# NOVEMBER 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

**Saturday & Sunday - October 17 & 18, 2026**

# 2026 ANNUAL PATIENT EDUCATION CONFERENCE

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

CARES Congenital Adrenal Hyperplasia Foundation

co-hosted with Weill Cornell Medicine

More than 150 individuals representing 25 states came together in New York City for our annual CARES Foundation Patient Education Conference. Over a day and a half, patients, families, medical professionals, and industry partners had the opportunity to learn from some of the leading experts in Congenital Adrenal Hyperplasia (CAH).

The feedback we received was both powerful and humbling. Participants shared that they learned more in a day and a half than they had throughout years of living with CAH. Many discovered that health concerns they had experienced were related to their condition, while others gained a better understanding of the importance of specialized care. In the days following the conference, we had already received numerous requests for referrals to CAH experts from individuals who recognized that their condition may not be optimally managed or that their care teams may lack the specialized knowledge they need.

The conference covered an incredible range of topics, including genetics, transition from pediatric to adult care, mental health, nutrition, GLP-1 medications, fertility, cardiovascular health, new treatments, and emerging research. Each presentation offered valuable insights and practical information to help individuals better understand and manage their health.

But as important as the education was, some of the most meaningful moments happened when patients and families connected with one another. They shared their experiences, their fears, their challenges, and their hopes with people who truly understood. For many, simply being in a room where they felt seen, heard, and understood was as valuable as the medical information they received. These connections are at the heart of what CARES does and remind us why creating opportunities for our community to come together matters so much.

We were also honored to host a special screening of "*Overlooked*", a documentary that follows one individual's journey with CAH. It offered another powerful opportunity to reflect on the realities of living with this condition and the importance of making sure the CAH community is seen, heard, and understood.

We are incredibly grateful to the experts who generously shared their knowledge, time, and compassion with our community. We also extend our sincere thanks to our host institution, Weill Cornell Medicine, and to the sponsors whose support helped make this conference possible.

Thanks to the generosity of our supporters, CARES awarded approximately $45,000 in scholarships to help patients and families attend. Many scholarship recipients had never before had access to CAH specialists or experts in the field. Helping make this knowledge and expertise accessible to those who need it most is one of the most meaningful ways we can support our community.

For our team at CARES, there is nothing more rewarding than creating opportunities for individuals and families to leave feeling more informed, more confident, and less alone.










## Special thanks to our sponsors for helping make the event possible!

2026 CAH Partner NEUROCRINE® BIOSCIENCES

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## Missed this year's conference?

Conference presentations will be available via recording for anyone interested in learning more. For additional information, please contact John@caresfoundation.org.

www.caresfoundation.org

NO ONE SHOULD FACE

# CAH ALONE

## Help make a difference in the lives of those living with Congenital Adrenal Hyperplasia (CAH) this holiday season!

A rare condition can be isolating in ways that only those living with it can truly understand, and other CAH families can feel impossibly far away. CARES Foundation exists to close that distance.

This year, our community grew stronger in real, measurable ways. Your gift helps continue to bring trusted information, meaningful connections, and vital support to CAH families when they need it most.

We truly thank you for your continued support & generosity as we continue our mission to improve the lives of those living with CAH!

To make your donation to CARES Foundation's Year-End Giving Campaign, you can **scan the QR code or visit:**

https://caresfoundation.app.neoncrm.com/forms/cares-foundation-2026-year-end-giving

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To learn more about our mission, and some of the resources & services we assist with, please visit: https://caresfoundation.org/cares-year-end-campaign/

# 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

This article is sponsored by Neurocrine Biosciences, Inc.

Crenessity® (crinecerfont) | NEUROCRINE® BIOSCIENCES

**¡Acompáñanos en McAllen, Texas!**

# Evento Educativo Sobre CAH en Español

Una oportunidad para aprender sobre CAH y CRENESSITY y escuchar experiencias de nuestra comunidad, todo en español.

**Saturday, November 21, 2026**
**Casa De Palmas, Trademark Collection by Wyndham**
**McAllen, Texas**
**11:30–2:00 PM CT**



## CRENESSITY 2-Year Data

*Presented by Dr. Alejandro Diaz, Pediatric Endocrinologist*

Learn more about CRENESSITY and hear the latest 2-year data.



## IN OUR WORDS: A Personal CAH Story

*Presented by Lauren, Patient Ambassador*

Hear Lauren share her personal experience living with classic CAH and connect through stories and shared experiences from the CAH community.

IN OUR WORDS

"Finding community gave me a sense of connection and hope. It reminded me that I wasn't the only person facing these challenges." – Lauren, Patient Ambassador

Regístrate aquí (Register Here)

Individuals are paid partners of Neurocrine.

**The program will be presented in Spanish and will include information about CAH and Crenessity.**

**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.**

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**Usos aprobados:**
CRENESSITY (crinecerfont) es un medicamento de venta con receta que se usa junto con glucocorticoides (corticoides) para controlar los niveles de andrógenos (hormona similar a la testosterona) en adultos y niños de 4 años de edad o más con hiperplasia suprarrenal congénita (CAH) clásica.

**INFORMACIÓN IMPORTANTE DE SEGURIDAD**

**No tome CRENESSITY si:**
Es alérgico a crinecerfont o a cualquiera de los ingredientes de CRENESSITY.

**CRENESSITY puede provocar efectos secundarios graves, que incluyen:**

**Reacciones alérgicas.** Los síntomas de una reacción alérgica incluyen opresión en la garganta, dificultad para respirar o tragar, hinchazón de los labios, la lengua o la cara, y erupción. Si tiene una reacción alérgica a CRENESSITY, busque ayuda médica de emergencia de inmediato y deje de tomar CRENESSITY.

**Riesgo de insuficiencia suprarrenal repentina o crisis suprarrenal debido a una cantidad insuficiente de glucocorticoides (corticoide).** La insuficiencia suprarrenal repentina o la crisis suprarrenal pueden ocurrir en personas con hiperplasia suprarrenal congénita que no toman suficiente glucocorticoides (corticoide). Debe continuar tomando su glucocorticoide (corticoide) durante el tratamiento con CRENESSITY. Ciertas afecciones como infección, lesión grave o choque pueden aumentar el riesgo de insuficiencia suprarrenal repentina o crisis suprarrenal. Informe a su proveedor de atención médica si sufre una lesión grave, infección, enfermedad o cirugía planificada durante el tratamiento. Es posible que su proveedor de atención médica necesite cambiar su dosis de glucocorticoides (corticoides).

**Antes de tomar CRENESSITY, informe a su proveedor de atención médica sobre todas sus afecciones médicas, incluido si:** está embarazada o planea quedarse embarazada, o está en período de lactancia o planea amamantar.

**Informe a su proveedor de atención médica sobre todos los medicamentos que toma,** incluidos los medicamentos de venta con receta y de venta libre, las vitaminas y los suplementos a base de hierbas.

**Los efectos secundarios más frecuentes de CRENESSITY en adultos incluyen** cansancio, dolor de cabeza, mareos, dolor articular, dolor de espalda, disminución del apetito y dolor muscular.

**Los efectos secundarios más frecuentes de CRENESSITY en niños incluyen** dolor de cabeza, dolor estomacal, cansancio, congestión nasal y sangrados nasales.

Estos no son todos los posibles efectos secundarios de CRENESSITY. Llame a su proveedor de atención médica para obtener asesoramiento médico sobre los efectos secundarios. Se le recomienda que informe a la FDA los efectos secundarios negativos de los fármacos de venta con receta. Visite MedWatch en www.fda.gov/medwatch o llame al 1-800-FDA-1088.

**Formas posológicas y concentraciones:** CRENESSITY está disponible en cápsulas de 50 mg y 100 mg, y como solución oral de 50 mg/ml.

**Consulte la Información de prescripción completa.**

# Eton Connect Peer Program

## Has your child been prescribed Alkindi Sprinkle® (hydrocortisone) oral granules?

Starting in October, Eton is launching the Eton Connect Peer Program to connect the adrenal insufficiency community with a real caregiver like yourself. The Eton Connect Peer Program offers 1:1 calls with an AlkindiPeer mentor who will share their personal experience caring for a loved one with adrenal insufficiency and using Alkindi Sprinkle as part of their treatment.



Visit **AlkindiSprinkle.com/eton-connect** or scan QR code to register for a 1:1 call with an AlkindiPeer

The Eton Connect Peer Program is administered by an independent third party, SmithSolve, a company dedicated to healthcare communications. All information during the registration process will remain confidential and solely for the purpose of participation.

### 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.**

**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 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.**

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A CLINICAL RESEARCH STUDY OF A POTENTIAL NEW TREATMENT FOR PEDIATRIC CONGENITAL ADRENALHYPERPLASIA(CAH) – **PARTA**

# Are You or Your Child Facing Challenges Due to CAH?

## Consider Joining a Clinical Research Study



The Balance-CAH Study is currently enrolling children and adolescents diagnosed with classic CAH to take part in research of an investigational study drug called atumelnant.

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. It can only be used in research studies like this one.

Those who qualify will receive the study drug and all study procedures at no cost. Additionally, reasonable costs for travel may be reimbursed when you visit the research center for study visits. This study will last about 4 months with up to 9 visits, 2 of which may be done by telephone.

**To participate in this study, you or your child must:**

- Be 1 to 17 years of age
- Have received a diagnosis of classic CAH
- Be on a stable glucocorticoid regimen
  - Includes: modified-release hydrocortisone, cortisone acetate, prednisolone, prednisone, methylprednisolone, and dexamethasone

**To learn more or to see if you or your child may qualify for the Balance-CAH Study, scan the QR code or visit CrineticsCAH.com.**

Crinetics Pharmaceuticals

Balance-CAH

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CRN04894-13_Recruitment Flyer Part A_V1_07/2025_NP-CAH-0098-1
BAL-ENUS-FLYA-V1-26JUN25

# Your child's health story, all in one secure place.

See your child's health journey from day one.

**One app. All providers.**
Access records from all of your child's healthcare providers without juggling multiple logins.

**See the whole picture.**
View your child's health info, including growth, lab results, medications, visits, imaging, and care notes.

**Ready to share.**
Securely share your child's records with healthcare providers and loved ones in just a few taps.




**Private.**
**Secure.**
**Research that makes a difference.**

Your child's de-identified records help researchers improve care for kids with classic CAH.

**Join today!**

CAHtalog.com

Sponsored by: NEUROCRINE BIOSCIENCES  Partnered with: CARES FOUNDATION  Powered by: PicnicHealth

## *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.

**SCAN OR SEARCH ON THE APP STORE 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".

eTon PHARMACEUTICALS  NEUROCRINE BIOSCIENCES  Walmart

# CAH Awareness Walks

**Thank you to all of the amazing event hosts, volunteers, and attendees that helped us raise awareness for & support those with CAH.**








## THANK YOU TO ALL WHO ATTENDED THE 1ST ILLINOIS CAH AWARENESS WALK, IN HUNTLEY, IL!

We're deeply grateful to everyone who came together to raise awareness and support the CAH community. A special thank you to our walk host, Becky, for doing such a wonderful job organizing and bringing this event to life. We also thank our generous sponsors for helping make this event possible.

### THANK YOU TO OUR SPONSORS!

CAH PARTNER 2026 NEUROCRINE® BIOSCIENCES | eton PHARMACEUTICALS | Crinetics Pharmaceuticals | FOR THE PEOPLE ENTERTAINMENT | Bay Hill Dental | Snelten & Sons Well & Pump Service | ATHLETICO PHYSICAL THERAPY









## THANK YOU TO THOSE THAT CAME OUT TO THE 6TH OHIO CAH AWARENESS WALK, IN VALLEY CITY, OH!

We're deeply grateful to everyone who came together to raise awareness and support the CAH community. A special thank you to our walk host, Chloe, for doing such an incredible job organizing and bringing this event to life. We also thank our generous sponsors for helping make this event possible.

### THANK YOU TO OUR SPONSORS!

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## THANK YOU FOR SUPPORTING THE 8TH FLORIDA CAH AWARENESS WALK, IN TITUSVILLE, FL!

We're deeply grateful to everyone who came together to raise awareness and support the CAH community. A special thank you to our walk host, Gretchen, for doing such an amazing job organizing and bringing this event to life. We also thank our generous sponsors for helping make this event possible.

### THANK YOU TO OUR SPONSORS!

CAH PARTNER 2026 NEUROCRINE® BIOSCIENCES | BRIDGEBIO | eton PHARMACEUTICALS | Crinetics Pharmaceuticals



## INTERESTED IN HOSTING A WALK IN YOUR AREA?

If you have any interest in hosting a CAH Awareness Walk in your area, please contact Dina Matos at dina@caresfoundation.org.

## CARES FOUNDATION'S FIRST EVER

# CAH Family Fun Days!

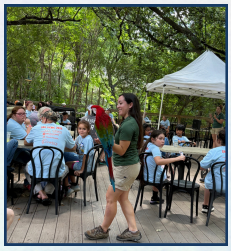
We had such a great time this year coming together, connecting & learning about CAH at our first ever Family Fun Days! Thank you to all of our participating centers of excellence, volunteers & everyone who helped make these such special events.

Make sure you are staying up-to-date with CARES Foundation's website & social media pages for more information on events like these!









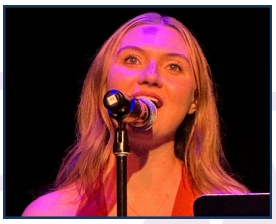

## Sept. 26, 2026 in Boston, MA

# CARES Cabaret Night

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

We want to extend our thanks to everyone who made it out to attend the first ever, CARES Cabaret Night! Thank you to our event host, Corrine Byrne, Club Cafe, and to all of the talented performers who helped make this such a special night!





## 11TH ANNUAL

# CLAY SHOOT FOR CARES

## LEHIGH VALLEY SPORTING CLAYS

Thank you to everyone who came out to support CARES Foundation at this year's Clay Shoot! Congratulations to all of our top performers, and a special thank you to all of those to helped to sponsor this event! In 11 years, the Clay Shoot for CARES has raised over $235k to help support those living with Congenital Adrenal Hyperplasia.







# 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 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/

*CARES Foundation's Podcast...*

# CAH Pulse

## Season 3 | Episode 6: Allyson Pt. 2

## The Good Kind of Stubborn: An Athlete's CAH Story

Can you compete in an Ironman while living with CAH? Allyson says, absolutely! In this episode of CAH Pulse, Allyson returns to share her lifelong journey as an athlete with CAH, which all began for her when she was a child as a competitive swimmer. Now, as a young adult, Allyson is training for her first half Ironman. We learn what training is like as a salt waster, the precautions she takes to stay safe, and what it means to be "Allyson stubborn."

With humor, determination and practical advice for athletes as well as parents, Allyson shares an inspiring message: CAH may be part of your life, but it doesn't have to define all that you can achieve.

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

**Recent Episodes:**

**Season 3 | Episode 5: Allyson's Journey:**
"Different is What Makes You Good"

**Season 3 | Episode 4: From Patient to Pioneer:**
Julia Anthony Always Goes Big

**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 I 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.

# Sign-up for text updates from CARES Foundation!



Stay up-to-date with all things in the CARES Community by opting-in to receive text messages about important events, campaigns & more!

Opt-in by logging into your CARES account, and updating your profile. There will be an option to opt-in to texting.

Login here: https://caresfoundation.app.neoncrm.com/login

## Available Now!

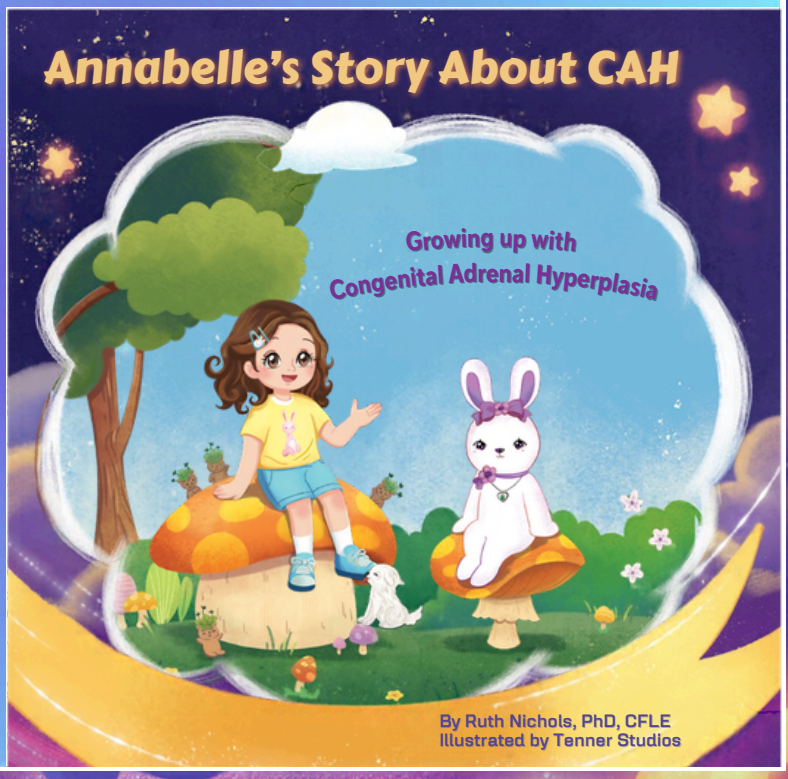
Ruth Nichols, PhD, CFLE

Learn more:
ruthnicholsphd.com/annabelles-story-about-cah/

### Join Annabelle and Violet!

This is a heartwarming narrative that helps children living with *Congenital Adrenal Hyperplasia* (CAH) navigate their treatment experiences with confidence.

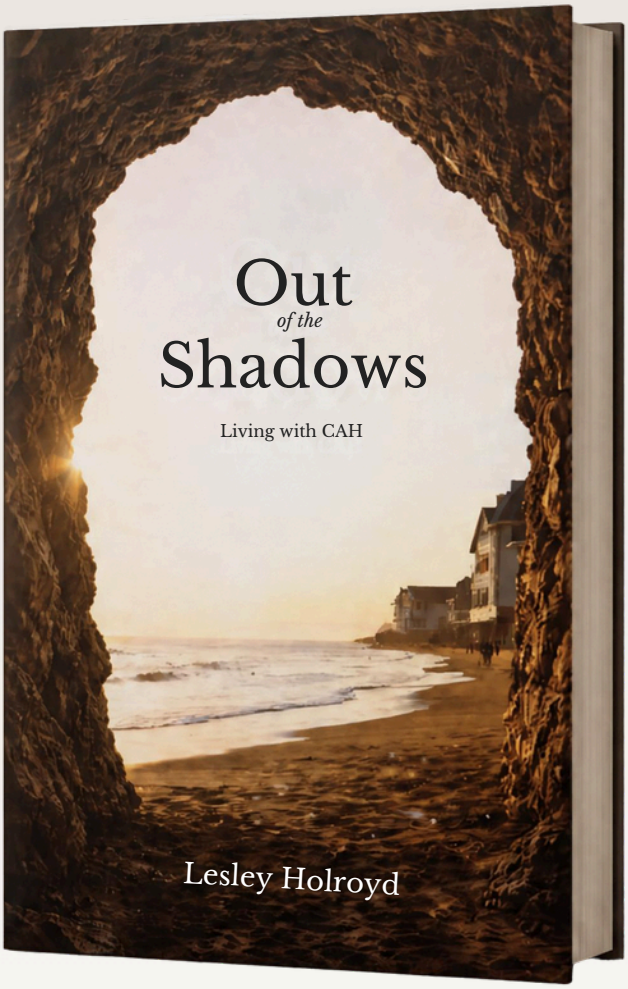
This book is designed to inform and empower children with the tools they need to confidently manage their diagnosis of CAH, inspiring them to live full, healthy lives.

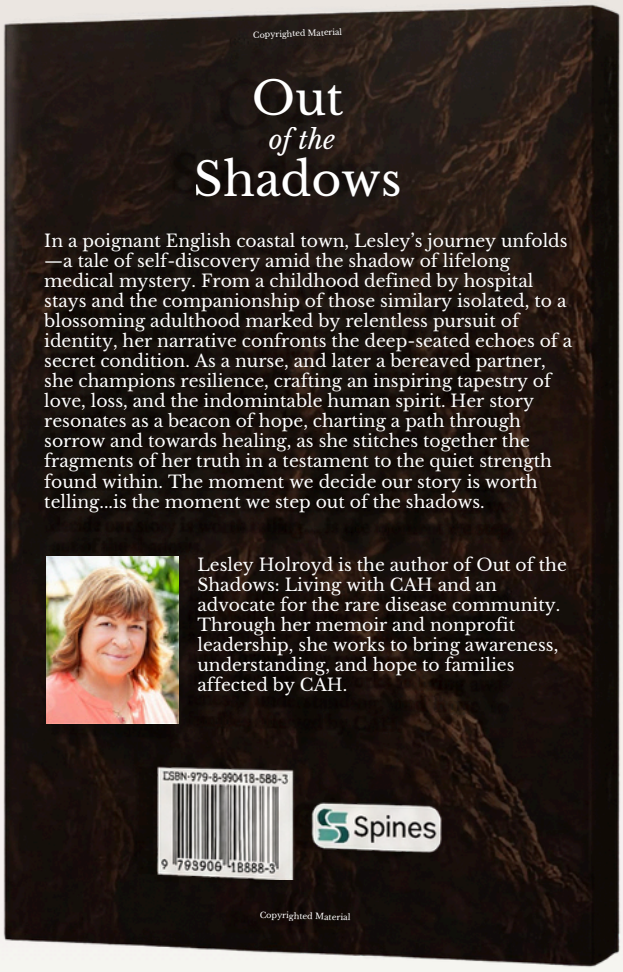


# Out *of the* Shadows

## Living with CAH

## by Lesley Holroyd




## AVAILABLE NOW VIA AMAZON LINK OR QR CODE BELOW

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

CARES CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

# Be Prepared!

## 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 unirte, haz clic en: https://caresfoundation.org/join-the-cares-community/

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

# CARES Foundation's Support Groups via Zoom

**Thursday, Nov. 12**

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

**Thursday, Dec. 3**

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

**Thursday, Dec. 10**

**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/**

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**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.**

## 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.

CARES FOUNDATION



# CONGENITAL ADRENAL HYPERPLASIA

## PATIENT EDUCATION GUIDE

**CLICK HERE FOR DIGITAL VERSION**

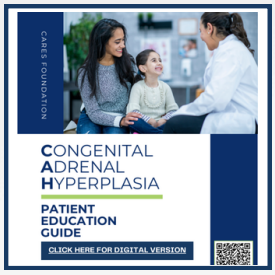
cares FOUNDATION

SCAN TO VIEW

# THE CARES SHOP

## STOCK UP ON 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**

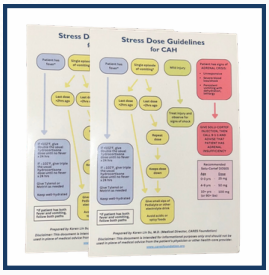
Memoir from CAH Patient & Advocate, Lesley Holroyd.




**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.

# 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**

## CAH PARTNER 2026

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

www.neurocrine.com

NEUROCRINE® BIOSCIENCES

CARES CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

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

**MAKE A DONATION**

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!