

Newborn Screening Awareness Month

SEPTEMBER

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!



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www.caresfoundation.org

Newborn Screening Awareness Month

According to the National Institute of Health (NIH)...

“Today, all 50 states, the District of Columbia, and the Commonwealth of Puerto Rico have newborn screening programs. This means that nearly every child born in the United States or Puerto Rico is screened shortly after birth.¹

- All states currently require newborn screening for at least 29 health conditions. Each state's public health department decides both the number and types of conditions on its testing panel.² Most states allow parents to opt out for religious or other reasons.³ Many states also offer supplemental screening programs that screen for disorders beyond those required by the state; costs for these supplemental tests are usually covered by insurance.
- About 4 million infants are born each year in the United States,⁴ and most of them are screened.
- Most states report participation of 99.9% or higher.
- The latest CDC data show that about 12,500 newborns each year are diagnosed with one of the core conditions detected through newborn screening. This means that almost 1 out of every 300 newborns screened is eventually diagnosed.⁵
- Early diagnosis and treatment in many cases can significantly improve the chances of healthy development and positive outcomes and nearly eliminates death from the conditions.”

Click here for full text:

(<https://www.nichd.nih.gov/health/topics/newborn/conditioninfo/infants-screened>)



Eunice Kennedy Shriver National Institute
of Child Health and Human Development



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 11, 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?

Are you an adult male between 18-60 years of age?

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.



Children's 1st Annual CAH CARNIVAL

THANK YOU TO EVERYONE WHO ATTENDED THIS YEAR'S EVENT!

We truly appreciate all who came out to the first annual CAH Family Fun Day with UT Southwestern Medical Center!

Thank you to all of the volunteers, sponsors, and event organizers for making this such a meaningful and successful event!



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FOUNDATION

UT Southwestern
Medical Center

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>

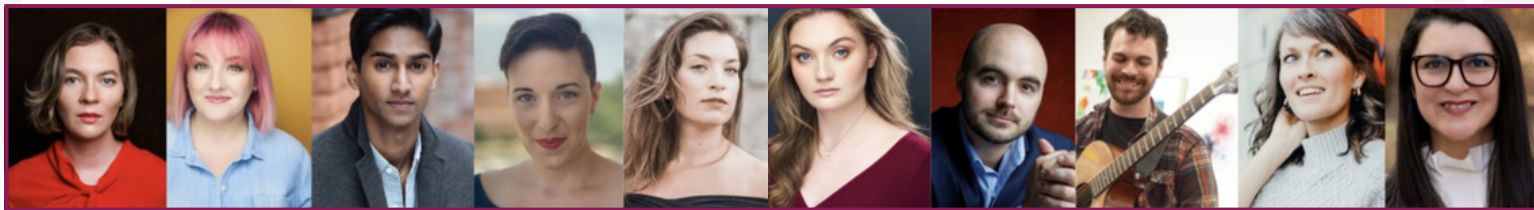


Sept. 26, 2026 at Club Café in Boston, MA

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!** Thank you to the Boston Symphony Orchestra and Lorelei Ensemble for their support in graciously donating tickets for our live auction.

Starring:

Corrine Byrne
Michael Maliakel
Jack Byrne
Sonja Tengblad
David Mather

Carley DeFranco
Rhaea D'Aliesio
Susan Dillard
Alice Byrne
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



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>



Life changes. Expert care is just a search away.

Search for specialists near you, so a life change never has to mean a gap in care.



Individuals are paid partners of Neurocrine Biosciences, Inc.

“We used it to find a doctor near my child’s college.”

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

“I wanted to find a doctor in my area”

However your life is changing, having the right care matters. A tool is available to help you find a doctor, wherever you are.

- ☒ Quickly locate experienced doctors near you
- ☒ See where they practice and whether they have participated in relevant clinical research or published medical 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 Care Near You](#)



Share Your Perspective:

Apply to Join Neurocrine's CAH Patient & Caregiver Advisory Council

Neurocrine Biosciences is seeking new members for its CAH Patient & Caregiver Advisory Council. Eligible applicants are adults living with classic congenital adrenal hyperplasia (CAH) and parents or caregivers of children with classic CAH who reside in the United States.

Established in 2024, the Council brings patient and caregiver perspectives into Neurocrine's work. As several founding members complete their terms, we are looking for new advisors who can build on the Council's work and bring a range of lived experiences.

As a Council member, you will have the opportunity to:



Share your lived experience

to help Neurocrine better understand the needs of people with CAH and their caregivers.



Connect with other

patients and caregivers who are passionate about improving life with CAH.



Provide feedback on educational resources, support programs, research, and future initiatives.



Learn how Council

feedback has informed Neurocrine's work through periodic updates.



Brainstorm and help shape resources and programs for the broader CAH community.

What *participation* involves:

- A two-year term.
- Participation in one annual in-person Council meeting (if your schedule allows), with reasonable travel expenses covered.
- Potential invitations to participate in virtual consultations, surveys, or other advisory activities during the year.
- Compensation for time spent participating in Council activities.



Actor Portrayal

No prior advocacy experience is required. We welcome applicants with different backgrounds, ages, life stages, treatment experiences, levels of CAH community involvement, and care settings, including community practices and specialty centers. We especially encourage adult men living with classic CAH to apply, as their perspectives are currently underrepresented on the Council.

If you are interested in sharing your experience to help inform Neurocrine's CAH work, we would love to hear from you.

Applications will be considered on a rolling basis but will close on September 18, 2026.

Apply Now

You Deserve *Brave* Science®

Sponsored and Developed by Neurocrine Biosciences, Inc.

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For your child with adrenal insufficiency, there's now a liquid option you can trust

Please see Indication and Important Safety Information below.

Current hydrocortisone replacement therapies come with challenges that can make accurate dosing harder than it should be.

The challenges with current options

Cutting or crushing tablets can be difficult

- Hydrocortisone tablets are not easy to split evenly. Uneven splits create uneven doses. And for a child whose daily health depends on getting the right amount of cortisol replacement, accurate dosing is crucial
- Children may also have trouble swallowing tablets, which can lead to missed or incomplete doses

Compounded liquids can bring uncertainty

- Compounded hydrocortisone preparations are made by mixing medications in pharmacies that aren't always held to the same strict oversight and manufacturing standards as FDA-approved medicines
- These preparations can change in potency and consistency from batch to batch, meaning your child may not receive the same dose every time

Now there's a liquid solution

The only FDA-approved liquid hydrocortisone



KHINDIVI™ (hydrocortisone) 1 mg/mL oral solution is a ready-to-use oral solution for children 5 years of age and older with adrenal insufficiency. That means pharmaceutical-grade consistency in every dose, without the uncertainty of compounding.

- No mixing, shaking, or refrigeration needed
- Designed to support accurate dosing when given as prescribed
- Administered with an oral syringe*
- Not for stress or acute event dosing

Ask your doctor about KHINDIVI today.

*Oral syringe provided by Anovo® Specialty Pharmacy.

†Commercially eligible patients can pay \$0 per month. Restrictions, limitations, and/or eligibility requirements may apply.



Please see below for Indication and Important Safety Information for KHINDIVI.

USE AND IMPORTANT SAFETY INFORMATION

USE

KHINDIVI is a prescription medicine used in children 5 years of age and older as replacement therapy when the adrenal gland is not making enough cortisol.

Limitation of Use: 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

Always give KHINDIVI exactly as your doctor has directed.

Do not take 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 KHINDIVI, watch your child closely for any changes. During periods of stress such as infections or after surgery, your doctor should switch to another oral hydrocortisone product and increase the dose.

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 build-up 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.

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. Contact your health care 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 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.

The most common side effects of KHINDIVI 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 KHINDIVI-treated pediatric patients with adrenocortical insufficiency who receive replacement corticosteroids.

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.

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





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®?

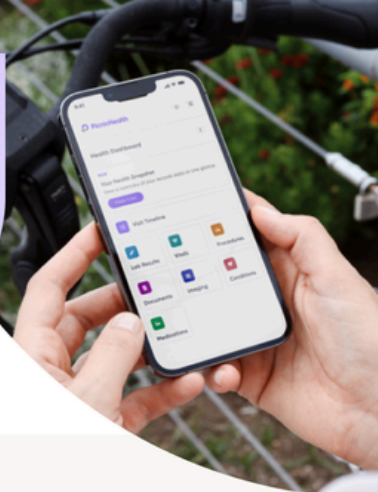
Furthermore, that they are not allowed to administer the shot even if you have it? We are at work to develop EMS protocols for emergency medical treatment of CAH and other adrenal insufficiencies. Too many people suffer from delayed medical care in emergency situations.

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/>

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.

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 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?

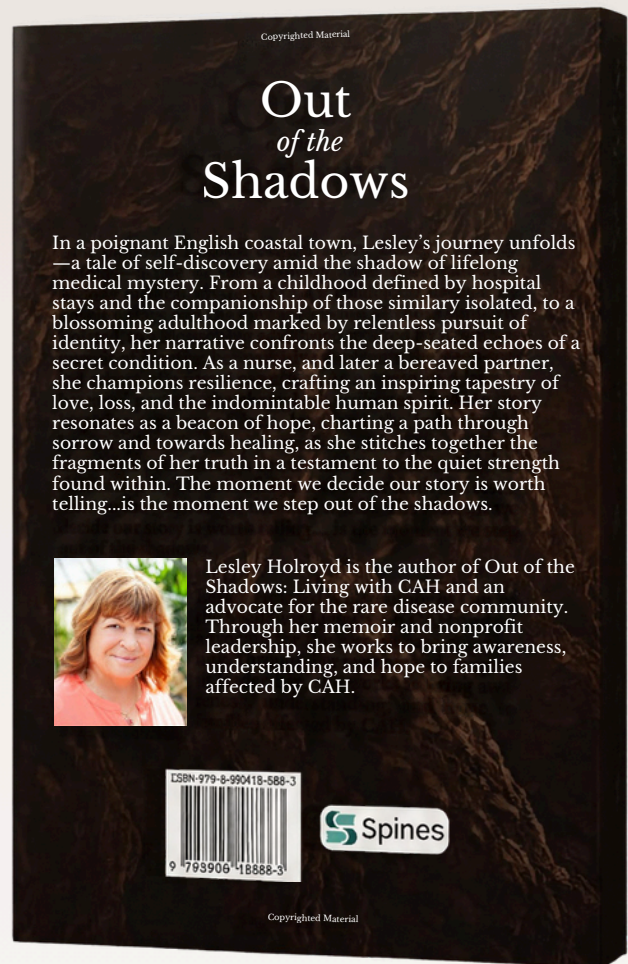
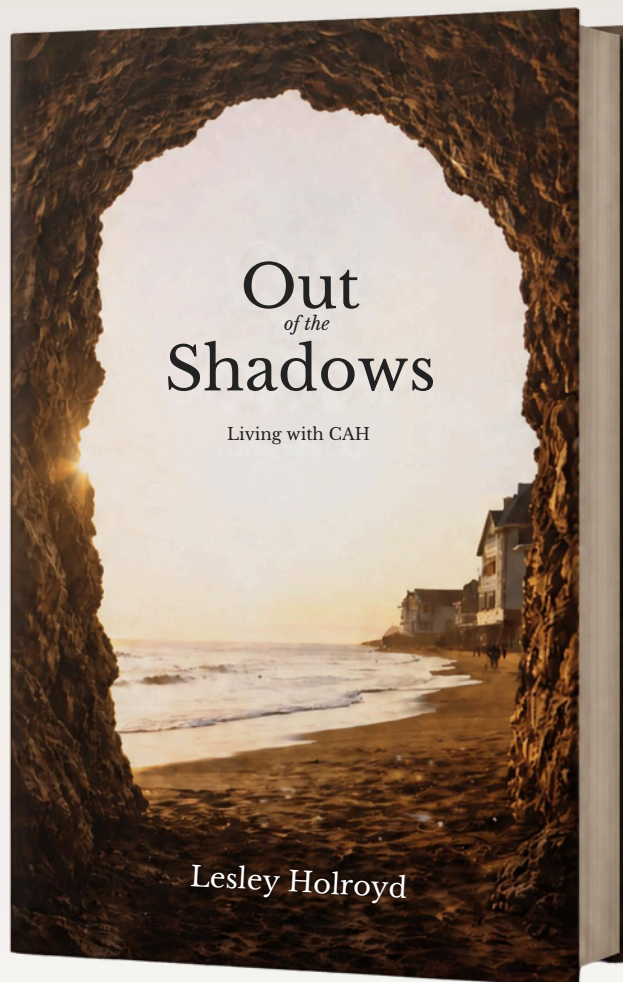
If you have any interest on being a guest on our podcast, please contact: dina@caresfoundation.org.



Out *of the* Shadows

Living with CAH

by Lesley Holroyd



AVAILABLE NOW VIA AMAZON (QR CODE BELOW)

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

xxcares
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ADRENAL
HYPERPLASIA FOUNDATION



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!](#)



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”.





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](#)



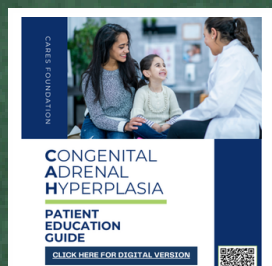


THE CARES SHOP

STOCK UP SOME OF THE IMPORTANT EMERGENCY ITEMS!

View our full catalog at:

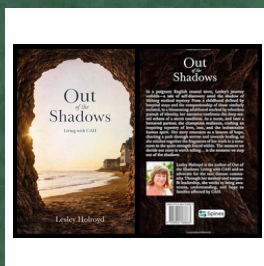
<https://caresfoundation.org/the-cares-shop/>



CARES PATIENT EDUCATION GUIDE

FREE DOWNLOAD

Helpful guide for patients/caregivers of those with CAH.



OUT OF THE SHADOWS BY LESLEY HOLROYD

AMAZON PURCHASE

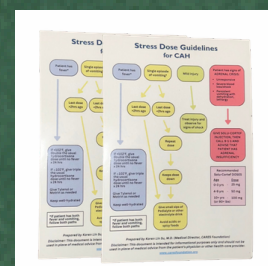
Memoir from CAH Patient & Advocate, Lesley Holroyd.



CAH PULSE COFFEE MUG

\$8.00

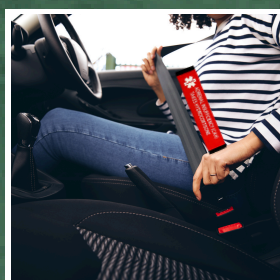
CARES CAH Pulse coffee mug (17oz.)



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!

