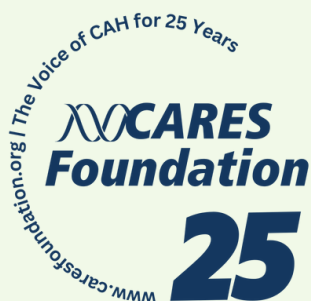


# MARCH 2025

*Learn about what's happening this month!*

In this edition, you can find the latest surrounding important research, community news, upcoming events & support group meetings, and more!

## CARES WEBSITE

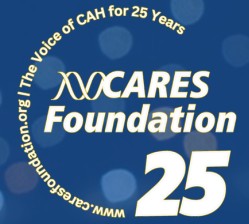


Follow us on social media for the most up-to-date news!



[www.caresfoundation.org](http://www.caresfoundation.org)

# 25TH ANNIVERSARY EVERYONE CARES GALA



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



Scan or click below to visit Gala Webpage

25th Anniversary Gala

## THIS YEAR'S HONOREES

Dr. Alejandro Diaz  
*Maria I. New Visionary Award*

Lesley Holroyd, RN  
*Pioneer Award*

Crinetics Pharmaceuticals  
*Corporate Partner Award*



## AUCTION ITEMS

If you have interest in donating an item/item(s) to our silent and/or live auction, please do not hesitate to reach out to [odaly@caresfoundation.org](mailto:odaly@caresfoundation.org) or please call our office at (866) 227-3737, toll-free.

If you have any questions about this year's event, please reach out to: [contact@caresfoundation.org](mailto:contact@caresfoundation.org)



## CAH Pulse | NEW EPISODE! Season 2 | Episode 5: Raelie "CAH Does Not Define THIS Ten Year Old!"



**WE NEED YOU!** Be a guest on **CAH Pulse!** Please contact: [dina@caresfoundation.org](mailto:dina@caresfoundation.org).

Is ten-year-old Raelie unphased by her CAH? Find out in this important episode of CAH Pulse where Stephanie and Dina speak with Amanda and her strong, brave and laid back 5th grade daughter, Raelie. This insightful mother-daughter duo gives us an up-close view through the window of their daily lives, where they are navigating and troubleshooting life with this rare condition. Amanda explains their family hardships, as well as their successes in managing her daughter's CAH which range from her unsurprising fears as a mom trying to keep Raelie safe, to her hopes that the struggle will become less and less as Raelie grows so that she can live life to its fullest like a typical kid should.

Amanda's unapologetic approach to parenting has helped Raelie become the responsible and informed kid that she is without allowing CAH to define her.

Dina also delivers hopeful news about the future progress of CAH treatments, and shares new information about the first officially approved CAH treatment for classic CAH in over 70 years!

**Scan the QR code or click below to listen to this episode & catch up on past episodes**

<https://cahpulse.podbean.com/>



# FIRST NEW TREATMENT FOR CLASSIC CAH IN OVER 70 YEARS!

## A New FDA-Approved Treatment for Classic Congenital Adrenal Hyperplasia (CAH)



CRENESSITY™ (crinecerfont) is a breakthrough therapy that enables people 4 years of age and older with classic CAH to lower androgen levels and reduce daily dose of steroids.

**CRENESSITY.com provides helpful resources to learn more.**

### Resources Available Now:

- Patient Brochure
- Caregiver Brochure
- Neurocrine Access Support Brochure

### Additional Resources Coming This Week:

- New Patient Videos Showing Real Experiences with CRENESSITY
- A Guide on Labs Relevant to CAH



For more information on CRENESSITY and to access the library of resources for patients and caregivers, please visit **CRENESSITY.com**



### 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](http://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](#).

# RARE DISEASE DAY

Thank you to all of those that shared their stories on Rare Disease Day (Feb. 28, 2025). We truly appreciate all of the support & advocacy efforts put forth by our community!

If you missed any stories or important resources, you can visit our website to learn more about CARES Foundation from Rare Disease Day!

- *Be Prepared in an Emergency Information & Links*
- *Stories & Videos from our community*
- *Visit Your Local Firehouse/EMS Station info*
- *Links to the CARES Shop for important items & resources*

Scan the QR code or visit below:

<https://caresfoundation.org/rare-disease-day-2025/>



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



TO [BE PREPARED FOR AN EMERGENCY](#), 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 TO 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 visits to local firehouse/EMS provider
- Our [Ask the Expert Program](#)

If you have any questions, you may reach out to:

[contact@caresfoundation.org](mailto: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](#)



# NEWLY DESIGNATED CENTER OF EXCELLENCE!

We are pleased to announce that **Nicklaus Children's Hospital/University of Miami Health System** has been designated as a comprehensive care center for CAH!



**Nicklaus  
Children's  
Hospital**



## \$25 in 2025

## CARES Foundation's 25th Anniversary

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).

Thank you for your continued support!



Donations can be made by [clicking on, or scanning the QR Code.](#)

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



# 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 principal 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](mailto:contact@caresfoundation.org) **Phone:** (908) 364-0272 **Toll Free:** (866) 227-3737



ALKINDI SPRINKLE® (hydrocortisone) oral granules: The first and only hydrocortisone treatment designed to help provide accurate and individualized dosing for newborns and children with adrenal insufficiency.<sup>1</sup>

**Please see Important Safety Information below.**

**Designed to help deliver accurate dosing for children with adrenal insufficiency.**

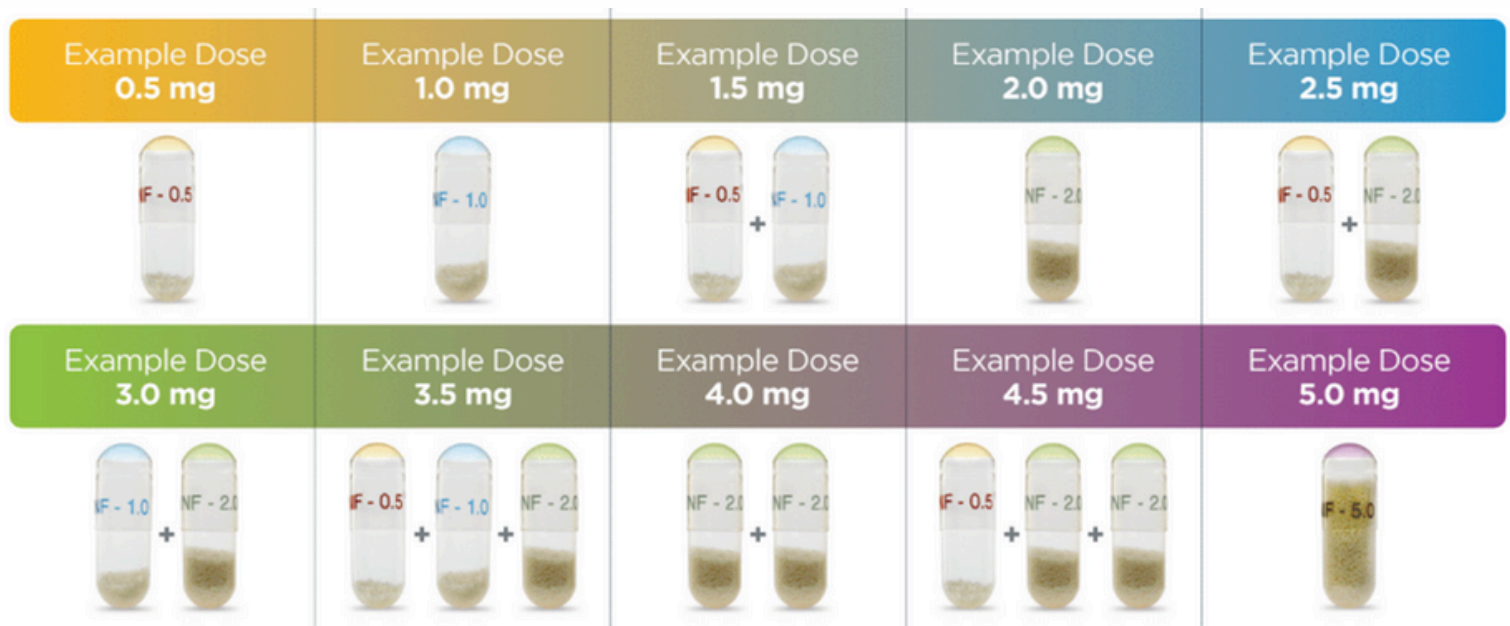
Accurate hydrocortisone dosing for children with adrenal insufficiency is possible with ALKINDI SPRINKLE\*. It's important to provide precise dosing tailored to the cortisol needs of patients, with the lowest, most effective dose.

ALKINDI SPRINKLE® is designed to help provide accurate dosing:

<ul style="list-style-type: none"> <li>The granules are available in 4 flexible dosage strengths: 0.5 mg, 1 mg, 2 mg, and 5 mg, and stored in easy-to-open, color-coded capsules for identification.</li> </ul>	<ul style="list-style-type: none"> <li>ALKINDI SPRINKLE can help individualize the specific cortisol needed for the lowest possible dose—no crushing, splitting, or compounding required.</li> </ul>
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\*When the entire dose is administered as directed.

Accuracy in every dose. Just sprinkle and go.



Capsules shown are not actual size.

Learn about the importance of accurate dosing at <https://www.facebook.com/ALKINDISPRINKLE/>

**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](https://www.alkindisprinkle.com/patient) for more information**

You are encouraged to report negative side effects of prescription drugs by contacting Eton Pharmaceuticals, Inc. at 1-855-224-0233 or the U.S. Food and Drug Administration (FDA) at [www.fda.gov/safety/medwatch](https://www.fda.gov/safety/medwatch) or call 1-800-FDA-1088.

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

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



21925 W. Field Pkwy #235, Deer Park, IL 60010 | (847) 787-7361

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1901-v1





Crinetics Pharmaceuticals is a clinical stage pharmaceutical company focused on the discovery, development, and commercialization of novel therapeutics for endocrine diseases and endocrine-related tumors. All of the company's drug candidates are orally delivered, small molecule new chemical entities resulting from in-house drug discovery efforts.

One important condition we are currently studying is congenital adrenal hyperplasia (CAH). We are developing a drug called CRN04894, an oral investigational medication that acts directly on the adrenal gland to block adrenocorticotropic hormone (ACTH) action and decrease steroid production. Study centers are enrolling participants for a Phase 2 clinical study, evaluating the safety and potential effects of CRN04894, an investigational once-daily oral drug for patients with CAH. This study will help us learn if CRN04894 is safe and effective in treating CAH. To find out more information about this study visit the study website:

[cares.TouCAHnstudy.com](https://cares.TouCAHnstudy.com)

By taking part in this study, you will help advance medical research. Because of volunteers like you, medical advances for CAH are possible.

Qualified participants must meet the following basic criteria:

- Are 18-75 years of age (16-75 in the US)
- Have been diagnosed with classic congenital adrenal hyperplasia (CAH) caused by 21-hydroxylase deficiency.
- Are on stable glucocorticoid replacement therapy for CAH (for example: hydrocortisone, prednisolone, prednisone, methylprednisolone)

Other eligibility criteria will apply. Qualified participants will receive the study drug, and study-related care and necessary travel expenses at no cost.

Visit: [cares.TouCAHnstudy.com](https://cares.TouCAHnstudy.com)



CRN04894-03 PAb sharing Text en-US, NP-CAH-000e-1 01/2024

# Warrior Bracelets | Little Words Project

CARES Foundation is teaming up with the Little Words Project to create "Warrior" bracelets for members of our community. CARES Foundation will receive a portion of the proceeds from the sale of each bracelet.



A "warrior" in CARES Foundation's community is someone that continues to battle to help improve their own life/the lives of those living with congenital adrenal hyperplasia (CAH).

The impact of your support resonates not only within our organization, but also in the broader community dedicated to enriching the lives of patients.

These bracelets will ONLY be available between April 1-June 30, 2025.

Look out for more information regarding these bracelets on CARES' social media & website

[www.caresfoundation.org](https://www.caresfoundation.org)



Preventing Adrenal Crisis Events

# PACE App

[Have you downloaded it yet?](#)

The Preventing Adrenal Crisis Events (PACE) app is available to patients, parents/caregivers, and medical professionals and is designed to provide readily accessible information and instructions for effectively managing AI (Adrenal Insufficiency). The app will include stress dosing and intramuscular injection techniques as well as other helpful tools.

**NOW AVAILABLE IN SPANISH!**

eTon  
PHARMACEUTICALS

NEUROCRINE  
BIOSCIENCES

Walmart



[\(Android App Store\)](#)



[\(Apple App Store\)](#)

## 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.**



RarePatientVoice.com





## 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?**

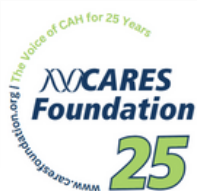
**¡NO TE OLVIDES de nuestro programa!**

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 PATIENT EDUCATION CONFERENCE**

**Held at Riley Hospital for Children in Indianapolis, Indiana**

If you are interested in attending this year's conference, and would like to be notified about when registration opens, please fill out the brief questionnaire linked 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!"



**#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**



**Scan the QR code to register!**

**OR VISIT:**

**[HTTPS://CARESFOUNDATION.ORG/IOWA-CAH-AWARENESS-5K/](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](mailto:dina@caresfoundation.org) for more information.**

Mon.	Tues.	Wed.	<b>CARES Event Calendar</b>	Thurs.	Fri.	Sat.
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**Make sure that you are staying up-to-date on everything happening in our community, by visiting the [Event Calendar!](#)**

**[Click here to see the full CARES Foundation Event Calendar](#)**



**SAVE THE DATE**

**WE ARE BACK IN PENNSYLVANIA!**

**May 31, 2025**

**Annual Pennsylvania  
CAH Awareness Walk**

**Zelienople, PA  
Zelienople Community Park**

**PLEASE LOOK OUT FOR MORE INFORMATION SURROUNDING THIS EVENT AS IT  
BECOMES AVAILABLE THROUGH CARES' SOCIAL MEDIA & WEBSITE**

**NEW EVENT!**



co-hosted with:



**Seattle Children's**  
HOSPITAL · RESEARCH · FOUNDATION

**June 7, 2025**

**1st Annual Washington  
CAH Awareness Family Fun Day**

**Woodland Park Zoo, Seattle, WA 98103**

CARES Foundation & Seattle Children's invite you to join us for the first ever **CAH Awareness Family Fun Day!** Spend your day at the Woodland Park Zoo, participate in interactive injection training sessions, enjoy arts & crafts with Camp Korey, and make sure to stay for the Pizza Party!

You can learn more & sign-up for this event by scanning the QR code above, or by visiting: <https://caresfoundation.org/cares-washington-family-fun-day/>.



# VIRTUAL COMMUNITY FUNDRAISERS



## Support CARES with Panda Express!

Place an online Pickup or Delivery order with Panda Express on March 7, 2025 and 28% of your sale will be donated back to CARES Foundation.

### WHEN

Friday, March 7, 2025  
Place your order for pickup or delivery on Thursday, March 7!

### WHERE

Available at Panda Express locations nationwide  
[www.pandaexpress.com](http://www.pandaexpress.com)

[PLACE YOUR ORDER HERE](#)

### HOW

Online orders only  
Apply code **9002400** in the Fundraiser Code box during online checkout at [www.pandaexpress.com](http://www.pandaexpress.com) or via App



## KRISPY KREME DONUTS TO SUPPORT CARES Foundation

From now through May 22, 2025, 50% of your order will be donated back to CARES Foundation when you purchase via our fundraising sales page!

You can make your purchase to support CARES Foundation by **SCANNING THE QR CODE** or [BY VISITING THE DIRECT LINK HERE](#).



#### 1. Order

Place an order for your dozen by using the form online



#### 2. Support

50% of each Original Glazed Dozen you order is donated back to the organization.



#### 3. Enjoy

Visit your local Krispy Kreme to pick up your Original Glazed Dozens!



# CARES Foundation's Support Groups via Zoom

## Thursday, March 6

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

## Thursday, March 13

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

## Wednesday, March 26

Spanish Speaking CAH Patients & Parents, 8:30PM(ET) via Zoom

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

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](mailto: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 you are 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](mailto:john@caresfoundation.org).



# The Voices Study | Learn more

The Voices Study is developing a new self-advocacy tool (with input from young people with CAH and other variations) to help them communicate their needs and healthcare preferences. **We invite young people with CAH to help finalize the questions in the new self-advocacy tool and/or provide feedback about it.**

Young people must be between the ages of 11-21 and must be able to understand basic sentences and questions in English to participate. Young people and families who qualify for the study and who participate will get paid for their time, earning up to \$230 depending on which parts of the project they are asked to participate in.

**Interested families** should reach out to the research coordinator, Alejandro Todd, at [datodd@childrensnational.org](mailto:datodd@childrensnational.org) or 301-765-5573 to see if they qualify. Alternatively, young people or their parents/guardians can fill out an interest form here: <https://redcap.link/VOICES>

The team is very neurodiversity affirming and supportive, and we welcome families from across the United States (*all appointments are conducted through Zoom*). We also thank the young people who have participated in previous phases of the study for such helpful feedback, and we look forward to working with them again.

[DATODD@CHILDRENSNATIONAL.ORG](mailto:DATODD@CHILDRENSNATIONAL.ORG)

[CLICK TO ACCESS INTEREST FORM](#)



## Applications are Open! 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 [here](#) to email Ben so the CAH Clinic can complete and send medical clearance forms for your application!

**You don't want to miss it!** 🐢🐢



# DOUBLE H RANCH Summer Camp WHERE KIDS CAN BE KIDS

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.**

## Camper activities

- » 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

### HOSPITAL PARTNER:

CARES Foundation

#### BASIC CAMPER ELIGIBILITY

- 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 [doublehbranch.org](http://doublehbranch.org) for complete list).
- Cognitive age of at least 6 years old.



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@doublehbranch.org  
518-696-5676 x 222

Scan to visit  
[doublehbranch.org](http://doublehbranch.org)  
for details & application



▶ **APPLY TODAY!** [VICTORYJUNCTION.ORG/CAMPERZONE-SUMMERCAMP/](https://victoryjunction.org/camperzone-summercamp/)



## Summer at Victory Junction

- JUNE **8-12** ▶ **BLEEDING/GI**  
SUNDAY-THURSDAY
- JUNE **15-19** ▶ **CEREBRAL PALSY**  
SUNDAY-THURSDAY
- JUNE **22-26** ▶ **SICKLE CELL/ONCOLOGY**  
SUNDAY-THURSDAY
- JUNE - JULY **29-2** ▶ **NEURO/GENETICS**  
SUNDAY-WEDNESDAY
- JULY **6-10** ▶ **PHYSICAL DISABILITIES/CRANIOFACIAL/  
SPINA BIFIDA**  
SUNDAY-THURSDAY
- JULY **13-17** ▶ **HEART/LUNG/KIDNEY**  
SUNDAY-THURSDAY
- JULY **20-24** ▶ **RHEUMATOLOGY/IMMUNOLOGY**  
SUNDAY-THURSDAY
- JULY **27-31** ▶ **SIBLINGS WEEK**  
SUNDAY-THURSDAY
- AUGUST **3-7** ▶ **PARTNERSHIP WITH  
AMERICAN DIABETES ASSOCIATION**  
SUNDAY-THURSDAY



## CAMPER Admissions

[camperadmissions@victoryjunction.org](mailto:camperadmissions@victoryjunction.org) | 336.498.9055

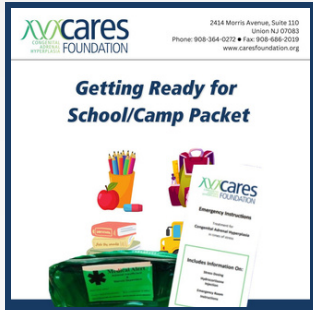
We believe that every child, no matter their illness or diagnosis, deserves to just be a kid. That's why we provide medically-safe camp experiences filled with discovery, friendship and a lot of laughter - always at no cost to families.

Learn more about the illnesses and medical conditions we serve:

[victoryjunction.org](https://victoryjunction.org)

# 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 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



**MEDICAL I.D. LUGGAGE TAGS**

**\$6.50**

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



**MEDICAL I.D. SHOE TAGS**

**\$5.50**

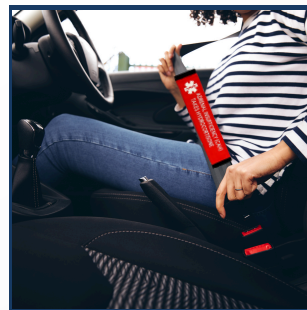
Small oval-shaped medical I.D. tags for the laces of your shoes, bags with strings, and other items.



**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://CARESFUNDATION.ORG/THE-CARES-SHOP/](https://caresfoundation.org/the-cares-shop/)**



# **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.

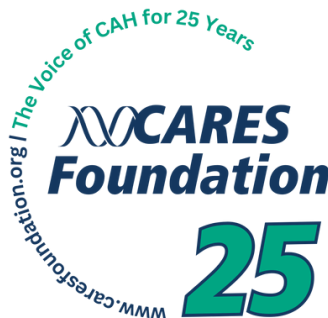
If you are having trouble accessing your account, or have any questions surrounding your profile, please do not hesitate to reach out to: [contact@caresfoundation.org](mailto:contact@caresfoundation.org).

**[LOGIN TO YOUR ACCOUNT HERE](#)**

## **CAH PARTNER 2025**

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

[www.neurocrine.com](http://www.neurocrine.com)



2414 Morris Avenue, Suite 110, Union NJ 07083

(908) 362-0272 Toll Free (866) 227-3737

**[MAKE A DONATION](#)**

**[JOIN OUR COMMUNITY](#)**

Gold  
Transparency  
2025

**Candid.**

If you have any questions about this update or the contents inside, do not hesitate to reach out to [john@caresfoundation.org](mailto:john@caresfoundation.org) with more information.

Thank you!

