



**PKD FOUNDATION**  
Polycystic Kidney Disease

**Chapter Handbook**  
**January 2018**

## **Chapter Structure**

Chapters are groups of volunteers, patients, family and friends who want to learn and connect with others in their community. Chapters have been forming to fight PKD since the 1980's, funding research, telling others about PKD and providing hope and a true sense of community to Chapter members. Our Chapters, and the volunteers who lead them, are the backbone of the PKD community.

PKD is one of the most common life-threatening genetic diseases and there is no cure. Today, treatment options are limited to dialysis and transplantation. PKD equally affects men, women and children – regardless of age, race, geography or ethnic origin. The often-devastating disease comes in two hereditary forms:

### **Autosomal Dominant Polycystic Kidney Disease (ADPKD)**

Parents with the dominant form of PKD have a 50 percent chance of passing the disease on to each of their children. Unlike some genetic diseases, ADPKD does not skip a generation. Approximately 10% of ADPKD patients are spontaneous mutations and have no family history. A spontaneous mutation is one that arises naturally and not as a result of inheriting a mutated gene from a parent or from exposure to agents that cause changes in genes.

### **Autosomal Recessive Polycystic Kidney Disease (ARPKD)**

ARPKD is a relatively rare form of PKD that affects 1 in 20,000 babies and often leads to death in the first month of life. Parents who carry the ARPKD gene have a 25 percent chance of passing the disease on to each of their children.

Local Chapters are led by volunteers who want to make a difference in the fight to END PKD. Chapter activities focus on five key areas:

#### **Education**

Educate patients and family members about PKD by planning education meetings or seminars. Promote education opportunities offered by the PKD Foundation the local community.

#### **Support**

Assist patients by providing guidance to locate resources available in the local community. Provide opportunities for PKD patients and their families to connect and support each other.

#### **Fundraising**

Execute a local Walk for PKD and with appropriate support consider a second fundraising event or activity providing a solid return on investment for the Foundation and its volunteers. Promote

national fundraising initiatives. Identify individuals, corporations and foundations interested in financially supporting the Foundation through a major gift.

### **Awareness**

Chapters play a significant role in expanding public awareness of PKD and the PKD Foundation by promoting local events to the PKD community and by participating in local awareness opportunities.

### **Advocacy**

Chapters can engage in advocacy efforts by educating Chapter members on our legislative priorities and by encouraging the local PKD community to support the PKD Foundation's advocacy efforts.

### **Chapter Leadership Structure**

The following are volunteer leadership positions for Chapters. The PKD Foundation Volunteer Engagement staff recruits volunteer leaders in a variety of ways, including but not limited to advertising on the Chapter webpage and recruitment emails. Chapter Coordinators, working with other volunteer leaders, will recruit additional Chapter volunteers through networking at Chapter events, utilizing local social media accounts and using recruitment resources available in the local community.

PKD Foundation Volunteer Engagement staff will work with local volunteer leadership to determine which Coordinator positions are critical to the success of your local Chapter.

#### Chapter Coordinator

The Chapter Coordinator represents the Foundation in the local community and acts as a liaison between the Foundation and local constituents (e.g. patients, families, health professionals, sponsors, etc.). The Chapter Coordinator creates and implements an annual plan and has administrative responsibility for the local Chapter (e.g. monitoring the Chapter email account, submitting Event Forms and updates for the Chapter webpage, etc). This position requires approximately four hours per month and a two-year commitment is required. Attendance at the annual Leadership Conference is a necessary component to equipping the Chapter Coordinator to do his / her job.

#### Education Coordinator

The Education Coordinator, working with the Chapter Coordinator, is responsible for providing opportunities for education and support for local patients, families and health professionals.

Responsibilities include: planning local education meetings and seminars, promoting education opportunities offered by the Foundation, providing guidance to locate resources available in the local community to those affected by PKD and providing opportunities for PKD patients and their families to connect with and support one another. This position could require three to six hours per month.

### Fundraising Coordinator

Chapters should consider holding a second fundraising event when they are consistently meeting their Walk goal and when the event will not interfere with the success of the Walk for PKD. The Fundraising Coordinator, working with the Chapter Coordinator and Volunteer Engagement Staff, is responsible for executing the activity with special attention paid to maximizing the return on investment (ROI) for the Foundation and the event's volunteers. Responsibilities include engaging participants, setting a budget, organizing a planning committee, securing monetary sponsorships and in-kind donations and managing event logistics (e.g. facility, catering, photography, auction items, etc). This position is also responsible for supporting third party event organizers, especially in terms of promoting the event locally. This position could require at least three to six hours per month, but more in the six months prior to the event.

### Walk Coordinator

The Walk Coordinator, working with the Chapter Coordinator and Walk for PKD Committee, is responsible for planning and executing the local Walk for PKD to raise critical funds for the PKD Foundation and grow awareness of polycystic kidney disease (both ADPKD and ARPKD). As the Walk for PKD comprises nearly one-third of the Foundation's annual revenue, its fundraising success is critical to the Foundation. Responsibilities include recruiting teams and participants that drive fundraising to meet the Walk goal, organizing a group of key volunteers, securing sponsorships and in-kind donations, managing event logistics, and working within a budget defined by PKD staff. . A two-year commitment is required of Walk Coordinators. Attendance at the annual Leadership Conference is a necessary component to the success of the local Walk for PKD.

## **Overview of the Volunteer Role**

### **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. A volunteer must be officially accepted prior to using the title of Chapter, Walk, Education or Fundraising Coordinator. Volunteers are not considered employees of the Foundation.

## **Representing the PKD Foundation**

Volunteers are asked to be considerate when contacting organizations or individuals on behalf of the PKD Foundation. Prior to any action or statement that might significantly affect or obligate the Foundation, volunteers should seek prior consultation and approval from an appropriate staff member. These actions may include but are not limited to: public statements to the press, coalition or lobbying efforts with other organizations, or any agreements involving contractual or other financial obligations. Only staff members of the PKD Foundation are authorized to sign contracts. 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.

## **Volunteer Training and Development**

Volunteer leaders will receive an orientation on the mission and vision of the PKD Foundation, and then specific training to provide them with the information and skills necessary to perform their roles. Trainings will be held in a variety of mediums including in-person, webinars, teleconferences, etc. Coordinators are asked to attend the annual Leadership Conference training held in June. The Foundation will pay for airfare and lodging for two Coordinators per Chapter to attend this training.

## **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. The following is a general list of Chapter Coordinator responsibilities:

- Communicate openly and proactively with other Chapter volunteers, ensuring their active involvement in Chapter activities.
- Work with your staff lead to create and implement an annual plan for your Chapter to include activities in all areas of the Chapter mission: fundraising, education, support, awareness and advocacy.
- Utilize training materials and opportunities provided by the Foundation including the Leadership Conference, webinars, teleconferences, Coordinator Resources pages, etc.
- Help recruit and manage Chapter volunteers to assist in planning events, meetings and activities that support the Chapter's mission. Communicate goals and follow up regularly to ensure volunteers have the support needed for Chapter-related activities.
- Communicate openly and proactively with PKD Foundation staff about Chapter activities, concerns, successes and needs. This includes providing forms and reports in a timely manner.

- Actively monitor the assigned <city>chapter@pkdcure.org email account (e.g. kansascitychapter@pkdcure.org) a minimum of three times per week.
- In conjunction with event leaders, ensure proper recruitment and training of day-of-event (DOE) volunteers to facilitate a well-run event for all participants.
- Ensure all event revenues (including checks, money orders, credit card forms, cash, etc.) are remitted to the PKD Foundation as soon as possible, at the latest within one week of receipt.
- Ensure that contact and other pertinent information for participants, volunteers, sponsors and supporters is appropriately gathered at Chapter events and submitted to the Foundation.
- As a Coordinator, you may be asked questions about the PKD Foundation, PKD (ARPKD & ADPKD). It is important that you explain that you are *not a medical professional* and their physician's instructions should always be followed.
- If a Coordinator is unable to continue in that 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. The volunteer Coordinator is expected to provide accurate, thorough and up-to-date information for their successor. The resigning volunteer Coordinator's assistance in providing candidate suggestions for the position would be greatly appreciated.

## **Chapter Expectations**

### **Education and Support**

- Hold at least two educational and/or support meetings each calendar year.
- Be responsive to community needs in providing support activities.
- Support and promote PKD Foundation education opportunities and resources.

### **Walk and Additional Fundraisings**

- Hold a Walk for PKD.
- Promote national fundraising initiatives in the Chapter area.
- Conduct additional fundraising activity with input from the volunteer engagement team.

### **Administrative**

- Attend conference calls with your staff lead minimum of twice annually or as needed.
- Attend Leadership Conference and participate in at least two Foundation training webinars.
- Monitor Chapter email account, webpage and Facebook; respond to inquiries in a timely manner.
- Keep updated on Coordinator resource page information by reviewing material at least once a month.

- Submit volunteer hours within two weeks of an event or monthly for ongoing activities. Submit gift-in-kind donation information within 30 days of the event for which contributions were received.

### **Other**

- Promote awareness of PKD and the Foundation.
- Support Foundation advocacy efforts.

### **Privacy of PKD Foundation Volunteers**

The Foundation respects and protects volunteers' privacy and will not release your personal contact information without prior permission. We will direct inquiries about the Chapter to the PKD Chapter email account, which is one reason it is very important to check for messages frequently. If someone is not able to use the email method of communication or specifically calls asking to talk to you, Foundation staff will contact you to request follow-up on the inquiry. In order to protect your privacy, it is important that you reply to communications using the Chapter email system and not your personal email address. With permission, your name will be placed on webpages and in emails to personalize the Chapters and build community.

### **Volunteer Advisory Committee**

The Volunteer Advisory Committee (VAC) is comprised of experienced Chapter volunteer leaders] from around the country who work to ensure the delivery of a rewarding volunteer experience. They represent volunteer leadership by providing guidance to PKD Foundation staff in the development of volunteer engagement strategies.

### **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.
- No volunteer will be terminated until the volunteer has had an opportunity to discuss the reasons for possible dismissal with supervisory staff.
- 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.

## **Policies and Procedures**

### **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 the Volunteer Engagement 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 Issues**

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 Coordinators 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 Coordinator. 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.

### **Evaluations**

Volunteers will work with the Volunteer Engagement Staff to periodically review their volunteer experience. The evaluation is an opportunity for both the volunteer and the Foundation to examine and improve their relationship. The evaluation process is utilized to

1. Review the performance of the volunteer
2. Seek suggestions from the volunteer on ways to enhance the volunteer's relationship with the Foundation
3. Convey appreciation to the volunteer
4. Determine the continued interest of the volunteer in continuing to serve as Chapter Coordinator, Education Coordinator and Fundraising Coordinator.

### **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 Volunteer Engagement Manager.

### **PKD Merchandise and Apparel Guidelines**

The PKD Foundation store is available online through a link at the website ([pkdcure.org](http://pkdcure.org)) and offers the opportunity to purchase brand-approved materials. Individuals are encouraged to purchase items from the Foundation store rather than creating their own merchandise or apparel. The Foundation does not reimburse for material or apparel created through individual printing and production. Items from the online store should not be sold at Chapter events including the Walk for PKD.

### **Reimbursement of Expenses**

Volunteers are eligible for reimbursement of reasonable expenses directly related to Chapter events planned on behalf of the PKD Foundation. For all expenses over \$100, Volunteer Engagement staff member must give approval.

### **Resignation**

If a Coordinator is unable to continue in a leadership 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, access to email and social media accounts will be removed and account login credentials will be updated. The volunteer Coordinator is expected to provide accurate, thorough and up-to-date information for their

successor. The resigning volunteer Coordinator's assistance in providing candidate suggestions for the position would be greatly appreciated.

### **Social Media Accounts**

If you decide to use Facebook, Twitter or other social media for your Chapter, please adhere to the following:

- **Be responsible and professional.** Chapter Coordinators are responsible for the content they publish on behalf of the PKD Foundation and their Chapter on any social media platform.
- **Respect confidentiality.** Coordinators 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 Chapter social media accounts should be uniform, coordinated and consistent with the Foundation's Brand Guidelines. Brand Guidelines are posted in the Coordinator Resource pages. This includes the Foundation's official logo, colors, font, etc.
- **Add value.** Social media communications from Chapters should be beneficial to the community. Content should be relevant and appropriate.
- **Be responsive.** If someone asks a question or comments, Coordinators 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 Resignation**

Volunteers may resign from their volunteer service with the PKD Foundation at any time. Volunteers who intend to resign should provide advance notice of their departure and a reason for their decision. Notice should be provided in writing to any member of the Volunteer Engagement team. Upon notice of resignation, passwords to official PKD Foundation email and social media accounts will be updated or restricted as appropriate. Volunteers are required to remove PKD Foundation email accounts from their smart phones immediately upon resignation. Exit interviews, where possible, should be conducted with volunteer leaders who are leaving. The interview should ascertain why the volunteer is leaving the position, suggestions the volunteer may have to improving the position, and suggestions as to volunteers that may be willing to serve in the vacated leadership role.

For questions about Policies and Procedures, contact:

**Nicole Harr, Director of Patient & Community Engagement**

[nicoleh@pkdcure.org](mailto:nicoleh@pkdcure.org) or 800.753.2873, ext.143

## **Chapter Programs & Services**

### **Education**

The PKD Foundation is committed to providing quality education programs for PKD patients and their families. As opportunities are planned for the Chapter, the Volunteer Engagement staff is here to help. Chapter education activities can include but are not limited to inviting guest speakers for a seminar. Offering a variety of education opportunities over the course of the year will ensure that you meet the needs of all Chapter constituents. The Volunteer Engagement staff can assist in focusing local education opportunities to fit the needs of your Chapter members.

### **Support**

Support is an important part of the Chapter's mission and can look very different in each Chapter. Providing support in your community can include listening and responding to constituents that reach out to you for support and information, organizing support meetings and connecting PKD patients in your area to other patients that have similar needs and concerns.

The PKD Foundation Discussion Forums are one way to connect your Chapter members to others. They provide a forum for patients, family and friends to make connections and share experiences. Join in the conversation and invite your Chapter members to participate as well. The PKD Foundation Discussion Forums sheet can be found at the end of this section.

### **Key Elements to a Chapter Education or Support Meeting**

No matter what type of meeting you are planning, *structure* is necessary. To help attendees feel comfortable, it is best practice to follow a similar structure at all of your meetings.

- *Welcome* everyone at the beginning of each meeting and provide a brief update from the PKD Foundation and your Chapter. (The Foundation will provide regular updates on the Education portal you can share.)
- The *body of the meeting* would be the discussion of the topic you have chosen or the speaker's presentation.
- *Close* your meeting by thanking everyone and reminding them of any upcoming Chapter activities or events.

### **Topic / Speakers**

People are more likely to attend an event that covers a topic of interest to them. Having a designated speaker is important, even if that speaker is a Chapter member and/or the presentation is brief. If you are planning a support meeting, you do not need to invite a speaker. However, it is still beneficial to plan a topic for discussion.

*Ready, Set, Meet!* is a program designed to help you plan your next education or support meeting. You will find topics important to PKD patients and families along with all of the resources you need to plan your next meeting without starting from scratch. *Ready, Set, Meet!* is available in the Education & Support section of the Coordinators resource page located at [pkdcure.org/coordinators](http://pkdcure.org/coordinators).

### **Location**

Hold your meeting in a neutral space that is centrally located. Hospitals and libraries often have rooms available for nonprofit use at no charge. The Foundation does not recommend that you have meetings in your home. While this may be convenient for you, it may not feel comfortable for first-time attendees. If your location requires insurance paperwork from the Foundation, please contact a member of the volunteer engagement team.

### **Resources**

The following resources are available to assist you as you plan and promote your education events.

- Email announcements to the local Chapter area
- Social media assistance
- Listing on the Chapter webpage and online registration
- Press release template and list of local media affiliates
- Event checklist
- In-kind donation receipt forms
- Day-of-event materials, including PKD information, brochures, directional arrows and name tags. (*Available upon request.*)
- Dedicated staff to support your Chapter's efforts
- *Ready, Set, Meet!*

Additional resources and best practices for your education meetings can be found in the Education section of the Coordinator resource page including timelines for planning, suggested topics, sample agendas, materials and resources that are available from the PKD Foundation.

Expenses & Reimbursements - When planning education and support meetings, please discuss expenses with the Volunteer Engagement staff and / or your staff lead.

### **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.

Your Chapter can participate in advocacy efforts both at the local and national level by visiting the district and state office of your state representatives and senators during congressional recess and by participating in signing up for Advocacy alerts and participating in National Advocacy efforts.

To find your elected officials visit our Advocacy Toolbox available at [pkdcure.org/advocate](http://pkdcure.org/advocate).

To learn more about the PKD Foundation's current legislative priorities visit our Advocacy Toolbox at [pkdcure.org/advocate](http://pkdcure.org/advocate).

### **Awareness**

Awareness is a top priority for the PKD Foundation and Chapters have a unique opportunity to expand public awareness of PKD and the PKD Foundation in local communities across the United States. If you are planning to participate in 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**

#### **Walk for PKD**

Started in 2000, the Walk for PKD has become the Foundation's signature fundraising event raising nearly \$28 million for PKD research, education and support. More than 50 Walks occur every year in cities across the United States with thousands of PKD patients, families and friends fundraising and walking together to end PKD. The Walks are organized and promoted by passionate and dedicated PKD volunteers and are the only nationally-run fundraising event aimed at finding treatments and a cure for PKD.

Walk for PKD will be the largest gathering of PKD patients in your areas. Take advantage of this opportunity to connect with Chapter constituents, community groups, medical professionals and local businesses. The Chapter Coordinator should ensure that Chapter and Foundation materials are available at the Walk, preferably at a Chapter Table with a volunteer available to connect with Walk participants.

#### **Non-Walk Fundraising Events and Activities**

In addition to the Chapter holding an annual Walk for PKD, Chapter Coordinators may have the opportunity to coordinate an additional fundraising event. Opportunities include:

1. Chapter Fundraising Event
2. Promoting National Fundraising Initiatives including elite marathons and our Fundraise Your Walk opportunities. Ongoing promotion of workplace giving and the Vehicle Donation program.

To understand which fundraising activity(s) is/are the best fit for your local Chapter, set up a meeting with a member of the Volunteer Engagement Staff.

### **Chapter Fundraising Event**

Chapters with a stable and successful Walk for PKD and ongoing local educational offerings are encouraged to consider implementing a Chapter fundraising event. Chapter fundraising events are typically led by the Chapter Coordinator or the Fundraising Events Coordinator and are supported by a committee of Chapter members and community members. The nature of the Chapter event will depend upon the interest of the local community. Examples are Cocktails for a Cure and a restaurant percentage of sales night.

### **How will the PKD Foundation support my fundraising event?**

The PKD Foundation staff is dedicated to helping you plan a successful and enjoyable Chapter fundraising event in your area. Upon submission of the event form, Volunteer Engagement staff will work with the organizer to set a fundraising goal and create an event management plan. The event form is available on the Coordinator resource page.

The following support services are available from the Volunteer Engagement Staff:

- Email announcements to the local Chapter area
- Social media assistance
- Listing on the PKD Foundation online event calendar
- Listing on the Chapter event page under the “Local Events” section
- Press release template and list of local media affiliates
- Sponsorship kit, including sample request letters and sponsorship menu template
- Letter of authenticity from the PKD Foundation
- Forms for accepting donations that are fully charitable donations to the PKD Foundation
- Day-of-event materials, including PKD Foundation signage, event signage templates, PKD information and brochures (*Available upon request.*)
- Day-of-event credit card processing capability (*Available upon request.*)
- Event Insurance (discuss need for insurance with Volunteer Engagement staff)
- Dedicated staff to support your fundraising efforts

### **How do I get started?**

Chapter Coordinators or Fundraising Event Coordinators interested in planning a fundraising event should fill out the form located on the coordinator resource page. The Fundraising Events Assistant will follow-up to discuss the event and begin the process of extending support services.

### **Promoting National Fundraising Initiatives**

Four National Fundraising Initiatives at the PKD Foundation provide meaningful and impactful ways for local Chapter members to connect with the organization. These initiatives include Workplace Giving, Vehicle Donation, Fundraise Your Way and our elite marathons. All Chapter Coordinators are strongly encouraged to share information about these programs in the local Chapter area. Promotional kits and materials are distributed monthly and are available on the Coordinator resource page to make promotion easy.

**Marathon Series** – The Marathon Series secures coveted spots in some of the nation’s top marathons including the TCS New York City Marathon and Bank of America Chicago Marathon. Runners may secure a spot on Team PKD by agreeing to a fundraising commitment.

Chapter leadership can support the Marathon Series by:

- Promoting the opportunity to secure a spot in these premiere races at local Chapter meetings and events and on social media. Promotional materials are available.
- Providing names of athletes who might be interested in fundraising for the PKD Foundation by running a marathon.

### **DIY for PKD**

Fundraise Your Way allows participants to use their passion to fuel their fundraising for the PKD Foundation. Participants may do just about anything to raise funds for the PKD Foundation, from doing a Polar Plunge to hosting a lemonade stand to organizing a work jeans day. Creativity and passion rules in this space so the opportunities to get involved are endless.

Chapter leadership can support the Fundraise Your Way program by:

- Promoting Fundraise Your Way at local Chapter meetings and events and on social media. Promotional materials are available.

For questions about fundraising events and activities, contact:

**Sue Full, Director of Community Fundraising**

[suef@pkdcure.org](mailto:suef@pkdcure.org) or 800.753.2873, ext. 136

### **Materials and Resources**

## **Overview**

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 Chapters are required to use. [All forms can be found on the Coordinator Resource page](#)

The Coordinator Resource Page can be found at [pkdcure.org/coordinators](http://pkdcure.org/coordinators).

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

## **Chapter Reflections / Annual Planning Guide**

Chapter Coordinators are required to participate in an annual reflection conference call scheduled during the last quarter of the calendar year. Coordinators will be asked to fill out a reflection questionnaire in preparation for the call. During the reflection call, you will discuss your annual plan for the upcoming year, enabling Foundation staff to be better prepared to provide resources and support for these events.

## **Budget Template**

A budget template is available to assist in planning fundraising events. The template is available on the Coordinator resource page and should be reviewed with the appropriate staff member during your planning process.

## **Chapter Webpage**

**Keeping your Chapter web page up to date will ensure that new visitors to your page are informed and will motivate them to get involved with your Chapter.** We do ask for your help in checking your Chapter webpage frequently and notifying us of any changes you would like. Please note that completing an Event Form will alert the Foundation that the event needs to be posted on your page.

## **Conference Call Line**

If the Chapter needs to utilize a toll-free conference call line to conduct Chapter business, contact the Volunteer Engagement staff for more information.

## **Communications to Chapter Constituents**

Email is the method used to promote meetings, education seminars, fundraising events and other important announcements. As soon as logistics are secured for a Chapter event, please fill out an Event Form. ***Completing an Event Form is absolutely necessary*** for the Foundation to promote your Chapter event. Depending on the type of event, the Foundation will send up to four emails to your Chapter’s mailing list promoting the activity; the first as a save the date, the second as



registration reminder, the third as a last chance to register and the fourth is a reminder. All emails will be scheduled by the PKD Foundation staff.

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 Chapter information. As such, the Foundation limits the number of emails for events. Additionally, the Foundation reserves the right to not send emails on behalf of your Chapter.

Coordinators are encouraged to communicate via email or phone as appropriate to local constituents. PKD Foundation staff will provide updated contact lists per request. It is important that Coordinators not email large groups through Chapter email accounts. Large group emails will alert spam. When emailing groups of constituents, please request an updated list and use each list for a maximum of two weeks.

### **Coordinator Connection**

This is a monthly coordinator newsletter that communicates a current and comprehensive message for all areas, Chapter, Walk, Education and Fundraising.

### **Coordinator Hot Sheets**

Coordinators may receive emails delivered to the Chapter email account with the subject line “Hot Sheet.” These messages contain important, time-sensitive information from the Foundation.

### **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 Coordinator resource page.

### **Google Documents**

Google documents are sometimes used to communicate information to and from Chapter Coordinators and can be utilized by many people at the same time. Google documents are located under the DRIVE tab at the top of your Gmail account.

### **Gmail Account**

The Foundation will provide you with an email account through Gmail (Google’s email platform) that works much like your personal Google or Yahoo mail system. You can send and receive emails, upload address books and connect within your Chapter by using this tool. We ask that you check the email account at least three times a week and respond to any communications in a timely manner. **You can also have the messages coming to the Gmail account forwarded to your personal email address. However, you should reply to messages from the Chapter email account to protect your privacy.**

You will be given a username and a password for the Chapter account. Please do not change the password for the account. When corresponding on behalf of the Foundation, please use your volunteer leadership title, of Volunteer Chapter Coordinator. Volunteer engagement staff can assist you in setting up a signature line.

**To sign into the Gmail account, go to: gmail.com**

Then enter your assigned PKD email (e.g. kansascitychapter@pkdcure.org) and your assigned password.

If you have your email forwarded to your personal email, please make sure to use the Chapter email address to send or reply to emails. This will allow sponsors, team captains, and participants to easily identify the message and also lends credibility to the information.

Visit the Coordinator resource page for instructions on how to forward the Chapter Gmail account to your personal email as well as adding the Gmail account to your smart phone.

**Please note:** Once your Chapter Coordinator service has ended, you will want to remove the PKD Foundation email account from your personal email account and your Smart Phone.

**Social Media Accounts**

The PKD Foundation utilizes social media to engage with the PKD community. Chapters may have local social media accounts that are primarily managed by volunteer Coordinators. If you are interested in starting a social media account, please review social media policies and contact your volunteer engagement staff lead for additional information. Volunteers are not permitted to set up social media accounts in connection with the PKD Foundation without prior permission from the PKD Foundation.

Helpful Social Media Tips

Social media exposure can feel like it is building slowly at first, but make it a regular part of your communication and it will grow.

- Utilize formats approved in the PKD Foundation style guide, located on the Coordinator resource page
- Post information, invitations, photos, links, etc., on the Chapter's social media pages
- Recognize teams, sponsors and volunteers. Highlight milestones in their success and be sure to tag them in the post for more exposure.
- Pace your messages. Don't post several messages in one day, but spread them out so you have regular messages reaching people consistently throughout the year.
- Be sure to promote upcoming events. You may want to start with one or two posts the month before and build to more frequent posts as you get closer to the event (week of event and a thank you after the event).

- After you post the information, be sure to share it with your own social media followers and ask Chapter constituents, Team Captains, top fundraisers, volunteers and others to do the same.
- Ask sponsors to like your social media pages and share Walk/event information on their pages

For additional resources to enhance your message, visit to the Coordinator Resource page.

If you have questions or would like more information on social media and best practices, please contact the Volunteer Engagement staff.

### **Logos**

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

### **Newsletters**

Information about your local events will be included in the PKD Foundation's monthly electronic newsletter - PKDnews. To ensure that your local information is included, please submit an event form as early as possible. Events that are scheduled for 30 days after PKDnews goes out are included.

### **Press Release Template**

A standard press release template is available and can be used for most meetings or events. Simply insert the event details and contact information and email it directly to your local media outlets

### **Forms**

**An Event Form must be submitted for every Chapter meeting or event.**

Receipt of this form at the Foundation office triggers marketing through the email process. One form is sufficient for ongoing, recurring meetings (e.g. support meetings). This form can be found on the Coordinator resource page.

Submit the Event Form as soon as you know your Chapter will be holding an event (a minimum of four weeks is needed for most events; three to four months is required for educational seminars and fundraising events). This form is **critical** to ensure proper planning, strong fiscal management, and clear communication with the Foundation office. For fundraising events, this form helps with proper coding when registrations and donations arrive at the Foundation's office.

## Chapter Deposit Form

In order for funds to be properly credited to Chapter activities, a Deposit Form must accompany all revenue sent 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.

The Deposit Form is available online at the Coordinator resource page.

- Upon receiving money for an event or as a donation, submit it to the PKD Foundation within one week using the Deposit Form.
- Use a separate Deposit Form for each event. If you have donations for multiple events, please use multiple forms.
- It is also important that you record the type of revenue received. You may have multiple revenue types for each event deposit.
  - ✓ **Event Gift:** A gift made to the Chapter with nothing in return.  
*You held a Chapter meeting and were given \$20 by an attendee as a donation.*
  - ✓ **Registration:** The assigned fee to take part in an event.  
*Your golf tournament has a \$200 registration fee/ticket price per player.*
  - ✓ **Sponsorship:** Funds given to offset the cost of the event; the sponsor receives predetermined benefits in return.  
*Your Education Seminar is sponsored by Athena Diagnostics for \$1,500; in return, they will have their name in the program and will be mentioned at the event.*
  - ✓ **Raffle / Auction:** Proceeds from holding a raffle or auction.  
*You receive two tickets to a sporting event and sell them in an auction.*
  - ✓ **Combined:** Cash from multiple donors.  
*You had a donation box at an event and it has \$90 in miscellaneous cash from donors you cannot identify.*
- Be sure to include any accompanying correspondence with the Deposit Form to the PKD Foundation.
- If you are sending more than \$1,000, please send the deposit in a traceable manner (i.e. Fed-Ex, DHL, UPS or USPS, but request tracking).
- Do NOT send cash\*. Have all cash converted to a cashier's check or money order. For liability reasons it is not advised that you transfer cash through your personal bank account. (\*Except for Day-of-Event Walk for PKD money.)
- If you are converting cash, please record the names, addresses, and donation amount of each cash donation and include on the Deposit Form so we may appropriately thank those donors. Without this documentation, converted cash will be coded as an event gift, not an

individual donation. Please ensure that the Deposit Form and gift amount totals are the same.

- Make a copy of the Deposit Form for your records before mailing.
- If you are depositing revenue from a silent auction, please include the top copy of all bid sheets and a Silent Auction Form with your Deposit Form. These documents are located on the Fundraising portal. We must have the participant's name, amount paid for item and the value of the item to accurately provide your participant with a receipt.

## **Expense Payments**

### **Direct Pay Request Form**

This form should be used to request that a vendor be paid directly for pre-approved Chapter-related expenses.

The Direct Pay Request Form is available on the Coordinator resource page and can be submitted online along with a copy of the invoice to be paid.

- To ensure timely payments, allow three weeks from the date of mailing the form and invoice for a vendor to receive a check.

Please contact the Community Fundraising Specialist at [fundraising@pkdcure.org](mailto:fundraising@pkdcure.org), if you have any questions regarding submitting direct pay or reimbursement requests.

### **Reimbursement Request Form**

This form should be used to request reimbursement for any pre-approved Chapter expenses paid for by a volunteer. *Receipts must be sent with the form in order for payments to be processed.*

Reimbursements for expenses related to special events must be included in your event budget. Reimbursements for purchases not in your budget over \$100 must be pre-approved by the Foundation.

The Reimbursement Request Form is available on the Coordinator resource page and can be submitted online along with receipts.

- Submit the Reimbursement Request Form and receipts within 45 days of an expense being incurred.
- In order for expenses to be appropriately coded, include an explanation of the expense. Examples include:

- ✓ Postage for golf tournament sponsor packets
- ✓ Refreshments for education meeting
- ✓ Copies of meeting agenda made at FedEx Office

- If you discover that a receipt is missing, you must complete the Missing Receipt Substantiation Form in order to request reimbursement. This form is available upon request. The Foundation auditors frown upon using this form in place of providing the actual receipts for reimbursable expenses. Please make every effort to submit the appropriate receipts with your reimbursement requests.

- Make a copy of the receipts and Reimbursement Request Form for your records if you mail the information.
- Please allow at least three full weeks for processing.

## **Gifts**

### **In-Kind Reporting Form**

A gift-in-kind is a non-monetary donation of goods such as auction items, food for a Chapter meeting, etc. Our auditors require that we provide them with a list of all of the gift-in-kind donations received by the Chapters. 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.” Another example lacking enough information would be “newspaper advertisement for a Chapter education event”; the description should be “one quarter page newspaper ad in the local newspaper that appeared one day.”

Please submit all gift-in-kind donation information to the Foundation within 30 days after the event for which the donations were received. We utilize an auto-submit form to submit in-kind donations; the link is available from the Coordinator resource page.

## **Incident and Injury Form**

This form must be completed and submitted if there is an accident, incident or injury at a Chapter event. It is available online on the Coordinator resource page.

### **Materials Order Form**

Materials are available for Coordinators to order for meetings and events though the Coordinator resource page. PKD Foundation print materials are available online in the [Media Center](#) of the website making it easy to download and print on your own. Visit the Coordinator resource page for the complete list of PKD Foundation promotional materials. Please allow two weeks to process your request.

**Media List**

To request a list of the local media outlets in your community, contact a member of the Volunteer Engagement staff.

**[Volunteer Hours Reporting](#)**

It is very important for the Foundation to capture the number of volunteer hours that are provided by and to our Chapters. Many companies match funds for volunteer hours and it is necessary to confirm the hours before the contribution can be received. Also, this information assists in demonstrating the level of volunteer commitment to funders and national and community leaders. Volunteer hours should be submitted within a week of an event or monthly for ongoing volunteer activities on the auto-submit form located on the Coordinator resource page.

**Quick Links to Additional Resources:**

For additional information and resources, be sure to regularly visit the [Coordinator resource page](#).

## **Volunteer Engagement Staff Contact Information**

PKD Foundation  
1001 101st Terrace Suite 220  
Kansas City, MO 64131  
1.800.PKD.CURE (1.800.753.2873)  
Fax: 816.931.8655  
[www.pkdcure.org](http://www.pkdcure.org)  
[volunteers@pkdcure.org](mailto:volunteers@pkdcure.org)

For general Chapter questions and questions about education, support, awareness and advocacy programs:

**Nicole Harr, Director of Patient & Community Engagement**  
[nicoleh@pkdcure.org](mailto:nicoleh@pkdcure.org) or 800.753.2873, ext.143

For questions about the Walk for PKD and non-Walk Fundraising Events:

**Sue Full, Director of Community Fundraising**  
[suef@pkdcure.org](mailto:suef@pkdcure.org) or 800.753.2873, ext. 136

### **Additional Volunteer Engagement Staff**

**Joseph Berrigan, Community Fundraising Specialist**  
[josephb@pkdcure.org](mailto:josephb@pkdcure.org) or 800.753.2873 ext. 178

**Julie Luttman, Volunteer Engagement Specialist**  
[juliel@pkdcure.org](mailto:juliel@pkdcure.org) or 800.753.2873, ext. 104

**Dana Gillis, Volunteer Engagement Coordinator**  
[danag@pkdcure.org](mailto:danag@pkdcure.org) or 800.753.2873, ext. 120