

Connecting With Your Local PKD Community

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PKD FOUNDATION
Polycystic Kidney Disease

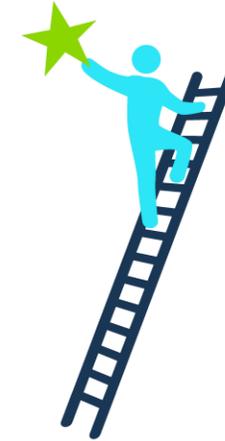
Training Agenda

- Outreach Ambassadors
 - What we have learned
 - Where we are today!
 - Outreach Ambassador Recruitment
- Centers of Excellence & Partner Clinics
 - Patient Advisory Panels
- Advocacy Update
- Building Relationships / Making Connections



History

- Peer Ambassador program launch 2022
 - 7 Peer Ambassadors
 - 7 Awareness Events
 - 5 Social Media Campaigns
- Transitioned to Outreach Ambassadors 2023
 - Increase education and awareness of PKD
 - Engage with Centers of Excellence where applicable
 - Develop relationships with community organizations and healthcare organizations



Where we are today...

▪ 12 Outreach Ambassadors!

▪ Welcome

- Lisa
- Marilyn
- Kenyatte
- Hernan
- Erica

Recruitment

▪ Communities with COEs

- Philadelphia
- Chicago
- Phoenix
- Minneapolis
- San Francisco
- Dallas
- Seattle



PKDF Centers of Excellence

Lavonne Nichols



Goal: to identify and support patient-centric clinics who know how to care for individuals with ADPKD

The Program's Mission

1. Ensuring better care for all individuals with ADPKD
2. Understanding ADPKD through research
3. Educating and empowering the community



2024 PKDF Kidney Clinics

PKD Foundation Kidney Clinics



57% program growth
28 new clinics

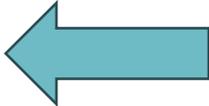


PKDF Care Centers

- Centers of Excellence
- Partner Clinics
- Pediatric Clinics



Centers Of Excellence Requirements

- Patient Navigator
- Patient Advisory Panel 
 - PKDF nominee
 - Meet once per year
 - Write a letter of recommendation for center to keep designation



Advocacy Updates

Nicole Harr



2024 Virtual Advocacy Day



We hope you will join us!

- Tuesday, April 9, 2024
- No advocacy experience necessary!
- Training session provided

- [RSVP](#)
- Block your calendar



Legislative Priorities

- Passage of the legislation that will remove disincentives to living organ donation and encourage individuals to give the generous gift of life as living organ donors
- Federal investment in PKD research, including through the Department of Defense's Peer Review Medical Research Program (PRMRP) under the Congressionally Directed Medical Research Program (CDMRP)
- Additional legislation that supports treatment and access to transplantation, particularly for PKD



PKD Communities

Lavonne Nichols



Community Engagement

Booth at Walk for PKD

- Staffed booth within 30-mile radius of the clinic
- Potential walk team

Promote PKDF community events

- Additional promotion for community events
- Introduce patient community to PKDF

Host community meeting

- Local speakers
- Meeting space
- Research lab tour / transplant center tour
- Share resources with local community



Your next steps...

- Register for Virtual Advocacy Day
- Planning call with Lavonne
 - <https://calendly.com/lavonnen/volunteer-program-calls>
- Build relationships in your community
 - Networking
 - Who do you know?
 - Community resources / activities
- Connect with PKD Connect Ambassador
- Utilize social media –if you like!
- **IMPLEMENT YOUR IDEAS!**
- Care Center Activities
 - Example: Jacksonville – Kidney Connect Community Event



Need support?

WE are here to HELP!

Volunteer Resource Page

- Event Form
- Training Series
- Handbook
- Resource Guide

Contact Lavonne

- lavonnen@pkdcure.org
- Call 816-268-8459

Contact Nicole

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Thank you!

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