



# JUNE 2026 MONTHLY UPDATE

## Congenital Adrenal Hyperplasia AWARENESS MONTH



### In this month's update:

- Participate in CAH Chats (webinars)
- Share your story with us
- Participate in events
- Access helpful links & resources
- Important research & publications

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



**cares**  
CONGENITAL  
ADRENAL  
HYPERPLASIA FOUNDATION

[www.caresfoundation.org](http://www.caresfoundation.org)



Visit the [CAH Awareness Month Webpage](https://caresfoundation.org/cah-awareness-month/) on the CARES Foundation website to find out more about some of our important resources, educational materials, helpful links, crucial shop items, and more!

- Patient Education Guide
- Ask the Expert Service
- Physician Referrals
- CAH Pulse Podcast
- The CARES Shop
  - Medical IDs, Emergency Response Kits, and more!
- EMS Advocacy Information

<https://caresfoundation.org/cah-awareness-month/>



# CAH Awareness Month Events

Throughout CAH Awareness Month, CARES Foundation will be hosting several educational webinars for those living with congenital adrenal hyperplasia.

## CAH Chats

All sessions will begin at 8:30PM(ET)

**June 10, 2026**

**Treating Adrenal Insufficiency: Don't Stress About It**

Karen Lin Su, MD

**June 17, 2026**

**College, Career, and Confidence: Navigating Care Transitions in CAH**

Louise Fleming, RN, PhD

**June 24, 2026**

**Closing the Emergency Care Gap for CAH**

Gretchen Alger Lin - CAH Parent and EMS Advocate

You must register for each webinar by visiting:

<https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=52&>

*\*You must login to your CARES account to register*

# What are you doing to raise awareness this month?

## Share your efforts with us!

- Visited your local firehouse/EMS station
- Took time to educate your friends & family
- Went to a CAH Awareness Walk
- Attended a CAH Family Fun Day
- Participated in the #CARESCChainChallenge
- Other

Please let us know more about what you are doing during CAH Awareness Month! We would love to help share your advocacy efforts with our community!

Email [john@caresfoundation.org](mailto:john@caresfoundation.org) if you would like to share!

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## Sharing your journey!

If you would like to share or update us on any part/parts of your CAH journey, please reach out to [john@caresfoundation.org](mailto:john@caresfoundation.org). Stories & perspectives help give others a sense of comfort in knowing that they are not alone on their CAH journey.

## Ways you can share

- A written entry of any length
- A video submission

Submissions can be any length, and we ask that you also please send a photo to accompany any written entries. Entries can be sent directly to [john@caresfoundation.org](mailto:john@caresfoundation.org).

If you have any questions about how to share your story via CARES Social Media on **#CAHAwarenessMonth**, please reach out to [john@caresfoundation.org](mailto:john@caresfoundation.org).





## I participated in the **#CARESCChainChallenge**

as a part of **CAH Awareness Month** in an effort to help support and recognize those who are living with congenital adrenal hyperplasia (CAH).

**I am nominating you to join me by donating \$10.00 or more and sharing this message with as many friends as you can!**



<https://caresfoundation.org/cah-awareness-month/>

*On behalf of CARES Foundation and the incredible community involved, we truly thank you for your consideration and support.*



# SHARE YOUR EMS EXPERIENCE

## 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.

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If you are interested in submitting your **Emergency Experience** with CARES, [please submit your story here](#) or reach out to [dina@caresfoundation.org](mailto:dina@caresfoundation.org) with your story.

[I WOULD LIKE TO SHARE MY EXPERIENCE](#)



# MAKE SURE THAT YOU 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.

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



**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.

Riley Hospital  
for Children



Children's Hospital  
Los Angeles (CHLA)



UT Southwestern Medical  
Center/Children's Medical Center



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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:



# Indiana Family Fun Day for Patients with Congenital Adrenal Hyperplasia Indianapolis Zoo, Indianapolis, IN 46222

**DATE: June 27, 2026**      **Check-in Begins: 9:00AM-12:00PM**

*Ticket & voucher pickup will be available at the tables outside the zoo entrance*

## Details:

- Spend your Saturday at the Indianapolis Zoo!
- Meet with other CAH patients, families, & medical professionals
- Register up to 3 Adults & 3 Youth (12 & Under) per family for free!
- Lunch Provided

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

If you have any questions, please email: [contact@caresfoundation.org](mailto:contact@caresfoundation.org)





**CARES Foundation's Podcast...**

# **CAH Pulse**

## **Season 3 | Episode 4: From Patient to Pioneer:**

### **Julia Anthony Always Goes Big**

Born with salt-wasting CAH before newborn screening existed, Julia Anthony spent much of her childhood, high school and even college days in hospitals dealing with adrenal crises; which did not stop her from playing sports or having plenty of fun. However, in hindsight, it did change her in a most positive way. In this inspiring and animated conversation, Dina and Stephanie uncover how Julia's experiences have shaped her into a humble CAH patient, fierce advocate and ambitious entrepreneur.

Julia opens up about the lessons she has learned, what has driven her to start her own company and why community, self-advocacy, and resilience matter so much. Honest, playful and emotional, this episode gives us a powerful reminder that it's possible to turn challenges into purpose.

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

#### **Recent Episodes:**

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

Becky's Unexpected Journey

##### **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



To listen to these episodes and all past episodes, **scan the QR Code** or visit: [cahpulse.podbean.com](http://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](mailto:dina@caresfoundation.org).



# CAH Adult Patient Wellness Retreat

Hosted by: CARES Foundation

A 3-Night Restorative Experience

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

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## Reconnect. Restore. Recharge.

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

*\*Funded by CARES Foundation*

## 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.*

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## 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:

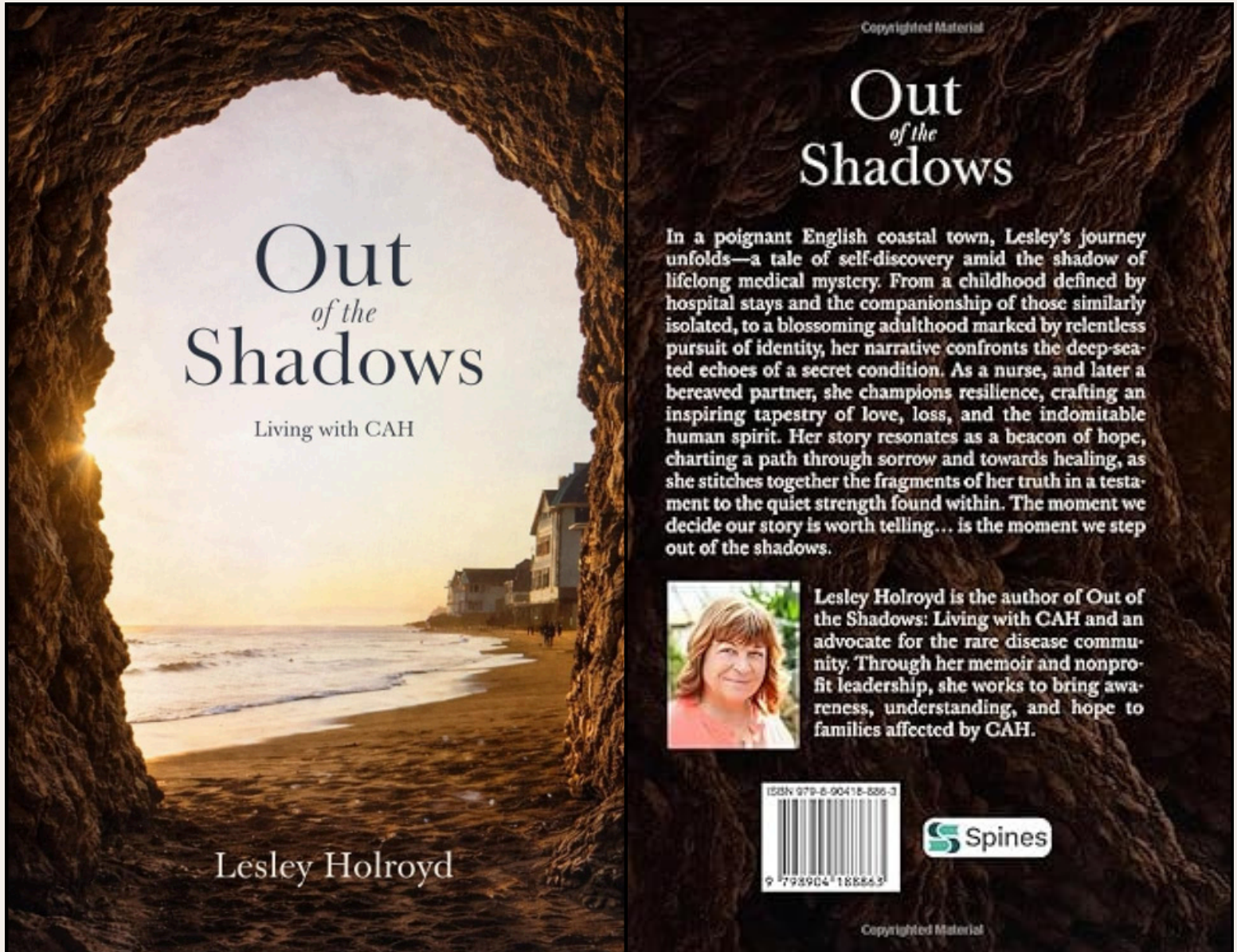
<https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=51&>



**AVAILABLE NOW ON AMAZON!**

**Read about Lesley Holroyd's CAH journey**

A portion of the proceeds will benefit the mission of CARES Foundation



**'Out of the Shadows | Living with CAH' by Lesley Holroyd**



# CONGENITAL ADRENAL HYPERPLASIA

## PATIENT EDUCATION GUIDE

[CLICK HERE FOR DIGITAL VERSION](#)



[SCAN TO VIEW](#)

# THANK YOU FOR ATTENDING THE 2ND ANNUAL PENNSYLVANIA CAH AWARENESS WALK!

Thank you to everyone who helped us raise awareness for CAH at this year's event! And a very special thank you to our event hosts, Amanda & Kaitlyn, and of course, to all of our volunteers for making this such a great event!



## THANK YOU TO OUR SPONSORS!



WINDROSE ANIMAL HOSPITAL



**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!**

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## 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>





## HAS YOUR CHILD BEEN DIAGNOSED WITH CAH?

We are looking for children who are between the ages of 3 months and under 4 years old with a diagnosis of classic congenital adrenal hyperplasia (CAH) to take part in a clinical research study.

The **CAH2032 Study** is investigating crinecerfont, a drug already approved for adults and children over the age of 4, to determine its safety and effectiveness in younger children.

**To learn more, talk to your child's doctor or contact the participating research site listed here.**

**Study Sponsor: Neurocrine Switzerland GmbH (NSG)**  
**Study Team Email: [nbi74788-cah2032clinical@neurocrine.com](mailto:nbi74788-cah2032clinical@neurocrine.com)**

# June is National CAH Awareness Month: A Time to Share Stories and Strengthen Community

Awareness starts with understanding—learn more about life with CAH.

Behind every CAH patient is a story of strength.

"Get connected, stay informed, and know it's manageable."

— Valerie, Caregiver Ambassador



Awareness Matters. [Learn More](#) →

Individuals are paid partners of Neurocrine.

Rare, but not alone—June is for the CAH community.

## 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.

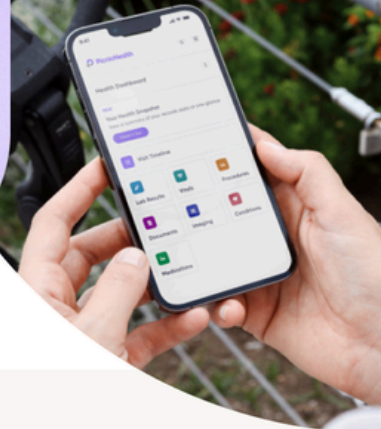
**The most common side effects of CRENESSITY in children include** headache, stomach pain, tiredness, nasal congestion, and nosebleeds.

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](http://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](#).

# Be a hero for the CAH community!



Help improve treatment and care for others with CAH by participating in the CAHtalog<sup>®</sup> Registry. CAHtalog is a comprehensive collection of clinical data from medical records from those living with classic congenital adrenal hyperplasia (CAH), designed to drive advancements in CAH research.

CAHtalog is open to adults and caregivers on behalf of their children living with classic CAH and who receive medical care in the United States.

Sign up on CAHtalog.com in less than 10 minutes. Here's what you can expect:



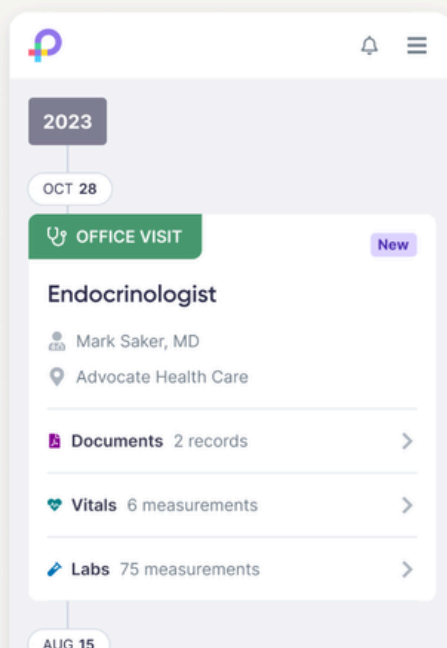
### After signing up, sit back and relax

Nothing else is required. PicnicHealth will collect your medical records on your behalf.






### We take your privacy seriously

All personal identifying information will be removed from your medical records



Receive comprehensive access to your medical history as a benefit of participating in CAHtalog:

-  PicnicHealth will organize your records from multiple providers so you can easily track your lab values, medications, images, and doctor's notes—all from your electronic device.
-  Share your medical history with anyone you trust, anywhere, anytime.
-  You'll earn \$50 for joining once you qualify, with the option to participate in additional compensated surveys.

# When it comes to your child's adrenal insufficiency, getting the dose right matters

Adrenal insufficiency means your child's body can't make enough cortisol on its own. **So every dose of hydrocortisone replacement therapy needs to be accurate.** Giving too little or too much can lead to serious health consequences over time.

## What can happen with too little (underdosing)

If your child consistently receives too low a dose of hydrocortisone, cortisol levels may stay too low, which can lead to:

- Adrenal crisis (a potentially life-threatening emergency)
- Malaise and persistent illness
- Low blood pressure (hypotension)
- Weight loss
- Salt cravings
- Electrolyte disturbances
- Virilization and rapid growth

## What can happen with too much (overdosing)

If your child consistently receives too high a dose of hydrocortisone, cortisol levels may become elevated, which can lead to:

- Excessive weight gain
- Short stature
- Cushing's syndrome
- High blood pressure (hypertension)
- Insulin resistance
- Osteoporosis
- Cardiovascular disease

**No representations are made for an effect of ALKINDI SPRINKLE or KHINDIVI on these conditions.**

## You deserve better than guesswork.

Talk with your child's doctor about which FDA-approved option may be right for your family.



For newborns and children with adrenal insufficiency  
Available in 0.5 mg, 1 mg, 2 mg, and 5 mg strengths

Learn more about [ALKINDI SPRINKLE](#).



For children 5 years and older with adrenal insufficiency  
A ready-to-use oral solution

Learn more about [KHINDIVI](#).

## Please see below for Indications and Important Safety Information for ALKINDI SPRINKLE and 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](mailto: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](https://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](mailto:OhioNBSFamilies@cchmc.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”.





## ASK THE EXPERT

**Dr. Karen Lin Su**

**CARES Medical Director**

**Do you need expert medical advice before your next appointment?**

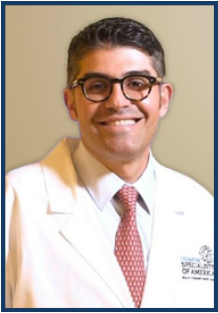
**Do you have unanswered questions about your treatment?**

**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.

# \* 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](mailto:contact@caresfoundation.org).



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



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

## Wednesday, June 3

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

## Thursday, June 4

Parents of CAH Children, 9:00PM(ET) via Zoom

## Thursday, July 9

Parents of CAH Children, 9:00PM(ET) via Zoom

## Thursday, June 30

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

If you are interested in participating in any of the above meetings, please reach out to: [support@caresfoundation.org](mailto: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](mailto:support@caresfoundation.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!**

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## **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!**

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## 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!**

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## **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>



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](mailto: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](mailto: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](mailto:contact@caresfoundation.org).

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## 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](mailto:dina@caresfoundation.org).

*(Only individuals who have not previously served can participate)*

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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](http://www.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](mailto: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](mailto: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](mailto:contact@caresfoundation.org).

[LOGIN TO YOUR ACCOUNT HERE](#)





# 20% OFF THE CARES SHOP

STOCK UP SOME OF THE IMPORTANT EMERGENCY ITEMS & RESOURCES ON SALE UNTIL JUNE 30, 2026!

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



**ADRENAL INSUFFICIENCY  
CAR SEAT STRAP**

~~\$12.00~~ \$9.60

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



**CAH PULSE  
COFFEE MUG**

~~\$8.00~~ \$6.40

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



**EMERGENCY  
SYRINGE BAG**

~~\$5.50~~ \$4.40

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



**EMERGENCY RESPONSE KIT  
(SET OF 3)**

~~\$5.00~~ \$4.00

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



**MEDICAL I.D.  
LUGGAGE TAGS**

~~\$6.50~~ \$5.20

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



**CAH/AI  
SHOE TAGS**

~~\$5.50~~ \$4.40

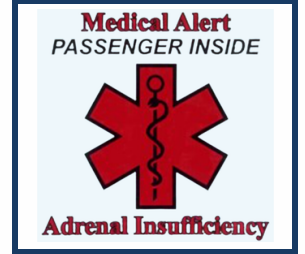
Small oval-shaped CAH/AI medical ID tag that can be threaded through laces, drawstring bags, etc.



**FRESH OUT OF CORTISOL T-SHIRT**

MULTIPLE SIZES

CARES Foundation Fresh out of Cortisol T-Shirt (Available in Men's/Women's/Youth)



**ADRENAL INSUFFICIENCY  
WINDOW CLING**

~~\$2.00~~ \$1.60

Window sticker/cling to quickly identify adrenal insufficiency in the event of a crisis

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](mailto: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](mailto: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](http://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](mailto:john@caresfoundation.org) with more information.

Thank you!

