

In this update, you will find important information on community updates, research, support groups, and upcoming events!

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

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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!



eTon

<u>(Android App Store)</u>

Walmart 2

NEUROCRINE[®]



<u>(Apple App Store)</u>



CAH Pulse | NEW EPISODE! Season 2 | Episode 3: Ryan The Son of a Rainbow Maker



In this memorable episode, Ryan, who has seemed to manage his classic salt wasting CAH head-on with an organized, matter of fact approach, has been faced with new challenges to consider now that he is in his 30's. Ryan's mom, Heidi, knew in his first 2 weeks of life that something was just not right with her baby and thanks to her intuition and diligence she did not stop until the hospital found a diagnosis. Once she was told her newborn had CAH, she began her quest to give Ryan the very best life she could, filled with independence, knowledge, responsibility and most of all positivity. Ryan credits his mom for being his rock, leading him to live a typical life filled with adventure, fun and love.

Join Stephanie and Dina as they visit with Ryan and unveil how he has navigated living with CAH from elementary school, through college and recently marriage as well as his difficult relationship with the powerful steriod "Dex" and how grateful he is for every one in his life who has helped him on his journey with this rare condition.

https://cahpulse.podbean.com/

Recent Episodes:

- Season 2: Episode 1: Living Life to it's Fullest
- Season 2: Episode 2: "I had no idea getting married and having children was a thing"

If you are interested, and would like to discuss sharing your story on our podcast, please contact: <u>dina@caresfoundation.org</u>.



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.

You must be registered with CARES to use this service. To join, click: <u>https://caresfoundation.org/join-the-cares-community/</u> CLICK HERE: <u>https://caresfoundation.org/ask-the-expert/</u> 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: <u>https://caresfoundation.org/join-the-cares-community/</u> Haga clic aquí: <u>https://caresfoundation.org/pregunta-el-experto/</u> para visitar esta pagina.

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



TO <u>BE PREPARED FOR AN EMERGENCY</u>, YOU MUST MAKE SURE YOUR LOCAL FIREHOUSE AND/OR EMS STATION IS AWARE OF YOUR OR YOUR CHILD'S ADRENAL INSUFFICIENCY/CAH STATUS! WE URGE YOU TO VISIT YOUR FIREHOUSE/EMS STATION RIGHT AWAY!

> CLICK HERE FOR OUR EMS ADVOCACY PAGE, WHERE YOU WILL FIND HELPFUL RESOURCES AND DOCUMENTS!

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 <u>Congenital Adrenal Hyperplasia</u> <u>Support Network on Facebook</u>. From our page, select MORE, then GROUPS. (<u>If you are on a mobile device</u>: 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's Support Groups via Zoom

December 5

Parents of CAH Children (School-Aged/Teens/Young Adults), 8:30PM(ET)

December 12

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

January 9

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

If you are interested in participating in any of the above meetings, please reach out to: <u>support@caresfoundation.org</u>.

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







All donations made on Giving Tuesday will be MATCHED UP TO \$25,000! Please consider GIVING to CARES by using the link in this post to donate and help

improve the lives of individuals with congenital adrenal hyperplasia! https://charity.pledgeit.org/caresgiving-2024

SCAN TO DONATE



CARES Foundation's 2024 Giving Campaign

We truly appreciate your consideration in helping us reach our year-end goal! None of what we have accomplished this past year could have been done without your support. Thank you for your belief in our mission.

CALL TO ACTION: All gifts make a difference! We need your help in making sure that our voices are heard in 2025 and beyond!



To learn more about how to make a donation, and to see some of the incredible accomplishments made within our community this year, please scan the OR code or visit https://charity.pledgeit.org/caresgiving-2024.

Wishing you a happy and healthy holiday season & new year!



If you have any questions, please reach out to: contact@caresfoundation.org

STAY UP TO DATE ON ALL THINGS CARES!

MAKE SURE TO VISIT THE WHAT'S HAPPENING NOW **& EVENTS PAGES ON OUR WEBSITE TO STAY UP TO DATE ON IMPORTANT INFORMATION AND EVENTS!**

WHAT'S HAPPENING NOW



in







CARES Foundation Endowment Fund

Securing a Future of Care and Hope

A Gift That Keeps on Giving

CARES Foundation's Endowment is designed to provide a stable, permanent source of funding. Your contribution will be carefully invested, with the annual returns supporting our mission in perpetuity. This means your single act of generosity will touch lives year after year, creating a ripple effect of positive change.

Every Gift Matters

Whether large or small, your contribution to the endowment fund is an investment in hope. It's a promise to future generations that they will have the resources, support, and opportunities they need to thrive despite CAH.

How an Endowment Grows...



forms the principal

The prinicipal is protected, invested, and continues to grow

A portion of the fund's value is distributed annually, forever

OUR ENDOWMENT ENSURES THAT THIS VITAL WORK CONTINUES FOR GENERATIONS TO COME

Ways to Give

Bequests: Include CARES in your will or living trust. Retirement Plan Assets: Name CARES as a beneficiary. Life Insurance: Designate CARES as a beneficiary. Securities: Donate stocks, bonds, or mutual funds. **Real Estate:** Gift property to make a significant impact.

Our Mission

CARES programs benefit more than 3,600 families and medical professionals across the United States and abroad. Our community represents every state in the United States and over 70 countries outside the US. These programs include:

- Grants to qualifying researchers for better treatment, better understanding of the disease, and a cure
- One-on-one support for affected individuals and their families
- Educational materials and information for those living with the daily challenges of CAH
- Educational programs for individuals, and their families and health care professionals
- Comprehensive bi-annual newsletters
- Physician referral service
- Advocate for comprehensive newborn screening
- Advocate for appropriate emergency medical care
- Support groups for affected individuals and their families

If you would like to name us in your Will/IRA, please add the following as a beneficiary:

Community Foundation of New Jersey c/o CARES Foundation Congenital Adrenal Hyperplasia Fund EIN 22-2281783

For more information regarding this process or specific donations, please contact:



Phone: (973) 267-5533 Toll Free: (800) 659-5533 Fax: (973) 267-2903

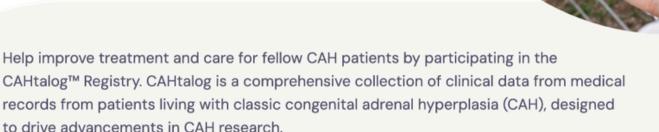
If you have any questions, please do not hesitate to contact CARES via email or by phone:

Email: contact@caresfoundation.org Phone: (908) 364-0272 Toll Free: (866) 227-3737

PicnicHealth G NEUROCRINE



Be a hero for the CAH community!



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:

- 1	
	Bar.

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 can be compensated for your time to complete optional short surveys twice a year.

Have questions or need help signing up? Email us at help@picnichealth.com.



ALKINDI SPRINKLE[®] (hydrocortisone) oral granules is the first and only hydrocortisone treatment designed to help provide accurate dosing for newborns and children with adrenal insufficiency.¹

Please see Use and Important Safety Information below.

Eton Cares: Insurance assistance to get started on ALKINDI SPRINKLE

Eton Cares is a patient support program designed to make it easier for you to get and stay on treatment with ALKINDI SPRINKLE. Your ALKINDI SPRINKLE prescription automatically enrolls you in Eton Cares.* A dedicated team of medical professionals are available to help you obtain insurance coverage approval and assist with getting your ALKINDI SPRINKLE delivery initiated within 24 hours.

Insurance Specialists will help you secure financial assistance for ALKINDI SPRINKLE through the Eton Cares Program or offer other sources of financial assistance.[†]



Medication for as little as \$0 per month* Call the Anovo® Specialty Pharmacy hotline to ask questions about ALKINDI SPRINKLE.

1-833-343-2500 Available Monday through Friday, 8 AM-5 PM CT

- 97% of ALKINDI SPRINKLE prescriptions were successfully onboarded and approved
- QuickStart Program provides medication in as soon as 24 hours during prior authorization*

See how Eton Cares helps families like yours https://www.alkindisprinkle.com/support/

Meet two families living life with ALKINDI SPRINKLE

Meet actual families living with congenital adrenal hyperplasia (CAH) and see how they are treating their little ones with ALKINDI SPRINKLE and with support from Eton Cares.



Watch their experiences with Eton Cares on AlkindiSprinkle.com https://www.alkindisprinkle.com/resources/_

*Restrictions, limitations, and/or eligibility requirements apply. *Anovo will work with the doctor to obtain insurance coverage. If insurance is denied, the patient may apply to the Patient Assistance Program. *For newborns awaiting hospital discharge, medication may be delivered in as soon as 24 hours. Typical delivery is 3 to 7 days.

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 <u>www.fda.gov/safety/medwatch</u> or call 1-800-FDA-1088.

Please see <u>full Prescribing Information</u> for more information.

Reference: 1. ALKINDI SPRINKLE. Package insert. Eton Pharmaceuticals, Inc; 2024.

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PATIENT RECRUITING

Share Your Experiences With CAH and Help Others

Pinpoint Patient Recruiting, a market research recruitment company, is looking for adults (ages 18+) who have been diagnosed with congenital adrenal hyperplasia (CAH), and caregivers of children living with CAH, to participate in online market research surveys and interviews. These opportunities will be conducted throughout the year to help researchers better understand the experiences and opinions of people living with CAH and caregivers of children living with CAH.

Those who qualify for and participate in a study will receive \$50 or more as a thank you for their time. All information and responses will remain confidential. The research opportunities are sponsored by pharmaceutical companies. No medication will be given or tested.

Interested?

To see if you qualify for these studies or to get more information, please visit <u>pinpointpatientrecruiting.com/cah-survey-cares</u> or Ingles Adams at <u>ingles@pinpointpatientrecruiting.com</u>.

2024 CAH EDUCATIONAL CONFERENCE The CAH Community CARES About Connectivity

At the 2024 CAH Educational Conference presented by CARES Foundation, Crinetics Pharmaceuticals developed and disseminated a survey completed by patients and caregivers. Participants were asked, "What is your favorite part of the CARES Conference?"

While the responses below provide different perspectives, connectivity was the central theme. Making connections at CARES helps the CAH community feel seen, heard, and understood...and keeps them coming back year after year.

What is your favorite part of the CARES conference?







NP-PAT-0027 10/2024

SAVE THE DATE: September 20 & 21, 2025

2025 ANNUAL CAH EDUCATION CONFERENCE

Held at Riley Hospital for Children in Indianapolis, Indiana

If you would like to be notified when registration for next year's conference is available, please complete the brief questionnaire by visiting the link below:

https://caresfoundation.app.neoncrm.com/np/clients/caresfoundation/survey.jsp?surveyId=36&

Testimonials from last year's conference in New Jersey:

"Great talks. We loved the new perspective and new context on exercise & diet. This was all very helpful!"

"Amazing! I wish I had those diagrams/videos when we were going through my daughter's surgery. I better understand what her surgery looked like."

"Very relevant information for my current stage in life. Top of mind and looking for this info. Very detailed and easy to follow."

"We heard many great presentations where presenters tried to break down a very confusing topic and had made it easier to understand."

"Loved hearing about things we need to think of in the future!"

"Incredibly knowledgeable and helpful. Presenters even stuck around to answer my questions. We learned a ton!"



Please join us for CARES Foundation's



25th Anniversary



Current, Chelsea Piers | Friday April 25, 2025

We encourage you to <u>SAVE THE DATE</u> for the upcoming 25th Anniversary Everyone CARES Gala, taking place on **Friday**, April 25, 2025 at Current, Chelsea Piers in New York, NY.

If you would like to donate any items to our silent and/or live auction, we encourage you to please reach out to <u>odaly@caresfoundation.org</u> or call **(866) 227-3737**, toll-free.



<u>This Year's Honorees</u> Dr. Alejandro Diaz | Maria I. New Visionary Award Lesley Holroyd, RN | Pioneer Award Crinetics Pharmaceuticals | Corporate Partner Award

RSVP to be notified!

To learn more about this year's Gala & how to be notified when tickets become available, scan the QR Code above, or visit:

https://caresfoundation.app.neoncrm.com/np/clients/caresfoundation/survey.jsp?surveyId=35&

Thank you to those who participated in the **7th Annual Florida CAH Awareness Walk**



Thank you to those who participated in the 9th Annual California CAH Awareness Walk



















#VIVISTRONG

May 3, 2025

2nd Annual Iowa CAH Awareness 5K

Des Moines Water Works, Des Moines, IA (Meeting at: Lauridsen Amphitheater)

CHECK-IN: 9:00AM | RACE STARTS: 10:00AM





IF YOU ARE INTERESTED IN HOSTING A WALK IN YOUR AREA, PLEASE VISIT: <u>HTTPS://CARESFOUNDATION.ORG/2024-CAH-AWARENESS-WALKS/</u>

WE ARE LOOKING FORWARD TO SEEING EVEN MORE OUR COMMUNITY AT OF THESE INCREDIBLE EVENTS IN 2025!









Join us at Double H to learn a new winters sport in a safe and inclusive environment! Learn more by visiting <u>doublehranch.org/programs/winter</u>

Activities include 1:1 instruction in alpine skiing or snowboarding with trained adaptive instructors. On Family Sleepover Weekends, family members can also take to the hill for group lessons. All programs and equipment are provided FREE of charge.

FEB. 14-17* JAN. 11 FEB. 22 JAN. 12 JAN. 17-20* FEB. 23 JAN. 25 FEB. 28-2* JAN. 26 MAR. 8 JAN. 31-2 MAR. 9 FEB. 8 MAR. 15 FEB. 9 MAR. 16

BASIC PARTICPANT ELIGIBILITY

- Campers aged 6-16 years old who have a qualifying medical diagnosis of Autism Spectrum Disorders, CAH, Cancer, Collagen Vascular Disease, Congenital Cardiac Defects, Hemophilia/von Willebrands, Shunt Dependent Hydrocephalus, Inflammatory Bowel Disease, Immune Disorder/HIV, Mitochondrial Disease, Neuromuscular Disorders, Sickle Cell Anemia, Solid Organ & Visceral Transplants, or Visual Impairments.
- For Family Sleepover Weekends, family members include immediate relatives and those who live in the same household as the medically qualifying camper.
- ALL campers and participating family members must be fully vaccinated in accordance with CDC recommendations, including the seasonal flu shot.

PLEASE UPDATE YOUR ACCOUNT INFORMATION!

Without the proper fields completed, you may be susceptible to missing out on important information and events! You can click the link below to log-in and edit any incomplete fields.

Please contact john@caresfoundation.org if you are concerned about your account's status!

LOGIN TO YOUR ACCOUNT HERE

BE PREPARED IN AN EMERGENCY

We want to remind you to check out some of the important tips & resources that we provide on the CARES Website to help you stay prepared in the event of an emergency, such as:

- Emergency Instruction Information
- Emergency Instructions Videos
- Resources for your visit to your local firehouse/EMS provider
- Our Ask the Expert Program

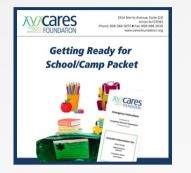
If you have any questions, you may reach out to: <u>contact@caresfoundation.org</u> Please visit: <u>https://caresfoundation.org/the-</u> <u>cares-shop/</u> to view some of the emergency items we carry in the CARES Shop, such as:

- Getting ready for school/camp packets
- Medical I.D. Cards & Adrenal Insufficiency Shoe Tags
- Emergency Response Kits
- Download links to the Preventing Adrenal Crisis Events (PACE) App

Click for CARES Foundation's Be Prepared in an Emergency Information

THE CARES SHOP

MAKE SURE THAT YOU STOCK UP SOME OF THE IMPORTANT EMERGENCY ITEMS THAT CAN BE FOUND IN OUR SHOP!



GETTING READY FOR SCHOOL/CAMP PACKET

\$4.00

Crucial tips and resources for back to school! (Includes 1 Emergency Response Kit)



EMERGENCY

SYRINGE BAG

\$5.50

Durable semitranslucent carry-case

for syringe or other

emergency items



EMERGENCY RESPONSE KIT (SET OF 3)

\$5.00

Includes 3 semitranslucent kits, and emergency instructions brochure & checklist

MEDI	CAL	I.D.
LUGGA	GE	TAGS

\$6.50

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



Medical Alert PASSENGER INSIDE

MEDICAL I.D. SHOE TAGS

\$5.50

Small oval-shaped medical I.D. tags for the laces of your shoes, bags with strings, and other items.



\$2.00

Window Cling to help EMS easily identify one's Adrenal Insufficiency



 Preventing Adrenal Crisis Events

 What is AI?

 What are the adrenal glands?

 What is adrenal insufficiency

 (A)?

 What causes AI?

ADRENAL INSUFFICIENCY SEATBELT COVER

\$12.00

Cover to go over you/your loved one's seatbelt to help identify in case of emergency

PREV	ENTING	ADREN	AL
CRISIS	EVENTS	(PACE)	APP

DOWNLOAD BELOW

<u>Apple App Store</u> <u>Google Play Store</u>

VISIT: <u>HTTPS://CARESFOUNDATION.ORG/THE-CARES-SHOP/</u>



CAH PARTNER 2024

A special thank you to Neurocrine Biosciences, for partnering with CARES Foundation in 2024! www.neurocrine.com

Platinum Transparency 2024

Candid.



2414 Morris Avenue, Suite 110, Union NJ 07083 (908) 362-0272 Toll Free (866) 227-3737

MAKE A DONATION

JOIN OUR COMMUNITY

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!

Wishing you and your loved ones a happy & healthy holiday season & new year!



