

CARES

Connections

Improving health, connecting people, saving lives

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Review of Health Problems in Adult Patients with Classic Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency

By Nicole Reisch

The introduction of newborn screening programmes in most Western countries for classic congenital adrenal hyperplasia due to 21-hydroxylase deficiency (CAH) enables timely introduction of life-saving glucocorticoid replacement in affected babies. Early diagnosis and optimised pediatric care not only successfully led to survival but also allow that almost all patients reach adulthood. Cohort studies in adults, however, provided evidence for significant health problems and co-morbidities of adult patients such as life-threatening adrenal crises, cardiovascular and metabolic health problems, fertility problems, benign endocrine tumours, and osteopenia and osteoporosis. This review summarises the current state of knowledge aiming to emphasize the necessity of primary and secondary prevention of additional long-term health issues as a major task of health professionals in the care of CAH.

Go here to download pdf of entire article: <https://www.thieme-connect.de/products/ejournals/pdf/10.1055/a-0820-2085.pdf>



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

Coming Summer 2021!

CARES Foundation, in partnership with Neurocrine Biosciences, is pleased to announce the launch of CAHtalog™ (Congenital Adrenal Hyperplasia: Patient and Clinical Outcomes in Real World Practice Settings). CAHtalog™ is a disease registry, a type of database that is used to collect and record information about people diagnosed with a specific disease for research and care purposes.

The main purpose of CAHtalog™ is to observe & assess how adults and children with CAH are managed by their doctors in a real-world setting. The registry will also provide a better understanding of the natural history of CAH and help raise awareness of CAH, which may lead to improvements in CAH patient care in the future.

The CAHtalog™ registry is purely observational and will not change current care, e.g. frequency of visits, lab tests, procedures, etc. It is also confidential and free of charge.

Beginning this summer, patients with classic CAH of all ages will be able to enroll, via their physicians, at participating sites and CARES Centers of Excellence. More information about this opportunity will be coming soon.

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A Message from the Executive Director



Dear Friend,

One year ago, most of us were in lockdown. Today, many of us are returning to a more “normal” routine with many back in their offices and in school. If the last year has proven anything, it is that we are resilient. Of course, many of us have witnessed the resilience of the CAH community long before COVID. CAH patients and families are among the strongest group of individuals I know. They fight to stay healthy by taking their medications on time, staying on top of doctors’ appointments, and submitting to lab work. Then there are the parents who remain vigilant over their children by seeking out the best medical care available, ensuring that caregivers, teachers, coaches, etc. are aware of their child’s medical condition and know what to do in an emergency, making sure that medications are always on hand, seeking second opinions and asking questions to educate themselves on the latest treatments, research and more. The daily resilience of our patients and parents is something I truly admire.

CARES is proud to continue working to help these patients and families live their best lives. We work closely with the pharmaceutical and biotech industry to bring new treatments to market, advance research, educate the community, provide support, and improve access to quality medical care.

The last several months have been exciting for our community as we:

- designated Children's Hospital of Philadelphia/University of Pennsylvania as a center of excellence for CAH
- developed a CAH registry that will be available in the US and Canada soon
- hosted our annual patient education conference
- expanded our support network
- saw a new medication (Alkindi Sprinkle) hit the market

In 2010 CARES began its collaboration with Diurnal Limited, a UK based biotech company that developed Alkindi Sprinkle (a new form of hydrocortisone for children) which became available in the US this past December. Over the years, we supported clinical trials for Infacort (development name for Alkindi), as well as Diurnal's other formulation, Chronocort (adult indication). More than 10 years later, we have seen that collaboration bear fruit as Alkindi Sprinkle which is designed for more precise dosing of hydrocortisone for infants and children hit the US market. This exciting development would not have been possible without the support of the CAH community including parents, patients and medical professionals. We are working with a number of other bioscience companies developing new treatments for CAH including Adrenas, Neurocrine and Spruce.

Another exciting development is our collaboration in the development of PACE, an app aimed at preventing adrenal crisis. It was developed with the assistance of the CARES community and will soon be expanded to a select few centers of excellence and other institutions.

CARES remains committed to the fight to preserve all medical treatments for CAH patients, including surgery. We continue to monitor and challenge legislative efforts to ban surgery. Our partners in this effort include patients, parents and other medical professionals who feel that surgery should continue to be available to children. Just days ago, the Pediatric Endocrine Society issued a statement on surgery. The Society advocates for continued education on the topic and a multi-disciplinary approach to decisions about surgery. They, like CARES, argue that medical care should not be legislated. We are grateful to the patients, parents and medical professionals who continue to be strong advocates for our community.

Finally, as we get ready to celebrate CAH Awareness Month in June, I urge you to take the opportunity to raise awareness of CAH by visiting your firehouse and advocating for emergency care; participating in clinical trials, attending a series of webinars planned for the month and participating in our annual Everyone CARES Gala which will once again be virtual. We are looking forward to honoring CAH health care heroes during the event and encourage you to nominate your personal hero. I hope to see you on June 25th!

Thank you for your resilience and bravery! You are my CAH heroes!



CAH

ongenital yperplasia
adrenal

AWARENESS

Month

JUNE 2021

CAH MASTER CLASS

In celebration of CAH Awareness Month, CARES will present weekly CAH webinars on a variety of topics led by CAH experts including:

Dr. Richard Auchus - Adult Endocrinologist, University of Michigan, Ann Arbor, MI

Dr. Louise Fleming - University of North Carolina, Chapel Hill, NC

Dr. Mitchell Geffner - Pediatric Endocrinologist, Children's Hospital Los Angeles, CA

Drs. Margaret Shnorhavorian and Patricia Fechner - Pediatric Urologist and Endocrinologist, Seattle Children's, Seattle, WA

Dr. Perrin White - Pediatric Endocrinologist, UT Southwestern Medical Center, Dallas TX

Webinars will be presented via Zoom on Wednesday evenings throughout June. More information regarding times and how to join will be posted soon!

Panda Express Fundraiser



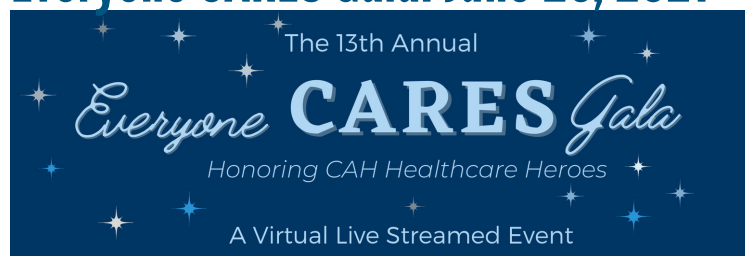
JUNE 4, 2021

Use our code (903652) and order online or through Panda Express app and CARES will receive 28% of pre-tax sales.

Good at all US locations, one day only!

Use this link to access online ordering: <https://rb.gy/ogxurz>

Everyone CARES Gala! June 25, 2021



Our annual gala will once again be a virtual, live streamed event scheduled for June 25, 2021. The gala is our biggest fundraising event. Proceeds from the event allow us to continue to advance our mission to offer programs & services that help CAH patients live better lives. We cannot fulfill our mission without your financial support. **Please join us!**

Visit our gala page today to sponsor, underwrite, donate and register!

<https://one.bidpal.net/caresgala2021>

We're counting on you!



We hope that you will make it a priority to spread awareness of CAH during June. Visit your firehouse and/or EMS station and let them know that you or a family member has CAH and discuss what to do in case of an emergency.

We encourage you to bring materials with you that include helpful tips for your visit, emergency instructions brochure and the EMS Medications Alert. (<https://tinyurl.com/3kmcameh>) Personal visits to firehouses and EMS stations are the most successful way to advocate for protocols. Do your part and help make a difference!

Remember to share and/or tag CARES in your CAH Awareness Month posts!

The 13th Annual

Everyone CARES Gala

Honoring Healthcare Heroes

JUNE 25, 2021

8:30PM Eastern/5:30PM Pacific



REGISTER TO ATTEND



Pay what you wish or register for free to attend the livestream

PURCHASE AN E-JOURNAL AD



Your own special message displayed on our website and during the event

SPONSOR



Become a sponsor & support our vital mission! Sponsor logos are featured on our website & during the event

UNDERWRITE



Fund the nuts and bolts of our special event

DONATE AUCTION ITEMS



Donate goods or services for our auction!

DONATE



Donate and make a difference in the lives of those with CAH

Excitement is building for our 13th annual gala celebration. We hope that you will join us for the live stream! This promises to be a special evening with silent and live auctions, special guests, entertainment and a celebration of our healthcare heroes!

Visit our gala site to learn how you can participate in this year's event
<https://one.bidpal.net/caresgala2021>

Nominate your CAH Healthcare Hero!



Celebrate your favorite CAH healthcare hero! Your hero/s can be a healthcare worker/team, a family member, or anyone who is a part of your CAH journey. All heroes will be honored during our 13th Annual livestream Gala!

Please send us a video telling us about your hero.

If you don't have a video, you can send a photo.

Videos should be 30 secs in length, maximum.

Email to bea@caresfoundation.org

Deadline is June 1st!

To nominate online, use this link: <https://pdf.ac/99AKI>

(This link is for a fillable pdf that you can complete online and submit directly to CARES. A photo release form is included for all video/photo submissions, as well as an e-journal ad form for the option of purchasing congratulatory ads)

Continued from page 1 - Research & Treatments



Recruiting Open for a Classic CAH Patient Survey

In partnership with CARES, Neurocrine Biosciences, a biopharmaceutical company, is recruiting 200 adults living with classic congenital adrenal hyperplasia (CAH) for an online survey to learn more about their preferences for a potential new medication. DRG (part of Clarivate), a health research company, is administering the survey. You can learn more about the survey and complete it here:

<https://tinyurl.com/3n7urnkj>, and you can email cah@clarivate.com with any questions.

Participation in the survey is on a "first come, first served" basis, so don't delay in signing up. Those who complete the survey will receive an electronic gift card as a thank you for their time. The results of the survey will be shared in an upcoming CARES newsletter.



The CAHtalytst Study is enrolling adult volunteers who have been diagnosed with classical congenital adrenal hyperplasia (CAH). They are looking for adults, 18 years of age and older to take part in this clinical research study. The primary purpose of this study is to evaluate the effectiveness of an investigational medication called crinecerfont compared to placebo in reducing daily glucocorticoid dosing and improving adrenal-related hormones. An investigational medication is one that has not been approved by regulatory health agencies.

To learn more, visit <https://cahtalytst.cahstudies.com/>



The CAHtalytst Pediatric Study is enrolling children and adolescents, ages 2-17 years, with classical CAH. The primary purpose of this study is to evaluate the effectiveness of crinecerfont. This pediatric study will work very much like the adult study (above). To learn more visit <https://cahtalytstped.cahstudies.com/>



FDA APPROVAL TO BEGIN CLINICAL TRIAL

Adrenas Therapeutics, a BridgeBio Pharma affiliate, is pleased to announce to patient advocates and to the broader CAH community that its Investigational New Drug application (IND) for CAH gene therapy is now open. An open IND means that Adrenas Therapeutics has permission from the FDA to proceed with their gene therapy trial in adults, ADventure CAH. Gene therapy is a new way of seeking to treat CAH that, for the first time, may offer people living with CAH the potential to make their own cortisol and aldosterone, in the right amounts and at the right times. The gene therapy will be administered via a one-time, intravenous infusion. Adrenas plans to begin enrollment at clinical sites located in the United States in 2021 and is currently working through start up activities with the clinical sites (<https://www.clinicaltrials.gov/ct2/show/NCT04783181>)



CARES is collaborating with SOLUTION Medical & others to support the development of an autoinjector for hydrocortisone sodium succinate.

SOLUTION Medical is making progress on a life-saving, reconstituting, autoinjector device which automatically mixes medication without requiring shaking or visual monitoring. Initial data shows our product mixes hydrocortisone sodium succinate (HSS) powder approximately 20X faster than the current standard of care in only one user step. They are presently working to optimize the product for manufacturing.

The immediate goal is to complete an aseptic manufacturability study with the device, by anyone at risk of an adrenal crisis regardless of location. Longer term, SOLUTION Medical envisions the device as applicable to many different drugs and treatments, allowing more at-home usage of a variety of medications requiring mixing directly prior to injection. To learn more, visit the website: <https://solutionmedllc.com/>



Diurnal is pleased to announce that the results of the international phase 3 clinical study of the development product Chronocort® in patients with Congenital Adrenal Hyperplasia (CAH) were recently published in the Journal of Clinical Endocrinology and Metabolism. This Phase 3 study was conducted in a total of 122 patients enrolled across 11 clinical sites in the US and Europe, the largest ever interventional clinical trial completed in CAH patients. The paper also included results for longer term treatment with Chronocort over a further period of 18 months.

The full publication can be found at: <https://academic.oup.com/jcem/article-lookup/doi/10.1210/clinem/dgab051>

On the back of these results Diurnal has been able to take Chronocort through a licensing process in Europe and has recently received a positive opinion from the Committee for Human Medicinal Products of the European Medicines Agency. This means that Chronocort should be licensed in Europe within 3 months.

Diurnal hopes to follow up this license with licensing in Great Britain and have used the results of this study, in discussion with the FDA, to plan a pivotal US clinical study with Chronocort. This study is planned to open at centers across the US later this year and will enroll up to 150 patients with classic CAH due to a deficiency of 21-hydroxylase. The study will be double blind, i.e. neither those taking part in the study or their doctors will know what treatment they are taking. Participants will be randomized to either Chronocort or hydrocortisone and will be on study for up to 15 months. At the end of the study participants can choose to continue into a follow-on study where all participants will receive Chronocort. More information regarding the study will follow soon and Diurnal will also be working with CARES to engage with the patient community to discuss the study and logistics so please watch this space.

- Dr John Porter, Medical Director, Diurnal

**Alkindi®
Sprinkle**
(hydrocortisone)
oral granules

The U.S. Food and Drug Administration (FDA) has approved ALKINDI® SPRINKLE (hydrocortisone) oral granules as replacement therapy for Adrenocortical Insufficiency (AI) in children under 17 years of age. ALKINDI® SPRINKLE is the first and only FDA approved granular hydrocortisone formulation for the treatment of adrenocortical insufficiency specifically designed for use in children.

For new article on Dosing & Safety Information, use this link:
<https://tinyurl.com/ydsakhzf>

Patient resources including administration videos, Spanish-translated medication guide and patient information are available here:
<https://tinyurl.com/68kc8ty4>

Ask your healthcare provider if ALKINDI® SPRINKLE is right for your child.



Development of an Adrenal Crisis Prevention Mobile Health Application

We are excited about the expansion of PACE (an adrenal crisis prevention mobile application) which has been developed by Louise Fleming, PhD, RN and her team of nurse researchers from NIH, Johns Hopkins All Children's Hospital, and CARES Foundation. The study was funded by the Pediatric Endocrinology Nursing Society (PENS).

The app:

- 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 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, family
- has a stress dose calculator for use with oral hydrocortisone

A pilot program with approximately 20 participants was completed this year. The quality of the app was assessed by the Mobile App Rating Scale (MARS). The study will soon be expanded to select CARES designated Comprehensive Care Centers, NIH, and the Children's Hospital of Alabama. It is our hope that it will become available to the general public within the year.

Developers and designers of the app recently presented at the PENS (Pediatric Endocrinology Nursing Society) Annual Conference.



Please check the CDC website (www.CDC.gov) on a regular basis and contact your doctor for specific recommendations.



We are in the late stages of evaluating tildacerfont, a new investigational drug that seeks to treat CAH. Besides potentially helping treat the disease, tildacerfont could significantly reduce the burden of steroids in CAH management. With your help, we can find a treatment specifically developed for CAH.

FREQUENTLY ASKED QUESTIONS

IS CLINICAL RESEARCH RIGHT FOR ME?

Volunteer participation in clinical research is a personal decision and can only be made by you.

Helping others with Classic CAH. By taking part in a clinical trial, you're contributing to science and helping to advance research that may improve quality of life for many people including yourself.

WHAT SHOULD I EXPECT IF I PARTICIPATE IN A CAHMELIA TRIAL?

Before joining a CAHmelia trial, you will be screened to check if the study is right for you. If eligible, you will:

- Begin taking study medication alongside your steroid regimen
- Keep an electronic diary to capture relevant daily information
- Receive a high standard of care with dedicated and experienced clinical staff

who will evaluate your health and progress

- All study-related care, including medical tests, clinical care, and the investigational study drug, will be provided at no cost to you
- Due to the impact of COVID-19, study visits are a combination of at-home visits, telemedicine visits and limited in-person visits

WHAT IS TILDACERFONT? Tildacerfont is a new oral, non-steroidal investigational medicine that is being studied for the treatment of classic CAH by blocking certain hormone receptors on the molecular level,

HOW DOES TILDACERFONT WORK? Tildacerfont works by blocking the CRFI receptor and thereby preventing ACTH overproduction and consequent androgen buildup.

IS TILDACERFONT SAFE? Tildacerfont is generally well tolerated in healthy volunteers and in patients with classic CAH

- No reported drug-related serious adverse events (SAEs)
- Generally well tolerated at effective doses
- Generally well tolerated across a diverse array of patients (old and young, male and female, better controlled, poorly controlled, normal and obese)

HOW WILL TILDACERFONT AFFECT HOW I LOOK/FEEL? Tildacerfont works to counteract classic CAH's effects on androgen production and may affect certain traits like body hair, weight, growth and acne. During your initial clinic visit, you'll have a chance to talk with doctors at length about how tildacerfont might affect your body. The studies will also assess how tildacerfont affects cholesterol, blood pressure, bone mineral density (BMD) and in males, testicular adrenal rest tumors (TARTS).

WHAT HAPPENS DURING THE TREATMENT PHASE? Participants in CAHmelia 203 or 204 will be randomized to either placebo or tildacerfont for 12 or 24 weeks, respectively.

All participants will have the opportunity to receive tildacerfont for at least 6 months. All participants will have periodic study visits during the treatment phase. During these visits, participants will meet with the study team, answer questionnaires, and have their blood

drawn for testing.

WHAT DOES IT COST TO PARTICIPATE IN A CAHMELIA STUDY?

- If you are selected to participate, you will receive all study-related care, including medical tests, clinical care, and tildacerfont tablets at no cost
- If the study site necessitates travel due to location, Clara Health will make travel arrangements and travel support with no out-of-pocket expenses incurred by you
- Travel support may also include meal expense reimbursement on study visit days
- You may be reimbursed a small amount for daily completion of your electronic diary confirming you took the study medication depending on the clinical trial site approval

For more Q&A click here:
<https://caresfoundation.org/wp-content/uploads/2020/12/CAHMELIA-FAQ-FINAL.pdf>



EDUCATION

Patient Education Conference

On April 24, 2021, CARES Foundation & Children's Hospital of Philadelphia co-hosted LEARNING ABOUT CAH: Updates & Management Tips, which was live-streamed to close to one hundred CAH patients, families and healthcare professionals.

We would like to extend our gratitude to all of the expert presenters:

- Maureen Baylis, RN**, Children's Hospital of Philadelphia (CHOP)
- Kamal Bharucha, MD**, BridgeBio
- Jean Chan, MD**, Neurocrine Biosciences
- Marissa Kilberg, MD**, CHOP
- Thomas Kolon, MD**, CHOP
- Oksana Lekarev, DO**, Weill Cornell Medical Center (WCMC)

- Ashwini Mallappa, MD**, National Institutes of Health (NIH)
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- Adam Shaywitz, MD**, BridgeBio
- Karen Su, MD**, WCMC
- Jason Van Batavia, MD**, CHOP
- Maria Vogiatzi, MD**, CHOP
- Alicia Weeks, MD**, Spruce Biosciences
- Amy Wisniewski, PhD** - Oklahoma State University
- Ron Wonsettler**, Eton Pharmaceuticals

Sessions were held on a variety of CAH topics and each session was followed by question & answer segments. There were also two sessions on Injection Training. Look for a recording on sale soon!

Special thanks to Dr. Maria Vogiatzi and Michelle McLoughlin for their effort in coordinating the event.



ADRENAL CRISIS & STRESS-DOSING VIDEOS AVAILABLE

Educational videos addressing adrenal crisis & stress-dosing are available for purchase in our online CARES Shop and available for viewing on our website.

To view:
<https://caresfoundation.org/multimedia-archives/emergency-patient-care-videos/>

To purchase:
<https://caresfoundation.z2systems.com/np/clients/caresfoundation/product.jsp?product=9&>

These videos are excellent training videos for parents, caregivers, friends, babysitters, and school personnel.

THE DOCTOR IS IN



Dr. Karen Lin Su
CARES Medical
Director



Now that summer is fast approaching, it is time to think about some precautions you can take to ensure that you or your child has a safe and enjoyable summer!

1. Extreme heat

Dehydration with salt loss through sweat is of particular concern for patients with CAH (especially for salt-wasters). If you/your child is going to be outside for an extended amount of time during extreme heat, please make sure that you have plenty of electrolyte-containing fluids available, along with snacks containing complex carbohydrates and salt.

Don't forget to apply sunscreen (at least SPF 30) and reapply after getting wet or every few hours (whichever comes first).

2. Increased physical activity

Once school is out, children are likely be more physically active, and they will be at risk for the same dangers that extreme heat can pose. The problems of dehydration with salt loss caused by the heat will be exacerbated by increased physical activity and exertion. Extra snacks and fluids are

particularly important for patients with CAH during strenuous exercise. Water alone does not provide adequate replenishment for what is lost during copious perspiration. Gatorade (or similar) provides electrolytes and glucose along with fluid replacement, but it may not contain enough sodium for salt-wasters who are sweating profusely. In these cases, salty snacks will also be necessary to make sure that hyponatremia (dangerously low sodium) does not occur. In certain situations, it may be appropriate to give extra fludrocortisone prior to a particularly strenuous activity, but do not do so without speaking to your endocrinologist first.

3. Trauma

Trauma can occur at any time, but increased outdoor activity creates more opportunities for accidents to occur. Be prepared for trauma by making sure you or your child is wearing a Medical Alert bracelet and Solu-Cortef is easily accessible at all times.

4. Travel

If you decide to travel this summer, check guidelines at your destination for possible quarantine mandates. 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 "Travel Guidelines" [Traveling with CAH/AI Packet](https://caresfoundation.org/cares-shop-ii/) in our CARES Shop for more helpful tips. <https://caresfoundation.org/cares-shop-ii/>

5. Summer Camp

In order for your child to remain safe during camp, whether it is a day camp or sleep-away camp, it is important to prepare ahead of time. If applicable, speak to the camp nurse about any medications your child requires during the day as well as when Solu-Cortef should be administered. Provide the camp with a letter from your doctor to keep on file. Also make sure that camp personnel understand the precautions detailed

under "extreme heat" and "increased physical activity."

Please see out [Getting Ready for School/Camp](https://caresfoundation.org/cares-shop-ii/) packet in our CARES Shop for additional information. <https://caresfoundation.org/cares-shop-ii/>



Sometimes it's difficult to get to the doctor. Sometimes you're not sure if your symptoms or condition warrant a doctor visit. Sometimes you're just curious.

We urge CAH patients and families to take advantage of our unique, "Ask-the-Expert" website feature. You can email questions, via online form, to CARES Medical Director, Dr. Karen Su. She will address your concerns, answer questions and offer advice via email in a timely manner.

Please, limit submissions to questions/concerns about CAH.

Visit our website to submit:

<https://caresfoundation.org/faqs/ask-expert/>



A veces es difícil ir al médico. A veces, no está seguro de si sus síntomas o afección requieren una visita al médico. A veces solo tienes curiosidad.

Alentamos a los pacientes y familias de CAH a aprovechar la función "Pregunte al experto" de nuestro sitio web. Puede enviar sus consultas por correo electrónico al experto Dr. Alejandro Díaz.

Él abordará sus inquietudes, responderá preguntas y ofrecerá asesoramiento por correo electrónico de manera oportuna. Limite las preguntas / inquietudes a los asuntos de CAH. Visite nuestro sitio web: <https://caresfoundation.org/pregunta-al-experto-en-espanol/>

ADVOCACY

Efforts Continue to Preserve Access to Surgery

CARES' SURGICAL PHILOSOPHY

CARES recognizes that any surgical decision, including timing, for some girls born with CAH is a deeply personal one to be made by the family in consultation with a multi-disciplinary team of CAH experts and evidence-based data. After careful consideration, decisions should be based on the specific medical situation of each individual. Due to the high complexity of these surgeries, CARES recommends that they be performed at one of our Centers of Excellence. CARES Foundation does not endorse any specific course of action, but supports all families under all circumstances.

CURRENT STATUS OF SURGERY BILLS

CALIFORNIA SB205 has turned in to a 2-year bill. We expect it will be reintroduced in January 2022.

NEW JERSEY AB5441 has been introduced but it has not yet been scheduled for a hearing.

TEXAS HB726 is stalled in committee.

RHODE ISLAND BILLS 593/6171 have been heard in the House and Senate. Discussions with bill sponsors and advocates are ongoing.

NEW YORK CITY BILL 1748A passed. We are working with the City Council and Governor's office to ensure that the right people are involved in education efforts.

Pediatric Endocrine Society Position Statement Regarding Surgery:

The PES believes that there can be no single approach to individuals with DSD conditions. The PES opposes government bans on genital surgery for DSD because legislation cannot integrate the myriad of factors that determine the choices for any specific individual. While deferring surgery may be the right decision for one person, a deferral may result in adverse mental health outcomes or suboptimal surgical outcomes in another individual. Instead, the PES believes that individuals with DSD deserve a comprehensive, individualized approach to care, ideally provided by a multidisciplinary team of expert and experienced providers.

Read full statement here: <https://tinyurl.com/48yksns2>



Did you know that most ambulances do not carry Solu-cortef®? Furthermore, that they are not allowed to administer the shot even if you have it? We are at work to develop EMS protocols for emergency medical treatment of CAH and other adrenal insufficiencies. Too many people suffer from delayed medical care in emergency situations.

A well-planned visit to your firehouse and/or EMS station could save your life or the life of a loved one. While on this visit, give them printed materials that you can download from our website. These include helpful tips for your visit, our emergency instructions brochure and advice on how to call attention to CAH/AI treatment by having them flag your residence for this condition.

Visit our webpage for more info and materials.

<https://caresfoundation.org/advocacy-ems-campaign/>

WEAR/CARRY MEDICAL ALERT!



Medical alert identification can take many forms, necklaces, bracelets, dog tags, purse/bag tags, shoe tags, etc., but whichever you choose, make sure it is highly visible to EMS personnel. All experts agree that wearing some type of medical alert is essential for those suffering from adrenal insufficiency. **This identification could save your life!** Learn more about medical I.D. on our website:

<https://caresfoundation.org/be-prepared-in-an-emergency/>



Find medical alert purse/bag tag & shoe tags in the CARES Shop.

<https://caresfoundation.org/cares-shop-ii/>



SUPPORT GROUPS

We can never thank our support group leaders enough for being there for others in our community. They are the "S" in CARES (congenital adrenal hyperplasia research, education + SUPPORT)! If you or a family member are newly diagnosed with CAH, have been struggling with living with CAH, or raising a child with CAH, one of our support group leaders has been in the same place and can offer you a listening ear and shared experiences.

Our support group leaders are a diverse group from all over the country and the world. They have kids with CAH; have CAH themselves; have lived with CAH for 6 decades; have played all sorts of sports; are jugglers; swam with the sharks in Bora Bora; studied abroad; done stand-up comedy; have 11 siblings; advocated with CARES for newborn screening for CAH in their state or country; have street raced cars; cliff dove in Mexico; delivered a calf in an open field; been Miss Dance USA of PA; skydived; advocated for local EMS protocols addressing adrenal crisis and so much more, as you can imagine.



Thurs., November 18, 2021 8:30PM (EST)

A psychologist, who specializes in treating patients with CAH, will be on the call.

Submit questions for the doctor in advance & register by emailing support@caresfoundation.org

SUPPORT GROUP MEETINGS

We continue to offer our support meetings. They have been changed to Zoom calls and it's been great seeing our volunteer experts and participants during the meetings. You are welcome to have your camera on or off during the meeting or just call in. In response to the

needs of our community, we recently had a special education lawyer on a parents' meeting and a psychologist on our women's meeting. Don't hesitate to let us know what would be helpful for you to discuss at an upcoming meeting. Here is our list of support meetings for the year:

<https://caresfoundation.org/event-calendar/>

REUNIÓN DE GRUPO DE APOYO TELEFÓNICO PARA PACIENTES Y PADRES DE CAH DE HABLA HISPANA

**October 20, 2021
8:30PM (ET)**



SECRET FACEBOOK GROUPS



NEWBORN
Support
GROUP

Another great resource are our CAH Champions, secret Facebook support groups. They cover many aspects of CAH: parents/caregivers of newborns; teens/young adults; men with CAH; parents/caregivers of twins; parents/caregivers of college students; 3 beta CAH; 11 beta CAH; 17 hydroxylase; parents/caregivers of children with NCAH; women with classical or non-classical CAH; CAH athletes; those with CAH-X (CAH + Ehlers Danlos Syndrome); women over 50; and partners/spouses. To participate in any of these groups or suggest a new group, email karenf@caresfoundation.org

Special thanks, again, to all of our support group leaders and healthcare professionals!



10 years of CAH Research Support

IFCAH First (DIGITAL) Symposium

Monday, June 14, 2021

4:00 pm to 7:00 pm (CET)

IFCAH is pleased to welcome all patients, patient families, researchers and clinicians to share their very last findings on CAH, obtained thanks to 10 years of IFCAH support.

International CAH experts will present their last results issued from their research work and respond to your questions.

Speakers:

- **Michel Polak:** IFCAH 10 years CAH funding projects
- **Gerard Conway (tbc):** CAH women fertility and pregnancy
- **Hedi Claahsen:** CAH men fertility: current insights on TART in male CAH patients
- **Li Chan:** Ways of Androgens decrease: ACTH inhibitors
- **Richard Ross:** Adrenal glucocorticoid replacement in CAH
- **Leonardo Guasti and Andreas Schedl:** Gene and cellular therapy

Free but mandatory registration here: <https://www.opinews.com/lfcach/?lang=en>

CARES

Comprehensive
Care
Centers

There are currently eight (8) CARES designated Comprehensive Care Centers/Centers of Excellence in the U.S.



Co-Medical Directors: Mitchell Geffner, MD and Mimi Kim, MD, MSc

Surgical Director: Roger De Filippo, MD

Care Center Coordinator: Janet Guerrero

New research from the CHLA

Comprehensive Care Center has shown that computers may be able to use subtle facial features to recognize CAH. This finding could lead to an improved understanding of CAH patients and was published in the scientific journal JAMA Network Open in November, 2020. Drs. Kim and Geffner teamed up with engineers and scientists from the University of Southern California Information Sciences Institute to study images of 102 patients with CAH and 144 control individuals. Through machine learning, a neural network trained in facial recognition was able to identify subtle differences in facial morphology—and correctly identify the patients with CAH—with greater than 90% accuracy.

The study represents an important step in the path to better identifying and understanding CAH. The findings establish, for the first time, that not only is there a link between facial morphology and CAH, but computers can detect this link and predict CAH based on facial features of patients.

For article about research:

<https://tinyurl.com/t38mwvs3>

To plan a visit to this center, visit the website: <http://www.chla.org/CAH>



WELCOME!

The Comprehensive Care Center at Children's Hospital of Philadelphia/Penn Medicine, is the most recent addition to our Centers of Excellence.

This center was designated earlier this year and is led by:

- **Director:** Maria G Vogiatzi, MD
- **Associate Director:** Julia Kharlip, MD
- **Pediatric Urologist:** Thomas Kolon, MD
- **Care Coordinator/Educator:** Michelle McLoughlin, CPNP

"At CHOP, we are dedicated to helping patients and their families fully understand CAH and all of their treatment options through a multi-disciplinary approach. As a Center of Excellence, our decades of experience allow us to better understand the variety of patients requiring individualized care."

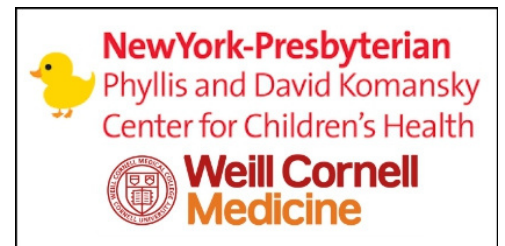
- Dr. Thomas Kolon, Surgical Director



"We understand that the care of a person with CAH can be challenging. We are here to help at every step, from bringing the latest treatment options, to tailoring the treatment plan to the individual needs, to providing support to patients and families in their decisions and efforts to manage CAH. We are proud of our dedicated team of experts who strive to provide comprehensive, integrated care from childhood to adulthood."

- Dr. Maria Vogiatzi, Medical Director

To plan a visit to this center, visit the website: <https://www.chop.edu/centers-programs/adrenal-and-puberty-center>



Medical Director: Karen Lin Su, MD
Associate Medical Director: Oksana Lekarev, DO
Surgical Director: Dix P. Poppas, MD, FACS

Dr. Karen Su, Medical Director, and Dr. Oksana Lekarev, Associate Medical Director presented a poster at the PES annual meeting along with Jennifer Apsan MD, Charlene Thomas MSc.

1. Division of Pediatric Endocrinology, Department of Pediatrics, Weill Cornell Medicine, New York Presbyterian Hospital, New York, NY, United States.
2. Division of Biostatistics and Epidemiology, Weill Cornell Medicine, New York, NY, United States

The presentation was a retrospective chart review (n=128 office visits) of pre-pubertal children with Classical CAH, and it was conducted at the New York Presbyterian/Weill Cornell Comprehensive Care Center for CAH. Data were extracted from one annual comprehensive visit each year between ages 7 to the onset of puberty. We compared adrenal control, testosterone levels, androstenedione levels, annualized growth velocity (AGV), bone age, blood pressure, BMI, steroid dose in those taking glucocorticoids twice daily (n=77) versus three times daily (n=51). Our results demonstrated that there is no difference in total daily steroid doses in BID versus TID steroid regimens. In terms of biochemical parameters, there was no difference in adrenal control or testosterone between the dosing groups. There was a lower androstenedione in the TID group. In terms of metabolic parameters, there may be a slight decrease in diastolic blood pressure in those with TID dosing though this may be clinically insignificant as both groups maintained normal diastolic blood pressures on average. In terms of growth parameters, there was no difference in annualized growth velocity or in bone age advancement between the groups.

In conclusion, based on the study there is no clear advantage to BID versus TID hydrocortisone dosing in the treatment of CAH in prepubertal children with classical CAH. Dosing regimens should be patient-centered and take into account daily schedules and real-world compliance with a mid-day dose. BID dosing does not appear to detract from overall adrenal control biochemically nor does it appear to impact growth parameters or bone age advancement. TID dosing will not increase total daily steroid doses, nor will it increase metabolic side effects of steroid regimens.

Congratulations to Drs. Su and Lekarev!



To plan a visit to the New York center, visit the website:

<https://pediatrics.weill.cornell.edu/divisions-and-services/comprehensive-care-center-congenital-adrenal-hyperplasia-cah>



COMPREHENSIVE CARE CENTER FOR CAH - Seattle Children's Hospital and University of Washington Medical Center, Seattle, WA

Medical Director: Patricia Y. Fechner, MD, FAAP, FACE

Co-Surgical Directors: Mark Cain, MD, FAAP, and Margaret Shnorhavorian, MD, MPH, FAAP, FACS

Seattle Children's has had an exciting first year as a CARES Foundation Level 1 Comprehensive Care Center for CAH and is so appreciative of the support that Seattle Children's has received from CARES.

Family support and education: Seattle Children's continues its collaboration with Camp Korey and have designated a week for "CAH Family Camp Korey Week" for families to enjoy a socially-safe, residential camp experience. It will be a time for families to spend time together doing fun outdoor activities. Sign up is now ongoing.

We are also in the process of launching support groups for parents and a separate one for teens to complement the CARES Foundation support meetings. Dr. Fechner had the opportunity to participate in the January CARES newborn support group and thoroughly enjoyed the experience. The center is looking forward to support groups for CAH children and families.

Regional access to care: During COVID, Seattle Children's Hospital and Regional Medical Center CAH CCC continues to provide medical and surgical care for children and families in the Pacific Northwest WWAMI region

including Washington, Wyoming, Alaska, Montana, and Idaho. This has been via a combination of in-person visits and CAH team telemedicine visits.

Research and Quality

International collaborations: Seattle Children's continues to partner with I-CAH as one of the few sites in North America. Dr. Shnorhavorian was invited to be a member of the I-CAH steering committee and a member of the I-CAH Quality Care Committee. *Congratulations!*

National and regional CAH Clinical Research trials led by Dr. Fechner and her team

Completed: Dr. Fechner and her team have completed one phase 2 study using Crinecerfont, an investigational corticotropin-releasing factor type-1 receptor antagonist in adults and are currently enrolling adolescents with classic CAH age 14-17 for a second phase 2 study.

Ongoing: Three ongoing studies for adults are being led by Dr. Fechner. The first two, CAHmelia is designed to evaluate the efficacy of Tildacerfont, an investigational, oral, once-a-day corticotropin-releasing factor type-1 receptor antagonist in two placebo-controlled, late stage clinical studies in adults with Classic CAH. The third study, CAHtalyst is evaluating the safety and efficacy of Crinecerfont in lowering high androgen levels. This is an 18-month study including a 6-month double-blind, placebo-controlled period followed by 12 months of open-label treatment.

Future: Planning for further studies for children and adolescents using the same investigational agents.

To plan a visit to the Seattle Children's center, visit the website: <https://www.seattlechildrens.org/conditions/congenital-adrenal-hyperplasia/>





COMPREHENSIVE CARE CENTER FOR CAH - Rutgers-Robert Wood Johnson Medical School (RWJMS), Child Health Center of New Jersey (CHINJ) New Brunswick, NJ

Co-Medical Directors: Ian Marshall, MD
Ahmed Khattab, MD, MSC

To plan a visit to this center, please visit the website:

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



COMPREHENSIVE CARE CENTER FOR CAH - UT Southwestern Children's Medical Center Dallas, Dallas, TX

Medical Director: Perrin C. White, MD
Contact info coming soon!



COMPREHENSIVE CARE CENTER FOR CAH - Cook Children's Health Care System, Fort Worth, TX

Medical Director: Paul Thornton, MD, BCh, MRCPI, DCh



To plan a visit to this center, visit the website:

<https://cookchildrens.org/urology/specialty-programs/Pages/Congenital-Adrenal-Hyperplasia.aspx>



Medical Director: Erica Eugster, MD
Associate Medical Director: Todd Nebesio, MD
Surgical Director: Richard C. Rink, MD
Care Center Coordinator: Heather Frady, RN

A study, "Majority of females with a life-long experience of CAH and parents do not consider females with CAH to be intersex", (<https://rb.gy/ovaiaq>) conducted by Riley Hospital for Children's Dr. Richard Rink, et. al, on behalf of Life with Congenital Adrenal Hyperplasia Study Group, was recently published in the Journal of Pediatric Urology [(2021) 17, 210.e1e210.e9].

The purpose of the study was to "assess opinions of females with CAH, and parents of female with CAH, about designating this population "intersex", particularly in legislation about genital surgery during childhood."

To plan a visit to the Riley Care Center, visit their website:

<https://www.rileychildrens.org/departments/congenital-adrenal-hyperplasia-program>



The CAH Comprehensive Care Center is comprised of a multi-disciplinary team of healthcare professionals who are experts or developing experts in the care of CAH. The goal is:

- to provide excellent care to patients with Congenital adrenal hyperplasia (CAH) from childhood to adulthood
- promote research that will improve patient lives
- educate patients, families and other healthcare providers in CAH and its management

Our newsletter, CARES Connections, is published bi-annually. For current information, look for our monthly email updates.

Monthly Updates



In these updates, and on social media, you will get information on all current programs, as well as important news about CAH treatment, clinical trials, research, support, etc.

Let us know if you are not getting our email updates, contact@caresfoundation.org

FUN-RAISING!



CHARITY STRIPE



On March 12, 2020, right before the lockdown began, East Woods School and Board of Trustees member Brian Stair & family hosted a basketball fundraiser for CARES!

The event featured a free throw challenge, Knock out, Skill Development, a concession stand and more! All in all a fun afternoon for East Woods School families AND a nice donation to CARES!

Thank you to the Stair Family and East Woods School



RARE DISEASE DAY® FEBRUARY 28 FUNDRAISERS

Eric Grabow & family hosted a month-long Facebook fundraiser in honor of Rare Disease Day. Eric is the father of three children with CAH and his efforts raised over \$1,000 for CARES. We are truly grateful for your efforts!

The Geletko family from Pennsylvania also hosted a fundraiser for Rare Disease Day and chose to raise money at their daughter Vivienne's school. They have two girls with CAH and have been members of the CARES community for many years and make it a priority to raise awareness of CAH in many ways. Thank you, Geletko family!

RARE DISEASE DAY, always in February, is a great time to raise awareness of CAH - one of over 6,000 rare diseases affecting 300 million people worldwide. Plan your own celebration for 2022 and don't forget to share it with CARES!



OneDigital, a national strategic advisory firm that focuses on driving business growth for employers of all sizes, hosted the **12th annual OneDigital Dash** a run

fundraiser which was presented virtually on Monday, October 26, through Sunday, November 1, 2020. The signature event raised a total of \$350,000 for nonprofit organizations nationwide and CARES is proud to announce that they were one of the fortunate beneficiaries of that prize!

Over the event's 12-year tenure, OneDigital has raised over \$800,000 while spreading awareness for nonprofit organizations.

OneDigital employee and CAH mom, Abbey Welsh, who had her own fundraising team, the DMV Dashers, was instrumental in securing a donation for CARES. We are grateful to Abbey and OneDigital for supporting our mission!



During this tumultuous year, shopping with Amazon has become the go-to way to shop. Many will continue to rely on Amazon's convenient way to shop, their outstanding inventory, fair prices, and fast delivery.

Make sure to visit Amazon Smile the next time you place an order. [Smile.amazon.com](https://smile.amazon.com)

Amazon donates to CARES every time you shop at no additional cost to you! You can use the same account that you use on your regular Amazon, simply by logging in on the Smile.Amazon.com page, after clicking "get started".

Please let us know if you need any assistance setting up your Amazon Smile account. contact@caresfoundation.org



"Matching gifts are a great source of additional revenue for nonprofits. In fact, an estimated \$2 to \$3 billion is donated through matching gift programs every year."

We hope that your company or corporation philanthropy includes a matching gift program and that you will choose CARES for your gift!

Check with your employer to see if they offer matching gifts, then just give us the company name, address, phone number & contact name (if available), and we'll do the rest!

Please also consider a recurring donation. You can schedule a donation weekly or monthly.

To make a donation with a matching and/or recurring gift option, please use this form: <https://caresfoundation.z2systems.com/np/clients/caresfoundation/donation.jsp>

If you have any questions, please contact: bea@caresfoundation.org.



What better way to celebrate a birthday or other special occasion than with a Facebook fundraiser for CARES!

It's easy and fun, and we can help you get yours off the ground. Follow these easy directions and you can do your part to support CARES and the CAH community. We celebrate our birthdays one day a year and by holding a Facebook fundraiser, you can help spread awareness of CAH and share your support of CARES with friends, family and colleagues.

To create a Facebook fundraiser for CARES, use this link while on Facebook: <https://tinyurl.com/4zfee6tk>



CAH CONGENITAL ADRENAL HYPERPLASIA AWARENESS WALKS 2021

SPONSOR!

DONATE!

FUNDRAISE!

START A TEAM!

REGISTER TO ATTEND!

2020 was a hard year for awareness walks but we are looking forward to a renewed season of events and hope that you will give it your all by sponsoring, donating, fundraising, starting a team, and attending!

We have one walk already scheduled for the fall, and will be announcing new dates soon!

4TH ANNUAL FLORIDA WALK

The walk will take place on November 6, 2021 in beautiful Titusville, FL. The event is open and we are ready to accept your registrations, donations, sponsorships and teams!

Please visit the Walk page for more details:

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



We are excited to hold our 6TH ANNUAL CLAY SHOOT FOR CARES after cancelation due to Covid last year. A date has not yet been confirmed but we would like to encourage you to support this event by

- SPONSORING
- UNDERWRITING
- DONATING

If you are interested in helping, please contact Bea, bea@caresfoundation.org.

We look forward to returning to Lehigh Valley Clays in Pennsylvania for some friendly (and yes, slightly competitive) sport shooting! Stay tuned to our website & social media for more info!

FAMILY FUNDRAISERS



The links were open and they wanted to play golf! The event hosts, Zack, Kaitlin & Jackson Porter, couldn't be happier that this year's annual event would not be hampered by the pandemic!

More than a hundred golfers took to the green on May 10th to help support CARES Foundation. The event featured 18-holes of golf, lunch, a tricky tray, raffles and tons of fun. This fundraiser provides golf fanatics a way to indulge in their beloved sport while doing a good thing for the CAH community.

You can still support this event by donating:

<https://caresfoundation.z2systems.com/donation.jsp?campaign=234&>



Thank you to our hosts, the Porters: Zack, Kaitlin & Jackson! Your hard work and enthusiasm are greatly appreciated!

Remember that CARES newsletters have gone green and are now only available electronically. Make sure we have your most current email address and contact information to ensure that you continue to receive newsletters and other important information, Send any updates to Odaly@caresfoundation.org.

DISCLAIMER: Any communication received from CARES Foundation, Inc., is for informational and educational purposes only and in no way should be taken to be the provision and practice of medical, nursing, or professional healthcare advice of your physician or other healthcare provider. You should not use this or any other CARES Foundation, Inc. communication to diagnose or treat CAH or any other disorder without first consulting with your physician or other healthcare provider. The articles presented in this newsletter are for informational purposes only and do not necessarily reflect the view of CARES Foundation, Inc.

CARES Connections

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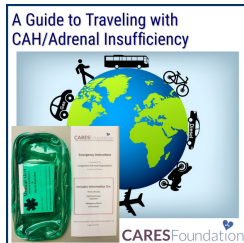
Visit the CARES SHOP

In our online CARES Shop, we offer many helpful tools to help improve the quality of your CAH life, as well as unique specialty items. Visit today!

<https://caresfoundation.org/cares-shop-ii/>

TRAVEL GUIDE with Shot Kit

Just in time for summer!



Traveling with CAH/Adrenal Insufficiency (AI) is all about being prepared, taking the proper precautions, and most of all, having fun! CARES Foundation's "Traveling with CAH Packet" will help you plan for a safe and healthy trip. The printed packet includes: a One-Shot Kit Bag for your Emergency Response Kit



PASS-THE-SALT TEE

Join the Adrenal family for a healthy, salt-filled meal and don't forget to pass the salt! These fun tees are bound to be a conversation-starter and a great way to spread awareness of CAH. They are made of high-quality Gildan Heavy Cotton™, in light, heather gray with the CARES logo and website on the back.

Emergency Response Kit - Set of 3

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. (Colors may vary from picture shown)



CARES' Emergency I.D. Tag

Attach to 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.

Raise Awareness!

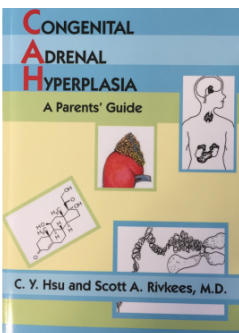
CARES' Car Magnet

CARES heart shaped magnet for your vehicle! 6"x6"



CARES' 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".



Congenital Adrenal Hyperplasia: A Parents' Guide

Takes a nuts and bolts look at CAH - what the condition is, how it is inherited, and how it is treated and monitored. This book on CAH is written for a lay audience and is welcomed by all patients, parents and healthcare professionals. By C.Y. Hsu and Scott A. Rivkees, MD



CARES' Keep Calm Mug

Finely-crafted ceramic mug with "Keep Calm and Give Solu-Cortef", the perfect mantra for caretakers of patients with CAH. A lovely gift idea!

Great end-of-year gift for school nurses!