CARES connections

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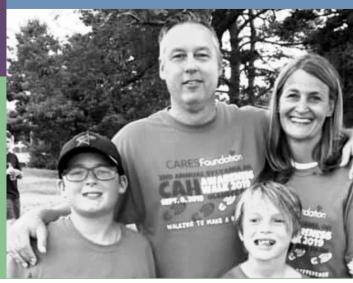
Improving health, connecting people, saving lives



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Emerging medical therapies for congenital adrenal hyperplasia

Phyllis W. Speiser, Zucker School of Medicine at Hofstra-Northwell Health

Introduction

Congenital adrenal hyperplasia (CAH) is caused by one of several inherited enzyme deficiencies. The most common form of the classic disorder, found in about 1:14,000 to 1:18,000 births, is steroid 21-hydroxylase deficiency. Mutations in CYP21A2 (P450c21) impair adrenocortical production of cortisol and frequently aldosterone and lead to the accumulation of adrenal sex steroids [1]. Allelic variation accounts for most phenotypic differences. Cardinal features of classic CAH include atypical development of the external genitalia in girls with manifest virilization. Both males and females have salt wasting with failure to thrive and potentially fatal hypovolemia and shock. Newborn screening, now universal in the US [2] and in many developed countries [3], can mitigate these complications (reviewed in 4). Despite life-saving glucocorticoid (GC) and mineralocorticoid (MC) oral therapies, treatment does not precisely replicate adrenal physiology. Individuals with CAH commonly experience adverse outcomes in terms of growth, metabolic, reproductive, and mental health [5,6]. This discussion of emerging medical treatments will be restricted to the classic or severe forms of steroid 21-hydroxylase deficiency.

Improved glucocorticoid delivery

Normal adrenocortical secretion has a circadian rhythm quite distinct from that of blood cortisol levels achieved by administering two or three daily oral doses of GC medication.[7,8] Hydrocortisone (HC) subcutaneous delivery for 6 months via a programmed pump in eight adults with classic CAH produced significant reduction in adrenal androgens with improvement in quality of life and fatigue. [9] Though conceptually attractive and perhaps applicable to highly motivated patients who are inadequately managed by conventional treatment, pump management is complex. An early trial with a once-daily modified-release oral HC preparation (Chronocort, Diurnal, Cardiff, UK) given to 16 adults with classic CAH decreased adrenal androgen pre-cursors despite a slightly reduced daily HC dose. [10] However, subsequent phase 3 trials apparently failed to demonstrate superiority to standard HC treatment and this potential new treatment is currently on hold. A different type of modified -release GC (Plenadren, Shire, London, UK) is approved in Europe for adrenal insufficiency but has not been formally tested in CAH.

In the US, the lowest-dose HC tablet is 5 mg, and in Europe 10 mg, excessive for infants and young children. Availability of pediatric-dose formulations would eliminate concerns about improper compounding of HC from tablets. [11,12] Based on favorable trial results, [13] the European Medicines Agency has approved very-low-dose HC 1 mg granules (Alkindi, Diurnal) for treatment of adrenal insufficiency or CAH in infants and children. A US Food and Drug Administration new drug application is said to be pending.

Androgen/estrogen antagonists and synthesis inhibitors

To ameliorate the effects of adrenal androgen excess, females with CAH often need treatment additional to GC replacement. Such treatments may include dermatologic therapies for acne and hirsutism or additional hormone treatments (or both) to regulate menses or aid conception. All steroidogenic pathways to androgens and estrogens depend on activity of the enzyme 17-hydroxylase/17, 20-lyase (P450c17, CYP17A1). Abiraterone acetate is an orally active, potent P450c17 inhibitor [14] indicated for treatment of castration-resistant prostate cancer, [15,16] Short-term adjunctive treatment with 250 mg/day abiraterone acetate alongside standard steroid replacement) normalized the pre-dose serum androstenedione levels in all six women with poorly controlled classic CAH. [17] Because abiraterone acetate also inhibits gonadal steroid production and could be

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A Message from the Executive Director

Dear Friend:

As another year comes to a close, we celebrate our greatest achievements and look forward with excitement to what lies ahead. We are confident that the future is bright for CAH patients.

This year has been marked by more awareness events, educational resources, a growing support network, increased interest in CAH research and celebrating those who have had such a significant impact on CARES and the CAH community. It has also been a year of fighting for the rights of patients and parents. And, it's been a sobering time, as we recognize that there's so much more to do. In the last few months, we lost three patients whose lives were cut short because of a lack of medical knowledge, not taking the disorder seriously or suffering from the effects of living with a life-threatening medical condition.

So, as we look forward to our 20th anniversary next year, we do so recognizing all that's been achieved and most importantly, all the work that must continue. We are proud of the lives that have been saved through newborn screening; the education that has been provided to patients and families; the research that has led to a better understanding of CAH; the improved medical care through our centers of excellence, physician referral program, and ask-the-expert service; the connections that have been made through face-to-face meetings, conferences and fundraising events; the support provided on a one-on-one basis, through support group leaders and conference calls; the life-saving EMS protocols; the advocacy on behalf of patients and families, and of the community we have built.

As we celebrate our accomplishments, we also look forward to igniting the future with more educational opportunities for patients, families and medical professionals; more research initiatives that will lead to better treatments and someday, a cure; more access to expert medical care; more advocacy, and unparalleled support for our community.

Your continued support, generosity and engagement will propel us into the next decade. I invite you to help us celebrate our legacy and ignite the future as we look forward to 2020!

Research continued from pg 1

teratogenic, its use in CAH would be limited to pre-pubertal children, women using contraceptives, or men who receive gonadal replacement. A clinical trial is under way in pre-pubertal children with CAH (ClinicalTrials.gov Identifier: NCT02574910) with the goal of minimizing exogenous GC and endogenous adrenal sex steroid hormone exposure in order to normalize growth and pubertal development.

Because abiraterone acetate also inhibits gonadal steroid production and could be teratogenic, its use in CAH would be limited to pre-pubertal children, women using contraceptives, or men who receive gonadal replacement. A clinical trial is under way in pre-pubertal children with CAH (ClinicalTrials.gov Identifier: NCT02574910) with the goal of minimizing exogenous GC and endogenous adrenal sex steroid hormone exposure in order to normalize growth and pubertal development.

Growth-promoting drugs

A systematic review and meta-analysis of adult height in individuals with classic CAH diagnosed before the age of 5 years included just over 1,000 children in 35 studies that met the eligibility criteria.[18] The pooled data indicated a corrected adult height standard deviation (SD) of -1.0. The average heights were 169 cm (66.5 inches) for men and 157 cm (61.8 inches) for women, both within the normal range for shorter than average adults in the general population. These data obviate the routine use of growth-promoting medications that are considered only for individuals whose heights were expected to be at least -2.25 SDs. Subgroup analysis revealed that the addition of early MC treatment was associated with increased height outcome.

A 2001 report tested growth hormone alone (n = 12) or in combination with leuprolide acetate (n = 8) to enhance growth in CAH patients with evidence of early puberty. Follow-up over 2 years showed improved predicted adult height, but as of this date, no data have been published to document actual adult heights. A proof-of-concept trial demonstrated that co-administration of growth hormone plus an aromatase inhibitor (again, alongside standard steroid replacement) improved adult height in a single adolescent male patient with CAH.

Since normal adult height may be achieved through judicious use of standard GC and MC therapies, further long-term prospective randomized and carefully controlled studies are needed to determine whether the use of growth -promoting drugs is safe and cost-effective in individuals with CAH. At present, such treatments are not considered standard care in children with CAH.

Other medical strategies

Reducing adrenocorticotropic hormone (ACTH) production is another mechanism for minimizing adrenal androgen excess. In a small trial of eight women with classic CAH, the selective corticotropin-releasing hormone receptor type 1 antagonist, NBI-77860, was added to conventional therapy, [21] resulting in a more than 40% reduction in the morning ACTH surge and about 27% lower serum 17OHP. Variable reductions of androstenedione and testosterone were observed. Mitotane, a different type of adrenolytic used for treatment of adrenocortical cancer and Cushing syndrome, was administered to a man with classic CAH and testicular adrenal rest tumors (TARTs) who was infertile for 2 years.[22] Adrenal androgen precursors were suppressed and TARTs regressed. Paternity was achieved following an increase in sperm count. Mitotane is a potential teratogen (pregnancy category D) and induces CYP3A4, increasing GC clearance, and therefore is not considered a useful adjunct to CAH therapy. ATR-101 (ClinicalTrials.gov Identifier: NCT02804178), which inhibits acyl co-A cholesterol acyl-transferase and shares some mechanisms with mitotane,[23-25] has been tested in adults with classic CAH; results of this trial have not yet been published.

Adrenalectomy

Adrenalectomy reduces virilization in females and permits decreased GC doses, but this is considered a rather radical approach because of surgical risk. Moreover, there is an increased risk of life-threatening adrenal crisis with absolute dependence on exogenous hormone replacement and loss of potentially beneficial hormones—for example, dehydroepiandrosterone (DHEA) and epinephrine—from the adrenal medulla. Another consideration is that adrenalectomy may inadvertently cause the development of gonadal adrenal rest tumors that secrete androgens.[26,27] For these reasons, the initial enthusiasm has been tempered by long-term complications. Individuals who are known to be non-adherent are poor candidates for adrenalectomy. A systematic review of bilateral adrenalectomy in CAH [28] identified 48 cases ranging from infancy to adulthood and most were carried out for uncontrolled androgen excess or iatrogenic Cushing syndrome (or both) caused by administration of large GC doses to achieve control. Post-operative amelioration of these symptoms was noted in most patients, including three women who were able to conceive following adrenalectomy. In contrast, about 40% of patients experienced adverse outcomes, including eight patients with adrenal crisis and one death in an infant. Five males developed adrenal rest tumors requiring surgical removal. Unexpectedly, two males had regression of TARTs. [28] The conclusion from this review is that adrenalectomy is effective for relief of refractory adrenal androgen excess, but that candidates for adrenalectomy must be chosen judiciously and educated extensively regarding post-operative risks.

Epinephrine deficiency

Individuals with classic CAH have adrenomedullary insufficiency because GCs are required for development and regulation of the adrenal medulla.[29] The physiologic responses of glucose, insulin, and leptin pathways are dysregulated during exercise among adolescent patients lacking both cortisol and epinephrine.[30,31] The clinical implications of epinephrine deficiency are not fully known, but it may contribute to hypoglycemia during febrile illnesses, especially in young children, and impair the response to stress.[32,33] Decreased epinephrine production has been observed in newborns with classic CAH compared with controls; norepinephrine levels were similar. [32] Epinephrine replacement or supplementation has not been studied. It is not known whether a compensatory norepinephrine response is sufficient.

Gene therapy

In two decades since the initial report that adenoviral gene therapy transiently restored enzyme activity in a mouse model of 21-hydroxylase deficiency,[34] there have been no human trials. Animal research is ongoing, and intravenous injection of an adenoviral-Cyp21a1 vector in such mice allowed functional enzyme expression in adrenal tissue, resulting in weight gain, near normal progesterone levels, and improved stress response for more than 15 weeks.[35] However, in another laboratory setting, the therapeutic effect lasted only 8 weeks.[36] Auto-transplantation of Cyp21a1-expressing broblasts into 21-hydroxylase-deficient mouse subcutaneous tissue or direct injection of adenovirus-Cyp21a1 constructs into mouse muscle demonstrated enzyme efficacy for about 4 weeks.[37] Thus, both adrenal and extra-adrenal induction of Cyp21a1 can temporarily ameliorate steroid metabolism in 21-hydroxylase null mice. It is unclear whether the murine data will be translated into effective human treatments. Permanent correction of mutations causing CAH with gene therapy directed at a patient's own adrenal stem cells would theoretically cure CAH and supplant imperfect steroid replacement. Cell-based therapies and gene-editing technology now in development may be options for disease cure in the future.[38] **FOR THE FULL ARTICLE WITH REFERENCE INFO, CLICK HERE.** (https://tinyurl.com/yxtw6xrn)

Adrenas Gene Therapy for CAH

Adrenas Therapeutics has been making good progress in its gene therapy program for CAH. Adrenas is on-track to file an IND (Investigational New Drug application with the FDA in 2020, which will enable us to begin enrollment in our clinical trial, CAH-101, in congenital adrenal hyperplasia. Throughout 2019, Adrenas has had several positive meetings and interactions with members of our Clinical Advisory Board, and a successful pre-IND meeting with the Food and Drug Administration (FDA), all of which reinforce our current goal of entering clinical trials in

2020. Our ultimate hope is that our proposed product (a gene transfer therapy) will allow both adult and pediatric patients with CAH the ability to produce their own cortisol, which may reduce or eliminate adrenal crises and may reduce or eliminate the need for oral cortisol supplementation, steroid stress dosing and mineralocorticoid treatment. Moreover,in the long term, re-establishment of a person's own cortisol production may reduce the signs and symptoms associated with excess androgen production and may reduce the side effects associated with chronic oral steroid treatment. The first-in-human trial of our proposed gene therapy is primarily designed to establish the overall safety and tolerability in adults with CAH, and also to identify the dose(s) that result in the production of levels of cortisol sufficient to reduce androgens and/or reduce or eliminate the need for oral cortisol supplementation. Once a safe, tolerable and effective dose is found in adults, we would plan to ask the FDA to allow us to expand the program to include dose-finding in adolescents and children.If you have questions, or would like more information about the Adrenas program in CAH, please contact David Rintell, at dr@bridgebio.com

CAHlibrate

Neurocrine Biosciences is conducting two studies, one for adults with CAH and the other for children, ages 14-17. The adult study for ages 18-50 is an open-label, multiple-dose clinical trial to assess the effect of investigational compound NBI-74788 on safety measures and hormone levels in adults with classic, 21-hydroxylase deficiency CAH. The pediatric study is also an open-label, multiple-dose clinical trial of the investigational medication NBI-74788. In this study they will assess the safety and tolerability of repeated doses of NBI-74788 in children and adults with CAH. Participation in this study includes a screening period, a baseline period, a treatment period, and a follow-up period. The maximum duration of study participation is nine weeks.
FOR MORE INFO ON THE PEDIATRIC STUDY
CLICK HERE (https://tinyurl.com/yyozba4h)
CLICK HERE FOR ADULT STUDY
(https://cahlibratestudy.com/see-if-you-qualify)

Spruce Biosciences Announces Positive Results from 12-week, Phase 2a study of Tildacerfont in Adults with CAH

Spruce Biosciences has recently announced results from the Ph2a 12 week trial of tildacerfont, an investigational, oral, once-a-day, corticotropin-releasing factor type-1 receptor antagonist. Use **this link** to view the press release on the outcome of the study (https://tinyurl.com/y6h375rk)

The Spruce team wants to thank the people, their families and clinical trial staff who have participated in and supported the understanding of this exploratory drug to date. We are excited to move forward into additional coming trials and we will be releasing more information soon about the pair of studies that we hope to provide the opportunity to enroll in within 2020. If you have interest in participating in the clinical trials, please reach out to your treating Endocrinologist and ask them if they have clinical trial opportunities. If you have suggestions on Endocrinologists with a strong interest in CAH then please reach out to **Spruce.** (https://tinyurl.com/y3nsrtta)

SEEKING CHILDREN FOR CAH STUDY: 'Abiraterone in CAH'

Patients with the severe, classic form of congenital adrenal hyperplasia (CAH) due to 21-hydroxylase deficiency are unable to synthesize cortisol (stress hormone) or aldosterone (salt retaining hormone) normally. These deficiencies can be treated with hydrocortisone or fludrocortisone, respectively. In patients who are not getting enough hydrocortisone, the adrenal gland secretes large amounts of androgens (male sex hormones). Excess androgens can cause the growth plates in long bones to close too early, leading to short adult height. Controlling androgen levels may require relatively high doses of hydrocortisone that can themselves slow down growth. If androgen synthesis could be blocked in prepubertal children, this might allow us to use lower doses of hydrocortisone and eventually result in CAH patients being taller as adults.

TO TAKE PART IN THIS STUDY, YOU MUST:

- Have classic CAH due to 21-hydroxylase deficiency
- Be 2-8 (girls) or 2-9 (boys) years old
- Be taking both hydrocortisone and fludrocortisone
- Not be in puberty

FOUR STUDY LOCATIONS:

South Central: UT Southwestern Medical Center/Children's Medical Center, Dallas, TX - East Coast: National Institutes of Health, Bethesda, MD - North Central: University of Michigan, Ann Arbor, MI - West Coast: Childrens Hospital Los Angeles, Los Angeles, CA

FOR MORE STUDY DETAILS AND CONTACT INFORMATION, USE THIS LINK
(https://tinyurl.com/y62un76b)

NIH National Institutes of Health

Stress Dosing and Illness Trends in Patients with Congenital Adrenal Hyperplasia

Ashwini Mallappa, MD., MHSc[1], Megan Parker, BS[1] and Deborah P. Merke, MD., MS[1,2]
[1] National Institutes of Health Clinical Center, [2] the Eunice Kennedy Shriver National Institute of Child Health and Human Development, Bethesda, Maryland, USA.

Introduction:
Congenital adrenal hyperplasia (CAH) is the most common cause of primary adrenal insufficiency during childhood. Patients with the classic (severe) form of congenital adrenal hyperplasia (CAH) have cortisol deficiency and are at risk for life-threatening adrenal crisis. Individuals with classic CAH and nonclassic CAH individuals on glucocorticoid treatment are particularly at risk for adrenal crisis when experiencing illness or injury. When illness or injury occurs, patients with CAH must receive glucocorticoid (hydrocortisone) stress dosing. Prevention of adrenal crisis in patients with adrenal insufficiency is crucial and is best accomplished through repeated education of patients and caregivers on the importance of stress dosing, when to do it, and how to do it. This education allows patients and caregivers to often be successful at managing illness and injury. However, some patients still experience adrenal crises requiring hospitalization. We studied over 2,000 visits from 156 patients with both classic and nonclassic CAH seen over 23 years to gain a better understanding of the rates and causes of stress dosing, illnesses, and the related consequences. Based on our findings from this study, we developed **new stress dosing recommendations** to more effectively prevent adrenal crisis (El-Maouche D, Hargreaves CJ, Sinaii N, Mallappa A, Veeraraghavan P, Merke DP. "Longitudinal assessment of illnesses, stress dosing and illness sequelae in patients with congenital adrenal hyperplasia". Journal of Clinical Endocrinology and Metabolism. 2018, PMID: 29584889; ClinicalTrials.gov Identifier NCT00250159)

Why is stress dosing important?
During times of physical stress, higher amounts of cortisol are necessary to maintain blood pressure and blood sugar. As patients with classic CAH have a defect in making cortisol on their own, they must receive additional amounts of hydrocortisone to combat physical stress, such as fever, vomiting, surgery, and injuries. This additional medication is called a "stress-dose" and it is vital in preventing adrenal crisis. Similarly, patients with non-classic CAH who are on glucocorticoid replacement therapy, need stress dosing at times of acute illness or injury as their adrenal glands have a blunted response to stress from exposure to glucocorticoids from an outside source. Delay in receiving this additional stress-dose can lead to hypoglycemia (low blood sugar), hypotension (low blood pressure), heart failure, and even death. Therefore, it is important for patients and caregivers to learn when to stress-dose and how to stress-dose. We teach our patients and families on the use of oral hydrocortisone for stress dosing in addition to their usual, daily glucocorticoid medications (hydrocortisone, prednisone, prednisolone, dexamethasone) for times of mild-moderate illnesses. We also teach patients and caregivers how to administer intramuscular hydrocortisone injections (Solu-Cortef) at times of severe illnesses.

What did the study show?
First, intensive, frequent, and repeated stress-dose teaching allowed patients to often successfully manage illnesses. However, some of our patients still encountered adrenal crises requiring ER visits or hospitalizations. Eleven of our pediatric patients experienced adrenal crises with significant hypoglycemia, sometimes even resulting in seizures. Gastrointestinal (GI) and upper respiratory infections (including ear ache, sore throat, sinusitis, all with fever) were the two most common events leading to adrenal crisis and hospitalization for our patients. Our study showed that rates of illness, the need to stress-dose, and risk factors for ER visits and hospitalizations differ between children and adults. We also found that levels of epinephrine, another adrenal hormone, may play a role in the rates of illness and ER visits. We concluded that revised guidelines for the management of illnesses in patients with CAH are needed and should be aimed at preventing hypoglycemia.

How do rates and outcomes of stress dosing differ between children and adults?
Rates of illness, the need to stress-dose, and risk factors for emergency room (ER) visits and hospitalizations differed with age. Children had higher rates of illnesses and stress dosing than adults. On the other hand, adults had more ER visits, hospitalizations, and adrenal crises. Additionally, we found a difference in the association between medications and stress dosing between children and adults. For children, lower hydrocortisone doses and higher fludrocortisone (Florinef) doses were associated with higher rates of stress dosing and illness. In adults, lower fludrocortisone doses were associated with higher rates of stress dosing and illness. Our findings suggest that adults may be more vigilant in monitoring their child's signs and symptoms of adrenal crisis than they are at monitoring and treating themselves.

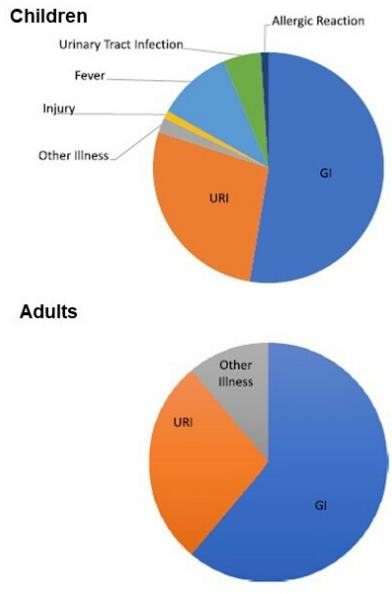
Table 1. Proposed New Guidelines for Stress Dosing in Patients with Adrenal Insufficiency

Type of Illness	Children	Adults
Minor illness or low-grade fever (>38°C children)	Two to three times the usual dose of glucocorticoids, divided into four doses (to be given every 6 h)	Take hydrocortisone 10 mg three times a day in addition to usual glucocorticoid regimen.
Major illness or high-grade fever (>39°C children)	Triple the usual dose of glucocorticoids and divide into four doses (i.e., take every 6 h). In addition, increased fluid intake and frequent ingestion of simple and complex carbohydrates	Take hydrocortisone 20 mg three times a day in addition to usual glucocorticoid regimen; increased fluid intake with frequent ingestion of simple and complex carbohydrates
All illnesses	15 g of simple carbohydrates (one-half cup juice, regular soda, or applesauce or three to four glucose tablets) for lethargy; increase fluids, simple and complex carbohydrates every 4–6 h. Hospital/physician evaluation for lethargy and decreased oral intake and urine output	30 g of simple carbohydrates (1 cup juice or regular soda) for lethargy; increase fluids. Hospital/physician evaluation for lethargy and decreased oral intake and urine output.
Vomiting	Repeat oral dose if child vomits within 1 h of medication. If child vomits again, administer intramuscular injection of hydrocortisone 50–100 mg/m^2. If unable to tolerate fluids, call emergency services for evaluation following intramuscular injection.	Repeat the dose if patient vomits within 1 h of medication intake. If patient vomits again, administer intramuscular injection of hydrocortisone 100 mg. If unable to tolerate fluids, call emergency services for evaluation following intramuscular injection.

Does the severity of CAH effect rates and out-comes of stress dosing?We found that children with classic salt-wasting CAH (most severe) had more ER visits than children with classic simple-virilizing CAH (less severe) and or children with non-classic CAH (least severe). In adults, however, differences in the severity of CAH did not play a role in the rates of ER visits. It is important to note that adrenal crisis is possible, although rare, in patients with non-classic CAH receiving glucocorticoid medication. Among our research participants, one patient with non-classic CAH was hospitalized for adrenal crisis associated with GI illness.

What types of illnesses are most likely to lead to adrenal crises?
In our study and in previous studies, GI illness was a leading cause of adrenal crisis, followed by upper respiratory tract infections (Yang, M. and P. C. White. "Risk factors for hospitalization of children with congenital adrenal hyperplasia." Clin Endo 2017, PMID: 28192635). In addition to GI illness and upper respiratory tract infections, injury, fever, urinary tract infections, and allergic reactions were factors that led to adrenal crises for children with CAH. Other illness that contributed to adrenal crises for adults included meningitis, dehydration, and intestinal obstruction. These trends are shown in Figure 1, adapted from El-Maouche D et al, Journal of Clinical Endocrinology and Metabolism.2018, PMID: 29584889.

Figure 1. What types of illnesses are most likely to lead to adrenal crises?



What are our new stress dosing recommendations?
We revised our stress dosing recommendations to include more frequent stress dosing during childhood. Children should take 2-3 times their usual dose of glucocorticoid medication every 6 hours. We recommend that adults take 10 or 20 mg of hydrocortisone three times a day, in addition to their usual glucocorticoid medication. Children and adults should increase their fluid intake and we recommend including sugar-containing fluids during illnesses. If vomiting occurs, children and adults should receive an injection of hydrocortisone (Solu-Cortef). We also updated our recommendations to include more carbohydrate intake during illness to prevent hypoglycemia (particularly in children) and its consequences. Our proposed new guidelines for stress dosing are provided in more detail in Table 1 (adapted from El-Maouche D et al, Journal of Clinical Endocrinology and Metabolism. 2018, PMID: 29584889).

SOLUtion Medical
Simplifying Adrenal Crisis Health Management

The mission of SOLUtion Medical is to simplify adrenal crisis health management. We pursue this mission by providing people reliable life-saving care and reclaimed confidence in times of medical crises, specifically those people living with Congenital Adrenal Hyperplasia (CAH), Addison's disease, and idiopathic adrenal insufficiency. These conditions can impart an adrenal crisis on an individual, a

medical emergency and potentially life-threatening situation caused by insufficient levels of the hormone cortisol. SOLUtion employs a range of strategies to achieve its mission including partnering with organizations working on behalf of those at risk of adrenal crisis, meeting families affected by adrenal insufficiency to learn their frustrations and listening to those affected by rare diseases to learn their stories.

SOLUtion's work is organized around three priority areas:

Innovation – The current standard of care in times of adrenal crisis for these conditions includes the reconstitution and administration of Solu-cortef, requiring an average of twelve user steps for injection. This protocol was designed to be utilized by trained medical personnel and not a layperson or an individual living with adrenal insufficiency. If a person is in an adrenal crisis, it is extremely difficult, if not impossible, to self-administer the medication in its current packaging. The TWISTJECT autoinjector by SOLUtion is an all-in-one reconstitution device specifically for drugs that require re-suspension and injection in emergency situations.

Advocacy – When you are too sick to speak up for yourself, you rely on others to advocate for you. What happens, however, when few people know how to help you because they've never heard of your rare disease? Lack of awareness also exists within the adrenal insufficient community, where people with one form of adrenal insufficiency might be unaware of people with other adrenal insufficiency conditions. SOLUtion is advocating for those with AI conditions both amongst the adrenal insufficiency community and the general public.

Education - Knowledge about adrenal insufficiency, and how to care for someone experiencing an adrenal crisis, is significantly lacking even within the medical world. This oftentimes leads to misdiagnoses and delayed care resulting in unnecessary illness and even death. SOLUtion is working hand in hand with its collaborative partners to compose and institute nationwide adrenal crisis CEU programs for education and medical personnel.

It is through firsthand experience struggling to properly use the current Act-o-vial® delivery system in times of adrenal crisis that Julia Anthony founded SOLUtion Medical. Julia is an individual with salt-wasting congenital adrenal hyperplasia and a proud recent Industrial Design graduate from Thomas Jefferson University the Medical University where she was born and diagnosed with SWCAH. With this design knowledge and her 27 years of experience living with SWCAH, Julia and the SOLUtion Medical team are developing a reconstituting auto-injector for the adrenal insufficiency community, including those with CAH and Addison's Disease.

The TWISTJECT auto-injector by SOLUtion provides users reliable life-saving care and reclaimed confidence in times of adrenal crises. In addition to incorporating user feedback into its design, SOLUtion aims to broaden the scope of public knowledge regarding life threatening adrenal insufficiency conditions. SOLUtion is proud to be collaborating with CARES, and other organizations as it continues to forge ahead. Follow SOLUtion on Facebook and Twitter to learn more!

A NOTE ABOUT SURVEY PARTICIPATION

Survey participation is crucial. CARES and their research partners and medical professional groups, etc., occasionally develop surveys to better help us serve the CAH community. Please participate to ensure your voice is heard and help us help you!

LIFE WITH CAH SURVEY

Beginning in July of this year, the Comprehensive Care Centers for CAH released a survey to the CAH community with the goal of doing a better job treating and supporting CAH patients and all affected members of the CAH community. The survey, "Life with CAH Research Survey" and questions are based on what people living with CAH think is important and should be studied. The survey has been distributed to the CARES community and posted on social media. **The survey will be released again, Nov. 5-12 and this will be your last opportunity to participate. Please look for an email from CARES in your inbox with a link OR contact us research@caresfoundation.org.** The centers appreciate the participation thus far and look forward to learning from the survey's data.

Children's Hospital Los Angeles
Cohen Children's Medical Center Northwell Health
Riley Hospital for Children Indiana University Health
Weill Cornell Medicine

EDUCATION

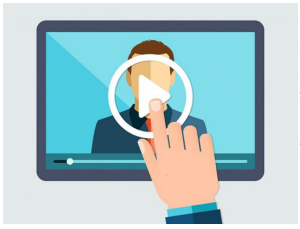
Riley Hospital for Children
Indiana University Health

The 2019 conference was hosted by Riley Hospital for Children in Indianapolis, IN, on May 11th. Attendees from all over the country & Pakistan, gathered in Indianapolis for an informative and helpful event that included sessions on topics such as: *Patient & Family-Centered Research, Psychosocial Aspects of CAH, Common Stressors and Coping Strategy for Parents of Children with CAH,* and *Transitioning to Adulthood and Beyond*. Attendees were also able to choose from break-out sessions on topics such as *Males with CAH* and new this year, *Teens with CAH* a Meet & Greet/art therapy project. Noted CAH healthcare professionals offered attendees an opportunity to ask questions on different discussion topics during the Q&A Panel. There were also sessions offered on Act-o-vial injection training.

We would like to thank the staff at Riley for doing a tremendous job coordinating this event. A special shout out to Heather Frady, R.N., who worked tirelessly to make this event a success.

SAVE THE DATE!

STAY TUNED FOR MORE DETAILS!



EDUCATIONAL VIDEOS AVAILABLE

Educational videos addressing Adrenal Crisis and Stress Dosing are available for purchase in our online **CARES Shop** and for free viewing on **our website.**

Numerous parents and patients have informed us that these videos have proven to be essential tools in educating caretakers, school personnel, babysitters and even emergency department staff. Videos for purchase come on a convenient flashdrive and include, CAH and Stress Dosing as well as Adrenal Crisis in an Emergency Setting.

THE DOCTOR IS IN

Dr. Karen Su CARES Medical Director

Dr. Su answers some common questions.

1. Should I stress-dose for a dental procedure, such as a cavity filling or tooth extraction?

If only local anesthesia is used (such as lidocaine), then stress-dosing is not necessary. If sedation is required, then yes, stress-dosing is recommended.

2. Do NCAH patients need to stress-dose?

NCAH patients who are not taking daily steroid treatment do not require stress-dosing. However, all patients who are on chronic steroid treatment require extra hydrocortisone during physical stress because their own ability to mount an adequate cortisol response is blunted by the steroid treatment they are taking.

3. Can CAH patients take natural adrenal supplements, such as bovine adrenal extract, instead of steroids?

CAH patients should not take bovine adrenal extract because it is essentially ground-up adrenal glands from cows. It is not purified and may contain many other hormones besides cortisol, such as epinephrine and norepinephrine, which can cause cardiacarrhythmias. Supplements are not regulated nor are the doses quantified. The treatment for CAH is hydrocortisone (which is identical in structure to cortisol) or other glucocorticoids (such as prednisone, dexamethasone) and in salt-wasters, fludrocortisone (which replaces aldosterone). These medications are regulated by the FDA and are consistent in their dosing and quality. Of note, these medications should also be given in tablet form (not compounded into a solution).

4. How can I tell if my child with CAH is receiving too much steroid treatment?

Possible signs of too much steroid treatment in a growing child are poor growth rate, excessive weight gain (particularly in the face and belly), a round moon-shaped face, hump at the back of the neck, significant stretch marks, high blood pressure and/or easy bruising.

5. Should CAH patients receive the flu vaccine?

The flu vaccine protects against influenza (flu), which is a viral respiratory infection that is highly contagious and potentially fatal. Complications from the flu may be particularly risky for CAH patients, who are risk for adrenal crisis. We recommend seasonal vaccination against the flu for most CAH patients.

If you have important questions that you would like to ask of our Medical Director, please feel free to use the **"Ask the Expert"** feature on our website: https://www.caresfoundation.org/faqs/ask-expert/

ADVOCACY

#CAHRights

We want to thank all of you who supported CARES' efforts to protect the rights of CAH patients and parents, keeping bans on restorative surgery for CAH girls at bay. . . for now. This battle has just begun, and we must continue to remain vigilant and alert to current resolutions and possible bills on the horizon in many states. Please stay tuned for updates from CARES and for ways in which you can help in this fight. Please continue to check us out on Facebook, Twitter and Instagram, and read your CARES' emails for the latest updates.

Speak up! ADVOCACY WORKS

Emergency Medical Service Protocols Update 2019

We continue to advocate for emergency protocols and progress has been made. Protocols are constantly being passed or updated around the country. Check **our website** (https://www.caresfoundation.org/) periodically OR this site: **http://www.emsprotocols.org** for updated protocols.

In the following states, paramedics/ALS are allowed to administer patient carried medications:

Alabama
Arizona
Arkansas- optional guidelines addressing adrenal crisis
California - Counties of Santa Cruz & Los Angeles
Florida - Broward County, Duval County, Leon County, Martin County, Orange County, Pinellas County, Santa Rosa County
Kansas - Johnson County
Kentucky
Maine
Maryland
Michigan
Minnesota-those under Alina Health can have an individualized care plan. They cover over 100 communities.
Missouri
Nevada- Clark County, North Lake Tahoe, Southern Region, Washoe County
North Carolina
Ohio - Washington Township in Montgomery County, Hamilton County
Washington - Seattle
Texas - Houston, Western Texas, Williamson County

Vermont
Washington, DC
Wyoming - Solu-Cortef® added to the state drug formulary which enables paramedics to administer.

Ambulances are allowed to carry Solu-Cortef® but patients/families typically must request this from their local EMS in these areas:
Connecticut - paramedics must carry a steroid. Families should request Solu-Cortef® to be one of the steroids carried.
Colorado - Lamar Ambulance Service Protocols, Northern Colorado, Boulder
Massachusetts
Montana
New Hampshire
New Jersey
Pennsylvania
Rhode Island
New York - Nassau and Western NY Region and Suffolk County
Oregon - Clatsop County
Tennessee
Texas - Fisher County
Vermont
Washington - South Pacific County

Look on our website for **tools when visiting your local EMS:** (https://tinyurl.com/y6722y9q) Visiting Your Local EMS Guidelines, Medication Safety Alert: EMS Protocols for Adrenal Crisis and Emergency Instructions Brochure. **Contact Karen at karenf@caresfoundation.org to discuss any questions.**

VISIT YOUR EMS PROVIDER

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 YOUR LOCAL EMS OFFICIALS ARE PREPARED TO HELP YOU OR YOUR CHILD IN THE CASE OF AN EMERGENCY!
- Bring local protocols (if available, **see our website, link above**), emergency instructions + the Medication Safety Alert: EMS Protocols for Adrenal Crisis.
- Have EMS flag your address or phone number.
- BEFORE calling 9-1-1, inject Solu-Cortef® THEN call
- Say you need paramedics/ALS to come because you have a person with adrenal insufficiency who is in adrenal crisis
- When paramedics arrive, have Solu-Cortef® and letter from the endocrinologist available

REMEMBER: Visiting your local EMS provider is one of the easiest and most productive acts of advocacy that YOU can achieve. Please, take the time today to visit your local firehouse or EMS station. Schools, churches, clubs, etc. are also great places to visit.

ALWAYS WEAR MEDICAL I.D.

ALWAYS WEAR YOUR MEDICAL IDENTIFICATION! Medical ID should include: Adrenal Insufficient/Steroid Dependent - Administer Solu-Cortef® with your appropriate dosage.

Did you know. . . that most smart phones have an emergency medical alert feature that you can program for your ailment/emergency requirements?
YES, and you should definitely set up your phone with your emergency information as soon as possible! Here is an article on **HOW-TO SET UP YOUR APPLE PHONE MEDICAL I.D.** (https://tinyurl.com/y2ctlafs)

Don't own an Apple? Check online for your phone brand and emergency ID instructions.

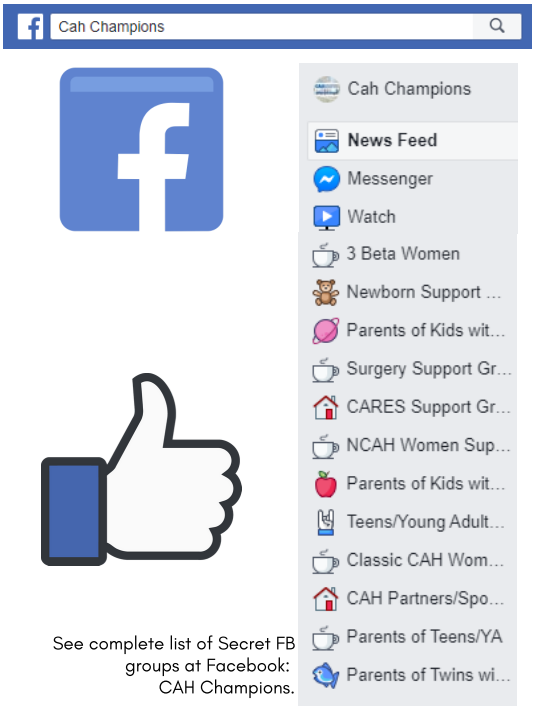
MAKING CONNECTIONS

CARES SUPPORT

We're here for you!

You can get the support you need in many ways:

- Regular Telephone Support Group Meetings
- Via "Ask the Expert" - our online feature that connects you to our Medical Director, Dr. Karen Su
- From one of our many Support Group Leaders by phone and/or email
- In our Facebook group - CAH Champions
- In one of our 20 secret Facebook groups
- By phone/email to any member of the CARES team during regular business hours



See complete list of Secret FB groups at Facebook: CAH Champions.

CARES Group Support Leaders

Our support group leaders are an invaluable part of our support structure. They are available to help a parent of a newly diagnosed baby unravel the tangle of information that needs to be processed. They share their experiences with and lend an ear to someone who has been struggling with symptoms. They offer understanding and hope. They show that dealing with CAH is manageable. Our specialized leaders help with specific issues such as: newborn support, women with classical or non-classical CAH, parents of children with non-classical CAH, parents of teens with CAH, exploring surgery, and women over 40 with CAH. We are fortunate to have 60 leaders around the country and 17 leaders in 13 countries. Support Group Leaders can be found on our website Support Group page.

CARES Telephone Support Meetings
CARES holds **support group meetings over the phone** with support group leaders and medical professionals available to answer questions and hold discussions with members on the call. Patients and family members are welcome to ask questions, participate in discussion or simply listen in. Currently, **CARES schedules the following types of calls on a regular basis:**

Parents of Newborns/Infants/Toddlers - For parents of children with CAH up through the age of 4.

Parents of Children/Teens/Young Adults - For parents of CAH affected children (ages 5-29). This meeting is divided into two sessions, the first hour of the call is for parents of children (ages 5-12), and the second is for parents of teens/young adults (ages 13-29).

Young Adults (ages 17-29) - This meeting is for CAH patients held 2 times a year.

Women with CAH - For CAH female adult patients, held 4 times a year.

ARE YOU IN NEED OF SOME SUPPORT? PLEASE REQUEST OUR FRIENDSHIP ON FACEBOOK - CAH CHAMPIONS. You can find a lot of helpful, supportive members of our CAH community there. YOU CAN ALSO use our 'ASK THE EXPERT' feature on our website, to get help from our Medical Director. NOT SURE WHAT TO DO? Please email us support@caresfoundation.org or call our office and ask for our Program Director, Karen. She will point you in the right direction.

CARES se complace en presentar el servicio "Preguntele al Experto" para pacientes y familias que hablan español

Nos complace anunciar que pronto tendremos un doctor "de guardia" quien habla español para atender a los pacientes y familias que prefieren comunicarse en este idioma. Este servicio funciona como el que actualmente ofrecemos en inglés: "Ask the Expert", excepto que ahora se pueden hacer preguntas y comentarios, y obtener respuestas en español. Pronto recibirán la notificación sobre la fecha de inicio de este servicio!

CARES to introduce "Ask the Expert" feature for Spanish speaking patients and families!

We are pleased to announce that we will soon have a Spanish speaking doctor "on call" for the convenience of our Spanish speaking patients & families. It will work just like our regularly featured, "Ask the Expert" except now you will be able to post questions and comments and get replies in Spanish. Look for upcoming announcement of start date!

Summer CAMPS

Medically Safe Camp Opportunities

We are so happy to have relationships with very special camps around the country and in the UK. These camps are free and open to children with medical issues. There are onsite medical facilities with volunteer nurses and doctors. The camper to counselor ratio is low to ensure all the children are well-cared for. Children are welcome to attend camps in many areas of the country. The purpose of these camps is to help children with medical issues to focus on just having fun! Some camps have weekend programs for families. This is a great way to get to know the camps before sending your child off on their own.

Your CAH child can look forward to Summer Camp, just like the rest of his/her friends! YOU can look forward to being able to relax, knowing that your child is in good hands! AND, a bonus, many of these camps are free!

Here are the camps and locations:

The Center for Courageous Kids **Scottsville, KY**

Hole in the Wall Gang Camp **Ashford, CT**

North Star Reach **Ann Arbor, MI**

Double H Ranch **Lake Luzerne, NY**

Camp Korey **Carnation, WA**

Dreamstreet **in Ojai, CA and Canyon Ranch, AZ**

Victory Junction **Randleman, NC**

The Painted Turtle **Lake Hughes, CA**

Over the Wall **in England**

A Personal Story

My name is Leontine Wallace. I am a Registered Nurse and Lactation Counselor, and this is my story about having a beautiful baby boy with SWCAH. Cyrus was born on 3/14/2018 at 35 weeks via C-section. He required CPAP, then surfactant and mechanical ventilation. Things did not look so good so they let me get out of bed to see him after just a couple hours. They did a full sepsis work up and we learned that he had Respiratory Distress Syndrome. It was very strange to not have my baby with me after birth. A dear friend who happened to be at the same hospital for personal health reasons sat with me and my

husband while I pumped every 2 hours. They say laughter is the best medicine and God truly blessed us with her humor and good company. I spent a lot of time praying, and pumping. I pumped on schedule every 2-3 hours for 20-30 minutes at a time. Miraculously, he came off the ventilator and went to CPAP the next day. We were able to spend two hours skin to skin. After another day on CPAP he transitioned to a nasal cannula with supplemental oxygen and I was finally able to try and nurse him. I didn't want to admit it but, I had my doubts that he would latch after 3 days away from me and not very much time skin to skin. As a Lactation Counselor I often say, "try, try, and try again." I knew that if it didn't work out now that it would in the future. The nurse at the hospital helped me latch him and I was so happy that he was nursing after just a couple attempts! Over the next few days his respiratory status was up and down. He had made a miraculous recovery considering everything and we just needed his lungs to heal a little more. After almost a week in the hospital, I was overjoyed that God had heard my prayers and was letting us take him home.

He was discharged from the NICU and we spent 3 very trying days at home. He was producing wet and stool diapers, but nothing felt "right." I couldn't put my finger on what was wrong. I called my closest friends to tell them how I felt. He was sleeping a little too much and wasn't really waking up all the way. They told me to talk with the medical care team. The doctor and the home care nurse provided reassurance; they were pleased that he was breastfeeding, sleeping, and pooping. It is normal for some breastfed babies to lose 10% of their body weight after birth, and since he had so much IV fluid his weight loss was considered normal. On the 4th day home I decided to bottle feed only and pump for the whole day to see exactly how much he was eating. By 8 pm, he

had only eaten 10 ounces. I made the decision to take him to the ER instead of waiting until Monday to see our primary care doctor. This decision to follow my heart saved his life. As it turns out, Cyrus had had a false negative newborn screening and was in adrenal crisis. The doctors were able to see past the negative newborn screening and do repeat blood testing. They then diagnosed him with SWCAH and started him on all the medications that he needed to thrive. He also received an NG tube to help him gain weight. He drank 30 mL of pumped milk mixed with salt 4 times per day on a schedule, had fludrocortisone and hydro -cortisone 3 times per day in a syringe, and nursed whenever he wanted in between. The nurse showed my husband and I how to crush the medication, mix it with milk, and administer it. Even though I am a nurse, I really did need to re-learn how to do all of this as a mom. After another two weeks in the hospital we were able to go back home, this time to stay.

I was able to pump and nurse for 17 months, thanks to God, the nurses and lactation staff at the University of Michigan Children's Hospital, the support of my family and co-workers, and the training that I have as a lactation counselor. It was not breast milk all the time. I went back to work full time after 8 weeks, and he was diagnosed with a milk protein intolerance at 3 months old. At that point I had to remove all dairy, soy, eggs, and corn from my diet. With full time work and drastic diet changes my supply dropped a bit. I did supplement with Alimentum formula after he was 6 months old and it helped us both. I am a big proponent of doing what is best for both mom and baby. For me, this meant being realistic about my expectations and definition of successful breastfeeding. Breastfeeding with CAH is challenging through the first months of life but, it can be done, and it is fun! The benefits of breastfeeding for mom and baby are numerous. When you breastfeed, you strengthen a physical/emotional attachment to your baby, help heal your body after birth, prevent disease in both you and your baby, and reduce the risk of SIDS. Some of my favorite moments of his babyhood are breastfeeding memories where he was snuggled comfortably in my arms, completely happy and at peace in this world.

I am so thankful for our son and the ability to connect with the CARES community. If you are breastfeeding an infant with CAH my best advice is to follow your heart, don't quit on your worst day, find your community of breast-feeding supporters, and if you feel like there is something "off" seek help from a professional in your community. If you have any specific questions about breastfeeding and medication administration, please feel free to reach out to me via e-mail at LMWAL@UMICH.EDU or by phone at 989-600-9399.

Have a wonderful and blessed holiday season, dear friends!

CAH AROUND THE WORLD

Congenital Adrenal Hyperplasia. 2020 IFCAH project grant support

IFCAH is a private fund, aimed to promote research on Congenital Adrenal Hyperplasia (CAH). In 2020, it launches its tenth call for proposals, in association with ESPE. A total amount of **350.000€** is associated to this program. **Participation is open worldwide** and will, if possible, include teams based in Europe**.**
Specific goals: **Increasing knowledge on pathophysiology of CAH.** The projects could be directly or indirectly targeted on CAH and **adrenal insufficiency,** which also includes research on **adrenal development, differentiation and homeostasis.** The expected results should potentially improve the knowledge on CAH and adrenal insufficiencies. Research on adrenal tumors and cancer is excluded from this call. **Prevention, diagnostic and treatment of natural or iatrogenic complications** Impact on fetal development, growth, puberty, effects on metabolic and cardiovascular systems, male and female fertility, bone density, immunity, infection, neuro cognition… **Proposition of new therapeutic targets and protocols** Pharmacotherapy, Development of gene or/and cellular therapy models.
Funding: Selected research projects will be supported up to **EUR150k** (total). Funding period will have to start at the latest 6 months after notification of the award and will not exceed three years. Funds will have to be used for expenses directly linked to the project, including specific equipment, operating costs or salaries of coworkers (with the exception of salaries of senior permanent staff of academic and governmental agencies which are not eligible). Indirect costs or managements fees are not eligible and must be covered by another source.
Eligibility: Applicants must hold an M.D., Ph.D., or equivalent academic degree and have a faculty position or equivalent at a college, university, medical school, or comparable institution. Only one project from a research team will be considered. Applications for the renewal of an IFCAH's support are accepted but applications for a different project, from a team previously supported by IFCAH, will not be considered, up to the end of its former grant.
Selection procedures: The information given on LOI will enable the scientific board of IFCAH-ESPE to access the priority of the projects and to determine whether the proposed research merits a full application. Applicants will have to inform on project positioning versus international competitors. Full applications will be requested from selected LOIs and submitted to peer-review. Final selection will take place after an oral project's presentation (on site in Paris or through video-conference) to the IFCAH-ESPE scientific board. Additional information is available on www.ifcah.com or by sending an email to cfp@ifcah.org. Specific forms for letters of intent can be obtained from cfp@ifcah.org Key Dates: January 15, 2020: Letters of intention (LOI) due date February 2020: LOI decision meeting April 2020: Full application due date (for accepted LOIs) June 15th, 2020: Audition of proposals, July 2020: Award notification

FUN-RAI$ING!

CAH AWARENESS WALKS 2019

A SPECIAL THANK YOU MUST GO OUT TO OUR CAH AWARENESS WALK HOSTS and VOLUNTEERS! Because of your dedication and hard work, CARES will benefit not only from the money raised, but because these events bring the CAH community together and together WE CAN MAKE A DIFFERENCE!

Our first walk of the 2019 season was held in **Hilliard, OHIO - June 30, 2019**
It was a beautiful day for a walk at Homestead Park at the Pine Pavilion. Tons of CAH families and patients gathered to raise awareness and have a little fun too. **Thank you to Megan Hamilton and family for hosting this event.**

Supporters in Hilliard, OH wind their way through Homestead Park

On **August 24, 2019,** CARES supporters gathered in **Milton, MA** – a new location, for the 3rd Annual MA Walk. Another beautiful day blessed this awesome event **hosted by Alex Dubois, the McCready family & Brian Paul Gannon. Thank you for your efforts.**

Kids hit the track for the MA Walk FUN RUN!

This young CARES supporter shows off her CAH Super Hero cape that she made at the NJ/NY Walk event!

Walkers of all ages showed their support at the CA Walk

The **2nd Annual Sylvania, OH Walk** came next, and again, CAH families came together on **September 8, 2019** to raise awareness and support CARES. Thank you to Krista Woodbury & family for hosting this successful event!

Pennsylvania walkers make their way through lovely Upper Saucon Community Park in Center Valley, PA

Ready to WALK in Maryland!

Helpful volunteers man the table at the Sylvania, OH Walk

NJ/NY Walkers heading for the Starting line

The 8th Annual NJ/NY Walk was held on **September 28, 2019 in Ridgewood, NJ.** This long-time running event always brings folks together from the tri-state area. Thank you to our hosts, Chad Lapp & Katherine Fowler!

October 5, 2019 was the date of the **4th Annual Pennsylvania Walk** held in beautiful Lehigh Valley, PA and hosted by Carlos DaSilva & family. Thank you for all your wonderful work.

The **6th Annual California Walk** was held on **October 6, 2019** at the Santa Anita Racetrack & Park in Arcadia, CA. The walk was a huge success and included new families for this annual event. A special thanks to our hosts, Erik Bogaard, Karen Bogaard, and Ryan Hendler as well as the staff from CHLA CAH Center of Excellence.

MD walkers wearing their shirts with pride!

Quiet Waters Park in Annapolis, MD was the setting for the **4th Annual Maryland Walk, held Saturday, Oct. 26th.** Attendees were treated to family fun and a pleasant fall day for awareness raising!

2nd Annual Florida Walk - Best wishes for a successful walk, which will be held on November 2, 2019. Thank you host, Lesley Holroyd for doing amazing work!

Young supporters abound at the MA Walk!

PA Walk supporters

PEER-TO-PEER: The Next Generation of Fundraising

PEER-TO-PEER FUNDRAISING (Social fundraising) is a simple, convenient, and effective way to raise awareness of CAH and funds for CARES! You use your social network to reach out to possible donors and spread the word about CAH. You can Fundraise in conjunction with one of our CAH Awareness Walk events, to celebrate your birthday or other momentous occasion, or to pay tribute to or honor a special someone just because you care. So please take a few minutes to set up your very own Fundraising page now! **CLICK HERE to get started!** (https://tinyurl.com/y44uglwa)

CLICK HERE for a printed guide (https://tinyurl.com/yypk85ag). **BETTER YET**, contact wendy@caresfoundation.org, and let her create a page for you!

FAMILY FUNDRAISERS

THE JAMES PARTY

The Coronado community was invited to the James Party 2019, Sunday, March 10, 2019 from 4 to 8 p.m. This event is a fundraiser hosted by Sue Shirey in honor of her son James, who passed away unexpectedly, at the age of 14 in 2009 of complications from CAH. This annual event was held at the Coronado Cays Yacht Club in California. The event featured a silent and live auction, music, laughs and a fantastic meal. The James Party raised over $10,000 for CARES and more money for Young Life Coronado, and the James Shirey Memorial Garden at Silver Strand Elementary. **To Sue Shirey and her family,** we extend our heartfelt congratulations on another successful event. Thank you for your generous and compassionate support!

CAPTAIN JACK'S QUEST FOR A CURE 2ND ANNUAL GOLF TOURNAMENT

This 2nd annual event was a huge success! Held at the beautiful Pine Hills Country Club in Plymouth, MA on Monday, May 13, the event attracted hundreds of golf enthusiasts and raised awareness of CAH and funds for CARES. Hosted by the Porters, Zack and Kaitlin, who were inspired to one day find a cure for CAH - the disorder affecting their young son (and future golfer!), Jackson. Golfers were treated to an amazing course, breakfast goodies and a delicious lunch.

There was a silent auction and many prizes were awarded. *Thank you for a job well done, Kaitlin & Zack.* We look forward to the 3rd Annual Quest for a Cure tournament! Stay tuned for more details.

SAVE THE DATE! for CAPTAIN JACK'S QUEST FOR A CURE 3RD ANNUAL GOLF TOURNAMENT - MAY 11, 2020

The 5th Annual Clay Shoot for CARES was once again held at Lehigh Valley Sporting Clays in Coplay, PA. Shooting enthusiasts traveled from near and far to be a part of this awareness-raising event! Attendees enjoyed a light breakfast then took to three levels of courses that makes its home in an abandoned 1800's cement quarry. After the shooting, guests were treated to a bountiful lunch. Prizes for 'Top Shooter' and 'Top Foursome' were awarded. *Thank you to Board of Trustees member, Carlos DaSilva for hosting very successful, FUNd-raising event*!

11th Annual
EVERYONE CARES
Gala
Friday, April 5, 2019

A Night Under the Stars

On Friday, April 5, 2019 close to 200 guests gathered "under the stars" of NYC for the 11th Annual Everyone CARES Gala! Guests were treated to a cocktail hour, followed by a gourmet meal, entertainment by a beautifully talented violinist, award presentations and live and silent auctions. It was a special evening filled with smiles as the CARES' honorees stepped up to the podium to accept their much-deserved awards. This year's honorees included **Carlos DaSilva**, CARES Board of Trustees member, CAH parent, and chair of both the annual Clay Shoot for CARES and the Pennsylvania CAH Awareness Walk. **Chad Lapp**, past president of the CARES Board of Trustees, was also honored for all his hard work and contributions to CARES which include co-hosting the NJ/NY CAH Awareness Walk for eight years and raising awareness and funds as an ultra-runner. This years' medical community honor went to **Dr. Oksana Lekarev** who was awarded the Maria New Award, newly named in honor of CARES' first-ever lifetime achievement award recipient, **Dr. Maria New**. Dr. Lekarev has served the CAH community with compassion and distinction for many years, and currently provides care as the Associate Medical Director of the CAH Comprehensive Care Center at New York Presbyterian/Weill Cornell Medical Center. There, she is also Asst Professor of Clinical Pediatrics and she is a member of CARES' Medical & Scientific Advisory Board. She was honored to receive the award named for her mentor, Dr. Maria New. Dr. New is a pioneer in the CAH field, having treated patients, conducted research, and written extensively about CAH for many years. Dr. New is a professor of Pediatrics and Director of the Adrenal Steroids Disorders Program at Mount Sinai School of Medicine. She is a member of the CARES Foundation Medical & Scientific Advisory Board and for the past half century, she has earned a reputation as one of the nations's leading pediatric endocrinologists. Her CAH studies have led to treatments to correct the disorder before the baby is born and she is one of the world's leading authorities on CAH.

Honorees Dr. Maria New (left) and Dr. Oksana Lekarev

Honoree Chad Lapp

Honoree Carlos DaSilva

Emcee, Dr. Mitchell Geffner

Please start making plans to join us in sunny California for this, our 20th Anniversary Gala! Contact Dina@caresfoundation.org for sponsorship information and look for more details, coming soon!

The CAREing Hearts Society

The CAREing Hearts Society was formed as a way to recognize the outstanding generosity of our top donors. This group of donors has made a significant impact on CARES Foundation and the development of our Comprehensive Care Centers, research, education and other programs and services. We wish to thank our Society members for playing an integral role in the success of CARES.

PIONEER LEVEL

Jessica Hall Upchurch & Matthew Upchurch - Virtuoso
Victoria Charitable Trust

VISIONARY LEVEL

The Deena Jo Heide-Diesslin Foundation
Concierge Imaging
HRI Health Research
Rhonda & Gregory Kraff
Kelly & Adam Leight
Heather McDonald, Esq.
Neurocrine Biosciences, Inc.
Pfizer
Anna Pinto - Micato Safaris
Drs. Karen & Edwin Su
Meridith & Daniel Taylor
William & Jennifer Trzos

CHAMPION LEVEL

Dr. Thomas & Karen Bogaard
TravCorp, USA
Mitzi & Bill Davis
Diurnal Limited
Alexandra Dubois
Chad Lapp
Cindy & Alan Macy
Marc & Marjorie McDonald
Ernest & Susan Mendes
Millendo Therapeutics
Oceania Cruises
Perkin Elmer Foundation
Spruce Biosciences
Rolex USA
Doug Zehner & Katherine Fowler

ADVOCATE LEVEL

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Age Wave
Alaris
Kathryn Ashenfelter
Olivia Bernabei
Capital One Bank
Carol Ciluffo
Carlos & Sonia DaSilva
HealthRise Solutions
Investors Bank
Tonya & Rick Judson
Arthur & Nancy Lee
Alex & Sari Lee
Jessica & Neil Margolies
MGM Resorts International
Oxeon Partners, LLC
Richard & Deborah Pendino
Trevor Price & Megan Sheetz
Dr. Richard Rink
Sandra & Mack Rose
Samlyn Capital, LLC
Barry Shier & Nicole Patterson
Carol & James Simpson
David & Betsi Steinberg
Diane Snyder & Albert Steren
Robert & Debbie Svendsen
Subhir & Rimda Wanchoo
Matt & Barbara Wilson

FRIEND LEVEL

Anonymous, Geneva
Susan & Carl Aycock
Baker & Hostetler, LLP
Bellagio
Sondra & Michael Brunone
Chevrolet21, Inc.
Pamela Chiles
Elizabeth & Wayne Chmiel
Coastline Travel Advisors
Diesslin & Associates
Andrew & Martin Farach-Colton
Global Credit Advisors
Indiana University
Karma Foundation
Kayak.com
J. Peter Kiers & Elizabeth Fugate
Jeffrey & Leah Kronthal
LB Industries
Susan & Norman Louie
Richard Orgell
JoAnn Kurtz-Ahlers
Marie France Perugini for John Stair
Marci & Adam Plissner
Protravel International
Rodrigo Quintanilla & Vivian Altman
Raffuel Surety Group
Hope & James Raphalian
Stephanie Rose
William Rosso
Joel Rothman
Royal Carribean/Azmara Club Cruises
Peter Schlegel
Joel & Ethel Sharenow
Spencers Welding Service, Inc.
Bonnie & Jeffrey Stevens
Jaynie & Woody Studenmund
TripMatters, Inc
Kenneth & Vicki Upchurch
Valerie Wilson
Valerie Wilson Travel
Kristi Wold
Mabel Yau, MD

OTHER WAYS TO SUPPORT CARES

FACEBOOK FUNDRAISING

Everybody's doing it for all types of reasons and occasions! It is very popular to go to Facebook before one's upcoming birthday, for instance, and start a fundraiser wherein you ask those who love you and want to post Birthday wishes. They can donate in honor of your special day in lieu of gifts! It's so easy for them to show how much they care. This is your chance to put your social media powers to work for CARES! It's simple and only takes a few clicks of your mouse.

USE THIS LINK FOR HELP IN STARTING YOUR FUNDRAISER TODAY:
https://www.facebook.com/fundraisers

goodsearch

Use GoodSearch search engine and a penny gets donated to CARES every time you do a search! Go to **GoodSearch.com** (https://www.goodsearch.org) and get started today. AND, if you're shopping online, you can visit GoodShop.com. Here you will find more than 900 top retailers. Choose to shop at one of these online stores, and a percentage of your purchases will be donated to CARES. When choosing CARES as your charity of choice, type in *CARES Foundation - Congenital Adrenal Hyperplasia*.

Care2Share Investors Bank supports CARES by providing regular donations through its Care2Share program. This program allows you to link your personal accounts at Investors with CARES Foundation, then, on a regular basis, Investors reviews the number of accounts linked to us, calculates the average balance in those accounts, and donates to us equal to a percentage of that average balance. It's totally free and with a little help from you, your family, friends, and colleagues, we can make a huge impact. Investors Bank customers, go to your local branch and ask them to link your account/s to CARES through the Care2Share program.

DOUBLE YOUR IMPACT WITH A MATCHING GIFT!

Does your employer offer a matching gift program? Recent statistics show that up to 65% of American companies/businesses of all sizes offer this type of giving program to their employees. We urge you to consider finding out about those opportunities at your place of employment the next time you donate to CARES!

AMAZON SMILE

This is a very simple way to do good for others. If you're already an Amazon shopper then you know how easy it is to shop on their website and with shipping bargains like Prime, the convenience is unbeatable. So now, take one extra step and instead of going to Amazon.com go to www.smile.amazon.com and designate CARES Foundation (type in as: *Congenital Adrenal Hyperplasia Research, Advocacy, etc.*) as your charity. Everything else is the same: your account number, your password information, your saved credit cards, shipping addresses, etc., all the same. Now, every time you purchase anything on AmazonSmile, a portion of the profits will come to us.

WELCOME ABOARD

We would like to extend a warm welcome to our newest members of our Board of Trustees, Timothy Roberts, PhD and Alan Macy.

Timothy Roberts, Ph.D.

Dr. Roberts is a nationally-recognized leader in defense capability and resource analysis. Director of a studies program with clients at the highest levels of the Department of the Navy and Office of the Secretary of Defense. Dr. Roberts currently works for the Center for Naval Analyses, operated by CNA Corporation in Arlington, VA. as a Research Team Leader in Aviation Systems and Technology. His studies program has driven major decisions by the most senior civilian and uniformed leaders of the Secretary of the Navy, Chief of Naval Operations, and Commandant of the Marine Corps. He is responsible for personnel management, business development, studies execution, and sponsor relations, as well as for the work of 26 F.T.E. Ph.D. staff. He is also responsible for business development training for the entire organization. Dr. Roberts has been awarded many academic and professional development honors and has written or contributed to more than 50 defense-related and academic publications.

Alan Macy

Welcome back Alan Macy! This is Mr. Macy's second stint on the Board after an absence of a few years. He is the Research and Development Director and co-founder of BIOPAC Systems, Inc. He designs biosignal measurement and analysis systems, used by educators and researchers in the life sciences. He is also the founder of the Santa Barbara Center of Art, Science and Technology. As an applied science artist, he specializes in the creation of cybernated art, interactive sculpture and environments.

NEW DIRECTIONS

ASRM names Dr. Ricardo Azziz as new CEO

The American Society for Reproductive Medicine (ASRM) announced in July, the appointment of Ricardo Azziz, MD, MPH, MBA to serve as the Society's Chief Executive Officer beginning in January 2020.Dr. Azziz is currently serving as Chief Officer, Academic Health and Hospital Affairs at the State University of New York System. Dr. Azziz, a Reproductive Endocrinologist is a fellow of both the American College of Surgeons and the American College of Obstetricians and Gynecologists. He is also a member of CARES' Medical and Scientific Advisory Board.

He began his career in academic medicine at University of Alabama Hospital. Prior to being appointed President of Georgia Health Sciences University, he served as department chair at Cedar Sinai, and Assistant Dean at UCLA. Having served on NIH study sections, FDA panels, state oversight commissions and others, Dr. Azziz has a long history of public service. He has served in leadership roles in medical organizations as well. He was the founding Executive Director of the Androgen Excess and PCOS Society. Dr. Azziz has authored more than 500 publications and is a leading authority on PCOS and androgen excess disorders. "We are thrilled to have landed a leader as accomplished as Dr. Azziz. His history as a clinician, investigator, teacher, mentor and most importantly as a leader makes him the perfect choice to lead ASRM into our next era." said Peter Schlegel, MD President of ASRM. "What an exciting opportunity this is" said Azziz. "To return to my intellectual roots in reproductive medicine, my organizational roots with ASRM, and my geographic roots in Birmingham is simply an opportunity I could not pass up." "I look forward to helping ASRM and its members achieve excellence in it."

CARES Foundation congratulates Dr. Azziz and wishes him all the best in this new endeavor.

Governor Ron DeSantis Announces Dr. Scott A. Rivkees as Florida Surgeon General

Dr. Scott A. Rivkees, a member of the CARES Medical and Scientific Advisory Board and co-author of CONGENITAL ADRENAL HYPERPLASIA: A PARENTS' GUIDE, was named as Florida Surgeon General and Secretary of the Florida Department of Health by Governor Ron DeSantis. Dr. Rivkees, a practicing pediatric endocrinologist, is also a professor and chair of the Department of Pediatrics at the University of Florida College of Medicine and physician-in-chief of UF Health Shands Children's Hospital, part of UF Health, the university's academic health center. He also serves as academic chair of pediatrics at Orlando Health and pediatric chair at Studer Family Children's Hospital at Sacred Heart in Pensacola. Dr. Rivkees has served as associate chair of pediatrics for research at the Yale University School of Medicine and on the faculty at Harvard Medical School. "Dr. Rivkees brings a wealth of experience and excellent credentials that fit glove-in-hand with Florida's needs. I look forward to working with Dr. Rivkees, whose leadership will be indispensable in addressing the opioid crisis facing our state and responsible implementation of medical marijuana now that a legislative solution is in place, among other important issues." Said Governor DeSantis. Dr. Rivkees is known as one of Florida's leading physicians and an internationally-renowned expert in his field. Lt. Governor Jeanette Nuñez said that she is confident that Dr. Rivkees "will inspire and spearhead innovative programs as Florida Surgeon General," he "understands the public health challenges facing Florida families and how the Department of Health can better work with its stakeholders to deliver on our commitment to a healthy Florida. In response to his being named, Dr. Rivkees said, "I am deeply honored to accept the appointment of Florida Surgeon General, a position that has the responsibility to ensure Florida's 21 million citizens have access to affordable, safe and quality healthcare."

Dr. Rivkees is a graduate of Rutgers University and the University of Medicine and Dentistry of New Jersey. He has authored more than 200 original articles, chapters, and editorials and he is the Editor-in-Chief of the International Journal of Pediatrics Endocrinology, and is a member and leader of many other medical organizations. As an internationally-renowned expert on developmental biology and pediatric endocrinology, Dr. Rivkees leads a vigorous clinical and basic science research program. He has won several awards and has been recognized for excellence in many medical arenas.

CARES Foundation congratulates Dr. Rivkees on this momentous achievement!

NEW! YOUNG ADULT ADVISORY BOARD

CARES has assembled a new group to aid our assistance to the young adult CAH population. This group will help raise awareness of CAH among other young adults about the unique challenges of managing CAH in young adulthood. Issues about medical provider options, health insurance, long term health effects of CAH, and family planning will also be discussed. Our current members include: Erik Bogaard, Ryan Hendler, Adrienne Marks, Julia Anthony, Amy Matthaler, Marc Pollack and Alana Tang. Thank you for volunteering for this new group which we hope will help us improve the lives of all living with CAH.

Comprehensive Care Centers for CAH

NY Presbyterian Hospital-Weill Cornell Medicine Comprehensive Care Center for CAH Wins Top Award!

The Comprehensive Center for CAH at the Komansky Children's Hospital- New York Presbyterian Hospital-Weill Cornell Medicine, won the top Basic Science Research Award at the Societies for Pediatric Urology Meeting in Scottsdale Arizona on Sunday September 28. The research team lead by CARES' Medical and Scientific Advisory Board Member and Chief Urologist of the Comprehensive Care Center for CAH, Dr. Dix Poppas, presented their work that is focused on developing a new model to study the genetic pathways involved in CAH in the Zebrafish. This model will allow the team to identify drugs that can increase the 21-hydroxylase enzyme activity in patients with CAH and eliminate the need for steroids. If successful, these drugs would provide an easier and less complicated treatment while reducing the side effects that are associated with taking steroids. The research team is excited about the future treatment options that could benefit CAH patients. The title of the research: *Modeling cyp21a2 Dependent Steroidogenesis in Zebrafish for Application in* Congenital Adrenal Hyperplasia. Jun Yao, PhD, Kiersten Craig, MD, MSE,Dix Poppas, MD, FACS and Yariv Houvas, MD, PhD.

This research was sponsored in part by CARES Foundation.

NewYork-Presbyterian Kids
Komansky Children's Hospital

The Comprehensive Care Center for CAH at Riley Hospital for Children

In addition to hosting the 2019 education conference, the center has published two peer reviewed research studies about CAH. The first one describes the creation of the first questionnaire that can be used to capture parents' perceptions about the appearance of their daughters' genitalia and, we hope, will be helpful in improving communication and care. The second study focused on future concerns that parents found stressful when they were considering surgery for their daughter. It turned out that, even when considering surgery, parents' biggest concerns focused on life-threatening issues and developmental concerns related to CAH. The study also revealed that while virtually every family planned to disclose details of treatment to their daughter when she was older, many were unsure how best to go about it. Finally, in collaboration with the other CAH Comprehensive Care Centers across the country, the Riley Hospital for Children Center launched the Life with CAH Study earlier this year. Through this study, the group hopes to learn about topics that people living with CAH (and their families) have previously told us are important to them. These include areas of particular stress, disclosing the CAH diagnosis and treatment history as well as making treatment decisions. The study is ongoing, and we hope to have first results available in 2020.

Riley Hospital for Children
Indiana University Health

tidbits

HELP US KEEP OUR DATABASE UP TO DATE

At CARES, our goal is to make life easier, safer, and healthier for our CAH community. **THE MORE INFORMATION WE HAVE, THE MORE WE CAN DO OUR JOB: HELP YOU!**

Please make sure that we have up to date contact information for you! It is especially crucial that you have a current email address on file, for we send our most important messages regarding research, like surveys, studies, and information on clinical trials. We also email to keep you abreast of CARES' activities and educational and special events. If you're not sure we have a working email for you, please contact us, contact@caresfoundation.org and we'll check. Please, may we also encourage you to **Join Our Community** (https://tinyurl.com/yxtdefht) and give us some information about you and the CAH afflicted individual/s in your life. You can join as a CAH patient, parent of a CAH patient, relative or friend of a CAH patient or as a Supporter/Friend of CARES. It only takes a few minutes of your time.

WE NEED YOUR HELP!

WE ARE IN NEED OF EXPIRED ACT-O-VIALS!

THESE ARE USED FOR INJECTION TRAINING.

PLEASE SEND TO US:

CARES FOUNDATION • 2414 MORRIS AVE, STE 110 • UNION, NEW JERSEY 07083

WE APPRECIATE YOUR HELP!

Let's Get Social!

Now, more than ever, it is important to have a large and effective presence on Social Media and WE NEED YOUR HELP!
PLEASE TAKE A FEW MOMENTS TO:
FOLLOW US ON **TWITTER,** @caresfoundation

FOLLOW US ON **INSTAGRAM,** caresfoundation

JOIN OUR **FACEBOOK** GROUP: **CAH Champions** (for CAH patients and families only and by request)
https://www.facebook.com/cah.champions

LIKE AND FOLLOW OUR **FACEBOOK** PAGE:
CARES Foundation https://tinyurl.com/y3nlbd77

CONNECT WITH US ON **LINKEDIN,**
https://www.linkedin.com/in/c-ares-foundation-a32795137/

In the year 2020, CARES will celebrate its 20th Anniversary. We look forward to many exciting moments celebrating the past and setting a course that will ignite our future. None of what we've done would be possible with your support.

HELP US KICK OFF 2020 WITH A GENEROUS DONATION! Look for our year-end campaign letter. We will include a survey to help us serve you better in the future. **Complete and return the survey**, and you will be entered to **win gift cards!**

We extend our deepest condolences to the families and loved ones of the three patients we lost in the last few months. Our thoughts and prayers are with them during their time of loss.

Ryan James Kennedy Torony

May 25, 1995 ~ May 31, 2019

New Haven, CT

Derek Stephen Yanes

July 7, 1973 ~ June 10, 2019

Brandon, FL

Cody Dale Lohman

October 22, 1996 ~ October 6, 2019

Indianapolis, IN

NEW IN THE CARES SHOP!

Have you visited our online store recently? With the holidays coming up fast, you might want to pay our shop a visit. We have some brand new CAH awareness items and many other items that are educational, gift-friendly, and perfect for the CAH patient or caregiver in your life!

NEW!! CAH AWARENESS PIN

Wear this CAH Awareness pin with pride and spread awareness of this rare disorder. Wear it daily and especially during CAH Awareness Month in June.

NEW!! CARES 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 CAH is!

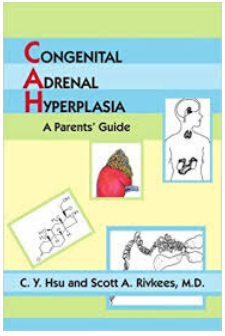
In Regular Cut/Men's, Women's, Youth & Toddler sizes!

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. 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 shown.

ADRENAL INSUFFICIENCY CAR 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 Grandma? Buy extras so you don't have to worry about moving it.



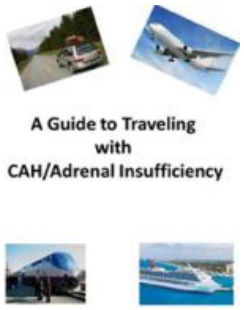
CONGENITAL ADRENAL HYPERPLASIA: A PARENTS' GUIDE

A valuable resource, this book takes a nuts-n-bolts look at CAH - what this condition is, how it is inherited, and how it is treated and monitored. Written for a lay audience, it is well-received by patients and parents. Written by: C.Y. Hsu and Scott A. Rivkees, M.D.

MEDICAL I.D. SHOE TAGS

FRONT BACK

Medical ID Shoe Tags are 2-ply red plastic oval tags (1"x1 1/2") with two holes (each 3/16" diameter). Laser engraved with emergency medical logo on front side and medical info on back side for privacy. Tell first responders how best to care for you in the event of an emergency. Perfect for active kids and adults! These custom Medical ID shoe tags are a great accessory for your shoes, backpack, or purse!



Traveling with CAH/AI Packet - Printed with Shot Kit

CARES Foundation's "Traveling with CAH Packet" will help you plan for a safe and healthy trip. This printed packet includes: NEW! One Shot Kit Bag for your Emergency Response Kit - Before Your Trip- What to Pack- Packing Tips- In Transit- After Your Trip- Medical Information Sample Letter- Emergency Information- About the Person with CAH- sample letter - Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A guide for affected individuals and their families- CARES Foundation Emergency Instructions brochure

THE OFFICIAL CARES FOUNDATION MUG

The 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!

VISIT THE CARES SHOP TODAY!

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

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Web: www.caresfoundation.org

Enjoy the upcoming holiday season ~

We wish you and yours a healthy, happy, and joyous 2020!