CARES connections

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Improving health, connecting people, saving lives

In This Issue

Testicular Adrenal Rest Tumors in Congenital Adrenal Hyperplasia

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Introduction
The classic (severe) form of congenital adrenal hyperplasia (CAH) is considered to be a life-threatening, chronic disease. In the last 20 years, improved diagnosis and treatment have allowed almost all children to reach adult life without serious complications. Therefore, long-term complications of CAH have become more important to address. It has been shown that some complications that appear in adulthood may have their origins in childhood and even infancy, so pediatricians have to be aware of signs of these complications.

One of the most serious long-term complications in adult men with the classic form of CAH is the presence of testicular adrenal rest tumors* (TART). These lesions were first described 40 years ago; since then, many case reports and small studies have described these lesions in greater detail. The tumors are always benign, are often present in both testes, and resemble adrenal tissue when investigated microscopically. The cells can produce typical adrenal hormones; therefore, they are called adrenal rest tumors. In this article, I will give an overview about what is actually known about these lesions.

How often are these tumors found in CAH patients?
The prevalence (frequency of presence) is reported between 0–95% and depends mainly on the method of tumor detection and the selection of patients.

How can the tumors be detected?
The tumors are located within the testes rather than the surface and therefore can be easily missed by palpation.

Ultrasound is a good and inexpensive method for detection of these tumors, and even small tumors of several millimeters can be detected. Some clinics use MRI, but the detection rate is no better than ultrasound, and it is much more expensive.

Are the tumors also found in childhood?
Yes, we can find these lesions already in childhood and even early infancy. In a recent study, we showed that there is an increase in number during puberty. Therefore, we recommend regular ultrasound in males with classic CAH starting at puberty.
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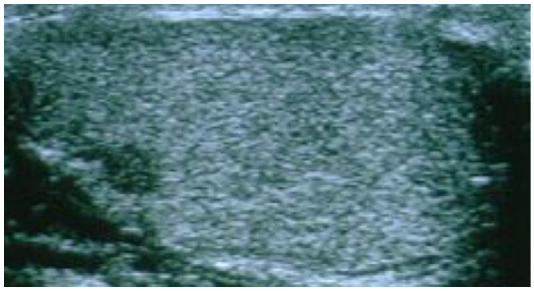


	Cabrera et al. [7]	Stikkelbroeck et al. [38]	Avila et al. [2]	Avila et al. [3]
Number	30	17	19	42
Age	17-43	16-40	5-27	5-31
Palpation	8/30 (27%)	6/17 (35%)	1/9 (5%)	2/42 (5%)
Ultrasound	9/18 (50%)	16/17 (95%)	8/19 (42%)	12/42 (29%)
Bilateral	k.A	10/16 (63%)	5/8 (63%)	9/12 (75%)

* Tumor is the medical term for a lesion or mass that can be felt or detected by ultrasound or MRI.

A Message from the Executive Director

Dear Friends,

Welcome to the new edition of CARES Connections! We have been hard at work since our last edition hosting two regional education conferences, a gala, three awareness Walks, sponsoring medical education, supporting research, developing new tools for patients, addressing the issue of nomenclature (classification of CAH), working on EMS protocols for adrenal insufficiency, strengthening our support network, and developing a new website to better serve the needs of the CAH community.

Education
Patient and medical education continues to be a focus of CARES. Over the last year we hosted two regional conferences aimed at educating patients and families – one at the CARES-designated "The Comprehensive Center for Congenital Adrenal Hyperplasia" at New York Presbyterian Weill Medical Center in New York and the other at Miami Children's Hospital in Florida. We also sponsored a symposium on Reproductive Health in CAH at the Endocrine Society Meeting in Chicago. With your support, we will continue to work to educate both patients and doctors to ensure that patients receive better care.

Awareness
Raising awareness about CAH is key to making progress in diagnosis, treatment and advancing research for CAH. On this front, we have increased the number of awareness walks we have hosted from one to three this year. Walks were held in New Jersey, California and Virginia. These walks are a great opportunity to connect patients and families, further educate them about treatment and research, and to teach others about what it's like to live with CAH. Similarly, our annual Gala brings together patients, families, medical professionals and supporters often for the first time.

We have witnessed firsthand the impact these events have had on patients and families. During one of the walks, a few families learned for the first time about the importance of having Solu-Cortef® on hand. It still amazes me that many doctors don't understand that it is a life-saving tool in the event of an adrenal crisis. What doesn't surprise me is hearing about the poor care so many patients continue to receive. Many of them think they are receiving good or adequate care until they talk to another patient or family who is indeed receiving appropriate care and realize their care is inferior at best. I am not exaggerating when I say that some of these events are "life changing" and urge you to participate in a future event.

Patient Resources
A significant amount of work has been done to improve the services offered to patients. In the last year we have strengthened our support network to include conference calls with various patient populations and started a new Facebook page to allow for the creation of secret pages in which patients can communicate with each other in a safe and secure environment. We have also completely overhauled our website. It is now easier to navigate, offering patients easier access to educational materials and other resources such as "Ask the Expert," CARES shop, and news on support network activities, and other events.

Our goal is to continually grow to serve you better. Let us know how we are doing and what you would like to see us do to make your life easier. Your feedback will help us help you!

Dina

[*continued from page 1*]

Are these tumors also found in non-classic CAH (NC CAH)?
There is discussion about this question. I have never found TART in NC CAH, but some authors describe them in the literature.

What kind of tissue are these lesions?
TART consist of cells that resemble adrenal cells: they look like adrenal cells and can produce adrenal hormones. Therefore, it was thought that these tumors consist of aberrant adrenal cells. In recent studies we found that the tumors consist of more embryologic-like cells that may already be present during pregnancy.

Why do these cells grow?
In CAH a pituitary hormone called ACTH (adrenocorticotropic hormone) is elevated due to the lack of cortisol. ACTH stimulates the adrenal gland, leading to hyperplasia (growth of cells). It is thought that the elevated ACTH may also play a role in the development of TART. In early descriptions, patients with TART mostly had poor adrenal control and high ACTH levels. Nowadays, we know that TART can also develop in well-treated patients, and there must be other factors besides ACTH that lead to tumor growth.

Why do these tumors develop?
The etiology of TART is still unknown. We know that the adrenal gland and testicular cells have a common origin; in early fetal life, there are cells containing both adrenal and testes features. During further development of the embryo, these cells differentiate and become testicular or adrenal cells, but both still in close relationship. During even further development, the testes will descend to the scrotum. It can be speculated that some of these embryological cells may persist within the testes. In healthy children, these cells diminish, but in the special situation of CAH with elevated ACTH, these cells persist and can grow during further life.

Do patients have complaints?
Most young adult patients do not have any complaints, and the lesions are found only by ultrasound. With larger tumors, some patients report pain or discomfort. Sometimes the tumors are found after evaluation for infertility.

Author	Original dosage	TART treatment
Mauritsen et al. 2010	HC 10 mg	HC 30 mg DXM 0.1 mg
Claahsen et al. 2007	HC 30 mg	DXM 0.75 mg
Collet et al. 2010	?	DXM 1 mg
Stikkelbroeck et al. 2001	HC 25 mg	DXM 3 dd 0.25 mg

What are the consequences of TART?
TART are typically located in the central part of the testes where all seminiferous tubules confluence together. In early stages, small multiple lesions exist without any consequences; however, after further growth, the lesions confluence to form a bigger lobed lesion that can lead to obstruction of the seminiferous tubules. This obstruction and possible other factors, such as local hormone production, may lead to infertility. Longstanding TART and obstruction can also lead to damage of the whole testes. This is called end-stage TART.

To describe the progression of TART during life, we introduced a classification of TART in 5 stages (see Figure 1).

What are the treatment options of TART?
A clear treatment protocol does not yet exist since the origin and the factors that contribute to tumor growth are still unclear. Because of the relation between tumor growth and poor hormonal control, the first step of treatment is optimizing glucocorticoid therapy, for example by using prednisone or dexamethasone. This is used in infertile male patients with TART on both sides who want to achieve pregnancy. By using high dosages of dexamethasone, some doctors describe shrinkage of the tumors and successful pregnancy.

However, side effects were often reported with dexamethasone, such as weight gain, hypertension and striae; therefore, most patients only use this medication incidentally to achieve pregnancy and are not really motivated to use this medication chronically. Furthermore, in growing children high dosages with glucocorticoids may lead to impaired final height.

In our center we used testes-sparing surgery in 8 adult patients with longstanding bilateral TART and infertility in an attempt to improve testicular function. We found end-stage damage of the testes in all patients during surgery and not surprisingly, testicular function did not improve. We concluded that with end-stage damage, surgery is not recommended unless there is pain or discomfort.

Are there other possibilities to improve fertility?
As long as there are no clear treatment options, we offer cryopreservation to all young adults with bilateral TART.

What are the future directions of our research?
We now focus on the origin of these lesions. We want to know the features and factors that contribute to tumor growth. With this knowledge we hope to develop treatment strategies to diminish or even prevent tumor growth.

Is TART a typical feature of CAH?
TART is mostly described in CAH, but there are other conditions with elevated ACTH that have been described very sporadically to have TART.

Do females also develop adrenal rests in their ovaries?
Some female patients with adrenal rests in the ovaries (OART) are described in the literature, but the presence is rare. Some systematic studies exist. One study in our center searched for OART with ultrasound and MRI, but did not find these lesions.

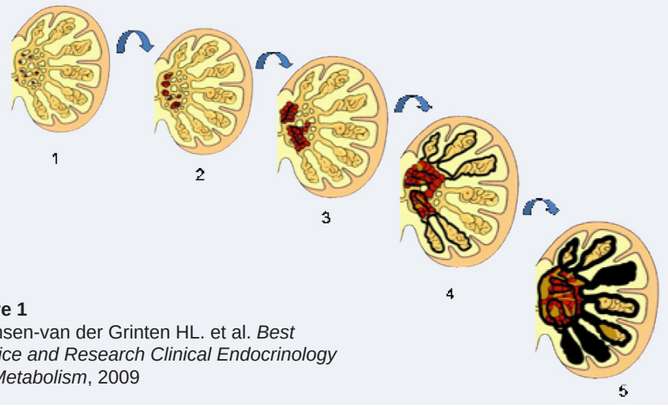
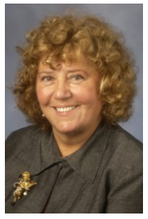


Figure 1
Claahsen-van der Grinten HL. et al. *Best Practice and Research Clinical Endocrinology and Metabolism*, 2009

RESEARCH (continued)

Noninvasive Prenatal Diagnosis of Congenital Adrenal Hyperplasia

Maria I. New, MD, Icahn School of Medicine at Mount Sinai



My team and I are the first and only center to carry out noninvasive prenatal diagnosis in congenital adrenal hyperplasia. The diagnosis of CAH in 14 families by this new technology was published in the *Journal of Clinical Endocrinology and Metabolism*. We were successful in this endeavor because of our collaboration with Professor Dennis Lo, who discovered cell-free fetal DNA in the maternal plasma in 1997. Based on this new finding and previous work on the genetic basis of CAH, I was presented with the prestigious Ipsen Award at the annual Endocrine Society meeting.

Currently, prenatal diagnosis of CAH is only clinically approved by the invasive method. The invasive method involves the surgical procedures of amniocentesis carried out at 14 weeks and chorionic villus sampling carried out at 12 weeks. As prenatal treatment with low-dose dexamethasone must begin before the 9th week of gestation to prevent the development of atypical genitalia in affected female fetuses, the genetic data from the invasive method does not arrive in time to treat. Thus, all fetuses at risk are treated, including male and unaffected female fetuses in whom the treatment is unnecessary. On the other hand, in the noninvasive prenatal diagnostic method, blood is drawn from the mother as early as six weeks of gestation, fetal sex is determined within 48 hours, and the genetic diagnosis of CAH is available by the ninth week of gestation, in time to avoid unnecessary treatment to male fetuses and unaffected female fetuses. In the future when this new technology is clinically available, only affected female fetuses will receive prenatal treatment with low-dose dexamethasone.

We are currently applying for funding for this project and remain dedicated to bringing noninvasive prenatal diagnosis of CAH to clinical use. We continue to collect DNA from expecting families interested in participating in future research to validate this new technique of noninvasive prenatal diagnosis.

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Updates from the NIH Clinical Center in Bethesda, Maryland

Ashwini Mallappa, M.D., and Deborah Merke, M.D., M.S.

We have had an ongoing Natural History Study of CAH at the NIH Clinical Center since October 2005. The NIH Clinical Center is the ideal place in which to carry out this study and is one of the few places in the world that facilitates the conduct of long-term studies of rare diseases. To date, recruitment has been very successful with 355 CAH patients, ages 6 months to 66 years, and 250 parents evaluated as part of this study, Protocol #06CH0011, Natural History Study of Patients with Excess Androgen (ClinicalTrials.gov Identifier #NCT00250159). Detailed clinical evaluations have revealed great variation in treatment approaches of referred patients, with only 30% of patients receiving therapies resulting in acceptable disease control. Abnormal growth and development of children, short stature in adults, cardiovascular risk factors, reduced bone mineral density and adrenal and testicular tumor formation are common. Clearly new treatments are needed. An overview of the clinical findings of our large cohort of patients was published in the *Journal of Clinical Endocrinology and Metabolism* in 2012 (1). We recently reported detailed bone mineral density (BMD) findings in our cohort of adults and found that >50% had low BMD. Findings from this study were published in *Clinical Endocrinology* early this year (2).

An important goal of the Natural History Study is to follow a large population of patients for referral to future treatment studies. We recently completed a clinical trial using Chronocort®, a newly developed, modified-release hydrocortisone capsule formulation. Chronocort® developed by Diurnal Limited, UK, is designed to mimic the normal cortisol circadian rhythm. Current available regimens to replace cortisol in CAH patients are suboptimal as they cannot replace this normal cortisol circadian rhythm. Many of the complications of CAH treatment at the present time may be due to our inability to mimic the natural biorhythm of cortisol secretion.

At the National Institutes of Health Clinical Center, 16 patients with classic CAH participated in a Phase 2 study designed to evaluate the effects of both short-term and long-term treatment (6 months) with Chronocort® (ClinicalTrials.gov Identifier: NCT01735617). This clinical trial began in December 2012 and was completed in December 2013. Thirteen patients were recruited through the NIH Natural History Study of Excess Androgen and three patients were recruited through a CARES advertisement.

All patients completed the study and tolerated the study medication with no major adverse events. Final results describing effectiveness will be published within the next several months. The information gained from this study is being used to design a multi-center international study aimed to start in 2015.

Another way to mimic the natural biorhythm of cortisol is to replace hydrocortisone as a continuous infusion using an insulin pump. In collaboration with Medtronic, who has kindly provided the pumps and supplies for this study, this pilot study began in August 2013. Eight adults with difficult-to-control CAH will participate in this pilot study. This study is ongoing.

We are very excited to report expansion of our research team. Dr. Rachel Morissette, Ph.D., completed her post-doctoral fellowship at the National Institute on Aging, National Institutes of Health in Baltimore, Maryland, and joined our team in June 2013. Dr. Morissette is using biochemical and molecular methods to study biomarkers of disease. Ms. Terri McHugh, RN, joined our team early this year. She has extensive nursing experience caring for children and adults with CAH in both inpatient and outpatient settings. She works as the research nurse on our team.

We continue to recruit patients of all ages with CAH (both classic and nonclassic) to the Natural History Study. The current wait time for an appointment is 4 to 6 months. Participants will be seen as outpatients at the NIH Clinical Center in Bethesda, Maryland, for a full evaluation and up to four visits. Patients will have a full report sent to their private physician. All testing is free of charge and will include:

- Genotyping
- Hormonal evaluation including evaluation for insulin resistance
- Bone age (growing children), ultrasound
- Bone density (patients 8 years and older)

For more information, please contact our research nurse Terri McHugh, RN, at ccdm-patient@mail.nih.gov.

We gratefully acknowledge the enthusiastic participation of our patients and their relatives, who make it possible for us to study CAH and develop new treatment approaches.

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Adrenomedullary Function in Newborns, Infants and Toddlers with Classical Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency

Mimi Kim, MD, Children's Hospital Los Angeles

This is a longitudinal study examining adrenomedullary function in very young children with classical CAH due to 21-hydroxylase deficiency, up until the age of 4 years old. We have reported that adrenomedullary function is decreased at birth in infants with CAH compared to controls (Kim, MS et al. Decreased Adrenomedullary Function in Infants with Classical Congenital Adrenal Hyperplasia. J Clin Endocrinol Metab 2014 Aug;99(8):E1597-601). We are now studying the natural progression of the epinephrine deficiency over time in young children. This is an important phase of adrenal development, as the major zones of the adrenal cortex become most discernible around 3 to 4 years of life. In addition, this age group has an increased risk for the rapid development of adrenal crises, including hypoglycemia. However, it is not known to what extent epinephrine deficiency is involved in these life-threatening adrenal crises during illness.

Look under Comprehensive Care Centers for additional information on current research. You can also find more details about CAH research on our website.

EDUCATION

Educational Videos

Our flash drive, which includes two videos addressing stress dosing and adrenal crisis, has been a big hit. We have heard from numerous parents and patients who have used it to educate school personnel and even emergency department staff.

To order yours, go to our website: www.caresfoundation.org.

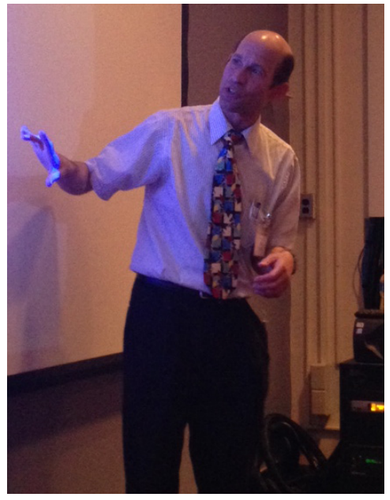
Videos cannot be reproduced without written consent of CARES Foundation.

Conferences

2014 Weill Cornell CAH Conference, New York

The 2014 Weill Cornell CAH Conference held on April 26th at The Comprehensive Center for Congenital Adrenal Hyperplasia at New York-Presbyterian Weill Cornell Medical College* was a huge success. Patients, parents and even medical professionals who do not have expertise in CAH but are treating patients attended the conference. Topics included CAH and the First Year of Life, Surgical Aspects in CAH: New Advances, Chronic Disease and Parenting, Updates on Prenatal Diagnosis, Transitioning for Adolescents to Adult Care, The Changing Needs of the Adult with CAH, CAH and Fertility, CAH and Dermatological Issues, Patient Tools for Living with CAH, Ask the Expert Panel, as well as individual and small sessions on Surgery and Chronic Disease and Parenting. Solu-Cortef® injection training was also provided.

* The Center is the first CARES-designated center of excellence for CAH.



Dr. Richard Auchus giving a presentation at the 2014 Weill Cornell CAH Conference.

Special thanks to our panelists and educators: Drs. Maria Vogiatzi, Dix Poppas, Richard Auchus, Cynthia Chen, Oksana Lekarev, Tara Matthews, Maria New, Tiffany Schumaker and Karen Lin Su; and Deborah Brown, Alexis Feuer, Denise Galan and Carey Reynolds.

Symposium on Reproductive Health in Congenital Adrenal Hyperplasia Draws 2,000 Doctors to Chicago

We were pleased to sponsor this important symposium at the 16th International Congress of Endocrinology jointly with The Endocrine Society 96th Annual Meeting and Expo in Chicago this June. The topics, presented by an international panel, included An Evolutionary Perspective in Adrenal Androgens and Reproduction presented by Dr. Ze'ev Hochberg from Israel; Challenges for Males with Classic 21-Hydroxylase Deficiency presented by Dr. Hedi Claahsen-van der Grinten of the Netherlands; and How Common is Sub-Fertility in Women with Non-Classical 21 Hydroxylase Deficiency presented by Dr. Philippe Touraine of France.

We are grateful to them for sharing their expertise with approximately 2,000 physicians from across the globe. We owe a debt of gratitude to Dr. Ellen Seely for chairing the session and to Dr. Richard Auchus for guiding us through the sponsorship process.

None of this would be possible without the financial support of our community. Thank you!

2015 Conferences

We are working on our 2015 conference schedule. Stay tuned to our website and your email for more information.

THE DOCTOR'S IN

Growth Hormone Therapy to Improve Adult Height in Patients with Congenital Adrenal Hyperplasia

Karen Lin Su, M.D.

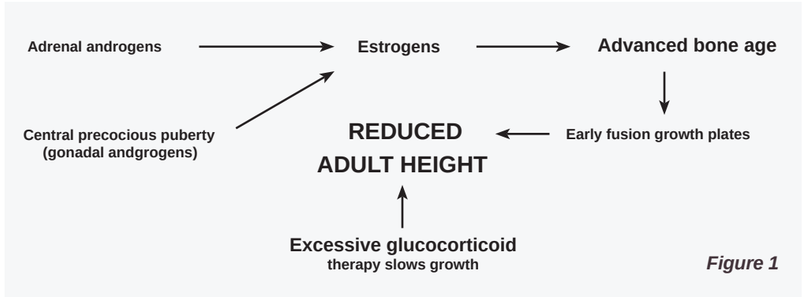


Figure 1

Many patients with CAH do not reach an adult height within their mid-parental target height range. In a meta-analysis of 18 studies published between 1977 and 1997, the overall average adult height was 11.0 cm (4.3 inches) below mid-parental target height for males and 8.7 cm (3.4 inches) below target height for females [1]. Another meta-analysis of 35 studies published between 1977 and 2008 reported an overall average final height of 9.7 cm (3.8 inches) below the population mean [2].

Factors Affecting Adult Height in CAH

There are several factors contributing to suboptimal adult height in patients with CAH. Excess adrenal androgens result in rapid growth during childhood; however, the estrogens produced from these androgens result in bone age advancement and premature fusion of the growth plates, ultimately compromising adult stature. Additionally, central precocious puberty may develop in patients with CAH due to androgen activation of the hypothalamic-pituitary-gonadal axis, exacerbating early closure of the growth plates. Finally, the treatment of CAH with chronic glucocorticoid therapy, even at replacement doses, has been associated with poor growth. Long-term glucocorticoid treatment during childhood, particularly during the pubertal growth spurt, can compromise final height (see Figure 1).

The long-acting synthetic glucocorticoids, such as prednisolone and dexamethasone, are more growth-suppressive than cortisone and hydrocortisone at equivalent glucocorticoid doses (Table 1). Therefore, the Endocrine Society Clinical Practice Guideline for CAH recommends hydrocortisone tablets as the preferred form of glucocorticoid replacement in growing patients [3].

Medication	Growth-Suppressing Effect Relative to Hydrocortisone at Equivalent Doses
Cortisone acetate	1
Hydrocortisone	1
Prednisone	1.25
Methylprednisolone	1.6
Dexamethasone	2.5
Prednisolone	4

Table 1: Longer-acting synthetic glucocorticoids (prednisone, prednisolone, methylprednisolone, and dexamethasone) are more growth-suppressive than cortisone and hydrocortisone even at equivalent doses.

Studies with Growth Hormone Treatment to Improve Adult Height in CAH

For CAH patients who develop central precocious puberty, LHRHa can effectively suppress puberty. However, treatment with LHRHa often causes slowing of growth and is unlikely by itself to significantly improve adult height. Treatment with growth hormone, on the other hand, has been shown to counter the growth-suppressing effects of glucocorticoids and LHRHa and could be useful in improving adult height. Earlier studies have shown that the combination of growth hormone (GH) and LHRHa is effective in improving height prediction and final height in non-CAH children with central precocious puberty [4-6].

Final adult height after GH treatment with or without LHRHa was reported in 34 patients with CAH [7]. To be included in the study, CAH patients had to have: 1) bone age >6 years, 2) bone age greater than 1 standard deviation (SD) ahead of actual age, 3) predicted adult height of at least 2 SD below mid-parental target height *or* at least 2 SD below the population mean (for females: predicted adult height under 60 inches; for males: predicted adult height under 65 inches), and 4) open growth plates (bone age <13 years in girls and <15 years in boys). Final adult height was significantly higher than baseline predicted height in both males (67.7 vs 64.1 inches) and females (63.9 vs 59.7 inches). The average gain in height was 3.6 + 2.6 inches for males and 4.1 + 1.5 inches for females.

The average amount of time on GH was 5.6 years in males and 4.5 years in females. The younger the patient was at the start of GH treatment, the greater the improvement in height. There was also a significant correlation between gain in height and duration of GH treatment.

The combination of LHRHa to GH did not result in better height gain than GH alone. The average gain in height was 3.6 inches in those treated with both GH and LHRHa and was 4.6 inches in those treated with GH alone. Subjects treated with GH plus LHRHa, however, started GH therapy at a later age compared to subjects treated with GH alone (8.9 vs 7.4 years). They also started GH with a more advanced bone age than those not treated with LHRHa (11.8 vs 9.9 years).

Classical patients started off with a lower height prediction than non-classical patients. However, the average gain in height was the same: classical (3.8 inches); non-classical (3.9 inches).

Adrenal control during the GH treatment period played an important role on the gain in height. Patients with poor adrenal control did not have as much gain in height from the GH therapy than those who were in fair or good adrenal control. It seems that as long as adrenal control was fair, GH treatment was equally effective in improving height outcome. It is also possible that the patients found to have poor adrenal control were non-compliant with both their glucocorticoid replacement and their GH treatment, even though the reported compliance with GH was >90%.

There were no reports of adverse events while on GH therapy.

Conclusion

GH alone or in combination with LHRHa appears to be an effective therapy for improving final adult height in CAH patients. In the 2010 Endocrine Society CAH Clinical Practice Guideline, GH treatment was not recommended as standard treatment for CAH patients due to limited data and because not all patients require intervention to reach an adequate final adult height [3]. The reports of GH treatment refer only to subjects with significantly compromised predicted adult heights due to advanced bone ages combined with reduced growth velocity. With newborn screening now in place in all 50 states in the U.S., early diagnosis and treatment will hopefully result in improved height outcome for all CAH patients. However, for those patients who are headed for an adult height well below the population mean, GH may be a viable option.

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ADVOCACY

CAH Nomenclature

Thank you to all who participated in our survey about current nomenclature (classification) describing a subset of CAH.

An umbrella term called Disorders of Sex Development was developed in 2006 by a consensus group to classify conditions in which there is an issue during fetal development of the X or Y chromosome, ovaries, testes, or genitalia. The use of this term is being looked at critically by the CAH community (along with other patient advocacy groups) because it is not a complete description of CAH and may be perceived negatively by patients. Through CARES focus group discussions, parents and patients have expressed their concerns about the potential misconceptions that could arise from having CAH linked to this nomenclature.

In order to get a better sense of patient and parent perception of this nomenclature, CARES Foundation conducted a survey of the CAH community regarding their thoughts on the issue. Close to 600 responses were received, and the results showed that the majority disliked the term and did not identify with it. The majority also felt that the term has a negative effect on the CAH community.

Based on these results, CARES has taken the position of not participating in research studies that use this term.

Emergency Medical Service Protocols for Adrenal Insufficiency

We extend our appreciation to everyone who continues to work on EMS protocols for adrenal insufficiency on the grassroots level. While state-by-state efforts are important, we are also meeting with members of Congress to develop legislation recommending the adoption of national protocols. Special thanks go to Congressman Leonard Lance from New Jersey for his support!

If you have experienced EMS or ER personnel lacking knowledge in the diagnosis

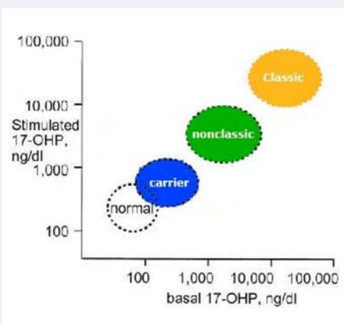
How to Diagnose NCAH

A single blood test, drawn in the morning and looking at adrenal steroid levels (17-hydroxyprogesterone (17OHP), androstenedione and testosterone), may be sufficient to make the diagnosis of NCAH, as long as the subject is not pregnant. A morning 17OHP level >1000 ng/dL (along with testosterone and androstenedione levels above normal range) would be consistent with CAH. An ACTH stimulation test is the gold standard to make the diagnosis if the labs values from the single blood test are equivocal. A dose of ACTH (adrenocorticotropic hormone) is given intravenously. Blood samples are taken before the medication is given and again an hour later.

Normal response to ACTH stimulation is to release cortisol into the bloodstream. In CAH blood samples taken after the dose of ACTH show large amounts of 17-OHP, the "raw material" from which cortisol is normally made. The results of the ACTH stimulating test are plotted on a "Nomogram," see figure at right, to determine whether the values indicate a diagnosis of NCAH or classic CAH.

Nomogram for comparing 17-OHP levels before and 60 minutes after a 0.25 mg iv bolus of cosyntropin in subjects with or without 21-hydroxylase deficiency. Note that the values for normals and heterozygotes (carriers) overlap. DNA testing and certain other hormone tests may also be used to confirm the diagnosis. (From Speiser and White; Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency; *Endocrine Reviews* 21(3): 245-291; 2000).

In children: The pediatrician can order a bone age – an x-ray of the child's hand and wrist that will tell whether any high hormone levels are affecting the child's adult height potential. If the child's bone age is advanced, then referral to a pediatric endocrinologist would be warranted for further work-up.



and treatment of adrenal crisis, please email your story to Karen at karenf@caresfoundation.org. We are sharing stories from those with CAH and other forms of adrenal insufficiency with legislators to demonstrate the need for national protocols.

Updates

• Alabama has an adrenal insufficiency protocol. EMS is allowed to administer patient-carried medications.

• Montana has adopted patient-carried medication protocols.

• New Jersey passed full protocols. Individuals must visit their local EMS to request emergency vehicles carry Solu-Cortef®.

• Seattle, Washington, now addresses adrenal insufficiency through Individualized Care Plans. Advanced Life Support (ALS) is permitted to administer patient-carried medication with a completed Individualized Care Plan.

With all of these protocols, it is very important to visit your local firehouse/ambulance and let them know who has adrenal insufficiency in your household. Bring a copy of the protocols found at http://www.caresfoundation.org/comprehensive-care-centers/emergency-medical-care/

MAKING CONNECTIONS

Support Network Update

Support Group Leaders
We are fortunate to have added more support group leaders helping those affected by CAH. These leaders are a great source of warmth, knowledge, experience and understanding at a difficult time for many. They are:

• Yvette Boose, Colorado
• Chad Michael Foster, Michigan
• Bobbi Anne Sisson, Mississippi
• Anne Claire, Teens and Young Adults with CAH
• Hope Holman, Women with NCAH
• Ruth Nichols, Parents of Teens and Young Adults with CAH
• Marc Pollack, Teens and Young Adults with CAH
• Rebecca Tapick, Women with NCAH
• Simona Geacar, Romania

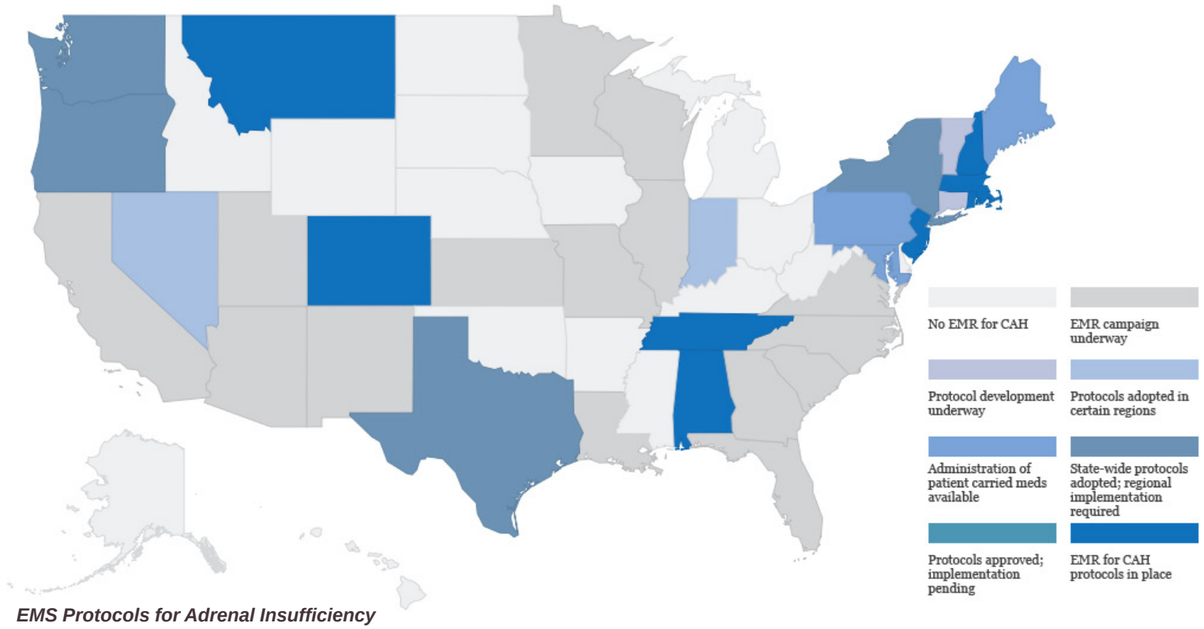
Moving On
We are very grateful to Stephanie Grubler for her many years as a dedicated support group leader in Connecticut. Thank you, Stephanie! We greatly appreciate all those who have served as support group leaders and have had to step down. You have made an important difference!

Telephone Meetings
We continue to hold our Newborn Support Group meetings on the second Thursday of the month at 9pm EST. Every month our leaders answer questions from curious and sometimes anxious parents about caring for an infant with CAH. We have participants from across the U.S. and as far away as India and Estonia.

Our meetings have expanded to include Women with CAH and Parents of Children, Teens and Young Adults. These calls will be alternating every other month, usually on the second Wednesday at 8:30-10:00pm EST Please check the calendar section of our website for meeting information, or contact Karen at karenf@caresfoundation.org.

Facebook
Our presence on Facebook continues to expand. The CARES Facebook page keeps our community connected on the latest events and news about CAH and CARES activities. And now, we have created the CAH Champions page with secret groups which offer a closed and safe environment in which to have conversations with others with similar experiences. Our secret pages include:

• 3 Beta Women
• 17 Hydroxylase
• Classic CAH Women Support Group
• Men with CAH
• NCAH Women Support Group



EMS Protocols for Adrenal Insufficiency

• Newborn Support Group
• Parents of Kids with CAH
• Parents of Teens/YA
• Surgery Support Group
• SWCAH Women
• Teens/Young Adults Support Group

We also have pages for those who live in the following states: Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Georgia, Idaho, Illinois, Indiana, Kansas, Kentucky, Louisiana, Massachusetts, Minnesota, Montana, Nebraska, Nevada, New Jersey, New York, Ohio, Oklahoma, Pennsylvania, Tennessee, Texas, Utah, Virginia, Washington, West Virginia, Wisconsin.

For more information on these pages, contact Karen at karenf@caresfoundation.org

Events
• Massachusetts
On September 14, Alex Dubois, MA support group leader and CARES trustee, gathered families from the Boston area. One of our CAH families, the Gleasons, hosted the event at their athletic facility, Athletic Revolution. The five families who attended, each with sons with CAH, had a great time utilizing the facility and enjoying each other's company.

• Ohio
Sara Teed, one of our Ohio leaders, once again held an outing for CAH families at the Cincinnati Zoo on September 20. Ohio, Kentucky and Indiana families were invited. The event was great fun for the children and parents!

• Pennsylvania
Debbie Cullen, our PA, MD and DE support group leader, held her 3rd annual bowling fundraiser. Pennsylvania friends and families enjoyed an afternoon of bowling and tricky tray items!

A huge *thank you* to all of our support group leaders who respond to those wanting to connect, hold meetings or events, dial-in to specialized support group calls, moderate secret Facebook pages and more. Your work is invaluable and the CARES community is so fortunate to have your help!

In-person Support Group Meeting
Mark your calendar and plan to join us for an in-person support group meeting Saturday, December 6th, 11 am.

The meeting will be held at the Comprehensive Center for Congenital Adrenal Hyperplasia at New York-Presbyterian/Weill Cornell Medical Center (525 East 68th Street, New York, NY). Please RSVP to karenf@caresfoundation.org.

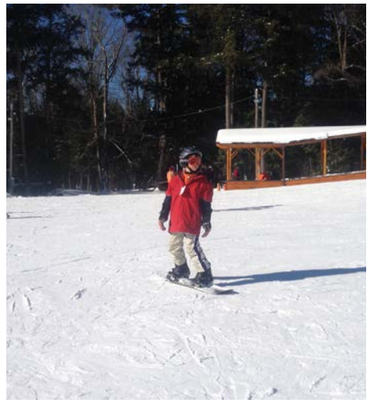
Doctors from the Center will be on hand to answer your questions. It's also a great opportunity to meet other patients and families. You do not have to be a patient at the Center to attend.

Year-Round Camp Opportunities

We continue to connect children with medically safe summer camp opportunities in different parts of the U.S. Most of these programs are free and some assist with transportation. This year's camps welcomed our CAH kids in Arizona, California, Kentucky, Upstate New York, North Carolina, Oklahoma and Washington. You don't have to live near the camp to attend. Children have traveled from Colorado, New Mexico and Utah to the New York camp.

This past spring, The Painted Turtle Camp in Lake Hughes, California, hosted a Special Diagnosis Family Weekend, March 14-16. Families enjoyed boating and fishing, arts and crafts, woodshop, music, and much more. Dr. Mimi Kim, pediatric endocrinologist from CHLA, was one of the volunteer doctors that weekend.

Center for Courageous Kids in Scottsville, Kentucky, held a Spring Weekend for CAH, April 11-13. Families came from far and wide to be with other CAH families in a relaxed and welcoming atmosphere. As one mom said, "How very much we enjoyed the Courageous Kids Camp in Kentucky. This facility was top-notch and very organized! It was so nice to attend such a well-planned event. It was a very nice retreat for our entire family."



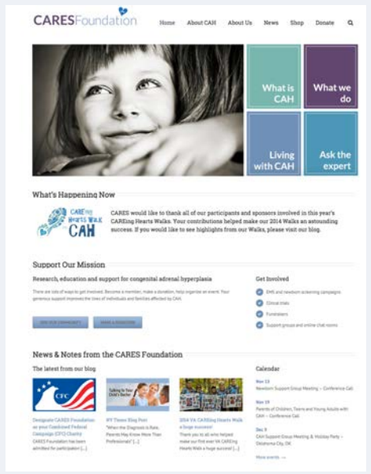
Snowboarding at the Double H Ranch in Lake Luzerne, New York.

SUCCEED Clinic held their annual camp at Schaeffer Farm in Noble, Oklahoma, on May 3-4. Patients and their siblings experienced a fun-filled weekend of meeting new people, outdoor cooking, archery, crafts, campfires, songs, games, and more. Traci Schaeffer, Oklahoma support group leader and SUCCEED Clinic pediatric nurse, coordinated the event.

Staying Connected Online – Our New Website

This fall, we unveiled our new website at www.caresfoundation.org. For more than 10 years, the site has been an invaluable tool for both our patient and professional communities, but it was time for a much needed makeover. With rapid changes in how we receive and share information, the site was redesigned to better meet the needs of the community by making the site more functional, intuitive, and aesthetically pleasing.

The new site has a clean, fresh look with easy to follow navigation. Other features include the ability for visitors to comment directly on articles, allowing for greater engagement within the community, sharing thoughts and advice, as well as the ability to quickly and easily share information with their personal and professional contacts via social media buttons (Facebook, Twitter, etc). We would love to know what you think about the new site. Please check it out and send your feedback to Dina@caresfoundation.org. Special thanks to Gattuso Media Design for designing and building the site.



Once again Double H Ranch in Lake Luzerne, New York, held a CAH session during their summer program. Wendy Thornley, our Connecticut support group leader, was one of the volunteer nurses that week. "Sebastian had such an amazing time at camp," sums up how most campers felt.

Double H Ranch offers Winter Adaptive Sports Weekends where families come to learn how to ski, snowboard, sled, play games, do crafts and more. The application deadline for Winter 2015 is December 1. "We had so much fun. It was a great mini vacation – no laundry, no cooking, plus skiing. I can't thank you enough for bringing Double H Ranch to the CARES community," shared a mom from New York. To apply, go to www.doublehranch.org.

Look for emails announcing camp opportunities or contact Karen at karenf@caresfoundation.org for more information.

CAH AROUND THE WORLD

International Update

Australia and Beyond

Congratulations to CLAN (Caring & Living As Neighbours) for the development of the *Leave No Child Behind* booklet launched at the recent UNDPI/NGO Conference in NYC!

CLAN is an Australian-based, not-for-profit, non-governmental organization (NGO), approved by AusAID for Overseas Aid Gift Deductibility Status (OAGDS) and the Australian Taxation Office for Tax Deductibility Status. CLAN is dedicated to the dream that all children living with chronic health conditions in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbors' children in wealthier countries.

France

Two organizations in France are currently dedicated to CAH: Association Surrénales and IFCAH. The former is focused on supporting relationships between patients and physicians, the latter on funding medical research.

Association Surrénales organizes a yearly international seminar dedicated to developing health professionals' knowledge about adrenal diseases and updating them on current research projects. In May 2014, the seminar was held in Paris and brought together 200 participants from western European countries.

For more information go to: www.surrenales.com.

IFCAH (International Foundation for CAH) was established in 2010. Each year, IFCAH awards 350,000€ to the most interesting projects as selected by its Scientific Committee in collaboration with the European Society for Pediatric Endocrinology. Projects funded in 2013 include:

• Project 1: Characterization of precursors of Testicular Adrenal Rest Tumors (TARTs) found in CAH patients. Investigator: Dr. A Swain, London, UK. Funding 115,000€

• Project 2: CAH beyond the age of 40 years: What challenges do we face and what do we need to monitor? Investigator: Dr. N Reisch, Munchen, Germany. Funding 85,000€

• Project 3: Development of non-invasive prenatal diagnosis of CAH using cell-free fetal DNA in the maternal circulation. Investigator: Dr. L. Chitty, London, UK. Funding: 50,000€

• Project 4: Cell therapy for the treatment of congenital adrenal hyperplasia (CAH) using an implantable medical device. Investigator: Dr. S. Bornstein, Dresden, Germany. Funding 73,000€

• Project 5: Combined cell and gene therapy as a novel approach for the treatment of human 21-hydroxylase deficiency. Investigator: Dr. M. Thomas, Grenoble, France. Funding 27,000€

For more information go to: www.Ifcah.org.

Netherlands

The Dutch Adrenal Society NVACP was founded in 1988 and has at present just over 1,300 members, representing the following adrenal diseases/disorders:

• Addison primary (incl. ex. Cushing without adrenals): 665 (50.8%)

• Addison secondary: 106 (8.1%)

• Addison tertiary (using corticosteroids for other diseases): 27 (2.1%)

• Cushing: 249 (19.0%)

• CAH/AGS: 196 (15.0%)

• Conn syndrome: 47 (3.6%)

• Miscellaneous: 19 (1.5%)

Our mission is to support and educate our members, their families, school employees, employers, and general practitioners, in an effort to help improve quality of life after diagnosis.

Often a diagnosis comes too late, resulting in significant complications and poor quality of life. However, there is one exception! Nowadays CAH is included in newborn screening tests. All babies in the Netherlands receive a screening test also called the "heel prick test," in which blood is drawn in the first ten days of life, irrespective of where they are born – at home or in the clinic.

For our young members, we have recently developed some animations to help them better understand their disease and to help them explain it to family members, at school, etc. Adults also use the animations to explain their disease. You can view these animations here: www.youtube.com/user/adrenalchannel.

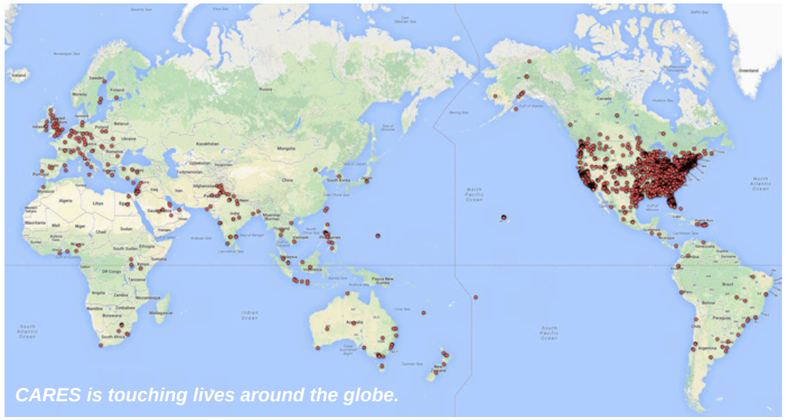
At this moment we are also working together with several European patient organizations on a standardized emergency card, which will include crucial minimal medical information that will be recognizable to ambulance personnel. We will keep you informed on our progress.

Starting January 1st, 2015, all ambulance personnel in the Netherlands will follow the same treatment procedures due to the adoption of an 'Adrenal Insufficiency Ambulance Protocol' in the event of adrenal crisis. If someone suffers from adrenal insufficiency, the ambulance will arrive and contact the specialist/endocrinologist/hospital. If necessary, they will inject with the appropriate medication (Solu-Cortef®) and transport the patient to the hospital. Currently, patients are taken to hospital and the effects of the adrenal crisis have already created significant harm. This is a huge improvement in treatment!

In the future, we would like to have a global meeting on CAH (similar to the meetings held this year in Oslo for Addison's and in Zurich for Cushing) where those involved with CAH work across the globe could meet to discuss mutual experiences and coordinate future activities for improved patient care "across borders."

One of our recent successes was the emergency kit. We are now working on the improved safety belt clip and the emergency card. We will continue to provide updates on these initiatives.

We have lots more information on our website. Feel free to contact us or consult our website (www.nvacp.nl) or our test-site (www.addisoncrisis.info). This website is "under construction"; we need your comments, advice and criticism.



CARES is touching lives around the globe.

A PERSONAL STORY

Wrapped in Miracles

by Michèle Janine Bacus

Every child is a miracle … this much I know. We celebrate their miraculousness from preconception dreams to postpartum bliss and beyond. My son, Maris Paul, is wrapped in tiny little miracles that have defined his life thus far. As I reflect, I celebrate his milestones, but equally as important, I am reminded of just how lucky we are to have him with us today.

I like to say that I waited a lifetime for Maris plus 296 days, 5 hours, and 19 minutes. Maris took his time to meet the world. I was a week past my due date and finally my OB/GYN made the decision to induce. We checked into the hospital Monday night, May 7th, 2012, and the induction process began. Seventeen hours later, with failure to progress, my body began to go into shock. The end result was an emergency C-section and a large loss of blood for me. I was given a transfusion, and I was not able to see my angelic 8 pound, 9 ounce baby boy until the next day. He was perfect. I, however, was far from it – I was in extreme pain. Due to the C-section, loss of blood, and trauma to my body, the decision was made to keep me in the hospital until late Saturday afternoon.

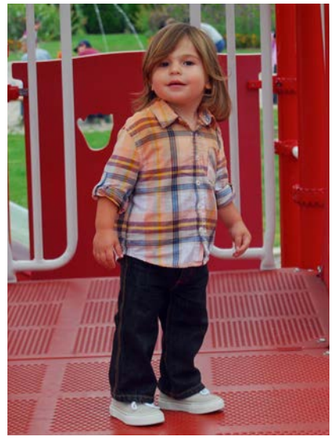
I always think these facts are important as I tell Maris's story. I feel that it is necessary to hear that I had an extended stay in the hospital because that means Maris stayed with me. He was under hospital and pediatric supervision for five days after his birth. When we were released that Saturday, he and I were given a seemingly clean bill of health. Even with those five days in the hospital, Maris was not on anyone's radar.

We went home and began the process of settling in as a family. My sister flew in from New York to help, and my mother would follow. The first few days were a blur. The following Wednesday, Maris was eight days old and that is when I noticed things begin to change. Our morning that Wednesday started off fine. I had errands to run. It was a beautiful spring day, and with Maris in tow, I went about my day. By late afternoon, I noticed something started to shift in my son. He became irritable. He was only eight days old, but he hadn't shown this behavior before. It was subtle, but it still bothered me. Then, as the evening progressed, he began to cry incessantly and was inconsolable. I tried to feed him and he wouldn't take to any of the variety of bottles I had for him. Finally, as the crying continued and evening approached, I relented and took him on a car ride. It seemed to help a bit. He slept, but he would whimper every now and again throughout the ride. He never went into a good deep sleep that a parent hopes for when you take that magical car ride. At the end of the evening, I remember looking at my sister and asking her, "do you think he is sick?" She responded, "I think you probably did too much with him today; you need to just stay home and take it easy."

I followed my sister's advice and had a lazy day the next day. I will admit, he seemed better. He slept well throughout the day and didn't seem as irritable. He still wasn't eating well and that was concerning to me. At the hospital, he really enjoyed his 2 ounces at a time. As the evening approached, the crying began again. I wondered if perhaps I was just going to have a colicky baby. He was struggling to eat, seemed lethargic and was just inconsolable. In my heart, I just felt something wasn't right – but what? It wasn't anything blaring. It was subtle things: lethargic, irritable, diminished appetite, inconsolable crying … any of this could be attributes of any typical newborn. We got through the night Thursday. I woke up Friday. Maris was now 10 days old, and I had a nagging feeling that something was *not* right. I recall it was a Friday because I thought to myself, I don't want to go through the weekend worrying. I thought, let me call the doctor while she has normal appointment hours. I called the pediatrician's office. I apologized in advance, saying, "perhaps I am just being a paranoid first-time mom, but something doesn't seem right. I was transferred to a nurse who thankfully said, "You know, it is probably best you just bring him in." Two hours later, my sister and I were heading into the pediatrician's office. I had plans with my girlfriend for lunch. I called her and said we may be a bit late. I had no idea what was in store for us.

> I had a nagging feeling that something was not right … I had no idea what was in store for us.

When I got to the office, the pediatrician asked my concerns. She began to examine him and then put him on the scale. He had lost enough weight since being discharged



from the hospital to cause concern. The examination continued and the nurses came in and began to check a variety of things. I was in such a daze for much of that visit in the pediatrician's office. I do remember they were trying to do a test on him and were having trouble getting a read. I believe it was a blood oxygen test. I don't know that the particular test they were doing has any relevance now … I also remember my pediatrician excused herself from the exam room. We were left in the room with just the nurses and eventually they excused themselves as well. The pediatrician returned about 20 minutes later. When she returned, she looked at my sister and I and said, "change of plans. You need to get to the ER at Children's Hospital immediately." I am so grateful my sister was with me that day. I honestly didn't process that statement. I called the friend that I was supposed to have lunch with and informed her that I may be later than expected. I dressed Maris, packed up my diaper bag, and looked at my sister who was equally confused. The pediatrician then got stern with us, said there was *no* time to explain, but something came up on his newborn screen that may explain what is happening. Children's Hospital is expecting you; I need you to get there immediately. I looked at my sister again, still not understanding and I wondered … his newborn screen, why are we finding out now – he is 10 days old?

That trip to the hospital was an eternity. I sat in the back seat with Maris holding his tiny hand while he cried. I had no idea what was going on or what to expect. I did not realize that my son was in full adrenal crisis and needed medical attention immediately or else he would die!

As we checked into Children's, it was a whirlwind … vitals, questions about family history, blood being drawn, doctors, nurses. I am not even sure in what order it all happened. I kept hearing sodium, potassium, 17 OH Progesterone. None of this was making sense. I was paralyzed by fear of what this all meant and praying that he would be okay. He was hooked up to machines and blood was drawn. EKGs were coming back irregular and he could barely lift his head. My little rosy-cheeked child seemed pale and gray. By the end of the night, only one thing was clear, that my little boy would not be coming home with me. He was admitted to the NICU and

> I realize that little miracles happen every day. Maris is proof of those miracles, and I realize that much hard work, advocacy, and education goes into making those miracles happen.

hospital staff and doctors hovered around him. I was frightened and confused.

The next morning shed some light, and it also revealed that our lives would now be forever changed with blood tests, medications, monitoring and doctors. Yet, I felt so incredibly blessed. The miracles surrounding my son appeared daily, and we woke up to another day with him, which was truly something to celebrate. The rules of his life were now different, but we had our son.

As we stood by his NICU crib over the next several days and he was stabilized, I learned so much. We were given the diagnosis of Congenital Adrenal Hyperplasia. I learned that he is salt wasting; I learned that my husband and I are both carriers unbeknownst to us, and I learned that my son being with us and recovering was truly a miracle. I was told that my son tested positive on the newborn screen. However, my husband and I were not made privy to the results. I also know now that our pediatrician was never properly notified. As I sit and write this today, I still don't know whom to blame for the failure in communication. I remember there were a variety of doctors who stopped by to see us. I can recall one doctor stopping by and introducing himself and talking about the diagnosis of CAH. As he set off to leave he said to me, "That is the Department of Public Health at work!" I gently corrected him and said, "Sir, I was not notified by Department of Public Health or notified by anyone for that matter. I noticed something was wrong with my son and I brought him to see the doctor." He apologized and said he was not aware of that.

Maris was released from Children's on May 28th, 2012. He was 20 days old. The first few days out required many trips back to the hospital and pediatrician for blood tests and monitoring. When we saw our pediatrician the first time after being released from the NICU, she apologized to me for her demeanor the day we were rushed to the hospital. She said she excused herself to request the results of the newborn screen and when she saw the results, she knew he was in bad shape. His numbers were off the charts. Now that he was stable, she could calmly tell me, "Michèle, if you had not brought him in that day, we more than likely would have lost him." I am still haunted by that.

I had many questions in the days and months that followed, and though I will have a lifetime of questions regarding my son and his health, one echoes the loudest for me – Where did the communication fail? We have made so much progress with newborn screens in all the states testing not only for Congenital Adrenal Hyperplasia but also for a variety of conditions that can prove critical/fatal if not treated in the first days of life, but I ask over and over again, how can the system be better? How could the information from the newborn screen be disseminated more effectively and efficiently to both doctors and parents? Maris came so close to being a statistic. What can be done differently to prevent a close call or perhaps even worse for another child.

As I reflect on the CAH diagnosis, I realize how blessed we are. I realize that little miracles happen every day. Maris is proof of those miracles, and I also realize that much hard work, advocacy, and education goes into making those miracles happen. Stabilizing and maintaining Maris's health to the point that he is now thriving is one such miracle. We have made huge strides. My hope is that our experience – Maris's story – can take us further. We have come so far on this journey, but as a community, we can still strive to go further.

FUN-RAISING

New York, New York

More than 200 guests joined Samantha Bee, the comedic actress best known as a correspondent for the Daily Show with Jon Stewart, who served as emcee for the Everyone CARES Gala, A Salute to Broadway. The event, held on March 28th at 230 Fifth in New York City, brought together patients, families and medical professionals for an unforgettable night of fun and celebration of the CAH community.

The evening included a cocktail reception, silent and live auctions, dinner, and an award ceremony recognizing the contributions of three distinguished honorees. The honorees were Dr. Karen Su, CARES Medical Director and pediatric endocrinologist at New York-Presbyterian/Weill Cornell Medical Center; Deborah Brown, a dedicated member of CARES Board of Trustees and co-chair of the Community Advancement Committee; and Diurnal Limited, a pharmaceutical company headquartered in the UK currently developing new treatment options for CAH. Their vision, commitment and dedication have helped to fulfill CARES' mission to improve the lives of the CAH community and to advance quality health care through support, advocacy, education and research.

The Gala raised more than $150,000 for CARES Foundation's programs and services. In addition to raising significant funds, the event also raised awareness and strengthened the sense of community by bringing together so many families and individuals affected by CAH.

Special thanks go out to the event committee, the honorees, the sponsors and all who took part in the magical evening. For more information, and to see pictures of the event, visit www.caresgala.org.

Top left: CARES Board of Trustees president Katherine Fowler with 2014 honoree Dr. Karen Su, and Dr. Maria New.

Top right: Katherine Fowler, 2014 honoree Deborah Brown, and Greg Kraff.

Middle: Drs. Richard Ross, Martin Whitaker, Deborah Merke, and David Eckland at the 2014 Everyone CARES Gala in New York City.

Right: 2015 CAREing Hearts Gala honorees Dr. Scott Rivkees, Marisa Lanford with her family, and Oceania Cruises. The 2015 Gala will be held on May 8th in Orlando, Florida.

CAREing Hearts Gala 2015 – Orlando, Florida

We are proud to announce the honorees for our 2015 Gala, which has been renamed "CAREing Hearts Gala." They are Dr. Scott Rivkees, Professor and Chair of the Department of Pediatrics at the University of Florida, Physician-in-Chief of Shands Children's Hospital, Academic Chair of Pediatrics at Arnold Palmer Children's Hospital, member of CARES' Scientific and Medical Advisory Board and co-author of *Congenital Adrenal Hyperplasia: A Parent's Guide*; Marisa Langford, a mother of four and a CARES Foundation support group leader since 2009; and Oceania Cruises, a luxury cruise line headquartered in Miami that has been a major supporter of CARES Foundation since 2011.

The event will take place on Friday, May 8th at the Marriott World Center in Orlando, Florida. For more information, contact Dina@caresfoundation.org.

Talk It or Walk It

This year's CAREing Hearts Walks have been an enormous success. New Jersey had its 3rd Annual CAREing Hearts Walk on September 28th at Wild Duck Pond Park in Ridgewood. California and Virginia entered the mix with their first ever CAREing Hearts Walks held on October 12th in Los Angeles and November 8th in Chesterfield. Hundreds of patients, families, friends and medical professionals came together to share experiences, learn about CAH, and network with each other. It was a rewarding experience to see families and supporters come together and enjoy a day of fun-filled activities and education.

Special thanks to Chad Lapp, Karen Bogaard, Cynthia Winze and Laurie Zehner for hosting the walks. We are also grateful to all the walkers, sponsors and supporters who helped make a difference in the lives of CAH patients. Thank you to the Division of Pediatric Endocrinology at Children's Hospital Los Angeles for providing injection training!

If you participated in one of the walks this year, let us know what you thought of the experience. If you didn't have the opportunity to join us, we hope you will join us next year.

Walking Together
Here's what one mom had to say about participating in a CAREing Hearts walk:

"Mothers find solace in each other's company. We share stories and strategies; we talk of teething, commiserate over colic, and collectively mourn loss of sleep. It makes us feel like we're not alone, like maybe we're not messing this whole parenting thing up and that at the end of the day, at the very least, someone else gets it. So, when you're the mother of a child with a rare, life-threatening medical condition that few can relate to, it can leave you feeling isolated on top of the emotional roller coaster you're already on.

Family and friends may not be able to understand the day-to-day struggles we face, but they love and support us with a vengeance. They put their support into action at that annual Walk for A Cure (CAREing Hearts Walk for CAH Awareness) in honor of our daughter, raising money for our cause. On this one day every year, I don't feel quite so alone in this fight as I walk with families who know our struggle intimately as they battle it everyday with their own child. And, when I glanced around the crowd walking with us and when the donations kept rolling in, I felt such love and gratitude that I know will see me through those bleak days. My daughter may not understand it just yet, but imagine how incredibly loved she will feel when she looks around and sees all those people who came out just for her.

Wouldn't it be awesome for every man, woman and child with CAH to feel such support? We may not be able to cure anyone just yet, but wouldn't it be great to let people know they are not alone, that someone does care? Just knowing you came out in support of them would be so rewarding for them and for you. Imagine instilling this value in our children now – what a compassionate world this place could be by the time they become adults.

Next year CARES will hold another walk, another chance to connect with families, another opportunity to demonstrate support, another way to raise money and awareness for a cause near and dear to all of our hearts. I hope to see you out there. I will be the one proudly walking with a fun-loving, exuberant, and super smart little girl, who happens to have CAH.

To our family and friends who came out this year and to those who donated: It means the world to us, and we thank you!"

Clockwise from top left: Chad Lapp running the North Coast 24 Hour Run; having fun at the Virginia CAREing Hearts Walk; Los Angeles walk; Kids' Fun Run at the New Jersey walk.

Chad Lapp Runs 24 Hour Marathon for 4th year in support of Andrew
We want to thank our very own Chad Lapp, Vice President of the Board of Trustees, for an amazing display of endurance and determination in completing another North Coast 24 Hour Run in Cleveland. This year marked his fourth run in support of five-year-old Andrew who served as his motivation as he ran a grueling 107.35 miles. Chad finished second in his age group and 13th overall while raising awareness and funds for Andrew who has salt-wasting CAH and others with CAH.

Over the past four years, Chad has raised more than $40,000 for CARES. Thank you Chad for your dedication and commitment!

Talk It!
Our Talk It campaign has come to a close with great success. The Talk It campaign provides an opportunity for those unable to attend our CAREing Hearts Walks or unable to host their own event, a simple approach to supporting CARES and raising funds for CAH.

Talk It! is a virtual fundraising campaign that allows participants to set up their very own web page to fundraise. From the comfort of their own home, they can make personal donations, request donations from friends and peers, and track their team's progress as donations grow. It's also an opportunity to raise awareness about CAH.

Each year, participants in our Talk It or Walk It campaign are entered in a drawing for one of three prizes. For each $500 raised, they get one entry. Congratulations to our winners!

This year's Talk It or Walk It campaign raised more than $75,000. Thank you for your support! We look forward to having you join us again next year.

Family Fundraising

No event is too small when it comes to supporting CARES! Oftentimes small, family hosted fundraisers are a great way to raise awareness of CAH while also providing a fun and enjoyable experience for our CAH community. Here are some examples of family hosted fundraisers held this year.

Party with a Purpose – California
Thanks to Sue Shirey for hosting Party with a Purpose, bringing together CAH families and supporters in Southern California for a night of music, dancing and raffles. The event raised more than $10,000 for CARES Foundation.

Girls Night Out – New Jersey
Our Girls Night Out event, hosted by Sari Lee, helped raise more than $2,000 as supporters met at CAN DO Fitness Club in Short Hills for a night of food, shopping and fun.

Family Fun Day - Illinois
The Quarter Auction, Buffalo Wild Wings and Family Fun Day fundraisers in Galesburg, planned by Meo Kyser, raised over $1,000.

A Big Thank You
We also want to extend our gratitude to Fred and Wendy Thornley for raising funds for CARES in celebration of Fred's birthday, and to Michelle Dearie for hosting a Christmas Stall to benefit CARES. *Thank you all for bringing patients and families together!*

If you would like to plan an event to benefit CARES, contact Dina at Dina@caresfoundation.org. Stay connected via our website and email to receive information on how to connect with individuals who are hosting events.

AmazonSmile

Help put more smiles on the faces of CAH patients by using AmazonSmile for your holiday (or everyday) purchases.

AmazonSmile is a simple and automatic way for you to support CARES Foundation every time you shop at no cost to you! When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as you do on Amazon.com. The only difference is that Amazon will donate a portion (0.5%) of your purchase price to CARES.

How to support CARES with AmazonSmile
On your first visit to AmazonSmile (www.smile.amazon.com), go to the bottom of the page, and in the box under "pick your own organization," type in Congenital Adrenal Hyperplasia Research, Education and Support. Once you select CARES Foundation, your account will be set to CARES for all future purchases. If you already shop with Amazon, you do not need to create a new account. Your account information is the same for AmazonSmile.

So go ahead and put a gift under the tree and a smile on many faces. Happy shopping!

Good Search

Raise money for CARES Foundation just by searching the web and shopping online!

Here's a great way to raise money for CARES! Use Yahoo! powered GoodSearch.com as your search engine and they'll donate about a penny to your favorite cause every time you do a search!

In addition, shop at their online shopping mall, GoodShop.com – where you can choose from more than 900 top online retailers – and a percentage of your purchases will go to the charity of your choice.

It quickly adds up! See the chart below for an example of how much we can earn. The sky's the limit! Searching has never been better! Here's the website: http://www.goodsearch.com.

No. of supporters	Avg. search/day	Est. revenue/year
100	2	$730
1,000	2	$7,300
10,000	2	$73,000

CAREing Hearts Society

We are pleased to introduce CARES Foundation's CAREing Hearts Society, launched in 2013 to recognize the outstanding generosity of our donors without whom CARES would not exist.

The impact this group of donors makes on CARES is significant. The development of Comprehensive Care Centers, research, and education, along with our other programs and services, is directly related to support we have received over time from these individuals.

We thank our Society members for playing an integral role in the success of CARES.

Pioneer
Jessica & Matthew Upchurch

Visionary
Kelly & Adam Leight
Heather McDonald
Meridith & Daniel Taylor
Victoria Charitable Trust
Anonymous

Champion
Cindy & Alan Macy
Marc & Marjorie McDonald
Ernest & Susan Mendes
Drs. Karen & Edwin Su
The Deena Jo Heidi-Diesslin Foundation

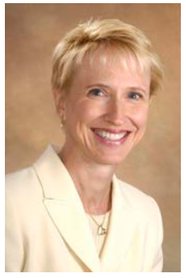
Advocate
Mitzi & Bill Davis
Alexandra Dubois
Doug Zehner & Katherine Fowler
Rhonda & Gregory Kraff
Chad & Sandra Lapp
Richard & Deborah Pendino
Sandra & Mack Rose
Dr. Diane Snyder & Albert Steren
Anonymous

Friend
Rodrigo Quintanilla & Vivian Altman
Susan & Carl Aycock
Sondra & Michael Brunone
Pamela Chiles
Jeffrey & Leah Kronthal
Alex & Sari Lee
Arthur & Nancy Lee
Anna Pinto
Hope & James Raphalian
Dr. Richard Rink
Dr. Peter Schlegel
Kenneth & Vicki Upchurch
Matt & Barbara Wilson
Stephanie Rose
Anonymous

WELCOME ABOARD

New Additions to the Board of Trustees

We want to extend a warm welcome to our new members of CARES Board of Trustees – Kathryn Ashenfelter, Karen Bogaard, Carlos Da Silva, Anthony Fine and Cynthia Winze.



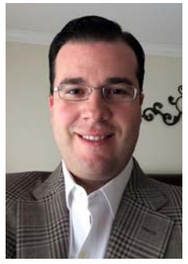
Kathryn Ashenfelter
Kathryn Ashenfelter of Denver, Colorado, comes to CARES with 30 years of finance and progressive leadership experience. She serves as Chief Financial Officer for Swedish Medical Center, a 368-bed acute care, full-service hospital in Englewood, Colorado, which is part of the HealthONE hospital system based in Denver.

In addition to CARES, she is active in a number of other organizations including the Epilepsy Foundation of Colorado, having served as President and Treasurer, and is the current Treasurer of Doctors Care of Colorado and the Colorado Humane Society. Ms. Ashenfelter received a Bachelor of Science Degree in Accounting from the University of Nebraska and is a Certified Public Accountant.

Karen Bogaard
A licensed physical therapist since 1980, Karen Bogaard provides Home Health services for patients who are homebound. She specializes in geriatrics and joint replacement rehabilitation services.

Karen is no stranger to volunteerism. She currently serves on the Board of Trustees of Flintridge Preparatory School in La Canada, California. She has also been extremely active with Crestview Preparatory School where she served on the Board of Trustees, having chaired it for two years. Prior to her Board position, she served on the Parent Association Board, serving as president of that board and benefit chair. Karen also served on the Auxiliary Board of St. Vincent Hospital in Los Angeles.

Karen Bogaard received her bachelor's and master's degrees from the University of Southern California. She and husband Tom, a urologist practicing in Los Angeles, have four children – one with CAH. They live in Pasadena.



Carlos Da Silva
As President of LB Industries, Inc. of Pennsylvania, Carlos Da Silva's responsibilities include general administration with special emphasis on finances, bonding and insurance, as well as day-to-day management of construction operations. Mr. Da Silva founded LB Industries in 2004. The company has established itself as a premier niche contractor for water and wastewater treatment authorities in Central New Jersey, Eastern and Central Pennsylvania.

Prior to LB Industries, Mr. Da Silva was Director of Financial Operations for EIC Associates, Inc., a diversified heavy civil construction firm with annual sales in excess of $60 million. He also served as a Senior Consultant at Arthur Andersen LLP, where he began his professional career.

A graduate of Lehigh University, Mr. Da Silva lives in Pennsylvania with his wife Sonia and their two sons – one of whom has CAH.

Anthony Fine
A native of England, Anthony Fine is Head of Finance and Planning Systems for Thomson Reuters Group. Before joining Thomson Reuters, he worked for Price Waterhouse Coopers in Sydney and London.

A graduate of Manchester University with a degree in Computer Science and Accounting, Anthony lives in New York City with his wife and two young children. His younger son was diagnosed with SWCAH, which caused him to take in interest in CARES Foundation. Anthony's hobbies include exercising, sports and traveling. He and wife, Dina, have volunteered for many years as guides for the Achilles Track Club, which enables disabled people to run, cycle and swim.

Cynthia Winze
Cynthia Winze, President and Owner of PSF Manufacturing Company, is a leader in creating silk florals, plants, trees and interior plantscapes. Cynthia and her team of artisans passionately create signature silk florals, accessories, and interior plantscapes that captivate the senses and elevate the environments in which they reside. For the past 10 years, Cynthia's driving passion is to make the lives of others better by making their surroundings beautiful. That passion has transformed into hundreds of successful and fulfilling partnerships, collaborations, and projects. PSF's partners include furniture stores, restaurants, corporate office spaces, historic architectural landmarks, residential developments, hospitality corporations, as well as collaborations for special events.

Prior to starting her own business, Cynthia worked as a regional asset manager for some of the nation's largest and most respected real estate development and investment firms. For 18 years, Cynthia managed 17 million square feet of class A, multi-use, and industrial real estate for Trammel Crow and Cushman & Wakefield. Cynthia also worked as a successful consultant for international clients, managing and expanding their domestic portfolio of commercial and residential holdings to 250 million dollars in investments.

Cynthia graduated from the University of Southern California with a degree in business. She is a cancer survivor and married with two children. She and her husband are also raising their beautiful five-year-old granddaughter who was diagnosed with CAH at birth. Cynthia resides in Southern California with her family.

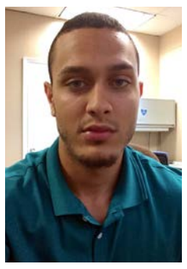
Scientific and Medical Advisory Board

Dr. Oksana Lekarev
Dr. Oksana Lekarev has been appointed to CARES Foundation's Scientific and Medical Advisory Board. Dr. Lekarev is an Assistant Professor of Pediatrics in the Division of Pediatric Endocrinology and Metabolism at Weill Cornell Medical College. She is also the Assistant Medical Director of the Comprehensive Care Center for Congenital Adrenal Hyperplasia at New York Presbyterian Hospital at Weill Cornell.

Dr. Lekarev graduated cum laude from Barnard College, Columbia University, with a BA in Linguistics. She went on to receive her medical degree from the University of Medicine and Dentistry of New Jersey – School of Osteopathic Medicine. Dr. Lekarev completed an internship in Pediatrics at the Robert Wood Johnson Medical Center in New Brunswick, NJ and residency in Pediatrics at Tufts-New England Medical Center in Boston, MA. She went on to complete a fellowship in Pediatric Endocrinology and Diabetes at the Mount Sinai School of Medicine in New York, NY. Her research and much of her academic work during her fellowship was on the subject of Congenital Adrenal Hyperplasia, conducted under the guidance of Dr. Maria New. She has published on the subject of CAH and other adrenal disorders in a number of peer-reviewed journals and textbooks.

Dr. Lekarev is excited to be involved with the CARES Foundation and its families and to be an integral part of The Comprehensive Care Center at Weill-Cornell.

A New Member of Our Team



Chris Gerena, Intern
We are pleased to welcome Chris Gerena to our staff. As an intern, Chris handles electronic communications for the CARES community, as well as maintaining web tools for fundraising events.

A recent graduate of Montclair State University, Chris plans to attend law school and become a JAG officer.

NEW DIRECTIONS

New Leadership

Katherine Fowler
CARES Foundation is pleased to announce that Katherine Fowler is the new President of the Board of Trustees. She is Vice President of Outpatient Services at Barnabas Health in New Jersey. Since joining CARES in 2009, Ms. Fowler has served as Vice President and Chair of the Fund Development Committee.

Her focus for her presidency includes expanding access to clinical information and expertise for all CAH patient and families. She is also leading the effort to develop a long-term strategic plan for CARES.

The mother of twins, she resides in New Jersey with her husband.

New President of the Pediatric Endocrine Society

Dr. Mitchell Geffner
Dr. Mitchell Geffner, Division Chief of the Center for Endocrinology, Diabetes, and Metabolism at Children's Hospital Los Angeles, and Professor of Pediatrics at the Keck School of Medicine of the University of Southern California, was recently elected President of the Pediatric Endocrine Society. The mission of PES is to advance the care of children and adolescents with endocrine disorders. With more than 1,300 members representing the multiple discipline of Pediatric Endocrinology, PES members are dedicated to research and treatment of children with endocrine disorders; reproductive, bone, thyroid, diabetes, obesity, growth, pituitary and adrenal. The Society works to promote the continuing education of its membership.

Dr. Geffner's goals for his presidency include improving PES's relationship with other societies including the Endocrine Society, ESPE, and PENS (among other groups); maximizing membership numbers through heightened recruitment and retention efforts; increasing corporate support with attention to transparency; moving forward on previously established initiatives related to journal affiliation and international outreach in Central America and the Caribbean; and creating a visiting fellowship program. We wish him much success in his new role!

Prestigious Honor

Dr. Maria New
Dr. Maria New, Director of the Adrenal Steroid Disorders Division at the Mount Sinai School of Medicine in New York, was awarded the prestigious Fondation IPSEN 2014 Endocrine Regulations Prize during The 16th International Congress of Endocrinology jointly with The Endocrine Society 96th Annual Meeting and Expo in Chicago. She presented the award lecture titled "Non-Invasive Prenatal Diagnosis of Congenital Adrenal Hyperplasia" at the Chicago meeting on June 23rd.

The prize is awarded annually to a researcher or a physician who has carried out work essential to a better understanding of the role of neuroendocrine interactions in regulating the body's major metabolic functions. It is bestowed for a particularly significant body of work rather than a single discovery. Dr. New joins a distinguished list of previous honorees, many of whom are Nobel Prize laureates. Congratulations on the well-deserved honor!

Comprehensive Care Centers for CAH

The Comprehensive Center for Congenital Adrenal Hyperplasia at New York-Presbyterian/Weill Cornell Medical College
Individuals with CAH may have a variety of medical needs that require access to a team of health care providers and multiple subspecialists. Furthermore, not all physicians are familiar with CAH and its management. For these reasons, having a "medical home" that provides a comprehensive approach to care is paramount for CAH patients and their families. In September 2009, CARES hosted a meeting of medical professionals that included representatives from multiple medical specialties, as well as patients and family members, to develop guidelines for Comprehensive Care Centers (CCC) for CAH. A summary of those guidelines was published in 2010 in the International Journal of Pediatric Endocrinology. Based on those guidelines, CARES solicited applications for a pilot CCC and in 2013, the New York-Presbyterian/Weill Cornell Medical College (WMC) was awarded the title of the first CARES-designated CCC for CAH in the United States.

The CCC at WMC brings together health care providers from multiple specialties with expertise in CAH. This team is able to provide expert care at all phases of a life of an individual with CAH: from newborn period to childhood, adolescence and adult life. The Center includes a medical and surgical

component that is under the direction of Drs. Maria Vogiatzi, Pediatric Endocrinology, and Dix Poppas, Urology.

The mission of the CCC at WMC is to provide excellent care, promote research that will improve patient lives, and educate patients, families and other healthcare providers in CAH and its management. The team includes pediatric and adult endocrinologists, urologists, nurse practitioners, patient care coordinators, dietitians, genetic counselors and reproductive specialists. The team's goal is to address not only the physical, but also the psychological needs of patients and families. For this reason, the center works with a psychologist who specializes in the care of children with chronic disorders and with Dr. Heino Meyer Bahlburg, a psychologist with wide experience in CAH. The Center organizes an interdisciplinary conference on CAH that is open to all physicians at WMC. In collaboration with CARES, it also hosts conferences that bring together speakers with various expertise in CAH in an effort to provide continuous education to patients and families. The Center is also implementing a transition program that prepares young patients to adult-oriented care.

Research being conducted includes an NIH supported study that examines surgical outcomes in patients with non-typical genital development, as well as a pilot study on the use of Metformin therapy in patients with CAH.

For more information or to make an appointment, visit: www.nyp.org/komansky/cah or call 212-746-3975 (medical) or 212-746-5337 (surgical).

Left: The New York Presbyterian Hospital/ Weill Cornell Medical Center in New York City is the first CARES-designated Comprehensive Care Center for CAH in the United States.

TIDBITS

CAH Parents as Patient Advocates

by Stephanie Erb

Having raised a SWCAH child who had many early complications, I garnered a great deal of knowledge about the trials and tribulations of raising a CAH kid, the *hard* way. Also, having worked as a consultant for CARES, I learned of the issues that other parents have all over the country. As we all know, each kid is different, and depending on what geographical area your family lives in, the methods of treatment vary a great deal. My hope is that some day in the not-so-distant future, a regular protocol for CAH kids will be well known, and implemented worldwide. For right now, though, a parent must educate themselves and seek out the CAH experts where they can.

So. My first advice is always *listen to your instincts*. If your kid is not growing, growing too fast, sick a lot, having problems with high blood pressure, has obesity issues, repeatedly has adrenal crises, or anything else that bothers you and it is not getting solved, it is time to find a CAH expert. What does that mean? It means a doctor who aids *many* kids with CAH – not three … not even ten …more than that … and usually they are found in more metropolitan areas. Ask CARES to help you find one. Luckily, due to technology, bloodwork and files can be transferred to an expert and they can offer their opinions about dosing methods or testing that may need to be done. Ideally, if you can make a onetime trip to visit an expert, that would be great, but a phone consult with exchange of your kid's information can also be really helpful.

Many parents are concerned that their home endocrinologist will feel slighted or angry at having a CAH expert check on your child, their patient. My simple answer to that is, *Tough!* A good doctor will want to know how to treat a CAH kid the best that they possibly can.

My own experience is that although I had a very well respected endocrinologist, my child was not only ill a lot, but her bone growth was not being checked regularly and it was getting out of hand. If her bone age is not monitored properly, I learned that my child could lose many inches off of her adult height, as her bones will fuse too early. I felt that she was not being carefully monitored, and I eventually listened to my instincts and found a doctor who treats many more CAH patients. If you cannot leave your child's endocrinologist like I did, at the very least you need to teach him/her how to dose and test a CAH child more properly by enlisting the help of an expert.

My suggestion would never be to fiddle with your child's dose or do anything without the expert chiming in. Finding the perfect dose of Cortef and Florinef (and yes, the stronger meds are not advised in little ones, and circadian dosing is also well-accepted) is an intricate thing. You are attempting to replace the hormones as *closely as possible* to what the child would normally make if they could. In order to do so, regular bloodwork (3 or 4 times a year), bone age X-rays, and exams by your child's endocrinologist are imperative, especially in the early years when your child is growing quickly.

If your endocrinologist is not watching these things closely, it may be time to get a second opinion. And if your child is having repeated adrenal crises, it is most definitely time to bring in the experts. In the meantime, read what you can, talk to CARES, and let your child's endocrinologist know that you would like to explore new solutions to manage your child's CAH.

I recently took part in the CARES walk in LA and got "re-schooled " on how to give the emergency shot. I am so glad I did, because I had forgotten *exactly* how to do it – it had been so long since I had even had to think about it! Please also make sure you feel comfortable with that process, as the ambulance and emergency room staff may not have a clue what CAH is or how to treat it. You cannot hurt your child by giving the shot – it is a onetime dose. But overdosing regular meds over a long period of time is another story, so if you feel something is wrong, get it checked out.

And you are not alone. I guarantee you each parent living with a child with CAH has their own anxieties about doing the right thing, including whether to give the shot. And don't get me started about school and babysitters, etc – well that is a later article. The more we demand that doctors know about CAH, the better it will be for us all. CARES has been instrumental in trying to increase international knowledge of CAH and its treatment, and my hope is that someday those doctors who really "have it down" can teach pediatric endocrinologists all over the world.

Helpful Products

Dealing with CAH on a daily basis involves careful planning and organization; here are some of the products and guides we offer to make your life easier living with CAH.

Buzzy

Buzzy is a palm-sized device combining cold and vibration that when placed between the brain and the pain, decreases sharp pains. His wings are icy cold, and his tummy vibrates when you touch his head. This confuses the body's nerves to block sharp feelings, just like rubbing a bumped elbow helps stop the hurt, or cool running water soothes a burn. Buzzy is ideal for blood draws, vaccinations, flu shots, dental procedures and more.

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

Adrenal Crisis Information & Training

One flash drive includes two videos addressing adrenal crisis. The videos include instructions on stress dosing and administering the Solu-Cortef® injection. The videos also review the signs, symptoms and treatment of adrenal crisis. (Windows formatted. Not compatible with Mac without additional software).

Traveling with CAH/AI Packet
Traveling with CAH/Adrenal Insufficiency (AI) is all about being prepared, taking the proper precautions, and most of all, having fun! Whether you or your loved one is staying overnight, leaving for a couple of days, or traveling to a foreign country, CARES Foundation's "Traveling with CAH Packet" will help you plan for a safe and healthy trip.

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

Getting Ready for School/Camp Packet
This packet aids in building a strong team of family, friends, health care providers, teachers and others to ensure the health and safety of your child with CAH while at school or camp.

Adrenal Insufficiency Window Cling

In case of a car accident, this sign will alert emergency medical staff that there is a passenger with adrenal insufficiency in the car. The sign "clings" to the car window with easy removal.

Adrenal Insufficiency Shoe Tags

This item is great for children who have trouble wearing a medical alert bracelet. In case of an emergency, this shoe tag will alert emergency medical staff that your child has adrenal insufficiency. Attach this tag to your child's shoelaces or other laced items.

Purchase these and other items from the CARES Shop at www.caresfoundation.org or call 866-227-3737.

Happy Holidays!

We want to wish you a very happy holiday and a happy, healthy and prosperous 2015.

Please consider CARES Foundation in your year-end giving. Thank you for your continued support!

CARES connections

Please remember that CARES Foundation newsletters have “gone green” and are now only available electronically. Please make sure we have your most current e-mail address and contact information to ensure that you continue receiving newsletters and other important information from CARES. Send your updated information to Odaly Roche at Odaly@caresfoundation.org.

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research, education and support for congenital adrenal hyperplasia