

# MAY 2025

## Learn about what's happening this month!

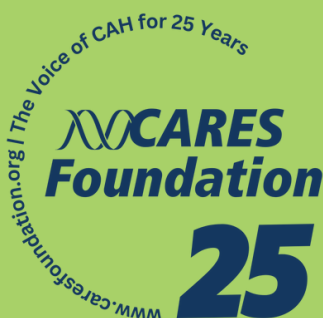
In this edition, you can find the latest surrounding important research, community news, upcoming events, support group meetings, and more!

CARES Foundation would also like to thank all those who had attended & supported this year's Gala in New York!



### In this month's update:

- Voice of the Patient Report
- Community Research
- Conference Save the Dates
- Upcoming Awareness Events
- Fundraising Opportunities



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



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



(908) 364-0272



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



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



Classic Congenital Adrenal Hyperplasia (CAH)

# Voice of the Patient Report

Externally-Led Patient Focused Drug Development Meeting  
(EL-PFDD)

Thank you to all who participated  
in our Externally-Led Patient  
Focused Drug Development  
(EL-PFDD) meeting with the  
FDA this past October!

Your participation gave voice to  
the CAH journey.



The full report can be viewed by using the QR Code below, or by visiting:  
[www.caresfoundation.org](http://www.caresfoundation.org)



Public meeting: October 1, 2024

Report published: April 17, 2025

Hosted by: CARES Foundation





Thank you to everyone that supported the...

25th Anniversary

# Everyone CARES Gala



and congratulations once again to our honorees!

*Maria T. New Visionary Award*

**Dr. Alejandro Diaz, Nicklaus Children's Hospital**

*Pioneer Award*

**Lesley Holroyd, RN**

*Corporate Partner Award*

**Crinetics Pharmaceuticals**



# CARES Foundation's Post Gala Auction

**BIDDING NOW CLOSES ON MON. MAY 5, 2025 AT 11:59PM(ET)**

**THIS AUCTION IS OPEN TO \*US RESIDENTS ONLY\***

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**Bid on items in the following categories:**

- One of a Kind
- Travel/Vacations
- Interactive Experiences
- Fashion
- Health/Wellness
- Sports

**Place your bids by scanning the QR Code or by visiting:**

<https://caresfoundation.betterworld.org/auctions/cares-pop-up-auction-2025>

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## **Logging into an existing/creating an account:**

If you attended our Gala in 2024 and/or 2025, you may already have an account to bid with. If so, we encourage you to sign-in with that information. If this is your first time bidding, an account can be made using the links below.

**Login to an Existing/Create Your Account here:**

[betterworld.org/sign-up/individual/](https://betterworld.org/sign-up/individual/)

**If you have any questions about this auction, please email:**

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

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**Place my bids:**

<https://caresfoundation.betterworld.org/auctions/cares-pop-up-auction-2025>



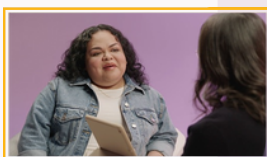
# CRENESSITY works directly to lower ACTH and androgens in people with classic CAH

Explore an interactive feature to learn how CAH affects the body and how CRENESSITY works.

Explore now at [CRENESSITY.com](https://www.crenessity.com)

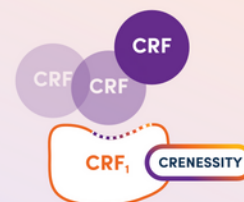
## Coming soon:

Keep an eye out for **new videos** featuring Lauren, a person living with classic CAH, and Dr. Lin, an endocrinologist, as they discuss how CAH affects the body and CRENESSITY's innovative approach to CAH management.



ACTH=adrenocorticotropic hormone; CRF=corticotropin-releasing factor; CRF<sub>1</sub>=corticotropin-releasing factor type 1.

With CRENESSITY, the binding of a hormone called CRF to CRF<sub>1</sub> in the **pituitary gland** is interrupted.



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## 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](https://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](#).

## This program is designed to help you manage treatment with ALKINDI SPRINKLE—and you're automatically enrolled!

Once prescribed ALKINDI SPRINKLE® (hydrocortisone) oral granules, you have automatic enrollment in Eton Cares, including access to professionals fully trained on adrenal insufficiency and ALKINDI SPRINKLE.



### Insurance Specialists

help you understand your benefits and help ensure prior authorization and insurance coverage



### Pharmacists

provide 24/7 support by phone, monthly refill reminders, and shipment alerts



### Nurse Ambassadors

provide regular check-ins and support, answering questions about your child's health and medication

### \$0 copay\*

### Covered by Medicaid in all 50 states

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



### Have questions?

Contact Anovo® Specialty Pharmacy at

**1-833-343-2500**

(available Monday through Friday, 8AM–5 PM CT)

### 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.

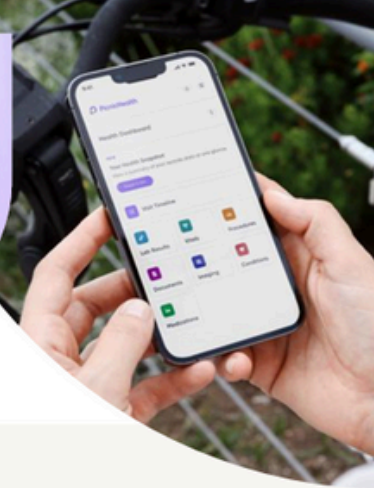
**Vaccination:** Administration of live vaccines may be acceptable in ALKINDI SPRINKLE-treated pediatric patients with adrenocortical insufficiency who receive replacement corticosteroids.

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.

# 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:



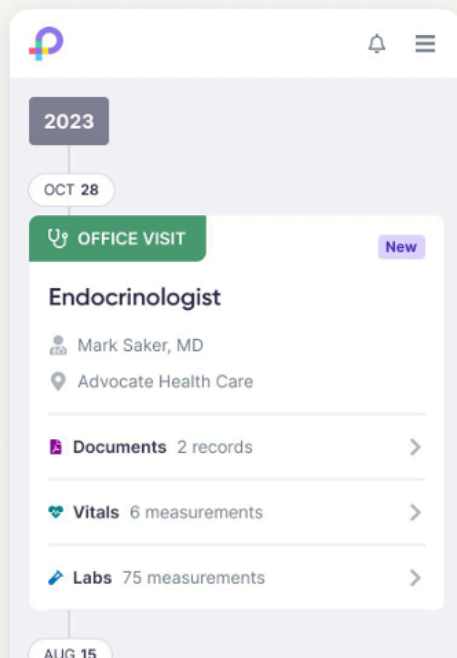
## After signing up, sit back and relax

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.





# CONNECT

## with Crinetics Patient Advocacy

Patients are at the heart of everything we do at Crinetics.

We deeply value our partnerships with advocacy groups and members of the patient community.

Our advocacy team is dedicated to listening, learning, and integrating patient insights to enhance every step of Crinetics' drug discovery and development journey.



**SCAN** to sign-up with Crinetics Patient Advocacy and stay connected



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.

NP-PAT-0040 3/2025





## DO YOU WANT TO BE A GUEST ON CAH PULSE?

Take advantage of this incredible opportunity to make a difference

Please reach out to [dina@caresfoundation.org](mailto:dina@caresfoundation.org) if you are interested in sharing your CAH story on our podcast. We truly appreciate all those who have joined us so far!

### LATEST EPISODE: Season 2 | Episode 7: Tim

#### *"Go Live Your Life as Normally as Possible" But...Nothing About CAH is Normal*



In the mid 1960's, Tim was diagnosed with CAH just weeks after he was born. His CAH simply didn't set off many alarms with his medical team, nor his parents. As a result, he seemed to breeze through time with little challenges and even went 50 years without a single adrenal crisis! However, Tim had learned some difficult news at the age of 30, thanks to the long term effects of prescribed prednisone, when a bone scan showed that he had severe osteoporosis. At 30 years old, Tim had the bone density of a woman in her 80's. He was finally feeling the effects of CAH. Up to that point his doctors told him to just "go live your life as normally as possible" but nothing is "normal" about CAH.

Join Stephanie and Dina as they speak to Tim, a dad to identical twin daughters and a champion of CARES Foundation, about his sudden change in medication, the physical challenges he experienced as a result, as well as an uncharacteristic and overwhelming feeling of sadness. Tim's roller coaster journey gives us the main facets and challenges of CAH but will leave you with much hope for the future.

You can find this episode, and past episodes of CAH Pulse, by scanning the QR Code, or visiting below:

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

## \$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.



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).





# 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), including affected individuals, caregivers, and medical professionals.

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

*Honor the warrior in your life with this impactful symbol.*

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

To purchase your warrior bracelets, please visit:

<https://www.littlewordsproject.com/products/giveback-warrior-4>



## 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 LINK HERE.



### 1. Order

Place an order for your dozen(s) 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 dozen(s)!





# 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](#)

## 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](#)

## **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!"

## **SAVE THE DATE: September 22, 2025**

## **CARES FOUNDATION'S PATIENT ADVISORY SUMMIT**

CARES will be seeking participants for its 2025 Patient Advisory Summit, concurrent with the 2025 CAH Patient Education Conference in Indianapolis, Indiana. The purpose of the advisory board is for representatives from the pharmaceutical industry to listen to patient/caregiver insights on living with and managing CAH.

*Participants will be compensated for their time.*

If you are interested in participating, please reach out to [dina@caresfoundation.org](mailto:dina@caresfoundation.org).

Please stay up-to-date with CARES Foundation's website & social media pages for more information on when registration will open for these events ([www.caresfoundation.org](http://www.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.

**Cash**

## 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





## 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.

*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)*

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](#)

**#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://CARESFUNDATION.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.**



**WE ARE BACK IN PENNSYLVANIA!**

**May 31, 2025**

# **Annual Pennsylvania CAH Awareness Walk**

**Zelienople, PA**

**Zelienople Community Park**

**CHECK-IN: 9:00AM | EVENT STARTS: 10:00AM**



**Scan the QR code to register!**

**OR VISIT:**

**[HTTPS://CARESFUNDATION.ORG/ANNUAL-PENNSYLVANIA-CAH-AWARENESS-WALK/](https://caresfoundation.org/annual-pennsylvania-cah-awareness-walk/)**

**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**

We invite you to join us for the first ever **CAH Awareness Family Fun Day!** Participate in interactive injection training sessions, enjoy arts & crafts with Camp Korey.

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/>.





# Inaugural SWING FOR CAH Golf Tournament



June 23, 2025 | Lunch begins at 12:00PM, Shotgun Start at 1:00PM  
Johnson City Country Club | Johnson City, Tennessee

Consider taking a “Swing for CAH” while supporting **CARES Foundation**! Our family is incredibly excited to partner with CARES for the **Inaugural Swing for CAH Golf Tournament** taking place **June 23, 2025 in Johnson City, TN**.

We envisioned organizing an event like this ever since shortly after our daughter was born, and we couldn't be more thrilled for the opportunity! We look forward to connecting with others in our community as we raise awareness and enjoy a fun-filled afternoon together on the course.

Our hope is through fundraising efforts, that we are able to make an impact in the CAH world as advancements are made toward better treatments and resources for individuals living with congenital adrenal hyperplasia.

**We hope you will consider joining us this summer- We would love to see you there!**

Calley, Nick & Lakelynn



## Registration

Register your team and enjoy 9-holes of golf in an effort to raise awareness for and support those living with congenital adrenal hyperplasia (CAH)! Proceeds to benefit: **CARES Foundation**

Tournament guests will have the opportunity to win big in the putting contest, have a chance at 9-holes of event prizes on the course and a chance to win special giveaways by local businesses and ARCCOS Golf.

You may also support the **Inaugural Swing for CAH** by attending as a lunch guest, sponsoring the event, or by making a donation to CARES Foundation.



If you are interested in learning more/attending this event, please visit:  
<https://caresfoundation.org/swing-for-cah/>  
or scan the QR Code in this flyer.

For any questions, you may reach out to: [contact@caresfoundation.org](mailto:contact@caresfoundation.org)

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



**SAVE THE DATE**

**October 11, 2025**

## **5th Annual Ohio CAH Awareness Walk**

**Mill Stream Park  
Valley City, OH**

**CHECK-IN: 9:30AM | EVENT STARTS: 10:00AM**

**PLEASE STAY UP-TO-DATE WITH CARES FOUNDATION'S  
WEBSITE & SOCIAL MEDIA FOR ALL UPDATES ON REGISTRATION**

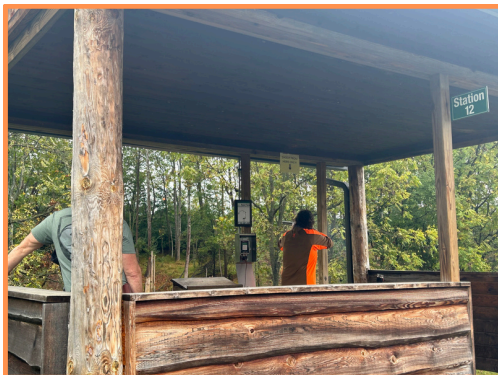
[WWW.CARESFOUNDATION.ORG](http://WWW.CARESFOUNDATION.ORG)

**SAVE THE DATE**

**10TH ANNUAL**

# **CLAY SHOOT FOR CARES**

**THURSDAY, OCTOBER 9, 2025  
LEHIGH VALLEY SPORTING CLAYS**



# CARES Foundation's Support Groups via Zoom

## Thursday, May 8

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

## Tuesday, May 13

CAH Women, 8:30PM(ET) via Zoom

## Wednesday, May 21

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](mailto:support@caresfoundation.org).

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

## JOINING THE CARES COMMUNITY

We encourage patients, family members, relatives, medical professionals, and others who are impacted by CAH to join our community. This account is completely free to create, and the best way to stay up-to-date on all important information, news, research, events, and more within the CARES Community!

[JOIN THE CARES COMMUNITY](#)

## PLEASE UPDATE YOUR ACCOUNT!

Without the proper fields completed, **you may be susceptible to missing out on important information and events!** Please click the link below to login to your account with CARES to edit any incomplete fields in your profile.

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

[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 [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).



## **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!** 🐢🐢

**Lake Hughes, CA**

**LEARN MORE HERE**



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



Scan to visit  
[doublehbranch.org](https://doublehbranch.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@doublehbranch.org](mailto:tbogucki@doublehbranch.org)  
518-696-5676 x 222




Randolph County, NC



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



## summer at Victory Junction

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

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

View our full catalog by visiting: <https://caresfoundation.org/the-cares-shop/>

## NEW ITEMS



### CAH PULSE COFFEE MUG

**\$8.00**

New CARES Foundation coffee mug (17oz.) with CARES and CAH Pulse Podcast Logos, CARES Website, and Phone.

Adult

CAH & AI Awareness [caresfoundation.org](https://caresfoundation.org)

Youth

CAH & AI Awareness [caresfoundation.org](https://caresfoundation.org)

### CAH & AI AWARENESS WRISTBANDS

**ADULT: \$1.00**

**YOUTH: \$1.00**

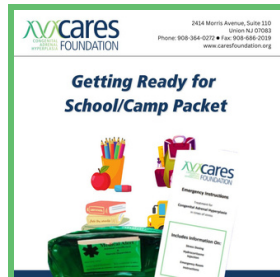
Silicone CAH & AI Awareness Wristbands. Separate adult & youth sizes are available.



### ADRENAL INSUFFICIENCY CAR SEAT STRAP

**\$12.00**

Velcro pullover strap to go over seatbelts to identify adrenal insufficiency in an emergency



### 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**

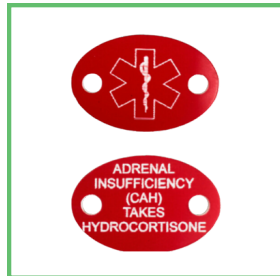
Includes 3 semi-translucent kits, and emergency instructions brochure & checklist



### MEDICAL I.D. LUGGAGE TAGS

**\$6.50**

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



### CAH/AI SHOE TAGS

**\$5.50**

Small oval-shaped CAH/AI medical ID tag that can be threaded through laces, drawstring bags, etc.



### FRESH OUT OF CORTISOL T-SHIRT

**MULTIPLE SIZES**

CARES Foundation Fresh out of Cortisol T-Shirt (Available in Men's/Women's/Youth)



### ADRENAL INSUFFICIENCY WINDOW CLING

**\$2.00**

Window sticker/cling to quickly identify adrenal insufficiency in the event of a crisis



## 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) 364-0272 Toll Free (866) 227-3737

[MAKE A DONATION](#)

[JOIN OUR COMMUNITY](#)

Gold  
Transparency  
2025

**Candid.**

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

Thank you!

