



PKD FOUNDATION

Polycystic kidney disease

**PEER
MENTOR
Handbook**

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Welcome

Dear volunteer,

Thank you for your commitment to the PKD Foundation! Volunteers are the heart of our organization and are critical to taking our mission to the communities we serve. Our volunteers contribute over 19,000 volunteer hours each year – valued at more than \$550,000. Our volunteer team makes the work we do possible.

You are joining over 200 volunteers that share in the mission to give HOPE. Together, we will build a community for everyone impacted by PKD.

As a volunteer, you have a true impact on the PKD community, and I could not be more excited to partner with you.

Welcome to the PKDF Volunteer Team!

A handwritten signature in black ink that reads "Nicole Chave". The signature is written in a cursive, flowing style.

About the PKD Foundation

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.

Our Vision

#endPKD

Our Mission

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

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 can 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 assist 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.

Outreach Ambassador

The Outreach Ambassador program is meant to build new bridges between the Foundation and previously underserved communities. The Outreach 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.

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.

To protect your privacy, it is important that you reply to communications using the community email account and not your personal email address.

Volunteer Code of Conduct

Volunteers shall act honestly and ethically while in the performance of their volunteer duties. Volunteers shall treat all PKD Foundation employees, volunteers, and community members with respect, courtesy, and dignity. Volunteers shall not discriminate and shall be respectful of ethnic, national, and cultural differences.

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, Sr. Director of Community Engagement
nicoleh@pkdcure.org or 800.753.2873, ext.143

PKD Connect Peer Mentor Program Overview

Welcome to the PKD Connect Peer Mentor Program! The PKD Foundation is honored that you would like to share your experiences living with PKD with others. No one should feel alone as they manage living with PKD. PKD Connect Peer Mentor Program connects volunteers that are living with PKD (peer mentor) with someone that is looking for support. You, as a peer mentor, can understand what your mentee is going through and can share experiences that will help them feel that they are not alone. Your goal is to listen and help your mentee(s) become their own best health advocate.

What is mentoring?

Merriam-Webster defines a mentor as “a trusted counselor or guide.” Peer mentoring is a relationship between two people that have shared experience(s) in common. The relationship is based on respect, responsibility, and a mutual understanding of what is helpful. At the core, mentoring means making yourself available to support someone when they need it in a way that is meaningful to the mentee. A mentoring relationship can be a short-term relationship or could last for months.

Expectations & requirements

PKD Connect staff members are here to supervise mentor / mentee relationships and help as needed. Staff members will meet regularly with peer mentors to provide support and to discuss progress. It is very important to be responsive to communications and to let PKD Connect staff members know if your availability changes. A two-year commitment to the program is required.

Peer mentor expectations

- Listen and understand what others are going through.
- Provide resources and information, support and encouragement to assigned mentees.
- Share their experiences with the people they are supporting.
- Help accomplish the mission of PKD Connect Peer Mentor Program.
- Report any concerns immediately to PKD Connect staff members.
- Two-year commitment to the volunteer role.

Peer mentor requirements

- Sign a volunteer agreement.
- Provide availability for mentoring calls.
- Promptly communicate availability changes
- Monitor email regularly
- Familiarity with Office 365 and Outlook email platform
- Reliable internet connection and smartphone or desktop access
- Submit call notes for every mentor / mentee call.
- Participate in ongoing training.
- Keep conversations confidential.

Respecting privacy & confidentiality

Confidentiality is extremely important. PKD Foundation staff will not share mentor's personal contact information with mentees. Mentors are provided with an email account and a phone number for communication with mentees.

It is important to document all calls with your mentees. We will use a shared spreadsheet to track mentees assigned to you, to document notes from your calls and the resources shared with mentees. As you document calls with mentees, please be general in nature. The mentor information spreadsheet that will be shared with you by PKD Connect staff should not be shared with anyone else.

Peer mentor volunteers will be asked to sign a volunteer agreement acknowledging their understanding of PKD Foundation privacy and confidentiality policies. We want to ensure that our volunteer mentors, as well as the people we support feel comfortable and confident sharing personal information and experience.

How to become a PKD Connect Peer Mentor

Submitting your application

The first step in becoming a PKD Connect peer mentor is submitting the Become a PKD Foundation volunteer form followed by our volunteer application and conflict of interest forms. Applications and conflict of interest forms will be reviewed by PKD Connect staff and mentors will be notified by email within two weeks of submission. PKD Connect staff is dedicated to ensuring that both mentors and mentees have a positive experience participating in the Peer Mentoring Program.

To ensure the program is successful and meaningful, we will work to keep a balance between the number of mentors and the number of mentees utilizing the mentoring service. If we are not accepting mentors, volunteers will be immediately notified and applications will be kept on file.

The final steps required to becoming a peer mentor is a background check and submitting our volunteer agreement.

Peer mentor training

PKD Connect Peer Mentors 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. Annual volunteer training may be held virtually via video conference and webinars or in person.

Peer mentors will be asked to attend ongoing training and participate in one-on-one calls with PKD Foundation staff. Peer mentor training will be an ongoing process and we thank our mentors in advance for taking the first steps in becoming a peer-to-peer mentor. So, let's get started!

Email Accounts

PKD Connect Mentors utilize a PKD Foundation email account for all communications with mentees. PKD Connect Mentors are responsible for checking email regularly and responding to mentees 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 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 Mentors 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.

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 it is 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 peer mentor, 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.

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

sample script 1

I can't answer specific medical questions.

"I am not a trained medical professional so I cannot answer that question. That is a great question to ask your doctor."

Mentor / mentee relationships

Matching your experience to the needs of others

The PKD Connect Center will connect individuals who call us, email us, or connect with us through social media with a mentor who has shared experiences. PKD Connect staff members will introduce mentors to mentees via the email address provided to our mentors. Peer mentors are required to use the provided phone number and email address to communicate with each person that you support.

Peer mentors will be asked to provide PKD Connect staff with preferred times of availability. Every effort will be made to match mentees with mentors based on experience and preferred availability. When we receive a mentor request, PKD Connect staff will reach out to a mentor to confirm the mentor is available to meet with the new mentee. Once the mentor confirms, an introduction email is sent to the mentor and new mentee. PKD Connect staff will also add your new mentor's name, phone number and email to your mentor information spreadsheet for easy access.

We want to help set you up for success so we will set the parameters up front, but it will be your responsibility to manage expectations for your availability for follow-up calls and email correspondence.

Once the initial introduction email is delivered, peer mentors should make every effort to follow up via email within two to three business days. If you are unable to respond due to vacations, illness, work, or family needs, etc., please let PKD Connect staff members know and we will follow up or assign another peer mentor. Agree on a time for your call upfront and log your scheduled peer support call on your mentor information spreadsheet. Don't be afraid to set boundaries up front.

At the time of the first scheduled call, you will need to call your mentee at the provided number. Remember: Do not share your personal phone number. Please use the Zoom mobile or desktop app.

Understanding the mentor-mentee relationship

To ensure a successful mentor / mentee relationship, it is important to define exactly what the relationship is from the beginning. For mentoring to be most effective, the roles and responsibilities of both mentors and mentees should be agreed upon from the very beginning of the relationship.

The mentor's role should include sharing experiences with mentees as appropriate, offering encouragement and support, celebrating success, providing feedback, and helping mentees find resources to help manage living with PKD. Mentors are not medical experts and cannot give advice. Mentors can and should collaborate with mentees but should not position themselves as experts. The mentors focus should be to support the mentee and help mentees become their own best advocate.

Mentees have their own role and responsibilities as well. Mentees should identify initial goals for the relationship, be open to feedback and take an active role throughout the relationship.

If a mentor feels that a mentee would be better matched with another mentor, please let PKD Connect staff know and we will take an active role in assisting both the mentor and the mentee.

sample script 2

Starting the call

Hello, my name is _____.
I'm the Peer Mentor that the PKD Foundation assigned to you. Is this still a good time to talk? Excellent.
It's my understanding that you requested a mentor to help you with. Is that correct? Do you mind if I ask you a few more questions to ensure I understand your situation?
Wonderful. . . .

Building connection & trust

Most, if not all, of your mentoring sessions will take place by phone or video conference. Developing skills to help build trust over the phone is critical to building a strong relationship. Being mindful and using responsive-listening skills build trust. Being mindful simply means to be 100% connected and present in the moment of conversation. Listen with empathy, rather than judgement. Responsive listening requires that you use your ears and your heart to help you choose a supportive response.

Everyone copes with PKD in their own way and in their own time. You may or may not agree with everything you hear, and you may or may not have shared the same experiences. It is important for mentors to understand and recognize when conversations with mentees create strong emotions for the mentors. Discussing some issues might create uncomfortable feelings for you. It is important for you as mentors to be aware of your own personal feelings and points of view and that you keep them from interfering with the support you are offering. If there are times when you are feeling overwhelmed as a mentor, this is the time to reach out to PKD Connect staff for support.

Clarifying top concerns

As mentors and mentees get to know one another, it is important to go over expectations for the relationship and clarify the mentee's top concerns. It may not be possible to address all your mentee's concerns during the first call. Understanding priorities and clear communication between mentor and mentee will set the relationship up for success right from the beginning.

Empathetic active listening

Tips for good listening skills:

- Show that you are interested in what your mentee is saying.
- Offer encouragement.
- Be present in the conversation.
- Spend more time listening than talking.
- Pay attention and jot down notes to help you stay focused on the conversation.
- Ask open ended questions to clarify what your mentee is sharing.
- Don't interrupt. Wait until the mentee finishes talking before you respond.
- Try to put yourself in your mentee's shoes.
- Paraphrase using your own words to clarify understanding.
- If you don't understand, be honest and let them know that you do not understand.
- Do not judge or show bias.

Self-care tips

There are many rewards that come with volunteering and mentoring others. It is very gratifying to know that you have been able to help others and lighten their burden. There are also challenges that may create additional stress for mentors. It is important to make sure that self-care is a priority and that mentors have a support system to turn to when in need of a listener.

Self-care is not just something to do when on vacation. When in need of self-care, try the following tips:

Take a break. Remember to give yourself time to rest.

Set goals. Break down your obligations to small, more attainable goals.

Say no. Don't take on more than you can handle.

Create a support system. Reduce stress in your life by asking others to help you.

Unplug. Allow time for mindfulness by taking a break from technology.

Above all, contact PKD Connect Center staff when in need of support. We are here to help and support our mentors and our mentees.

Managing conversation challenges

It is natural to want to “fix” the problem. Mentors may want to give advice based on personal experience or use personal experiences to guide mentees to the “right” answer. This can derail your conversation and your mentor / mentee relationship. It is not a mentor's job to advise, direct, provide answers or solutions. It is appropriate to share personal experiences, but the mentee is responsible for evaluating their own situation.

Mentors must always remind mentees that they are not medical professionals and cannot evaluate the mentee's health or provide recommendations for treatment. It is always the mentee's responsibility to follow up with their health professionals and discuss all questions and concerns.

Asking questions is a great way to gain clarification and understanding when you aren't sure how to support a mentee. Give your mentee time to respond and reflect on your question. A moment of silence and reflection is okay. Too many questions all at once may be overwhelming.

Keep the conversation focused on the mentee. There are times when sharing experiences can be beneficial but as a mentor, it is always your decision how much of your personal story you would like to share.

Mentor / mentee engagement

You now have your first mentee assignment. You have communicated with your mentee and have determined the time for your call. Let's get ready for the call!

Be on time! This builds trust and shows your new mentee that you value them.

Explain your role as a peer mentor. Let your mentee know that you are there to listen, but you are not there to provide medical advice or counseling services. You are there to share their journey and provide support and encouragement.

Listen and learn about the concerns your mentee brings to the call. Develop some specific goals that your mentee wants to discuss with you.

Show interest in the conversation.

Focus on helping your mentees be their own best advocate.

Provide the mentee with resources to address the concerns that they bring up during the call.

If your mentee asks you questions that you do not know the answer to, write it down and let your mentee know you will follow up on this question with PKD Connect staff members.

After the call, document the call on your mentor information spreadsheet and list the resources provided.

Be prepared to follow up with your mentee after a few days to see if the information was helpful and if you can connect him / her with additional information.

Organizing your calls

Each call will be different, but you can plan to organize your calls in a basic format that will help keep things on track.

Goal setting. At the beginning of each call, make sure you identify the goals for the call. Clarify what you hope to accomplish. You may not be able to cover all the mentee's concerns in one call so set the expectation up front.

Sharing. Listen to the mentee's concerns and share experiences that may help support the mentee's goals for the mentoring session.

Reflecting, As the end of the scheduled time approaches, it is time to reflect on the session, determine if goals were met and schedule the next call.

Clarifying boundaries

Set boundaries up front. Ask your mentee what his / her goals are for the first call. Clarify the top concern(s). You may need to choose one or two concerns to address during a call session. Let your mentee know if any of the concerns listed need to be addressed by a health professional and be honest that you cannot provide medical advice.

sample script 3

Setting boundaries

“So there are no surprises, I'd like to give you an idea of what to expect, timewise on these calls. Typically, the first call (today's call) is a bit longer than the calls to follow. Today's call usually runs about 40–50 minutes. On subsequent calls, however, our schedules are blocked for a 30-minute time frame. I find the best way to maximize call time is to work from a list of questions that you've prepared in advance of the call. It may also be helpful to know that while my availability varies, when I am available, I block calls between the hours of 9–2 PST, Mon.–Fri.”

Ending the call & post-call reflection

When the end of the scheduled time for the call is approaching, begin to think about how to end the call. It is important to make sure that your mentee feels successful from the mentoring session. How the call ends will reinforce a positive experience and set up future mentoring sessions for success as well.

- Ask the mentee if he/she feels that immediate concerns have been addressed.
- Schedule a follow up call.
- Review resources that were discussed to address mentee's concerns.
- Determine what topics are of concern for follow up calls.

Encourage mentees to spend some time reflecting on the conversation before the next call and to document thoughts and actions based on the conversation. Keep a list of new concerns or questions in preparation for the next call.

Record keeping and follow-up

PKD Connect volunteer mentors are required to provide documentation of every call. This is important to the success of the program and will help PKD Connect staff evaluate the program and provide the resources necessary to ensure that our mentors have the training and resources to support their mentees.

Please fill out the mentor information spreadsheet within 48 hours after your call. Report any concerns you may have regarding the call immediately.

What to do if you need help

If you do not know how to best support a mentee, be honest with your mentee. If you feel uncomfortable, it is okay to let your mentee know that you need to consult with PKD Foundation staff members. Sometimes, those that reach out to us for support need more support than a volunteer is qualified to provide. If you feel that is the case, be honest with your mentee and ask them if it would be okay to transfer the call to the PKD Foundation Hope line.

Even though it is unlikely, peer mentors should be prepared if a mentee shares information that causes you concern for his / her safety or the safety of others. The PKD Connect Peer Mentoring Program is not a crisis service, and our volunteers are not trained to offer the support necessary to help a mentee through an emergency. Peer mentors can: listen, remain calm, encourage problem solving and provide resources to help the mentee get the help needed.

If you feel your mentee needs more support than you are qualified to provide, help your mentee identify his / her support system and provide the Crisis Text line as a resource. Be honest with your mentee, let him / her

sample script 4

Call Completion

“I see we’re nearing the end of our call, so let’s see how we did. While I know you may have more questions, tell me, did I address your immediate area of concern? Just so you know, this doesn’t have to be the last time we discuss this topic. We can continue to discuss this area of concern during future calls, if you’d like?”

Preparing for Next Call

“Would you like to schedule another call, or would you prefer to process what we discussed first? If you choose to continue, I’d like to encourage you to keep a list of future topics, so we can discuss them on future calls. Either way, keeping a list will help you drive your best path forward.”

know you are concerned about him / her and that you will need to follow up with the PKD Foundation staff.

Please notify PKD Connect staff immediately when you feel you are not qualified to support your mentee. If you feel your mentee is in danger of self-harm, help your mentee contact the Crisis Text line or National Suicide Prevention Hotline. Please notify PKD Connect staff immediately.

PKD Hope Line: 844.PKD.HOPE
Crisis Text Line: 741741
National Suicide Prevention Hotline: 800.273.8255
suicidepreventionlifeline.org

Ending a peer-to-peer relationship

Most likely, peer-to-peer relationships will end naturally as mentees feel they have received the support and information needed at the time. Quite often, our mentors report that they had a great conversation with a mentee and the mentee doesn't feel the need to schedule ongoing calls. This is okay!

Sometimes, mentees want to discuss experiences that you, as a mentor, have not experienced in your own journey with PKD. We can always introduce a mentee to another PKD Connect mentor at any time and this is okay, too!

If you feel that a relationship with a mentee is no longer productive or no longer feels positive, it is your responsibility to gently conclude the relationship. If you feel at any time that a mentee is not a good match for you as a mentor, please let PKD Connect staff know immediately.

A peer-to-peer relationship can be ended at any time by the mentor or the mentee. It may be that there are other resources that can be offered to assist your mentee.

If you need assistance, please contact PKD Connect staff for help.

sample script 5

Ending a relationship

MENTOR: "Now that we've had four sessions, how do you feel about continuing or ending future engagement?"

MENTEE: "I haven't really thought about that. I do feel like I can move forward on my own, but can we keep the door open if I feel the need to talk again sometime in the future?"

Contact Information

PKD Foundation

1001 101st Terrace Suite 220 Kansas City, MO 64131

800.PKD.CURE (800.753.2873)

Fax: 816.268.8496

pkdcure.org

Peer Mentor Program

peermentors@pkdcure.org

Hope Line

844.PKD.HOPE

844.753.4673

PKD Connect Staff

Nicole Harr

Sr. Director of Community Engagement

nicoleh@pkdcure.org

800.753.2873, ext.143

816.268.8483

