CARES Connections

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Improving health, connecting people, saving lives

In This Issue

MANAGEMENT OF ENDOCRINE DISEASE: Gonadal dysfunction in congenital adrenal hyperplasia

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Gonadal dysfunction is an adverse outcome in patients with congenital adrenal hyperplasia (CAH), which may become apparent already during puberty. Clinical consequences of gonadal dysfunction include menstrual disturbances in females and hypogonadism and impaired fertility in males and females. In males, gonadal dysfunction can be caused by primary gonadal failure due to testicular adrenal rest tumours (TART), and by secondary gonadal failure due to poor hormonal control. In females, gonadal dysfunction can result from an overproduction of adrenal androgens including 11-oxygenated C-19 androgens and progestins, and rarely from ovarian adrenal rest tumours. In all patients with CAH, optimal hormonal control is the key for adequate gonadal function. Therefore, regular measurements of adrenal steroids and/or their metabolites should be performed. In addition, markers of the hypothalamus-pituitary-gonadal axis need to be assessed. In females, the regularity of the menstrual cycle should be evaluated. In males, regular evaluation for TART using ultrasonography is recommended from the start of puberty or even earlier when poor hormonal control is present. When TART is present, counselling on cryopreservation of semen should be offered.

Go here to download pdf of entire article: https://tinyurl.com/94dn7xcu

From Decades of Pioneering Research to Pivotal Clinical Studies: The Journey of a Promising Investigational Therapy for Classic CAH

By Dimitri Grigoriadis, Ph.D., Chief Research Officer and Eiry Roberts, Ph.D., Chief Medical Officer at Neurocrine Biosciences

Since the introduction of cortisone treatment in 1950, there have not been any new therapies for congenital adrenal hyperplasia (CAH). At Neurocrine Biosciences, we are committed to developing new and better treatment options for patients with CAH to help make disease control and symptom management easier. As we enroll two global, registrational clinical studies for our promising investigational therapy for classic CAH, we look back at the company's journey in this field to see just how far we've come, and the potential that hopefully lies ahead.

Dimitri E. Grigoriadis, Ph.D., Chief Research Officer at Neurocrine Biosciences, spent most of his career studying corticotropin-releasing factor (CRF), a key hormone that regulates the release of adrenocorticotropic hormone (ACTH), the driver of elevated androgen levels in individuals with classic CAH. Dr. Grigoriadis previously worked with some of the top experts in CRF research, including Wylie Vale, Ph.D., a researcher and professor at the Salk Institute, one of the world's preeminent institutions for basic research. Dr. Vale's mentor and advisor was Roger Guillemin, Ph.D., a co-recipient of the 1977 Nobel Prize for Physiology or Medicine for his work with CRF. A world-renowned expert in his own right in the field of CRF and other peptide brain hormones and

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A Message from the Executive Director

Dear Friends,

As 2021 comes to an end, I want to take the opportunity to thank you for entrusting CARES to help you navigate the world of CAH. Whether you are a patient, parent, loved one, friend, medical professional, researcher or volunteer, we view you as an integral partner within our CAH family. You help us learn more about the needs of patients and caregivers. Medical professionals whose care you rely on, learn from patients and caregivers every day. Researchers working on new treatments aimed at improving your overall health, are reassured of the importance of their work through interactions with patients and caregivers. What we all have in common is a deep desire to help those living with CAH to live their best lives, despite their diagnosis.

Together with all of the members of our community, our organization continues to make strides to help improve the lives of all affected by CAH. How do we do it?

- Provide access to quality medical care with referrals to experts at our centers of excellence and other institutions
- Provide educational opportunities through patient education conferences and webinars
- Work with members of industry as they develop and bring to market new treatments for CAH
- Offer tools and resources to help you manage life with CAH
- Provide one-on-one support
- Offer support group meetings to connect you with peers and medical experts
- Advocate for the preservation of treatment options
- Create opportunities for you to meet others facing your same challenges

As I reflect on the year, a few events stand out as highlights. First, the visit to the specialty pharmacy that distributes Alkindi® Sprinkle, the newest form of hydrocortisone on the market, that especially benefits our younger patients. The first in-person CAH Awareness Walk since 2019. It was extremely emotional, as some patients and families met others "just like them" for the first time. Then, just days ago, visiting a laboratory where an extraordinary team of scientists and support staff are developing a gene therapy for CAH.

There is such promise in the world of CAH right now, with new treatments on the horizon, more expert care and more support than ever. Help us continue to serve you better with your ideas, suggestions and support. If you can, please consider adding CARES to your year-end giving.

Thank you for your partnership!

From the entire team at CARES, we wish you a happy and healthy 2022!

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and receptors, Dr. Vale was the first to describe and isolate CRF in 1981 and went on to co-found Neurocrine Biosciences.

As a direct result of his expertise in CRF research, Dr. Grigoriadis built a CRF antagonist platform at Neurocrine Biosciences that led to the development of crinecerfont, an investigational, oral, non-steroidal CRF type 1 receptor antagonist for the potential treatment of classic CAH due to 21-hydroxylase deficiency (21-OHD). By blocking CRF, crinecerfont has the potential to directly decrease the high levels of ACTH that lead to elevated androgen levels in individuals with CAH.

Neurocrine Biosciences has evaluated crinecerfont in more than 800 clinical study participants. Crinecerfont has demonstrated a favorable safety profile through Phase 1 and Phase 2 studies, with good tolerability and no drug-related serious adverse events reported to date. A Phase 2 study in adult patients with classic CAH demonstrated meaningful reductions in key CAH hormones, including ACTH, 17-hydroxyprogesterone (17-OHP), the main adrenal androgen androstenedione (A4), testosterone in females and A4 to testosterone ratio in males following 14 days of treatment with crinecerfont. These results support the potential of crinecerfont to enable better adrenal androgen control for patients that could support improved symptoms, allow lower dosing of glucocorticoids and avoid complications related to high steroid doses.

Neurocrine Biosciences is currently enrolling patients in two Phase 3 studies evaluating crinecerfont. The CAHtalyst Study (CAHtalystStudy.com) is a Phase 3 global, registrational study for adult patients with classic CAH ages 18 years and older. The CAHtalyst Pediatric Study (CAHtalystPediatricStudy.com) is a Phase 3 global, registrational study for pediatric patients ages 2-17 with classic CAH.

With crinecerfont, Neurocrine Biosciences hopes to provide a treatment option for patients with classic CAH that has the potential to improve disease-related symptoms and reduce the risk of developing well-known adverse effects associated with life-long exposure to higher than replacement level doses of glucocorticoids.

Beyond our development work at Neurocrine Biosciences, our researchers are also committed to deepening the scientific and medical communities' understanding of the real-world impact of CAH. We are collaborating with CARES Foundation on the development of the CAHtalog™ patient registry. CAHtalog™ (Congenital Adrenal Hyperplasia: Patient and Clinical Outcomes in Real World Practice Settings) is a disease registry – a type of database that is used to collect and record information about people diagnosed with a specific disease. Neurocrine is working with PicnicHealth to create a registry of de-identified medical records from consenting patients, all without the need for in-person visits. In the registry, people living with CAH will consent to have PicnicHealth collect medical records on their behalf, which will be digitized and anonymized to create a de-identified CAH database and shared back with patients via their own PicnicHealth timeline (https://demo.picnichealth.com/).

If you are interested in enrolling in or learning more about the CAHtalog™ patient registry, the enrollment website will be available in December (look out for future announcements) or email cahregistry@Picnichealth.com.

Neurocrine Biosciences is quickly approaching its 30th anniversary, marking decades of innovation and relentless efforts to develop compounds that target CRF and other disease-causing mechanisms within the interconnected pathways of the nervous and endocrine systems. For more information about Neurocrine Biosciences and crinecerfont, visit neurocrine.com.

To learn more about our Phase 3 study in adult patients with classic CAH (age 18 years and older), visit CAHtalystStudy.com.

To learn more about our Phase 3 study in pediatric patients with classic CAH (ages 2-17 years), visit CAHtalystPediatricStudy.com.

***Dimitri E. Grigoriadis, Ph.D.**, was appointed Chief Research Officer in 2013. Dr. Grigoriadis oversees all research functions, including drug discovery, biology and chemistry, and has led such functions since 2006. Dr. Grigoriadis joined Neurocrine Biosciences in 1993, established the pharmacology and drug screening groups and was most recently a Neurocrine Biosciences Fellow and Vice President of Discovery Biology. Prior to joining Neurocrine Biosciences, he was a Senior Scientist in the Neuroscience group at the DuPont Pharmaceutical Company from 1990 to 1993. Dr. Grigoriadis received his B.Sc. from the University of Guelph in Ontario, Canada, and his M.Sc. and Ph.D. in Pharmacology from the University of Toronto, Ontario, Canada. He conducted his postdoctoral research at the National Institute on Drug Abuse in Baltimore, MD from 1987 to 1990.*

***Eiry Roberts, Ph.D.** was appointed Chief Medical Officer in January 2018 and is responsible for all clinical development and medical affairs activities at Neurocrine. Dr. Roberts has over 25 years of research and development experience in the pharmaceutical industry across all phases of drug development from research through commercialization in multiple therapeutic areas, including neuroscience, inflammation, oncology and metabolic diseases. She joined Neurocrine from Eli Lilly and Company where she held various positions during her tenure, including Vice President, Clinical Pharmacology, and Vice President of R&D, BioMedicines Business Unit. Dr. Roberts also has extensive leadership and business development experience, including the management of strategic alliances, business partnerships and venture capital collaborations. Dr. Roberts is a physician who trained in pharmacology and medicine in the UK, qualifying from the University of London in 1987. Her post-graduate clinical training was in clinical pharmacology and cardiology at St. Bartholomew's Hospital and the Royal London Hospital.*

CAHtalog™

Congenital Adrenal Hyperplasia
Patient & Clinical Outcomes in Real-World Practice Settings

UPDATED PLATFORM - Winter 2021!

CARES Foundation is launching CAHtalog™, a patient registry. Beginning this winter patients with classic CAH of all ages will be able to enroll online for the registry.

CAHtalog™ (Congenital Adrenal Hyperplasia: Patient and Clinical Outcomes in Real World Practice Settings) is a disease registry -a type of database that is used to collect and record information about people diagnosed with a specific disease. In the registry, people living with CAH will consent to have a company called PicnicHealth to collect, digitize and encrypt medical records on their behalf, which will be combined into a de-identified CAH database.

The main purpose of the CAHtalog™ registry is to obtain information about how adults and children with CAH are managed by their doctors in a real-world setting. The registry will provide doctors, patients, and health care professionals with a better understanding of how CAH is managed. It will also give a better picture of the natural history of CAH and will help raise awareness of CAH, which may help improve the care of future CAH patients. As a benefit of participation, you will receive all your records digitally in one place for you to use and reference for your care.

The CAHtalog™ registry is purely observational and it takes just a few minutes to contribute to CAH research. It is a confidential registry and there is no cost to participate.

More information to come about this exciting opportunity!

Diurnal is a European, UK-headquartered, specialty pharmaceutical company dedicated to developing medicines to improve lifelong treatment for rare and chronic endocrine conditions, including Congenital Adrenal Hyperplasia and Adrenal Insufficiency.

Following European and British licensing of Diurnal's oral modified-release formulation of hydrocortisone (development name Chronocort®), Diurnal has been able to move ahead with a US registration study.

The CONnECT study will be run in the US, Japan, Turkey and France and will be enrolling first patients before the end of the year. The study will be a blinded study (i.e patients and their endocrinologists will not know what treatment they are on) and will trial Chronocort against Cortef. Details of the study can be found on the Clinicaltrials.gov website (www.clinicaltrials.gov Study ID NCT05063994). At the end of this study eligible participants can choose to continue into a follow-on study where all participants will receive Chronocort.

The study will be recruiting up to 150 participants aged 16 and over with classic CAH due to a deficiency of 21-hydroxylase. We will be providing details for those considering participation soon. In the meantime, you can get further information from the Diurnal website (www.diurnal.com).

ALKINDI® Sprinkle Precise Dosing Video & Support Info

About ALKINDI® SPRINKLE

ALKINDI® SPRINKLE is an immediate -release oral hydrocortisone granule preparation that has been specifically designed to meet the dosing needs of pediatric patients with adrenocortical insufficiency. Prior to ALKINDI® SPRINKLE's approval, parent caregivers had to cut or split higher strength hydrocortisone tablets to achieve the lower doses required for small children, which could result in inaccurate dosing. Taste-masking excipients that are acceptable for pediatric use eliminate the bitter taste of hydrocortisone. ALKINDI® SPRINKLE has a shelf life of three years at ambient temperature and does not require refrigeration.

Please visit https://www.alkindisprinkle.com/patient/resources/ for helpful patient resources that include:

- Referral Form
- Administration Videos in English and Spanish - includes a Live Demonstration Video featuring a 5-year old child self-administering the medication
- Prescribing Information
- Medical Guide & Instructions
- Safety Information

CARES' Executive Director Visits Anovo Rx

After more than a decade of working with Diurnal and later Eton Pharmaceuticals, Dina Matos, CARES Executive Director, had the privilege of seeing, up close, Alkindi® Sprinkle, a new form of hydrocortisone. She traveled to Memphis in late June to meet with teams from Eton Pharmaceuticals and Anovo RX. Eton is the manufacturer of Alkindi® and Anovo, a specialty pharmacy, distributes the medication.

After seeing the medication in person, Dina commented, "it gave me a new appreciation for how convenient it is for infants and children." She was very impressed with the dedication and commitment of both teams. Their number one priority, shared by CARES, is the patient. The group discussed caregiver education, access to the medication and customer service. Dina left the meeting assured that the Alkindi® team is thoroughly committed to improving the lives of our youngest patients. She looks forward to continue working with them to bring this very promising product to patients.

The Anovo team

Learn about the Potential of Gene Therapy for Classic CAH

Adrenas Therapeutics is a company that was created with a single mission: to work with scientists, physicians, and patients in developing a gene therapy for people affected by CAH. Adrenas' investigational one-time gene therapy is now in clinical trials, and was recently granted Fast Track Designation by the FDA. Adrenas is a subsidiary of BridgeBio, a public company dedicated to finding, developing, and delivering breakthrough medicines for genetic diseases to patients as quickly and safely as possible.

Adrenas
a bridgebio company

Adrenas' investigational gene therapy for CAH may offer the potential for the body to naturally make its own cortisol and aldosterone with a single infusion.

Clinical Trial Now Enrolling

FOR INFORMATION: www.cahgenetherapy.com

A special thanks to the CARES Foundation for partnering with Adrenas for a recent webinar. A recorded version of the webinar will be available at www.adrenastx.com.

What is the potential benefit of gene therapy for CAH?

- If successful, gene therapy for CAH may restore the body's hormone and steroid balance by enabling people with CAH to naturally make their own cortisol and aldosterone.
- It could also allow for people with CAH to eliminate or significantly reduce their daily glucocorticoid or mineralocorticoid doses.

What is gene therapy? And how does it apply to CAH?

- Gene therapy aims to treat genetic conditions by enabling the body to produce a critical protein that is missing.
- Gene therapy does this by using a delivery vehicle to provide a functioning copy of a gene into cells that are missing or do not have a fully functioning copy of that gene.
- People with CAH due to 21-hydroxylase deficiency have changes (mutations) in the CYP21A2 gene. The CYP21A2 gene is important for the production of 21-hydroxylase, a critical enzyme necessary for proper function of the adrenal glands. Mutations in CYP21A2 cause 21-hydroxylase to either not be produced or not be fully functional.

How is Adrenas' investigational therapy designed to work?

- Adrenas' investigational gene therapy uses a common virus called adeno-associated virus (AAV) as the delivery vehicle for the CYP21A2 gene. You can think of AAV as a "delivery truck," with the cargo being a functional gene. AAVs used in gene therapy are not associated with any known diseases in people, which is why they are used in gene therapy as the transport vehicles to deliver functioning genes into the body.

Is gene therapy new?

- Although AAV gene therapy is new to CAH, it's not new. A number of AAV gene therapies have been approved by the FDA.
- Gene therapies have also been studied extensively in clinical trials for adults with hemophilia.
- In total, gene therapies have been used to treat more than 3,500 people around the world, and more patients are being treated with gene therapy every day. There are currently 100+ active AAV gene therapy trials for a variety of diseases.
- Long-term safety information, for both the approved gene therapies and those still in development, continues to be collected. The American Society of Gene and Cell Therapy and has additional information about gene therapies on its website: https://patienteducation.asgct.org/gene-therapy-101.

Does AAV modify my genetic material?

- Unlike CRISPR and other forms of gene editing, and unlike other types of gene therapy, AAV gene therapy is specifically designed to avoid becoming part of your cell's genetic material or DNA, and it does not get passed down to your children.

How often will patients in the clinical study need to get an infusion?

- Adrenas' investigational gene therapy is designed as a one-time intravenous infusion.

How long does a one-time infusion of gene therapy last?

- Some AAV gene therapies have been shown to last for several years — even up to 10 years in an ongoing study. Because this is still a new science, long-term studies are being conducted to better understand how long the effects of AAV gene therapy will last.

When will adolescents, children, or infants be eligible for participation in the investigational gene therapy trial?

- To follow guidelines provided by the FDA, the first clinical trial will be conducted in adults (ages 18 and above). Once an appropriate dose is found in adults with classic CAH, we plan to begin trials in children and adolescents with classic CAH.

Where can I go for additional information or for information to share with my doctor?

- www.cahgenetherapy.com
- www.adrenastx.com
- https://asgct.org/

CARES Team Visits BridgeBio Lab

CARES' Executive Director, Dina Matos, Board Chair, Louise Fleming, and Board of Trustees member, Lesley Holroyd, recently took a trip to North Carolina to visit the BridgeBio/Adrenas Laboratory where the innovative gene therapy treatment is being designed. It was exciting to see this complex process live and up close!

PACE
PREVENT ADRENAL CRISIS EVENTS

ADRENAL CRISIS PREVENTION APP IS HERE!

CARES' very own Board of Trustees Chair, Louise Fleming, PhD, RN, and her research team from NIH, Johns Hopkins, AL Children's Hospital and CARES Foundation announce the release of the PACE app for use by adrenal insufficient patients and parents/caregivers.

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ABOUT THE CAHTALYST AND CAHTALYST PEDIATRIC CLINICAL TRIALS

CAHtalyst STUDY

About the Clinical Trial

A randomized, double-blind, placebo-controlled clinical trial to evaluate the safety and efficacy of crinecerfont (NBI-74788) in adults with classic congenital adrenal hyperplasia (CAH), followed by open-label treatment with crinecerfont. The sponsor of this clinical trial is Neurocrine Biosciences, Inc.

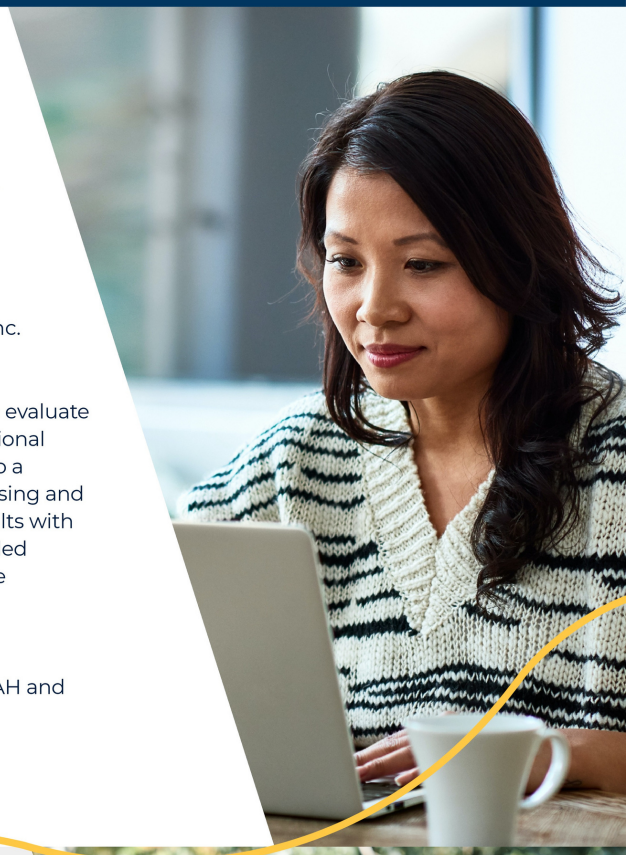
Trial Purpose

The primary purpose of this clinical trial is to evaluate the safety and effectiveness of an investigational medication called crinecerfont, compared to a placebo, in reducing daily glucocorticoid dosing and improving adrenal-related hormones in adults with classic CAH. After the initial placebo-controlled treatment period, all participants will receive treatment with crinecerfont for one year.

Population

Adults at least 18 years of age with classic CAH and a stable glucocorticoid dose regimen.

LEARN MORE



CAHtalyst pediatric study

About the Clinical Trial

A randomized, double-blind, placebo-controlled clinical trial to evaluate the safety and efficacy of an investigational medication called crinecerfont (NBI-74788), compared to a placebo, in reducing daily glucocorticoid dosing and improving adrenal-related hormones in pediatric patients with classic CAH, followed by open-label treatment with crinecerfont. The sponsor of this clinical trial is Neurocrine Biosciences, Inc.

Trial Purpose

The primary purpose of this clinical trial is to evaluate the safety and effectiveness of an investigational medication called crinecerfont in children and adolescents with classic CAH. After the initial placebo-controlled treatment period, all participants will receive treatment with crinecerfont for six months.

Population

Children and adolescents between 2 and 17 years of age with classic CAH and a stable glucocorticoid dose regimen.

Neurocrine BIOSCIENCES

TO LEARN MORE, VISIT CAHSTUDIES.COM

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What the PACE app does:

- Describes the accepted guidelines for oral glucocorticoid stress dosing in children and adults with adrenal insufficiency (AI)
- Instructs persons, including the individual with AI, to recognize the signs and symptoms of adrenal crisis and how to respond effectively
- Demonstrates correct use of the hydrocortisone Act-O-Vial and intramuscular injection technique in the event of adrenal crisis
- Shows an animated training video explaining AI - designed for teachers, babysitters, friends, and family
- Has a stress dose calculator for use with oral hydrocortisone

CAHMELIA 203 204

The CAHmelia clinical trials are exploring a new investigational treatment for **classic CAH.**

CAHmelia 203 and CAHmelia 204 are clinical trials to test tildacerfont in adults with classic CAH, which may offer you and your loved ones hope of a brighter future - one where you may not have to **choose between symptom management and long-term health.**

Tildacerfont is a new type of **oral, once-daily** investigational treatment - **one that is not a steroid** - that is currently being tested in adults with classic CAH. By reducing the amount of androgens your body makes, tildacerfont may improve your classic CAH symptoms.

This investigational treatment will not replace your steroid treatment buy may allow you to manage your disease with lower amount of steroids at normal or near-normal doses.

Who can take part in this trial? You may be able to take part if you:

- Are at least 18 years of age
- Have a confirmed diagnosis of classic CAH due to 21-OH deficiency
- Have been on the same daily dose of steroids (GC's and/or mineralocorticoids) for at least 1 month before started trial.

Both trials are open for enrollment.

Tildacerfont is an investigational treatment not authorized for use in people outside the clinical trial.

For more information go to:
https://www.clarahealth.com/studies/cahmelia

EDUCATION

CARES Connections

Did you know that ALL issues of the CARES' newsletters are available on our website? There is tons of information right at your fingertips! Visit our newsletter archives page today.
https://caresfoundation.org/cares-connections-newsletters-archive/

Adrenal Crisis and Stress Dosing Videos are a Valuable Resource

Have you seen our important videos that give you the tools you need to cope with an adrenal crisis and stress dosing during illness, injury or emergency? Please take some time to watch online, or purchase on flashdrive from our CARES Shop.

ONLINE LINK:
https://caresfoundation.org/emergency-care-videos/
SHOP LINK: https://tinyurl.com/33eba7cy

CAH MASTER CLASSES

As part of our CAH Awareness Month celebration in June, we offered the CAH community a series of free webinars on a variety of CAH topics. The goal was to expand our community's knowledge of CAH and raise awareness of this rare disorder by ending each session with a question and answer segment. If you missed any of this series, please visit our website to watch online today!
https://caresfoundation.org/cah-master-classes/

We are planning additional Master Class sessions for 2022. Please let us know what topics you would like us to cover!

THE DOCTOR IS IN

Dr. Karen Su
CARES Medical Director

Guide to Medications and How They Work

Glucocorticoids

As a class, glucocorticoids are similar to the adrenal hormone cortisol, which is deficient in patients with CAH and other forms of adrenal insufficiency. They also lower adrenal androgen production, which is increased in CAH. There are several different oral glucocorticoids commonly used for regular chronic replacement of cortisol.

- ***Hydrocortisone*** (Cortef): structurally identical to cortisol, it is considered to be the most physiologic of the pharmacological glucocorticoids. It has both glucocorticoid and mineralocorticoid (see below) activity. With the exception of cortisone, it is the least potent of the available glucocorticoids, and is the shortest-acting (given 2-3 times/day). Compounded liquid suspensions of hydrocortisone are unreliable and should not be used.
- ***Cortisone acetate:*** slightly less potent than hydrocortisone, it must be converted to active cortisol in the body using an enzyme called 11ß-hydroxysteroid dehydrogenase type I.
- ***Prednisone/Prednisolone:*** 4-5 times as potent as hydrocortisone and longer-acting (given 2x/day). Considered to be more growth suppressive than hydrocortisone even at equivalent glucocorticoid doses, so usually not recommended in growing children.
- ***Dexamethasone:*** 40-80 times as potent as hydrocortisone and very long-acting (given once a day). Not generally used in growing children because difficult to titrate at very small doses and tends to suppress growth.

Mineralocorticoids

Mineralocorticoids are similar to aldosterone, which is deficient in patients with salt-wasting CAH. They act on the

mineralocorticoid receptor in the kidneys to reabsorb sodium and excrete potassium.

- ***Fludrocortisone:*** acts on the mineralocorticoid receptor to replace aldosterone; also has some glucocorticoid activity; comes as 0.1 mg tablets
- ***Hydrocortisone:*** acts on the mineralocorticoid receptor also, but much higher doses are needed (40 mg of hydrocortisone is roughly equivalent to 0.1 mg of fludrocortisone)

Androgen receptor blocker

- ***Spironolactone:*** blocks the androgen receptor, so it prevents any androgens that are circulating in the blood from causing symptoms (such as acne, excess facial/body hair, or signs of early puberty). When the androgens are very high, though, higher doses may be required to be effective. Unfortunately, spironolactone also blocks the aldosterone receptor, so at high doses it can cause salt-wasting even in non-salt-wasters.

Oral contraceptive pill (OCP)

Oral contraceptive pills regulate menstrual cycles and can lower ovarian androgen production. The estrogen component increases sex hormone binding globulin, so more testosterone is bound and there is less free testosterone circulating (thereby reducing symptoms). While OCPs alone do not substantially reduce adrenal androgens in CAH, they can reduce some of the bioavailable androgens and are useful for individuals with concomitant polycystic ovarian syndrome.

Other Forms of CAH

11β-hydroxylase deficiency

- Second most common form of CAH (about 5-8% of CAH cases)
- Caused by mutations in the CYP11B1 gene
- Classical and non-classical (NC) forms have both been reported, but NC is rare and does not usually cause hypertension
- Clinical features that are **similar** to 21-hydroxylase deficiency include atypical genitalia in 46,XX patients with the classical form, early onset of pubic hair/acne/axillary hair or odor, tall stature in childhood, early fusion of growth plates, and irregular periods
- A clinical feature that is **different** from 21-OH deficiency is hypertension (high blood pressure) rather than salt-wasting, although some newborns and infants may initially have salt-wasting
- Laboratory features include **low** potassium, **low** renin, mildly to moderately elevated 17OHP, elevated deoxycorticosterone (DOC), elevated 11-deoxycortisol, and elevated androgens

3β-hydroxysteroid dehydrogenase deficiency

- Very rare (less than 0.5% of CAH cases)
- Caused by mutations in the HSD3B2 gene
- Severe form causes salt-wasting and cortisol deficiency
- Can cause atypical genitalia in both 46,XX and 46,XY individuals
- Existence of a non-classical form is controversial
- Clinical features that are similar to 21-hydroxylase deficiency include salt-wasting, cortisol deficiency, early onset of pubic hair/acne/axillary hair or odor, and irregular menstrual periods
- Laboratory features include **low** sodium, **high** potassium, elevated renin, elevated DHEA, elevated 17-hydroxypregnenolone, and relatively low 17-hydroxyprogesterone, androstenedione and testosterone

17α-hydroxylase/17,20-lyase deficiency

- Extremely rare (incidence is about 1:1,000,000 births)
- Caused by mutations in the CYP17A1 gene
- Clinical features include hypertension, atypical genitalia in 46,XY individuals, and lack of pubertal development
- Laboratory features include **low** potassium, **low** renin, undetectable androgens, low 17OHP, low 17-hydroxypregnenolone, elevated deoxycorticosterone, elevated corticosterone, and elevated progesterone

Pandemic

With Covid vaccines now available to everyone 5 years of age and older in the U.S., new cases and hospitalizations are declining and many states have eased restrictions. However, the CDC continues to recommend wearing masks and social distancing in public indoor places. Outdoor activities remain safer than indoor activities in enclosed spaces. Remember to stress-dose for any febrile illness. Make sure you have enough medication on hand in case you need to quarantine.

Flu Prevention

- Early fall is the time to start thinking about immunizing your child against the influenza virus, which causes the "flu."
- Because any severe illness can precipitate an adrenal crisis in individuals with CAH, it is better to be protected ahead of time. Speak to your primary care doctor about the flu vaccine, which is inactivated and cannot cause influenza. It is safe for administration in individuals with CAH.
- Avoid close contact with anyone who is sick.
- When coughing or sneezing, cover your mouth and nose with a tissue. Wash your hands frequently, and avoid touching your eyes, nose, and mouth, which are susceptible areas for germs to enter the mucous membranes.
- Stay hydrated, get enough sleep, and try to eat a nutritious, well-balanced diet.

Stress-dosing when sick

- Stress-dosing is not needed for minor illnesses, such as a common cold, if there is no fever.
- Febrile illnesses:
  - For fever <102 degrees F, double the usual total daily amount of hydrocortisone and divide into 3-4 equal doses. Doses should be given every 6-8 hours until the fever is gone. For specific dosing instructions, ask your endocrinologist.
  - For fever >102 degrees F, give three times the usual total daily amount of hydrocortisone and divide into 3-4 equal doses. Doses should be given every 6-8 hours until the fever is gone. For specific dosing instructions, ask your endocrinologist
- Vomiting:
  - For a one-time episode of vomiting, repeat the dose if vomiting occurred within one hour of taking an oral dose of hydrocortisone. Otherwise, monitor for continued vomiting. If vomiting persists and you are unable to hold anything down by mouth, then give

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FUN-RAISING!

CAH AWARENESS WALKS 2021

A beautiful day to walk for CARES and CAH awareness! It was an amazing turn out for this 1st annual Long Island, NY event.

We would like to thank **the Stair Family** for hosting our first live walk event in East Islip, NY on Sept. 18, 2021! Nearly 90 supporters showed up to walk at the lovely Heckscher State Park! **Thank you to all the volunteers, donors, and attendees as well as our sponsor Neurocrine Biosciences.**

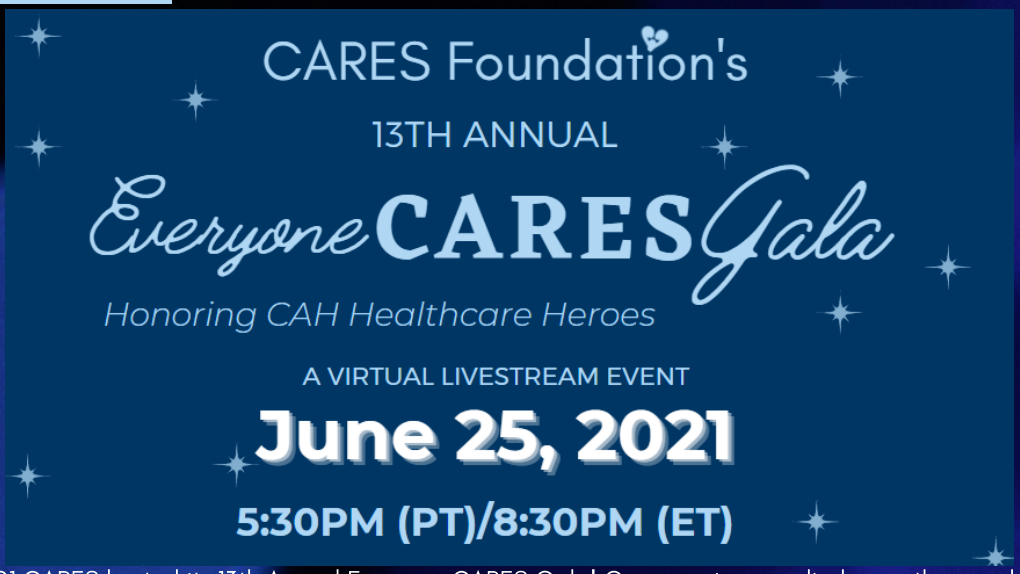
FLORIDA

November 6, 2021
Titusville, FL

Supporters braved the inclement Florida weather to attend our 2nd and last live walk of the season. They were treated to lots of fun activities including a candy-filled piñata, face painting, music and a challenging limbo contest for kids of all ages! There was also an opportunity to discuss clinical trials with a team from Neurocrine Biosciences.

There were many new faces at this 4th annual event that joined the walk across the Max Brewer bridge.

A special thank you to our amazing chair, **Lesley Holroyd!** She did an amazing job! Thanks also to our sponsors, **Cotiviti** and **Neurocrine Biosciences**, as well as the volunteers, donors, and all attendees. We look forward to seeing you next year!



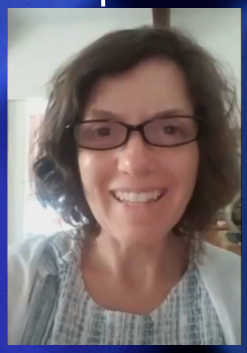
On June 25th, 2021 CARES hosted its 13th Annual Everyone CARES Gala! Once again, we relied upon the wonders of technology to live stream this special event that included a salute to CAH healthcare heroes. Our gala emcee was CAH parent and CARES supporter, Sue Shirey and included messages from CARES' Gala Committee members, our Executive Director, Dina Matos, Board of Trustees Chair, Louise Fleming, and many more. An abundance of prizes were auctioned during our silent auction as well as an exciting live auction led by Kenneth Shirey.

Emcee Sue Shirey

Auctioneer, Ken Shirey

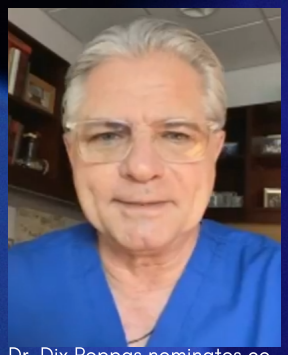
Board of Trustees Chair, Louise Fleming

We paid tribute to CAH Healthcare Heroes!


Julie Gillis nominates Dr. Karen Su, as her hero

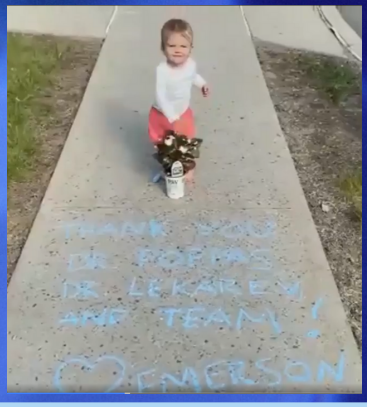
Katherine Fowler nominates Dina Matos as her hero


Lesley Holroyd nominated her dear, departed husband, Alan as her hero


Dr. Dix Poppas nominates co-worker, Denise Galan, CPNP as his hero


Deputy Fire Chief, Scott Vivier from Henderson, NV, received two nominations for hero!

Dr. Wesley Robertson is honored as Bella Shackley & Family's hero


Emerson, Jes & Ashley Brown pay tribute to Dr. Dix Poppas, Dr. Oksana Lekarev & the entire team at the Comprehensive Care Center for CAH, NY Presbyterian/Weill Cornell Med. Center

Joey Fleming, along with his family, honored Priscilla Rhodes, Phlebotomist, as their hero

Dr. Karen Su, CARES Medical Director and Medical Director of the Comprehensive Care Center for CAH at NY Presbyt/Weill Cornell Medical Center was honored as a hero

Gala Committee member, Ryan Hendler kicked off the *Honoring Our CAH Healthcare Heroes* segment

Gala Co-Chair, Karen Bogaard starts off the evening

Gala Co-Chair, Lesley Holroyd offers encouraging words about CARES

CARES' Executive Director, Dina Matos welcomed everyone

Entertainment included a video performance featuring performer Anthony Paul, with dancers Yana Berry and Bri Nixon. Two separate youth bands from the School of Rock in Long island rounded out the entertainment .

Thank you for your generous support!

Our 14th Annual

Everyone CARES Gala

June 4, 2022

Sony Pictures Studios

Culver City, California

Let us know if you would like to be a part of the planning committee.
Email Dina@caresfoundation.org

FUN-RAISING continued fr pg 9

CONGRATULATIONS TO OUR TOP THREE AWARENESS WALK FUNDRAISERS!

As part of our 2021 virtual walk season, we held a contest to see who could raise the most money hosting their own peer-to-peer fundraiser. This year, our top three fundraisers were:

GRAND PRIZE WINNER: LESLEY HOLROYD, FLORIDA

Wins an Apple Ipad!

2ND PLACE WINNER: VIRGINIA STAIR, NEW YORK

Wins a $150 Gift Card!

3RD PLACE WINNER: ABIGAIL WILSON, FLORIDA

Wins a $100 Gift Card!

THANK YOU ALL FOR MAKING A DIFFERENCE!

Family Fundraisers

May 10, 2021 marked the date of the 4th Annual Captain Jack's Quest for a Cure Golf Tournament, at the Pinehills Golf Course in Plymouth, MA. Close to 150 guests took part in this special event, playing golf, having a meal, as well as participating in an auction and a raffle. This event was a huge success, bringing CAH families and friends together, raising awareness and much-welcomed funds for CARES!

Thank you to our generous hosts, Zach, Kaitlin and Jack Porter!

This annual event is looked forward to by many golfers and friends who travel far and wide to support Captain Jack.

A beautiful fall day in Lehigh Valley, Pennsylvania, clay-shoot enthusiasts, breakfast, lunch and trophies made for a spectacular event for this year's 6th Annual Clay Shoot for CARES!

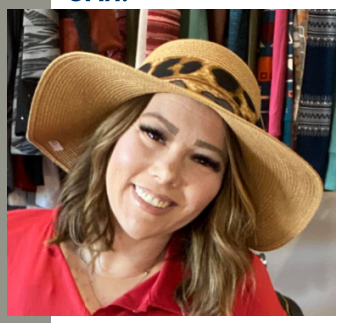
There were 60+ shooters anxious to get back to it after last year's event was canceled due to the pandemic. Thankfully, our host was not deterred this year and delivered on a good time for all.

Special thanks to host, Carlos DaSilva, as well as underwriters: AFN, USA; LB Industries; Ironbound Cleaning Services; Kappe Associates; MAC Installations, LLC; and Raffuel Surety Group.

THANK YOU to Sung Kim who raised money for CARES for his birthday in honor of his daughter with CAH!

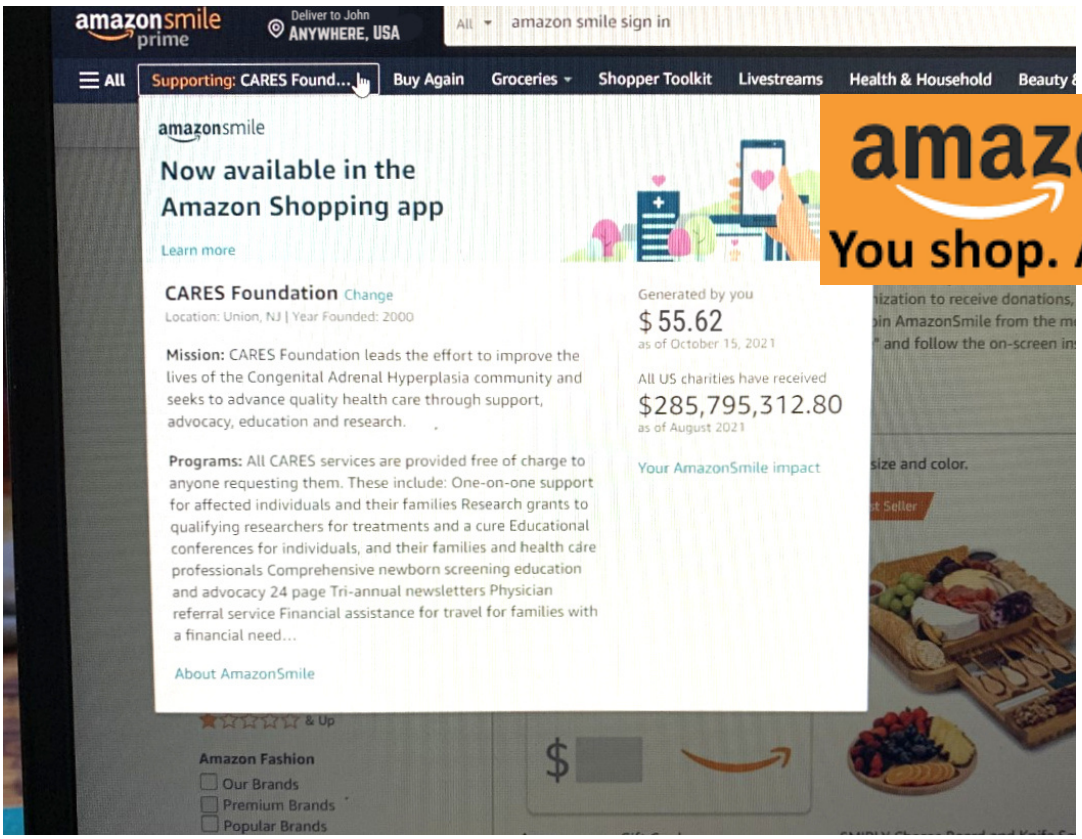
Sung also, along with his partners @RyanRozbiani and @omgitsfake of Trading Together (@flagrantfinance), encourages enthusiasts to purchase trading-themed merchandise and is donating a portion of the proceeds to CARES! **THANK YOU!**

THANK YOU to Krysten Pipitt who donated a portion of profits made at her Lularoe online clothing shop to CARES in honor of her friend's daughter who passed away from complications due to CAH.



CELEBRATE FACEBOOK STYLE! We encourage all of our community members to remember CARES when celebrating their special occasions and offer your friends, family and colleagues the chance to make a difference in the lives of all who are affected by CAH. Facebook fundraisers are easy to set up and raise funds for CARES throughout the year. ***THANK YOU TO ALL OF OUR FRIENDS WHO HOSTED BIRTHDAY and OTHER SPECIAL OCCASION FUNDRAISERS ON FACEBOOK THIS YEAR!***

OTHER WAYS TO SUPPORT CARES



amazonsmile
You shop. Amazon gives.

ARE YOU DOING YOUR AMAZON SHOPPING VIA AMAZONSMILE?

Please make the switch to Amazon Smile today. Designate CARES as your charity of choice, and when you buy, CARES will receive a portion of the proceeds. This is a simple way to make a difference because, chances are, you're already using Amazon for your shopping needs. Make the switch today and go to: https://smile.amazon.com/ To designate CARES, type "CARES Foundation" in search box, then carefully select **CARES Foundation, Union, NJ.** Everything else about your account is the same.

GIVINGTUESDAY

November 30th marks the date of the 2021 Giving Tuesday worldwide giving event. It's THE day to give back, to pay forward, to support nonprofits, charities, people in your community. "*Everyone has something to give and every act of generosity counts.*" Be a part of this special day and support CARES Foundation, the only nonprofit dedicated solely to the CAH community. PLEASE GIVE

Spend GIVINGTUESDAY at PANDA EXPRESS & GIVE to CARES Foundation November 30, 2021

PANDA EXPRESS CHINESE KITCHEN

VIRTUAL COMMUNITY FUNDRAISERS

Online orders only Apply code 905370 in the Coupon Code box during online checkout at order.pandaexpress.com or via App and CARES will receive 28% of pre-tax sales.
GOOD AT ALL US LOCATIONS, ONE DAY ONLY!

Continued from pg 8

injectable hydrocortisone (Solu-Cortef®) as instructed by your endocrinologist and go to the emergency room.

Trauma

- Trauma can occur at any time, but icy roads and participation in winter sports create more opportunities for accidents to occur. Be prepared for trauma by making sure you or your child is wearing medical alert I.D. and that Solu-Cortef® is easily accessible at all times.

Travel

- Be sure to keep handy plenty of fluids and snacks, extra medication, Solu-Cortef®, and a letter from your doctor explaining your medical condition and what treatment you require. It may be helpful to obtain the name of a local doctor and hospital in case of an emergency.

Please see our *"Guide to Traveling with CAH/AI"* (www.caresfoundation.app.neoncrm.com/np/clients/caresfoundation/product.jsp?product=17&) for more helpful tips. (Free download available in the CARES online Shop).

ADVOCACY

VISIT YOUR EMS PROVIDER

Patients, families and volunteers are constantly working to change protocols across the US to address adrenal crisis. We try to keep our website as up to date as possible. Feel free to share with us more recent protocols that you've discovered in your area.

When you go visit your local EMS take along these tips for a successful visit: https://tinyurl.com/w342m8na to alert them to your or your loved one's CAH status. Coming soon, an EMS training resource list which will include contacts for discussing EMS training as well as access to online training videos for EMS providers and guidelines for best medication timing & dose to treat adrenal crisis. This resource list will also include a link to our website which features:

- *Adrenal Crisis in the Emergency Setting* video
- *CAH and Stress Dosing* training video
- CARES Emergency Instructions

EMERGENCY REMINDERS:
Visit your local EMS near your home, child's school and/or your workplace BEFORE an emergency occurs.

IT IS YOUR RESPONSIBILITY to make sure that your local EMS officials are prepared to help you or your child in case of an emergency!

For more information on EMS, adrenal crisis, and other resources, visit https://caresfoundation.org/advocacy-ems-campaign/ AND https://caresfoundation.org/be-prepared-in-an-emergency/

ALWAYS WEAR MEDICAL I.D.
Medical ID should include: Adrenal Insufficient/Steroid Dependent - Administer Solu-Cortef® at appropriate dosage.

A medical I.D. could save your life!

SUPPORT

CARES strives to offer the most comprehensive support programs for our CAH community. We aim to improve our offerings and outreach so that more of those impacted by CAH can benefit.

CARES Support

We have traditional one-on-one over the phone support; secret Facebook groups geared toward specific groups; and Zoom support group meetings with experts available to answer questions. This is a unique opportunity for patients and parents/caregivers to gather valuable information.

We have also introduced **special support group meetings** with a variety of specialists. **We hosted one in March of 2021, featuring, Greer Gurland, Esq.**, an attorney specializing in education who provided guidance and answered questions on school issues when dealing with CAH children.

On October 7, 2021, we had a **special meeting, "Navigating the ER and Your Local EMS", with Craig Cooley, MD, MPH, EMT-P, FACEP.** Dr. Cooley gave the history and structure of ERs, EMS and ambulances, along with a practical look at ways to make the ER/EMS systems work for one with rare disorders.

CARES support also includes support group leaders. These leaders are available to guide and offer assistance to CAH patients, parents and caregivers who sometimes need to hear from a fellow CAH community member. There are support group leaders in 37 states, 11 foreign countries, and 14 more leaders by specialized topic.

We'd like to welcome our newest support group leader, Heather. Heather lives in Texas, is in her 30's, and has SWCAH. We are excited to have her as part of our support team and thank her for connecting us with Dr. Cooley.

If you'd like to be supported in a different way, let us know by emailing, support@caresfoundation.org. We welcome ideas and suggestions.

Please visit the support page on our website for more resources: https://caresfoundation.org/support/

As a reminder, if you are on Facebook, follower, CARES has established this **CAH Champions** profile for patients and families to exchange information, friendly advice, and to share CAH stories. If you have already joined the CARES community, simply click on *+add Friend*.

Your request will be reviewed by a member of our staff and then you will be able to get started taking advantage of this wonderful social connection!

CAH Champions also includes secret groups comprised of friends who are interested in specific CAH topics. These groups include:

- 3 Beta Women
- Newborn Support
- Parents of Kids with CAH and NCAH
- Parents of Kids with NCAH
- Classic CAH Women Support Group
- Teens/Young Adults Support Group
- Men with CAH
- Adoption
- Grandparents/Grand-caregivers

If you have not yet joined the CARES community, we urge you to do so today: https://caresfoundation.org/join-the-cares-community/

As part of the CARES community, you will receive the latest news and updates about CAH treatments, clinical trials, research opportunities, as well as CARES events, including support group meetings.

A PERSONAL STORY

Training a Low-Cortisol Detecting Service Dog

My name is Lexi, I am 16, and a junior in high school. I was born in April of 2005 and the newborn screening panel didn't have CAH on it until July of 2005. Shortly after I was born, I had many ups and downs and my parents and doctors figured out that I had CAH and worked to help stabilize me. Fast forward to 2019, I was talking with my endocrinologist, trying to figure out a solution for the lack of emergency CAH health support available at my college, and we discussed training a service dog. In California, in the K-12 public schools, nursing support is mandatory for students with CAH, however when I started college, there was lack of emergency health care on campus. I liked the idea of a service dog and started looking further into this as an option. There hasn't been a lot of research done on how to train CAH service dogs, so I took it upon myself and started by researching service dogs for diabetics. I discovered that the process for scent training dogs is universal.

You start by finding a dog that will best fit you, your lifestyle, and your family. The first step is basic obedience training. This is very important as your dog must learn to always obey your command and be well-behaved. Then you start your public access training (basic obedience for out in public and how a service dog should act), after that, you will start the CAH scent training, which completes your dog's training.

I began the process by collecting low-cortisol level samples with cotton balls. This sample is collected first thing in the morning, as early as possible, before you take your morning cortisol dose. You do this by shoving a cotton ball in your mouth and letting it soak up all your saliva. You can freeze them up to 2 months before use or use them right away for training. The scent training begins with teaching your dog to sniff on command. A great place to do this is at a hardware store garden department like Home Depot or Lowes. These are great places to walk with lots of smells around. This process will help when you start using your saliva samples, it will make it much easier for you to indicate what you need the dog to do. Once you've go that down then you move to a jar with one of the samples that you have collected. You need to get them used to smelling the samples, then start pairing that with an alert (paw, nose bump, nose push, jumping) and when they are adept at that, you start mixing in normal samples. These normal samples are collected 30 minutes after you have taken your medication. Mix these with only one low-cortisol sample. Don't reward them until they find the low sample. It's ok at the beginning if they don't alert you because you just want them to find it. Then when your dog starts to get the hang of recognizing the low sample, you start adding treats and toys around the samples as a distraction. As you are doing this make sure you are switching the order of the jars around.

Now you will go back to some basics and take a sample (cotton ball or roll), put it in a baggy and hide it on you. Once they find it and alert you, they will start to understand the smell will be on you and not just in some jars on the ground. Then you go out in public, for example a pet store, and practice again them finding it on you. Then go to regular stores, school, restaurants, etc. and practice it there. It takes a long time, so don't give up.

There will be lots of ups and downs in this training and it will get hard. Sometimes it will seem like it's not possible, but don't stop. Remember, I'm happy to help.

This is an overview of just scent training. There's so much more to service dog training; ADA public access test and training, basic obedience, and love and care. These dogs have such an important job, and you want to make sure you balance their life out with fun and work. The dog will be your best friend and I believe, if you do owner training (yourself) you grow so close to them and create such a strong bond. You can get a fully trained service dog, but they cost so much, and you miss out on creating the strong bond that is formed when the dogs are young.
Please reach out to me if you have any questions. I have started my own business and would be happy to help you if you would like to start training your dog.

If you'd like to learn more, you can email me at: Kellergirls1524@gmail.com

Disclaimer: This personal story is intended for informational and educational purposes only and in no way should be taken to be the provision or practice of any professional healthcare advice or services. Before starting any program, contact your healthcare professional.

CENTERS OF EXCELLENCE

CARES
Comprehensive Care Centers

. . . taking care of CAH patients & families across the country

Our eight Centers of Excellence offer patients an expert team of health professionals who specialize in the treatment of patients with congenital adrenal hyperplasia. Specialized care is provided for patients throughout their lifetime and extra effort is made to ease the transition from pediatric to adult care. We encourage patients and families to seek out care at any of our centers. We plan to offer more centers in the future.

Children's Hospital Los Angeles:
4650 Sunset Blvd. MS #61
Los Angeles, CA 90027

University of Southern California/Keck Medical Ctr
8700 Beverly Blvd.
Los Angeles, CA 90048

For appointments contact:
Janet Guerrero, Comprehensive Care Center Coordinator,
323-361-4630
janguerrero@chla.usc.edu or
VISIT WEBSITE:
https://www.chla.org/congenital-adrenal-hyperplasia-cah-clinic

UT Southwestern Children's Medical Center
1935 Medical District Drive
Dallas, Texas 75235

For appointments, contact Merritt Lamm or Emily Silva, (214) 456-5980

New York-Presbyterian/Weill Cornell Medical Center
525 East 68th Street, Box 103
New York, NY 10065

(646) 962-3442, Option 1
Email, Attn: Koree Richardson, Coordinator - kor2005@med.cornell.edu

VISIT WEBSITE:
https://www.nyp.org/komansky/comprehensive-center-for-congenital-adrenal-hyperplasia

Rutgers-Robert Wood Johnson Medical School (RWJMS), Child Health Center of New Jersey (CHINJ)
200 Somerset Street
New Brunswick, NJ 08901

VISIT WEBSITE: https://www.rwjbh.org/bristol-myers-squibb-childrens-hospital-at-rwjuh/treatment-care/endocrine-disease/

Children's Hospital of Philadelphia
Main Hospital
3401 Civic Center Blvd.
Philadelphia, PA 19104-4399

For appointments, (215) 590-3174

VISIT WEBSITE:
https://www.chop.edu/centers-programs/adrenal-and-puberty-center

Cook Children's Medical Center
801 7th Avenue
Fort Worth, TX 76104

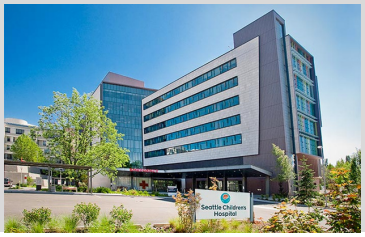
VISIT WEBSITE:
https://www.cookchildrens.org/services/urology/specialty-programs/congenital-adrenal-hyperplasia

Riley Hospital for Children/ Indiana University Health 705 Riley Hospital Dr
Indianapolis, IN 46202

(317) 412-1206
VISIT WEBSITE:
https://www.rileychildrens.org/departments/congenital-adrenal-hyperplasia-program

Seattle Children's Hospital and University of Washington Medical Center
4800 Sand Point Way NE
Seattle, WA 98105

For appointments: (206)987-0304 or toll free, (866)987-2000
VISIT WEBSITE: https://www.seattlechildrens.org/conditions/congenital-adrenal-hyperplasia/



To celebrate the giving season, most items in our shop will be discounted by 20-50%! November 26th through December 31, 2021

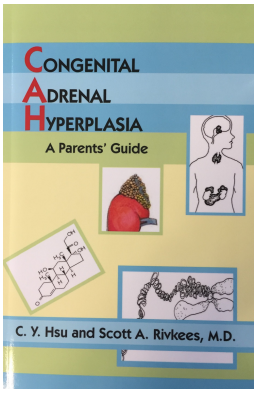
VISIT THE CARES SHOP

In our online store, you will find helpful tools to make living with CAH a little bit easier as well as an assortment of items to help raise awareness of this rare disorder.

THE OFFICIAL CARES FOUNDATION MUG . . . a perfect holiday gift!

Beautiful 17 oz. ceramic mug with CARES logo, website and signature heart! Use at home or at the office - a conversation starter for CAH awareness!

EMERGENCY RESPONSE KITS - Perfect for school, camp, clubs, sports, and leaving with the baby sitter! Clear, plastic, water-resistant bags just the right size for your Emergency Response Kit. Emergency wallet card and Emergency Instructions brochure are included. Purchase our package of 3 kits and have extra for all your needs - keep one in a purse, backpack, at Grandma's, etc. Colors may vary from picture.



Congenital Adrenal Hyperplasia: A Parents' Guide takes a nuts-and-bolts look at CAH-what this condition is, how it is inherited, and how it is treated and monitored. This book on CAH, written for a lay audience, will be welcomed by all patients, parents, caregivers, and healthcare professionals.

- By C.Y. Hsu and Scott A. Rivkees, M.D.

CARES Emergency I.D. Luggage Tag

Luggage tag good for a purse/bag, backpack or suitcase. Includes emergency instruction card.

These 4.25" x 2.75" x 0.125" thermo polyurethane tags have a soft, faux suede feel and clear PVC panel display window with writable information card and adjustable buckle strap closure. Good for any bag!

Medical ID Shoe Tags

2-ply red plastic oval tags (1"x1 1/2") with two holes (each 3/16" diameter). Laser engraved with medical id logo on front side and personal info on back side for privacy.

Tell First Responders how best to care for you in an event of an emergency Perfect for active kids and adults!

Adrenal Insufficiency Window Cling

In case of a car accident, this sign will alert emergency medical staff that there is a passenger with adrenal insufficiency in the car. The sign "clings" to the car window and can be easily removed. Have two cars or want to leave one with a caregiver? Buy extras so you don't have to worry about moving it.

CARES Foundation CAH Awareness Pin

Wear this fashionable, lapel pin to help RAISE AWARENESS of CAH. This silver pin is tie-tack style and works on any garment in any location. Measures roughly 1.25"x.75"

CARES "Pass the Salt" T-Shirt

We think you'll enjoy this creative way to spread awareness of CAH! Wear this fun, CARES tee around & you will surely be asked by at least one person, "What is CAH?"

CARES Magnet

CARES heart shaped magnet. Spread awareness of CAH by placing this nicely-sized heart magnet on your vehicle. 6"x6"

CARES Foundation

Visit today! https://caresfoundation.org/cares-shop-ii/

Please remember that CARES Foundation newsletters have "gone green" and are now only available electronically. Please make sure we have your most current email address and contact information to ensure that you continue receiving newsletters and other important information from CARES. Send your updated information to Odaly Roche at Odaly@caresfoundation.org.

Disclaimer: any communication from CARES Foundation, Inc. is intended for informational and educational purposes only and in no way should be taken to be the provision or practice of medical, nursing or professional healthcare advice or services. The information should not be considered complete or exhaustive and should not be used in place of the visit, call, consultation or advice of your physician or other healthcare provider. You should not use the information in this or any CARES Foundation, Inc. communication to diagnose or treat CAH or any other disorder without first consulting with your physician or healthcare provider. The articles presented in this newsletter are for informational purposes only and do not necessarily reflect the views of CARES Foundation, Inc.

CARES Connections

CARES Foundation, Inc.
2414 Morris Avenue, Suite 110
Union, NJ 07083

Phone: 908-364-0272
Toll Free: 1-866-CARES37
Fax: 908-686-2019
Email: info@caresfoundation.org
Web: www.caresfoundation.org

CARES Foundation

We are rebranding! Look out for our new logo - coming soon!

Announcing dates for 2022!

June 4, 2022 - 14th Annual *Everyone CARES* Gala
Sony Pictures Studios - Culver City, CA

October 8, 2022 - Patient Education Conference
Cook Children's Health Care System - Fort Worth, TX

Year End Giving 2021

Reflect on what CARES means to you and give generously this year so that we can continue to serve you

CARES Foundation

Happy Holidays!

From all of us at **CARES**