CARES Connections

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In This Issue

Screening for Anxiety and Depression in Children with Congenital Adrenal Hyperplasia

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What is already known on this topic?

Congenital adrenal hyperplasia (CAH) is a chronic genetic condition that has been associated with behavioral mental health changes due to its chronic nature and exposure to elevated androgen levels.

What this study adds?

After undergoing validated mental health screening, children and adolescents with CAH may not present with an increased prevalence of anxiety and depression as prior studies may suggest.

Abstract

Objective: Congenital adrenal hyperplasia (CAH) is an inherited condition in which individuals require multiple daily doses of medication and are at risk for life-threatening adrenal crisis. The chronic nature and severity of CAH place children at risk for psychiatric morbidity. The aim was to assess the degree of anxiety and depressive symptoms in children with CAH.

Methods: A cross-sectional cohort study of children (7-17 years) with CAH and their caregivers were recruited between May and December 2021. Children with hypothyroidism (HT) and their caregivers served as unaffected controls. Validated mental health questionnaires [Children's Depression Inventory 2 Self Report-Short (CDI-2), Screen for Child Anxiety Related Disorders (SCARED), Patient Health Questionnaire modified for Adolescents (PHQ-A); self and proxy] were completed by participants at one clinic visit. Higher scores indicated greater symptoms of anxiety and depression.

Results: A total of 60 children and 56 parents participated. Among the children 34 had CAH (68% female, mean age 11.41±2.5, CAH duration 8.5±4.1) and 26 had HT (73% female, mean age 12.7±2.9 years, HT duration 6.0±4.2 years). There was no increase in anxiety and depression symptoms in children with CAH compared to controls. In sub-analyses, children with CAH and controls reported a greater number of anxiety and depression symptoms than their caregivers on the SCARED and CDI-2, respectively. There was no association between adrenal control and the degree of anxiety or depression symptoms

Conclusion: Children with CAH do not have more symptoms of anxiety or depression compared to controls. Child and caregiver-proxy responses lack agreement, suggesting that children with CAH may continue to benefit from routine mental health evaluation, regardless of voiced caregiver concern.

Keywords: Anxiety, depression, congenital adrenal hyperplasia

Introduction

Mental health has become a greater focus in the management of pediatric chronic illness in the last decade, especially as children with chronic conditions are living longer lives and there is an emphasis on improving quality of life (1,2). There has subsequently been a move to integrate mental health assessment and treatment into routine care. Studies thus far have suggested that children with chronic illness present with higher levels of depressive symptoms than healthy peers and that the degree of depressive symptoms can differ between different chronic illnesses (3). Similarly, anxiety is prevalent in those with chronic illness, and children with anxiety and a physical illness may present with more emotional and functional impairment than children with anxiety who do not have a physical

A Message from the Executive Director

Dear Friends,

Welcome to another edition of CARES Connections! I am thrilled to share some exciting updates and opportunities with all of you.

First and foremost, I want to extend my heartfelt gratitude for your unwavering support and commitment over the past year. Your contributions have been instrumental in propelling our mission forward and creating positive change within our community.

In the spirit of celebration, I am delighted to invite you to our 16th Annual Everyone CARES Gala at Sony Picture Studios! It promises to be an unforgettable evening filled with community, inspiration, and recognition as we come together to honor Dr. Patricia Fechner, Alex Dubois and Adrenas Therapeutics who have made significant contributions to the CAH community. Mark your calendars and join us for a night of celebration and appreciation!

Furthermore, I am delighted to share that we recently had the privilege of another visit with patients and caregivers to the Bridgebio Gene Therapy Lab. This opportunity has provided attendees with invaluable insights and hope for groundbreaking advancements in CAH treatments. Additionally, we are excited to have had the opportunity to meet the scientific founder of Adrenas Therapeutics and learning more about his vision for advances in treatments within this vital field.

We are thrilled at the success of our newest venture, our podcast, CAH Pulse! Each month, I am joined by my co-host, Stephanie Erb to bring you captivating conversations and thought provoking discussions from patients, families and professionals. Their journeys are inspirational, and educational. If you would like to participate in the podcast, please contact us.

As we look ahead, I am eager to highlight our 2024 Patient Education Conference scheduled for this fall in New Jersey. This event will serve as a pivotal platform for bringing together patients, caregivers and experts to learn and make invaluable connections.

We are also looking forward to another insightful and inspirational Patient Advisory Summit. It will be another opportunity for patients and caregivers to share their journey with members of the biotech community as they work to develop novel treatments.

Finally, I extend a special invitation for your participation in our Externally Led Patient Focused Drug Development meeting in October. This will be one of only about 100 meetings since the inception of the PFDD program. The insights and experiences you will be able to share with the FDA will guide them as they make critical decisions related to the future of new treatments/therapies for CAH.

Your involvement in these events is crucial, and your contributions are deeply valued. Together, we can continue to make a meaningful impact and improve the lives of individuals living with CAH.

I look forward to your participation!

Warm regards,

Dina M. Matos
Executive Director

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illness (4). Research groups have explored the relationship between mental health and pediatric chronic disease in many conditions, such as juvenile idiopathic arthritis and inflammatory bowel disease (5,6). However, there has been limited research into mental health in the pediatric congenital adrenal hyperplasia (CAH) population (7,8,9).

CAH is an inherited, life-long condition that is most commonly caused by a deficiency in the 21-hydroxylase enzyme. This enzyme deficiency disrupts the steroid biosynthesis pathway by decreasing cortisol production and upregulating levels of 17-hydroxyprogesterone (17-OHP). Elevations in 17-OHP shift the pathway towards increased androgen synthesis. Classical and non-classical CAH differ in the degree of enzyme deficiency. Classical CAH presents as either salt-wasting or simple virilizing types. Salt-wasting CAH, accounting for approximately 75% of classical cases, is the most severe form of CAH as it is also due to suboptimal aldosterone production which, without treatment, leads to life-threatening hyponatremia and hyperkalemia (10). Simple virilizing CAH does not present with a significant degree of mineralocorticoid deficiency but does present with considerable elevations in androgen synthesis, leading to genital atypia in biological females. Non-classical CAH is the least severe form because of a milder enzyme deficiency and can present in childhood with premature adrenarche.

CAH often involves the administration of multiple daily medications, in some cases from birth. Since individuals with CAH have glucocorticoid deficiency and a degree of mineralocorticoid deficiency, they remain at risk for life-threatening adrenal crisis if medication is not taken as directed. CAH, more commonly classical CAH, leads to excess androgen production and, therefore, infant girls may present with varying degrees of genital atypia. Moreover, as children with CAH develop, growth acceleration and pubertal advancement may occur at earlier stages, especially if they are not in optimal adrenal control. Given the chronic nature, severity and physical stigmata of CAH, individuals are at risk for psychiatric morbidity.

Prior studies have largely been limited to the adult CAH population. Men with CAH have been found to have increased rates of psychiatric disorders and suicidality, especially in those who experienced a delayed diagnosis of CAH (11). Women have been noted to have increased anxiety, and women with classical CAH (particularly, simple virilizing CAH) have double the risk of having a psychiatric diagnosis compared to age-matched controls (7). Review of the literature has found few dedicated pediatric studies evaluating mental health in children with CAH and conclusions have been variable (7,8,9). As such, there remains a need to further characterize mental health concerns in the pediatric CAH population. The aim of this study was to assess the degree of anxiety and depression symptoms in children and adolescents with CAH using validated mental health questionnaires during a routine follow-up visit.

Methods

Participants

Children diagnosed with CAH or hypothyroidism (HT) and who were between the ages of 7-17 years and their respective caregivers were eligible for this single-center, prospective, observational cohort study. All the prospective participants with CAH had 21-hydroxylase deficiency. Sex of children was specified by karyotype analysis in those found to have atypical genitalia only. To the best of our knowledge, all children were raised in accordance with their chromosomal sex. A non-CAH control group was deemed necessary given the baseline mental health concerns stemming from the Coronavirus disease-2019 (COVID-19) pandemic, which was concurrent with the study period.

Children with HT (congenital or autoimmune) were chosen as the control group as they also have a chronic illness, require daily administration of medication, and have frequent medical visits and laboratory assessments, similar to children with CAH. In addition, children with HT have a bimodal age of presentation similar to CAH; congenital HT and classical CAH are often diagnosed in the newborn period and autoimmune HT and non-classical CAH are diagnosed in later childhood. However, unlike the CAH population, children with HT do not share the added stressors associated with physical stigmata (from hyperandrogenism or precocious puberty) and adrenal crisis (requiring glucocorticoid stress-dosing and hospitalization). All children with HT were biochemically euthyroid at the time of questionnaire administration.

Participants were recruited from the pediatric endocrinology and urology clinics at New York-Presbyterian Hospital/ Weill Cornell Medical Center (NYPH/WCMC). NYPH/WCMC is one of eight CAH Comprehensive Care Centers in the United States. Study assessments were completed over seven months from May 2021 to December 2021. Child and caregiver participants were excluded if unable to read English and if child participants had another chronic illness (diabetes or nephropathy) or malignancy

A total of 116 participants (60 children and 56 caregivers) completed questionnaires on anxiety and depression symptoms. Two caregivers completed separate proxy forms as they had two children with CAH. One caregiver did not complete proxy forms for their two children with CAH.

Data Collection

Written consent was obtained from caregivers and written assent from child participants. All caregivers completed a demographic questionnaire. One-time questionnaires were completed at a single routine clinic visit. Children completed questionnaires privately, and all children ages 7-11 years were offered help in reading and clarifying questions. Intelligence levels were not separately measured in child participants but all children, to the best of our knowledge, were in his or her appropriate grade level, on discussion with the caregivers. Children were told that if there were concerns of harm to self or others, confidentiality would be broken and parents and appropriate individuals would be notified.

Measures

Children completed age-appropriate questionnaires on anxiety and depression. All caregivers completed an associated proxy questionnaire.

Upon completion, child questionnaires were scored immediately. Higher scores indicated a greater number of symptoms of anxiety or depression. A risk assessment flowsheet, including need for emergency

Screen for Child Anxiety Related Disorders (SCARED) (13): A 41-item self-report screening for anxiety disorders and validated for ages 8-18 years, which takes approximately 10 minutes to complete. It includes five subscales: panic disorder or significant somatic symptoms, generalized anxiety disorder, separate anxiety disorder, social anxiety disorder and significant school avoidance. A total score of ≥25 (“at-risk”) may indicate the presence of an anxiety disorder.

Patient Health Questionnaire modified for Adolescents (PHQ-A) (14): A 9-item measure assessing for symptoms of depressive disorders, validated for ages 11-17, which takes approximately two minutes to complete. A total score of ≥10 (“at-risk”) has good sensitivity for major depressive disorder. Suicide risk is screened with Yes/No questions.

Caregivers were given proxy forms of all the child questionnaires.

Pre-pandemic General Population Normative Data: The data was

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used and available for the SCARED (13) and CDI-2 (12).

SCARED Normative Data: Participants included 635 healthy young people (7 to 18 years old) and parent dyads and questionnaires were completed before 2019.

CDI-2 Normative Data: Participants included up to 1,100 healthy young people (7 to 17 years old) and parent dyads. Data based on participant age and gender were available.

PHQ-A normative data was also available but our study's sample size was insufficient to draw meaningful conclusions.

Adrenal Control

Adrenal control was based on 17-OHP values obtained over the prior 12-month period. Levels were drawn 1-2 hours after a morning hydrocortisone dose (normal practice at this center). Adrenal control was determined if participants had at least four 17-OHP levels in the prior twelve-month period. "Good" control was defined as 17-OHP <1.000 ng/ dL greater than or equal to 75% of the time, "moderate" if 17-OHP <1.000 ng/dL more than 25% and less than 75% of the time, and "poor" if 17-OHP <1.000 ng/dL less than or equal to 25% of the time."

Statistical Analysis

Descriptive statistics were used to describe the cohort of patients using n (%) and mean, standard deviation, median, interquartile range for categorical and continuous factors. Chi-square test or Fisher's exact test was used to compare the proportion of "at-risk" individuals between CAH and HT children. Wilcoxon rank sum test was used to compare raw scores from each questionnaire (SCARED, CDI-2, and PHQ-A) between children with CAH and HT, as well as their caregivers. Kruskal-Wallis test was used to compare raw scores of each questionnaire across different disease classifications (CAH: salt-wasting, simple virilizing, non-classical) or adrenal control (poor, fair, good). When comparing the general population to our cohort of CAH and HT children, a t-test was used. Linear mixed modelling was used to determine difference in scores on the questionnaires between children and caregivers.

All p-values were two-sided with statistical significance evaluated at the 0.05 alpha level. Ninety-five percent confidence intervals for all parameter estimates of interest were calculated to assess the precision of the obtained estimates. All analyses were performed in R version 4.0.5 (R Foundation for Statistical Computing, Vienna, Austria).

For analyses pertaining to adrenal control, patients included had four 17-OHP completed at NYPH/WCMC. Patients who completed 17-OHP levels at a different hospital were removed.

Results

Baseline Characteristics

Baseline characteristics are summarized in Table 1. Sixty children, ages 7-17 years, completed an anxiety and/or depression questionnaire based on age eligibility. Fifty-eight parent participants completed an anxiety and/or depression proxy questionnaire (Table 2).

Participant Anxiety

Of the children who completed the SCARED (CAH n=30, HT n=25), there was no difference in total scores between the CAH and HT groups (p=0.2). Similarly, there was no difference in at-risk scores between the CAH and HT groups (p=0.4), scoring "at risk" in 33% and 44%, respectively. Seven children in each group had a history of anxiety based on caregiver report, and the difference in social anxiety scores was not significant (p=0.6). There was no difference in scores among the other subscale categories.

Table 1. Child participant characteristics

Child characteristic	CAH (n = 34)	Hypothyroidism (n = 26)
Disease classification, n (%)	Classical: 23 (68) Non-classical: 11 (32)	Congenital: 7 (27) Autoimmune: 19 (73)
Sex, %		
Male	32	27
Female	68	73
Mean ± SD age at assessment, years (SD)	11.41 ± 2.54	12.68 ± 2.91)
Median age at diagnosis, years (IQR)	0.04 (0.00, 7.16)	6.9 (0.4, 11.9)
Mean ± SD duration of condition, years	8.48 ± 4.12	5.99 ± 4.21
Race/ethnicity, %		
Non-hispanic white	67.6	53.8
Hispanic	14.7	23.1
Asian	8.8	15.4
Multiracial	2.9	3.8
Other	5.9	3.8
Insurance type, %		
Private	79	96
Public	21	4
Family income, %		
<$100,000	26.5	19
≥$100,000	58.8	73
Declined	8.8	8
Unknown	5.9	0
Reported prior history of anxiety or depression, n (%)	7 (22)	5 (19)

SD: standard deviation, IQR: interquartile range, CAH: congenital adrenal hyperplasia

Participant Depression

Sixty children completed the CDI-2 (CAH n=36, HT n=26) and there was no difference in total T-scores (p=0.4) or at-risk scores (p=0.5). Caregivers identified three children with CAH and two children with HT as having a history of depression; there was no difference in total T-scores in this subset (p>0.9). Twenty-nine children completed the PHQ-A (CAH n=13, HT n=16). Children in the CAH group were found to have lower mean total scores than the HT group (p=0.038) but had no difference in at-risk scores (p=0.4). Of note, 87.5% (14 of 16) children in the HT group had a history of autoimmune HT. One child was found to have suicidal ideation in the HT group.

Table 2. Parent participant characteristics

Parent characteristic	CAH (n = 32)	Hypothyroidism (n = 26)
Sex, %		
Male	19	23
Female	81	77
Mean age at assessment, years (SD)	45 (6)	47 (6)
Highest level of education, n (%)		
High school or less	5 (16)	1 (3)
Associate or bachelor	16 (50)	10 (39)
Master/professional	11 (34)	15 (58)
Marital status, n (%)		
Divorced/separated/widowed	4 (13)	1 (4)
Married	27 (84)	21 (81)
Single	1 (3)	4 (15)
Reported prior history of anxiety or depression, n (%)	15 (47)	9 (35)

SD: standard deviation, CAH: congenital adrenal hyperplasia

Child versus Caregiver Proxy Scores

As seen in Figure 1 [next page], differences were noted between child and caregiver scores on all questionnaires. After evaluating SCARED mean total scores, both the CAH (p<0.001) and HT (p<0.001) groups showed that children reported a greater number of anxiety symptoms than reported by their respective caregivers. Similarly, children in both groups reported a greater number of depression symptoms than reported by their respective caregivers (CAH p=0.002 and HT p<0.001). With PHQ-A scores, there was no significant difference in scores between children with CAH and their caregivers (p=0.300). However, children with HT reported a greater number of depression symptoms than their caregivers reported (p=0.005). After controlling for age, a difference remained between children and caregivers in both their SCARED and CDI-2 scores (p<0.001).

Figure 1. Child and parent scores on the CDI-2, SCARED, and PHQ-A
CAH: congenital adrenal hyperplasia, CDI-2: Children's Depression Inventory 2 Self Report-Short, SCARED: Screen for Child Anxiety Related Disorders, PHQ-A:

Adrenal Control and Mental Health

Adrenal control was determined in a subset of 23 children as only 23 children had at least four 17-OHP levels in the prior 12-month period. Table 3 includes the number of participants deemed to be in good, fair or poor adrenal control. There was no difference in adrenal control between the salt-wasting, simple virilizing and non-classical CAH groups (p=0.11). Moreover, there was no difference in adrenal control when comparing classical (salt-wasting and simple virilizing)

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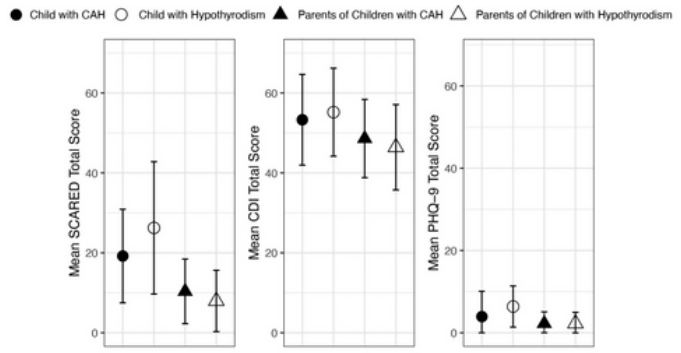
Patient Health Questionnaire modified for Adolescents



and non-classical CAH groups (p=0.2). Seventy-eight percent of participants were considered to have fair or good control (22% poor, 43% fair, 35% good).

For children with CAH who scored as at-risk on the SCARED and CDI-2, there was no difference in adrenal control (p>0.999). Of children who scored at-risk on the SCARED (n=10) and had available 17-OHP levels (n=7), 86% (6 of 7) had 17-OHP levels that were considered fair or good. Similarly, 86% (6 of 7) of those who scored at risk on the CDI-2 had 17-OHP levels that were considered fair or good. Adequate analysis for the PHQ-A would have been unreliable due to small sample size so was not performed.

Our results, albeit in a small sample, suggest that children with CAH have no difference in the number of anxiety symptom scores comparing those aged 7-11 years with 12-17 years (p=0.500), illustrated in Table 4. Interestingly, there was a difference in the depression symptom scores comparing the same age groupings, with the 7-11 year group having higher CDI-2 scores (p=0.016). The HT group showed no difference in scores with regards to anxiety and depression symptoms between the two age groups (p=0.300).

COVID-19 Pandemic Comparisons

Anxiety

As seen in Table 5, when the CAH and HT groups were separately compared to the pre-pandemic general population, both the CAH and HT groups had significantly higher anxiety symptom scores (p=0.0051 and p=0.0004, respectively).

Depression-Gender

With regards to depression based on the CDI-2, CAH boys were found to have lower depression scores compared to both HT boys and pre-pandemic population boys (p=0.026 and p=0.031, respectively). There was no difference in scores between HT boys and pre-pandemic population boys (p=0.31). CAH and HT girls had higher depression scores compared to pre-pandemic population girls (p=0.02 and p=0.04, respectively). There was no difference in scores between CAH and HT girls (p=0.5).

Table 3. Adrenal control among CAH child participants

	Adrenal control		
	Poor (25% or less), n = 5[1]	Fair (25 to 74.99%), n = 9[1]	Good (75% or more), n = 8[1]
CAH diagnosis			
Simple-wasting	2 (40)	7 (78)	4 (50)
Simple virilizing	2 (40)	1 (11)	0 (0)
Non-classical	1 (20)	1 (11)	4 (50)
Prior genitoplasty			
No	0 (0)	2 (33)	1 (33)
Yes	1 (50)	4 (67)	2 (67)
Pending	1 (50)	0 (0)	0 (0)
Unknown	3	3	5

[1]n (%).
CAH: congenital adrenal hyperplasia

Depression Age

There was no significant difference in depression scores with regards to age (7-12 years and 13-17 years groups) between the CAH and HT groups (7-12y p>0.9 and 13-17y p=0.140). There was no difference in scores with regards to the same age groups between the CAH and pre-pandemic general population (7-12y p=0.1 and 13-17y p=0.98) and between the HT and pre-pandemic general population (7- 12y p=0.16 and 13-17y p=0.09).

Table 4. Median scores in CDI-2 and SCARED comparing younger and older age groups

Characteristic	7-11 years, n = 21[1]	12-17 years, n = 13[1]	p value[2]
CDI-2 total score			
CAH	52 (48, 60)	44 (43, 50)	**0.016**
HT	48 (45, 59)	55 (48, 65)	0.400
SCARED total score			
CAH	22 (15, 29)	11 (7, 28)	0.500
HT	17 (14, 29)	25 (15, 40)	0.300

[1]Median (IQR).
[2]Wilcoxon rank sum test.
CAH: congenital adrenal hyperplasia, HT: hypothyroidism, CDI-2: Children's Depression Inventory 2 Self Report-Short, SCARED: Screen for Child Anxiety Related Disorders

Table 5. General child population vs. child participant scores

Mean total calculated scores (SD)	CAH	HT	General	p
SCARED[1]	19.2 (11.71)	26.24 (16.57)	12.65 (9.37)	CAH vs. HT p = 0.2 CAH vs. Gen **p = 0.0051** HT vs. Gen **p = 0.0004**
CDI-2				
Age[2]				
7-12 years	3.8 (3)	4.17 (3.33)	2.7 (2.82)	CAH vs. HT p = 0.8 CAH vs. Gen p = 0.0977 HT vs. Gen p = 0.1567
13-17 years	5.44 (3.97)	5.71 (4.48)	3.48 (3.42)	CAH vs. HT p = 0.14 CAH vs. Gen p = 0.976 HT vs. Gen p = 0.0866
Gender[3]				
Female	4.78 (3.18)	5.32 (4.36)	3.09 (3.36)	CAH vs. HT p > 0.900 CAH vs. Gen **p = 0.02** HT vs. Gen **p = 0.04**
Male	1.45 (1.97)	4.14 (2.85)	2.95 (2.99)	CAH vs. HT **p = 0.035** CAH vs. Gen **p = 0.0313** HT vs. Gen p = 0.3137

[1]CAH n = 30, HT n = 25, General population n = 635.
[2]7-12 years: CAH n = 25, HT n = 12, General population n = 600; 13-17 years: CAH n = 9, HT n = 14, General population n = 500.
[3]Female: CAH n = 23, HT n = 19, General population n = 524; Male: CAH n = 11, HT n = 7, General population n = 522.
SD: standard deviation, CAH: congenital adrenal hyperplasia, HT: hypothyroidism, CDI-2: Children's Depression Inventory 2 Self Report-Short, SCARED: Screen for Child Anxiety Related Disorders

Discussion

Current standard of care guidelines for CAH management recommend that individuals undergo mental health evaluations given the psychological and physical stressors that may surround a diagnosis of CAH (10). Contributing factors towards this recommendation include CAH being a chronic disease, risk of severe electrolyte imbalance, presence of genital atypia, signs of hyperandrogenism and caregiver distress. Our findings demonstrate that children and adolescents with CAH do not have a greater degree of anxiety or depression symptoms as compared to controls unaffected by CAH. These results challenge the notion that individuals with CAH, especially children and adolescents, may be at higher risk for having mental health concerns, specifically anxiety and depression. Findings from earlier CAH studies that included children with CAH have reported varying conclusions with regards to mental health.

A large, Swedish retrospective cohort study of women and girls with CAH (7) identified girls less than 12 years of age as having an increased risk of a psychotic disorder (p<0.05) but this conclusion was limited by low statistical power. Risk of any psychiatric disorder, including anxiety, increased in those greater than or equal to 18 years of age. The authors note that the odds of having a psychiatric disorder was higher in those born before 1986, which was the year in which newborn screening for CAH was just introduced. Children who participated in our study were diagnosed with CAH after the advent of CAH newborn screening in the United States, which may have allowed for more prompt recognition of classical CAH and initiation of hormone treatment, lessening the continued exposure to elevated androgens that has been associated with increased rates of psychopathology (8).

Mueller et al. (8) conducted a prospective cohort study from 2002-2009 to characterize psychiatric morbidity in children (ages 8-18 years) with genetic etiologies of hyperandrogenism, including classical CAH. Their results revealed that 19% of females and 21% of males with classical CAH had anxiety disorders. Major depression was within the

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category of "mood disorder" and was evident in 0% of CAH females and 3% of CAH males. A limitation of this study was its lack of a control group, as the authors argued a healthy control group could not control for both the experiences of a chronic medical condition and genetic contributions to a psychiatric disorder. Our study selected children with HT as control participants. HT is a chronic condition that has a similar bi-modal age of diagnosis distribution as CAH. Pediatric HT management involves chronic medical therapy but neither has the additional concerns for serious illness and hospitalization nor the physical stigmata related to hyperandrogenism. Our data suggest there was no difference in at-risk anxiety and depression symptom scores between children with CAH and HT. Among those with classical CAH, at-risk scores for anxiety and depression symptoms were 26% (5 of 19) and 22% (5 of 23), respectively. Additionally, parents of children were asked to self-report their own history of anxiety and depression. In children with CAH who scored at-risk for anxiety, 38% (3 of 8) of parent participants also had a history of anxiety and 57% (4 of 7) of depression. Similarly, of children with HT who scored at-risk for anxiety, 45% (5 of 11) of parents also had a history of anxiety and 12% (1 of 8) of depression. We therefore did not find a statistical difference between the parents of children with CAH and HT. Previous studies have suggested that carriers of CAH may have psychological vulnerability to stress (15,16). None of our parent participants were carriers of CAH. If there were parent participants found to be carriers, it would be difficult to determine whether it is the carrier status itself or the responsibility of caring for a child with CAH that may cause the vulnerability to stress.

Our findings agree with a recent retrospective review of behavioral health diagnoses from a large pediatric database (PEDSnet) that abstracted at least one outpatient visit from 2009-2019 (CAH n=1647, controls n=6588). Their results found that children with CAH, when compared to controls, did not have a statistically significant increase in anxiety or depressive disorder diagnoses (9). The authors argue that there may be a higher risk of developing and diagnosing mental health disorders during adolescence. Our results, although from a small sample, suggest that children with CAH have no difference in the number of anxiety symptoms between 7-11 years and 12-17 years. However, there was a difference with regards to depression symptoms with the 7-11 year-old group having higher CDI-2 scores. The HT group showed no difference in anxiety and depression symptom scores between the two age groups. Younger age at CAH diagnosis and a diagnosis of classical CAH may have contributed to the younger age group having higher CDI□2 scores. In our cohort, the median age at CAH diagnosis was 0.00 years versus 2.25 years between the 7-11 and 12- 17 year old age groups, respectively. A larger percentage of the younger age group compared to the older age group had classical CAH (71% vs. 61.5%). Children with classical CAH, as compared to non-classical CAH, have a younger age at diagnosis, higher rate of genital atypia and may have a more significant concern for adrenal crisis given the greater degree of enzyme deficiency. Larger studies could help investigate and further delineate these possible contributing factors. Of note, prior studies have shown that individuals with classical CAH may also have decreased adrenomedullary function that can potentially affect their ability to cope with psychological stressors (17,18). Our data did not assess adrenomedullary function in our patients to challenge this conclusion.

In adult men with CAH, Falhammar et al. (11) found that the risk of psychiatric morbidity increased in men born before the introduction of CAH newborn screening, possibly due to prolonged androgen exposure. Elevated androgens are thought to play a role in behavior in children with CAH (8,19). However, associations with anxiety and depression have not been as clear. Our study is one of the first to examine whether a child's degree of adrenal control correlates with anxiety or depression. Eighty percent were found to be in fair or good control. Though we acknowledge that the sample size for this sub-analysis was very small, there was no significant increase in anxiety or depression symptom scores in those with poor control.

In March 2020, the COVID-19 pandemic was at its peak. Our study recruitment began approximately one year after this time, in May 2021, and continued until December 2021. During this recruitment period, several studies reported increased rates of anxiety and depression in the pediatric population (20,21,22). Given the influence of the pandemic on mental health, it was important for our study to include a control group of children since they, too, similarly experienced the potential mental health consequences of the pandemic. Our study participants, both CAH and HT controls, had overall higher anxiety symptom scores compared to the pre-pandemic pediatric population. With regards to depression, girls from both the CAH and control groups, had higher depression symptom scores when compared to the pre-pandemic population; this finding is similar to what has been found in recent studies (21,22).

Interestingly, boys with CAH were found to have lower depression symptoms scores compared to both HT controls and the pre-pandemic population, although as our sample size was small, it is difficult to deduce reasons for this.

It is important to note that child scores for anxiety and depression (CDI-2) were higher than reported by parents in both CAH and HT groups. Internalizing symptoms include feelings of anxiety, loneliness and sadness (23). Angold et al. (24) found that by late adolescence, at least 20% of females and 7% of males exhibit internalizing symptoms. Children also often report internalizing symptoms at higher rates than their parents consider (25). Our results suggest that children with CAH may benefit from routine mental health evaluations, regardless of voiced caregiver concern, given the lack of agreement between child and parent proxy responses.

A few theories emerged as to why our cohort of children with CAH were not found to have an increased predominance of anxiety or depression symptoms when compared to HT controls. Our institution is considered a Center for Excellence in CAH, the first of eight designated centers by CARES Foundation. It was our experience after engaging with children and their families during visits that parents expressed a confidence in the care provided to their children. Patients are seen by a pediatric endocrinologist with extensive experience with CAH treatment and management. They are expected to follow up every three months in order to allow for careful dose adjustments that help optimize growth and development. As previously mentioned, nearly half of our CAH participants were found to be in good adrenal control. Androgens play a role in human behavior (26) and elevated androgens have been associated with an increase in severe behavioral symptoms in girls with CAH (27). In our cohort of females with classical CAH, 69% (n=11) underwent genitoplasty and 6% (n=1) were planning to undergo later in the year. Prior studies have suggested that adults with an XX karyotype and classical CAH supported genitoplasty within the first year of life (28). Whether completion and timing of genitoplasty is truly correlated with mental health outcomes is not clear, as no long-term observational studies have been completed. Our results show that 67% (6 out of 9) of children with a history of genitoplasty did not score at□risk for anxiety and 73% (8 out of 11) did not score at-risk for depression.

Study Limitations

There were several limitations with our study. Our study recruitment was at a single institution and completed over a seven-month period. As CAH is a rare condition with an incidence of approximately 1:14,000 to 1:18,000 births (10), the sample size of a single institution obtained during this time period was fairly significant. However, expanding the study to include multiple institutions over a longer study interval would potentially change or strengthen our findings. Moreover, our study highlights the pediatric CAH population at a

(Continued from Pg. 6)

center of excellence in which children are given specific expert care, and we recognize that the study results may not be generalizable. Therefore, it would be valuable to expand the study to patients who are both at centers of excellence and not at centers of excellence. Our study used validated mental health questionnaires that were free (SCARED, PHQ-A) or low-cost (CDI-2), and of a short time-commitment. The main limitation of these questionnaires was that these are self-report measures, which may introduce bias compared to an independent evaluator. However, these questionnaires are the most commonly used research self-report measures for youth depression and anxiety, as well as the most frequently used screening tools in pediatric clinical practice. Though the questionnaires used were reliable general screeners for anxiety and depression, they were not specific to CAH-related concerns. A questionnaire including topics on gender identity, genital surgery and body image may provide a more comprehensive view and insight into anxiety and depression symptoms in the CAH population. This study included parent participants with a history of anxiety and/or depression. As children may have a genetic predisposition to anxiety and depression (29), our study is limited by the absence of exclusion of these few parent participants who reported such history. Our study included participants with both classical and non-classical CAH. There have been reports regarding anxiety in adults with non-classical CAH that has suggested that having non-classical CAH may contribute to anxiety (30) and that females with non-classic CAH can have higher anxiety scores as compared to age and sex-matched controls (31). However, we acknowledge that those with non-classical CAH versus classical CAH may have different degrees of mental health concerns. Additionally, elevated 17-OHP levels were used as a biochemical marker for anxiety in our study but elevated dehydroepiandrosterone sulfate and pregnenolone sulfate levels may also have an effect on anxiety (30). With regards to our control group, the majority of HT participants did not have congenital HT so comparisons between those with classical CAH were affected by sample size. We recognize there was a female predominance in our sample. Therefore, our results cannot necessarily be extrapolated to males. Lastly, this study was completed one year after the start of the COVID-19 pandemic, a time during which there was evidence of increasing rates of anxiety and depression among youth. We attempted to control for the overall increase in mental health concerns by the inclusion of the HT control group. Although our findings on anxiety and depression were similar to what had been found in the general youth population during this time, it would be important to replicate this study several years removed from the pandemic to ascertain whether the increased mental health concerns were related to the pandemic or are inherent to the HT population.

Conclusion

Our study suggests that children with CAH do not have a greater degree of anxiety or depression symptoms compared to controls with HT, despite having more unique risk factors for increased psychiatric morbidity. Expertise in care, frequent patient follow-up and good adrenal control may have played a role in alleviating anxiety and depression symptoms. Our study also illustrates the ease and benefit of mental health questionnaire administration at routine visits, especially as mental health evaluations by trained providers are currently difficult to obtain due to resource availability, scheduling difficulties and insurance barriers. Moreover, such screenings at routine visits can highlight any differences in patient-caregiver perspective with regards to internalizing symptoms of anxiety and depression. Future multicenter studies that are several years removed from the COVID-19 pandemic will better aid in the understanding of mental health in children with CAH and whether further measures should be considered in optimizing CAH care.

Acknowledgements

The authors would like to thank the Comprehensive Care Center for Congenital Adrenal Hyperplasia at Weill Cornell Medicine for its support of this patient database and manuscript.

Ethics

Ethics Committee Approval: This study was approved by the Weill Cornell Medicine Institutional Review Board, approval #20-04021748, date: 22.02.2022.

Informed Consent: Written consent was obtained from caregivers and written assent from child participants.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: Corinne Catarozoli, Karen Lin-Su, Marianne Jacob, Oksana Lekarev, Design: Karen Lin-Su, Marianne Jacob, Oksana Lekarev, Data Collection or Processing: Charlene Thomas, Karen Lin-Su, Marianne Jacob, Oksana Lekarev, Analysis or Interpretation: Charlene Thomas, Karen Lin-Su, Marianne Jacob, Oksana Lekarev, Dix Poppas, Literature

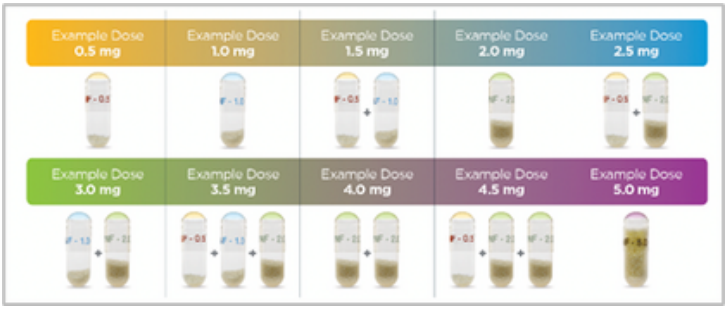
Search: Karen Lin-Su, Marianne Jacob, Oksana Lekarev, Dix Poppas, Writing: Corinne Catarozoli, Charlene Thomas, Karen Lin-Su, Marianne Jacob, Oksana Lekarev.

Financial Disclosure: The authors acknowledge the support from the Weill Cornell Medicine Department of Pediatrics Fellowship Research Grant towards subject participation.

References

https://caresfoundation.org/wp-content/uploads/2024/03/Scientific-Article-References-NL-26.pdf

(Continued from Pg. 7)



WHY ALKINDI SPRINKLE?

Accuracy is critical when managing pediatric adrenal insufficiency because treatment has a narrow therapeutic dosing window.2 Treating children outside this window can result in poor health outcomes beyond youth and into adulthood. 3-6

Remember to always give ALKINDI SPRINKLE exactly as prescribed by your doctor.

Eton Cares: Comprehensive and personalized support that puts patients first.

Insurance Specialists
Ensure you understand your benefits and help your doctor's office verify and obtain prior authorization and insurance coverage.

Pharmacists
Provide 24/7 support by phone, monthly worry-free refill reminders, and shipment alerts.

Nurse Ambassadors
Provide regular check-ins, answer questions about your child's health and medication, and support you through treatment.

Medication for as little as $0 per month*

Prescriptions for ALKINDI SPRINKLE must be submitted to Anovo® Specialty Pharmacy.

- 97% of ALKINDI SPRINKLE prescriptions are successfully onboarded and approved†
- QuickStart Program provides medication as quickly as 24 hours during prior authorization‡

For more information, visit https://www.alkindisprinkle.com/support/ to learn more.

*Restrictions, limitations, and/or eligibility requirements apply.

†Anovo will work with the doctor to obtain insurance coverage. If insurance is denied, the patient may apply to the Patient Assistance Program.
‡For newborns awaiting hospital discharge, medication may be delivered in as soon as 24 hours. Typical delivery is 3 to 7 days.

USE AND IMPORTANT SAFETY INFORMATION

USE

ALKINDI SPRINKLE is a prescription medicine used in children from birth to less than 17 years old as replacement therapy when the adrenal gland is not making enough cortisol.

IMPORTANT SAFETY INFORMATION

Always give ALKINDI SPRINKLE exactly as your doctor has directed.

Do not take ALKINDI SPRINKLE 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 ALKINDI SPRINKLE, watch your child closely for any changes. If your child doesn't get the entire dose of ALKINDI SPRINKLE because of vomiting or spitting some granules out, contact your doctor to see if another dose is needed.

Infections: all infections should be treated seriously, and stress dosing of hydrocortisone should be started early. Taking ALKINDI SPRINKLE should not stop your child from being vaccinated but let your healthcare provider know prior to vaccination.

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.

Changes in Vision: tell your doctor if your child has blurred vision or other vision problems during treatment with ALKINDI SPRINKLE.

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.

Gastrointestinal 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 ALKINDI SPRINKLE include retaining fluids, changes in glucose tolerance, high blood pressure, behavioral and mood changes, greater appetite, and weight gain.

Please visit ALKINDISPRINKLE.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.

References
https://caresfoundation.org/wp-content/uploads/2024/03/Eton-References.pdf

Preventing Adrenal Crisis Events **AVAILABLE IN SPANISH SOON!!!**

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.

Email support@caresfoundation.org for the Access Code

(Apple App Store Only) https://apps.apple.com/us/app/pace-by-chaicore/id1490431010

(Android App Store Only) https://play.google.com/store/apps/details?id=com.jafproductions.PACEAndroidNew&pcampaignid=web_share

eTon PHARMACEUTICALS NEUROCRINE BIOSCIENCES Walmart

Please join us for...

Sony Pictures Studios | April 27, 2024

Please use the link below to visit this year's gala website to view more information on our honorees, the venue, and our silent & live auction items. Here you can also find out more information on how to purchase tickets, sponsorships, online e-journal ads, and underwriting opportunities. (Scan the QR Code to be taken directly to the gala website)

Our Honorees

Alexandra Dubois, Visionary Award
Dr. Patricia Y. Fechner, Pioneer Award
Adrenas Therapeutics, Corporate Partner Award

Visit our Gala Website: https://caresfoundation.org/16th-annual-everyone-cares-gala/

2024 CAH Awareness Walks

Register for a walk near you!

Find all walks at: https://caresfoundation.org/2024-cah-awareness-walks/

1st Annual
Iowa CAH Awareness 5k
Des Moines Water Works - Des Moines, Iowa
May 18, 2024

REGISTER

CHECK-IN: 9:00AM | 5K BEGINS: 10:00AM
https://caresfoundation.org/desmoinescah5k/

SCAN

2nd Annual
Washington CAH Awareness Walk
Magnuson Park - Seattle, Washington
June 1, 2024

REGISTER

CHECK-IN: 10:30AM | WALK BEGINS: 11:00AM
https://caresfoundation.org/2nd-annual-washington-cah-awareness-walk/

SCAN

4th Annual
Ohio CAH Awareness Walk
Highbanks Metro Park - Lewis Center, Ohio
September 14, 2024

REGISTER

CHECK-IN: 9:00AM | WALK BEGINS: 10:00AM
https://caresfoundation.org/4th-annual-ohio-cah-awareness-walk/

SCAN

If you are interested in hosting a walk in your area in 2024, please contact dina@caresfoundation.org for more information.

Please consider your participation...

Tuesday, October 1, 2024
Patient-Focused Drug Development Meeting

CARES Foundation will be virtually hosting an Externally-Led Patient-Focused Drug Development Meeting on October 1, 2024. Please consider joining us in making a difference in the lives of those with CAH through this incredibly crucial meeting!

What is Patient-Focused Drug Development?

Patient-Focused Drug Development (PFDD) is a systematic approach to help ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.

Audience

We encourage all who are interested to participate. This meeting is intended for anyone with a connection to Congenital Adrenal Hyperplasia (CAH).

The key participants in PFDD meetings are patients, patient representatives, patient advocates, caregivers, loved ones, and anyone with a lived experience with the disease or condition. While patients and caregivers share their perspectives, key stakeholders are in listening mode as part of the audience. These stakeholders may include:

- FDA and other regulatory/federal agencies
- Medical product developers
- Academic researchers
- Clinicians and healthcare professionals

Panelists

We are looking for panelists to participate in this meeting that are interested in discussing their life with CAH, as well as current/future treatments.

How can I participate?

To learn more about how you can participate in this meeting, please contact pfdd@caresfoundation.org.

For more information on the upcoming PFDD Meeting, please visit: https://caresfoundation.org/externally-led-patient-focused-drug-development-el-pfdd/

SAVE THE DATES

September 20, 2024

2024 Patient Advisory Summit

New Brunswick, NJ

CARES is seeking participants for an advisory board to be held concurrent with the *2024 CAH Patient Education Conference in New Brunswick, NJ*. The purpose of the advisory board is for representatives from the pharmaceutical industry to listen to patient/caregiver insights on living with and managing CAH. This group is eager to learn more about CAH from this community to inform their product development activities. All pharmaceutical companies involved, have CAH treatments/therapies in development.

Specifically, we are looking for participants who meet the following criteria:

- Parents/Caregivers of age groups; Adults; Confirmed diagnosis of Classic CAH/caretaker for an individual with Classic CAH (patient can be younger than 18); Not currently participating in a CAH clinical trial; Must physically attend all days of the CAH Patient Journey Advisory Summit and Patient Education Conference; U.S. resident; Willing to share experience of living with Classic CAH/caring for someone living with Classic CAH; A current member of the CARES community (free to join: www.caresfoundation.org/join-the-cares-community)

If you are interested in participating in this event, please contact dina@caresfoundation.org.

September 21 & 22, 2024

2024 Patient Education Conference

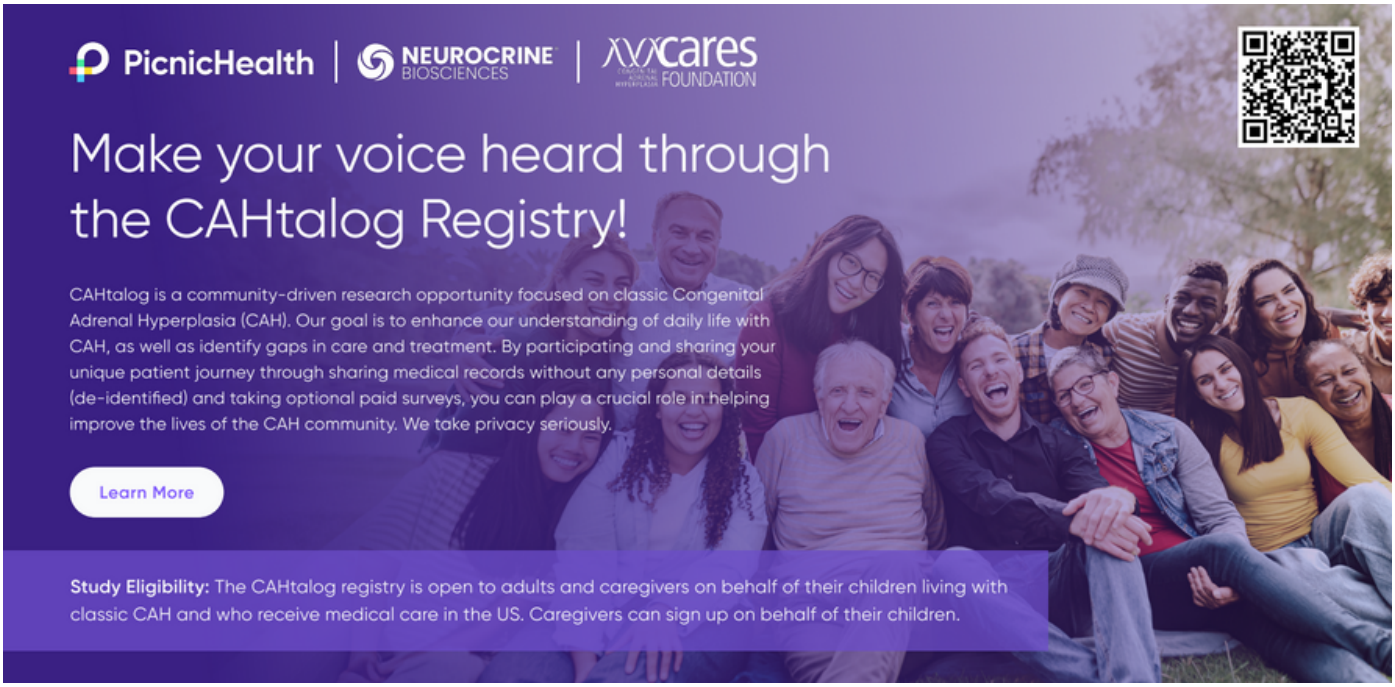
Robert Wood Johnson University Hospital, New Brunswick, NJ

Mark your calendars for the 2024 Patient Education Conference presented by CARES Foundation & Rutgers Robert Wood Johnson Medical School/Rutgers Child Health Institute and take advantage of this incredible opportunity to connect with Medical Professionals, Industry Professionals, and other CAH Families.

Interested in learning more about specific topics?
Email odaly@caresfoundation.org to let us know what you would like to see covered at this year's conference!

Can I be notified when registration opens?
Email john@caresfoundation.org to be added to our mailing list for the 2024 Patient Education Conference.

LIMITED SCHOLARSHIPS AVAILABLE



What Is The CAHtalog Registry?

CARES Foundation, Neurocrine Biosciences and PicnicHealth have partnered to establish the CAHtalog™ registry. CAHtalog is a patient registry, or collection of clinical patient data, for patients living with classic CAH. Its mission is to advance CAH clinical research and in turn improve the quality of life for those living with classic CAH. Neurocrine and CARES Foundation are committed to sharing the de-identified data from CAHtalog with qualified researchers because it's in the patient community's best interest to advance CAH research as quickly as possible across the broader research community.

"The more CAH patients that register, the more data will be available for research. CAH has come a long way from my birth and that is all due to research and patients being willing to share their CAH journey."

Lesley

CAHtalog Registry Participant

How It Works

STEP 1

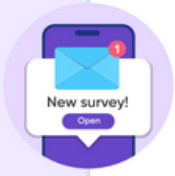
Tell Us About Your Care.

Just answer a few questions about yourself and the names of your primary care and endocrine doctors. With your consent, PicnicHealth will do all the hard work of collecting medical records from your clinicians on your behalf–including paper-based records, imaging, and doctors' notes.

STEP 2

Your Records At Your Fingertips.

PicnicHealth will organize and digitize all of your records from all healthcare systems you've visited in the last 5+ years in one secure, easy-to-use platform at no cost. The PicnicHealth team will continue to update your medical records for you on a regular basis. You can share your records securely with your trusted loved ones or other healthcare providers in real-time. This may especially help if you're facing a medical emergency in an out-of-area hospital that doesn't already have access to your medical records.



STEP 3

Earn Up To $150 A Year Completing Short Surveys At Home

When you join the registry, you will be invited to complete paid health and well-being surveys from your PicnicHealth account. These optional surveys help researchers understand your daily experiences and capture insights that may not be available in your medical records.

STEP 4

Help Researchers Further Their Understanding Of Classic CAH

We employ our proprietary technology to extract only the information valuable to researchers and replace personally identifiable information with randomized ID numbers. Your data is then assigned a unique code and combined with others to create a comprehensive data report, accessible to CAHtalog researchers via a secure portal.

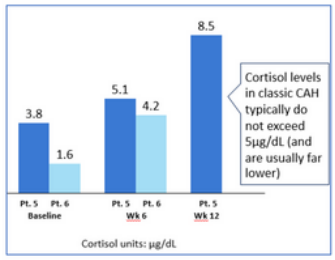
Adrenas
a bridgebio company

January 8, 2024

Dear CAH Community Members,

Adrenas Therapeutics, a BridgeBio company, appreciates your ongoing interest in our investigational gene therapy for adults with classic Congenital Adrenal Hyperplasia (CAH) due to 21-hydroxalyse deficiency. We are pleased to share an update on the phase 1/2 ADventure trial.

- Participants and Dose Levels: A total of seven participants have been dosed with Adrenas' investigational gene therapy, BBP-631: two participants at each of Dose Levels 1, 2, and 3. An additional Dose Level 4 has been added in response to encouraging emerging data. One participant has received Dose Level 4, with a second participant planned for early 2024.
- Observed Safety: The investigational gene therapy has been well tolerated by all participants. To date there has been a single serious adverse event at Dose Level 1 related to redness at the infusion site, which fully resolved and which was deemed by the treating physician to be unrelated to the gene therapy. No further skin reactions were observed in Dose Levels 2 through 4. Of course, more time and data from more participants are still needed to characterize the safety profile of BBP-631. Based on the detailed evaluation of each participant's safety data, as well the overall safety profile to date of BBP-631, an independent Data Safety Monitoring Committee (DSMC) approved each dose escalation through Dose Level 4. All participant data will continue to be evaluated at regular intervals by the DSMC.
- Potential Efficacy: Early data show robust changes in a direct precursor to the production of cortisol, 11-deoxycortisol, in those participants dosed at higher doses. The increase in 11-deoxycortisol reflects 21-hydroxylase activity and is translating into an early, steady increase in cortisol production. While more data are needed to explore the magnitude of cortisol production at higher doses of BBP-631 and also to fully characterize the durability of this effect, the current data represent the first demonstration of an investigational approach allowing people living with CAH to increase their own (endogenous) production of cortisol.



Adrenas' goal for the ADventure trial is to confirm the safety and potential efficacy of Adrenas' investigational gene therapy on adrenal-related hormones at a variety of dose levels, aiming to find an optimal dose level before advancing the program. While we are encouraged by this progress, Adrenas will continue to collect and closely review all data on the potential impact of BBP631 in people living with CAH. We will continue to update the community with our evolving understanding later in 2024.

Adrenas acknowledges the tremendous contributions of those participating in the ADventure trial, as well as the patient advocacy groups, clinical research sites and investigators, and the broader CAH community. We are grateful to all of you for your ongoing collaboration and support.

Sincerely,
The Adrenas Therapeutics Team

For information visit cahgenetherapy.com and https://clinicaltrials.gov/ct2/show/NCT04783181

The Pursuit of Life-Changing Science in Neuroendocrine Disorders

Neurocrine Biosciences co-founder, Wylie Vale, Ph.D.

Pursuing new treatments for neurological diseases and disorders requires a deep understanding of the biology of these complex conditions and an unwavering commitment to the lengthy drug development process. For more than three decades, Neurocrine Biosciences, Inc. has been dedicated to discovering and developing life-changing treatments for patients with debilitating neuroendocrine, neurological and neuropsychiatric disorders. Neurocrine's heritage in neuroendocrine disorders is even found in the company's name, a blending of the words neurologic and endocrine. An example of their dedication can be seen in the company's work in congenital adrenal hyperplasia (CAH).

Neurocrine's focus on neuroendocrine disorders, including CAH, began with co-founder Wylie Vale, Ph.D. Dr. Vale was a professor at The Salk Institute, a nonprofit scientific research organization, where he made contributions to Nobel Prize-winning work in endocrinology, specifically around the biology of CAH. Dr. Vale discovered and studied corticotropin-releasing factor (CRF), an important stress hormone that regulates the release of adrenocorticotropic hormone (ACTH) by the pituitary gland.

CRF, as Dr. Vale discovered, played a key part in the HPA axis (the stress response system consisting of the hypothalamus, pituitary gland and adrenal glands) which is disrupted in CAH. By uncovering the role of CRF in this key CAH pathway, Dr. Vale enabled researchers at Neurocrine to uncover how a genetic mutation that causes deficiency of the enzyme 21-hydroxylase (21-OHD) affects the production of adrenal hormones, such as cortisol and aldosterone. 21-OHD is now known to be the hallmark of the severe form of the condition.

Years of research have culminated in the study of crinecerfont, an investigational selective CRF1 receptor antagonist being studied by Neurocrine to help reduce and control excess adrenal androgens in patients with CAH due to 21-OHD.

Highlighting its ongoing commitment to neuroendocrinology, Neurocrine acquired Diurnal Ltd in 2022, a global pharmaceutical company focused on chronic endocrine conditions, combining the companies' expertise for the advancement of new therapies. Moreover, Diurnal's location in Cardiff, United Kingdom expands Neurocrine's global footprint, paving the way for Neurocrine to help more people with neuroendocrine disorders beyond the United States.

"We are proud to work closely with CARES Foundation on a variety of important initiatives that support the CAH community, such as coordination of the CAHtalog patient registry, planning for the Everyone CARES Gala and participation in the organization's Patient Advisory Summit to help inform our drug development programs," said Eiry W. Roberts, M.D., Chief Medical Officer at Neurocrine Biosciences. "We are truly inspired by those impacted by CAH. This inspiration fuels our commitment to meet the unique needs of the patients we serve."

You can learn more about Neurocrine's dedication to the pursuit of life-changing science at Neurocrine.com.

CAH PARTNER 2024

NEUROCRINE BIOSCIENCES

SOLUtion

SOLUtion was founded to solve the challenge of adrenal crisis. We have excitingly expanded upon our first solution, the TwistJECT™ autoinjector, and have added a second product to our product pipeline—our pre-filled syringe. With our broadened proprietary delivery device portfolio we aim to provide patients, caregivers, and clinicians convenient and easy to use options for use at home and in healthcare settings.

As our company continues to innovate and grow, we're always open to connecting with patients, advocates, and caregivers who share our vision for the future.

These products are hoped to be brought to market in the coming 2-3 years.

We invite folks to follow us online or reach out to hello@solutionmedco.com to learn more about our exciting projects and explore potential collaborations.

Noteworthy

Rare Disease Day

We would like to extend our heartfelt gratitude to everyone who shared their story and/or made a donation to CARES in recognition of Rare Disease Day in 2024. Your support has a crucial impact in helping to improve the lives of those living with CAH. Thank you to all who participated!

JUNE IS CAH Congenital Adrenal Hyperplasia AWARENESS MONTH

June is CAH Awareness Month!

Stay tuned to information on awareness activities via the CARES monthly updates and on our website.

Share your ideas with us.
john@caresfoundation.org.

CARES Foundation Endowment Fund

Leave a meaningful gift that will have an enduring impact on the CAH community!

We have created an endowment fund account at the Community Foundation of New Jersey to ensure the longevity of our organization. Please consider giving to it.

A bequest can be arranged in a variety of ways. It can take the form of cash, property, or a part of your estate's remaining value. Including the CARES Foundation Congenital Adrenal Hyperplasia Endowment Fund into your Will could be a beneficial component of your plans, lowering your taxable estate while achieving your philanthropic objectives.

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

For more information regarding this process or specific donations, please contact:

COMMUNITY FOUNDATION OF NEW JERSEY Phone: 973.267.5533 Toll-Free: 800.659.5533 Fax: 973.267.2903

Ways to Contribute

- **Name us in your Will or estate**
- **Real Estate**
- **Shares of appreciated stock**
- **IRA RMDs**
- **Cash**
- **Interest or Shares of Operating Business**

Thank you for considering CARES Foundation!

RAREis Scholarship Fund

Powered by the Everylife Foundation

APPLICATIONS OPEN FROM MARCH 18 - April 22, 2024
RARESCHOLARSHIP.ORG

CARES Foundation would like to take a moment to welcome the newest members of our Board of Trustees! Thank you to Charles and Jeffrey for your commitment to helping improve the lives of those living with Congenital Adrenal Hyperplasia.

Charles Jarmon

Charles has held crucial roles such as being the Chief Operating Officer (COO) at Murray Hill Medical Group (NY) and being the Administrative Director in the Department of Emergency Medicine and Department of Surgery at The Brooklyn Hospital Center (NY). Charles is currently an Adjunct Assistant Professor at Hofstra University in the School of Health Professions, and is also an active member of The National Disaster Medical System (NDMS), where he serves as a paramedic. Charles lives in New York with his family.

Jeffrey Purnell

Jeff values the CARES mission and is excited about contributing to the CARES community. After a 35-year career in hi-tech at Cisco, Hewlett-Packard, and 2 early-stage startups, Jeff is now an Executive Coach who helps leaders increase their leadership effectiveness, career success, and personal wellbeing. Jeff lives in the San Francisco Bay area with his wife and enjoys travel, hiking, and psycho-spiritual development. One his greatest joys is being a father and now a grandfather.

Education

CAH Pulse
NEW EPISODE OUT NOW!

Episode 5: Lindsey
I Wish I Had Known More When I Was 16, 15 even 14

In this impactful episode Lindsey opens up to Dina and Stephanie about many topics, including an overdue conversation that she wishes she had had 20 years ago, as well as a detailed account of her recent life-threatening adrenal crisis, a first on CAH Pulse.

"We can assume kids are gonna have questions; so create a relationship outside of CAH and the rest will follow". said the warm-hearted and outspoken young woman.

This episode, as well as all of our episodes for the CAH Pulse Podcast are available on all platforms! Please visit https://cahpulse.podbean.com/.

If you would like to have your story featured on a future episode, please reach out to dina@caresfoundation.org.

cares CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

A PERSONAL STORY

My name is Nancy. I have CAH. I was born in 1974. Luckily for me, I have an older sister who also has CAH. After her birth, my mom's subsequent pregnancies were tested for CAH. I was therefore diagnosed in utero, and my mom was treated with dexamethasone during her pregnancy with me. This spared me the need for urogenital surgery. I have lived a mostly-normal life, with just taking various corticosteroids daily. I participated in soccer, softball, basketball and badminton as a youth. I even went camping overnight away from home. And not the camping in cabins, either. The kind where you hike in and sleep in a tent and dig your own toilet. I went away from home for college and worked in veterinary medicine for 25 years as a licensed veterinary technician. Two years ago, my body got too tired to continue working in vet med, and I transitioned to working in a human pharmacy.

My husband and I adopted two sons from foster care and enjoy the adventure of being parents to two teenagers! I love to walk/run 5k and 10k races.

I am excited about the new treatments on the horizon for CAH, and am thankful to have found CARES Foundation.

Special thank you to Nancy for sharing your story!

THE DOCTOR IS IN

Dr. Karen Lin Su
CARES Medical Director

Sodium Content in Food

In addition to taking hydrocortisone and fludrocortisone, babies with salt-wasting CAH require extra sodium supplementation during infancy because breast milk, formula, and baby food have very little sodium. The usual daily supplemental requirement for infants with salt-wasting CAH is about 1000 to 2000 mg per day of sodium chloride (400 mg to 800 mg of sodium). It can be prescribed as a solution or as sodium chloride tablets to be dissolved in water. If neither of these forms is available, regular table salt can be used instead. One teaspoon of table salt contains 2300 mg of sodium.

Once they are eating regular table food, the sodium content is generally high enough that extra supplementation is no longer necessary, but it can be helpful to know approximately how much sodium is being consumed.

Depending on their blood pressure, older children and adults may also need to know how much sodium they are consuming.

Discuss with your physician how much sodium you or your child should aim for each day.

Requirements may be higher during extreme heat or during strenuous exercise.

Item	Portion	Sodium (mg)
Apple Juice	1 Cup	7mg
Club Soda	12 Fl. Oz.	75mg
Milk	1 Cup	124mg
Orange Juice	1 Cup	2mg
Soy Milk	1 Cup	29mg
Tomato Juice (with salt added)	1 Cup	877mg
Butter (salted)	1 Tbsp.	117mg
Butter (unsalted)	1 Tbsp.	2mg
Cheese, Cheddar	1 Oz.	176mg
Cheese, Feta	1 Oz.	316mg
Cheese, Parmesan, grated	1 Tbsp.	93mg
Cheese, Swiss	1 Oz.	74mg
Egg, whole	1 Medium	55mg
Yogurt, plain, low-fat	8 Oz.	159mg
Avocado	1 Oz.	3mg
Banana	1 Banana	1mg
Blueberries	1 Cup	9mg
Melon, Honeydew	1 Cup	17mg
Olives, ripe, canned	5 Large	192mg
Bagel, plain	3.5" Bagel	379mg
Bread, mixed-grain	1 Slice	127mg
Bread, whole-wheat	1 Slice	148mg
Croissant, butter	1 Crossaint	424mg
Noodles, Chinese, Chow-Mein	1 Cup	198mg
Pretzels (salted)	10 Pretzels	1029mg
Chickpeas, canned	1 Cup	718mg
Refried Beans, canned	1 Cup	753ng
Beef, ground, extra lean	3 Oz.	60mg
Beef, top sirloin	3 Oz.	56mg
Turkey, cooked/roasted	3 Oz.	66mg
Soy Sauce	1 Tbsp.	914mg
Pickles, Cucumber, Dill	1 Pickle	833mg
Ketchup	1 Tbsp.	178mg
Table Salt	1 Tsp.	2325mg

cares SUPPORT

Support Group Leaders

CARES support groups and private Facebook groups are available in a wide variety of demographics for any type of CAH patient or caregiver. Some groups meet for beneficial discussions that ultimately have the goal of providing necessary support in the areas you may need! Share your experience.

Leaders are also organized by topics like "Women", "Teens & Young Adults", "Parents of Newborns", "Parents of Teens & Young Adults", "Men", "LGBTQIA+", etc. We hope that you will take advantage of this program. We appreciate our leaders and know that they are there for you when you need extra support!

Support Group Meetings

These meetings are hosted on Zoom and there is always a CAH-expert medical professional 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 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/).

Please visit our support pages on our website to see if there is a leader in your area. https://caresfoundation.org/support/

Upcoming Support Group Meetings

April 11, 2024

SUPPORT GROUP MEETING* for Parents of CAH Children (Newborn-Age 5), 9:00PM(ET)

May 9, 2024

SUPPORT GROUP MEETING* for Parents of CAH Children (Newborn-Age 5), 9:00PM(ET)

May 14, 2024

SUPPORT GROUP MEETING* for CAH Women, 8:30PM(ET)

May 22, 2024

SUPPORT GROUP MEETING* for Parents of CAH Children (School-Aged/Teens/Young Adults), 8:30PM(ET)

June 13, 2024

SUPPORT GROUP MEETING* for Parents of CAH Children (Newborn-Age 5), 9:00PM(ET)

July 11, 2024

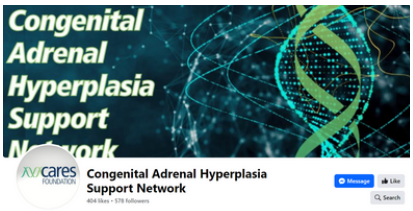
SUPPORT GROUP MEETING* for Parents of CAH Children (Newborn-Age 5), 9:00PM(ET)

September 12, 2024

SUPPORT GROUP MEETING* for Parents of CAH Children (Newborn-Age 5), 9:00PM(ET)

Please contact support@caresfoundation.org to confirm your attendance at any of the listed meetings! (More dates can be found on our Event Calendar)

Support can also be found on our Facebook page.



Here you will find several private groups where members share stories and experiences! Click the link below to be taken directly to our profile:

https://www.facebook.com/profile.php?id=100088886342973

Private Facebook Groups

(YOU MUST BE A MEMBER OF THE CARES COMMUNITY TO JOIN ANY PRIVATE FACEBOOK GROUPS) Join here: https://caresfoundation.org/join-the-cares-community/

If you would like to join any of the listed Private Facebook Groups that you see here, please visit Congenital Adrenal Hyperplasia Support Network on Facebook and request access to join a specific group/groups directly through our profile by selecting 'More' and then

'Groups'. (If you are on a mobile device, select 'About' then 'Groups').

- Teens with CAH
- Surgery
- Parents/Caregivers of Teens with CAH
- Grandparents of CAH Children
- Parents of Kids with NCAH
- Men with CAH
- 3 Beta Women
- Bereavement Support Group
- 11 Beta
- Parents of Kids with CAH
- LGBTQIA+
- CAH Women 50+
- CAH-X (CAH + EDS)
- Mexico CAH
- CAH Athletes
- Parents of Young Adults (Ages 25-35)
- Adoption & CAH
- Newborns
- Classic CAH Women
- CAH Partners/Spouses 17 Hydroxylase
- Parents and Caregivers of Girls with NCAH
- CARES Support Group Leaders
- Men & Dads with Sons with CAH

If you are having trouble, or have any questions, please reach out to: john@caresfoundation.org

We remind you not to give medical advice here. All medical questions should be addressed by a physician or other healthcare professional. We offer an Ask-the-Expert program on our website where you can email your questions/concerns to Drs. Su and Diaz. https://caresfoundation.org/ask-the-expert/

Thank you for your continued support!

If you are seeking expert CAH medical care, then plan a visit to one of 8 CARES-designated Comprehensive Care Centers for CAH. These are highly specialized care centers that offer care throughout a patient's life cycle.

Children's Health/UT Southwestern Medical Center
1935 Medical District Dr
Dallas, Texas 75235

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

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

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

For appointments contact: Janet Guerrero, Comprehensive Care Center Coordinator, 323-361-4630 janguerrero@chla.usc.edu

VISIT WEBSITE

Children's Hospital of Philadelphia/ Main Hospital
3401 Civic Center Blvd.
Philadelphia, PA 19104
Penn Med – Philadelphia, PA

For appointments, 215-590-3174
VISIT WEBSITE

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

VISIT WEBSITE

New York-Presbyterian/Weill Cornell Medical Center
525 E 68th St,
New York, NY 10065

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

VISIT WEBSITE

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

Comprehensive Care Center Coordinator – Heather Frady, RN - Email Heather Frady
(317) 412-1206
VISIT WEBSITE

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

For appointments: (206)987-0304 or toll free, (866)987-2000
VISIT WEBSITE

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

VISIT WEBSITE

VISIT OUR CENTERS OF EXCELLENCE WEBPAGE FOR MORE INFORMATION ON OUR COMPREHENSIVE CARE CENTERS: https://caresfoundation.org/centers-of-excellence/

Medically-Safe Summer Camps

The Painted Turtle

a seriousfun camp founded by paul newman

Kidney Disease & Transplant and Adrenal Insufficiency Summer Session

This 5 day Summer Session is free for all who attend! (June 16-June 20)

Program Highlights

Enjoy activities like swimming, archery, fishing, ropes course, horseback riding, arts & crafts, and more! Each activity is designed with campers in mind.

- Cozy Cabins of up to 8 campers
- Cabin Counselors to ensure camper safety and fun!

Camper Requirements

- Between the ages of 7 &16
- Have a minimum developmental age of 5 years
- Be able to function and participate in a group setting
- Able to communicate needs independently
- Can be without family members for the duration of the camp session (summer camp)

The following conditions are served during this session:

- Adrenal Insufficiency
- Congenital Adrenal Hyperplasia
- General Nephrology-decreased kidney function
- Kidney Disease and Transplant
- Peritoneal Dialysis

For more information please contact **Camper Admissions at admissions@thepaintedturtle.org or 661-724-1768**

OVER THE WALL

25 years · a seriousfun camp

Experience the mischief and magic of Over The Wall's free and transformative activity camps. Over The Wall help children and young people reach beyond the boundaries of their health challenge. We offer both residential camps and Camp in the Cloud, which is our camp-at-home experience. All of our services enable our campers to build confidence by trying new things, creating friends, having fun and making lifelong memories!

To find more information about Over the Wall and their upcoming activity camps, please visit: https://www.otw.org.uk/types-of-camp/

Dream Street

JUNE 30-JULY 3, 2024

APPLY ONLINE

dreamstreetfoundation.org
Call for more information:
(424) 333-1371

SUMMER CAMP
AGES 4-14

Doctors and nurses at camp all week!

Open to patients who are on treatment or have recently finished. Siblings welcome.

Camp and transportation provided free of charge.

DREAM STREET FOUNDATION

A camp for children with chronic and life threatening illnesses

flying horse farms

a seriousfun camp

EXPERIENCE MORE AT CAMP! 2024

Campers with congenital adrenal hyperplasia generally qualify for the Rare Disease camp session held between July 20-25, 2024. They are also likely eligible for family camp weekends, as well as the Ranger or Trailblazer programs. For a full list of camp dates, please visit: https://flyinghorsefarms.org/come-to-camp/camp-schedule/

CAMP AT A GLANCE

- $0 Cost to campers & families
- 200+ acres to explore
- An average of 90+ volunteers at each session
- 24/7 onsite medical care
- Located 40 minutes north of Columbus, Ohio and 90 minutes southwest of Cleveland, Ohio right off I-71

FIVE FAST & FUN REASONS TO EMBRACE CAMP

1. **WellNest Wellness:** For campers to experience all camp has to offer, their health and safety needs must be met-as a medical specialty camp, Flying Horse Farms prioritizes safety first.
2. **Challenge By Choice:** Campers are given the opportunity to embrace new experiences like exploring the ropes course, taking aim at archery, and diving in with friends at the pool.
3. **Sense of Belonging:** Campers build lasting bonds with peers who understand and see them beyond their diagnosis and form lifelong friendships.
4. **Self Advocacy:** Campers learn to navigate their medical conditions, confidently gain skills, and find new independence that is carried beyond a camp session.
5. **More Smiles:** Camp is a place were more smiles happen because kids get to be kids.

Flying Horse Farms is a medical specialty camp that provides healing, transformative experiences for children with serious illnesses and their families - free of charge. Campers range from 7-21 and have diagnoses including cancer, heart conditions, rheumatologic diagnoses, blood disorders, lung conditions, gastrointestinal disorders, craniofacial diagnoses, rare diagnoses, spinal cord diagnoses, and mental health conditions.

DOUBLE H RANCH Summer Camp

WHERE KIDS CAN BE KIDS

This summer at Double H Ranch, hundreds of kids living with serious illnesses will have the chance to experience camp in a unique way-purposefully designed, fully adapted, and medically safe. Our team of trained staff and licensed medical professionals ensure a safe environment so your camper can focus on having fun. All programs are FREE of charge.

Camper activities

- Archery
- Arts & Crafts
- Boating
- Fishing
- High Ropes Course
- Horseback Riding
- Swimming
- Talent Show
- And So Much More!

2024 CAMP DATES

SESSION 1:	JUN 20-25
SESSION 2:	JUN 28-JUL 3
SESSION 3:	JUL 6-11
SESSION 4:	JUL 15-20
SESSION 5:	JUL 23-28
SESSION 6:	JUL 31-AUG 5
ALUMNI:	AUG 8-12

BASIC CAMPER ELIGIBILITY

- Medically Qualifying Diagnosis of one of the following... CAH, Cancer, Collagen Vascular Diseases, Congenital Cardiac Defects, Hemophilia/von Willebrands, Inflammatory Bowel Diseases, Immune Disorders/HIV, Mitochondrial or Metabolic Diseases, Select Neuromuscular Disorders, Select Rare Diseases, Shunt Dependent Hydrocephalus, Solid & Visceral Organ Transplant, or Sickle Cell Anemia
- Campers aged 6-16 years old for Sessions 1-6. Campers aged 17-21 who have previously attended a Double H program for the Alumni Session.
- Cognitive age of at least 6 years old.

Campers are asked to submit an online application with a current physical form and immunization record.

Double H Ranch

Double H Ranch, located in New York's Adirondack park, provides specialized programs and year-round support for children and their families dealing with life-threatening illnesses. All programs are FREE of charge.

Founded by Charles R. Wood & Paul Newman

QUESTIONS? CONTACT:
Tara Bogucki,
Admissions Director
tbogucki@doublehranch.org
518-696-5676 x 222

Scan to visit doublehranch.org for details & application.

CAMP BOGGY CREEK

July 15-19, 2024

Immune Deficiency Group

Children suffering from congenital adrenal hyperplasia (CAH), a form of adrenal insufficiency, an endocrine disorder, are eligible for our Immune Deficiency group of campers.

Please click below for more information for this specific group:

Immune Deficiency Group (July 15-19)

Ways to Support CARES

HOST A FACEBOOK FUNDRAISER!

Have you got a birthday coming up, or a wedding anniversary, retirement, or other special occasion? To honor this special event, try raising money for CARES on Facebook. It's easy to do and Facebook takes you through setting up a fundraiser step-by-step. They even published a guide for your convenience: https://tinyurl.com/pvub644a Make sure to share your fundraiser and use hashtags to bring attention to the CARES community & others with CAH. (#caresfoundation, #congenitaladrenalhyperplasia, #CAH, etc.)

Please keep us in the know by tagging CARES Foundation in your fundraiser post!

Thank you to everyone who has raised money so far!

If you've already hosted a Facebook fundraiser for CARES please let us know that too. We'd like to show our gratitude.

Walmart SPARK

Every time you shop at Walmart.com, you are able to round up and direct Network for Good to support CARES Foundation!

Visit the link or QR Code to see our Page!
https://www.walmart.com/nonprofits/5c53a68e-bace-4c07-a4d2-4ba53a91df19/profile

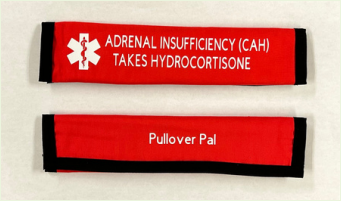
THE CARES SHOP

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

In our online store you can find helpful tools and resources that can make living with CAH a little bit easier. Check out our assortment of items that promote raising awareness for CAH throughout everyday activities.

Traveling with CAH/AI Packet Printed with Shot Kit

The Traveling with CAH/Adrenal Insufficiency (AI) Packet is all about being prepared, taking the proper precautions, and most of all, having fun! Let CARES help plan for a safe and healthy trip.



Seatbelt Cover

Wrap this simple & convenient cover over your seatbelts, bicycles, and other items to ensure that any emergency team on hand can be prepared in the event of adrenal crisis.

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 I.D. logo on front side and personal info on back side for privacy.

CARES Foundation Ceramic Mug

This beautiful 17 oz. ceramic mug is a great conversation starter for CAH Awareness whether you're at home, work, or wherever you drink your morning coffee/tea.

Emergency Response Kit (Set of 3)

Clear, plastic, water-resistant bags just the right size for your Emergency Response Kit. Emergency wallet card and Emergency Instructions brochure are included.

CARES Emergency I.D. Luggage Tag

The CARES Emergency I.D. Luggage Tag will typically fit easily onto any purse/bag, backpack or suitcase. This item includes an emergency instruction card.

FIND THESE ITEMS AND MORE AT THE CARES SHOP!

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.

www.CARESFoundation.org

CONGENITAL ADRENAL HYPERPLASIA FOUNDATION

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