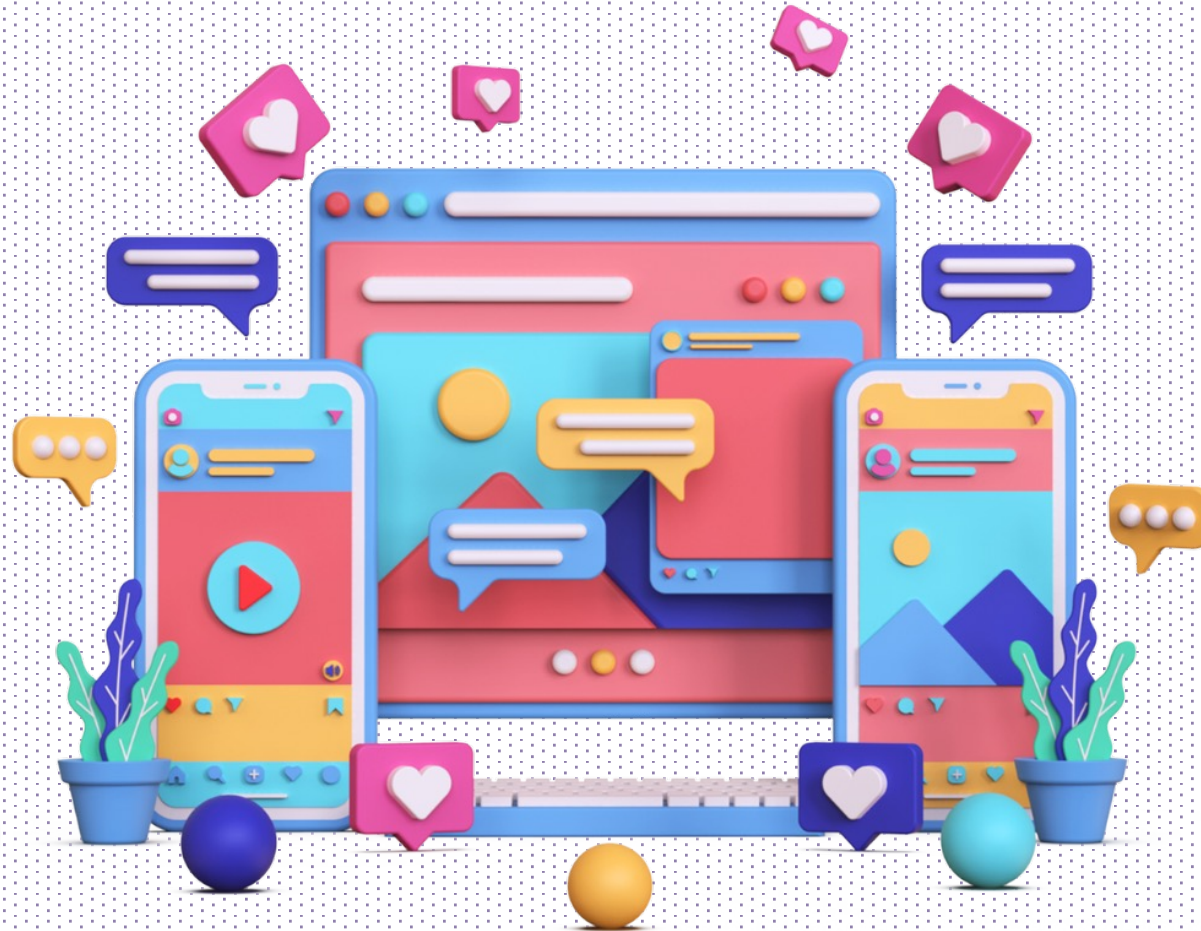


Social Media Training

Wednesday, July 12, 2023



PKD FOUNDATION
Polycystic Kidney Disease



Social media is always changing!



Facebook

36,199 followers

Instagram

7,399 followers

Twitter

8,667 followers

LinkedIn

3,628 followers

YouTube

5,421 subscribers

TikTok

436 followers



PKD FOUNDATION
Polycystic Kidney Disease



What should I post???



Goal for **Community Pages** is to **connect with your community.**

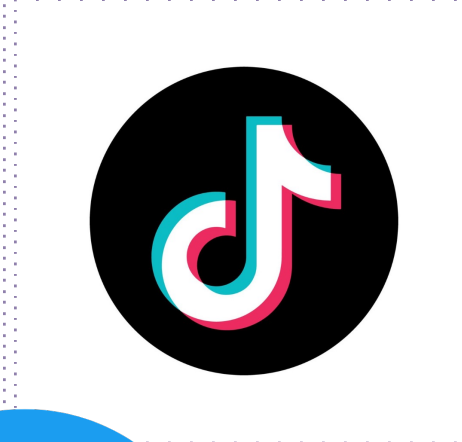
- Share your story
 - Ask your community members to post individually and you can share to your page
- Promote community events
 - Like an upcoming meeting or your local Walk
 - Make sure to include links, date, time, and place
- Share Resources
 - [Your local COE](#)
 - [Resource Library](#)
 - [Webinars](#)



Goal for Individuals is to raise awareness and build community.

- Share your story
- General posts about PKD
 - <https://pkdcure.org/volunteers/social-media-guidelines/>
 - <https://pkdcure.org/what-is-pkd/>
- Promote PKDF initiatives you are involved with
 - I'm advocating on virtual advocacy day
 - I'm participating in clinical research
 - I'm walking at the Walk for PKD

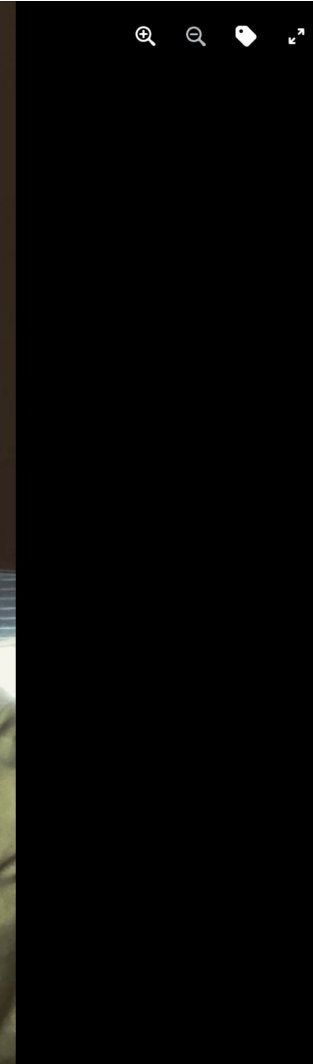





Examples



Share Your Story



 **PKD Foundation**
Published by Hootsuite · February 23 · 🌐

"I'm sure a lot of the kidney warriors out there can relate to this moment.

Sitting in your car in the hospital car park regrouping after an appointment.

I've done this countless times over the years. Whether it be trying to absorb the terrifying information just delivered, understanding what it all means, facing the fear, telling yourself to be brave. There's been tears, there's been anxiety and sometimes just a moment to breathe and regroup.

All in the car, in the hospital car park.






This morning it was the same but different. This time feeling humbled and grateful. My numbers are rock solid, I feel incredible and the fear is gone.




I told my doctor how amazing he is and thanked him. He replied, by telling me there's nothing in my way now.

Cheers and have an awesome Thursday 🍷"


Can you relate to this feeling? Check out @therenalcode on Instagram, where they are documenting their journey with PKD!
#endPKD See less







Edit

   424 73  28 

 Like  Comment  Share

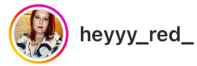
Most relevant ▾

 Write a comment...



Share Your Story



heyyy_red_



Liked by raghav_sambyaljk21 and others

heyyy_red_ Today I make 6 months post kidney transplant!!! 🥳

I can tell you my kidney (Alfie) is doing great...we are at 0.97% which is an awesome number for my creatinine. Doctors say I'm on auto pilot and to keep up the great work. I am officially OFF the transplant list.



totydixon

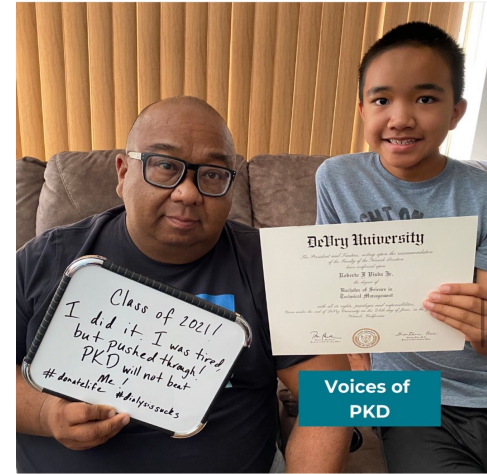
The University of Kansas Health System



Liked by marinaskidneyjourney and others

totydixon Kidney transplant: successful. Thanks to Zach Andersen for saving my life.

View all 8 comments



Liked by oneeyedmonster and 218 others

pkdfoundation "My husband's name is Rob Visda. When he was diagnosed with PKD at 18, he was going through the process of enlisting in the Marines. He inherited the disease from his mom's side of the family. Because of his diagnosis of PKD, he was not accepted into the service. Finding this out did not defeat the person he was at his young age but it did change his career path.

His kidneys failed after he started his career as a State of California correctional officer. He has now been on dialysis for five years. For his first year, he was doing his treatments in the center and now he does his dialysis at home. Home treatments allow him to work and provide for his family. When he's tired from dialysis, he makes it a point to listen to his body instead of pushing his limits. I'm his care partner, and since the COVID-19 pandemic, I've been able to work from home which has made it less stressful on my part.

My husband is on the transplant list along with many others. He is O positive and can only receive a transplant from O. He recently graduated college from DeVry University which was a true accomplishment for him. This was also his way of showing his son that even in the darkest of times, you can still achieve anything and everything."



Carousel Posts



Liked by 4menaj and others

npyee27 Thank you everyone who came this morning to support! It was good seeing everyone. I am always blown away by the amount of support. You guys all made... more

View all 4 comments

npyee27 @dahlia_bautistalong that's okay! There will always be next year 😊

npyee27 @dahlia_bautistalong yes except during Covid it was online! Okayyy see ya next year 🙌

September 25, 2022



Liked by 4menaj and others

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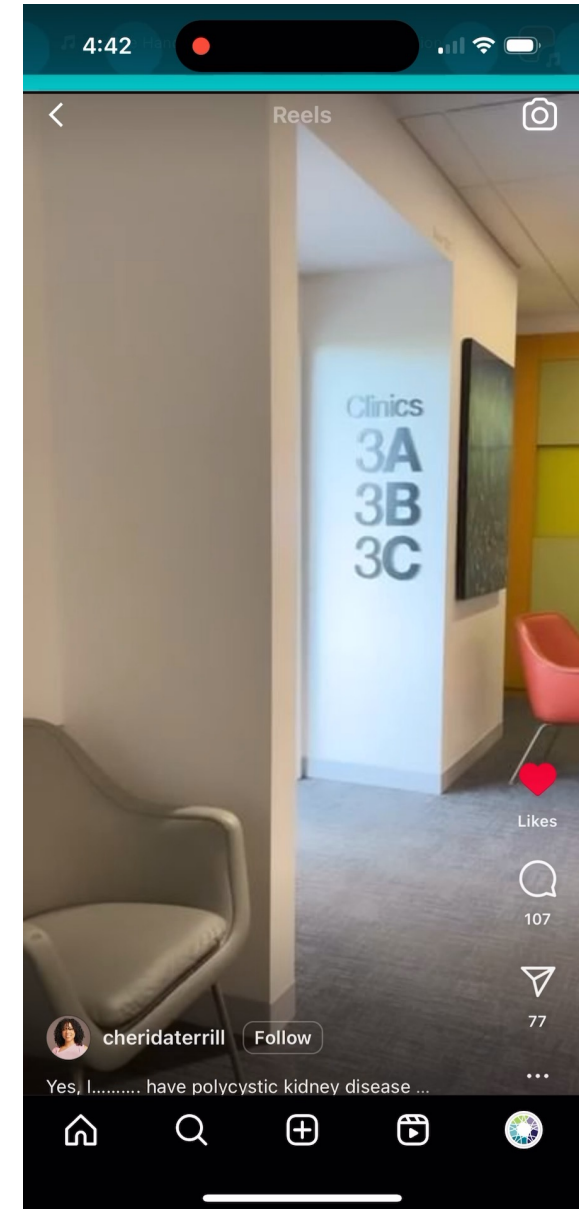
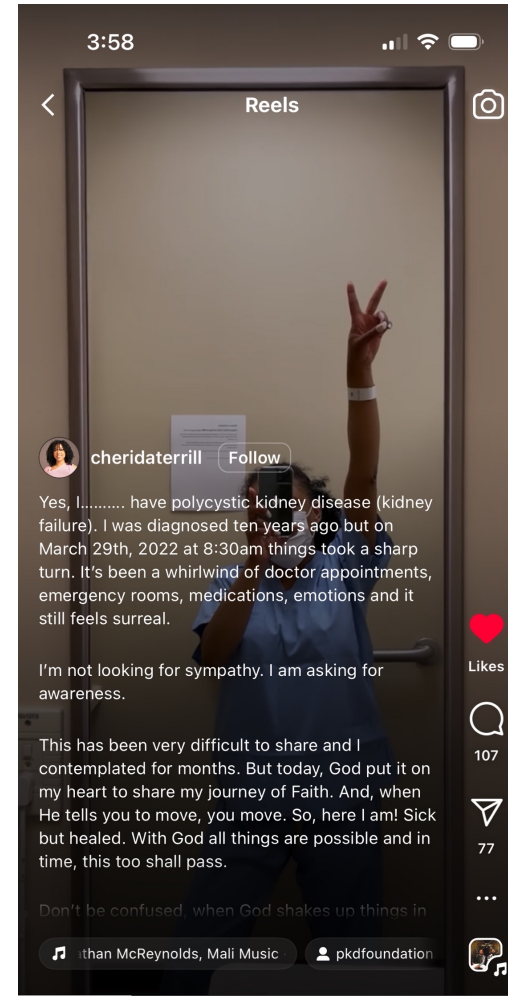
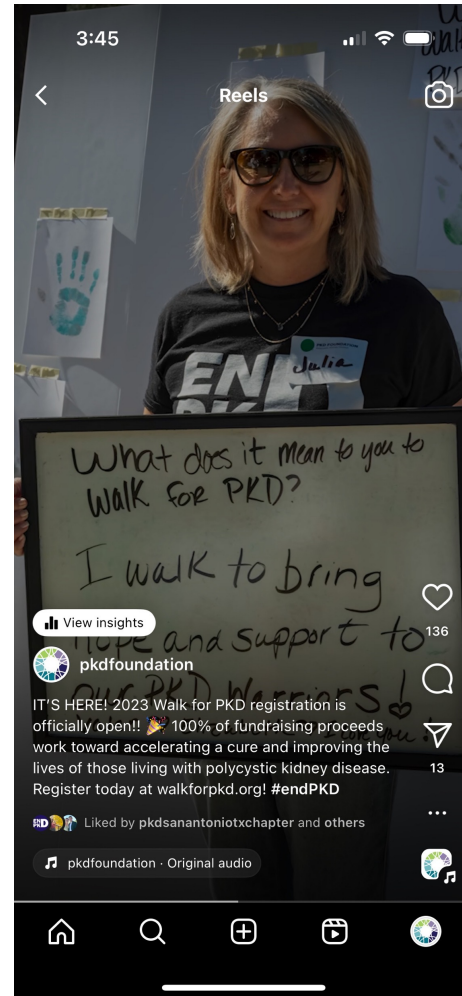
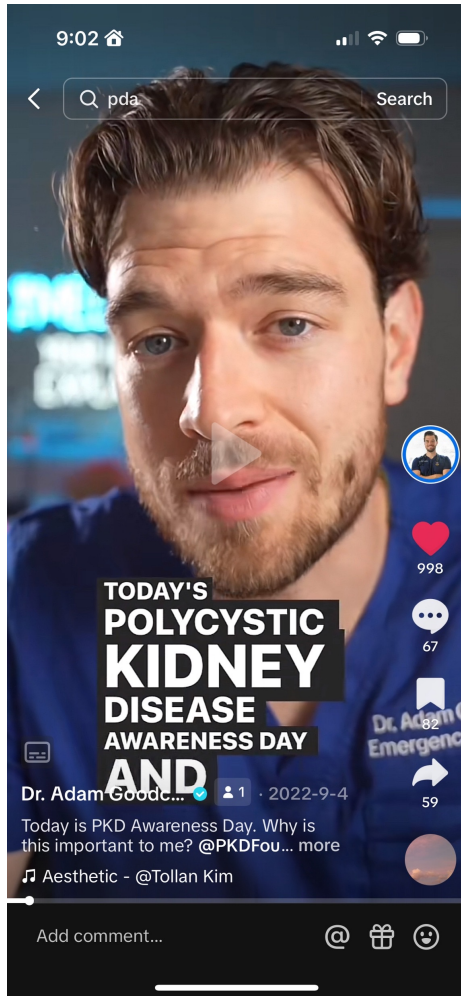
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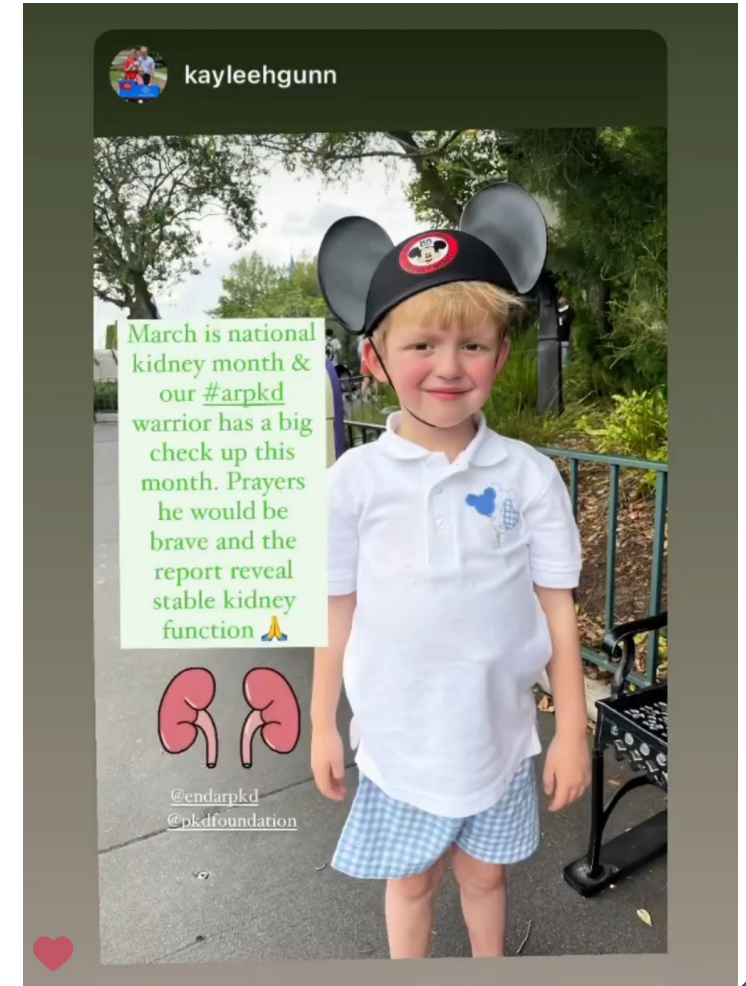
September 25, 2022



Reels & Tik Tok



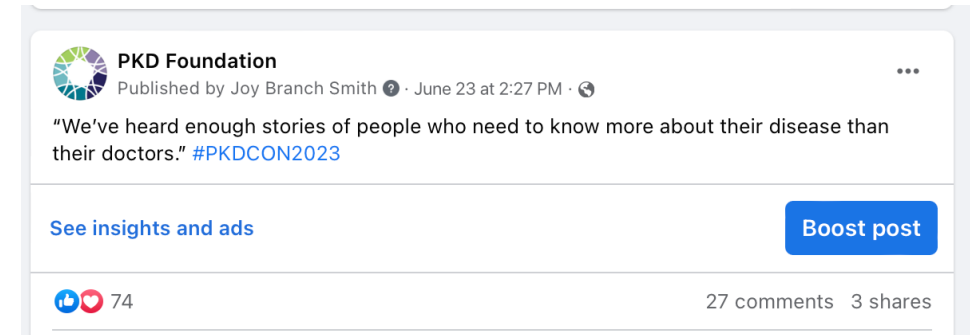
Stories



Twitter, Threads, & Text Posts

- Twitter
 - Primarily for text posts
 - Text & tweet limit for free Twitter users
- Threads
 - NEW
 - Meta's rival to Twitter

■ <https://www.nytimes.com/2023/07/10/podcasts/the-daily/threads-meta-twitter-musk.html>



Twitter, Threads, & Text Posts



PKD Foundation - North Texas Community

October 29, 2022 · 🌐



Today's Walk for PKD Schedule. Rain should stop by 8 a.m. 🤩

8 am – Registration opens, booths set up, and participants start to arrive – At this time volunteers should have their area set up and ready to interact with participants. It is typically slow at first and will pick up closer to 9am. DJ will start to play music.

9 am- Children's Walk around the park – NCL volunteers can help us lead the children on their Walk

9:15 – Announcements

9:30 – Start Line Ceremony and Walk begins – I have worked with the City to define the Walk route. We will be walking approximately 1 mile around Southlake Town Center. NCL volunteers will be out on the route and cheering at the finish line as participants cross.

10 am – Participants return from the Walk, visit booths and mingle. Participants typically stay around 20 – 30 minutes post Walk. As they start to leave, the music will stop, we will then start to clean up and take down all of the event signs, and equipment.

Around 10:30 am – Tear down and clean up. I anticipate everything to be done by 11:30 at the latest. The second shift of NCL volunteers will be leaving at 10:30 and not be around to help with clean up. We will need as many as possible to stay around to help with this.



Honorable Mentions

- YouTube
 - Long form video content
- LinkedIn
 - Primarily for professional updates
 - Volunteers in the past have added their volunteer position to their LinkedIn.

The screenshot shows a LinkedIn post from the PKD Foundation. The post features a photo of three women on a stage during a panel discussion. The photo is titled "ESTABLISHING NONPROFIT CREDIBILITY" and includes the following text: "Katrina VanHuss, CEO and Founder, Turnkey for Good", "Brea Kratzert Todd, Vice President, Business Development, Wounded Warrior Project", and "Krystn Kuckelman, Vice President of Community Development, PKD Foundation". The hashtag #connectatcollab is also visible. The post is from the PKD Foundation, which has 3,654 followers and posted it 1 month ago. The post text reads: "Our very own [Krystn Kuckelman](#) representing the PKD Foundation at the Classy Collaborative. ❤️". A comment from Jamie Bearse, MPA (He/Him) is visible, stating: "Fantastic first day at the [Classy](#) Collaborative. ...see more". The post has 1 comment and is shared by Krystn Kuckelman and 22 others.

PKD Foundation
3,654 followers
1mo · 🌐

Our very own [Krystn Kuckelman](#) representing the PKD Foundation at the Classy Collaborative. ❤️

Jamie Bearse, MPA (He/Him) · 2nd
NonProfit CEO @ ZERO Prostate Cancer | Named 9X in NonProfit Times' Best Places to Work for | Strategist | Fun...
1mo · 🌐

Fantastic first day at the [Classy](#) Collaborative. ...see more

ESTABLISHING NONPROFIT CREDIBILITY

Katrina VanHuss
CEO and Founder,
Turnkey for Good

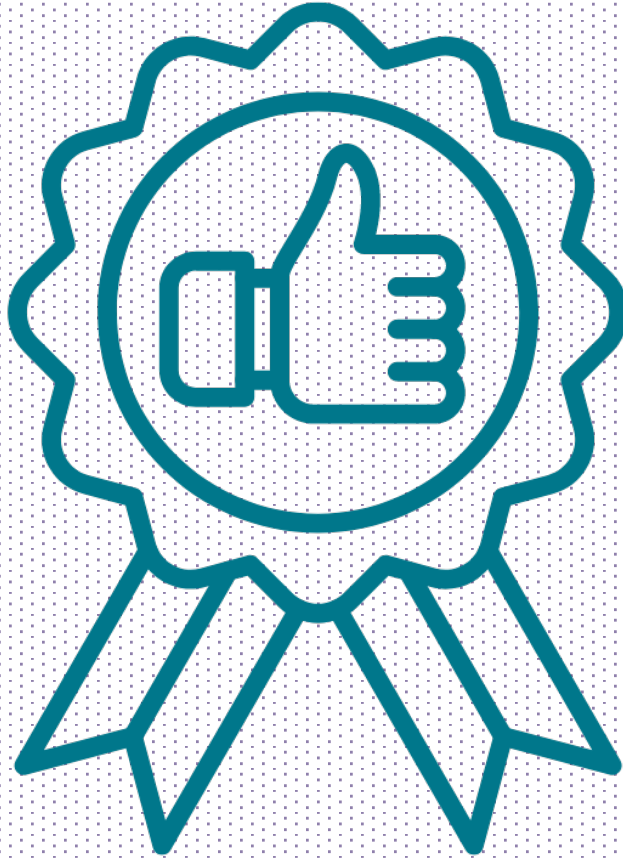
Brea Kratzert Todd
Vice President,
Business Development,
Wounded Warrior
Project

Krystn Kuckelman
Vice President of
Community Development,
PKD Foundation

#connectatcollab

[CC](#) Krystn Kuckelman and 22 others 1 comment





Other General Best Practices



Responding to Comments / DMs

- Be respectful
- Good steward of customer service
- Point them in the right direction (may ask them to contact us)
 - pkdcure@pkdcure.org
 - 816.931.2600



Approach with Caution

- Don't give out medical advice
- Use caution when posting research or medical content from other sources
- Watch out for scams



The image shows a screenshot of a Facebook post. At the top, the user's profile picture is a circular icon of a woman with blonde hair. To the right of the profile picture, the name "Qüéēñ Phõzèz" is displayed in blue, followed by a red star icon and the text "recommends PKD Foundation." Below the name, the date "April 1, 2022" and a globe icon are visible. The main text of the post reads: "I promised that I'm going to testify if my trading was successful' It takes so much time and effort to know the right Trade expert to win trade, After all my research I came in contact with her and I've learned a lot with her in this few months. I'm so impressed with the profit she helped me made, What I love about her is consistency, she's awesome. I just made my withdrawal of 15,000\$ USD to my bank account now. Reach out to her for the best forex trading result. Contact her via Email: mildredgarrett023@gmail.com WhatsApp +15109044097". At the bottom right of the post, there is a speech bubble icon with the number "2". Below the post content, there are three buttons: "Like" with a thumbs-up icon, "Comment" with a speech bubble icon, and "Share" with a share icon. At the very bottom, there is a text input field with the placeholder "Write a comment..." and several icons for adding content: a profile picture icon, a video icon, a smiley face icon, a camera icon, a GIF icon, and a sticker icon.



PKDF Branding

- Colors
 - Teal #00778b
 - Purple #25205d
 - Light Teal #6fb9c3
 - Light Purple #8f80ac
 - Green #a3cf5e
- Profile images
- Font: Montserrat, free on Google



PKD FOUNDATION

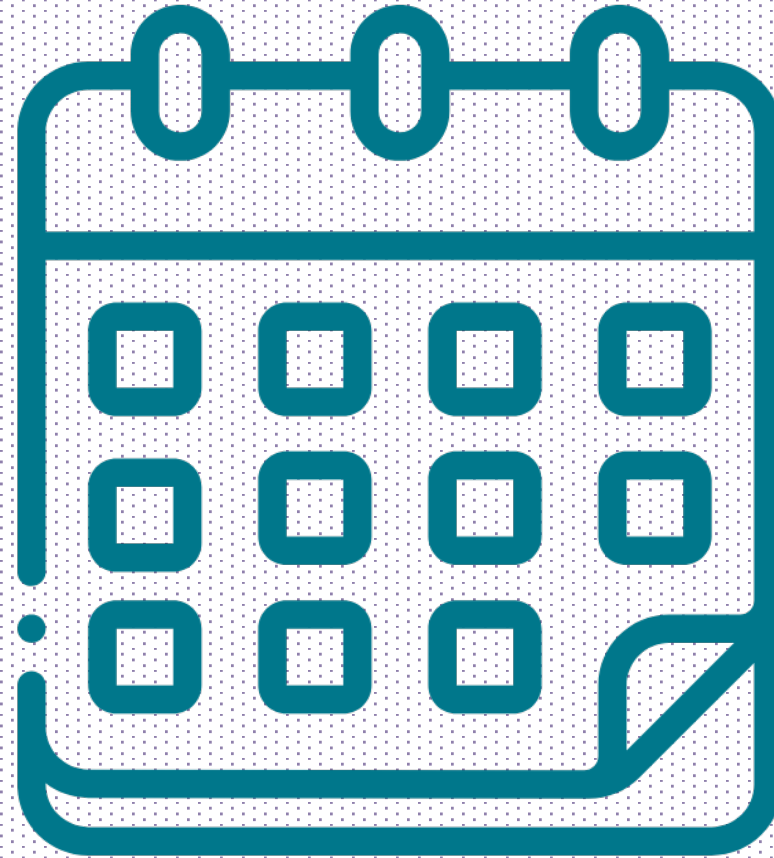
Polycystic kidney disease



Hashtags

- Are a feature on every platform except Threads
- #endPKD
- #pkdawareness, #polycystickidneydisease, #voicesofpkd, #pkdwillnotbeatme, #WalkforPKD
- Follow specific hashtags on Instagram and TikTok





Upcoming Social Media Events



PKD Awareness Day

- September 4th
 - Goal is to raise awareness and get eyeballs on all things PKD
- PKD facts, will update by September
- Share your story, share an update
- Day in the life of someone with PKD
- Share a message of hope to others newly diagnosed



Walk for PKD

- Walk Social Media Toolkit is live!
- <https://walkforpkd.org/social-media-toolkit/>



Resources

- <https://pkdcure.org/volunteers/social-media-guidelines/>
- Canva: <https://www.canva.com>
- Adobe express: <https://www.adobe.com/express/>
- Contact me 😊
 - joyb@pkdcure.org



Q&A

