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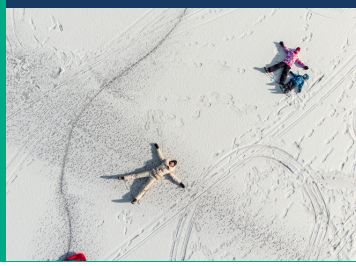

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Arterial stiffness and shortened QTc interval are associated with androgen and ACTH levels in classic congenital adrenal hyperplasia

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Context

Cardiometabolic complications are increasingly recognized in congenital adrenal hyperplasia (CAH) due to 21ß-hydroxylase deficiency, but adult data remain limited.

Objective

To evaluate cardiovascular and metabolic alterations in adult patients with classic CAH under glucocorticoid treatment, compared to matched controls.

Methods

A cross-sectional study was conducted on adults with classic CAH and sex- and BMI-matched controls. Cardiovascular and metabolic variables and parameters were collected in all patients.

Results

The study enrolled 32 CAH patients and 73 controls. In univariate analyses, CAH patients showed significantly shorter QTc intervals (p=0.004), longer QRS duration and shorter RR intervals, in comparison with controls. Even in presence of a more favorable hypertensive (lower diastolic blood pressure and higher heart rate variability) and metabolic profile (lower fasting glucose, LDL cholesterol, triglycerides, and higher HDL), CAH patients had higher Ambulatory Arterial Stiffness Index (AASI) (p=0.006). Multivariate regression confirmed the association between CAH and both increased AASI (EC 1.131, p<0.001) and shortened QTc (EC 0.977, p=0.039), adjusting for all potential confounders. Within the CAH group, 17-hydroxyprogesterone was positively associated with AASI (EC 1.001, p=0.049), while ACTH (EC 0.999, p=0.021) was inversely associated with QTc, after correction for all clinical confounders. Propensity score-matched analysis with 1:2 matching ratio, based on the same regression models, confirmed that CAH diagnosis was associated with AASI (p<0.001) and QTc (p=0.004).

Conclusions

Adults with classic CAH show increased arterial stiffness and altered cardiac repolarization, likely linked to chronic hormonal imbalance. These findings underscore the need for cardiovascular monitoring in long-term CAH management.

Keywords

cardiovascular risk, congenital adrenal hyperplasia, 21-hydroxylase deficiency, arterial stiffness, androgens, ACTH, QTc

For Tables and Figures: https://caresfoundation.org/wp-content/uploads/2025/10/Arterial-stiffness-and-shortened-QTc-interval-are-associated-with-androgen-and-ACTH-levels-in-classic-congenital-adrenal-hyperplasia.pdf

Introduction

Congenital adrenal hyperplasia (CAH) encompasses a group of rare autosomal recessive disorders characterized by impaired cortisol synthesis and hyperandrogenism in classic form. The most common type of CAH, 21ß-hydroxylase deficiency, accounts for over 90% of CAH cases and includes both the simple virilizing and salt-wasting forms (1), with a variety of clinical manifestations depending on the entity of the enzyme deficits. According to national registries, the estimated worldwide incidence ranges from 1:14,000 to 1:18,000 births. However, the prevalence is believed to be even higher in small, genetically isolated populations where consanguineous marriages are common (2).

Classic CAH due to 21ß-hydroxylase deficiency is a complex disorder requiring a multidisciplinary approach to manage its comorbidities, particularly metabolic and cardiovascular complications, highlighting the importance of long-term follow-up. Moreover, there is evidence of a reduced fertility due to hyperandrogenism as well as to an increased incidence of testicular adrenal rest tumors (TARTs) in males (3, 4) and polycystic ovarian morphology (PCOM) in females (5).

Current treatment strategies for classic CAH remain suboptimal, as available glucocorticoids (GCs) fail to effectively suppress androgen hypersecretion and mimic endogenous cortisol secretion (6). Over the past decade, studies have shown that GCs dosage is often supraphysiological, increasing the risk of metabolic and cardiovascular complications and leading to higher morbidity rates (7). Recent findings suggest that modified-release formulations of hydrocortisone may help improve patients' quality of life while reducing morbidity (8). However, till now, cardiovascular and metabolic risk in CAH patients has primarily been evaluated through small-scale retrospective studies, often yielding heterogeneous results (9, 10).

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A Message from the Executive Director

Dear Friend,

It is with immense pride and deep gratitude that I welcome you to this edition of CARES Connections, marking a significant milestone—the 25th anniversary of CARES Foundation.

For a quarter-century, we've stood together—patients, families, clinicians, researchers, and advocates—united in our mission to improve the lives of those affected by Congenital Adrenal Hyperplasia (CAH). This anniversary is not just a celebration of the past—it's a recommitment to our future.

To commemorate this milestone year, we launched a new season of our podcast series, featuring powerful personal stories and expert insights that reflect on the progress we've made—and the vital work ahead.

One of the most moving moments this year was our Patient Education Conference in Indianapolis, which brought together individuals and families from across the country—many attending a CAH conference or meeting another person with CAH for the first time, even into their 40s. The power of connection was undeniable. We were proud to award over $40,000 in scholarship funds, breaking down financial barriers so more individuals could access expert medical guidance and community support.

In our ongoing commitment to education, we also released a comprehensive Patient Education Guide, providing individuals and families with reliable, accessible, and up-to-date information about living with CAH. This new resource reflects the high standards of care and education we strive to deliver every day.

This anniversary year also marked a major step forward in clinical care: we were thrilled to welcome Nicklaus Children's Hospital and the University of Miami Health System as the 9th CARES-designated Center of Excellence. Their addition expands our network of expert CAH care and brings us closer to our goal of ensuring every patient has access to specialized, coordinated treatment.

Research remains a core focus of our mission. We are currently conducting a Quality of Life survey to better understand the lived experiences of people with CAH—and to examine how expert care impacts outcomes. Importantly, this study will also compare the quality of care received in the U.S. and abroad, helping us advocate more effectively for improvements in care and access worldwide.

As we look ahead to the next 25 years, one thing is clear: we cannot do this work without you. I invite you to support our year-end fundraising campaign, which fuels our programs, research, education, and outreach. Your generosity directly impacts lives—and helps ensure that no one facing CAH ever feels alone.

Thank you for being an essential partner in our journey. Together, we are stronger—and together, we will shape a better future for everyone affected by CAH.

With gratitude,

Dina M. Matos
Executive Director

(continued from page 1)

Therefore, giving the rarity of the disease, the aim of the present study was to assess the cardiovascular and metabolic risk in adult patients with classic CAH due to 21ß-hydroxylase deficiency undergoing treatment with GCs formulations in comparison with a cohort of matched patients adding statistical correction to avoid potential sources of bias.

Materials and Methods

A cross-sectional study was conducted on 1) adult patients with CAH due to 21ß-hydroxylase deficiency diagnosed in the last 10 years, and 2) a control group, matched for sex and BMI. All participants were recruited from the gynecological endocrinology, andrological and adrenal diseases outpatient clinic of the Division of Endocrinology, Diabetes, and Metabolism of the City of Health and Science University Hospital of Turin.

Inclusion criteria required the ability to provide informed consent and a diagnosis of classic CAH according to international guidelines, confirmed through genetic testing. Patients were excluded if they suffered from other endocrine disorders (e.g., Addison's disease, Cushing's syndrome, pheochromocytoma/ paraganglioma, adrenal-secreting adenoma), were pregnant or breastfeeding, used medications affecting hormone levels (e.g., corticosteroids for other indications), or had pre-existing cardiovascular diseases (e.g., heart attack, stroke).

Controls were selected from a group of patients undergoing urine metanephrine analysis, in whom the suspicion of pheochromocytoma/ paraganglioma was ruled out.

The study was approved by the hospital's Ethics Committee in accordance with the principles of the Declaration of Helsinki. All participants provided informed consent. Data collection was fully anonymized using a coding system to ensure privacy and confidentiality, with each participant assigned a unique identification code for anonymity.

Data Collection

Anthropometric, biochemical, and instrumental evaluations were performed for each patient, including comorbidity assessment, with data updated at the last follow-up. According to WHO criteria (11), patients were classified as overweight (BMI 25–29.9 kg/m²), class I (30–34.9), class II (35–39.9), or class III obesity (≥40). Biochemical parameters included blood glucose, lipid panel, creatinine, and eGFR (CKD-EPI formula). Based on ADA guidelines (12), patients were categorized as having impaired fasting glucose (100–125 mg/dL), impaired glucose tolerance (2-h post-OGTT 140–199 mg/dL), or diabetes mellitus (random glucose >200 mg/dL, fasting ≥126 mg/dL, OGTT >200 mg/dL, or HbA1c ≥48 mmol/mol). Dyslipidemia was defined per ESC guidelines (13): LDL ≥116 mg/dL (low risk), ≥100 (moderate), ≥70 (high), or ≥55 (very high risk); HDL <40 mg/dL (males) or <50 mg/dL (females); triglycerides ≥150 mg/dL. Electrocardiography (ECG) was also performed, with assessments including heart rate (HR), PQ and RR intervals, and the corrected QT interval (QTc) using Bazett's formula. PQ and RR intervals were analyzed to evaluate cardiac conduction, while QTc was examined for potential ventricular repolarization abnormalities.

Blood pressure measurements

Office blood pressure (BP) values were collected according to guidelines (14). BP control was defined as an average office BP <140/ 90 mmHg. All patients underwent 24-hour ambulatory blood pressure monitoring (ABPM) using an automated, noninvasive oscillometric device (TM-2430; Intermed S.r.l., Milan, Italy). Measurements were taken every 15 minutes during the daytime and every 20 minutes at night. Valid ABPM recordings required >80% successful measurements.

Controlled ambulatory BP was defined based on current guidelines (14). Heart rate variability (HRV) was calculated as the standard deviation of daytime, nighttime, and 24-hour heart rate (HR) from ABPM data. The nocturnal BP profile was categorized as: a) reverse dipping: nighttime BP higher than daytime BP, b) reduced dipping: nighttime BP reduction of 0-10%, c) normal dipping: nighttime BP reduction of 10-20% and d) extreme dipping: nighttime BP reduction >20%.

The ambulatory arterial stiffness index (AASI) was determined using a proposed formula (15).

Statistical analysis

Continuous variables were reported as median and 25th–75th percentiles due to their non-normal distribution (as assessed by the Shapiro-Wilk test), while categorical variables were expressed as absolute and relative frequencies (%). Comparisons between CAH patients and controls were performed using the Mann–Whitney U test for continuous variables and Fisher's exact or Chi-square test for categorical variables, as appropriate.

Multiple linear regression models were used to investigate associations between clinical and biochemical variables and cardiovascular outcomes (AASI and QTc interval). Two models were constructed: one including the whole population and another restricted to the CAH group to explore the influence of specific hormonal variables. Despite the non-normal distribution of several independent variables, linear regression analysis was considered appropriate, as the key assumptions relate to the distribution of residuals rather than of raw data. Visual inspection of diagnostic plots confirmed the approximate normality, linearity, and homoscedasticity of residuals in all models.

To further minimize selection bias, propensity score matching (PSM) was applied using the same covariates included in the regression models, with a 1:2 matching ratio (CAH:controls). Matching balance was evaluated by comparing baseline characteristics before and after matching.

A priori power analysis was performed to determine the required sample size to detect a clinically meaningful difference in Ambulatory Arterial Stiffness Index (AASI) between groups. Assuming a two-tailed α of 0.05, a power of 80%, and a moderate effect size (Cohen's d = 0.6), a minimum of 30 CAH patients and 69 controls was estimated to be necessary. Our final sample (32 CAH and 73 controls) exceeds this threshold, confirming adequate statistical power to test the primary hypothesis.

All statistical tests were two-sided, and a p-value <0.05 was considered statistically significant. Analyses were conducted using STATA version 18.0 (StataCorp, College Station, TX, USA).

Results

Enrolled population was composed of 105 subjects, 32 classic CAH patients and 73 controls (Figure 1). Out of the 32 CAH patients: 21 were females (66%) and 11 were males (34%), their median age was 25 (19.5–29.5) years. Most patients were diagnosed at birth, with a median disease duration of 24 (19–29) years (Tables 1, 2).

Regarding GCs therapy, most CAH patients (22 cases, 68.8%) were treated with hydrocortisone (HC), while 5 patients (15.6%) received dual-release HC (DR-HC) and another 5 patients (15.6%) were on a combination therapy (HC or cortisone acetate plus dexamethasone). Salt-wasting forms (28 cases, 87.5%) were treated with fludrocortisone. The median daily HC equivalent dose was 20.0 (20.0–25.0) mg, and the median daily dose of fludrocortisone was 100 (67.5–100) µg.

When compared to the control group, CAH patients were younger (25, 19.5–29.5 vs 33, 26–37 years, p=0.035) and had a significantly lower body weight (62, 56–73.5 vs. 72.5, 64–90 kg; p=0.006). Office systolic blood pressure (SBP) (130, 125–130 vs 120, 110–130 mmHg; p<0.001) and smoking prevalence (46.6% vs. 12.5%; p<0.001) were significantly higher among controls, compared to CAH patients. CAH patients had significantly higher potassium levels (4.2, 4.0–4.5 vs. 4.1, 3.7–4.3 mmol/L; p=0.031) and lower fasting blood glucose (76, 72.5–85.5 vs 85, 76.5–94 mg/dL; p=0.007), compared to controls. However, no differences were found in the prevalence of impaired fasting glucose or diabetes mellitus. CAH patients' lipid profile differed significantly from the control group, with a lower total cholesterol (161, 139–188 vs 192, 171–223 mg/dL, p<0.001); higher HDL cholesterol (56, 46–63 vs 47.5, 39-60; p=0.033), lower triglycerides (75, 54–106 vs 100, 75 157; p=0.025) and lower LDL-cholesterol (82.4, 73–110 vs 121.8, 97.6-143.2; p<0.001). No differences in terms of kidney function were found between the groups.

Patients with CAH exhibited a shorter QTc (395, 378–401 vs 410, 390–430 ms, p<0.006) and RR interval (849, 740–915 vs 900, 790–1000 ms, p=0.045) and a longer QRS complex (90, 82–105 vs 80, 80–100 ms; p=0.004) (Table 1). The mean diastolic blood pressure (DBP) at ABPM, was significantly lower in CAH patients in the 24-hour (73.3, 66.9–77 vs 76.7, 71.7-82.2 mmHg; p=0.025), as well as taking into consideration daytime (78.3, 68.3-81.4 vs 80.5, 74.9-90.3 mmHg; p=0.020) and nighttime (60.9, 55.1-65.4 vs 67.2, 59.2-73.5 mmHg; p=0.007). Heart rate variability (HRV), measured through ABPM, showed differences between the groups with a higher variability in CAH patients during the 24-hour period (14.2, 12.3-17.5 vs 11.4, 9.5-14.9 bpm; p=0.007), as well as in daily hours (13.1, 11.3-15.5 vs 10.7, 8.5-13.9 bpm; p=0.002), in comparison with the control group. No differences were found in dipping profile among the two groups.

The Ambulatory Arterial Stiffness Index (AASI), evaluated through ABPM, was significantly increased in patients with CAH compared to controls (0.430, 0.380-0.550 vs 0.350, 0.260-0.440; p=0.006).

Multiple linear regression and propensity score matched analyses

Multiple linear regression showed that CAH diagnosis (exponentiated coefficient [EC] 1.131, 95% CI 1.061-1.205; p<0.001) was positively associated with AASI, correcting for age (EC1.004, 95% CI 1.000-1.008; p=0.034), male sex, BMI (EC1.008, 95% CI 1.003-1.011, p<0.001), glucose alterations, LDL-cholesterol and smoking habit (Table 3– Model A). When the regression was calculated considering only the CAH group, a significant association was found between 17α -hydroxyprogesterone (17αOHP) levels (EC 1.001, 95% CI 1.000-1.0002; p=0.049) and AASI, correcting for the same covariates (Table 3– Model B).

In another multiple linear regression model, the length of the CAH diagnosis (EC0.977, 95% CI 0.956-0.999; p=0.039) proved to be negatively associated with QTc interval at the ECG, when correcting for age, male sex, potassium levels, BMI, ABPM 24- hour mean SBP and smoking habit (Table 4, Model A). When the model was applied to CAH patients only, ACTH (EC0.999; 95% CI 0.999-1.000; p=0.021) seems to be related to a shorter QTc, when normalizing for age (EC0.998, CI 95% 0.996-0.999; p=0.012), androstenedione levels, BMI, ABPM-24-hour mean SBP and smoking habit (Table 4, Model B).

When the two subgroups were studied through the propensity score matched analysis with a 1:2 matching ratio, based on the same regression models, CAH diagnosis confirmed a significant positive association with increased AASI (EC0.09, 95% CI 0.069-0.117; p<0.001) and a negative association with the QTc interval length (EC-0.028, 95% CI-0.046 - -0.009; p=0.004) (Table 5).

Discussion

The results of the present study show that adult patients affected by classic CAH due to 21ß-hydroxylase deficiency present an increased arterial stiffness, assessed by AASI, and a shorter QT interval, when compared with controls.

We included a sample of adult classic CAH patients and compared its metabolic and cardiovascular features with a control group of young patients (<40 years) with the suspicion of pheochromocytoma/paraganglioma, in whom a chromaffin tumor was excluded. Despite a poorer metabolic and cardiovascular profile of the control group, the AASI appeared to be higher in CAH patients when compared to controls. The multiple regression model confirmed this association when normalizing for variables such as age, sex, BMI, the presence of glucose metabolism alterations, LDL-cholesterol levels and smoking habit; with CAH patients showing a higher risk of having an increased AASI, furthermore confirmed by matching the two groups through a propensity score-matched analysis, based on the same regression models. When replicated among the CAH group, the multiple regression model showed a positive relationship between 17αOHP levels and AASI. Although previous studies on AASI as a cardiovascular parameter in adult CAH patients are lacking, a study conducted on pediatric CAH reported an increased AASI in Del/Del and Del/I2G genotypes and found a relationship with urinary cortisol, cortisol area under the curve and cortisol after the first dose of HC (16). Several studies have found a positive relationship between CAH and an increased thickness of the carotid-artery intima media (17), with a significant correlation between a worse vascular system health and 17αOHP levels (18), despite HC equivalent doses, highlighting the possible role of androgen excess on carotid atherosclerosis. Other cardiac alterations, such as prolonged isovolumetric relaxation and mitral deceleration times have been reported in CAH adolescents in relationship with hydrocortisone exposure and elevated testosterone levels (19).

Heart-rate variability (HRV) was also significantly lower in our control group compared to CAH patients, in addition to the worse conventional risk factors presented, strengthening our findings. HRV is a robust prognostic indicator of cardiovascular health, reflecting autonomic balance and cardiac–brain communication: higher HRV denotes increased parasympathetic tone and superior cardiac fitness, whereas lower HRV is associated with elevated cardiovascular risk (20–22). The subgroup of CAH patients still showed markedly increased arterial stiffness despite better cardiovascular health markers. This finding underscores an intrinsic vascular dysfunction in CAH that appears independent of traditional metabolic and lifestyle risk markers and could be linked to circulating androgen levels.

Patients with CAH present a duration of the QTc interval that could be modulated by the combination of excess hormones expressed. In the present study, we found a significant effect of CAH on QTc values, with smaller intervals when compared with the control group even after a propensity score matched analysis, further affirming the link between CAH and modulation of the QTc interval.

When applying the same model on the CAH group only, ACTH seems to be negatively associated with QTc interval length. A previous study (23) found an association between women with CAH and a shorter QTc interval, linking this alteration to lower FSH levels and a higher progesterone/estradiol ratio. Although gonadotropins were not measured in the present study, a higher ACTH is associated with an increased secretion of adrenal steroids with a potential increased impact on gonadotropins, which could lead to an impaired LH pulsatility and to lower FSH levels as a feedback mechanism (24), partially explaining the similar features found in our study.

Despite the use of a rigorous study protocol, our study shows some limitations. The sample size and the cross-sectional nature of the study may limit the generalizability of results, moreover the impact of different GCs treatment approaches on cardiometabolic features have not been studied due to the small sample size. It will be essential to extend the research to a larger sample and a multicenter context. The analysis of the link between hormone levels, such as ACTH and sexual hormones and cardiovascular parameters may provide further insights into the management of CAH.

In conclusion, the present study has provided new insights into the understanding of cardiometabolic pathophysiology of classic CAH due to 21ß-hydroxylase deficiency. Significant differences were found in parameters of arterial stiffness (AASI) and the QTc interval, and androgen and ACTH excess could lead to these cardiovascular alterations. Further prospective studies are needed to confirm our findings.

Data availability statement

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Ethics statement

The study was approved by the Ethics Committee of the City of Health and Science University Hospital of Turin. It was conducted in accordance with the Declaration of Helsinki. All participants provided written informed consent prior to their inclusion in the study.

Author contributions

LC: Formal analysis, Data curation, Writing– original draft, Writing– review & editing, Investigation, Methodology. MD: Writing– original draft, Data curation, Investigation, Methodology, Conceptualization. CS: Data curation, Writing– review & editing, Investigation. BB: Data curation, Investigation, Writing– review & editing. MB: Writing– review & editing, Data curation, Investigation. GMon: Writing– review & editing, Formal analysis. FP: Investigation, Formal analysis, Writing– review & editing. CL: Conceptualization, Writing– review & editing, Investigation. GMot: Validation, Methodology, Supervision, Writing– review & editing. MP-C: Validation, Data curation, Formal analysis, Writing original draft, Supervision, Writing– review & editing, Methodology. RG: Conceptualization, Data curation, Project administration, Validation, Writing– review & editing, Methodology, Supervision, Investigation, Writing– original draft.

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Allergic reactions. Symptoms of an allergic reaction include tightness of the throat, trouble breathing or swallowing, swelling of the lips, tongue, or face, and rash. If you have an allergic reaction to CRENESSITY, get emergency medical help right away and stop taking CRENESSITY.

Risk of Sudden Adrenal Insufficiency or Adrenal Crisis with Too Little Glucocorticoid (Steroid) Medicine. Sudden adrenal insufficiency or adrenal crisis can happen in people with congenital adrenal hyperplasia who are not taking enough glucocorticoid (steroid) medicine. You should continue taking your glucocorticoid (steroid) medicine during treatment with CRENESSITY. Certain conditions such as infection, severe injury, or shock may increase your risk for sudden adrenal insufficiency or adrenal crisis. Tell your healthcare provider if you get a severe injury, infection, illness, or have planned surgery during treatment. Your healthcare provider may need to change your dose of glucocorticoid (steroid) medicine.

Before taking CRENESSITY, tell your healthcare provider about all of your medical conditions including if you: are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

The most common side effects of CRENESSITY in adults include tiredness, headache, dizziness, joint pain, back pain, decreased appetite, and muscle pain.

The most common side effects of CRENESSITY in children include headache, stomach pain, tiredness, nasal congestion, and nosebleeds.

These are not all the possible side effects of CRENESSITY. Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch at www.fda.gov/medwatch or call 1-800-FDA-1088.

Dosage Forms and Strengths: CRENESSITY is available in 50 mg and 100 mg capsules, and as an oral solution of 50 mg/mL.

Please see full Prescribing Information and Patient Information.

You're invited!

Webinar on Crenessity (crinecerfont) with Dr. Alejandro Diaz

Dear CARES Community,

Neurocrine Biosciences is a neuroscience-focused, biopharmaceutical company with a simple purpose: *to relieve suffering for people with great needs.*

To support the classic congenital adrenal hyperplasia (CAH) community, Neurocrine is dedicated to making information and knowledge about clinical trial data accessible.

Dr. Alejandro Diaz will present data from the Phase 3 Clinical Trials of Crincerfont for both adult and pediatric patients with classic Congenital Adrenal Hyperplasia.

Please see Important Safety Information for CRENESSITY (crinecerfont) below and Patient Information.

Event Details:
November 12, 2025 between 8:00-9:30PM Eastern

What to Expect:

- Overview of the Phase 3 clinical trials of CRENESSITY (crinecerfont) presented by Dr. Diaz
- Neurocrine Access Support information provided by Kimberly Golynskiy, Sr. Director, Patient Support Services at Neurocrine Biosciences
- An interactive Q&A Session led by Dina Matos, Executive Director of CARES Foundation

Interested in joining? Secure your spot here. **Register Here**

We hope to see you there.

Crenessity® (crinecerfont)
Capsules 50mg, 100mg

Approved Uses:

CRENESSITY (crinecerfont) is a prescription medicine used together with glucocorticoids (steroids) to control androgen (testosterone-like hormone) levels in adults and children 4 years of age and older with classic congenital adrenal hyperplasia (CAH).

IMPORTANT SAFETY INFORMATION

Do not take CRENESSITY if you: Are allergic to crinecerfont, or any of the ingredients in CRENESSITY.

CRENESSITY may cause serious side effects, including:
Allergic reactions. Symptoms of an allergic reaction include tightness of the throat, trouble breathing or swallowing, swelling of the lips, tongue, or face, and rash. If you have an allergic reaction to CRENESSITY, get emergency medical help right away and stop taking CRENESSITY.

Risk of Sudden Adrenal Insufficiency or Adrenal Crisis with Too Little Glucocorticoid (Steroid) Medicine. Sudden adrenal insufficiency or adrenal crisis can happen in people with congenital adrenal hyperplasia who are not taking enough glucocorticoid (steroid) medicine. You should continue taking your glucocorticoid (steroid) medicine during treatment with CRENESSITY. Certain conditions such as infection, severe injury, or shock may increase your risk for sudden adrenal insufficiency or adrenal crisis. Tell your healthcare provider if you get a severe injury, infection, illness, or have planned surgery during treatment. Your healthcare provider may need to change your dose of glucocorticoid (steroid) medicine.

Before taking CRENESSITY, tell your healthcare provider about all of your medical conditions including if you: are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

The most common side effects of CRENESSITY in adults include tiredness, headache, dizziness, joint pain, back pain, decreased appetite, and muscle pain.

The most common side effects of CRENESSITY in children include headache, stomach pain, tiredness, nasal congestion, and nosebleeds.

These are not all the possible side effects of CRENESSITY. Call your healthcare provider for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch at www.fda.gov/medwatch or call 1-800-FDA-1088.

Dosage Forms and Strengths: CRENESSITY is available in 50 mg and 100 mg capsules, and as an oral solution of 50 mg/mL.

Please see full Prescribing Information.

PATIENT AND CAREGIVER EXPERIENCES WITH HYDROCORTISONE INJECTIONS IN ADRENAL CRISIS: A MIXED-METHODS CROSS-SECTIONAL STUDY

Background: Adrenal crisis is the leading cause of death in patients with adrenal insufficiency, and prevention requires immediate parenteral hydrocortisone administration. However, most patients do not receive their home emergency hydrocortisone injection. Our study aimed to investigate barriers and enablers to using emergency hydrocortisone injections in managing adrenal crises.

To view the full study, please visit:
https://www.frontiersin.org/journals/endocrinology/articles/10.3389/fendo.2025.1544502/full

QUALITY OF LIFE STUDY (Classical CAH)

Living with Congenital Adrenal Hyperplasia: Global Insights on Health Outcomes, Quality of Life, and Adrenal Crisis Experiences

A collaboration between *CARES Foundation* & *The University of Virginia*

Thank you for your willingness to participate in this study. This survey is intended for caregivers/ parents/guardians of children between the ages of birth-17 years of age and adults (18 years or older) with classic (salt-wasting) congenital adrenal hyperplasia (CAH). Your insights are valuable in helping us better understand the diverse perspectives and experiences within the Congenital Adrenal Hyperplasia (CAH) community.

This survey is designed to explore health-related and quality of life information; differences between U.S. and international participants; and patient experiences with adrenal crisis events and CAH treatment/ management. Please answer the questions to the best of your knowledge and remember that the answers to this survey are confidential.

If you don't feel like you qualify to participate in this study, please contact me (lfleming@virginia.edu) before continuing the survey. This survey should take approximately 20-30 minutes to complete.

PLEASE COMPLETE BY NO LATER THAN NOVEMBER 10, 2025. To access this survey, please scan the QR code or visit:
https://virginia.az1.qualtrics.com/jfe/form/SV_396wIpuCrbNrTkW

If after completing the survey, you have questions regarding your care or feel you need additional support, please contact your healthcare provider or CARES Foundation (www.caresfoundation.org).

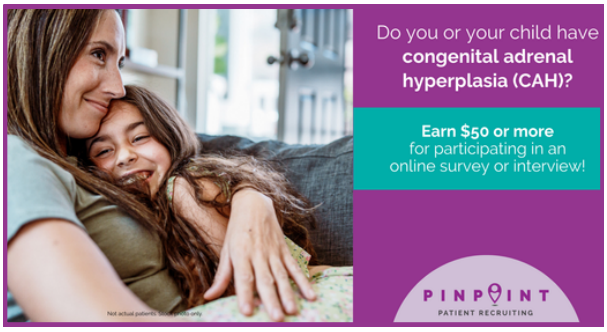
SHARE YOUR STORY WITH CARES!

EMERGENCY CRISIS/EMERGENCY ROOM EXPERIENCES

Please share any negative/unacceptable experiences you have had at while in a crisis situation/emergency room visit concerning you/your loved one's congenital adrenal hyperplasia (CAH).

WE NEED YOUR VOICE! We intend to compile these experiences together and share them with providers and legislatures in an effort to improve the nature of these situations going forward. Stories can be shared anonymously, and we encourage you to share as much as possible.

If you are interested in submitting your **Emergency Experience** with CARES, **please submit your story here** (**https://caresfoundation.app.neoncrm.com/survey.jsp?surveyId=41&**) reach out to **dina@caresfoundation.org** with your story.



Share Your Experiences With CAH and Help Others

Pinpoint Patient Recruiting, a market research recruitment company, is searching for people who are interested in participating in ongoing virtual market research opportunities that help researchers better understand the experiences and opinions of people living with CAH and caregivers of children living with CAH.

The format of opportunities will include online surveys and online interviews. People who participate in the opportunities will receive $50 or more as a thank you for their time and participation.

Who is eligible to participate?

- **adults (ages 18+) who have been diagnosed with congenital adrenal hyperplasia (CAH)**
- **caregivers of children (under the age of 18) who have been diagnosed with congenital adrenal hyperplasia (CAH)**

All information and responses will remain confidential. The research opportunities are sponsored by pharmaceutical companies. No medication will be given or tested. Participants must be current residents of the United States.

Interested?

To be notified about these market research opportunities or to learn more, please visit www.pinpointpatientrecruiting.com/cah-survey-cares or contact Kim Slusher at: kim@pinpointpatientrecruiting.com.

2025 ANNUAL PATIENT EDUCATION CONFERENCE

at Riley Hospital for Children in Indianapolis, Indiana *WAS A HUGE SUCCESS!*

Co-host
Riley Children's Health
Indiana University Health

A special thank you to Riley Children's Health - Indiana University Health, all of our outstanding presenters, event sponsors, and of course to all of those who attended this year's conference!

The event was a resounding success marked by learning, shared experiences, and the forging of powerful personal connections. The exchange of knowledge created a dynamic environment for growth and collaboration.




Thank you to all who contributed to making it such a meaningful & impactful gathering!

SAVE THE DATE FOR NEXT YEAR'S CONFERENCE

October 17 & 18, 2026
New York City

Thank you to this year's sponsors! We truly appreciate your support.

This weekend would not have been possible without the presence and support of our generous sponsors! Thank you for taking the time to join us and help educate our community on some of your groundbreaking research and studies!

CAH PARTNER 2025 NEUROCRINE BIOSCIENCES · Pfizer · eTon PHARMACEUTICALS · Crinetics Pharmaceuticals · bridgebio · PicnicHealth · Lundbeck · PANTHER RARE

Did you miss the conference and want to access the recorded sessions?

Please email john@caresfoundation.org for access to this year's conference recordings.

SAVE THE DATE

18TH ANNUAL

Everyone CARES Gala

Sony Pictures Studios

April 18, 2026

Culver City, CA




Honoring...

Richard Rink, MD, FAAP, FACS | Distinguished Professor Emeritus, Pediatric Urology
Surgical Director, CARES Comprehensive CAH Center
Riley Hospital for Children
Lifetime Achievement Award

Robert Farber, PhD | Vice President, Clinical Development
Crinecerfont Program Lead
Neurocrine Biosciences
Pioneer Award

Sue Shirey
Founder/Treasurer
The James Shirey Foundation
Community Partner Award

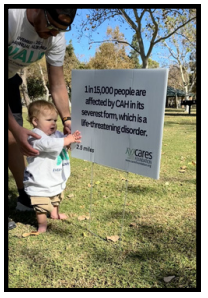
Community Events

Saturday, November 15, 2025
10th Annual California CAH Awareness Walk

Yorba Regional Park, Anaheim, CA

Check-in: 9:30AM | Walk Starts: 10:00AM

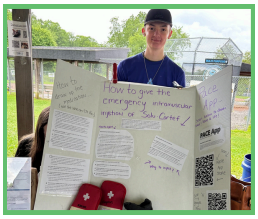
Scan to learn more/register or visit:
https://caresfoundation.org/annual-california-cah-awareness-walk/



2025 CAH Awareness Walks

Thank you to all of our hosts, volunteers, sponsors & participants!

Thank you to everyone who participated in this year's CAH Awareness Walks across the country! So far this year, CAH Awareness Walks were hosted in Iowa, Pennsylvania, and Ohio. We hope you had an amazing experience learning, connecting with others, and raising awareness with the CARES Community!



CAH Awareness Walks are a great way to engage your local community! If you are interested in hosting a walk in your area in 2026, please contact dina@caresfoundation.org for more information on how to get started.

10TH ANNUAL

CLAY SHOOT for CARES

THANK YOU TO ALL WHO CAME OUT TO SUPPORT CARES Foundation & our mission!

Because of the generosity of our participants & sponsors, we are happy to announce that we have raised over **$208,711.79** in the last 10 years!

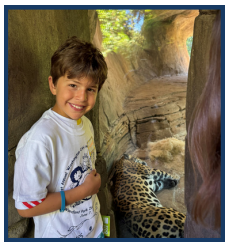
We look forward to seeing everyone again next time!

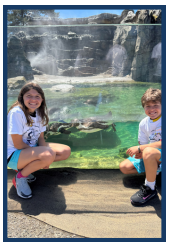
1st Annual Washington CAH Awareness Family Fun Day

Woodland Park Zoo, Seattle, WA

Thank you to everyone who came out to support the CAH Community on June 7!

A special thank you to Seattle Children's for helping put together this incredible event!





Inaugural

SWING FOR CAH

Golf Tournament

We would like to extend our gratitude to all of this year's participants & sponsors, and hope everyone had a great time raising awareness for our community!

Khindivi™ (hydrocortisone) 1 mg/mL oral solution

Now Available | **For children aged 5 years and older with adrenal insufficiency**

ORAL HYDROCORTISONE

Now in a ready-to-use liquid

Introducing KHINDIVI™ (hydrocortisone) 1 mg/mL oral solution

The only FDA-approved oral liquid hydrocortisone solution for children aged 5 years and older with adrenal insufficiency.

KHINDIVI is not approved for stress dosing.

Designed to get dosing right every time

New KHINDIVI oral liquid hydrocortisone helps make dosing easy so you can feel confident your loved one is getting the accurate dose they need every time.

- **Ready-to-use liquid designed for accurate dosing***
  *When entire dose is given as directed.
- **No cutting, splitting, or crushing tablets—simply a liquid**
- **No need for refrigeration, mixing, or shaking**

Medication for $0 per month†

Eton Cares is the full-service support program for children taking KHINDIVI and their families. Once prescribed KHINDIVI, you're automatically enrolled in Eton Cares for prescription refill reminders, shipment alerts, and support throughout the treatment journey.

Call the Anovo® Specialty Pharmacy hotline with questions about KHINDIVI at

1-833-343-2500

(available Monday through Friday,8 AM–5 PM CT)

†Commercially eligible patients can pay as little as $0 per month. Restrictions, limitations, and/or eligibility requirements may apply.

USE AND IMPORTANT SAFETY INFORMATION

USE

KHINDIVI is a prescription medicine used in children 5 years of age and older as replacement therapy when the adrenal gland is not making enough cortisol.

Limitation of Use: KHINDIVI is not approved for increased dosing during periods of stress or acute events. Use a different hydrocortisone-containing drug product for stress dosing.

IMPORTANT SAFETY INFORMATION

Always give KHINDIVI exactly as your doctor has directed.

Do not take KHINDIVI if you are allergic to hydrocortisone or any of its other ingredients.

Adrenal Crisis: Giving too low a dose or stopping medication can cause low levels of cortisol, which can result in serious illness or death. Treatment with intravenous hydrocortisone should be started immediately. When switching from another type of hydrocortisone to KHINDIVI, watch your child closely for any changes. During periods of stress such as infections or after surgery, your doctor should switch to another oral hydrocortisone product and increase the dose.

Systemic Adverse Reactions Due to Inactive Ingredients

Hyperosmolarity: KHINDIVI is not approved in children less than 5 years of age. The inactive ingredients in KHINDIVI can cause dangerous fluid imbalances.

Metabolic Acidosis and Other Adverse Reactions: Some ingredients in KHINDIVI may cause a build-up of acid in the body, low blood sugar, or injuries to the liver, kidneys, or brain, that may increase the risk of adrenal crisis.

Laxative Effects Due to Inactive Ingredients: Some ingredients in KHINDIVI may cause stomach upset resulting in vomiting and/or diarrhea and could increase the risk of adrenal crises in patients.

Immunosuppression and Increased Risk of Infection With Use of a Dosage Greater Than Replacement: Use of a greater than replacement dosage can suppress the immune system and increase the risks of new infections. Contact your health care provider if any infections develop.

Growth Retardation: The long-term use of corticosteroids in high doses may cause growth retardation in children.

Decrease in Bone Density: Corticosteroids can affect your child's bone growth and strength.

Cushing's Syndrome Due to High Doses of Corticosteroids: Treatment with high doses of corticosteroids can cause Cushing's Syndrome. Treatment should be limited to the smallest dose required, and your child's growth and development monitored appropriately.

Psychiatric Changes: Corticosteroids can change your child's behavior or mood. Tell your doctor if your child has periods of extreme happiness, extreme sadness, hallucinations, or depression.

Changes in Vision: Tell your doctor if your child has blurred vision or other vision problems during treatment with KHINDIVI.

Gastrointestinal Adverse Reactions: Tell the doctor if your child has stomach pain, upset stomach, black, tarry stools, or vomiting of blood. These could be signs of ulcers or tears in the stomach or intestines. Taking anti-inflammatory nonsteroidal drugs, like ibuprofen, naproxen, or aspirin, can increase the risk of ulcers or tears.

The most common side effects of KHINDIVI include retaining fluids, changes in glucose tolerance, high blood pressure, behavioral and mood changes, greater appetite, and weight gain.

Vaccination: Administration of live vaccines may be acceptable in KHINDIVI-treated pediatric patients with adrenocortical insufficiency who receive replacement corticosteroids.

Please visit KHINDIVI.com/patient for more information.

You are encouraged to report negative side effects of prescription drugs by contacting Eton Pharmaceuticals, Inc. at 1-855-224-0233 or the U.S. Food and Drug Administration (FDA) at www.fda.gov/safety/medwatch or call 1-800-FDA-1088.

Please see full Prescribing Information for more information.

eTon PHARMACEUTICALS

21925 W. Field Pkwy #235, Deer Park, IL 60010 | (847) 787-7361

2145-v1

PicnicHealth | NEUROCRINE BIOSCIENCES | XXcares FOUNDATION

Be a hero for the CAH community!

Help improve treatment and care for others with CAH by participating in the CAHtalog® Registry. CAHtalog is a comprehensive collection of clinical data from medical records from those living with classic congenital adrenal hyperplasia (CAH), designed to drive advancements in CAH research.

CAHtalog is open to adults and caregivers on behalf of their children living with classic CAH and who receive medical care in the United States.

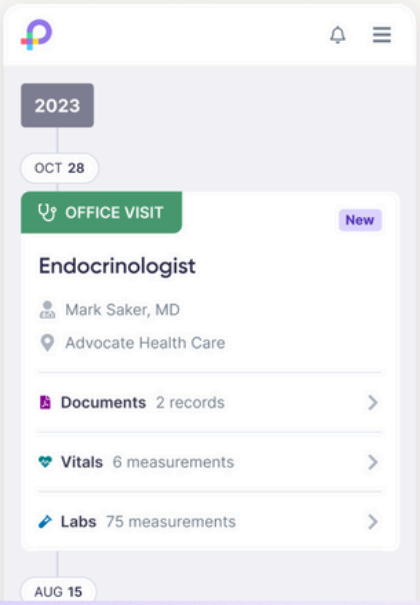
Sign up on CAHtalog.com in less than 10 minutes. Here's what you can expect:

After signing up, sit back and relax

Nothing else is required. PicnicHealth will collect your medical records on your behalf.

We take your privacy seriously

All personal identifying information will be removed from your medical records



Receive comprehensive access to your medical history as a benefit of participating in CAHtalog:

- PicnicHealth will organize your records from multiple providers so you can easily track your lab values, medications, images, and doctor's notes—all from your electronic device.
- Share your medical history with anyone you trust, anywhere, anytime.
- You'll earn $50 for joining once you qualify, with the option to participate in additional compensated surveys.

Have questions or need help signing up? Email us at help@picnichealth.com.

Are You or Your Child Facing Challenges Due to CAH?

Consider Joining a Clinical Research Study

Crinetics is a pharmaceutical company that develops much-needed therapies for people with endocrine diseases. We are currently enrolling adults and children who have been diagnosed with classic congenital adrenal hyperplasia (CAH).

The Calm-CAH (adult) and Balance-CAH (pediatric) studies are looking to understand the safety and effectiveness of an investigational study drug, atumelnant, whether it may reduce the dosage needed for steroid medications like glucocorticoids (GCs), and how it may help manage symptoms of CAH.

To participate in these studies, you or your child must:

- Be 1 to 74 years of age
- Have received a diagnosis of classic CAH
- Be on a stable GC regimen (for example: modified-release hydrocortisone, cortisone acetate, prednisolone, prednisone, methylprednisolone, and dexamethasone)

Additional requirements apply, which the study team will discuss with you.

Atumelnant is an investigational study drug, which means it has not been approved by any regulatory authority and is still under investigation as a potential treatment for CAH.

Crinetics Pharmaceuticals

Balance-CAH | Calm-CAH

To learn more or to see if you or your child may qualify, scan the QR code or visit CrineticsCAH.com.

CRN04894-12 and 13_Print Ad_V1_07/2025_NP-CAH-0114-1
CAH-ENUS-PAGAD-V1-4SEP25

CONGENITAL ADRENAL HYPERPLASIA

PATIENT EDUCATION GUIDE

CAREs CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

TO VIEW THE FULL TEXT, PLEASE SCAN THE QR CODE OR VISIT:

HTTPS://CARESFOUNDATION.ORG/WP-CONTENT/UPLOADS/2025/10/FINAL-VERSION-DIGITAL-PATIENT-EDUCATION-GUIDE-SEPT.-2025.PDF

SCAN TO VIEW THE FULL TEXT

CARES FOUNDATION

THE DOCTOR IS IN

DR. KAREN LIN SU
CARES MEDICAL DIRECTOR

Q&A

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. Should I stress-dose before strenuous exercise or competitive sports games?

Patients with classical CAH may have impaired exercise tolerance and a blunted blood glucose response during intense exercise, but it appears to be from inadequate adrenaline rather than cortisol. Giving extra hydrocortisone does not improve performance and does not improve blood glucose response. It is more prudent to have extra snacks available before, during, and after exercise. It is also important to stay hydrated with both water and salt, especially for salt-wasters.

3. Do I need to stress-dose for psychological stress, such as exams?

No, you do need to stress-dose for stressful events, such as difficult exams or life stressors that are not medical in nature. Prolonged elevated cortisol is not beneficial and can cause the same side effects as over-treatment (see #4).

4. What are signs of too much steroid treatment?

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

5. Do NC-CAH patients need to stress-dose?

NC 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.

6. If I am taking Crenessity (crinecerfont), do I still need to take hydrocortisone?

Crenessity lowers ACTH, which can decrease adrenal androgen production, but it does not replace cortisol. You may be able to take a lower dose, but yes, you still need to take glucocorticoid (hydrocortisone) replacement and you still need to stress-dose for any febrile illness, trauma, or surgery.

7. 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 cardiac arrhythmias. 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. Compounded hydrocortisone is also not recommended. Hydrocortisone is available as tablets, sprinkles, and now a liquid solution (for age 5 years and older).

8. 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. The injection form is inactivated, so it cannot cause the flu. If fever develops after the vaccine, stress-dose as recommended by your endocrinologist.

FUNDRAISING | Make a difference today!

CARES Foundation's 2025 Year-End Campaign

Your year-end gift can help us build on our successes and tackle the challenges that lie ahead for those affected by congenital adrenal hyperplasia. Any amount you intend to give will directly support our efforts to provide education, advocacy, and research for CAH. *We truly appreciate your support of our mission!*

Visit this link to make your donation: https://caresfoundation.app.neoncrm.com/forms/cares-2025-year-end-campaign

CARES Foundation Donor Privacy and Confidentiality Policy

CARES Foundation respects the privacy of its donors and prospective donors and believes it is of paramount importance to maintain the trust and confidence of our community. This policy provides transparency regarding our practices for the collection, use, and protection of donor information.

To view the full CARES Foundation Donor Privacy and Confidentiality Policy, please visit the link in the button below:

CARES Foundation Donor Privacy and Confidentiality Policy (https://caresfoundation.org/wp-content/uploads/2025/10/CARES-Donor-Confidentiality-V.0.478.pdf)

On November 22, a member of our community, Jes Barron, will be running in the ***63rd Annual JFK 50 Mile*** in Boonsboro, MD!

Please consider supporting Jes and the CAH community during this challenging journey to inspire those with CAH and other chronic conditions.

"I can show my daughter and others with chronic conditions that we are not broken, we can do hard things, and we can live full meaningful lives."

To make your donation, please **scan the QR Code** in this image, **or visit**:
https://caresfoundation.app.neoncrm.com/forms/jes-barrons-50-mile-ultramarathon

CARES Foundation Endowment Fund | *Securing a Future of Care and Hope*

A Gift That Keeps on Giving

CARES Foundation's Endowment is designed to provide a stable, permanent source of funding. Your contribution will be carefully invested, with the annual returns supporting our mission in perpetuity. This means your single act of generosity will touch lives year after year, creating a ripple effect of positive change.

Every Gift Matters

Whether large or small, your contribution to the endowment fund is an investment in hope. It's a promise to future generations that they will have the resources, support, and opportunities they need to thrive despite CAH.

How an Endowment Grows...

- An establishing gift is made and forms the principal
- The prinicipal is protected, invested, and continues to grow
- A portion of the fund's value is distributed annually, forever

Ways to Give

Bequests: Include CARES in your will or living trust.
Retirement Plan Assets: Name CARES as a beneficiary.
Life Insurance: Designate CARES as a beneficiary.
Securities: Donate stocks, bonds, or mutual funds.
Real Estate: Gift property to make a significant impact.
Cash

If you would like to name us in your Will/IRA, please add the following as a beneficiary:
Community Foundation of New Jersey
c/o CARES Foundation Congenital Adrenal Hyperplasia Fund EIN 22-2281783

If you have any questions, please do not hesitate to contact us via email or by phone:
Email: contact@caresfoundation.org **Phone:** (908) 364-0272 **Toll Free:** (866) 227-3737

December 2, 2025

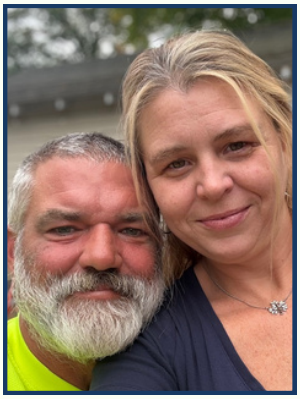
GIVING TUESDAY

All donations made on Giving Tuesday will be MATCHED UP TO $25,000!

Please consider **GIVING to CARES** by using the link in this post to donate and help improve the lives of individuals with congenital adrenal hyperplasia! (https://caresfoundation.app.neoncrm.com/forms/giving-tuesday-december-2-2025).

Noteworthy

A Personal Story...



Hello everyone. My name is Dustin and I have CAH. From my earliest memories, doctors, hospitals, blood work and x-rays to this day has been a roller coaster. At an early age we were told I wouldn't live past 13, then 18, then told I can live a "normal" life. I've always been the different one in the family and amongst friends. When I was younger I was always the tallest and strongest, and always on medication, to being the "short stocky" one always on medication. But with the ups and downs of living with CAH I have managed to live a pretty good life. My wife and I just celebrated 22 years of marriage, my oldest daughter just turned 21, and we have a 7 year old son. Yes my kids are 14 years apart! We can blame CAH! CAH isn't a death sentence, it's a lifestyle. Be open about it with family and friends. Take your meds and stress dose when needed. Take a break when you feel tired. But have fun! Live life to the fullest !

We want to thank Dustin for sharing his story with us!

DO YOU WANT TO BE A GUEST ON CAH PULSE?

Take advantage of this incredible opportunity to make a difference in our community

Please reach out to dina@caresfoundation.org if you are interested in sharing your CAH story on our podcast. We truly appreciate all those who have joined us so far!

Season 2 | Episode 10: Brittany: Demanding Change After a Lack of Answers and Getting Nowhere

Scan or visit: cahpulse.podbean.com

In this uplifting episode, Stephanie and Dina speak to Brittany, an outspoken 29-year-old living with CAH. A self described "open book", Brittany shares her life's journey from her diagnosis as a toddler, thanks to her mother's intuition and advocacy, to her drive to find a cure for CAH. Along the way Brittany reveals she has suffered from weight gain, severe acne and even a femoral stress fracture. Her path also includes a life changing moment after meeting others for the first time who are also living with CAH, with help from CARES. Brittany's collective experiences have inspired her to make a difference in the CAH community by helping to connect others. She makes clear her inclination that there be more research, more mental health understanding and awareness, to eradicate the use of steroids and to finally find a cure. Oh, and don't forget the donuts...

Want to catch up on other episodes? Visit www.cahpulse.podbean.com.

Season 2 | Episode 9: Kristina: We're going to call your baby...'Baby'" – Removing the Stigma from CAH

Season 2 | Episode 8: Lesley and Louise: No Shame! Putting an End to the Secrecy of CAH

Season 2 | Episode 7: Tim: "Go Live Your Life as Normally as Possible" But...Nothing About CAH is Normal

Season 2 | Episode 6: Dr. Su: Words of Wisdom: Clearing up the Confusion of Stress Dosing

(Apple App Store)

(Android App Store)

Preventing Adrenal Crisis Events

PACE App

Have you downloaded it yet?

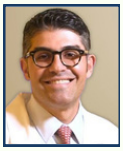
The Preventing Adrenal Crisis Events (PACE) app is available to patients, parents/caregivers, and medical professionals and is designed to provide readily accessible information and instructions for effectively managing AI (Adrenal Insufficiency). The app will include stress dosing and intramuscular injection techniques as well as other helpful tools.

Scan the QR codes or search 'PACE by Chaicore' in either the Apple or Android App Store.

Now available in Spanish

ASK THE EXPERT

Do you need expert medical advice before your next appointment?
Do you have unanswered questions about your treatment?
Then, DON'T FORGET about our program!
Click here: https://caresfoundation.org/ask-the-expert/



PREGUNTA EL EXPERTO

Necesita asesoramiento médico experto antes de su próxima cita?
¿Tiene preguntas sin respuesta sobre su tratamiento?
¡NO TE OLVIDES de nuestro programa!
Haga clic aquí: https://caresfoundation.org/pregunta-el-experto/

You must join the CAH Community on the CARES Foundation website to take advantage of our services. Please visit the link below to join our community if you have not already: https://caresfoundation.org/join-the-cares-community/

Support

Support Group Meetings via Zoom

Our support groups are available in a wide variety of demographics. Groups meet via Zoom for beneficial discussions that ultimately have the goal of providing necessary support in the areas that you may need! A CAH expert/medical professional will be there to answer your questions in between doctor appointments or in times of worry or concern.

Use our Event Calendar (https://caresfoundation.org/calendar/) regularly for upcoming dates for these meetings. Registration in advance is required and all you have to do to register is send an email to support@caresfoundation.org with the date of the meeting you'd like to attend. To attend, you must first Join the CARES Community. (https://caresfoundation.org/join-the-cares-community/).

Upcoming Meetings (Please contact support@caresfoundation.org to confirm your attendance at any of the listed meetings!)

Oct. 22, 2025 | 8:30PM(ET) via Zoom
Spanish Speaking CAH Patients & Parents

Nov. 5, 2025 | 8:30PM(ET) via Zoom
Young Adults with CAH

Nov. 13, 2025 | 9:00PM(ET) via Zoom
Parents of CAH Children (Newborn-Age 5)

Dec. 4, 2025 | 8:30PM(ET) via Zoom
Parents of CAH Children (School-aged/Teens/Young Adults)

Dec. 11, 2025, 2025 | 9:00PM(ET) via Zoom
Parents of CAH Children (Newborn-Age 5)

Support Group Leaders

Support Group Leaders are organized by state/topic. We appreciate our leaders and know that they are there for you when you need extra support! Please visit our website to see if there is a leader in your area. https://caresfoundation.org/support/

Support can also be found on our Facebook page by visiting Congenital Adrenal Hyperplasia Support Network.

Interested in joining any of our secret Facebook groups? Visit: Congenital Adrenal Hyperplasia Support Network on Facebook. When on our Profile, select '***More***' and then '***Groups***' to view all joinable groups. (If you are on a mobile device, select '**About**' then '*Groups*'). Click on the group(s) you would like to join, and then request access. We will then review your request, and follow-up as soon as possible.

YOU MUST BE A MEMBER OF THE CARES COMMUNITY TO JOIN ANY PRIVATE FACEBOOK GROUPS

Join the CARES Community here: https://caresfoundation.org/join-the-cares-community/

Medically-Safe Camps

To learn more information about some of the medically-safe summer camps for CAH Patients offered on our website, please visit: https://caresfoundation.org/cah-medically-safe-summer-camps/.

PLEASE UPDATE YOUR ACCOUNT!

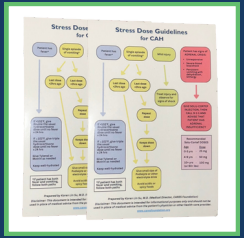
Don't miss out on important information and events!

Please visit: https://caresfoundation.app.neoncrm.com/login to view your account with CARES and edit any incomplete fields in your profile.

THE CARES SHOP

Make sure to stock up on CAH awareness-related items & resources today!
View our full catalog by visiting: https://caresfoundation.org/the-cares-shop/.

NEW ITEMS!



STRESS DOSING GUIDELINES MAGNET

$2.50

Stress dosing guidelines in a convenient 4" x 6" magnet to be placed in your home.

CAH PULSE 17OZ. COFFEE MUG

$8.00

Coffee mug (17oz.) with CARES and CAH Pulse Podcast Logos, CARES Website, and Phone.

ADRENAL INSUFFICIENCY CAR SEAT STRAP

$12.00

Velcro pullover strap to go over seatbelts to identify adrenal insufficiency in an emergency

ADRENAL INSUFFICIENCY WINDOW CLING

$2.00

Window sticker/cling to quickly identify adrenal insufficiency in the event of a crisis

EMERGENCY SYRINGE BAG

$5.50

Durable semi-translucent carry-case for syringe or other emergency items.

EMERGENCY RESPONSE KIT (SET OF 3)

$5.00

Includes 3 semi-translucent kits, and emergency instructions brochure & checklist.

MEDICAL I.D. LUGGAGE TAGS

$6.50

Medical Alert I.D. for luggage, backpacks, and other items when traveling.

Please remember that CARES Foundation newsletters have "gone green" and are available digitally. Please make sure we have your current email address to ensure that you continue receiving newsletters and other important information from CARES. Send any updates to john@caresfoundation.org.

cares CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

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