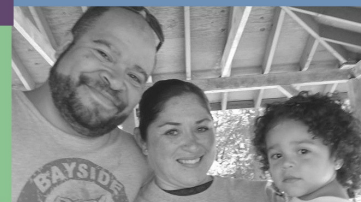


Improving health, connection people, saving lives



In This Issue

Research	
Congenital Adrenal Hyperplasia: A Systematic Review and Meta-Analysis	1
The Neuroimaging, Emotions and Appetite Testing (NEAT) Study	4
GEMini CAH - Genetic Exploration and Modification Initiative for CAH	5
A Phase 2, Multiple Dose Escalation Study to Evaluate the Safety and Efficacy of SPR001 in Adults with CAH	5
New Study by Neurocrine: Adults with CAH	5
New Study for Children with CAH: 'Abiraterone in CAH'	5
Executive Director's Message	2
Education	6
The Doctor Is In	6
Advocacy	7
Making Connections	7
A Personal Story	8
CAH Around the World	8
Fun-Raising	9
Welcome Aboard	13
New Directions	13
tidbits	14

Cardiovascular and Metabolic Outcomes in Congenital Adrenal Hyperplasia: A Systematic Review and Meta-Analysis

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Congenital adrenal hyperplasia (CAH) refers to a group of autosomal recessive disorders characterized by impaired biosynthesis of cortisol affecting ~1 in every 15,000 live births (1). The most common form of CAH presenting in infancy, referred to as classic congenital adrenal hyperplasia (CCAH), is due to a mutation in CYP21A2, the gene encoding the 21-hydroxylase enzyme. CYP21A2 mutation is seen in ~95% of all CCAH cases and is characterized by cortisol deficiency, with or without aldosterone deficiency and androgen excess (1, 2). Depending on the extent of enzyme impairment, CCAH is subclassified as either salt losing or simple virilizing (3). Nonclassic congenital adrenal hyperplasia (NCCAH), estimated at 0.1% to 1% or even higher depending on ethnicity and race, is usually detected in later childhood, adolescence, or adult life, and it is associated with relatively mild enzyme impairment (4, 5). Although the latter group often does not require continuous or lifelong glucocorticoid treatment, many patients with NCCAH receive glucocorticoids for durations ranging from months to many years to control androgen excess.

Early diagnosis and treatment of CCAH are essential for the prevention of morbidity and mortality. The goals of management are to provide adequate supplementation for adrenal insufficiency (glucocorticoids ± mineralocorticoids), as well as control androgen excess (glucocorticoids). The balance between the two is the main challenge in clinical practice, as control of androgen excess can require supraphysiological or subphysiological glucocorticoid replacement. Both excessive glucocorticoid and mineralocorticoid supplementation might lead to increases in cardiovascular risk factors. In contrast, poor compliance or insufficient glucocorticoid therapy can lead to androgen excess, infertility, and development of adrenal crest tumors (6, 7).

Clinical practice varies in terms of the steroid type and regimen chosen. However, many patients may be receiving supraphysiological amounts of glucocorticoids. Cardiovascular outcomes related to steroid therapy in patients with CAH are unclear. We conducted a systematic review of the published

literature to appraise and summarize the evidence regarding cardiovascular and metabolic outcomes in terms of hypertension, hyperlipidemia, glucose intolerance, and carotid intima thickness in patients with CAH treated with glucocorticoid and mineralocorticoid replacement therapy compared with controls without CAH.

RESULTS

We included 20 studies (Fig. 1). Fourteen studies contributed data to the meta-analysis. Study characteristics are presented in Table 1, with more details in the online repository (12). All of the studies were observational (14 longitudinal, six cross-sectional) with moderate to high risk of bias. Several other large observational studies of individuals with CAH did not provide detailed data to be included in the meta-analysis. Studies with more than 50 individuals (27–34) are summarized qualitatively.

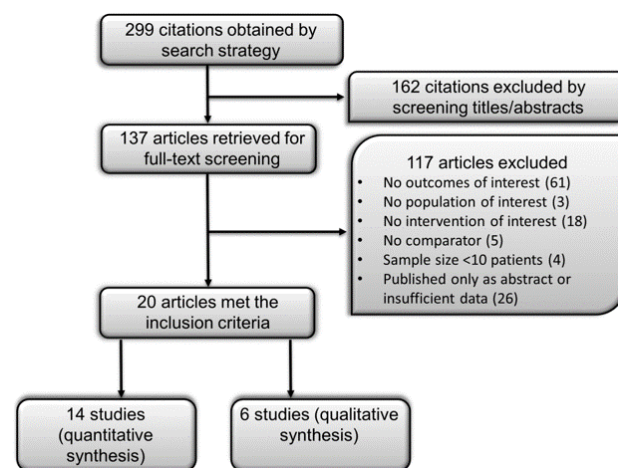


FIGURE 1. The process of study selection.

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A Message from the Executive Director



Dear Friends:

Welcome to a new edition of CARES Connections!

This has been a year of making connections, growing our community, more education, increased support and advocacy.

Our awareness walks have been an excellent opportunity to make connections, raise awareness and build community across the country. We've added walks in Florida and in Ohio, this year with two walks. These events have provided an opportunity for families to meet, patients to share stories and for professionals to educate our community. We are grateful to the patients and families who have hosted and participated in these events. We look forward to continue growing our awareness opportunities and hosting more walks in 2019.

The year had us crisscrossing the country. Our annual patient education conference was held in Los Angeles, we participated in the annual Endocrine Society meeting in Chicago, hosted the first annual Golf Tournament in Massachusetts and held walks in Florida, Maryland, Pennsylvania, Ohio, California, New Jersey and Massachusetts. There is no better feeling than to see the appreciative smiles of patients and families who are learning to manage CAH, making real connections with other patients and families, and most importantly for me, seeing our children grow up! "My kids" as I call them, always give me a reason to smile. There's nothing better than their hugs to make my heart sing. The hugs and tears of grateful parents are what keep us going. There is nothing more powerful than the appreciation we feel from our community.

There are good moments and challenging moments. This year has been a difficult year for patients and parents who are faced with the difficult decision of selecting genital surgery for themselves or their children. There have been legislative and advocacy challenges. Parents have been vilified for deciding to give their female children an opportunity to live as healthy a life as possible – being able to experience healthy sexual relationships, normal menstrual cycles and looking and feeling like the females they are. We are grateful for our patients and parents who have spoken out on their behalf and on behalf of their children and the CAH community at large. The fight is only beginning as challenges to access to care, parents' rights to make medical decisions for their children (a basic right of parents), and the rights of patients who deserve a healthy life are threatened by misled legislators and activists who pretend to fight for patients, but in reality are harming them. We will continue to fight for access to care for CAH children and for the rights of parents to make decisions for their children in all aspects of their life.

So, in closing, I ask that you continue to fight the fight with us and emerge as a hero for our patients.

Gratefully,

Research continued from pg 1

Study ID	Country	Study Design	Age Group	Sample Size	Overall Methodological Quality
Studies included in quantitative synthesis					
Botero <i>et al.</i> , 2000 (13)	Colombia	Case-control	Children	14	Low
Charmandari <i>et al.</i> , 2002 (14)	Germany	Case-control	Children	18	Moderate
Sartorato <i>et al.</i> , 2007 (15)	Italy	Case-control	Adults	19	Moderate
Falhammar <i>et al.</i> , 2007 (16)	Sweden	Case-control	Adults	61	Moderate
Zimmermann <i>et al.</i> , 2010 (17)	Romania	Case-control	Children and adolescents	27	Low
Williams <i>et al.</i> , 2010 (18)	United Kingdom	Case-control	Children	25	Moderate
Mooij <i>et al.</i> , 2011 (19)	Netherlands	Case-control	Adults	27	Low
Falhammar <i>et al.</i> , 2011 (20)	Sweden	Case-control	Adults	30	Moderate
Harrington <i>et al.</i> , 2012 (21)	Australia	Case-control	Children	14	Low
Wasniewska <i>et al.</i> , 2013 (22)	Italy	Cross-sectional	Adolescents	18	Moderate
Amr <i>et al.</i> , 2014 (23)	Egypt	Case-control	Children	32	Moderate
Subbarayan <i>et al.</i> , 2014 (24)	United Kingdom	Case-control	Children and adolescents	107	Low
Marra <i>et al.</i> , 2015 (25)	Italy	Cross-sectional	Adolescents	20	Moderate
Akyürek <i>et al.</i> , 2015 (26)	Turkey	Case-control	Children and adolescents	25	Low
Studies included in qualitative synthesis					
Arlt <i>et al.</i> , 2010 (27)	United Kingdom	Cross-sectional	Adults	203	NA
Finkelstein <i>et al.</i> , 2012 (28)	United States	Cross-sectional	All	244	NA
Krone <i>et al.</i> , 2013 (29)	United Kingdom	Cross-sectional	Adults	153	NA
Han <i>et al.</i> , 2014 (30)	United Kingdom	Cross-sectional	Adults	199	NA
Falhammar <i>et al.</i> , 2015 (31)	Sweden	Case-control	All	588	NA
Bonfig <i>et al.</i> , 2016 (32)	Germany	Case-control	Children and adolescents	716	NA

NA, not assessed.

Table 1. Description of Included Studies

Meta-analysis

The 14 included studies (12 longitudinal, two cross-sectional) reported data for 437 patients (300 children/adolescents and 137 adults, aged 14 months to 63 years). The average dose of glucocorticoid was 9 to 26.5 mg/m²/d of hydrocortisone equivalent. Glucocorticoid types and regimens varied between studies and within individual studies. Most of the studies did not report on the fludrocortisone dose. Biochemical assessment in relation to hyperandrogenemia and CAH control (e.g., concentrations of androstenedione and 17-hydroxyprogesterone) was reported in only four of 14 studies. Control populations consisted of healthy individuals without CAH mostly matched for age, sex, and BMI.

The results of meta-analyses are summarized in Table 2. Patients with CAH on glucocorticoid replacement had higher systolic blood pressure (SBP) and diastolic blood pressure (DBP) than controls. Patients with CAH had no significant differences in fasting blood glucose, blood glucose after 2-hour glucose tolerance testing, fasting insulin, or 2-hour insulin concentration after glucose load. Patients with CAH had higher homeostatic model assessment of insulin resistance than the controls. Patients with CAH and controls had similar concentrations of total cholesterol, low-density lipoprotein cholesterol, high-density lipoprotein cholesterol, and triglycerides. Patients with CAH had higher carotid intima thickness than the controls.

Table 2. Meta-Analysis Results

Outcome	WMD	95% CI
SBP, mm Hg ^a	4.4	3.3 to 5.6
DBP, mm Hg ^a	2.4	0.5 to 4.2
Fasting blood glucose, mg/dL	-2.35	-5.21 to 0.51
2-h blood glucose (GTT), mg/dL	10.24	-0.07 to 20.55
Fasting insulin, mU/L	1.17	-0.32 to 2.267
2-h insulin, mU/L	5.96	-8.37 to 20.34
HOMA-IR ^a	0.49	0.02 to 0.96
Total cholesterol, mg/dL	2.70	-1.55 to 6.96
LDL cholesterol, mg/dL	0.43	-2.70 to 3.56
HDL cholesterol, mg/dL	3.43	-0.67 to 7.52
Triglycerides, mg/dL	3.33	-3.40 to 10.06
Carotid intima thickness, mm ^a	0.08	0.01 to 0.15

Positive numbers indicate higher values in individuals with CAH.

Positive numbers indicate higher values in individuals with CAH. Abbreviations: GTT, glucose tolerance test; HDL, high-density lipoprotein; HOMA-IR, homeostatic model assessment of insulin resistance; LDL, low-density lipoprotein; WMD, weighted mean difference.

^aDenotes a statistically significant difference (P < 0.05).

Subgroup analyses

Subgroup analyses were feasible for only a few comparisons. Subgroup analysis by age showed that the patients with CAH had higher SBP than the controls only in children and adolescents (results in adults were nonsignificant), whereas patients' DBP was significantly higher than that of the controls only in adults (results in children were nonsignificant).

Other subgroup analyses by age suggested that children and adolescents with CAH had lower fasting glucose and higher total cholesterol than the controls. The increase in carotid intima thickness was more pronounced in adults than in children and adolescents.

Data were unavailable for other planned subgroup analyses based on variables such as age at diagnosis, sex, genotype, dose of steroid, type of steroid, duration of treatment, method of measuring blood pressure, and CCAH vs NCCAHA.

Other observational studies

Other observational studies with >50 individuals (27–34) that did not provide detailed data for inclusion in the meta-analysis are summarized qualitatively. In a cross-sectional analysis of 199 adults with CAH in the UK CAH Adult Study (27, 29, 30), higher rates of hypertension (HTN) were observed in patients with CAH diagnosed late (after 1 year) than in those diagnosed early, and HTN rates were also higher in women treated with glucocorticoids only than in those treated with both glucocorticoids and mineralocorticoids. Blood pressure was not different between the groups with different genetic mutations, and women with classic CAH had increased DBP. In a Swedish population-based study (31) studying 558 patients with CAH compared with 58,800 controls matched for sex, age, and birthplace, CAH was associated with an increased frequency of HTN. In a cross-sectional study (28) of 244 patients with CAH conducted at the National Institutes of Health, elevated blood pressure was more common in patients with CCAH than in patients with NCCAHA. In a German cohort of 716 children and adolescents (32), the prevalence of HTN was 12.5%, was higher in younger children than in adolescents (18.5% vs 4.9%), and was higher in salt-wasting CAH than in simple virilizing CAH. Until 8 years of age, fludrocortisone dose but not hydrocortisone dose was correlated significantly with blood pressure. In a Brazilian case-control study (34), HTN was found in 12% of patients, and heterozygotes for the Bcl polymorphism within intron 2 of the glucocorticoid receptor (NR3C1) gene exhibited higher SBP than wild-type subjects. Völkl et al. (33) showed that daytime and nighttime SBP were also significantly elevated, whereas daytime DBP was significantly lowered and was normal during the night, and overall, there was a normal nocturnal drop in SBP but not in DBP. Other findings from the Swedish cohort (31) were that patients with CAH had higher prevalence rates of HTN, hyperlipidemia, atrial fibrillation, venous thromboembolism, obesity, and diabetes.

Quality of evidence

The quality of evidence (i.e., certainty in these estimates) was low due to the observational nature of the evidence, the moderate to high risk of bias, and the high degree of heterogeneity. Overall, the studies relied on surrogate outcomes, with minimal data on hard end points.

Main findings

This systematic review and meta-analysis suggested that, compared with controls without CAH, individuals with CAH had increased SBP, DBP, insulin resistance, and carotid intima thickness. No statistically significant difference was noted in fasting blood glucose or lipids. We were unable to draw conclusions regarding the effects of several important variables such as sex, glucocorticoid type and dose, fludrocortisone dose, and genotype. Data on cardiac events were sparse. However, ample evidence suggests that these surrogate cardiometabolic risk factors are associated with increased future cardiac events. For example, in the Framingham Heart Study cohort, a stepwise increase in cardiovascular event rates was noted in adult men with higher baseline blood pressure categories (35). Other epidemiological studies (36–40) have also demonstrated that, in men and women in different age groups, SBP and DBP had a continuous and graded positive association with cardiovascular disease outcomes. However, no such conclusions could be drawn based on isolated measurements of blood pressure in children.

Limitations and strengths

There were several limitations to this systematic review and meta-analysis. The

quality of evidence (i.e., certainty in these estimates) was low due to the observational nature of the evidence, the high risk of bias, the reliance on surrogate outcomes, and the heterogeneity of the included studies. The age at which the steroid therapy was initiated and the duration of follow-up were not specified in most studies. Data were not available to perform several important planned subgroup analyses comparing outcomes by sex, BMI, or weight z score; number of salt-wasting episodes; CAH genotype; type and dose of steroid used; duration of steroid therapy; and method of blood pressure measurement. Notably, blood pressure was measured by different methods (supine, upright, and 24-hour ambulatory measurements) in these studies. Data were not available separately for patients with NCCAHA.

The strengths of this review were related to the comprehensive literature search, a priori established protocol, and duplicate process of study selection and appraisal.

Implications

On the basis of the results of this systematic review and meta-analysis, we conclude that patients with CAH might demonstrate increased cardiovascular and metabolic risk compared with reference population controls. Potential contributing factors include excessive therapy with glucocorticoids or mineralocorticoids and uncontrolled androgen excess. Therefore, efforts should be exerted to minimize these possible contributors (41). Administering close to physiological doses of glucocorticoids and using the lowest needed doses of mineralocorticoids are essential. Additional attention should be paid to maintaining a healthy body weight and BMI, both of which are known correlates of higher blood pressure. Promising approaches with new modified-release and pediatric-specific low-dose glucocorticoid formulations might be additional tools that could help in achieving these goals (42). Careful monitoring of symptoms and signs of excessive glucocorticoid dosing is important. Increased dosing of glucocorticoids is appropriate in patients with febrile illness, major surgery, or trauma; however, it should not be implemented in the presence of other types of mental and emotional stress or minor illnesses or before routine physical exercise. Adolescents and adults should be monitored as per standard guidelines for the development of metabolic syndrome, hyperlipidemia, and hypertension. Preemptive lifestyle counseling to reduce cardiovascular risk is paramount. Studies evaluating strategies to reduce the risk of metabolic and cardiovascular outcomes in patients with CAH are needed.

Conclusion

Individuals with CAH demonstrate a high prevalence of cardiovascular and metabolic risk factors; however, we found no evidence of actual morbidity or mortality due to cardiac events. Long-term prospective studies are warranted to assess strategies for reducing cardiovascular risk in individuals with CAH.

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Full Reference List available here: <https://www.caresfoundation.org/wp-content/uploads/2018/11/REFERENCE-LIST.pdf>

The Neuroimaging, Emotions and Appetite Testing (NEAT) Study



From the CAH Comprehensive Care Center at CHLA

The Neuroimaging, Emotions and Appetite Testing (NEAT) Study is about obesity, appetite, emotions, and how the brain develops in children. We have found that parents are interested in learning more about these areas, and so are we. We are interested in understanding obesity in children and adolescents with CAH, given the increased prevalence of obesity (up to double!) beyond normative pediatric populations. We are also interested in various stages of emotional

development and behavior in CAH youth. We are applying the newest imaging. We are currently at the halfway point for total participants in our study, so there is still room to join. The study visit consists of two sessions that include a physical exam, X-ray of left hand, computer-based tests, blood sample, a magnetic resonance imaging (MRI) session to safely obtain a picture of the child's body (no radiation involved), and parental questionnaires. The parent and child can receive up to \$185 for completing all portions of the study, and a picture of the child's actual brain! If you are interested in having your child participate in this exciting CAH study in Los Angeles please contact us at CAH@chla.usc.edu or hross@chla.usc.edu.

GEMini CAH - Genetic Exploration and Modification Initiative for CAH

From the CAH Comprehensive Care Center at NY Presbyterian/Weill Cornell

A Chemical-Genetic Approach to Identifying Drugs for Inducing CYP21As Expression

We are working on a chemical-genetic approach to identifying drugs for inducing CYP21A2 expression. Most patients with CAH have some function of their CYP21 A2 gene. We have developed a novel chemical screening platform suitable for identifying drugs that alter cyp21a2 expression in zebrafish. The identification of drug compounds will be followed up with genetic approaches in zebrafish and extended to human cell lines for further characterization. Our studies raise the possibility that it may be possible to repurpose select drugs to improve treatment of patients with CAH and improve their quality of life.

Precision Genetic Moderation of Human CYP21A2 for Treatment of CAH

We are also working on a genetic model in human adrenal cells to replace the defective gene with a functioning gene using CRISPR technology. If successful in the human cell line, we will proceed to animal models. We hope this approach could lead to eliminating the need for CAH to take medications and allow their own bodies to produce the needed hormones to allow for normal adrenal function.

RESEARCH OPPORTUNITY!

Spruce Biosciences is conducting a research study to evaluate a new medication for adult CAH patients

A Phase 2, Multiple Dose Escalation Study to Evaluate the Safety and Efficacy of SPR001 in Adults with CAH

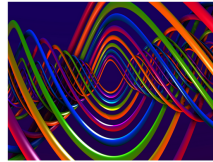
This study is for an investigational, once-a-day pill for CAH, designed to correct hormone imbalance and potentially reduce the necessary dose of traditional steroid medications. If you are 18 years of age or older,

and have been diagnosed with classic CAH, you may qualify to participate. Participants will receive study-related care and medication at no cost, and compensated for your time and travel. Use this link to see if you qualify:

<https://clinicaltrials.gov/ct2/show/NCT03257462?term=NCT03257462&rank=1>

CARES Foundation does not counsel individual patients either for or against participation in any specific research study. Prospective volunteers should always carefully review the study's informed consent documentation and discuss the pros and cons of their participation with trusted advisers, including their health care providers and family members. For more information on research participation, check out www.hhs.gov/ohrp/education-and-outreach/about-research-participation/index.html

NEW Adult CAH Study



(CAH), ages 18-50, needed for a clinical trial of the investigational compound NBI-74788. Neurocrine Biosciences, Inc. is conducting an open-label, multiple-dose clinical trial to assess the effect of NBI-74788 on safety measures and hormone levels in adults with classic, 21-hydroxylase deficiency CAH. The study will be conducted in approximately 16 to 20 females and males with CAH. Two independent dosing groups of NBI-74788 (approximately 8 to 10 patients per group) will be evaluated following repeated-dose administration of the study drug. For more information go here:

<https://clinicaltrials.gov/ct2/show/NCT03525886?term=neurocrine+biosciences&cond=congenital+adrenal+hyperplasia&rank=1>



SEEKING CHILDREN FOR NEW 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

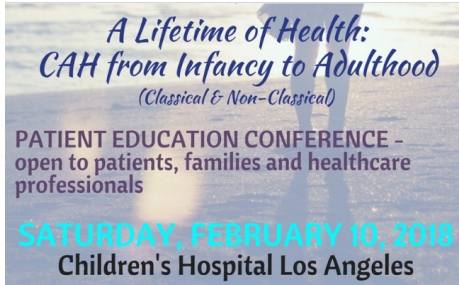
FOR MORE STUDY DETAILS AND CONTACT INFORMATION, USE THIS LINK: <https://www.caresfoundation.org/wp-content/uploads/2018/08/Abiraterone-Flyer-7-5-18.pdf>

Check our website for ongoing studies, trials and research.

<https://www.caresfoundation.org/clinical-trials-an-overview/>

EDUCATION

Patient & Family Education Conferences



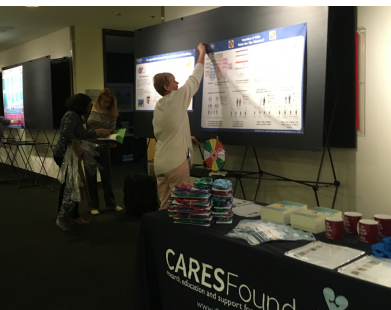
A Lifetime of Health: CAH from Infancy to Adulthood

The 2018 conference was hosted by Children's Hospital Los Angeles on February 10, 2018. Close to 80 attendees joined sessions on topics that included:

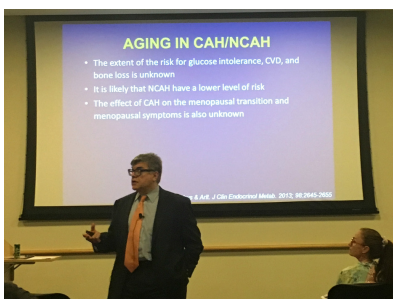
Maternal and Fetal Health Surgical Perspectives Adults and CAH New Research and Development



Attendees were also able to choose from several break-out sessions on topics such as Wellness and Mental Health and Emergency Issues.



A panel discussion was also held with noted CAH healthcare professionals and attendees were offered the opportunity to ask questions on different discussion topics. There were also sessions offered on Act-o-vial training.



It was a very successful event and we appreciate the efforts of the medical professionals and staff at CHLA.

2019 CAH Patient and Family Summit, Riley Hospital/Indiana University Health, Indianapolis, IN, SATURDAY, MAY 11, 2019



STAY TUNED for registration information for the 2019 education conference.

EDUCATIONAL VIDEOS AVAILABLE

Educational videos addressing Adrenal Crisis and Stress Dosing are available for purchase in our online CARES Shop and for 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

Karen Lin-Su, M.D.
CARES Medical Director

Flu Prevention

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

Stress-dosing when sick

- Stress-dosing is not needed for minor illnesses, such as a common cold, if there is no fever.
- Febrile illnesses: For fever <102 degrees F,

double the usual total daily amount of hydrocortisone and divide into 3 equal doses. Doses should be given every 8 hours until the fever is gone. For fever >102 degrees F, give three times the usual total daily amount of hydrocortisone and divide into 3 equal doses. Doses should be given every 8 hours until the fever is gone.

- Vomiting: For a one-time episode of vomiting, repeat the dose if vomiting occurred within one hour of taking an oral dose of hydrocortisone. Otherwise, monitor for continued vomiting. If vomiting persists and you are unable to hold anything down by mouth, then give injectable hydrocortisone (Solu-Cortef) as instructed by your endocrinologist and go to the emergency room.

Trauma

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

Travel

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

Please see our "Travel Guidelines" for more helpful tips.

Stress-dosing for outpatient procedures

Always consult with your endocrinologist regarding the need for stress-dosing for outpatient procedures. However, here are some general guidelines:

- Procedures that are performed under local anesthesia, such as dental work, do not require any additional hydrocortisone.
- Procedures performed under sedation usually warrant stress-dosing prior to the procedure, but generally do not require additional hydrocortisone after the procedure if able to go home.
- Procedures performed under general anesthesia will require IV hydrocortisone prior to the procedure as well as during the procedure if it lasts 2 hours or longer. Additional stress-dosing after the procedure will depend on the patient.

Have a safe and fun holiday season!!



ADVOCACY

#CAHRights

Efforts to protect the rights of CAH patients and parents are ongoing as new resolutions and legislature to ban restorative genital surgery on infants and young children threatens this right every day.

Activist groups still mistakenly link CAH girl patients to their efforts in demanding rights for intersex persons. CARES stands with all CAH patients and parents to protect their rights and access to care.

We applaud the efforts made by the CAH community in standing up for these rights. Due to many of your efforts and a show of force at the AMA House of Delegates Meeting in November, the AMA released this statement: *The American Medical Association (AMA) House of Delegates has adopted new ethical guidance from the Council on Ethical and Judicial Affairs (CEJA) for physicians to help parents and their children. Regarding difficult medical decisions involving pediatric patients, AMA Immediate Past President David O. Barbe, MD states that "The AMA's new ethical framework emphasizes a shared decision-making process where doctors help parents reach clarity and empower choices carefully tailored for each patient."* We consider this a victory.

We will remain vigilant on your behalf to any new legislation that threatens these rights and will keep you informed about how you can take part. Please continue to check us out on Facebook, Twitter and Instagram, and read your CARES' emails for the latest updates.

Emergency Medical Protocols Update

MEDICATION SAFETY ALERT



(EMS PROTOCOLS FOR ADRENAL CRISIS)

The work on protocols for adrenal insufficiency continues across the U.S.

*There are pre-hospital protocols in place in:

- | | |
|---------------|--------------|
| Colorado | Pennsylvania |
| Massachusetts | Rhode Island |
| Montana | Tennessee |
| New Hampshire | Vermont |
| New Jersey | |

*They are also in parts of:
New York
Oregon
Texas
Washington
Wyoming

*In these states, ambulances are allowed to stock and administer Solu-Cortef®.
*Typically, an affected family must request local EMS to carry medication.

In the following states, paramedics or advanced life support (ALS) personnel may administer a patient's emergency medication:

- | | |
|-------------|-----------------|
| Alabama | Maryland |
| Arizona | Michigan |
| Connecticut | Missouri |
| Kentucky | North Carolina |
| Louisiana | Washington, DC. |
| Maine | |

and parts of: California, Florida, Kansas, Illinois, Indiana, Minnesota, Nevada, Ohio, Washington. and Wisconsin

Volunteers continue to work in the following states for protocols:

- | | |
|------------|----------------|
| California | Louisiana |
| Delaware | New Mexico |
| Georgia | South Carolina |
| Hawaii | Virginia |
| Indiana | Utah |

There are efforts in two states for the development of legislation regarding EMS protocols. Also, a National EMS advisory was created this year as a simple guideline on optimal treatment for an adrenal crisis. It will be sent to national EMS organizations and local EMS agencies.

REMINDER to Visit Your Local EMS:

- Alert them of your adrenal insufficiency status in order for them to flag your address and phone number in case you have an emergency.
- Check the EMS pages on our website for protocols in your state. Print them out and bring them on your visit. MANY EMS personnel do not know about adrenal insufficiency protocols.
- You can ask to speak with the EMS trainer to ensure EMS personnel responding to emergency calls are educated on adrenal insufficiency. CARES has a resource training list to share with them. Just email karenf@caresfoundation.org for more details.
- Check and see if your state has an alert program for those with health issues e.g. Special Needs Alert Program (SNAP) in DE, Special Needs Tracking & Awareness Response System (STARS) in IL, MI, OK, WI, and Yellow Dot AL, FL, IL, NY, ME, PA & UT.

Visit Your EMS Provider

ASK YOUR LOCAL EMS IF YOUR AREA HAS A PROGRAM.

Use this link to get tips for a successful EMS provider visit: <https://www.caresfoundation.org/wp-content/uploads/2017/05/CARES-Visit-your-EMS-provider-UPDATE-5.24.17.pdf>.

Print a copy of our Emergency Instructions from this link (<https://caresfoundation.org/wp-content/uploads/2016/07/EmergencyBrochure.pdf>) and bring them with you.

ALWAYS WEAR MEDICAL I.D.



<https://www.myhardhatstickers.com/emergency-medical-information-hard-hat-labels>

MAKING CONNECTIONS



SUPPORT GROUP LEADERS

When new people join our CARES community, they are asked if they would like to be contacted by a CARES Support Group leader. These leaders are a great source of warmth, knowledge, experience and understanding when one is confronted with the difficult news that they or a loved one are diagnosed with CAH. We are very fortunate to have these extremely caring leaders offering support and sharing their CAH experiences. We currently have 60 leaders across the United States and 16 leaders in 12 other countries. Some leaders specialize in particular areas of CAH and offer support to different members of the community. For example, there are leaders for Adult Women with SWCAH, Men with CAH, Parents of Newborns with CAH, etc. We are pleased to welcome the following newest members of our support group leader team:

- Gabrielle Portillo-Wightman:** Arizona and Young Woman with SWCAH
- Natalie Elms:** Southern California
- Mariana Chaluja:** Florida, Newborn and Spanish
- Melissa and Chuck Axtell:** Oklahoma and New Hampshire
- Lydia Melancon:** Ohio and Colorado, Women with SWCAH
- Heather Ford:** Louisiana
- Stacie Faciane:** Louisiana
- Travis and Jaimie Hall:** Upstate New York and Delayed/No Surgery
- New international leaders:**
- Paul Hower:** Ireland
- Salman Munir:** Pakistan
- Joseph Wiredu:** Ghana

Our 60 US and 16 international support group leaders are an invaluable resource to our community. They support patients and family members near and far, always ready to lend an ear, share their experiences and offer support over the phone, email and through social media. They are the backbone of our support services by helping people through very difficult and uncertain times in their lives. We greatly appreciate their time and energy and willingness to be there for others.

Support Group Leaders can be found on our website www.caresfoundation.org. Navigate from the top menu on our homepage 'About Us' to 'Resources' to 'Support Groups'.

TELEPHONE SUPPORT GROUP 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 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 4 times a year.

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

IN-PERSON SUPPORT GROUP MEETINGS

We try to schedule as many face-to-face, in-person support groups as possible. It is important to gather our CAH community together so that they can meet with CAH experts and other healthcare professionals to discuss the disorder, answer questions, alert people to new developments, research, studies, etc. and hopefully improve the quality of life for all CAH affected individuals in attendance.

In 2017 there were two meetings, one at CHLA in Los Angeles, CA on January 28th. This meeting, "Infant & Toddler Support Group Day for CAH", was held for parents of CAH infants and toddlers and gave them an opportunity to build relationships with fellow families and learn valuable information from guest speakers and the CHLA CAH medical team. On Saturday, March 18th, our Comprehensive Care center at New York Presbyterian/Weill Cornell Medical Center hosted meeting for all CAH patients

and families with the same goals for CAH.

New York Presbyterian/Weill Cornell Medical Center also hosted our most recent in-person support group meeting on October 27, 2018. Patients and their families gathered to hear the latest news regarding CAH and gained tools for better living with CAH. There was injection training, presentations, discussions and a special opportunity for patients to be a part of a Focus Group sponsored by a company that is interested in conducting a clinical trial for a new CAH therapy.

**Medically Safe Camp Opportunities**

Each year, CARES connects CAH families to camps, family weekends and other group activities at programs that offer medically safe environments and trained staff. Most of these programs are free and some even assist families with transportation. This is a great way for CAH families to bond with other CAH families, share stories, and have tons of fun!

These camps are located in different states all over the country and you don't have to be a resident of that state to attend.

CARES usually releases a list of available programs early in the year to the CAH community. Each of these

camps holds one or more sessions that are geared toward kids with adrenal insufficiency and/or CAH. Some of the popular camp offerings came from Camp Corey in Carnation, WA; The Center for Courageous Kids in Scottsville, KY; Double H Ranch in Lake Luzerne, NY; Dreamstreet in Ojai, CA and in Canyon Ranch, AZ; Hole in The Wall Gang Camp in Ashford, CT; The Painted Turtle in Lake Hughes, CA; Victory Junction in Randleman, NC; and new last year, a camp for our U.K. families, Over the Wall Camp.

Several of these camps also offer a Family Weekend in which a child can visit with their entire family. The Center for Courageous Kids has hosted several of these family weekends and The Painted Turtle in California also hosts a spectacular family & educational day. Fun for the whole family!

Double H Ranch in Lake Luzerne, NY recently announced their 2018 Adaptive Winter Sports Program offering 5 Free Family Sleepover weekends throughout the winter months. You can apply for a weekend on their website: www.doublehcamp.org or call Tara Bogucki, 518-696-5676 Ext: 222.

Look for our complete camp offerings announcement early next year!

A PERSONAL STORY**Saying Yes To CAH**

All we really knew before adopting a three year-old girl from China was that she probably had CAH. The typical shock of adjusting to this diagnosis was a non-issue for us because, other than a video of her adorable belly laugh among the rows of cribs in her orphanage, her diagnosis was the only thing we knew about her. We said yes to so many unknowns and eight months later, knowing no more about her than when we initially said yes to her cute little picture,

we were on a plane to bring her home.

We read all the scary stuff from the beginning and prepared ourselves for a medically fragile child. As it turns out, "fragile," is the last word I would now use to describe our little heroine. She may have salt wasting CAH, but she was not treated for her first three years of life and she has never had a crisis. We now treat her and watch her carefully, of course, but CAH does not slow her down. She swallows or chomps {shudder} those bitter little pills without complaint and swaggers through doctors' offices and labs like she owns the places. She has charmed the socks off everyone we know and I can't believe that one year ago we had not even met her yet. Like many other parents who have adopted abroad, we realize that saying yes to a diagnosis allowed us to say yes to so much more!



She has a BIG personality and her diagnosis is the very least of her. She loves clowning around, snuggling, getting into everything, stripping at inappropriate times and sassing us with all her new English words.

In this season of giving thanks, we want to thank the CAH community for being so incredible. Throughout our journey to bring our little girl home this year, we were immediately embraced by fellow parents of CAH kids, and supported by experts and advocates like the CARES Foundation. To be sure, this journey is just beginning and there are some big milestones ahead, but with such a supportive community we can face those without fear.

Katie Jay is an adoption attorney living in South Florida

CAH AROUND THE WORLD**FRANCE****IFCAH 2019**

In 2019 IFCAH (International Fund raising for Congenital Adrenal Hyperplasia) in partnership with ESPE (European Society for Pediatric Endocrinology) launches its ninth Call for Projects.

Background

IFCAH is a private fund, aimed to promote research on Congenital Adrenal Hyperplasia (CAH). In 2019, it launches its ninth 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 the disease - The projects could be directly or indirectly targeted on CAH, but the expected results should potentially help the knowledge of CAH.

Prevention, diagnostic and treatment of natural or iatrogenic complications - Impact on foetal development, growth, puberty, effects on metabolic and cardiovascular systems, male and female fertility, bone density, immunity, neuro cognition.

Proposal 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 a mail to cfp@ifcah.org. Specific forms for letters of intent can be obtained from cfp@ifcah.org



Florida walkers on the Max Brewer bridge.

FLORIDA - The 1st Annual i am CAH Walk/Run Florida, was held in sunny Titusville at the Sandy Point Park, on March 10. Long-time supporter and support group leader, Lesley Holroyd did an amazing job of hosting this wonderful event. Thank you!

PENNSYLVANIA - Center Valley's Upper Saucon Township Community Park was, again, the setting of the 3rd Annual i am CAH Walk/Run. In spite of the rainy weather, tons of folks showed up to participate on Saturday, May 19th. Many thanks to Carlos DaSilva and his family for hosting this event again.



Rain didn't dampen the spirits of these PA participants!

MARYLAND - Games, contests, balloons and a tricky tray were all a part of this year's 3rd Annual Maryland Walk/Run held again at the beautiful Quiet Waters Park. This event was successfully hosted by the Watson family and we appreciate their hard work and dedication!



Maryland folks brought their A-game!

COLUMBUS (HILLIARD) OHIO - This 1st Annual Walk/Run is one of two Ohio events this year. Megan Hamilton and family did an amazing job of hosting this event at the Homestead Park Pine Pavilion. Over 100 participants were treated to beautiful weather,

family, friends and fun! Thank you Hamilton family for a job well done!

TOLEDO (SYLVANIA) OHIO - On September 8th, Krista Woodbury and family hosted this exciting new event held at The Olander Park. Close to 130 people gathered to show their support and were treated to a fun run, face painting, a tricky tray, bonding and lots of fun with family and friends.



Woodbury family bonding at the Sylvania, Ohio 1st Annual Walk

CALIFORNIA - They spread awareness of CAH in the sunny state of California at the 5th Annual walk/run at the spectacular Santa Anita Racetrack & Park in Arcadia. A good time was had by all on Sunday, October 7th and we'd like to thank our hosts: Karen Bogaard, Erik Bogaard, Pam Kilgore, Stacey Shackley, Hillary Hendler and Ryan Hendler, our sponsors, and the CHLA team!



Injection training, courtesy of the staff from CHLA at the CA event.

NEW JERSEY/NEW YORK - In an effort to expand our reach, we included New York in this 7th Annual event held only minutes away from Manhattan at the Saddle River Park in Ridgewood, NJ. The rain and cold didn't stop supporters from showing up on Saturday, October 13th, and we had a great event with a kids' fun run, tricky tray, injection training (Thanks Drs. e Lekarev and Su!) and more. Thank you to our hosts, Katherine Fowler and Chad Lapp!



Lots of fun prizes won during the NJ/NY walk/run Tricky Tray!

MASSACHUSETTS - Woburn MA's Horn Pond Conservation Area was the place to be for the 3rd Annual MA Walk/Run. This year's event was held on Sunday, October 21st and was well-attended by CAH

FUN-RAISING!



CARES hosted 7 Walk/Run events this year and it was a very successful season of events. Our goal this year was to involve more people as participants and **social fundraisers**, and the turnout and support has been tremendous! We believe that the power of social fundraising helps us to spread awareness of CAH and can double, even triple your single donation's impact on the lives of those affected by CAH. Please let us help you set up your very own fundraiser!

patients and families. Thank you to our hosts, Alex Dubois and Katie Dilly!



Team Lily makes a grand entrance at the MA Walk/Run!

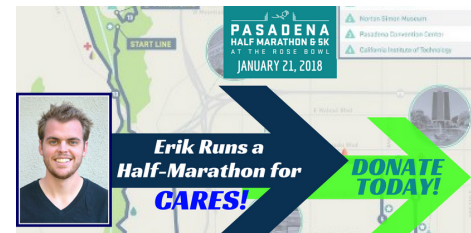
FAMILY FUNDRAISERS

THE JAMES PARTY

Held annually in California, this fundraiser is a big hit with the colleagues, family and friends of CARES Community member and support group leader, Sue Shirey. Sue hosts this event in honor of her son, James, who passed away from complications with CAH. Always a memorable evening of dinner, dancing, auctions and friendship, this event raises much-needed funds for CARES Foundation and awareness of CAH!

EMILIA LEITE'S 90TH BIRTHDAY

What better way to honor a loved one on their birthday than by holding a fundraiser for their favorite charity?! That's exactly what CARES Board of Trustees member, Carlos DaSilva & family did for their dear grandmother as they celebrated her milestone birthday in January. We appreciate the donations made in her name.



ERIK RUNS THE 1/2 MARATHON FOR CARES

Erik is the son of our Board of Trustees Chair, Karen Bogaard, and a CAH patient. Erik took to the streets of Pasadena and participated in the Pasadena Half Marathon & 5K at the Rose Bowl on January 21, 2018. He asked friends and family to pledge support to his efforts by donating to CARES Foundation. We thank Erik for his consideration of CARES and for encouraging other runner to do the same at their next run event.



Captain Jack on the green.

CAPTAIN JACK'S QUEST FOR A CURE INAUGURAL GOLF TOURNAMENT

On May 15, 2018, hundreds converged on a lush green golf course in Sandwich, MA for the Inaugural Captain Jack's Quest for A Cure Golf Tournament. Hosted by the Porters, Zack and Kristin, who were inspired to raise awareness and one day find a cure for CAH - a disorder affecting their young son (and future golfer!), Jackson. The tournament attracted golfers from all over the country and was a huge success. Golfers were treated to an amazing course, breakfast goodies and a delicious lunch. There was an auction and many golf prizes were awarded. Thank you for a job well done, Kristin & Zack. We look forward to the **2nd Annual Quest for a Cure tournament on MAY 13, 2019 in Plymouth, MA.**



Chad Lapp at mile marker 32

CHAD DOES IT AGAIN!

Chad Lapp, past chair of the CARES Board of Trustees, and long-time supporter, who has been running for many years, spreading the word about CAH, paying tribute to his friend, CAH patient, Andrew, and raising many dollars for CARES, all while doing what he loves! This year, May 17-20, Chad ran in the '3 Days at the Fair', 72-hour race in Augusta, New Jersey. We are very thankful to have Chad and his family as members as part of the CARES community and very grateful for his endless support!



Clay Shoot Foursome readies to shoot.

CLAY SHOOT FOR CARES

The 3rd Annual Clay Shoot was held on September 14th and was a big success! Clay-shooting enthusiasts traveled from near and far to be a part of this idyllic day! Shooters were treated to a light breakfast, then took to the three levels of courses artfully etched into 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 this fun event!

CYCLE FOR CARES

For many years, CAH mom, CARES Board of Trustee Secretary, and support group leader, Alex Dubois, has hosted a cycling fundraiser in her home town. Alex's son, James, has CAH and as a family they have contributed to the success of CARES in helping all those affected. Folks enjoy an opportunity to get healthy while helping others at the same time! Thank you, Alex! We appreciate your efforts!



CYCLING FOR CARES at Cyclatown in Hingham, MA



The **10th Anniversary EVERYONE CARES Gala** was held in beautiful Rancho Palos Verdes, California this year, and the Terranea Resort location did not disappoint! Guests arrived to this Godfather-themed event dressed to the nines and eager to pay tribute to our distinguished honorees, Dr. Mimi Kim from CHLA and Medical Director of the CHLA Comprehensive Care Center of Excellence for CAH, Clay D. Upchurch, CAH patient and CARES supporter, and his mother, Jessica Hall Upchurch, Past Chair of the CARES Board of Trustees, long-time advocate, and supporter.



Gala committee co-chairs, Matthew Upchurch and Anna Pinto



Karen Bogaard, (Board Chair), Jessica Upchurch, (Honoree), Clay Upchurch, (Honoree), Dina Matos, (Executive Director)



Dr. Mitchell Geffner, Dr. Mimi Kim, (Honoree), Karen Bogaard, (Board Chair)



Friends of all ages enjoyed the festivities.



Members of the CAREing Hearts Society receive special awards.

Over 200 guests were treated to a cocktail hour on the beautiful patio with the Pacific Ocean as a backdrop, followed by a gourmet meal, entertainment by a jazz ensemble, award presentations and live and silent auctions. It was a spectacular evening full of camaraderie and special moments. Congratulations, again to our honorees! Many thanks to all of you for supporting this annual event and CARES Foundation, AND **special thanks** to our event planner, Extraordinary Wedding Arches, <https://www.extraordinaryweddingarches.com/> and to our Gala Committee, co-chaired by Anna Pinto (Micato Safaris, <https://www.micato.com/>) and Matthew Upchurch (Virtuoso, <https://www.virtuoso.com/>).

Please join us

11th Annual Everyone CARES Gala

honoring



CHAD LAPP



CARLOS DASILVA



DR. OKSANA LEKAREV

Friday, April 5, 2019 - New York City

If you are interested in donating auction prizes, sponsorships, or underwriting for this event, please contact dina@caresfoundation.org.

We hope to see you there!

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

David Diesslin -The Deena Jo Heide-Diesslin Foundation
Concierge Imaging
HRI Health Research
Rhonda & Gregory Kraff

Kelly & Adam Leight
Heather McDonald, Esq.
Pfizer

Anna Pinto - Micato Safaris
Drs. Karen & Edwin Su
Meredith & Daniel Taylor
William & Jennifer Trzos

CHAMPION LEVEL

Dr. Thomas & Karen Bogaard
Erika Bradley - TravCorp, USA
Mitzi & Bill Davis
Diurnal Limited

Alexandra Dubois
Chad Lapp
Cindy & Alan Macy
Marc & Marjorie McDonald

Ernest & Susan Mendes
Oceania Cruises
Perkin Elmer Foundation

Dr. Dix & Dorothy Poppas
Rolex USA
Doug Zehner & Katherine Fowler

ADVOCATE LEVEL

Barbara Abell
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
Neil & Jessica Margolies
MGM Resorts International
Neurocrine Biosciences, Inc.
Oxeon Partners, LLC
Barry Shier & Nicole Patterson

Richard & Deborah Pendino
Trevor Price & Megan Sheetz
Dr. Richard Rink
Sandra & Mack Rose
Samlyn Capital, LLC
Carol & James Simpson

David & Betsi Steinberg
Diane Snyder & Albert Steren
Robert & Debbie Svendsen
Subhir & Rimda Wanchoo
Matt & Barbara Wilson

AFN
Susan & Carl Aycock
Azamara Club Cruises
Baker & Hostetler, LLP
Bellagio
Sondra & Michael Brunone
Chevrolet21, Inc.
Pamela Chiles

Elizabeth & Wayne Chmiel
Diesslin & Associates
Andrew & Martin Farach-Colton
J. Peter Kiers & Elizabeth Fugate
Global Credit Advisors
Janet Green
Karma Foundation

FRIEND LEVEL
Kayak.com
Jeffrey & Leah Kronthal
LB Industries
Susan & Norman Louie
Richard Orgell
Marci & Adam Plissner
Protravel Intern
Rodrigo Quintanilla & Vivian Altman

Hope & James Raphaelian
Stephanie Rose
William Rosso
Joel Rothman
Peter Schlegel
Joel & Ethel Sharenow
Spencers Welding Service, Inc.
Spruce Biosciences

Bonnie & Jeffrey Stevens
Jaynie & Woody Studenmund
TripMatters, Inc
Kenneth & Vicki Upchurch
Valerie Wilson
Valerie Wilson Travel
Kristi Wold

OTHER WAYS TO SUPPORT CARES

amazon smile



You shop. Amazon gives.

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, type in www.smile.amazon.com and designate CARES Foundation as your charity. Everything else is the same: your account, your password information, your saved credit cards, shipping addresses, etc., all the same. Now, every time you purchase anything on Amazon, a portion of the profits will come to us.



GoodSearch and GoodShop

Let's face it, you're on the computer daily and spend a lot of time searching for everything on Google or Bing or Safari, etc. Switch to

GoodSearch search engine and a penny gets donated to CARES every time you do a search! Go to GoodSearch.com 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*.

Fundraising Made Easy investorsBank



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 makes a donation 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!

FACEBOOK FUNDRAISER



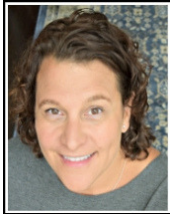
FACEBOOK FUNDRAISING

Use the power of social media to help charities and non-profits that are near and dear to your heart. Facebook makes fundraising simple and you can do it

with just a few clicks of a mouse. Many of our Facebook friends raised a lot of money for us in the past couple of years and the number of fundraisers has tripled! Birthdays, Anniversaries and other momentous occasions are the perfect time to host your fundraiser for CARES! Visit our homepage, www.caresfoundation.org to find a step-by-step guide for help. Thank you to all of our friends for your outstanding Facebook fundraising efforts!

WELCOME ABOARD

We would like to extend a warm welcome to our newest members of our Board of Trustees, Michèle Janine Bacus, Jessica Margolies, and Stacey Jackson Shackley.



Michèle Janine Bacus

Michèle's son Maris was born in May of 2012. At 10 days old he was rushed to the ER in full adrenal crisis. With his diagnosis came many questions and some answers of what life would be like with a child with CAH. She was so grateful when support came from the CARES Foundation.

After the diagnosis, Michèle knew that she wanted to become involved in any way she could. She was thankful when given the opportunity to reach out to other parents with a newly diagnosed child as the newborn support group leader for CARES Foundation. Over the past several years, she has connected with families across the country and overseas. She considers it a blessing to share stories with other parents, learn from each other, ease fears, and offer support. Most recently, she was appointed to the Community Advancement Committee of CARES.

Anytime you are dealing with a child with medical issues, the support community is vital - this truth is heightened when that condition is a rare disease. She hopes to always be able to be a part of this community in any way and offer any support that may be needed.

With a background in the arts and education, Michèle is currently savoring every moment of staying home with her rambunctious son! While she realizes his diagnosis does not define them, she also realizes that it has guided her to be as active as possible within this community. She is honored to be a part of CARES Foundation.

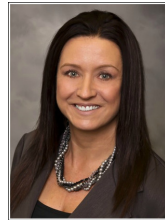


Jessica Margolies, Esq.

Jessica is the Associate General Counsel and Compliance Officer at Samlyn Capital, LLC,

an investment adviser based in New York City. Jessica received her J.D. from New York University School of Law and a B.A. in Political Science from The University of Michigan. She is originally from Chappaqua, New York and currently resides in New York, New York, with her husband and two young daughters.

Jessica is very close to someone who was diagnosed with CAH at birth, and they have relied on and utilized the resources provided by CARES for more than a decade. After Jessica learned this, she wanted to become involved and looks forward to participating in the growth of CARES and the support community.



Stacey Jackson Shackley

Stacey and her husband Don have been married for seven years and have a five-year-old daughter with CAH. She also has sixteen and eighteen-year-old daughters from her previous marriage. She has lived in Las Vegas for nineteen years and has been a Realtor for the last seventeen. She chose that profession so that she could contribute to their household income, but she has a flexible schedule so that she can be actively involved with her family and community. Before being a Realtor, she worked for Southwest Airlines in the Customer Service department for ten years. Basically, she has been in the business of helping and serving people her entire life. It's what Stacey enjoys doing.

In her spare time, she and her family do a lot of traveling, go ATV riding, camping, golfing, and any other activity that gets them outside and connected with my family.

NEW DIRECTIONS



BOARD OF TRUSTEES CHAIR, KAREN BOGAARD

Karen, our Board of Trustees Chair since January 2018, lives in Pasadena, California with her husband, Tom, an Urologist. They have four children: Andrew, John, Erik, and Katherine. Erik (26 years-old) has salt-wasting CAH.

She is a physical therapist with a current focus on orthopedics and joint replacement rehabilitation. She has both undergraduate and graduate degrees from the University of Southern California.

Karen's volunteer experience includes:

- St. Vincent's Medical Center Auxiliary Board member
- Crestview Preparatory School (LaCanada, CA): Parent Association Board, including President

- Crestview Preparatory School Board of Trustees, including Board Chair for 6 years
- Flintridge Preparatory School (LaCanada, CA) Board of Trustees, including roles as Secretary and Chair of Committees on Trustees (6 years)

Karen says, "Come visit if you are in California! We walk to the Rose Bowl from our home which is mighty convenient and fun!"

tidbits



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**, <https://twitter.com/caresfoundation>

FOLLOW US ON **INSTAGRAM**, <https://www.instagram.com/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://www.facebook.com/caresfoundation/>

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

A greater presence on social media ...

- helps raise awareness of CAH
- promotes education of CAH
- helps in advocating for patient and parental rights

ACCESS TO MEDICATIONS A BULLETIN FROM THE NADF

National Adrenal Diseases Foundation

Dear NADF Members and Friends,

We are aware that there is a backorder of Teva Pharmaceutical Industries' product fludrocortisone acetate, with potential stoppage of production by Teva. (Barr Pharmaceuticals was acquired by Teva in 2008) .

The Board of NADF has been investigating and monitoring this situation closely for the last few weeks.

Some of our members have found that the pharmacy they routinely order their medications from are telling them that they are no longer able to obtain fludrocortisone acetate. We want to inform you that there are other manufacturers of fludrocortisone acetate including Impax Laboratories, Inc. and AvKARE , which continue to make our life-preserving aldosterone hormone replacement fludrocortisone acetate, so we are not in danger at this time of a full lack of medication access.

When you attempt to order fludrocortisone acetate from your pharmacy, be sure to tell them that the product is available from other distributors and manufacturers including :

Impax Laboratories

- May need to be accessed via pharmaceutical distributors Ameri-Source or Cardinal ; has been regularly available through OptumRx Mailorder
- Some pharmacies may need to order through "Global Pharmaceuticals" which is an arm of Impax, and some patients will see Global as the name on their packaging

AvKARE

- AvKare is a source for many government sponsored programs in the US, so veterans, those insured by the DOD and other government employees may need to ask for the AvKare product

The FDA's ANDA number for this product is: 040431

Should you need assistance obtaining fludrocortisone acetate:

- 1.) Ask your pharmacist if they have contacted their wholesaler network and exhausted all options
- 2.) Contact your insurer or call the PBM/pharmacy benefits number on your insurance card
- 3.) If you are still not able to obtain your fludrocortisone acetate, please contact NADF at nadfsupport @ nadf.us

SURVEY PARTICIPATION



Survey participation is crucial. CARES occasionally develops surveys to better help us serve the CAH community. Please participate to ensure your voice is heard!



**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!



MARK YOUR CALENDARS AND MAKE PLANS NOW for these EXCITING EVENTS!

Check our online [Calendar of Events](https://www.caresfoundation.org/event-calendar/) - <https://www.caresfoundation.org/event-calendar/> regularly, so you don't miss a thing.



2nd Annual FLORIDA i am CAH CARES Foundation ANNUAL WALK/RUN Titusville, FL



11th Annual EVERYONE CARES Gala
Connecting the CAH Community
New York City, NY



2019 CAH PATIENT & FAMILY SUMMIT
Riley Hospital for Children
Indiana University Health
Indianapolis, IN



2nd Annual Golf Tournament
Plymouth, MA

Getting to know the CARES Team

In case you've ever wondered or maybe have been a little curious, we thought we'd share a few things about the CARES Team with all of you. We've spoken to you on the phone, emailed you and sent you letters but we rarely get to come together face-to-face. It has been a pleasure to serve you, the CAH community, and we wish you the happiest of holidays and look forward to a bright and prosperous New Year!

Dear CARES Team, what accomplishment from the past year are you most proud of?

I am proud of the National EMS Advisory that I worked on over the last year with Dr. Mitchell Geffner from our California center of excellence and one of our volunteers in Canada, Gino Innamorato. This fine-tuned document provides a simple guideline on how to treat someone in an adrenal crisis when 9-1-1 has been called. The Advisory has been endorsed by the Endocrine Society, Pediatric Endocrine Society, a number of other rare disease organizations and our comprehensive care centers. We anticipate sending it to local EMS, national EMS organizations along with making it available to school nurses, other healthcare professionals and our community. ~ **Karen**

Being a part of a growing organization and being able to help my team put the pieces together, in helping our community on a day to day basis. ~ **Odaly**

My greatest accomplishment in 2018 is the impact I made in our office for planning and organizing. I upgraded to QuickBooks online seamlessly. I moved our prior files, verified for errors and continue to maintain our books. ~ **Bea**

I am proud of modernizing our database and implementing our CRM platform into daily operations. By having a software system like Neon, CARES is more efficient and better able to do all the things that make a non-profit more profitable. It has been my task to learn the ins and outs of this platform and I strive every day to stay abreast of its features and advancements. I appreciate my fellow employees and our leader, who are patient and eagerly 'try' all the new stuff I present. ~ **Wendy**

I'm most proud of how I brought the CARES community together to protect the rights of parents to make medical decisions for their children. The patients and parents who have so passionately shared their stories with legislators, reporters and the medical community at large are my heroes! I'm so fortunate to be associated with such an amazing community. ~ **Dina**

I am proud of the work we have done at CARES delineating CAH first and foremost as an adrenal disorder and providing a voice to our CAH patients, so that treatment options (including surgery) are not limited for them. ~ **Dr. Su**

Dear CARES Team, what are your favorite things to do during the holidays?

Bea:

1. Craft night making tree trimmings
2. Decorate a gingerbread house
3. Christmas movie night
4. Go sledding

Dina:

1. Make year-end gift to favorite charities
2. Decorate home for the holidays
3. Visit Rockefeller Center (NYC)
4. Spend time with family and friends



Dr. Karen Su, our Medical Director



THE CARES TEAM: (left to right) Karen, Bea, Odaly, Dina & Wendy

Odaly:

1. Decorating my tree
2. Making "Coquito" (<http://www.elboricua.com/coquito.html>)
3. Christmas caroling (Parrandas style <https://en.wikipedia.org/wiki/Parranda>).

Wendy:

1. Decorating
 2. Attending Holiday parties!
 3. Listening to my daughter sing in the choir for Christmas Eve mass
 4. Reading the *Cajun Night Before Christmas*, in my best Cajun accent, to my kids on Christmas Eve
- You can get your very own copy of this great book on AmazonSmile: <https://smile.amazon.com/Cajun-Night-Before-Christmas%2%AE-Christmas/dp/0882899406/>

Karen:

1. I love putting fresh greens (that I get from the Christmas tree sale at the end of my street) all over my house. They are so fragrant + festive!
 2. I love buying gifts for people that I think they will enjoy. I'll see something and just know it's for a particular person. It's like a scavenger hunt.
 3. I love listening to Christmas carols while making cookies for my neighbors.
- See Karen's favorite cookie recipe here: <https://www.allrecipes.com/recipe/23751/soft-molasses-cookies-v/>

Dr. Su:

1. Spending time with friends and family
2. Holiday parties
3. The Park Avenue Tree Lighting (with Christmas carols)
4. Alvin Ailey

We wish you and yours a delightful holiday season!

May joy, love, comfort and peace abound



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.

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CARESFoundation

VISIT THE CARES SHOP <https://caresfoundation.z2systems.com/np/clients/caresfoundation/giftstore.jsp>

In our online store, you will find great gift ideas for that special CAH someone, as well as tools to use to make living with CAH a little bit easier.

MEDICAL I.D. SHOE TAGS

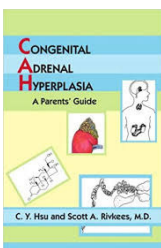


Medical ID Shoe Tags are 2-ply red plastic oval tags (1"x1 1/2") with two holes (each 3/16" diameter).

Laser engraved with medical id logo on front side and personal info on back side for privacy.

Tell First Responders how best to care for you in an emergency. Perfect for active kids and adults! These custom Medical ID shoe tags are a great accessory for your shoes, backpack or purse!

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 welcomed by patients and parents. Written by: C.Y. Hsu and Scott A. Rivkees, M.D.

BUZZY



Buzzy is a palm-sized device combining cold and vibration. His wings are icy cold, and his tummy vibrates when you touch his head.

This confuses the body's nerves to block sharp pain feelings, just like rubbing a bumped elbow helps stop the hurt, or cool running water soothes a burn. Buzzy is ideal for blood draws, vaccinations, flu shots, dental procedures and more.

BUZZY DELUXE KIT



Deluxe Kit includes a Buzzy and everything else you'll need for a smooth visit to the doctor, hospital, or lab.

- *DistrACTION Cards
- *Cold Tote Bag keeps gel wings frozen for trips to the doctor's office and also makes a great lunch bag!

EMERGENCY KIT BAG RESPONSE KIT



Perfect for school, camp, clubs, sports and for leaving with the babysitter! A clear, plastic, water-resistant bag just the right size for your Emergency Response Kit. Emergency instructions brochure and wallet card long with

Emergency Response Kit checklist included.



WELCOME BACK A CLASSIC: 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!

BE A CAH HERO!

2018 Annual Giving Campaign

Please give generously.

