



## Newsletter

Winter 2025

Hello CKiD families! We're excited to share the latest updates and information about the Chronic Kidney Disease in Children (CKiD) study. Thank you for being an essential part of this important research — your participation is helping shape the future of kidney care for children & young adults such as yourself!

### Digital Detox Challenge

#### 1. Unplug for 1 Hour Daily

**What to do:** Set aside one uninterrupted hour each day—no phones, no laptops, no screens.

**Why it works:** Breaks from screen time boost mental clarity, reduce eye strain, and ease anxiety.

#### 2. Set Digital Curfews

**What to do:** No devices 1 hour before bed and 30 minutes after waking.

**Why it works:** Sleep improves and stress decreases when blue light and notifications are removed.

#### 3. Practice Mindful Usage

**What to do:** Before unlocking your phone, ask: “Why am I doing this?”

**Why it works:** Increases awareness and helps curb impulsive scrolling.

#### 4. Nature Over Notifications

**What to do:** Replace 30 minutes of screen time with outdoor activity—walk, garden, or just sit.

**Why it works:** Nature restores mental energy and reduces dependence on digital entertainment.

#### 5. Substitute Screens with Pages

**What to do:** Read a physical book for 15–30 minutes a day instead of social media.

**Why it works:** Reading improves focus and relaxes the brain without screen stimulation.

#### 6. Silence the Distractions

**What to do:** Disable social media notifications and log out of apps not in use.

**Why it works:** Reduces temptation and fosters long-term digital discipline.

### Study Progress Update

#### Cohort 4 Recruitment:

We are thrilled to share that recruitment for Cohort 4 is underway! For this enrollment period we are focusing on teens and young adults ages 16 years – 22 years old so we can take a closer look at heart health and the experience of transitioning to adult care. Our goal is to enroll another 200 participants in the study. We have enrolled 89 participants so far!

#### New Study Procedure:

We have added a new study procedure to learn more about how CKD affects heart health. This is called the cardiopulmonary exercise test (CPET). The CPET looks at how your heart and lungs respond to exercise as you pedal on a stationary bike. Some participants who are 16 years old or older with CKD Stages 3-5 will complete this test.



## CKiD Participant Spotlight

### Tell us a little bit about yourself!

I grew up on a farm outside a small town in Kansas with my parents and two younger brothers. I got E.coli when I was 4 years old which led to Hemolytic-Uremic Syndrome (HUS). Landing me a stay of 31 days in the hospital. Five years later, I was diagnosed with Type 1 Diabetes. Doctors saying that the injury to my kidneys also injured my pancreas.

Throughout my years coming to the hospital, I knew I wanted to go into the medical field. After finishing high school, I completed the Radiologic Technology program and went on to get a bachelor's degree in health service administration. I now work at a rural hospital in the radiology department doing x-rays and CAT Scans. I met my husband, Garret, in 2020 and we got married in 2024. We moved back to our hometown and are now working on building a house for us and our two dogs.

### What is a hobby you enjoy?

I enjoy reading, being outside, and spending time with my husband and dogs.

### If you could visit anywhere in the world, where would you go?

If I could visit anywhere in the world, it would be Greece!



Karlie, 27 years old

### What was your motivation for participating in the CKiD Study?

I began participating in the CKiD at a very young age, but one thing I remember is my parents giving me the option of being in the study. They sat me down at a visit and explained that the study would help get information to help other kids. They didn't tell me I had to do, or that I needed to do it, but that it was my choice. As a young child, I didn't know what that would entail, but I knew if doing this study would help other kids, it was something I was going to do.

### What has been your favorite thing about participating in the CKiD Study?

My favorite thing about participating in the study is the relationships I have been able to create and foster throughout my years in the study. Being able to see the same research nurses every visit and know they have watched me grow up and they have been there for every stage of life. Also, just being able to see how the CKiD Study has grown and changed over the years to not only include more participants but gather ...



## CKiD Participant Spotlight Continued ...

... more information as it watches those who are no longer in pediatric care. It is pretty special to think about all the kids and families this study helps and will continue to help as the years go on.

### **What have you learned when transitioning from pediatric to adult nephrology care? What advice would you give to others?**

Something that I have learned about transitioning from pediatric to adult nephrology care is that you become your own advocate. In pediatric care, it feels like you have a team with parents, caregivers, nurses, etc., these people help with appointments, medications, understanding lab results, and what the expectations are moving forward. In adult care, you are expected to take charge and have an understanding for these things. You are in charge of the outcomes as they aren't going to hold your hand through it. You must be your own advocate and stand up when you don't agree with a plan of care or need a better explanation of things in order to receive the care you want. The biggest adjustment for me was knowing what questions to ask at appointments. Growing up my mother always knew what questions to ask the doctor when maybe a lab was a little elevated or remember something that was said at a prior appointment.



In adult care, it has taken me a while to fully understand lab results and how medications interact to be able to ask those types of questions rather than just agree and move on with the appointment. I would encourage all those transitioning to adult care to not be afraid to ask questions. That is why you have a nephrologist, so that you don't have to know everything. I felt like I had a better relationship with my nephrologist once I was able to ask questions and feel like I was a part of the care team.

### **Where do you see yourself in 5 years?**

In 5 years, I see myself still being involved with CKiD in whatever way I can. This study will continue to help children with kidney disease, and I would like to continue doing my part in helping. I see myself with a family whether that be fostering kids or getting more dogs and just being happy and thankful with what life has been given to me.



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## STAY CONNECTED

### CKiD Participant and Family Council (PFC)

Are you 18 years old or older! We want to hear from you! Did you know that CKiD has a Participant and Family Council you can join! This group helps guide the study by sharing ideas and feedback about what matters most to participants and families. Your voice matters to us and can help improve CKiD for everyone!

PFC Committee Member: "As a parent of a child with CKD I'm very passionate about learning everything I can about the disease as well as giving back to the doctors and researchers who have given so much time to us, by participating in studies and providing feedback that help improve care for our kids. I've learned so much from being a part of the PFC and I look forward to learning more!"

**Learn more via link or QR code:**

<https://bit.ly/4iTgFL>

**Interested?**

Contact Dr. Cozumel Pruette at [csouthe1@jhmi.edu](mailto:csouthe1@jhmi.edu) or 410-955-2467



### Join CKiD Families Facebook Group

via link or QR Code:

[www.facebook.com/groups/ckidstudy/](https://www.facebook.com/groups/ckidstudy/)

You will be asked to answer Facebook Group Questions and provide Verification Code: **Kidney123**



\*Digital Detox Source: Anandpara G, Kharadi A, Vidja P, Chauhan Y, Mahajan S, Patel J. A Comprehensive Review on Digital Detox: A Newer Health and Wellness Trend in the Current Era. Cureus. 2024 Apr 22;16(4):e58719. doi: 10.7759/cureus.58719. PMID: 38779255; PMCID: PMC11109987.