PKD community who understands issues affecting PKD patients and knows how to engage Congress in support of legislation that funds PKD research, innovation, and treatment.

As state leaders you will be responsible for:

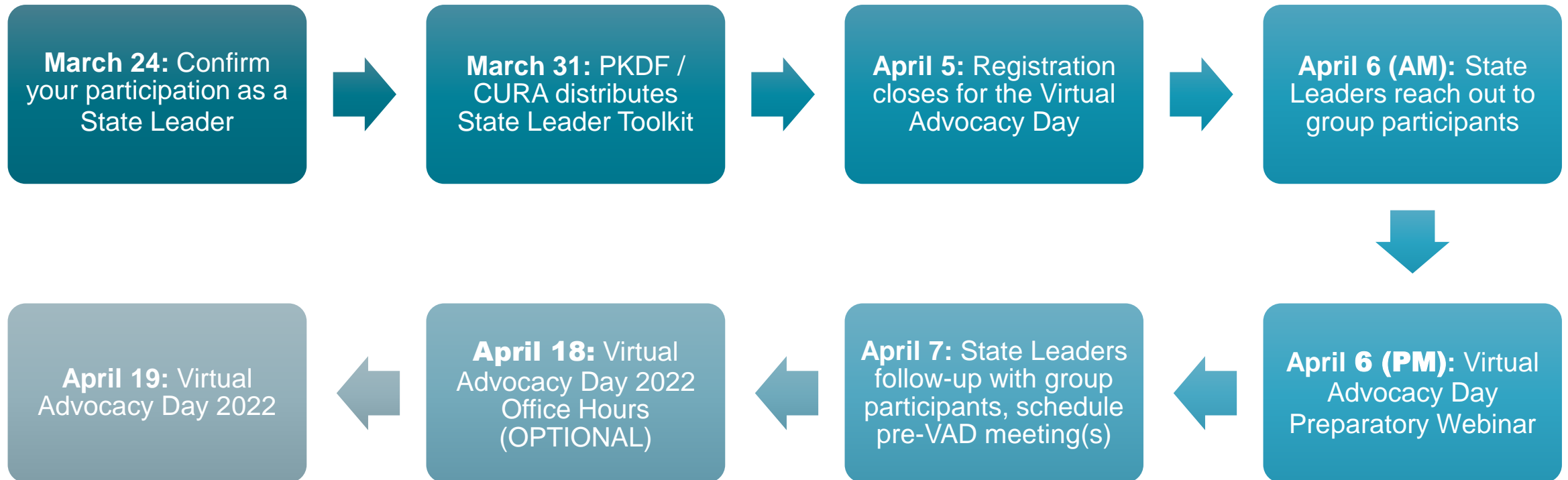
- Connecting with your group participants ahead of the Virtual Advocacy Day
- Fielding questions from advocates from your district/state
 - General questions regarding how to advocate, where to go for more information about specific legislation, etc. Note – PKDF/CURA will be available to field more difficult questions.
- Leading meetings with Members of Congress and/or congressional staff
- Following-up with your delegation following the Virtual Hill Day
- **Optional:** Volunteering to serve as a State Leader for states without ACN Champions available to participate



INPUT FROM PAST STATE LEADERS



NEXT STEPS



QUESTIONS?



BREAKOUT!



BREAKOUT ROOM PROMPTS

- *Brief* introduction (Name, hometown, how long you've been a Champion, whether you participated in last year's VAD)
- Did you participate in last year's Virtual Advocacy Day?
- Do you plan to attend this year's Virtual Advocacy Day?
 - If "No": Why not? (Unavailable, Uninterested, etc.)
 - If "Yes": Do you plan to serve as a state leader?
 - Is there anything that PKDF/CURA can do to make you feel more comfortable?
- Is there anything you'd recommend PKDF/CURA emphasize in pre-VAD trainings?



Contact Us



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