



# May 2024

In this update, you will find important information about research, education, events, new developments in the community, and more!

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Click the icons below to follow us on social media for the most up-to-date news!





**Tuesday, October 1, 2024**

# **Patient-Focused Drug Development Meeting**

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## **What is Patient-Focused Drug Development?**

Patient-Focused Drug Development (PFDD) is a systematic approach to help ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.

## **Audience**

The key participants in PFDD meetings are patients, patient representatives, patient advocates, caregivers, loved ones, and anyone with a lived experience with the disease or condition. While patients and caregivers share their perspectives, key stakeholders are in listening mode as part of the audience. These stakeholders may include:

- FDA and other regulatory/federal agencies
- Medical product developers
- Academic researchers
- Clinicians and healthcare professionals

## **How can I participate?**

To learn more about how you can participate in this meeting, please contact [dina@caresfoundation.org](mailto:dina@caresfoundation.org).

***This meeting may be the only opportunity for the CAH community to share their journeys with the FDA!***

For more information please visit <https://caresfoundation.org/pfdd-planning/>.

## September 20, 2024

# 2024 Patient Advisory Summit

## New Brunswick, NJ

CARES is seeking participants for an advisory board to be held concurrent with the 2024 CAH Patient Education Conference in New Brunswick, NJ. 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. This group is eager to learn more about CAH from this community to inform their product development activities. All pharmaceutical companies involved, have CAH treatments/therapies in development.

### Specifically, we are looking for participants who meet the following criteria:

Parents/Caregivers of age groups; Adults; Confirmed diagnosis of Classic CAH/caretaker for an individual with Classic CAH (patient can be younger than 18); Not currently participating in a CAH clinical trial; Must physically attend all days of the CAH Patient Journey Advisory Summit and Patient Education Conference; U.S. resident; Willing to share experience of living with Classic CAH/caring for someone living with Classic CAH; A current member of the CARES community (free to join: [www.caresfoundation.org/join-the-cares-community](http://www.caresfoundation.org/join-the-cares-community))

If you are interested in participating in this event, please contact [dina@caresfoundation.org](mailto:dina@caresfoundation.org).

## September 21 & 22, 2024

# 2024 Patient Education Conference

## Robert Wood Johnson University Hospital, New Brunswick, NJ



Mark your calendars for the 2024 Patient Education Conference presented by CARES Foundation & Rutgers Robert Wood Johnson Medical School/Rutgers Child Health Institute and take advantage of this incredible opportunity to connect with Medical Professionals, Industry Professionals, and other CAH Families.

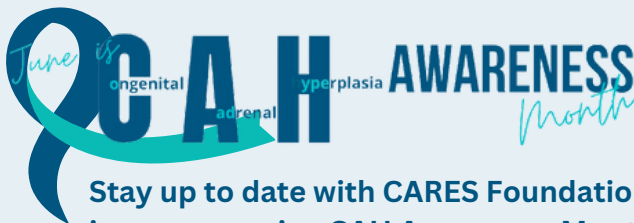
### Interested in learning more about specific topics?

Email [odaly@caresfoundation.org](mailto:odaly@caresfoundation.org) to let us know what you would like to see covered at this year's conference!

### Can I be notified when registration opens?

Email [john@caresfoundation.org](mailto:john@caresfoundation.org) to be added to our mailing list for the 2024 Patient Education Conference.

**LIMITED SCHOLARSHIPS AVAILABLE**



Stay up to date with CARES Foundation's website to learn more about how you can take part in our upcoming CAH Awareness Month Campaign!

[What's Happening Now](#)

## VISIT US AT ENDO 2024!

Boston, Massachusetts

June 1-4



**Thank you to all who attended  
this year's Everyone CARES Gala!**

**We look forward to seeing you again at next  
year's event, and hope for an even bigger  
turnout for the CAH Community!**



**[Click here to view our full gallery](#)**

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.

Spanish version now available

Sponsored by:



(Android App Store Only)



(Apple App Store Only)

## CAH Pulse Check out our latest episode!



### Episode 6: David & Brianne

The Hospital Refused to Recognize my Daughter as a Girl



Join Stephanie & Dina, as David and Brianne open up about their harrowing journey from their daughter's adrenal insufficiency to her atypical genitalia. They explain the hardships of giving birth with COVID-19 protocols, including social distancing and the miscommunication it had caused. They also lament about the hospital staff's position of not recognizing their daughter as a girl with the recommendation that they wait to name their baby.

This episode, as well as all of our episodes for the CAH Pulse Podcast are available on all platforms! Please visit <https://cahpulse.podbean.com/>.

If you would like to have your story featured on a future episode, please reach out to [dina@caresfoundation.org](mailto:dina@caresfoundation.org).



# CARES Foundation Endowment Fund

**Leave a meaningful gift that will have an enduring impact on the CAH community!**

We have created an endowment fund account at the Community Foundation of New Jersey to ensure the longevity of our organization. Please consider giving to it.

A bequest can be arranged in a variety of ways. It can take the form of cash, property, or a part of your estate's remaining value. Including the CARES Foundation Congenital Adrenal Hyperplasia Endowment Fund into your Will could be a beneficial component of your plans, lowering your taxable estate while achieving your philanthropic objectives.

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

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

## Ways to Contribute

- Name us in your Will or estate
- Real Estate
- Shares of appreciated stock
- IRA RMDs
- Cash
- Interest or Shares of Operating Business

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



Phone: 973.267.5533 Toll-Free: 800.659.5533 Fax: 973.267.2903

**Thank you for considering CARES Foundation!**



# Make your voice heard through the CAHtalog Registry!

CAHtalog is a community-driven research opportunity focused on classic Congenital Adrenal Hyperplasia (CAH). Our goal is to enhance our understanding of daily life with CAH, as well as identify gaps in care and treatment. By participating and sharing your unique patient journey through sharing medical records without any personal details (de-identified) and taking optional paid surveys, you can play a crucial role in helping improve the lives of the CAH community. We take privacy seriously.

[Learn More](#)

**Study Eligibility:** The CAHtalog registry is open to adults and caregivers on behalf of their children living with classic CAH and who receive medical care in the US. Caregivers can sign up on behalf of their children.

## What Is The CAHtalog Registry?

CARES Foundation, Neurocrine Biosciences and PicnicHealth have partnered to establish the CAHtalog™ registry. CAHtalog is a patient registry, or collection of clinical patient data, for patients living with classic CAH. Its mission is to advance CAH clinical research and in turn improve the quality of life for those living with classic CAH. Neurocrine and CARES Foundation are committed to sharing the de-identified data from CAHtalog with qualified researchers because it's in the patient community's best interest to advance CAH research as quickly as possible across the broader research community.



"The more CAH patients that register, the more data will be available for research. CAH has come a long way from my birth and that is all due to research and patients being willing to share their CAH journey."

**Lesley**  
CAHtalog Registry Participant

## How It Works

### STEP 1

#### Tell Us About Your Care.

Just answer a few questions about yourself and the names of your primary care and endocrine doctors. With your consent, PicnicHealth will do all the hard work of collecting medical records from your clinicians on your behalf—including paper-based records, imaging, and doctors' notes.



### STEP 2

#### Your Records At Your Fingertips.

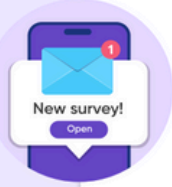
PicnicHealth will organize and digitize all of your records from all healthcare systems you've visited in the last 5+ years in one secure, easy-to-use platform at no cost. The PicnicHealth team will continue to update your medical records for you on a regular basis. **You can share your records securely** with your trusted loved ones or other healthcare providers in real-time. This may especially help if you're facing a medical emergency in an out-of-area hospital that doesn't already have access to your medical records.



### STEP 3

#### Earn Up To \$150 A Year Completing Short Surveys At Home

When you join the registry, you will be invited to complete paid health and well-being surveys from your PicnicHealth account. These **optional** surveys help researchers understand your daily experiences and capture insights that may not be available in your medical records.



### STEP 4

#### Help Researchers Further Their Understanding Of Classic CAH

We employ our proprietary technology to extract only the information valuable to researchers and replace personally identifiable information with randomized ID numbers. Your data is then assigned a unique code and combined with others to create a comprehensive data report, accessible to CAHtalog researchers via a secure portal.





**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)

CRN04894-03 PAG Sharing Text en-US, NP-CAH-0006-1 01/2024



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)



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

**Please see Important Safety Information below.**

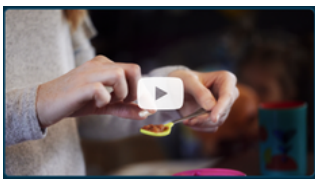
Many parents and caregivers know the struggle of giving their child medicine, especially when faced with the added challenge of splitting, crushing, or compounding the medication.

ALKINDI SPRINKLE hydrocortisone oral granules take a new approach, coming in a granular form to be sprinkled onto a small amount of food, or directly into your child's mouth.

While this sprinkle method might seem like a win for easier administration, there's a potential hurdle: **unfamiliarity**.

**ALKINDI SPRINKLE has a taste and texture could be completely new and unexpected for a child.** Here's what parents or caregivers might encounter:

**Texture:** Sprinkle medications may have a gritty or sandy texture that's different from the smooth textures of common children's foods. This could be off-putting to a child used to the feel of yogurt or applesauce.



So, while the sprinkle format is a creative way for easier dosing and potentially more enjoyable medicine time, it's important to consider the taste and texture challenges.

After giving ALKINDI SPRINKLE on a small amount of food or directly into your child's mouth, follow with a sip of fluids, such as water, milk, breast milk, or formula right away to ensure all granules are swallowed.

<https://www.alkindisprinkle.com/resources/>



**Insurance Specialists**

Ensure you understand your benefits and help your doctor's office verify and obtain prior authorization and insurance coverage.



**Pharmacists**

Provide 24/7 support by phone, monthly worry-free refill reminders, and shipment alerts.



**Nurse Ambassadors**

Provide regular check-ins, answer questions about your child's health and medication, and support you through treatment.

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

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

**1-833-343-2500**

**Available Monday through Friday, 8 AM-5 PM CT**

**See how Eton Cares can help families like yours**

<https://www.alkindisprinkle.com/support/>

\*Restrictions, limitations, and/or eligibility requirements apply.

\*Anovo will work with the doctor to obtain insurance coverage. If insurance is denied, the patient may apply to the Patient Assistance Program.

\*For newborns awaiting hospital discharge, medication may be delivered in as soon as 24 hours. Typical delivery is 3 to 7 days.



**USE**

ALKINDI SPRINKLE is a prescription medicine used in children from birth to less than 17 years old as replacement therapy when the adrenal gland is not making enough cortisol.

**IMPORTANT SAFETY INFORMATION**

**Always give ALKINDI SPRINKLE exactly as your doctor has directed.**

**Do not take ALKINDI SPRINKLE if you are allergic to hydrocortisone or any of its other ingredients.**

**Adrenal Crisis:** giving too low a dose or stopping medication can cause low levels of cortisol, which can result in serious illness or death. Treatment with intravenous hydrocortisone should be started immediately. When switching from another type of hydrocortisone to ALKINDI SPRINKLE, watch your child closely for any changes. If your child doesn't get the entire dose of ALKINDI SPRINKLE because of vomiting or spitting some granules out, contact your doctor to see if another dose is needed.

**Infections:** all infections should be treated seriously, and stress dosing of hydrocortisone should be started early. Taking ALKINDI SPRINKLE should not stop your child from being vaccinated but let your healthcare provider know prior to vaccination.

**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.

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 [Prescribing Information](#) for more information.

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**eTon**  
PHARMACEUTICALS



Neurocrine is proud to support the  
**16th Annual  
Everyone CARES Gala**  
and the  
**CAH patient community**

 **NEUROCRINE<sup>®</sup>**  
BIOSCIENCES

# UPCOMING SUPPORT GROUPS

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

**May 9**

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

**May 14**

CAH Women, 8:30PM(ET)

**May 22**

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

**June 13**

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

**July 11**

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

CARES Foundation plans to host more support group meetings via zoom in 2024. Please stay up to date with our calendar and social media for more information regarding upcoming support groups. If you have any questions regarding support groups, please contact: [support@caresfoundation.org](mailto:support@caresfoundation.org)

If you have not already, make sure to like and follow our Facebook Page. Here you can also find a variety of our Private Facebook Support Groups.

[Congenital Adrenal Hyperplasia Support Network](#)

[\*\*VISIT HERE\*\*](#)



# 2024 CAH Awareness Walks

Register for a walk near you!



Find all walks at: <https://caresfoundation.org/2024-cah-awareness-walks/>

May 18, 2024

**1st Annual**

**Iowa CAH Awareness 5k**

Des Moines Water Works - Des Moines, Iowa



**CHECK-IN: 9:00AM | 5K BEGINS: 10:00AM**

<https://caresfoundation.org/desmoinescah5k/>

June 1, 2024

**2nd Annual**

**Washington CAH Awareness Walk**

Magnuson Park - Seattle, Washington



**CHECK-IN: 10:30AM | WALK BEGINS: 11:00AM**

<https://caresfoundation.org/2nd-annual-washington-cah-awareness-walk/>

September 14, 2024

**4th Annual**

**Ohio CAH Awareness Walk**

Highbanks Metro Park - Lewis Center, Ohio



**CHECK-IN: 9:00AM | WALK BEGINS: 10:00AM**

<https://caresfoundation.org/4th-annual-ohio-cah-awareness-walk/>

October 26, 2024

**7th Annual**

**Florida CAH Awareness Walk**

Valicenti Pavilion - Titusville, Florida

**LINK  
COMING SOON**

If you are interested in hosting a walk in your area in 2024, please contact [dina@caresfoundation.org](mailto:dina@caresfoundation.org) for more information.

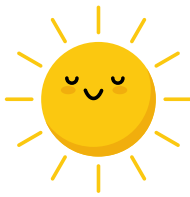
MAKE SURE TO VISIT THE **WHAT'S HAPPENING NOW & EVENTS** PAGES ON OUR WEBSITE TO STAY UP TO DATE ON IMPORTANT INFORMATION AND EVENTS!

**[WHAT'S HAPPENING NOW](#)**

**&**

**[EVENTS](#)**

# Medically-Safe Summer Camps



For more information regarding the below Summer Camps, please visit:

<https://caresfoundation.org/cah-medically-safe-summer-camps/>



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

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



### 2024 CAMP DATES

- SESSION 1: JUN 20-25
- SESSION 2: JUN 28-JUL 3
- SESSION 3: JUL 6-11
- SESSION 4: JUL 15-20
- SESSION 5: JUL 23-28
- SESSION 6: JUL 31-AUG 5
- ALUMNI: AUG 8-12

### BASIC CAMPER ELIGIBILITY

- o Medically Qualifying Diagnosis of one of the following... CAH, Cancer, Collagen Vascular Diseases, Congenital Cardiac Defects, Hemophilia/von Willebrand's, Inflammatory Bowel Diseases, Immune Disorders/HIV, Mitochondrial or Metabolic Diseases, Select Neuromuscular Disorders, Select Rare Diseases, Shunt Dependent Hydrocephalus, Solid & Visceral Organ Transplant, or Sickle Cell Anemia
  - o Campers aged 6-16 years old for Sessions 1-6. Campers aged 17-21 who have previously attended a Double H program for the Alumni Session.
  - o Cognitive age of at least 6 years old.
- Campers are asked to submit an online application with a current physical form and immunization record.



Scan to visit: [doublehranch.org](https://doublehranch.org) for details & application.



Double H Ranch  
a seriousfun camp

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.

QUESTIONS? CONTACT:  
**Tara Bogucki,**  
Admissions Director  
[tbogucki@doublehranch.org](mailto:tbogucki@doublehranch.org)  
518-696-5676 x 222



Camp Korey is more than a camp, it's a place where children with life-altering medical conditions can just be kids, completely free of charge.

At Camp Korey kids receive the specialized medical care they need, while also enjoying a fun and unforgettable camp experience! Our unique combination of camp fun and pediatric medical care provides parents, guardians, and campers with peace of mind.

ELIGIBLE CAMPER CONDITIONS INCLUDE BUT ARE NOT LIMITED TO:

- Genetic Bone Disorders
- Reconstructive Pelvic Medicine
- Cancer and Blood Disorders
- Bone Marrow + Solid Organ Transplants
- Cardiac Disorders
- Genetic and Chromosomal Abnormalities
- Neurologic Conditions
- Craniofacial Abnormalities
- Bladder Extrophy

Please reach out to [admissionsteam@campkorey.org](mailto:admissionsteam@campkorey.org) or call (360) 416-4113 to see if your camper is eligible.

Apply today at [campkorey.org/](https://campkorey.org/)

### CAMPER + FAMILY SESSIONS

Jun 30-Jul 3  
General Conditions

Aug 18-21  
General Conditions

### CAMPER + BLOCK SESSIONS

Jul 7-11  
Respiratory + Neurologic + General Conditions

Jul 14-18  
Solid Organ Transplant + Cardiac

Jul 21-25  
Skeletal Dysplasia + Metabolic Bone Disorders

Jul 27-30  
Sibling Camp

Aug 4-8  
Reconstructive Pelvic Medicine + Differences in Sex Development + Bladder Extrophy

Aug 11-15  
Sickle Cell + Blood Disorders + Bone Marrow Transplant



**Kidney Disease & Transplant and Adrenal Insufficiency Summer Session**

This 5 day Summer Session is free for all who attend! (June 16-June 20)

### Program Highlights

Enjoy activities like swimming, archery, fishing, ropes course, horseback riding, arts & crafts, and more! Each activity is designed with campers in mind.

- Cozy Cabins of up to 8 campers
- Cabin Counselors to ensure camper safety and fun!

### Camper Requirements

- Between the ages of 7 & 16
- Have a minimum developmental age of 5 years
- Be able to function and participate in a group setting
- Able to communicate needs independently
- Can be without family members for the duration of the camp session (summer camp)

### The following conditions are served during this session:

- Adrenal Insufficiency
- Congenital Adrenal Hyperplasia
- General Nephrology-decreased kidney function
- Kidney Disease and Transplant
- Peritoneal Dialysis

For more information please contact **Camper Admissions** at [admissions@thepaintedturtle.org](mailto:admissions@thepaintedturtle.org) or 661-724-1768



Experience the mischief and magic of Over The Wall's free and transformative activity camps. Over The Wall help children and young people reach beyond the boundaries of their health challenge. We offer both residential camps and Camp in the Cloud, which is our camp-at-home experience. All of our services enable our campers to build confidence by trying new things, creating friends, having fun and making lifelong memories!

To find more information about Over the Wall and their upcoming activity camps, please visit: <https://www.otw.org.uk/types-of-camp/>

Dream Street

JUNE 30-JULY 3, 2024

APPLY ONLINE

[dreamstreetfoundation.org](https://dreamstreetfoundation.org)  
Call for more information:  
(424) 333-1371

SUMMER CAMP  
AGES 4-14

Doctors and nurses at camp all week!

Open to patients who are on treatment or have recently finished. Siblings welcome.

Camp and transportation provided free of charge.



A camp for children with chronic and life threatening illnesses



EXPERIENCE MORE AT CAMP!  
2024

Campers with congenital adrenal hyperplasia generally qualify for the Rare Disease camp session held between July 20-25, 2024. They are also likely eligible for family camp weekends, as well as the Ranger or Trailblazer programs. For a full list of camp dates, please visit: <https://flyinghorsefarms.org/come-to-camp/camp-schedule/>

### CAMP AT A GLANCE

- \$0 Cost to campers & families
- 200+ acres to explore
- An average of 90+ volunteers at each session
- 24/7 onsite medical care
- Located 40 minutes north of Columbus, Ohio and 90 minutes southwest of Cleveland, Ohio right off I-71

### FIVE FAST & FUN REASONS TO EMBRACE CAMP

1. **WellNest Wellness:** For campers to experience all camp has to offer, their health and safety needs must be met as a medical specialty camp, Flying Horse Farms prioritizes safety first.
2. **Challenge By Choice:** Campers are given the opportunity to embrace new experiences like exploring the ropes course, taking aim at archery, and diving in with friends at the pool.
3. **Sense of Belonging:** Campers build lasting bonds with peers who understand and see them beyond their diagnosis and form lifelong friendships.
4. **Self Advocacy:** Campers learn to navigate their medical conditions, confidently gain skills, and find new independence that is carried beyond a camp session.
5. **More Smiles:** Camp is a place where more smiles happen because kids get to be kids.

Flying Horse Farms is a medical specialty camp that provides healing, transformative experiences for children with serious illnesses and their families - free of charge. Campers range from 7-21 and have diagnoses including cancer, heart conditions, rheumatologic diagnoses, blood disorders, lung conditions, gastrointestinal disorders, craniofacial diagnoses, rare diagnoses, spinal cord diagnoses, and mental health conditions.



## ASK THE EXPERT

**Dr. Karen Lin Su**

CARES Medical Director

Do you need expert medical advice before your next appointment?

Do you have unanswered questions about your treatment?

Then, **DON'T FORGET** about our program!

Questions answered, worries alleviated, suggestions offered, CAH medical advice for you and your loved ones.

You must be registered with CARES to use this service. To join, click: <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.

## 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, WHERE YOU WILL FIND HELPFUL RESOURCES AND DOCUMENTS!**

# CHECK OUT OUR SHOP

**Get ready for CAH Awareness Month with 15% off until May 31, 2024!**



**Fresh out of Cortisol T-Shirt**

**\$13.00**

Unisex/Men's, Women's Slim-Fit, Youth, & Toddler sizes



**Salt of the Earth T-Shirt**

**\$14.00**

Unisex/Men's, Women's Slim-Fit sizes



**Congenital Adrenal Hyperplasia T-Shirt**

**\$14.00**

Unisex/Men's, Women's Slim-Fit sizes



**Emergency Syringe Bag**

**\$5.50**

Durable semi-translucent carry-case



**Adrenal Insufficiency Seatbelt Cover**

**\$12.00**

Cover to go over a seatbelt, and other similarly shaped items



**CARES Foundation Sticker Sheet**

**\$2.00**

Stickers for your laptop cases, travel mugs, and more!

**MORE ITEMS AT**

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# 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](mailto:john@caresfoundation.org) if you are concerned about your account's status

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