

Volunteer Connection

Feb. 20, 2024



PKD FOUNDATION
Polycystic Kidney Disease

Community Fundraising



Walk for PKD

- Tentative launch late spring
- 2 virtual options
 - Walk Your Way
 - ARPKD Fund
- Walk Training, Tuesday, March 26
 - Local sponsorship and corporate development
 - Team captain calling and engagement plan
 - Committee roles



Community Engagement



Community Volunteers

By the numbers...

- 49 PKD Connect Ambassadors
- 36 Walk Ambassadors
- 4 Fundraising Ambassadors
- 9 Outreach Ambassadors



247 Total
Volunteers!!

Volunteers needed...

- PKD Connect Ambassadors
 - Birmingham
 - Chicago
 - Houston
 - Indianapolis
 - Iowa
 - Northeast Ohio
 - Denver
 - Las Vegas
 - Philadelphia
 - Western New York
- Walk Ambassadors
 - Denver
 - Connecticut
 - Philadelphia



2024 Virtual Advocacy Day



We hope you will join us!

- Tuesday, April 9, 2024
- No advocacy experience necessary!
- Training session provided
- [Register today!](#)



Marketing



March is National Kidney Month!

- Kidney Month
 - World Kidney Month
 - World Kidney Day
 - Fundraising plan



Volunteer Social Media Policy Update

- Volunteers are not permitted to set up social media accounts in connection with the PKD Foundation without prior permission from the PKD Foundation.
- Volunteers must ensure that all social media content aligns with the mission, values, and objectives of the PKD Foundation. **If your actions on social media do not align with our mission, values, and objectives, we reserve the right to take corrective action.**



Volunteer Social Media Policy Update

- Your posted content must align with and not contradict or conflict with any official partnerships, affiliations, or vetted associations of the organization. If you are not sure if the content aligns, please contact your staff lead before posting.
- Finally, we do share information from sources outside of PKDF. If our national page shares an outside source, you may also share any of these posts locally. If you run across relevant information that you would like to share, please confirm with your staff lead before posting.



Advancement



Support the PKDF with a gift from your IRA

- IRA Charitable Rollover Gift
 - Made by owner of an IRA directly to charity – QCD (qualified charitable distribution)
 - Must be 70½ or older
 - Can transfer up to \$100,000 per year
 - Can help meet your RMD (required minimum distribution – age 73)
 - Reduce Taxable Estate
- 59½ +
 - At age 59½, you can withdraw funds without facing additional penalties
 - You may choose to donate directly from your IRA to qualified charitable organizations
 - Provides tax advantages while also supporting causes you care about
- www.pkdflegacy.org



Before making any decisions regarding withdrawals or contributions to your IRA, it's important to consult with a financial advisor or tax professional who can provide personalized advice based on your individual financial situation and goals.



HELP CHANGE THE COURSE OF PKD

Join the movement to #endPKD with a monthly gift

People with PKD count on the PKD Foundation to fund research for treatments and, ultimately, a cure for the disease. When you commit to a monthly gift, you invest in the future of people with PKD and their loved ones. With your ongoing gift, we can expand research toward a cure.

WHY MONTHLY GIVING?

SUSTAINED IMPACT: Monthly donations provide a steady flow of support for ongoing initiatives such as PKD research, care, and education.

EFFORTLESS GIVING: Set it and forget it – hassle-free, automatic contributions make donating easy.

EXCLUSIVE UPDATES: Enjoy personalized insights into the impact of your generosity through regular updates.



SCAN ME



Become part of the PKD Foundation's path to a cure.



Monthly Donations

- There is a renewed focus on Monthly contributions to the PKDF.
- Currently, we have approx. 285 recurring donors who contribute \$150,000 annually
- Promotion for this program will increase over the Spring, including:
 - An ad in the next issue of PKD Life
 - Promotion throughout Social Media and PKD News during Kidney Month



Research



Top 10 Research Questions



PKD FOUNDATION
ADPKD REGISTRY

- What are good **predictors** and factors that contribute to the **risk of rapid progression/early loss of function**?
- What factors best help describe the sub-groups at different risk for **kidney and non-kidney** manifestations? (*e.g., kidney/stones, liver manifestations, vascular manifestations*)?
- What is the clinical presentation of patients with PKD1, PKD2, and other cystic genes?
- What is the **effect of race or ethnicity on disease progression or risk factors** (*including timing of diagnosis, rate of disease progression, etc.*)?
- What indicators can be used and validated to distinguish slow from rapid progression in **early-stage adult ADPKD**?
- Which clinical sites have patients who fit specific clinical trial criteria?
- What is the real-world effectiveness **and long-term safety of therapies** to treat of ADPKD?
- What factors are associated with severity of **abdominal and flank pain**?
- What is the best timing and sequencing of **interventions to slow or prevent** kidney disease progression?
- How does patient **emotional burden** change as PKD disease progresses?

We hope these will encourage both:



Patient participation

&



Researcher data requests



PKD Foundation Kidney Clinics



57% program growth
28 new clinics

- Center of Excellence
- Partner Clinic
- Pediatric Clinic



COE Program Impact

13,000

Individuals with
ADPKD seen at PKDF
clinics

20%

Increase in new
patients to those
clinics since launch
of the program

5

New
Pediatric
Clinic
designations



PKD FOUNDATION
WALK_{FOR}PKD

*Expect your local clinic to participate in the
Walk for PKD*



Q & A

