



*Things you can do on*

# Rare Disease Day

## Visit Your Firehouse

To be prepared for an emergency, you must make sure your local firehouse and/or EMS station is aware of your or your child's adrenal insufficiency/CAH status! We urge you to visit your firehouse/EMS station right away!

## Join the CAHtalog Patient Registry

CARES Foundation, partnering with Neurocrine Biosciences and PicnicHealth, has established the CAHtalog™ (Congenital Adrenal Hyperplasia: Patient and Clinical Outcomes in Real-World Practice Settings) registry. The goal of the registry is to support patient-centered research that will enhance the scientific community's foundational knowledge of classic CAH and ultimately improve the lives of patients who live with it every day. Participants can contribute to classic CAH research and share their unique patient journey and voice without the need for in-person visits - and all information will be kept private and secure. After enrollment, participants will have ready access to their digital medical records in one place.

With the CAHtalog™ registry, you get access to your complete medical records and you can change what researchers know about classic CAH to help improve care and treatments - plus earn up to \$150 a year when you complete optional surveys!

Join now: [https://picnichealth.com/CAH?utm\\_source=CARES&utm\\_medium=nat\\_advocacy&utm\\_campaign=cah](https://picnichealth.com/CAH?utm_source=CARES&utm_medium=nat_advocacy&utm_campaign=cah)

## Download the PACE App

The Preventing Adrenal Crisis Events (PACE) app is available to patients, parents/caregivers, and medical professionals and is designed to provide readily accessible information and instructions for effectively managing AI (Adrenal Insufficiency). The app will include stress dosing and intramuscular injection techniques as well as other helpful tools.

Apple App Store: <https://apps.apple.com/us/app/pace-by-chaicore/id1490431010>

Android App Store: [https://play.google.com/store/apps/details?id=com.jafproductions.PACEAndroidNew&pcampaignid=web\\_share](https://play.google.com/store/apps/details?id=com.jafproductions.PACEAndroidNew&pcampaignid=web_share)

For the access code, please reach out to: [support@caresfoundation.org](mailto:support@caresfoundation.org).

## Listen to the CAH Pulse Podcast

CAH Pulse takes us on a journey to educate and bring attention to the challenges and triumphs of individuals living with Congenital Adrenal Hyperplasia (CAH). Each month patients, family members, medical professionals, researchers and caregivers share their stories, experiences and advice living with this challenging condition. Our hope is to further connect and champion this incredible community.

Listen to our newest Episode, as our most recent guest Lindsey shares her compelling story of growing up in the Midwest as a typical girl with friends, playing sports, going to college, and now at 30 working as a geographic information systems technician. Lindsey opens up to Dina and Stephanie about many topics, including an overdue conversation that she wishes she had had 20 years ago, as well as a detailed account of her recent life-threatening adrenal crisis, a first on CAH Pulse.

You can listen to this episode and all other episodes at <https://cahpulse.podbean.com/>!

