

AUGUST 2026 MONTHLY UPDATE

Find the latest surrounding important research, community news, upcoming events, support group meetings, & more!



- See what's new!
- Participate in events
- Helpful links & resources
- Find important research & publications

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



cares
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

www.caresfoundation.org

Children's 1st Annual CAH CARNIVAL

30 AUGUST 2026

11:00 am - 2:00 pm

CHILDREN'S HEALTH SPECIALTY CENTER

2350 N Stemmons Fwy, Dallas, TX 75207

PLEASE NOTE: This event is for established patients of the center.

Step right up! Endo proudly invites you to our first annual Carnival Event! Enjoy food, games, prizes, laughs and unforgettable fun with the team. Don't miss out on the excitement.

This event is designed to bring together patients and families for a day of education, connection, and community support as they navigate their medical journeys.

Guest can register for free using the link or QR code below!



Register:

<https://caresfoundation.org/texas-family-fun-day/>

 **cares**
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

UTSouthwestern
Medical Center



CARES Foundation's

2026 ANNUAL PATIENT EDUCATION CONFERENCE

Co-hosted with:

NewYork-
Presbyterian

Saturday, Oct. 17 (8:00AM-5:15PM) & Sunday, October 18 (8:00AM-12:45PM)
New York Presbyterian-Weill Cornell Medical Center, New York, NY



Join us for the **2026 Annual CARES Foundation 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!



Registration (Must register by Sept. 25, 2026)

To learn more about this year's event, please scan the QR code or visit, <https://caresfoundation.org/annual-patient-education-conference/>.

Interested in applying for a scholarship?

A limited number of scholarships are available via the **Conference Webpage**.

***Scholarships must be submitted by NO LATER THAN SEPTEMBER 18, 2026!**

Interested sponsoring this year's conference?

Please email Bea@caresfoundation.org to learn more about sponsorship opportunities.

This year's conference has been sponsored by:



If you have any questions about the 2026 Patient Education Conference, please do not hesitate to reach out to contact@caresfoundation.org.



APPLY TODAY!

CARES Foundation's
CARES FOUNDATION'S
PATIENT ADVISORY SUMMIT



Monday, October 19, 2026

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

Are you interested in helping to shape the future of CAH treatments?

If yes, then please consider participation in our 2026 Patient Advisory Summit on October 19, 2026 in New York City and complete the Interest Form using the link below.

***MUST LOGIN TO CARES PROFILE TO ACCESS:**

[Complete the Patient Advisory Summit Interest Form](#)

PLEASE NOTE: To be eligible, you must not have previously participated in the Patient Advisory Summit.

If you are selected as a participant, you will join a group of individuals living with CAH and CAH caregivers in a meeting with the leading companies developing new CAH treatments. ***You will be paid for your time and your hotel stay will be covered. You may apply for a scholarship for travel as well.***

Conference Scholarship Application

To access the scholarship application for this year's conference, please [click here](#).

If you have any questions about the 2026 Patient Education Conference, please do not hesitate to reach out to contact@caresfoundation.org.



Illinois CAH Awareness Walk

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>



Sept. 26, 2026 at Club Café in Boston, MA

CARES CABARET NIGHT

A Million Dreams - An Evening of Music, Storytelling & Impact

****Featuring Broadway star Michael Maliakel and Boston based vocalists!***

About the Event

Join us for an unforgettable evening of musical storytelling starring some of Boston's **most celebrated vocalists!** This special cabaret raises awareness for congenital adrenal hyperplasia (CAH) while supporting the mission of CARES Foundation.

The evening will also feature a **silent auction with fabulous prizes!**

Starring:

Corrine Byrne	Carley DeFranco
Michael Maliakel	Rhaea D'Aliesio
Jack Byrne	Susan Dillard
Sonja Tengblad	Alice Byrne
David Mather	Kathleen Byrne

The Band

Rachel Mackenzie, Piano
Jack Byrne, Guitar
Adam Clarke, Bass
Jonathan Hess, Drums

Music Direction

Rachel Mackenzie

Cabaret Created by: CAH Parent Advocate, Corrine Byrne

Music Direction: Pianist and Vocalist, Rachel Mackenzie



Interested in Attending?

Visit: <https://caresfoundation.org/cares-cabaret-night/> to learn more & get your tickets!

Questions?

Email: contact@caresfoundation.org



Questions Along the Way?

Support is within reach.

One-on-one, personalized support throughout your journey with CRENESSITY



✓ Dedicated Care Coordinators

✓ Coverage and insurance support

✓ Financial assistance programs for eligible patients

*Terms and Conditions Apply

✓ Personalized guidance throughout the treatment journey

✓ Knowledgeable pharmacists ready to answer questions 24/7

"Managing my Classic CAH comes down to staying consistent and being proactive about what I might need." - Wyatt, Patient Ambassador



Individual is paid partner of Neurocrine.

[Explore Access Support](#) →

Learn more about the resources available to patients and caregivers.

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](#).



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 crinercerfont, 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

Share Your Experience with Pediatric Adrenal Insufficiency

As an AlkindiPeer, your story can help inspire and educate others

If you are a caregiver of someone living with adrenal insufficiency who is taking ALKINDI SPRINKLE® (hydrocortisone) oral granules, Eton Pharmaceuticals invites you to become an AlkindiPeer by joining Eton Connect, a new Eton Cares Program® experience for caregivers to share their journeys and connect with those impacted by adrenal insufficiency. Eton Connect Peers will have the opportunity to share their experience with:



Challenges & unmet needs of adrenal insufficiency



How ALKINDI SPRINKLE impacts daily life



Tips for managing care



Resources available for support

What is an AlkindiPeer?

Peers are representatives of Eton Pharmaceuticals and will speak publicly about their experiences with adrenal insufficiency and AlkindiPeers will participate in virtual and in-person engagements, sharing their journey with members of the community.

Who can become AlkindiPeer?

- Individuals caring for someone who:
- Is living with pediatric adrenal insufficiency
 - Has been prescribed ALKINDI SPRINKLE and has been on treatment for at least 6 months
 - Is under the age of 10

What do AlkindiPeers do?

AlkindiPeers will share the story of their experience and insights with other caregivers in the adrenal insufficiency community. Activities may include in-person meetings, virtual engagements and calls, and additional opportunities over the course of the year or longer.

AlkindiPeers will be compensated for their time.

How do I participate?

If you are interested in being considered for the Eton Connect program, please contact Eton's independent community engagement partner, SmithSolve, at Eton@SmithSolve.com. Please include your and the patient's name, age, hometown, diagnosis, time on ALKINDI SPRINKLE, and a brief note on why you'd like to become an AlkindiPeer.

If selected as an AlkindiPeer, you will be asked to sign an agreement and a consent regarding sharing your personal information. Please note that space is limited and we may not be able to accommodate all who apply at this time. We appreciate hearing from you, and there may be additional opportunities for participation in the future. Training will be provided.

USE AND IMPORTANT SAFETY INFORMATION

USE

ALKINDI SPRINKLE is a prescription medicine used in children from birth to less than 17 years old as replacement therapy when the adrenal gland is not making enough cortisol.

IMPORTANT SAFETY INFORMATION

Always give ALKINDI SPRINKLE exactly as your doctor has directed.

Do not take ALKINDI SPRINKLE if you are allergic to hydrocortisone or any of its other ingredients.

Please see additional Indication and Important Safety Information on back

IMPORTANT SAFETY INFORMATION (cont'd)

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, 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.

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. Monitor patients for signs and symptoms of infections.

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.

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

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.

Gastrointestinal 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.

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

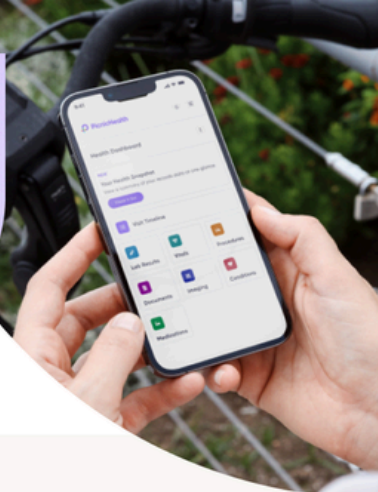
Vaccination: Administration of live vaccines may be acceptable in ALKINDI SPRINKLE-treated pediatric patients with adrenocortical insufficiency who receive replacement corticosteroids.

Please visit [ALKINDISPRINKLE.com/patient](https://www.alkindisprinkle.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](tel: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](tel:1-800-FDA-1088).

Please see [full Prescribing Information](#) for more information.

Be a hero for the CAH community!



Help improve treatment and care for others with CAH by participating in the CAHtalog[®] 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.

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**.



Could **YOU** be in our next PLC?



CONSIDER PARTICIPATING IN OUR PATIENT LEADERSHIP COUNCIL

At Crinetics, we believe patient-focused drug development is vital. We value the patient's voice and encourage patient input into our clinical development programs and beyond. We are creating new medicines that will hopefully benefit patients with various rare diseases. Patient insight is very important to us, yet equally important is that our efforts are both meaningful and make sense for patients in those communities.

One way we do this is by implementing a Patient Leadership Council (PLC) to give patients a "seat at the table." PLC members review and discuss a variety of topics, and their input helps Crinetics make decisions along the pathway from molecule to medicine.

HOW TO APPLY APPLICATION PROCESS

- 1 Individuals who are interested may self-nominate directly to Crinetics at crinetics.com/patient-leadership-council or through Patient Advocacy Group leaders.
- 2 Informational interviews will be conducted with each patient or care-partner (family, spouse, friend) that has volunteered.
- 3 A group of 8-10 PLC members will be chosen. Each PLC will be limited in size to allow for a deep discussion throughout the year.
- 4 All interested participants will be notified of their selection for a PLC.
- 5 Selected members will receive contracts covering their rights and obligations before their first PLC meeting participation. PLC selection will prioritize diversity and other factors that may be relevant to the drug development program.

PARTICIPATION REQUIREMENTS

- Diagnosis with the specified rare disease, or care-partner of someone diagnosed with the disease.
- Willingness to provide open, honest, constructive feedback and input.
- Comfortable speaking in a small group setting.
- Respect for fellow PLC members.
- Ability to participate via video conferencing on camera from a computer or tablet.
- United States citizen or lawful permanent resident.
- Sign and adhere to nondisclosure agreement (NDA) for information disclosed and discussed during meetings.
- Must not be a current participant in a clinical study sponsored by Crinetics.
- Agreement to not engage in an advisory role with another pharmaceutical company while serving on the Crinetics PLC. Patient Advocacy Organization Leaders may be the exception to this rule.



PLC MEETING SCHEDULE

- Participation in 3-4 PLC meetings per year. Meetings will typically be virtual. In the event a meeting can be held in person, travel expenses will be paid by Crinetics.
- Ad hoc meetings may occur throughout the year. PLC members will be notified in advance and schedules will be coordinated for any additional meetings.
- Requires a one-year commitment, with the option to serve for up to 2 years. The anticipated time commitment will be 1 to 2 hours for each video meeting and 0.5-1 hour for any prework if specified.

EXAMPLES OF TOPICS THAT MAY BE DISCUSSED

- Patient journey to diagnosis
- Patient treatment experience
- Clinical study feedback (protocols, patient experience, patient materials, patient reported outcomes, education, informed consent forms)
- Educational needs (materials, videos, etc.)
- Unmet needs in the specific medical condition
- Access or barriers to medical care & health insurance and other challenges

CRINETICS COMMITMENT

- Respect will be given to all opinions and each individual PLC member as they express their unique views. Crinetics reserves the right to remove any PLC members that cannot meet this requirement.
- Crinetics is committed to maintaining your privacy. While PLC Meetings will be recorded and transcribed, the input and content from PLC meetings will be conveyed in a de-identified manner, unless additional permissions are obtained.
- PLC applicant and member contact information will be utilized for administrative use only.

COMPENSATION

- PLC members will be compensated for their time contribution at \$125.00 per hour.
- PLC members will be required to fill out IRS Form W-9, which will be provided before the first meeting.
- If required to travel, Crinetics will cover all travel-related expenses consistent with Crinetics travel standards, which will be included in the contract.

**Scan the QR code or enter the link below
to apply for the Patient Leadership Council**

crinetics.com/patient-leadership-council





Have you or a loved one
been diagnosed with
**Classic Congenital
Adrenal Hyperplasia
(CAH)?**



We're looking for
**ADOLESCENT PATIENTS
& CAREGIVERS**
of
**CHILDREN AGES
4-17**



**PARTICIPATE IN A
90 MINUTE
WEB ASSISTED
PHONE INTERVIEW**



**REWARD OF
\$200
PLUS \$50 
UPON CONFIRMATION
OF DIAGNOSIS**

Ohio CAH Awareness Walk

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>



REGISTER TODAY!

11TH ANNUAL

CLAY SHOOT FOR CARES

THURSDAY, OCTOBER 8, 2026

LEHIGH VALLEY SPORTING CLAYS

RAIN OR SHINE!

JOIN US FOR CLAY-SHOOTING FUN IN BEAUTIFUL LEHIGH VALLEY, PA!

8:30AM - Breakfast & Registration

9:30AM - Clay Shoot Start

Lunch immediately following the Clay Shoot



For complete event information and/or sponsorship & underwriting opportunities, please contact:

Carlos DaSilva at cdasilva@lbindustriesinc.com

Register by scanning the QR Code or by visiting:

<https://caresfoundation.org/clay-shoot-for-cares/>



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>



SAVE THE DATE

SATURDAY, APRIL 10, 2027

19TH ANNUAL

Everyone CARES Gala

Liberty House | Jersey City, NJ

Honorees

Ian Marshall, MD

RWJ/Barnabas Health

Jessica Margolies, Esq.

Eton Pharmaceuticals

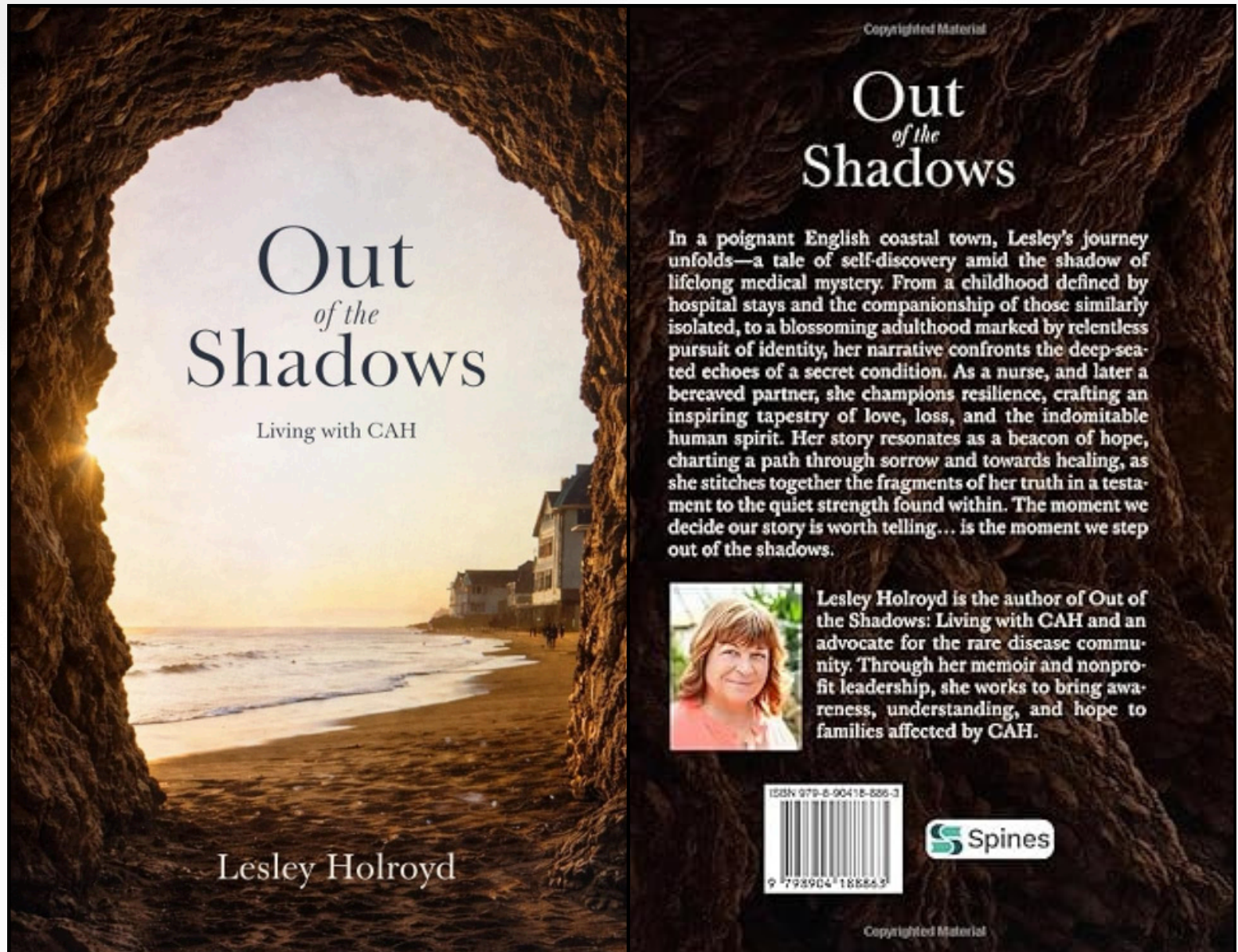
Stay up-to-date with CARES Foundation's
website & social media for more information.

 **cares**
CONGENITAL
ADRENAL
HYPERPLASIA FOUNDATION

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



CARES Foundation's Podcast...

CAH Pulse

Season 3 | Episode 5: Allyson's Journey (Part I):

"Different is What Makes You Good"

In this encouraging episode of CAH Pulse, Dina and Stephanie talk to Allyson who is gracefully navigating life with CAH. Allyson eagerly shares her journey from being diagnosed at birth to becoming an athlete, an aspiring mentor for others in the CAH community and a motivated, thriving young adult.

An avid swimmer and rock climber, there's no mistaking Allyson's positivity and drive when she lovingly mentions her supportive parents who allowed her to live as a typical child. When she opens up about her surgeries, her seizures, college life and the biggest challenge of all; finding an adult endocrinologist who actually knows what CAH is... it becomes apparent that Allyson finds power in being an open book.

Finally, Allyson doesn't miss a chance to share her mindset about living with this rare and difficult condition; giving sage advice to parents, kids and young adults so they too can gain the strength to resist limitations and most of all shame. Her inspiring words that being different "is what makes you, good" is also what makes this memorable episode of CAH Pulse so hopeful.

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

Recent Episodes:

Season 3 | Episode 4: From Patient to Pioneer:

Julia Anthony Always Goes Big

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



Be sure to subscribe! 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.



Mon.	Tues.	Wed.	CARES Event Calendar	Thurs.	Fri.	Sat.
------	-------	------	----------------------	--------	------	------

Stay up-to-date on everything happening in our community, by visiting the [Event Calendar!](#)



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, Sept. 10

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

Wednesday, Sept. 16

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

Thursday, Sept. 24

CAH Women, 8:30PM(ET) via Zoom

Thursday, Oct. 8

Parents of CAH Children (Newborn-Age 5), 9:00PM(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.



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”.





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.

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

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



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](#)



Be Prepared for Back to School!

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.



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.





CONGENITAL ADRENAL HYPERPLASIA

PATIENT EDUCATION GUIDE

[CLICK HERE FOR DIGITAL VERSION](#)



[SCAN TO VIEW](#)

GET READY FOR BACK TO SCHOOL WITH THESE IMPORTANT ITEMS!

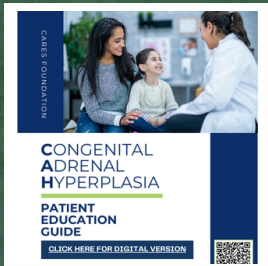


THE CARES SHOP

STOCK UP SOME OF THE IMPORTANT EMERGENCY ITEMS!

View our full catalog at:

<https://caresfoundation.org/the-cares-shop/>



CARES PATIENT EDUCATION GUIDE

FREE DOWNLOAD

Helpful guide for
patients/caregivers
of those with CAH.



OUT OF THE SHADOWS BY LESLEY HOLROYD

AMAZON PURCHASE

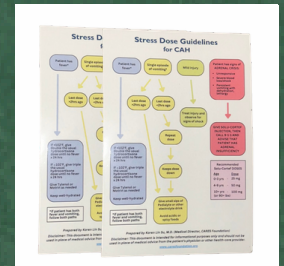
Memoir from CAH
Patient & Advocate,
Lesley Holroyd.



CAH PULSE COFFEE MUG

\$8.00

CARES CAH Pulse
coffee mug
(17oz.)



CARES STRESS DOSING MAGNET

\$2.00

Stress dosing
guidelines
(4" x 6" magnet)



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

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!

