

# IN THIS UPDATE, YOU WILL FIND IMPORTANT INFORMATION ABOUT RESEARCH, EDUCATION, **EVENTS, NEW DEVELOPMENTS IN** THE COMMUNITY, AND MORE!

# **CLICK THE ICONS BELOW TO FOLLOW US** ON SOCIAL MEDIA FOR THE MOST **UP-TO-DATE NEWS!**











# **CAH AWARENESS MONTH**

2024 SOCIAL MEDIA CAMPAIGN



This June we are excited to take part in <u>CAH AWARENESS MONTH</u>! Join us as we learn more about congenital adrenal hyperplasia, some of the crucial stories in our community, as well as important tips & advice from CARES.

If you would like to share your CAH journey through CARES, we ask that you please submit a written story of any length, as well as any photo/photos that you would want included with your submission.

If you have any questions, or would like to learn more about how you can share your CAH journey please do not hesitate to reach out! All questions and submissions can be directed to: john@caresfoundation.org.

### YOUR STORY

READ SOME OF THE INCREDIBLE, AND COURAGEOUS STORIES FROM MEMBERS IN OUR COMMUNITY.

### CAH Trivia



LEARN MORE ABOUT IMPORTANT FACTS SURROUNDING CAH THROUGH OUR SOCIAL MEDIA POSTS.

# WHY WE DO



FIND OUT MORE ABOUT CARES FOUNDATION'S MISSION TO HELP IMPROVE THE LIVES OF THOSE LIVING WITH CAH.

# HEAR PATIENTS & PARENTS



CAH PULSE

CHECK OUT OUR
PODCAST, CAH PULSE,
AS WE HIGHLIGHT OUR
MOST RECENT EPISODES
THROUGHOUT THE
MONTH!

### ONLINE ACTIVITIES



STAY UP TO DATE WITH CARES' SOCIAL MEDIA THIS JUNE FOR DIFFERENT CHANCES TO WIN A CARES T-SHIRT THROUGH ONLINE ACTIVITIES!

# **INTERESTED IN MAKING A DONATION TOWARDS CARES?**

Donations towards our CAH AWARENESS MONTH Campaign can be made on the CARES website, or by scanning the QR code in this post.

MAKE A DONATION TOWARDS CARES FOUNDATION



We truly appreciate your support.

None of what we do is possible without our community!



# Tuesday, October 1, 2024 Patient-Focused Drug Development Meeting

# 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 virtual meeting, please contact <u>pfdd@caresfoundation.org</u>.

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

For more information, please visit: <a href="https://caresfoundation.org/externally-led-patient-focused-drug-development-el-pfdd/">https://caresfoundation.org/externally-led-patient-focused-drug-development-el-pfdd/</a> or you may also use the links below.

**About Patient-Focused Drug Development** 

**Goals & Objectives** 

Register for the PFFD Meeting being held virtually on October 1, 2024

# 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.

### <u>Specifically, we are looking for participants who meet the following criteria:</u>

- 1. Parents/Caregivers of specific age groups
- 2. Adults
- 3. Confirmed diagnosis of Classic CAH/caretaker for an individual with Classic CAH (patient can be younger than 18)
- 4. Not currently participating in a CAH clinical trial
- 5. Must physically attend all days of the CAH Patient Journey Advisory Summit and Patient Education Conference
- 6. U.S. resident
- 7. Willing to share experience of living with Classic CAH/caring for someone living with Classic CAH
- 8. A current member of the CARES community (free to join: <a href="www.caresfoundation.org/join-the-cares-community">www.caresfoundation.org/join-the-cares-community</a>)

If you are interested in participating in this event, please contact <a href="mailto:dina@caresfoundation.org">dina@caresfoundation.org</a>.

# 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.

If you would like to learn more, and/or register to attend, please use the link provided below!

### **LINK TO REGISTER COMING SOON**

Interested in learning more about specific topics?

Email <a href="mailto:odaly@caresfoundation.org">odaly@caresfoundation.org</a> to let us know what you would like to see covered at this year's conference!

# **LIMITED SCHOLARSHIPS AVAILABLE**

CARES Foundation is able to provide scholarship(s) to these events **[2024 Patient Advisory Summit; 2024 Patient Education Conference]** through the completion of a scholarship application. If you are interested in applying for this scholarship, please reach out to **john@caresfoundation.org** to receive a scholarship application.

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 - NEW EPISODE Check out our latest episode!



# Episode 7: Marc - Living Life to it's Fullest

"Nothing holds me back"



Join Dina and Stephanie as they speak with Marc and hear his inspiring story of hope and relief in the face of a life-long incurable condition.

Marc's calm and poise will leave you embracing his empowering direction for adults, parents and kids growing up with salt wasting CAH.

Hear more about the journey of 2 brothers learning how to advocate for themselves, take their own medicine, play sports (even in the heat of the summer) and live life to it's fullest without pretense or worry.

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

If you would like to have your story featured on a future episode, please reach out to 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**

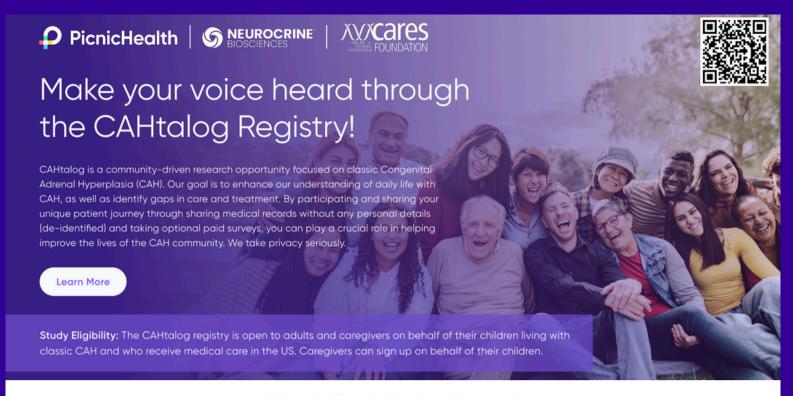
- Name us in your Will or estate
- Real Estate
- Shares of appreciated stock
- IRA RMDs
- Cash
- Interest or Shares of Operating Business

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



**F NEW JERSEY** Phone: 973.267.5533 Toll-Free: 800.659.5533 Fax: 973.267.2903

Thank you for considering CARES Foundation!



### What Is The CAHtalog Registry?

CARES Foundation, Neurocrine Biosciences and PicnicHealth have partnered to establish the CAHtalog<sup>™</sup> 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 :

### 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.



# las **CAH Awareness Month**

Adrenas Therapeutics salutes the CARES Foundation for their valuable role in providing information, resources, and support for people living with CAH!

Classic CAH Investigational Gene Therapy
Clinical Trial Enrolling

To learn more, visit www.cahgenetherapy.com

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# AT CRINETICS, WE BELIEVE PATIENT-FOCUSED DRUG DEVELOPMENT IS VITAL.

We value the patient's voice and encourage patient input into our clinical development programs and beyond.

CONSIDER PARTICIPATING IN OUR CONGENITAL
ADRENAL HYPERPLASIA PATIENT LEADERSHIP COUNCIL.

crinetics.com/patient-leadership-council

NP-PAT-0007 5/2024











# **UPCOMING SUPPORT GROUPS**

If you are interested in participating in any of the below meetings, please reach out to: <a href="mailto:support@caresfoundation.org">support@caresfoundation.org</a>

## June 13

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

# July II

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

## September 12

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

## September 18

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

## September 26

CAH Women, 8:30PM(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: <a href="mailto:support@caresfoundation.org">support@caresfoundation.org</a>

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



# 2024 CAH Awareness Walks Register for a walk near you!



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

Thank you to all of those who participated in our CAH Awareness Walks in May!







lowa
CAH Awareness 5k

We look forward to seeing our community at more walks across the United States in 2024!

June I, 2024

# 2nd Annual Washington CAH Awareness Walk

Magnuson Park - Seattle, Washington



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

https://caresfoundation.org/2nd-annualwashington-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-ohiocah-awareness-walk/ October 26, 2024

# 7th Annual Florida CAH Awareness Walk

**Valicenti Pavilion - Titusville. Florida** 



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

https://caresfoundation.org/7th-annual-flordiacah-awareness-walk/

If you are interested in hosting a walk in your area in 2024, please contact <a href="mailto:dina@caresfoundation.org">dina@caresfoundation.org</a> 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



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

Can be without family members for the duration of the camp session (summer camp)

The Painted Turtle

. Cozy Cabins of up to 8 campers

Kidney Disease and Transplant

. Cabin Counselors to ensure camper safety and fun!

Have a minimum developmental age of 5 years

Able to communicate needs independently

Bea able to function and participate in a group setting

The following conditions are served during this session:

For more information please contact Camper Admissions at

**OVER THE WALL** 

+25+ gears

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/

admissions@thepaintedturtle.org or 661-724-1768

Program Highlights

with campers in mind.

Camper Requirements · Between the ages of 7 &16

· Adrenal Insufficiency Congenital Adrenal Hyperplasia General Nephrology-decreased kidney function

· Peritoneal Dialysis

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

> Kidney Disease & Transplant and Adrenal Insufficiency Summer Session

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

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 ent so your camper can focus on having fun. All programs are FREE of charge



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





SESSION 1: JUN 20-25 SESSION 2: JUIN 28-JUIL 3 SESSION 3: JUL 6-11

SESSION 4: JUL 15-20

JUL 23-28 JUL 31-AUG 5







### BASIC CAMPER ELIGIBILITY

- CAH, Cancer, Collagen Vascular Diseases, Congenital Cardiac Defe Hemophilia/von Willebrands, Inflammatory Bowel Diseases, Immur Disorders/HIV, Mitochondrial or Metabolic Diseases, Select Neuromuscular Disorders, Select Rare Diseases, Switch Heuromuscular Disorders, Select Rare Diseases, Shunt Dependent Hydrocephalus, Solid & Visceral Organ Transplant, or Sickle Cell An Campers aged 6-19 years old for Sessions 1-6. Campers aged 7-21 wave previously attended a Double H program for the Alumni Session Cognitive age of at least 6 years old.

  Campers are asked to achieve the competence of the Session of t

Campers are asked to submit an online application with a current physical form and



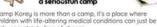
tbogucki@doublehra 518-696-5676 x 222











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:

- 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 or call (360) 416-4113 to see if your camper is eligible.

Apply today at campkorey.org!

### CAMPER + FAMILY SESSIONS



Aug 18-21

### CAMPER + BLOCK SESSIONS













JUNE 30-JULY 3, 2024

dreamstreetfoundation.org Call for more information: (424) 333-1371





flying horse farms



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-scl

### 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

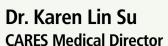
### FIVE FAST & FUN REASONS TO EMBRACE CAMP

- 1. WellNest Wellness: For campers to experience all camp has to offer, their health and safety needs must be metas 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 were 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





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: <a href="https://caresfoundation.org/join-the-cares-community/">https://caresfoundation.org/join-the-cares-community/</a> CLICK HERE: <a href="https://caresfoundation.org/ask-the-expert/">https://caresfoundation.org/ask-the-expert/</a> 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: <a href="https://caresfoundation.org/join-the-cares-community/">https://caresfoundation.org/join-the-cares-community/</a>

Haga clic aquí: <a href="https://caresfoundation.org/pregunta-el-experto/">https://caresfoundation.org/pregunta-el-experto/</a> para visitar esta pagina.

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



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

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

# CHECK OUT OUR SHOP

# Visit the link in this post to view our full shop!



## Fresh out of Cortisol T-Shirt

\$13.00

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



# **Emergency Syringe Bag**

\$5.50

Durable semi-translucent carry-case



### Salt of the Earth T-Shirt

\$14.00

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



### Adrenal Insufficiency Seatbelt Cover

\$12.00

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



## Congenital Adrenal Hyperplasia T-Shirt

\$14.00

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



### CARES Foundation Sticker Sheet

\$2.00

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

# MORE ITEMS AT

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

# PLEASE UPDATE YOUR ACCOUNT INFORMATION!

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

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

# LOGIN TO YOUR ACCOUNT HERE

# **CAH PARTNER 2024**



Platinum Transparency 2024

Candid.



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

**MAKE A DONATION** 

**JOIN OUR COMMUNITY** 

**VISIT OUR WEBSITE HERE**