

2020 SOCIAL MEDIA TOOLKIT



Thank you for participating in the 2020 Walk for PKD. We're so excited that you are joining us to push research forward!

We've put together this toolkit to provide you with resources that will help you spread the word about your Walk for PKD event, raise PKD awareness, and boost fundraising efforts using social media.

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In this toolkit we've included:

- General info about PKD
- Talking points for the Walk for PKD
- 2020 Walk for PKD: Why we walk
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General info about PKD

- There are two types of PKD: autosomal dominant (ADPKD) and autosomal recessive (ARPKD). ADPKD is the more common type and affects more than 600,000 Americans and 12.4 million people worldwide. ARPKD is a rare form of the disease that occurs in 1 in 20.000 children worldwide.
- A typical kidney is the size of a human fist and weighs about a third of a pound. PKD kidneys can be much larger, some growing as large as a football, and weighing up to 30 pounds each.
- The number of cysts can range from just a few to many. The size of the cysts can range from a pinhead to as large as a grapefruit.

- Although the primary sign of PKD is cysts in the kidneys, there are other symptoms that can occur in various areas of the body.
- The first treatment approved in the U.S. for ADPKD was tolvaptan.
- Tolvaptan slows kidney function decline in adults at risk of rapidly progressing ADPKD.
- The PKD Foundation not only supported early studies that led to the development of tolvaptan as a treatment, but also helped guide PKD patients to the clinical trials.
- The PKD Foundation is the only organization in the U.S. dedicated to funding research for PKD treatments and a cure.

Talking points for the Walk for PKD

- 100% of all funds raised from the #WalkforPKD go toward research for more treatments and a cure.
- More than 10,000 strong, the Walks are the largest gathering of PKD patients, family, friends, researchers, healthcare providers, and supporters.
- There are more than 50 Walks annually across the country. A Virtual Walk is also available if you can't find or attend a Walk in an area near you.
- The Walks bring entire families together to honor loved ones, foster a sense of community, and provide hope for a future without PKD.
- Walk for PKD events have raised over \$30 million.
- The Walk for PKD has been going strong for 19 years.



2020 Walk for PKD: Why we walk

Why do you Walk for PKD? Mom? Dad? To honor a loved one? To raise awareness? There are thousands of people with thousands of reasons why they Walk for PKD, but we all share the same goal. To #endPKD.

In 2020 we're telling the world why we Walk with the hopes of reaching others who share our whys, but haven't taken the steps to actually join the Walk.

This year, help us to connect others who want to join our cause:

- 1. Download and print our "I Walk for" template at walkforpkd.org
- 2. Fill in the blank on the template with the reason you Walk for PKD.
- 3. Take a picture with your "I Walk for" template.
- 4. Share to social media: Facebook, Instagram, Twitter, even Linkedin
- Tag us using our handle @PKDFoundation and include the hashtag #WhyWeWalk and #WalkforPKD

We'll be sharing your posts on our various social media platforms throughout the season. For ideas and inspiration, please see the sample posts below:







Make sure to include these hashtags in your posts:

#WalkforPKD #WhyWeWalk

Using social media

Facebook is more than just a place to see what your graduating class is up to. It's a platform that has enabled us to broadcast topics that we care about to the entire world! Crafting the perfect post to do just that doesn't have to be stressful. In fact, it can be fun!

Here are some tips to help:

Be you!

When writing a social post, think about how you'd write to a friend. You're not giving the State of the Union address, you're simply telling people about an event or cause that you're excited about.

No essays

You have a short amount of time to catch your online communities' attention. Make your social post short and concise. Give them just enough information to compel them to click your link or want to know more. Have too much to say? That's good, turn it into a separate post for another time!

Be authentic

No one likes to feel like they are being sold. When promoting the Walk, be human. Show, don't tell. Share your personal Walk experience. Share why you got involved with the Walk; why is it important to you?

Pictures

Adding the walkforpkd.org link and sharing the link preview is great sometimes, but mix it up and use photos from the Walk, too. Share pictures from previous years or share pictures from the PKD Foundation-just make sure you tag us!

Post examples that can be used on Facebook, Twitter, and Instagram

"I have polycystic kidney disease (PKD), a genetic disease that can eventually lead to kidney failure, and I #WalkforPKD because I know that 100% of the donations raised from the events go toward research for more treatments and a cure."

"I'm so excited for this year's #WalkforPKD with the @PKDFoundation! It's the largest gathering of the PKD community, and I love getting to meet others that understand my PKD journey." "My #WalkforPKD team, [team name], has raised [amount] so far! I'm so proud of us! Help us reach our goal by donating [team link]."

"Help move PKD research forward. The #WalkforPKD is your chance to make a difference in the lives of thousands in America and millions worldwide who have PKD. Donate until Dec. 31 to help us reach our \$2 million goal!"

Hashtag help

Put simply, a hashtag is what connects your social content to a community. Hashtags also make your content searchable and relevant to the subject you are posting about.

For example, say you want to post about an upcoming Chapter meeting for the PKD Foundation. The difference between the two posts below is that one is now archived into a feed with all other existing #endPKD posts and the other is not.

"I can't wait for our next Chapter meeting about post-transplantation! #endPKD"

"I can't wait for our next Chapter meeting about post-transplantation!"

For the Walk, please focus on using the following hashtags in your Walk related posts:

#endPKD

#WalkforPKD

If you want to find others posting about the same thing, try searching one of those hashtags and engage with others participating.

It's Walk day—now what?

It's now the moment we've all been waiting for—your Walk for PKD event is today! Don't get shy, now! Use your event day to broadcast all of the hard work you and your community have done. Share photos and videos throughout the day on your social media pages (Chapter and personal), and don't forget to use the hashtag #WalkforPKD.

Check out the new Why We Walk video and the Walk for PKD PSA (60 second) and get other shareable graphics and videos at walkforpkd.org/walk-toolbox/marketing-materials.