



PKDCONNECT

A Community of Care

**PKD CONNECT
AMBASSADOR**

Handbook

2022

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Welcome

Dear volunteer,

Thank you for your commitment to the PKD Foundation! Since our founding in 1982, volunteers have been the heart of our organization. Just in 2021 alone, volunteers contributed more than 19,000 volunteer hours — that's valued at more than \$550,000! This team of volunteers makes the work we do possible.

You're joining hundreds of volunteers who share in the PKDF mission to give hope. Together, we'll continue building a community for everyone impacted by PKD. As a PKDF volunteer, you'll make a difference and have a true impact on the PKD community by driving our work in research, advocacy, education, and awareness forward.

We're excited that you're joining our volunteer team and we look forward to partnering with you. Welcome to the PKDF volunteer team!

Best,



Andy Betts
President & CEO

The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD). We fund research, education, advocacy, support, and awareness on a national and local level.

About the PKD Foundation

#endPKD

Our Vision

WE GIVE HOPE.

We fund researchers, advocate for patients, and build a community for all impacted by PKD.

PKD Foundation Mission

The PKD Foundation does not provide medical advice. Information provided to patients, family and friends through our website, educational resources, local events and peer-to-peer mentoring program is meant to educate and support our constituents on topics important to disease management. PKD Foundation resources are based on advice and opinion provided by PKD experts but does not constitute medical advice. We strongly recommend that care and treatment decisions related to specific health concerns be made in consultation with the patient's health professional team.

Volunteering with the PKD Foundation

Volunteers are the heart of the PKD community. The PKD Foundation volunteers are making a difference every day at the national level and in local communities across the U.S.

Building communities for all impacted by PKD is a part of our mission. By engaging volunteers in local communities across the U.S., we are able to expand our reach and bring the mission of the PKD Foundation to patients and families impacted by PKD.

When you join the PKD Foundation volunteer team, your time and efforts support the mission of the PKD Foundation and ensure that no one faces PKD alone.

Definition of a Volunteer

A volunteer is anyone who, without compensation or expectation of compensation beyond reimbursement of expenses, performs a task at the direction of and on behalf of the PKD Foundation. Volunteers are not considered employees of the Foundation.

Representing the PKD Foundation

Volunteers are authorized to act as representatives of the PKD Foundation as specifically indicated within their job descriptions and only to the extent of such written specifications.

All PKD Foundation volunteers are required to complete a volunteer application and conflict-of-interest form. All volunteers with access to constituents or constituent data must also participate in a background screening.

PKD Foundation Volunteer Opportunities

PKD Connect Ambassador

PKD Connect Ambassadors play a vital role in supporting the PKD community in local areas across the United States and serve as the front line for individuals new to the PKD Foundation. In this role, volunteers provide educational opportunities and support to their local PKD community and connect individuals to PKD Foundation programs and services as appropriate.

PKD Connect Peer Mentor

PKD Connect Peer Mentors provide resources, guidance, motivation, and emotional support to an individual impacted by PKD. Peer mentors are familiar with difficulties associated with polycystic kidney disease (PKD) and are willing to share their own experience with PKD to support and encourage others.

Advocacy Champions Network (ACN)

The PKD Foundation Advocacy Champions Network (ACN) is vital to raising awareness of PKD and increasing research dollars to bring treatments and therapies to patients, and to provide the best care for those who are reliant on dialysis or a kidney transplant to survive.

PKD Connect Interpreter

PKD Connect Interpreters will translate emails and assist with returning phone calls on an as-needed basis. Volunteers will connect individuals with PKD Foundation programs and services as appropriate and assists with building a sense of community for non-English speaking patients and families.

Walk for PKD Ambassador

Walk for PKD Ambassadors serve an important role in their community. They are responsible for planning and executing their local Walk for PKD with support from PKD Foundation staff. This volunteer role raises important financial support and plans an event that brings the local PKD community together. Your contribution will help to fulfill our vision to end PKD.

Fundraising Ambassador

The Fundraising Ambassador plays an important role in the local PKD community by identifying local fundraising opportunities and organizing the event. With support from PKD Foundation staff, your contribution will facilitate fundraising that supports the mission of the PKD Foundation.

Stakeholder Reviewer Panel

Stakeholders will serve on the larger Grant Review Committee and incorporate the views of persons affected by PKD into the PKDF research grant review process. Stakeholders will read and evaluate research study applications for relevance to the PKD community's needs and concerns and actively participate in peer review panel discussions.

Registry Patient Advisory Group

The Registry Patient Advisory Group will provide oversight and guidance on the development and execution of the PKDF Patient Registry. A Patient Advisory Group will serve as a working group under the PRAC and will elect a representative to sit on quarterly PRAC meetings.

Peer Ambassador

The Peer Ambassador program is meant to build new bridges between the Foundation and previously underserved communities. The Peer Ambassadors Program will also guide communities of color through the Foundation's resources on disease management, treatment options, and navigating health care systems.

Community Reaction Panel

The PKD Foundation Community Reaction Panel provides feedback on pre-determined topics of interest to Industry Alliance partners and regarding PKD Foundation programs and services. The panel consists of patients and caregivers with varied experiences across the continuum of disease progression and includes experience with ADPKD and ARPKD.

PKD Foundation Volunteer Policy

Confidentiality

Volunteers are responsible for maintaining the confidentiality of all proprietary or privileged information (including PKD status) to which they are exposed while serving as a volunteer, whether this information involves staff, volunteers, vendors or any other person or entity.

Conflict of Interest

No volunteer for the PKD Foundation shall derive any personal profit or gain, directly or indirectly, by reason of his or her volunteer activities with the organization. Each individual shall disclose in writing to PKD Foundation staff any personal interest which he or she may have in any matter related to the Foundation's operation and shall refrain from participation in any decision on such matter. Volunteers shall refrain from using any contact information of PKD constituents for personal, non-Foundation related purposes at any time while volunteering for the Foundation. The PKD Foundation staff shall have final authority in determining if a conflict exists between an individual's activities and their role as a volunteer for the organization.

Copyright / Ownership

Material produced by volunteers for the PKD Foundation, including graphics, web page designs, newsletter designs, special event logos and themes, etc. becomes the property of the PKD Foundation upon submission. No marketing or promotional material for the PKD Foundation, the Walk for PKD or any other event may be created without prior approval of Foundation staff.

Database Release

The PKD Foundation maintains a confidential and proprietary database of constituents, whereby information is disseminated, contributions are solicited, advocacy is generated and overall support is enhanced. The PKD Foundation has devoted over 30 years to developing a mailing list for the sole purpose of fulfilling our mission.

Mailing, phone and email lists are entrusted to volunteers for their use. Lists may be used solely for the purpose of communicating and promoting the advancement of the mission of the PKD Foundation. Volunteers may not use any list or contact information they receive in the course of their volunteer relationship with the Foundation for any purpose other than to promote the mission and activities of the Foundation.

A separate list may not be maintained by the volunteer. New contacts, deletions or changes to the list must be shared with the PKD Foundation so that the constituent receives all pertinent follow-up communication and future Foundation newsletters, meeting announcements, event invites, etc.

Social Media

PKD Connect Ambassadors are not required to be active on social media. Volunteers that choose to utilize social media as part of their volunteer role are asked to follow PKD Foundation social media guidelines. New social media accounts representing the PKD Foundation must be set up by PKD Foundation staff and volunteers may not change PKDF social media account passwords.

Social media guidelines are included in this handbook and are also posted on the Volunteer Resource pages.

Inappropriate Communications

If at any point you receive any email or social media communication that you feel for any reason is inappropriate and you believe you have received it in conjunction with your involvement with the PKD Foundation, please forward the email and other details about the communication to the Director of Community Engagement or your staff lead.

Reimbursement of Expenses

Volunteers are eligible for reimbursement of reasonable expenses directly related to events planned on behalf of the PKD Foundation. All expenses require pre-approval by the Director of Community Engagement. Volunteers will be required to submit a reimbursement request form with receipts and an ACH form for approval. Finance will process the reimbursement via ACH within 30 days of receipt of complete documentation.

Resignation

If a volunteer is unable to continue in their role, notice of such a decision should be communicated as soon as possible to PKD Foundation staff. The initial notice may be oral but final resignation should be made in writing. Upon receipt of resignation, if applicable, access to email and social media accounts will be removed and account login credentials will be updated. The volunteer is expected to provide accurate, thorough and up-to-date information for their successor. The resigning volunteer's assistance in providing suggestions for the position would be greatly appreciated.

Privacy of PKD Foundation Volunteers

The Foundation respects and protects volunteers' privacy and will not release personal contact information. Volunteers that will be communicating with constituents, members of the community, businesses, etc. will be provided with a pkdcure.org Office 365 account to protect your personal contact information. Volunteers of the PKD Foundation are required to use volunteer accounts provided when communicating with anyone outside of the PKD Foundation staff.

We will direct inquiries about local communities to the community email account. In order to protect your privacy, it is important that you reply to communications using the community email account and not your personal email address.

Each local community has a web page that is used to promote local activities and PKD Foundation programs and services. PKD Connect Ambassador's name, bio and headshot are added to community web pages to encourage local connection and grow local communities. PKD Connect Ambassadors are asked to provide a picture and brief bio to be displayed on the community web page.

Service at the Discretion of the PKD Foundation

The PKD Foundation gratefully accepts the service of all volunteers with the understanding that such service is at the discretion of the Foundation.

- Volunteers who do not adhere to the rules and procedures of the Foundation, or who fail to

satisfactorily perform their volunteer assignment, are subject to dismissal.

- Possible grounds for dismissal may include, but are not limited to, the following:
 - > unresponsiveness
 - > gross misconduct or insubordination
 - > theft of property or misuse of Foundation materials
 - > engaging in behavior that poorly reflects on the Foundation
 - > engaging in abuse or mistreatment of constituents, staff, or other volunteers
 - > failure to abide by Foundation policies and procedures
 - > failure to satisfactorily perform assigned duties.

Volunteer Rights and Responsibilities

Volunteers are a valuable resource to the PKD Foundation, its staff and constituents. Volunteers have the right to be given meaningful assignments, effective supervision and recognition. In return, volunteers agree to actively perform their duties to the best of their abilities and remain committed to the goals and policies and procedures of the Foundation.

For questions about Policies and Procedures, contact: Nicole Harr, Director of Community Engagement nicoleh@pkdcure.org or 800.753.2873, ext.143

PKD Connect Ambassador

What is a PKD Connect Ambassador

PKD Connect Ambassadors are individuals with a passion for supporting their local PKD community and serve as a frontline for patients and families new to the PKD Foundation. PKD Connect Ambassadors act as a liaison between the Foundation and local community comprised of patients, families, caregivers, PKD parents, local health professionals, etc.

PKD Connect Ambassadors support the needs of their local community by:

- responding to members of their local community;
- Promoting and utilizing PKD Foundation provided education and resources;
- offering support to small groups of patients and caregivers;
- connecting individuals with PKD Foundation programs and services.

Expectations & Requirements

PKD Connect staff members are here to provide guidance and support to our volunteers. We will provide the training and resources necessary for you to fulfill the responsibilities of your volunteer role.

PKD Connect Ambassador Responsibilities

- Communicates openly and proactively with local PKD community

- Connects individuals in the PKD community to PKDF information and resources such as:
 - > PKD Connect Peer Mentor program
 - > ADPKD patient registry
- Maximizes the utilization of PKDF resources
- Directs PKDF constituents to appropriate educational resources based on the constituent's relationship with PKD and their individual journey with PKD
- Informs individuals about PKDCON offerings
- Shares PKDF fundraising opportunities
 - > Walk for PKD
 - > Fundraise Your Way
 - > Local fundraising events
- Serves as a liaison to the Community Walk Organizer
 - > Assists with promoting the Walk for PKD locally
 - > Understands volunteer opportunities associated with the local Walk event
- Facilitates educational opportunities in the local community utilizing PKDF-provided education
 - > Focuses on developing an action plan with constituents to encourage healthy, positive change
 - > Emphasizes positive, action-oriented communication
- Assists groups of individuals through their PKD journey
- Engage with constituents
- Value each individual as a person
- Develop mutual trust and respect
- Maintain confidentiality
- Emphasizes positive, action-oriented communication
- Does not provide medical advice
- Does not provide crisis intervention

In order to provide volunteers with continued support and to ensure continuity of support and resources available to the local PKD community, we ask that our volunteers commit to the following:

- Participate in onboarding training sessions
- Participate in conference calls/role-specific training sessions
- Communicate regularly with PKD Foundation staff lead
- Monitor email regularly
- Two-year commitment to the volunteer role
- Familiarity with Office 365 and Outlook email platform
- Reliable internet connection and smartphone or desktop access
- Access to reliable transplantation

Volunteer Training and Development

PKD Connect Ambassadors are required to complete volunteer onboarding training which includes an orientation on the mission and vision of the PKD Foundation, general information about PKD and an overview of volunteer resources and procedures. These training sessions are recorded and available online to be viewed at the volunteer's convenience.

Volunteer conference calls will be held regularly via video conference and will be recorded. These training calls will provide updates from PKD Foundation and an introduction to new resources available for the PKD community. Ambassadors will be asked to attend ongoing role specific training as needed. Annual volunteer training may be held virtually via video conference and webinars or in person.

Biannual Conference Calls

PKD Connect Ambassadors are asked to attend reflection / annual planning calls at the end of each calendar year and a mid-year check-in call to evaluate progress. These calls provide an opportunity for both the volunteer and the Foundation to assess the needs of the volunteer and the local community.

During conference calls, expect to:

- Reflect on the past year and set goals for the following calendar year.
- Provide suggestions as to resources, tools or information needed to help you in your volunteer role.
- Determine the interest of the volunteer in continuing to serve in the volunteer role.

Understanding Basic PKD Facts

The PKD community is generally very well educated about their disease, however volunteers may be asked specific medical questions. As a PKD Connect Ambassador, it is your responsibility to remind those that you are supporting that you cannot provide medical advice but can suggest resources that will address specific medical concerns. A resource guide is available on the Volunteer Resource pages that will help direct you to resources to share with the PKD community.

General information

- Polycystic kidney disease is a chronic, genetic disease, causing uncontrolled growth of fluid-filled cysts in the kidneys often leading to kidney failure. PKD affects all races and ethnicities. There is no cure. But there is hope.
- There are two types of PKD, both are genetic: autosomal dominant (ADPKD) and autosomal recessive (ARPKD).
- ADPKD is the more common type of PKD and occurs in 1 in 500 to 1 in 2000 live births and is estimated to affect more than 600,000 Americans and 12.4 million people worldwide. The number of patients currently diagnosed in the U.S. is 140,000, giving ADPKD orphan drug status for any emerging therapies.
- ARPKD is a rare form of PKD that occurs in 1 in 25,000 children worldwide.

Autosomal dominant polycystic kidney disease (ADPKD)

- ADPKD is one of the most common, life-threatening genetic diseases. In ADPKD, fluid-filled cysts develop and enlarge in both kidneys, eventually leading to kidney failure. It is the fourth leading cause of kidney failure and more than 50 percent of people with ADPKD will develop kidney failure by age 50. Once a person has kidney failure, dialysis or a transplant are the only options.
- ADPKD is a painful disease that impacts quality of life. A typical kidney is the size of a human fist and weighs about a third of a pound. Polycystic kidneys can be much larger, some growing as large as a football. Kidneys can develop cysts ranging in size from as small as a pinhead to as large as a grapefruit.
- Unlike some genetic diseases, ADPKD does not skip a generation meaning it often affects many people in one family. Approximately 10 percent of the people diagnosed with ADPKD have no family history of the disease, with the disease developing as a spontaneous (new) mutation. Once a person has ADPKD, even though a spontaneous mutation, they have a 50 percent chance of passing it on to each of their children.
- There is currently only one treatment for ADPKD in the U.S.

Autosomal recessive polycystic kidney disease (ARPKD)

- ARPKD is a relatively rare form of PKD that affects 1 in 25,000 children worldwide. ARPKD can cause death in the first month of life. However, almost 80 percent of ARPKD children now survive the newborn period. In recessive disorders, such as ARPKD, the child must inherit a copy of the gene from each parent. Since the parents each have only one copy of the disease gene, they do not have the disease and are referred to as “carriers.” Parents who carry the ARPKD gene have a 25 percent chance of passing the disease on to each of their children.
- All children with ARPKD also have the liver abnormality called congenital hepatic fibrosis (CHF) that may lead eventually to enlargement of the liver and spleen.
- Approximately one-third of children with ARPKD who survive the newborn period, will need dialysis or transplantation by age 10. Previously thought to be a fatal condition, the prognosis for children with ARPKD has improved dramatically
- ARPKD is still a disease that devastates families, and dramatically affects quality of life for children who have it. For those who have lost a child to ARPKD, their lives are changed forever.

Provide resources, not answers!

The PKD community looks to the PKD Foundation for the most accurate and up to date information available to help manage living with PKD. The PKD Foundation provides a comprehensive resource library to address topics of importance to the PKD community across the continuum of disease management. Our web content is reviewed and updated regularly as are the resources you will find in the resource library.

As a PKD Connect Ambassador, you will be asked specific medical questions. PKD Foundation

staff and volunteers must not provide medical advice. Only a patient's health care professionals can provide medical advice. As a volunteer representing the PKD Foundation, it is your responsibility to recognize when you are being asked to provide medical advice and to direct patients and caregivers to PKD Foundation resources. It can sometimes be difficult to determine the difference between providing facts and giving advice. When in question, always refer them to the Hope line or pkdconnect@pkdcure.org.

A good rule of thumb — if you can find information at pkdcure.org or in a patient handbook that addresses a question or concern, feel free to direct them to the PKD Foundation resource. If you are unable to find a resource to address a concern, please refer them to the Hope line or pkdconnect@pkdcure.org.

From time to time, the PKD Foundation shares information of interest to the PKD community, mainly through our social media channels, that is not found at pkdcure.org. Feel free to share this information on local social media accounts but we ask that you do not share unapproved or unvetted information. Your role as a PKD Connect Ambassador is to connect the local community to information and resources provided by the PKD Foundation.

A [resource guide](#) is available on the Volunteer Resource pages that will help direct you to resources to share with the PKD community.

Volunteer Resources and Communication

Community Email Accounts

PKD Connect Ambassadors utilize a PKD Foundation email account for all community business communications. PKD Connect Ambassadors are responsible for checking email regularly and responding to the local community and PKD Foundation staff. If a volunteer is unable to respond to email for a period of time, volunteers are required to notify their staff lead.

During the onboarding process, PKD Foundation staff will share instructions about how to access the community email account. Volunteers are asked to use the login credentials provided to access the account and are asked not to change the password to the account. PKD Connect Ambassadors are asked to check the email account a minimum of three times per week and respond to any communications in a timely manner.

Upon resignation from a PKD Foundation volunteer role, email account passwords will be changed immediately, and volunteers are asked to remove PKD Foundation email accounts from smart phones.

Social Media Accounts and Guidelines

PKD Connect Communities utilize social media to connect with and grow local communities. Facebook is the preferred social media for local communities. During onboarding, login

credentials to all local social media accounts will be provided, if applicable. Volunteers are asked to utilize social media following PKD Foundation guidelines and to not change passwords. PKD Connect Ambassadors are not required to be active on social media.

If you decide to use social media for your community, please adhere to the following:

Be responsible and professional. PKD Connect Ambassadors are responsible for the content they publish on behalf of the PKD Foundation and their community on any social media platform.

Respect confidentiality. Volunteers or PKD patients may not post content that discloses any confidential information about the PKD Foundation. Do not publish or report conversations that are meant to be private or internal to the Foundation.

Correct your mistakes. If you make a mistake, be upfront and quick with your correction. Please advise your staff lead of the matter.

Respect PKD Foundation branding. All community social media accounts should be uniform, coordinated, and consistent with the Foundation's Brand Guidelines. Brand Guidelines are posted in the Volunteer Resource pages. This includes the Foundation's official logo, colors, font, etc.

Add value. Social media communications from communities should be beneficial to the community. Content should be relevant and appropriate.

Be responsive. If someone asks a question or comments, volunteers should respond as soon as possible. If you're not sure how to answer the question or respond to the comment, contact your volunteer engagement staff lead.

Volunteer Resource Pages

PKD Foundation staff maintain volunteer resource webpages to keep volunteers informed and to ensure that tools and resources for PKD Foundation volunteers are readily available. These pages are not available at pkdcure.org. PKD Foundation volunteers will be provided direct URLs to access the volunteer resource pages. Announcements, training materials, information and volunteer forms are easy to access by visiting pkdcure.org/volunteers.

Volunteer Forms

In order to streamline the flow of information and to ensure that requests, orders, reimbursements, etc., are handled correctly, the Foundation has several forms that PKD Connect Ambassadors are required to use. All forms can be found on the [Volunteer Resource page](#).

Most forms are set up to "auto-submit," meaning that once the form is completed click submit to send the form to staff members.

Event Form

An Event Form must be submitted for every community meeting.

Receipt of this form at the Foundation office triggers PKDF staff to set up a registration page so constituents can RSVP to attend and to send emails to promote the meeting to the local community. One form is sufficient for ongoing, recurring meetings. We ask that event forms be

submitted a minimum of six weeks prior to a community meeting.

Deposit Form

In order for funds to be properly credited to community activities, a Deposit Form must accompany all revenue mailed to the Foundation. Every effort is made to process funds and thank donors within five business days of receipt of funds, this time frame will be longer during Walk season and at the end of the year.

Direct Pay Request Form

This form is used by our fundraising volunteers and should be used to request that a vendor be paid directly for pre-approved expenses.

Reimbursement Request Form

This form is used by our fundraising volunteers and should be used to request reimbursement for any pre-approved event expenses paid for by a volunteer. Receipts must be sent with the form for payments to be processed. All expenses require pre-approval by the Director of Community Engagement.

In-Kind Reporting Form

A gift-in-kind is a non-monetary donation of goods such as water or food for a community meeting, etc. Our auditors require that we provide them with a list of all of the gift-in-kind donations received by PKD Foundation volunteers. It is necessary to include a complete description of the item that was donated so the gift can be appropriately acknowledged according to IRS requirements. For example, rather than just saying “bottled water,” it’s required to put a quantity such as “three cases of 24 bottles of water.”

Please submit all gift-in-kind donation information to the Foundation within 30 days after the event for which the donations were received.

Incident and Injury Form

This form must be completed and submitted if there is an accident, incident or injury at a community meeting or event.

Volunteer Hours Reporting

Our volunteers give more than 25,000 hours of time annually to support the PKD Foundation mission to #endPKD. Volunteers should report their hours by submitting them via [volunteer hours submission form](#) within one week of the occurrence. Not only does this information demonstrate the level of volunteer commitment to funders and national /community leaders, but many companies also match funds for volunteer hours.

Communication

Volunteer Connection

This is a monthly electronic newsletter that communicates a current and comprehensive message for all PKD Foundation volunteers. This email communication is delivered to the personal email account provided to the Foundation by the volunteer.

Hot Sheets

Hot Sheets are used to communicate important, time-sensitive information from the PKD Foundation. Hot Sheet emails are delivered to the PKDF provided email account with the subject line “Hot Sheet.”

Additional Information and Resources

PKD Foundation print materials

PKD Foundation print materials are available for volunteers to use as needed. Print materials are available online in the [Resource Library](#) of the website making it easy to download and print on your own. If you have questions about how to use print materials, please contact your staff lead.

Foundation Financial Information

The PKD Foundation’s Annual Report, 501(C)(3) tax exempt letter, tax ID number, audit and a list of the Board of Trustees is available on the volunteer resource page.

Logos

Raising awareness of polycystic kidney disease and the work of the PKD Foundation and its volunteer-led communities is a key step in fulfilling the mission of the organization. All logos, graphics, etc. must be used following the Editorial guidelines located on the volunteer resource page, to ensure consistency and promote and increase the recognition of the disease, the Foundation, and its brand.

Volunteer Training

The PKD Foundation values our volunteers and is committed to providing the training, resources, and tools necessary to be successful in a PKD Foundation volunteer role.

Onboarding training sessions and resources are posted on the volunteer resource pages and are updated as needed.

Volunteer training calls are also recorded and posted on the volunteer resource page for convenience. If volunteers are unable to attend training or conference calls, we ask that the recording be reviewed as soon as possible.

Additional training sessions are available as needed in the training section of the volunteer resource pages.

Hosting a Community Meeting

What is a community meeting?

A community meeting is an opportunity for local patients and families to gather in support of each other and to learn valuable information to help them manage living with PKD.

The PKD Foundation is committed to providing quality education and support programs, both at the national and local level. As opportunities for learning and support are planned for the local community, the Community Engagement staff is here to help. PKD Connect staff members will assist volunteers with planning local meetings and choosing topics that utilize and/or complement PKD Foundation national patient education offerings.

Our goal is to work toward quarterly meetings in each local community. PKD Foundation staff will work with PKD Connect Ambassadors to reach this goal.

Where Do I Start?

New PKD Connect Ambassadors are asked to plan the first community meeting within 6 months of accepting the volunteer role and the Community Engagement staff is here to assist with the planning process. It's as easy as one, two, three!

1. **Planning meeting** PKD Connect Ambassadors will meet with their staff lead to choose the topic and walk through the planning process for the first community meeting.
2. **Host the community meeting** Community Engagement staff will attend the first virtual community meeting to support you as the volunteer and to provide resources.
3. **Follow-up meeting** Following the first community meeting, PKD Connect Ambassadors will meet with their staff lead to discuss follow-up and plans for future community meetings.

Community meetings can include activities such as:

- Review and discussion of an existing PKD Foundation patient education resource, such as a webinar recording.
- Gathering to support one another, share individual experiences and share PKD Foundation resources to help manage PKD.
- Invite a local expert to present a topic that complements PKD Foundation patient education.

Promoting Community Meetings

Email is the primary way the PKD Foundation uses to invite the local community to attend community meetings. As soon as details are finalized for a community meeting, please fill out an [Event Form](#). Completing an Event Form is necessary for the Foundation to promote and support community activities.

Please note that the Foundation sends numerous emails to its constituents throughout the year. The goal is to keep people informed while not overwhelming their inboxes with Foundation and local community information. As such, the Foundation limits the number of local community emails.

PKD Connect Ambassadors are encouraged to promote community meetings utilizing local social media and email as appropriate. PKD Foundation staff will provide a list of registered attendees ahead of each community meeting. Emailing local constituents that have

registered or attended a community meeting is a great way to help boost attendance.

Key Elements to a Community Meeting

Following an agenda, even an informal agenda, helps you facilitate the meeting effectively and keeps attendees focused on the topic and discussion.

Welcome and Introductions

- Welcome everyone as they sign into a virtual meeting.
- Take a moment to provide a brief update from the PKD Foundation at the beginning of each meeting.
- Introduce yourself and key volunteers to meeting attendees.

Discussion Topic

The body of the meeting is the discussion of the topic you have chosen or the speaker's presentation.

PKD Journey

When focusing on peer-to-peer support, allow time for meeting attendees to share experiences and where they are in their personal journey with PKD.

Take Action

The end of the meeting is a great opportunity to encourage attendees to leave the meeting with a plan of action, such as a resource to review or a question to ask their health care team.

Keeping the Community Engaged

Research

Since the PKD Foundation was founded in 1982, it has invested over \$50 million in more than 1,300 research, clinical and scientific grants, awards, fellowships, and scientific meetings. The research department has also launched the largest patient powered ADPKD Registry.

PKD Connect Ambassadors can support the PKD Foundation's research efforts by staying informed. Sign up to receive clinical trial alerts so you will know when trials are recruiting in your local community. Encourage members of the local community to stay informed about current research and to participate in the ADPKD Registry. If using social media, share research related posts to help keep the local community informed.

Advocacy

Since its inception in 1982, the PKD Foundation has worked to raise awareness of PKD and impact elected officials' views on legislation and policies that benefit PKD patients and research efforts. The PKD Foundation is a strictly nonpartisan organization, and our mission is to find treatments and a cure for PKD. The PKD Foundation does not support or oppose individual office holders, political parties or candidates. We focus our efforts on raising awareness of PKD among elected officials and educating them about our research efforts.

PKD Connect Ambassadors have a unique opportunity to help support the PKD Foundation's advocacy efforts by signing up to receive advocacy alerts and staying informed. If using social media, share advocacy related posts to keep the local community aware of important advocacy updates.

Education and Support

The PKD Foundation is committed to providing quality education and support programs, both at the national and local level. Handbooks are available to help patients and families understand PKD, manage their disease and advocate for the highest quality health care. The resource library offers the education needed to answer questions about PKD.

In addition to planning local programs to support the needs in your community, PKD Connect Ambassadors can direct patients and family members to resources available online and offer the support needed to help patients advocate for themselves.

Awareness

Awareness is a top priority for the PKD Foundation and PKD Connect Ambassadors expand public awareness of PKD and the PKD Foundation in local communities across the United States. If you have the opportunity to attend a community health fair, speak to a civic organization, share PKD materials with health professionals, or any other awareness activity, please submit an event form so that we can provide you with the materials you need for success.

Fundraising

100% of Community Fundraising dollars supports research! Walk for PKD Ambassadors and Fundraising Ambassadors work with our Community Fundraising Department to plan fundraising events in local communities. PKD Connect Ambassadors act as a liaison to the Walk Ambassadors by promoting the Walk during community meetings, sharing on social media, and by understanding volunteer opportunities associated with the local Walk event.

Contact Information

PKD Foundation

1001 E. 101st Terrace Suite 220
Kansas City, MO 64131
800.PKD.CURE (800.753.2873)
Fax: 816.268.8496
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