FEBRUARY 2025

RARE DISEASE DAY

RARE DISEASE DAY IS TAKING PLACE ON February 28, 2025. we urge you to advocate and spread awareness for CAH throughout the month, and to take advantage of all that CARES has to offer.

Learn more about some of the important resources, and advocacy efforts from CARES Foundation!



GET YOUR GALA TICKETS TODAY!

In this update, you will find more information on how you and your party can attend the 25th Anniversary Everyone CARES Gala, taking place at Current, at Chelsea Piers, in NY on April 25, 2025.

We look forward to seeing you in April!



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











FIRST NEW TREATMENT FOR CLASSIC CAH IN OVER 70 YEARS!





CRENESSITY™ (crinecerfont) is Now Available for Adults and Children with Classic CAH

Most patients will pay \$10 or less per month for CRENESSITY*

With Neurocrine Access Support for CRENESSITY, you have a dedicated Care Coordinator, backed by a team, to lean on for guidance and advice.

Visit **Neurocrine Access Support** for more information on how we can help.

*Additional terms and conditions apply.





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.

HOW TO TAKE PART IN #RAREDISEASEDAY!

FEBRUARY 28, 2025

SHARING YOUR CAH STORY WITH OUR COMMUNITY

If you would like to share any part/parts of your CAH journey with us, please reach out to john@caresfoundation.org. The stories and perspectives shared can give others a sense of comfort in knowing that they are not alone on their CAH journey.

WAYS YOU CAN SHARE

- A written entry of any length
- A video submission

Submissions can be any length, and we ask that you also please send a photo to accompany any written entries. Entries can be sent directly to john@caresfoundation.org. If you have any questions about how to share your story via CARES Social Media on #RareDiseaseDay2025, please reach out to john@caresfoundation.org.

OR YOU CAN ALSO...

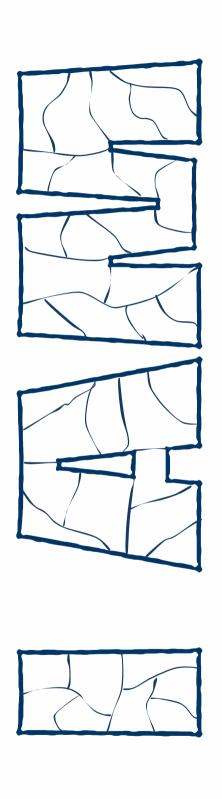
SEND US YOUR ARTWORK TO BE FEATURED ON OUR INSTAGRAM STORY!

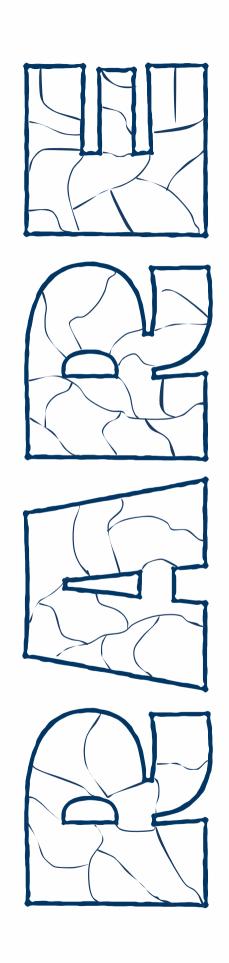
On the next page, we have included an "I AM RARE" coloring sheet. Members of our community can color and have their art displayed on CARES' social media & website! All you need to do is:

- 1. Print the next page
- 2. Color in with crayons, colored pencils, markers, etc.
- 3. Take a picture of/with the finished product
- 4. Send the picture to john@caresfoundation.org to be featured on our social media & website

If you post any pictures on your social media accounts, make sure to tag @caresfoundation and use the hashtags: #RAREDISEASEDAY #CARESFOUNDATION #IAMRARE #CAH









WWW.CARESFOUNDATION.ORG

Please join us for CARES Foundation's...



25th Anniversary

Everyone CARES Gala

Current, Chelsea Piers | Friday April 25, 2025

<u>TICKETS ARE NOW AVAILABLE</u> for the upcoming *25th Anniversary Everyone CARES Gala*, taking place on **Friday**, **April 25**, **2025** at Current, at Pier 59 at Chelsea Piers in New York, NY.

If you are interested in donating an item/item(s) to our silent and/or live auction, we encourage you to please reach out to odaly@caresfoundation.org or call (866) 227-3737, toll-free.



This Year's Honorees

Dr. Alejandro Diaz | Maria I. New Visionary Award Lesley Holroyd, RN | Pioneer Award Crinetics Pharmaceuticals | Corporate Partner Award

VISIT OUR GALA WEBSITE TO PURCHASE TICKETS & LEARN MORE ABOUT THIS EVENT



CAH Pulse | NEW EPISODE!

Season 2 | Episode 4: Abby

CAH Mom? Or NASCAR Driver?



In another compelling episode, Dina and Stephanie introduce us to Abby, a mom of two small boys, one of which is her "salt-waster". Little Nash is only seven months old, but he is already doing amazing things like swallowing medication in pill form & being the happiest, most joyful baby that Abby could have hoped for. Although proving to be challenging, his family is managing his CAH quite well.

However, not everything with baby Nash is status quo. One night when her husband was out of town, Abby was faced with what to do when baby Nash was throwing up uncontrollably and turned a shade of white that she had never seen before. What unfolds next is a learning experience every new CAH parent should hear.

Abby tells her frightening story about what she was sure was her baby's first adrenal crisis. It began with her NASCAR ride to the hospital, to then telling her 7-month-old not to be so dramatic during a blood draw, to finally emphatically explaining to the doctors that she knows what her baby needs. Abby is a true crusader as a new CAH mom. Her superpower has been the ability to continuously learn as she goes from a group of doctors and advocates, but above all, she is learning the most from her own experiences while understanding what works best for her child on his life-long journey with CAH.

https://cahpulse.podbean.com/

If you are interested in sharing your story on our podcast, please contact: dina@caresfoundation.org.



CARES Foundation is celebrating 25 years in 2025!

Thank you for your continued support

Throughout the year, we will be highlighting important milestones & achievements made by our community in the past quarter-century.

In order to continue making a lasting difference in our community, we encourage anyone who is able, to commit \$25.00 each month in 2025 towards our mission. Help support & improve the lives of those living with congenital adrenal hyperplasia (CAH).







Donations can be made by clicking the link in this image, or scanning the QR Code.

Thank you for your consideration of our cause. For any questions, you may reach out to: contact@caresfoundation.org.









Improving Health...connecting people...saving lives

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...



An establishing gift is made and 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







Be a hero for the CAH community!



Help improve treatment and care for fellow CAH patients by participating in the CAHtalog™ Registry. CAHtalog is a comprehensive collection of clinical data from medical records from patients 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:



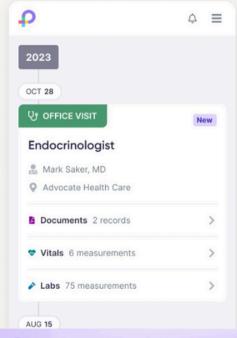
After signing up, sit back and relax

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





Crinetics Announces Positive Topline Results From Phase 2 TouCAHn Study of Atumelnant in Congenital Adrenal Hyperplasia (CAH)

Highlights From Phase 2 TouCAHn Study





Investigational atumelnant is a novel, once-daily oral candidate in development for the treatment of classic CAH



After 12 weeks of treatment with atumelnant, many participants saw a normalization of A4 levels and substantial reductions in 17-OHP (across dose groups)



Atumelnant was generally well tolerated in this study. The most common treatment-emergent adverse events included headache (7/28) and fatigue (5/28)



Phase 3 adult and Phase 2b/3 pediatric studies expected to begin in 2025. Learn more about the Phase 2 study by reading the full Crinetics press release: https://bit.ly/406s5K8

Thank You

Thank you to the extraordinary individuals living with CAH who helped make this study a success by telling us what they needed from a new therapy and participating in this clinical study.

ALKINDI SPRINKLE® (hydrocortisone) oral granules: Treatment specifically designed to provide accurate, easy-to-measure doses for newborns and children with adrenal insufficiency.



Ensure your child receives the correct dosage that their doctor prescribes.

Getting the right dose is crucial when treating children with adrenal insufficiency.

What happens if the dose isn't right?

The right amount of hydrocortisone is essential for keeping children with adrenal insufficiency healthy. Giving too much or too little can lead to issues, so it's important to follow the prescribed dose.

Overdosing

Taking too much hydrocortisone can lead to:

- Growth issues
- High blood pressure
- Weight gain

Underdosing

Not enough hydrocortisone can result in:

- Poor stress response
- Low blood pressure
- Weight loss

Crushing or splitting tablets, whether at home or through a pharmacy, can lead to dosing inaccuracy.

This can result in giving too much or too little medication because:

- Tablets may not be measured or split evenly
- Crushed pieces can vary in size

Accurate dosing is especially important for newborns and children with adrenal insufficiency. ALKINDI SPRINKLE helps ensure your child gets the correct dose every time.

Learn more about accurate dosing https://www.facebook.com/ALKINDISPRINKLE/

USE AND IMPORTANT SAFETY INFORMATION USF

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 <u>ALKINDISPRINKLE.com/patient</u> 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 <u>full Prescribing Information</u> for more information.

21925 W. Field Pkwy #235, Deer Park, IL 60010 | (847) 787-7361 © 2025 Eton Pharmaceuticals. All rights reserved. Eton and ALKINDI SPRINKLE are trademarks of Eton Pharmaceuticals. 1816-v1



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/</u> <u>cah-survey-cares</u> or contact Ingles Adams at <u>ingles@pinpointpatientrecruiting.com</u>.

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!









(Android App Store)



(Apple App Store)

JOIN RARE PATIENT VOICE

SHARE YOUR OPINION!

Patients (16+) & family caregivers professionally diagnosed with a condition, disease, or disability have the opportunity to share their opinions through surveys to improve medical products & services.

GET PAID!

Participants in our studies receive compensation at a rate of \$120 USD per hour.

HAVE AN IMPACT ON PATIENTS' LIVES!

We connect you with researchers developing products and services to benefit you and others with your condition.

Over the past 10 years,
Rare Patient Voice has paid
patients & caregivers over \$13 million.



#VIVISTRONG

May 3, 2025

2nd Annual lowa CAH Awareness 5K

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

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



Scan the QR code to register!

OR VISIT:

HTTPS://CARESFOUNDATION.ORG/IOWA-CAH-

AWARENESS-5K/







If you are interested in hosting a walk or 5k event in your area, please contact dina@caresfoundation.org for more information.

Mon. Tues. Wed. CARES EVENT CAIENDAY Thurs. Fri. Sat.

Make sure that you are staying up-to-date on everything happening in our community, by visiting the <u>Event Calendar!</u>

Click here to see the full CARES Foundation Event Calendar



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.

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."

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



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!

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: contact@caresfoundation.org

Please visit: https://caresfoundation.org/the-cares-shop/ 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

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



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 <u>MORE</u>, then <u>GROUPS</u>. (<u>If you are on a mobile device</u>: <u>ABOUT</u>, then <u>GROUPS</u>).

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

Thursday, February 13

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

Wednesday, February 26

Young Adults with CAH, 8:30PM(ET) via Zoom

Thursday, March 6

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

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

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>.



Applications are <u>Open!</u>Free Adrenal Summer Camp

The Painted Turtle is a free summer camp at Lake Hughes for kids 7 - 16 years old with medical conditions.

Join fellow CAH children and friends for Kidney Disease & Transplant and Adrenal Insufficiency Summer Session at The Painted Turtle from June 13 - 18!

Click <u>here</u> to email Ben so the CAH Clinic can complete and send medical clearance forms for your application!

You don't want to miss it!





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

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.

2025 LESSON DATES

JAN. 11	FEB. 14-17*
JAN. 12	FEB. 22
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

LEARN MORE

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.



This summer at Double H Ranch, hundreds of kids living with serious illnesses will have the chance to experience camp in a unique way - purposefully designed, fully adapted, and medically safe. Our team of trained staff and licensed medical professionals ensure a safe environment so your camper can focus on having fun. All programs are FREE of charge.



- » Archery
- » Arts & Crafts
- » Boating
- » Fishing
- » High Ropes Course
- » Horseback Riding
- » Swimming
- » Talent Show
- » And So Much More!









LOCATED IN:

LAKE LUZERNE, NEW YORK



CAMP DATES:

Session 3: June 8-13, 2025

BASIC CAMPER ELIGIBILITY

HOSPITAL PARTNER:

CARES Foundation

- Campers aged 6-16 years old, or 17-21 and have previously attended a Double H program for the Alumni Session.
- Diagnosis of CAH or other medically qualifying diagnoses (see doublehranch.org for complete list).
- Cognitive age of at least 6 years old.



Scan to visit doublehranch.org for details & application

Double H Ranch, located in New York's Adirondack park, provides specialized programs and year-round support for children and their families dealing with life-threatening illnesses. All programs are FREE of charge.

Founded by Charles R. Wood & Paul Newman

QUESTIONS? CONTACT:

Tara Bogucki, **Admissions Director** tbogucki@doublehranch.org 518-696-5676 x 222





FEBRUARY 27 **2025**



VICTORY JUNCTION 4500 ADAM'S WAY RANDLEMAN, NC 27317



Target audience

ANYONE INTERESTED CAN ATTEND, BUT THE CONFERENCE IS DESIGNED FOR CHILD LIFE PROFESSIONALS, NURSES, & SOCIAL WORKERS

conference betails

THE EVENT IS FREE TO ALL INDIVIDUALS AND INCLUDES: CONTINUING EDUCATION UNITS . LUNCH & SNACKS INTERACTIVE SESSIONS . INTENTIONAL NETWORKING **FUN CAMP EXPERIENCES**

e-register Her



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 MEDICAL I.D.

LUGGAGE TAGS

\$6.50

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







What is Adrenal Grisis Events
What is AI?

What are the adrenal glands? +

What is adrenal insufficiency +

(AI)?

What causes AI? +

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.

ADRENAL INSUFFICIENCY

WINDOW CLING

\$2,00

Window Cling to help EMS easily identify one's Adrenal Insufficiency ADRENAL INSUFFICIENCY
SEATBELT COVER

\$12,00

Cover to go over you/your loved one's seatbelt to help identify in case of emergency PREVENTING ADRENAL CRISIS EVENTS (PACE) APP

DOWNLOAD BELOW

Apple App Store

Google Play Store

VISIT: HTTPS://CARESFOUNDATION.ORG/THE-CARES-SHOP/



CAH PARTNER 2025

A special thank you to Neurocrine Biosciences, for partnering with CARES Foundation in 2025!

www.neurocrine.com

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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!