

MAY 2026

In this month's update, find the latest surrounding important research, community news, upcoming events, support group meetings, and more!



- Community Research
- Upcoming Events
- Fundraising Opportunities
- and more!

Follow us on social media for the most up-to-date news!



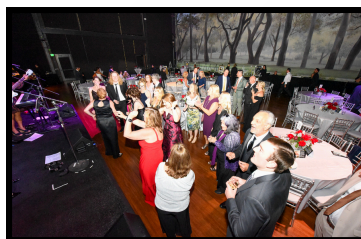
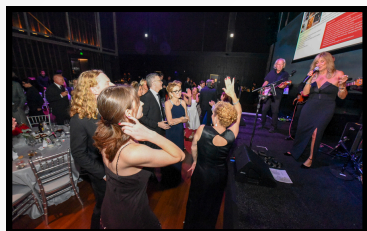
cares
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

www.caresfoundation.org

THANK YOU TO EVERYONE THAT SUPPORTED THE...

18th Annual

EVERYONE CARES GALA



AND ONCE AGAIN, CONGRATULATIONS TO OUR HONOREES!

LIFETIME ACHIEVEMENT AWARD

Dr. Richard C. Rink, Riley Hospital for Children

PIONEER AWARD

Robert Farber, PhD, Neurocrine Biosciences

COMMUNITY PARTNER AWARD

Sue Shirey, The James Shirey Foundation



**2nd
Annual**



Pennsylvania CAH Awareness Walk

When: May 16, 2026

Starts: 10:00AM

Where: North Park, Allison Park, PA

Learn More/Register

If you would like to register for this event, please visit:

<https://caresfoundation.org/annual-pennsylvania-cah-awareness-walk/>

Can't Attend but want to donate?

Donations can be made towards this event by visiting:

<https://caresfoundation.app.neoncrm.com/forms/2026-annual-pennsylvania-cah-awareness-walk>





CARES Foundation's Podcast...

CAH Pulse

Season 3 | Episode 3: A Mother's Gut is Never Wrong

Becky's Unexpected Journey

In this powerful episode of CAH Pulse, Becky, shares her deeply personal journey navigating her newborn daughter's unexpected CAH diagnosis. What was planned to be a joyful home birth turned into a whirlwind of uncertainty, medical urgency, and a near death experience for her newborn.

From frustrating medical guidance and the uncertainty of not knowing the sex of her baby to the emotional highs and lows and finding the right support, Becky's story highlights the importance of community, and trusting your gut as a mother.

Join Stephanie and Dina for this heartfelt conversation which will serve as an inspiring reminder of a mother's intuition, the importance of finding a center of excellence, and the resilience families ultimately discover when faced with the unexpected.

Catch up on all of the latest episodes of CAH Pulse!

Recent Episodes:

Season 3 | Episode 2: Lupe and Christina

Raising a CAH Superstar

Season 3 | Episode 1: Karter - "You gotta just do it"

Insights, Positivity, and Advice from a Seventeen-Year-Old Salt Waster

Season 2 | Episode 12:

Non-Classical CAH - Fertility Treatment and the Importance of Genetic Testing

Season 2 | Episode 11:

Dimitri: The Long Game of Drug Discovery

Season 2 | Episode 10:

Brittany: Demanding Change After a Lack of Answers and Getting Nowhere



To listen to these episodes and all past episodes, **scan the QR Code** or visit: cahpulse.podbean.com.

Do you want to be a guest on CAH Pulse?

If you have any interest on being a guest on our podcast, please contact: dina@caresfoundation.org.



**3rd
Annual**

cares
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

Iowa CAH Awareness 5K

When: June 6, 2026

Starts: 10:00AM

Where: Prairie's Edge Nature Center, Cresco, IA

**REGISTER BY 12:00PM(ET) WEDNESDAY, MAY 13, 2026
TO RESERVE AN EVENT T-SHIRT!**

Learn More/Register

If you would like to register for this event, please visit:

<https://caresfoundation.org/iowa-cah-awareness-5k/>

Can't Attend but want to donate?

Donations can be made towards this event by visiting:

<https://caresfoundation.app.neoncrm.com/forms/3rd-annual-iowa-cah-awareness-5k>



SAVE THE DATES!



Family Fun Days

We're excited to invite you to take part in CAH Family Fun Days hosted by our centers of excellence nationwide. These gatherings are a great opportunity to connect with other individuals and families affected by CAH in a welcoming and relaxed environment.

Children's Hospital of Philadelphia (CHOP)



Riley Children's Hospital



Children's Hospital Los Angeles (CHLA)



UT Southwestern Medical Center/Children's Medical Center



Attendance is free for patients of the centers and their families; however, registration is required.

We hope to see you there!

More information about these events & how to register is/will be made available on our website at: <https://caresfoundation.org/cah-awareness-family-fun-days/>

REGISTER TODAY!

SCAN HERE



co-hosted with:



Seattle Children's
HOSPITAL · RESEARCH · FOUNDATION

2nd Annual Washington Family Fun Day Woodland Park Zoo, Seattle, WA 98103

DATE: June 6, 2026

TIME: 10:00AM-2:00PM

*Zoo grounds will be accessible at 9:30AM

(Registration begins: 9:30AM)

Details:

- Spend your day at the Woodland Park Zoo
- Participate in interactive injection training sessions
- Enjoy Arts & Crafts with Camp Korey
- Make sure to stay for the Pizza Party

You can sign-up for this event by registering with the QR code above, or by visiting: <https://caresfoundation.org/cares-washington-family-fun-day/>.

If you have any questions, please email: contact@caresfoundation.org

REGISTER TODAY!

SCAN HERE



co-hosted with:



1st Annual

North Texas Family Fun Day

Fort Worth Zoo, Fort Worth, TX 98103

(Picnic Pavillion)

DATE: June 6, 2026

TIME: 11:00AM-1:00PM

Details:

- Spend your Saturday at the Fort Worth Zoo!
- Meet with other CAH patients, families, & medical professionals
- Education & Injection Training
- Lunch Provided

You can sign-up for this event by registering with the QR code above, or by visiting: <https://caresfoundation.org/cares-north-texas-cah-awareness-family-fun-day/>

If you have any questions, please email: contact@caresfoundation.org

Life Changes. Your Care Can Stay on Track.

Wherever life takes you, connect to CAH care with Find a Doctor

A tool to help you find endocrinologists with CAH experience – so you can stay connected to care wherever you are.

“We used it to find an endocrinologist near my child’s college.”

“I checked to see if my new job location had CAH specialists nearby.”

“I wanted to find an adult endocrinologist in my area.”



However your life is changing, having the right care matters.

A tool is available to help you find pediatric and adult endocrinologists with CAH experience—wherever you are.

- Quickly locate doctors experienced in CAH care near you.
- See where they practice and whether they have participated in CAH research or published CAH materials.
- Contact offices directly from the tool once you find the right doctor.

Whether you're transitioning to adult care, relocating, or planning ahead, support is within reach.

Find CAH Care Near You →

Approved Uses:

CRENESSITY (crinecerfont) is a prescription medicine used together with glucocorticoids (steroids) to control androgen (testosterone-like hormone) levels in adults and children 4 years of age and older with classic congenital adrenal hyperplasia (CAH).

IMPORTANT SAFETY INFORMATION

Do not take CRENESSITY if you: Are allergic to crinecerfont, or any of the ingredients in CRENESSITY.

CRENESSITY may cause serious side effects, including:

Allergic reactions. Symptoms of an allergic reaction include tightness of the throat, trouble breathing or swallowing, swelling of the lips, tongue, or face, and rash. If you have an allergic reaction to CRENESSITY, get emergency medical help right away and stop taking CRENESSITY.

Risk of Sudden Adrenal Insufficiency or Adrenal Crisis with Too Little Glucocorticoid (Steroid) Medicine. Sudden adrenal insufficiency or adrenal crisis can happen in people with congenital adrenal hyperplasia who are not taking enough glucocorticoid (steroid) medicine. You should continue taking your glucocorticoid (steroid) medicine during treatment with CRENESSITY. Certain conditions such as infection, severe injury, or shock may increase your risk for sudden adrenal insufficiency or adrenal crisis. Tell your healthcare provider if you get a severe injury, infection, illness, or have planned surgery during treatment. Your healthcare provider may need to change your dose of glucocorticoid (steroid) medicine.

Before taking CRENESSITY, tell your healthcare provider about all of your medical conditions including if you: are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

The most common side effects of CRENESSITY in adults include tiredness, headache, dizziness, joint pain, back pain, decreased appetite, and muscle pain.

The most common side effects of CRENESSITY in children include headache, stomach pain, tiredness, nasal congestion, and nosebleeds.

These are not all the possible side effects of CRENESSITY. Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch at www.fda.gov/medwatch or call 1-800-FDA-1088.

Dosage Forms and Strengths: CRENESSITY is available in 50 mg and 100 mg capsules, and as an oral solution of 50 mg/mL.

Please see full [Prescribing Information](#) and [Patient Information](#).

Survey Opportunity

Classic CAH Community Survey

Adults with Classic CAH and caregivers are invited to share their experiences

Paid Online Survey for Classic CAH

- Adults living with **classic congenital adrenal hyperplasia (CAH)**, as well as parents or caregivers of children with classic CAH in the United States, are invited to participate in an online survey study.
- The survey takes approximately **30–45** minutes to complete. Participants who qualify and complete the survey will receive **\$100** as a thank-you for their time.
- This survey aims to better understand the real-life experiences of people living with classic CAH and their families, including how the condition may impact daily life and care. Insights from the survey will help increase understanding of CAH and raise broader awareness of the condition.

All responses are anonymous and confidential.



Interested? Start by answering a few short questions to see if you qualify, or contact *Ashley* at ashley@pinpointpatientrecruiting.com

[Complete the survey here](#)



RARE DISEASE REGISTRIES LIKE CAHTALOG®
TURN EXPERIENCES INTO KNOWLEDGE

When communities contribute real-world health data, researchers gain a clearer picture of how conditions like CAH affect people over time, supporting better understanding and stronger research.



Through the CAHtalog® registry

226

individuals have contributed their lived experiences since 2022

262,000+

medical records have been securely collected

5

research publications have been generated using registry data



Sharing experiences has helped expand the data available for CAH research. CAH has come a long way since I was born, and that progress reflects years of research and patients being willing to share their journeys.



Lesley
Research participant

Take the guesswork out of your child's hydrocortisone dosing

When it comes to your child's hydrocortisone treatment, giving the right dose every time matters. But splitting tablets correctly—or even getting your child to swallow the dose— isn't always easy. There's a better way.

Two options that help make it easy to give the right dose



ALKINDI SPRINKLE® (hydrocortisone) oral granules

For newborns and children with adrenal insufficiency

Easily find your child's correct dose with color-coded capsules of ALKINDI SPRINKLE

- Available in 4 strengths so you can give the lowest possible dose without crushing or splitting tablets
- Capsules are easy to open—simply sprinkle the granules onto soft food or directly into your child's mouth

Designed with kids in mind.

Alkindi Sprinkle
(hydrocortisone)
oral granules



KHINDIVI™ (hydrocortisone) 1 mg/mL oral solution

For children aged 5 years and older with adrenal insufficiency

KHINDIVI is designed to help you get the prescribed dose right every time*

- A liquid option for children who have trouble swallowing pills or don't like the taste of tablets
- Ready to use—no refrigeration, mixing, or shaking required
- A syringe† lets you measure your child's exact prescribed dose

Dosing made easier.

Khindivi
(hydrocortisone)
1 mg/mL oral solution

*When entire dose is given as directed.
†Syringe provided by Anovo[®] Specialty Pharmacy.

Learn more about [ALKINDI SPRINKLE](#).

Learn more about [KHINDIVI](#).

USE AND IMPORTANT SAFETY INFORMATION FOR:

- ALKINDI SPRINKLE® (hydrocortisone) oral granules and
- KHINDIVI™ (hydrocortisone) 1 mg/mL oral solution

USE

ALKINDI SPRINKLE

ALKINDI SPRINKLE is a corticosteroid indicated for replacement therapy in pediatric patients with adrenocortical insufficiency.

KHINDIVI

KHINDIVI is a corticosteroid indicated as replacement therapy in pediatric patients 5 years of age and older with adrenocortical insufficiency.

Limitation of Use for KHINDIVI

KHINDIVI is not approved for increased dosing during periods of stress or acute events. Use a different hydrocortisone-containing drug product for stress dosing.

IMPORTANT SAFETY INFORMATION FOR ALKINDI SPRINKLE AND KHINDIVI

WHEN USING ALKINDI SPRINKLE OR KHINDIVI

Always give ALKINDI SPRINKLE or KHINDIVI exactly as your doctor has directed. Do not take ALKINDI SPRINKLE or KHINDIVI if you are allergic to hydrocortisone or any of its other ingredients.

Adrenal Crisis: Giving too low a dose or stopping medication can cause low levels of cortisol, which can result in serious illness or death. Treatment with intravenous hydrocortisone should be started immediately. When switching from another type of hydrocortisone to ALKINDI SPRINKLE or KHINDIVI, watch your child closely for any changes. If your child doesn't get the entire dose of ALKINDI SPRINKLE because of vomiting or spitting some granules out, contact your doctor to see if another dose is needed. When taking KHINDIVI during periods of stress, such as infections or after surgery, your doctor should switch to another oral hydrocortisone product and increase the dose.

Immunosuppression and Increased Risk of Infection With Use of a Dosage Greater Than Replacement: Use of a greater than replacement dosage can suppress the immune system and increase the risks of new infections or exacerbation of latent infections with any pathogen, including viral, bacterial, fungal, protozoan, or helminthic infections. Contact your healthcare provider if any infections develop.

Growth Retardation: The long-term use of corticosteroids in high doses may cause growth retardation in children.

Decrease in Bone Density: Corticosteroids can affect your child's bone growth and strength.

Cushing's Syndrome Due to High Doses of Corticosteroids: Treatment with high doses of corticosteroids can cause Cushing's syndrome. Treatment should be limited to the smallest dose required, and your child's growth and development monitored appropriately.

Psychiatric Changes: Corticosteroids can change your child's behavior or mood. Tell your doctor if your child has periods of extreme happiness, extreme sadness, hallucinations, or depression.

Changes in Vision: Tell your doctor if your child has blurred vision or other vision problems during treatment with ALKINDI SPRINKLE or KHINDIVI.

Gastrointestinal Adverse Reactions: Tell the doctor if your child has stomach pain, upset stomach, black, tarry stools, or vomiting of blood. These could be signs of ulcers or tears in the stomach or intestines. Taking anti-inflammatory nonsteroidal drugs, like ibuprofen, naproxen, or aspirin, can increase the risk of ulcers or tears.

Vaccination: Administration of live vaccines may be acceptable in ALKINDI SPRINKLE-treated and KHINDIVI-treated pediatric patients with adrenocortical insufficiency who receive replacement corticosteroids.

ADDITIONAL IMPORTANT SAFETY INFORMATION FOR KHINDIVI

Systemic Adverse Reactions Due to Inactive Ingredients

Hyperosmolarity: KHINDIVI is not approved in children less than 5 years of age. The inactive ingredients in KHINDIVI can cause dangerous fluid imbalances.

Metabolic Acidosis and Other Adverse Reactions: Some ingredients in KHINDIVI may cause a buildup of acid in the body, low blood sugar, or injuries to the liver, kidneys, or brain that may increase the risk of adrenal crisis.

Laxative Effects Due to Inactive Ingredients: Some ingredients in KHINDIVI may cause stomach upset, resulting in vomiting and/or diarrhea and could increase the risk of adrenal crises in patients.

ADVERSE REACTIONS

The most common side effects of ALKINDI SPRINKLE or KHINDIVI include retaining fluids, changes in glucose tolerance, high blood pressure, behavioral and mood changes, greater appetite, and weight gain.

Additional side effects of KHINDIVI are reactions to inactive ingredients.

FOR ADDITIONAL INFORMATION ON ALKINDI SPRINKLE AND KHINDIVI

If you are being treated with ALKINDI SPRINKLE, please visit ALKINDISPRINKLE.com/patient for more information. If you are being treated with KHINDIVI, please visit KHINDIVI.com/patient for more information.

You are encouraged to report negative side effects of prescription drugs by contacting Eton Pharmaceuticals, Inc. at 1-855-224-0233 or the U.S. Food and Drug Administration (FDA) at www.fda.gov/safety/medwatch or call 1-800-FDA-1088.

Please see full Prescribing Information for more information on [ALKINDI SPRINKLE](#) and [KHINDIVI](#).

Study Opportunity for Adults Living with Classic Congenital Adrenal Hyperplasia

What is this study about?

The purpose of this online survey study is to understand symptoms and experiences with congenital adrenal hyperplasia (CAH) from the perspective of adults living with CAH.

What is involved?

Participants will complete 2 online surveys on their computer or mobile device: a baseline survey and then a follow-up survey about 1 week later. The surveys will include a series of questions that ask about symptoms and experiences living with CAH.

The surveys will take less than an hour in total and participants will receive payment for completing the surveys.

No treatment is provided as part of this study. 4



Who can participate?

We are seeking adults (18+ years) living in the United States who have been diagnosed with classic CAH by a healthcare professional.



*Viewing this on your phone?
Just press and hold
the QR code, then tap
the link that appears.*

How can I participate?

If you are interested in participating or would like more information, please contact the study's recruitment partner Global Perspectives at eirini.kamperou@iqvia.com (please include this subject line in your email: CAH Online Survey) or follow the QR code to the left to be contacted by Global Perspectives.

This study is being conducted by IQVIA Inc, a research organization working closely with Crinetics Pharmaceuticals, Inc to help them better understand the patient experience.

Are You or Your Child Facing Challenges Due to CAH?

Consider Joining a Clinical Research Study



Crinetics is a pharmaceutical company that develops much-needed therapies for people with endocrine diseases. We are currently enrolling adults and children who have been diagnosed with classic congenital adrenal hyperplasia (CAH).

The Calm-CAH (adult) and Balance-CAH (pediatric) studies are looking to understand the safety and effectiveness of an investigational study drug, atumelnant, whether it may reduce the dosage needed for steroid medications like glucocorticoids (GCs), and how it may help manage symptoms of CAH.

To participate in these studies, you or your child must:

- Be 1 to 74 years of age
- Have received a diagnosis of classic CAH
- Be on a stable GC regimen (for example: modified-release hydrocortisone, cortisone acetate, prednisolone, prednisone, methylprednisolone, and dexamethasone)

Additional requirements apply, which the study team will discuss with you.

Atumelnant is an investigational study drug, which means it has not been approved by any regulatory authority and is still under investigation as a potential treatment for CAH.



To learn more or to see if you or your child may qualify, scan the QR code or visit CrineticsCAH.com.



YOUR VOICE MATTERS

Has your baby received a positive newborn screening result in the state of Ohio? We invite you to join our Newborn Screening Family Advisory Committee.

Why Join?

Your experience matters. By sharing your story and perspective, you can help improve newborn screening systems, support other families, develop educational materials, and guide health professionals and policymakers in creating more family-centered care.

Who Should Join?

Parents and caregivers whose child received a positive newborn screening result for genetic disorders (endocrine and metabolic); sickle cell disease; congenital heart defects or early hearing disorders since 2016 in the state of Ohio.

What to Expect

- Orientation and training
- One-hour, quarterly virtual meetings through 2028
- Opportunities to share feedback on educational materials, outreach, and services
- A supportive space where your insights are valued
- Participants are encouraged to attend all sessions
- Incentives for your time and participation

Contact Us At:

OhioNBSFamilies@cchmc.org



**1st
Annual**

cares
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

Illinois CAH Awareness 5K

When: September 6, 2026

Starts: 10:00AM

Where: Deicke Park, Huntley, IL

**REGISTER BY 12:00PM(ET) FRIDAY, AUGUST 14, 2026
TO RESERVE AN EVENT T-SHIRT!**

Learn More/Register

If you would like to register for this event, please visit:

<https://caresfoundation.org/annual-illinois-cah-awareness-walk/>

Can't Attend but want to donate?

Donations can be made towards this event by visiting:

<https://caresfoundation.app.neoncrm.com/forms/1st-annual-illinois-cah-awareness-walk---donations?campaignId=328>



**6th
Annual**

cares
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

Ohio CAH Awareness 5K

When: October 3, 2026

Starts: 10:00AM

Where: Mill Stream Park, Valley City, OH

**REGISTER BY 12:00PM(ET) FRIDAY, SEPTEMBER 4, 2026
TO RESERVE AN EVENT T-SHIRT!**

Learn More/Register

If you would like to register for this event, please visit:

<https://caresfoundation.org/ohio-cah-awareness-walk/>

Can't Attend but want to donate?

Donations can be made towards this event by visiting:

<https://caresfoundation.app.neoncrm.com/forms/6th-annual-ohio-cah-awareness-walk?campaignId=323>



NEW DATE:

**8th
Annual**



Florida CAH Awareness Walk

When: October 10, 2026

Starts: 10:00AM

Where: Sand Point Park, Titusville, FL

**REGISTER BY 12:00PM(ET) MONDAY, SEPTEMBER 14, 2026
TO RESERVE AN EVENT T-SHIRT!**

Learn More/Register

If you would like to register for this event, please visit:

<https://caresfoundation.org/annual-florida-cah-awareness-walk/>

Can't Attend but want to donate?

Donations can be made towards this event by visiting:

<https://caresfoundation.app.neoncrm.com/forms/8th-annual-florida-cah-awareness-walk>



CAH Patient Wellness Retreat



Hosted by: CARES Foundation

A 3-Night Restorative Experience

September 17-20, 2026 | Canyon Ranch, Tuscon, AZ

Reconnect. Restore. Recharge.

Join us for an exclusive 3-night wellness retreat designed specifically for adults living with Congenital Adrenal Hyperplasia.

Retreat Experience Includes:

- Expert-led wellness and educational sessions
- Group discussions and peer connection
- Stress management and mindfulness practices
- Movement and fitness classes
- Chef-prepared nutritious meals
- Access to world-class spa and fitness facilities
- Time to relax, reflect, and build lasting community

Eligibility Requirements

- Be registered with CARES Foundation before 12/31/25.
- Have a confirmed diagnosis of CAH
- Be between 25–70 years of age
- Reside in the United States

From all qualified applicants, **10 participants will be selected to attend.*

Interested in Applying? **SPACE IS LIMITED**

You must be a member of CARES to participate. To learn more about how to be entered into the applicant pool, please visit:

<https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=51&>



Sept. 26, 2026 in Boston, MA

CARES CABARET - A Million Dreams

An Evening of Music, Storytelling & Impact

About the Event

Join us for an unforgettable evening of musical storytelling starring some of Boston's most celebrated vocalists under the music direction of pianist and vocalist **Rachel Mackenzie**.

This special cabaret raises awareness for **congenital adrenal hyperplasia (CAH)** while supporting the mission of the CARES Foundation, whose aim is to improve the lives of individuals and families living with this complex condition.

The evening will also feature a **silent auction with fabulous prizes**, helping expand awareness and support for CARES Foundation programs.

Learn more by visiting:

<https://caresfoundation.org/cares-cabaret-night/>

SAVE THE DATE!

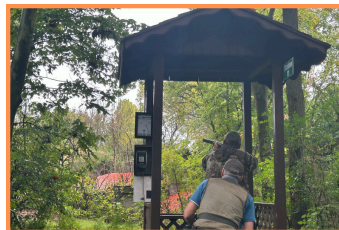
11TH ANNUAL

CLAY SHOOT FOR CARES

THURSDAY, OCTOBER 8, 2026

LEHIGH VALLEY SPORTING CLAYS

JOIN US for clay-shooting fun in beautiful Lehigh Valley, PA!



If you would like to be notified when registration opens, please email: contact@caresfoundation.org.

2026 ANNUAL PATIENT EDUCATION CONFERENCE

Saturday & Sunday - October 17 & 18, 2026

New York Presbyterian-Weill Cornell Medical Center, New York, NY

We invite you to join CARES Foundation for the **2026 Annual CARES Foundation's Patient Education Conference!**

We are looking forward to a weekend filled with informative speakers & helpful breakout sessions, the chance to meet & connect with other patients, parents, families, medical professionals, and more!

If you would like to participate in patient/caregiver panels:

Adult Men

Adult Women

Teens

Transition to Adulthood

Please contact dina@caresfoundation.org as soon as possible!



If you are interested in learning more about registration when it becomes available, please reach out to contact@caresfoundation.org.

CARES FOUNDATION'S PATIENT ADVISORY SUMMIT

Monday, October 19, 2026

CARES is seeking patients and caregivers living with Classic CAH to join an advisory session concurrent with the 2026 CAH Patient Education Conference in New York City. The purpose of the advisory board is for representatives from the pharmaceutical industry to listen to patient/caregiver insights on living with and managing CAH.

Participants will be compensated for their time.

If you are interested in participating, please reach out to dina@caresfoundation.org.

(Only individuals who have not previously served can participate)

We ask that you please stay up-to-date with CARES Foundation's website & social media for more information on when registration for these events will open. (www.caresfoundation.org)

Preventing Adrenal Crisis Events

PACE App

Have you downloaded it yet?

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.

Now Available in Spanish

SCAN TO DOWNLOAD!



(APPLE APP STORE)

This application can also be found on the Apple App Store, by searching “PACE by ChaiCore”.



(GOOGLE PLAY STORE)

This application can also be found on the Google Play Store, by searching “PACE by ChaiCore”.



VISIT BOTH YOUR HOME'S AND SCHOOL'S EMS/FIREHOUSE!



Did you know that most ambulances do not carry Solu-cortef®?

Furthermore, that they are not allowed to administer the shot even if you have it? We are at work to develop EMS protocols for emergency medical treatment of CAH and other adrenal insufficiencies. Too many people suffer from delayed medical care in emergency situations.

A well-planned visit to your firehouse and/or EMS station could save your life or the life of a loved one.

While on this visit, give them printed out materials that you can download from our website. These include helpful tips for your visit, our emergency instructions brochure, and advice on how to call attention to CAH/AI treatment by having them flag your residence for this condition.

Visit: <https://caresfoundation.org/be-prepared-in-an-emergency/>

Be Prepared for Travel! Stay prepared in the event of an emergency

We want to remind you that there are great resources for travel, emergency situations, and available in our shop to ensure that you are well-prepared no matter where you are.

We encourage you to visit both of our [Be Prepared in an Emergency](#) and [EMS Advocacy](#) pages on the CARES Website. Here you will find a variety of tools such as:



- Information regarding signs of adrenal crisis
- [CARES Emergency Instructions Brochure](#)
- Printable Medical ID Cards
- [Medication Safety Alert Letter](#)
- [Emergency Instruction Video](#)
- [The PACE \(Preventing Adrenal Crisis Events\) App](#)
- Links to many helpful items in [the CARES Shop](#)

If you have any ideas for helpful tools/resources that we may be able to offer/provide, please do not hesitate to reach out to contact@caresfoundation.org.

CARES FOUNDATION



CONGENITAL ADRENAL HYPERPLASIA

PATIENT EDUCATION GUIDE

[CLICK HERE FOR DIGITAL VERSION](#)



[SCAN TO VIEW](#)





SHARE YOUR STORY WITH CARES! EMERGENCY CRISIS/EMERGENCY ROOM EXPERIENCES

We ask that you please share any negative/unacceptable experiences you have had at while in a crisis situation/emergency room visit concerning you/your loved one's congenital adrenal hyperplasia (CAH).

WE NEED YOUR VOICE! We intend to compile these experiences together and share them with providers and legislatures in an effort to improve the nature of these situations going forward. Stories can be shared anonymously, and we encourage you to share as much as possible.

If you are interested in submitting your **Emergency Experience** with CARES, [please submit your story here](https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=41&) (<https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=41&>) reach out to dina@caresfoundation.org with your story.



ASK THE EXPERT

Dr. Karen Lin Su

CARES Medical Director

Do you need expert medical advice before your next appointment?

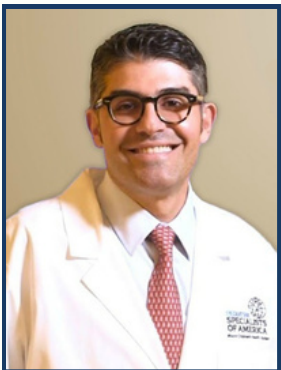
Do you have unanswered questions about your treatment?

Then, DON'T FORGET about our program!

Questions answered, worries alleviated, suggestions offered, CAH medical advice for you and your loved ones.

Register with CARES to use this service. To join, click: <https://caresfoundation.org/join-the-cares-community/>

CLICK HERE: <https://caresfoundation.org/ask-the-expert/> to visit this page.



PREGUNTA EL EXPERTO

Dr. Alejandro Diaz

Director of the Division of Endocrinology at Nicklaus Children's Hospital in Miami

¿Necesita asesoramiento médico experto antes de su próxima cita?

¿Tiene preguntas sin respuesta sobre su tratamiento?

¡NO TE OLVIDES de nuestro programa!

Preguntas respondidas, preocupaciones aliviadas, sugerencias ofrecidas, consejos médicos de CAH para usted y sus seres queridos.

Debe estar registrado en CARES para utilizar este servicio.

Para unirse, haz clic en: <https://caresfoundation.org/join-the-cares-community/>

Haga clic aquí: <https://caresfoundation.org/pregunta-el-experto/> para visitar esta pagina.

Mon.	Tues.	Wed.	CARES Event Calendar			Thurs.	Fri.	Sat.
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Stay up-to-date on everything happening in our community, by visiting the [Event Calendar!](#)



Annual
Pennsylvania
CAH Awareness Walk



3rd Annual
Iowa
CAH Awareness 5K



1st Annual
Illinois
CAH Awareness Walk



6th Annual
Ohio
CAH Awareness Walk



8th Annual
Florida
CAH Awareness Walk

See more upcoming events, support group meetings, and family fundraisers by clicking below!

[Click here to see the full CARES Foundation Event Calendar](#)

CARES Foundation's Support Groups via Zoom

Thursday, May 14

Parents of CAH Children (Newborn-Age 5), 9:00PM(ET) via Zoom

Tuesday, May 19

Parents of CAH Children (Newborn-Age 5), 9:00PM(ET) via Zoom

Wednesday, May 27

Parents of CAH Children (School-aged, Teens, Young Adults), 8:30PM(ET) via Zoom

Wednesday, June 3

Spanish Speaking CAH Patients & Parents, 8:30PM(ET) via Zoom

If you are interested in participating in any of the above meetings, please reach out to: support@caresfoundation.org. **YOU MUST BE PART OF THE CARES COMMUNITY TO JOIN.**

(Free to join) Join by visiting: <https://caresfoundation.org/join-the-cares-community/>

Please remain active on CARES social media, and make sure you are checking your email/ the [CARES Event Calendar](#) regularly for any support group updates. If you have any questions regarding support groups, please contact: support@caresfoundation.org.

2026 **SUMMER** SCHEDULE

VICTORY JUNCTION
a seriousfun camp
Founded in honor of Adam Petty

- JUNE 14-18** | ▶ **BLEEDING/GI**
Sun. - Thur.
- JUNE 21-25** | ▶ **CEREBRAL PALSY**
Sun. - Thur.
- JUN-JUL 28-2** | ▶ **SICKLE CELL/CANCER/IMMUNOLOGY**
Sun. - Thur.
- JULY 5-8** | ▶ **NEURO GEN/AUTISM**
Sun. - Wed.
- JULY 12-16** | ▶ **PHYSICAL DISABILITIES/ SPINA/
ACHONDROPLASIA/CRANIOFACIAL**
Sun. - Thur.
- JULY 19-23** | ▶ **HEART/LUNG/KIDNEY/RHEUMATOLOGY**
Sun. - Thur.
- JULY 26-30** | ▶ **SIBLINGS WEEK**
Sun. - Thur.
- AUGUST 2-6** | ▶ **GENERAL SESSION**
Sun. - Thur.

At Victory Junction, we enrich the lives of children who are living with complex medical and physical needs by providing life-changing, fun, and empowering camp experiences at no cost to families. During summer sessions we serve ages 6-17.

Questions?: camperadmissions@victoryjunction.org | (336) 495-2069



IT'S FREE!





Have you joined any of our Private Facebook Groups?

CARES Foundation's private Facebook groups are a great way to connect with members of our community and share your experiences.

3 Beta Women

11 Beta

17 Hydroxylase

Adoption & CAH

Bereavement Support Group

CAH Athletes

CAH Partners/Spouses

CAH Women 50+

CAH-X (CAH + EDS)

CARES Support Group Leaders

Classic CAH Women

Grandparents of CAH Children

LGBTQIA+

Men w/ CAH

Men and Dads with Sons with CAH

Mexico CAH

Newborns

Parents/Caregivers of Girls with NCAH

Parents/Caregivers of Teens with CAH

Parents of College Students with CAH

Parents of Kids with CAH

Parents of Kids with NCAH

Parents of Young Adults (Ages 20-35)

Surgery

Teens with CAH

Young Adults with CAH (Ages 21-35)

To join our private Facebook groups, you must **request access** by visiting [Congenital Adrenal Hyperplasia Support Network on Facebook](#). From our page, select **MORE**, then **GROUPS**. (If on a mobile device: **ABOUT**, then **GROUPS**). You should now be able to view and click on the group/groups that you are interested in, and can then request access to join those specific groups/groups.

If you are having trouble accessing a certain group, or have any outstanding requests for access, please do not hesitate to contact john@caresfoundation.org.

JOINING THE CARES COMMUNITY

We encourage patients, family members, relatives, medical professionals, and others who are impacted by CAH to join our community. This account is completely free to create, and the best way to stay up-to-date on all important information, news, research, events, and more within the CARES Community!

[JOIN THE CARES COMMUNITY](#)

PLEASE UPDATE YOUR ACCOUNT!

Without the proper fields completed, **you may be susceptible to missing out on important information and events!** Please [click the link below to login](#) to your account with CARES to edit any incomplete fields in your profile.

If you are having trouble accessing your account, or have any questions surrounding your profile, please do not hesitate to reach out to: contact@caresfoundation.org.

[LOGIN TO YOUR ACCOUNT HERE](#)



THE CARES SHOP

STOCK UP SOME OF THE IMPORTANT EMERGENCY ITEMS & RESOURCES THAT CAN BE FOUND IN OUR SHOP!

View our full catalog at: <https://caresfoundation.org/the-cares-shop/>

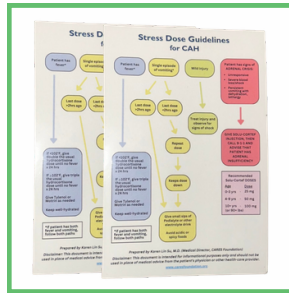
CHECK OUT OUR NEWEST ITEMS!



CAH PULSE COFFEE MUG

\$8.00

New CARES Foundation coffee mug (17oz.) with CARES and CAH Pulse Podcast Logos, CARES Website, and Phone.



CARES STRESS DOSING MAGNET

\$2.00

Stress dosing guidelines in a convenient 4" x 6" magnet to be placed in your home.



ADRENAL INSUFFICIENCY

CAR SEAT STRAP

\$12.00

Velcro pullover strap to go over seatbelts to identify adrenal insufficiency in an emergency



MEDICAL I.D.

LUGGAGE TAGS

\$6.50

Medical Alert I.D. for luggage, backpacks, and other items when traveling



EMERGENCY

SYRINGE BAG

\$5.50

Durable semi-translucent carry-case for syringe or other emergency items



EMERGENCY RESPONSE

KIT (SET OF 3)

\$5.00

Includes 3 semi-translucent kits, and emergency instructions brochure & checklist

If you are having any trouble with your order, we ask that you please do not hesitate to reach out to our office via phone (toll-free) or email.

Email: contact@caresfoundation.org | Phone (Toll-Free): (866) 227-3737

PLEASE NOTE (INTERNATIONAL ORDERS ONLY):

If you are shopping outside of the Continental U.S., please contact us at contact@caresfoundation.org before making any purchases. Shipping rates will vary.



CAH PARTNER 2026

A special thank you to Neurocrine Biosciences,
for partnering with CARES Foundation in 2026!

www.neurocrine.com



2414 Morris Avenue, Suite 110, Union NJ 07083
(908) 364-0272 Toll Free (866) 227-3737

[MAKE A DONATION](#)

[JOIN OUR COMMUNITY](#)

Gold
Transparency
2025

Candid.

If you have any questions about this update or the contents inside, do not hesitate to reach out to john@caresfoundation.org with more information.

Thank you!