

Leading a PKD Community

Let's get started

Nicole Harr

Sr. Director of Community Engagement



PKD FOUNDATION
Polycystic Kidney Disease

Training Agenda

- What is a PKD Connect Ambassador?
- PKD Communities
- Centers of Excellence
- Let's Get Planning!



PKDCONNECT

A Community of Care



What is a PKD Connect Ambassador?

PKD Connect Ambassadors play a vital role in providing local support for PKD communities across the United States and serve as the frontline for individuals new to the PKD Foundation.

In this role, volunteers provide educational opportunities and support to their local PKD community while connecting individuals to PKDF programs and services as appropriate.



What do PKD Connect Ambassadors do?

- Serves as a "connector": local PKD community to PKDF
- Assists local community members through their patient journey
- Plans Community Meetings
- **No one walks alone with PKD.**



PKDCONNECT
A Community of Care



PKD Communities





Oehrlein EM, Schoch S, Majercak K, Gressler LE, Constantino R, Perfetto EM on behalf of Patient Experience Mapping Working Group. Patient Experience Mapping Toolbox. National Health Council; 2021. Available from: <https://nationalhealthcouncil.org/resources/patient-experience-map>



Responsibilities

- Connects individuals to PKDF information and resources
 - ADPKD Registry
 - PKD Connect Mentoring Program
 - PKDCON
 - Walk for PKD
- Maximizes utilization of PKDF resources
- Shares opportunities
- Liaison with Walk Ambassador
- Maintain confidentiality

**PKDF Volunteers do not
give medical advice!**



PKDF Support!

Communication

- Community email
 - Volunteer uses to communicate while doing business on behalf of PKDF
- Volunteer News
 - monthly electronic newsletter

Resources

- Volunteer Training
- Volunteer Connection Calls
- Volunteer Resource pages
 - pkdcure.org/volunteers



PKDF Centers of Excellence



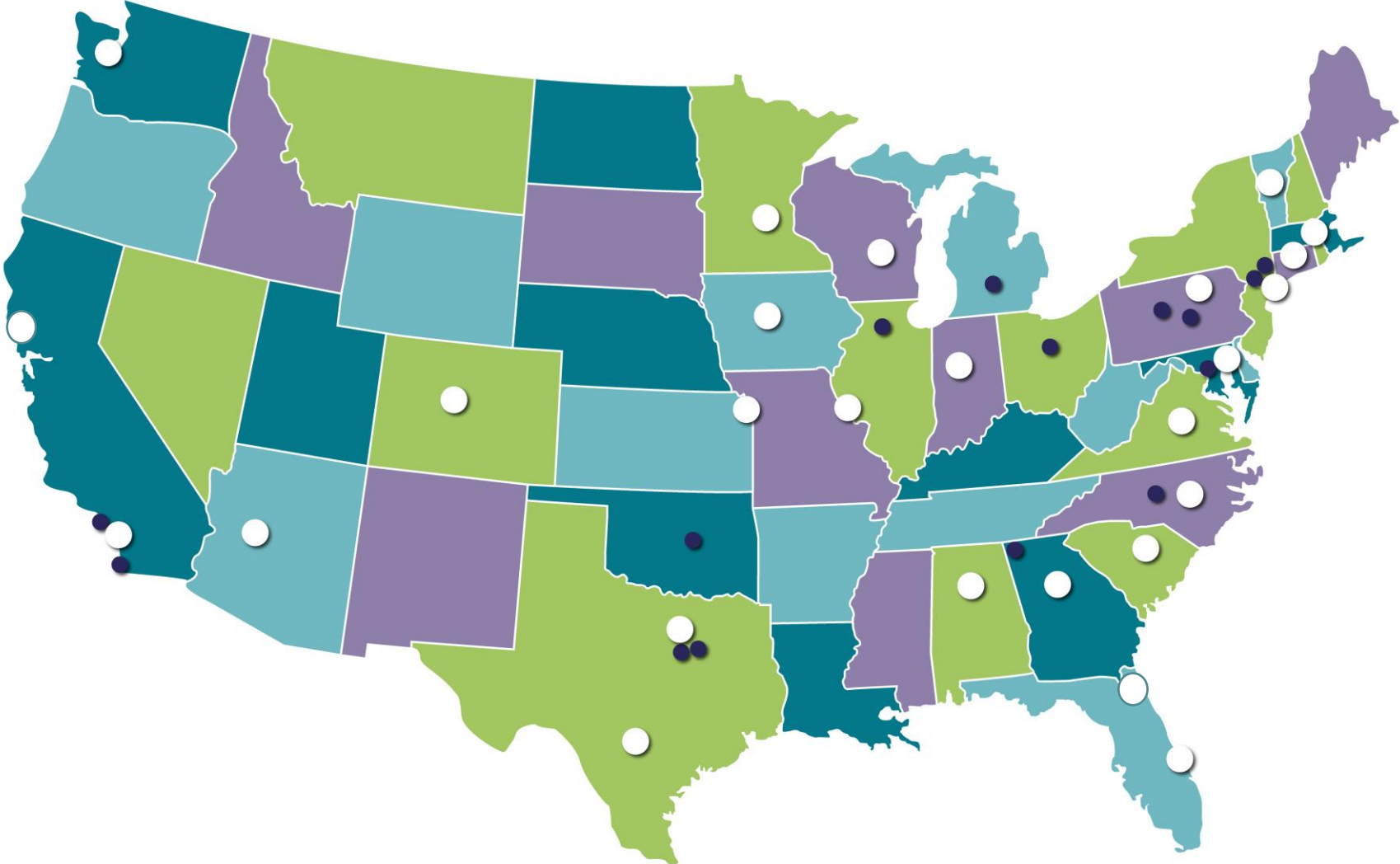
Goal: to identify and support patient-centric clinics who know how to care for individuals with ADPKD

The Program's Mission

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



42 Centers of Excellence and Partner Clinics



PKDF Care Centers

- 28 Centers of Excellence
- Patient Advisory Panel
- 14 Partner Clinics



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



What is a community meeting?

No one faces PKD alone.





Let's Get Planning!



Reflection & planning

Looking back

- Accomplishments
- Challenges

- *What worked / what didn't?*

Looking ahead

- Goals
- Meeting topics

- *What do you need to be successful next year?*



Event form

- Event date
- Start time / end time
- Event topic / description
- PKDF resources
- Local speaker
 - Name
 - Contact information
- Recurring meetings



Let's get the word out!

PKDF

- Set-up registration page in Classy
- Post meeting information on community web page
- Schedule email promotion
- Schedule reminder email
- Registered list

PKD Connect Ambassador

- Review web page & email draft
- Post registration link on local Facebook account
- Save the date to past meeting attendees



Who do we email?

PKDF



PKD Connect Ambassador

- Registration list
- Walk team captains / participants
- Community Interest List



Best practices for local education...

- Complements PKDF patient education
- Must be approved by PKDF staff
- Not recorded
- Local speaker
 - Conflict of Interest form
 - Speaker agreement
 - Disclosure slides
 - Care Center Network

Reflection & planning calls
Event form



- Submit an event form in advance!



Community meeting agenda

TAKE ACTION



- **Welcome and Introductions**
- Discussion Topic
- PKD Journey
- **Take Action**
- **Follow Up**



Be prepared to share...

ADPKD
Registry

Walk for
PKD

PKD
Connect
Peer Mentor

Advocacy
Alerts

ACT Alerts

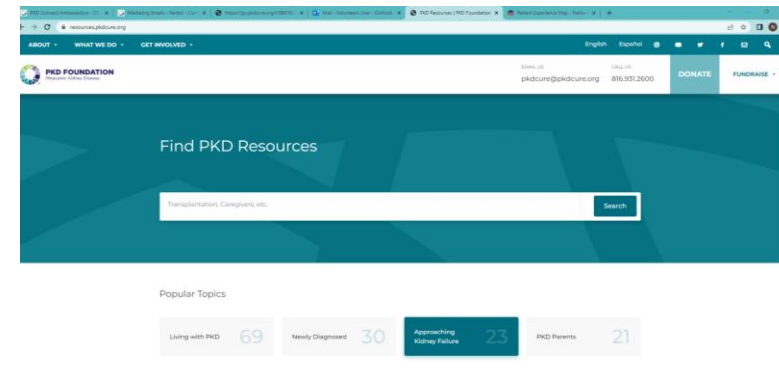
Join
#teamPKD

Voices of
PKD

HOPE line

PKDCON

■ Resource Library



■ Resource Guide

- *For volunteers only!*



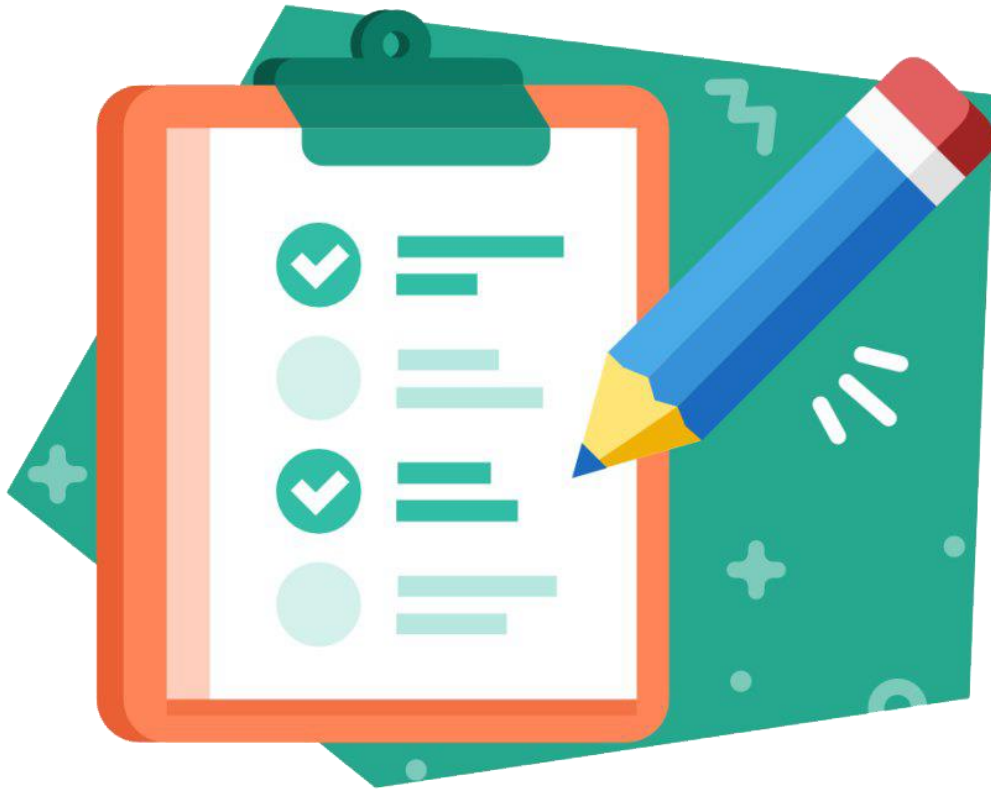
Hosting a community meeting



Empower patients to improve their outcomes by providing local resources that enables the patient to advocate for better health care, and to make daily decisions to promote their health.



Don't forget the follow-up



- Update attendance
- Follow up email
 - Thank meeting attendees
 - Share resources with those that were unable to attend
- Volunteer hours = IMPACT



Community Meeting Tool Kits



- [Volunteer Resource Home Page](#)
- [PKD Connect Ambassadors](#)
 - Resources
 - Event form
 - Handbook
 - Resource Guide
 - [Community Meeting Tool Kits](#)



Need support?

WE are here to HELP!

Volunteer Resource Page

- Event Form
- Training Series
- Handbook
- Resource Guide
- Community **Meeting** Tool Kits

Contact Nicole

- nicoleh@pkdcure.org
- Call 816-268-8483

Contact Lavonne

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



Thank you!

Nicole Harr

Sr. Director of Community Engagement

Nicoleh@pkdcure.org

816-268-8483

Lavonne Nichols

Community Engagement Strategist

Lavonnen@pkdcure.org

816-268-8459

