CARES connections

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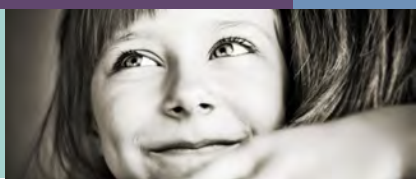
Improving health, connecting people, saving lives



In This Issue

Why Do Women with Non-classic Adrenal Hyperplasia Have Infertility? Can Early Treatment Reduce These Problems?

Ricardo Azziz, MD, MPH, MBA
President, Georgia Regents University and CEO, Georgia Regents Health System; Professor, Obstetrics, Gynecology, Medicine and Medical Humanities

21-hydroxylase (21-OH) deficiency non-classic adrenal hyperplasia (NCAH) is one of the most common human genetic (autosomal recessive) disorders, affecting approximately 1 in 1000 to 5000 individuals. Clinically (meaning what can be seen by the naked eye or through a medical examination), women with NCAH tend to suffer from excess male-like hair growth (hirsutism), irregular menstruation, and lowered fertility potential.

Regarding infertility, it is important to understand that while many women with NCAH may have difficulty conceiving, many patients with NCAH are able to have children naturally. In other words, women with NCAH have a lower fertility potential than normal, but by no means are they sterile or unable to conceive at all. Also, we should remember that fertility (or infertility) depends on a couple's expectations. Having one child, or even two children, over a few years of unprotected intercourse may be perfectly acceptable to some couples, particularly if they are young. To others, this may constitute infertility.

Why do women with NCAH have lowered fertility potential (also called subfertility)? In general, it is because women with NCAH overproduce male hormones (also called androgens) and progesterones (like 17-hydroxyprogesterone and natural progesterone itself).

Many women with NCAH suffer from clinically obvious excess male hormone production (hyperandrogenism). The excessive male hormone production in patients with NCAH initially comes from the adrenal (more precisely, the zona reticularis of the adrenal cortex). Because of the abnormal function (or amount) of the enzyme 21-OH in NCAH (a direct result from the original genetic defect), the adrenal cortex tends to overproduce the androgen androstenedione (a problem that is not life-threatening) while trying to keep cortisol (a steroid essential for life) production in the normal range. The excess androgen production by the adrenal in most NCAH patients begins or worsens around the time of puberty.

The excess androstenedione produced is then easily converted to a more potent androgen called testosterone, or even to the most potent of male hormones, dihydrotestosterone. This conversion occurs in the adrenal itself, as well as in the liver, fat, and many other tissues in the body, resulting in the excess male hormone effect we generally see in women with NCAH.

The excess androgens can cause a number of effects:

• The excess male hormones affect the skin, resulting in excess body [*continued on page 3*]

A Message from the Executive Director

Dear Friends,

We just celebrated our first CAH Awareness Month in June. During the celebration we saw an increase in the number of individuals visiting our Facebook page and following us on Twitter to read the CAH fact of the day. Our posts reached thousands of people across the globe who are always eager to learn and help educate others about CAH. Thank you to all who helped spread awareness.

Since our last edition, we have been busy creating tools for educating patients and professionals, opening our first center of excellence for CAH, connecting patients and families, working on EMS protocols, and raising awareness with our first CAH awareness walk and our gala. In this issue of *CARES Connections* we want to give you a brief look into our work.

Raising Awareness of CAH

Raising awareness has been a key component of our work over the last several months. We have done this through increased participation in social media outlets including Facebook, Twitter, Google+, YouTube and LinkedIn; as well as through events such as our first annual CAREing Hearts Walk for CAH Awareness; Trick-Hoops and Alley-Oops with the Harlem Wizards; Everyone CARES Gala – A Night at the Montage; as well as other CAH-family hosted events across the country. We are grateful to all who participated in these events and helped promote them. It is only through increased awareness that we will continue to educate others about CAH and secure the resources to continue to grow our programs and services.

Education

Education continues to be a key component of our work. Whether through social media, videos, guides, or conferences, we are expanding our educational opportunities.

Last year, we held two conferences, one at New York-Presbyterian/Weill Cornell Medical Center in New York and the other at Children's Hospital Los Angeles in California. Hundreds of patients, families and professionals benefited from sessions offered by some of the top CAH experts.

This year's conference, which will take place at Miami Children's Hospital in Miami, Florida, on October 19th, promises to be one of our most successful conferences in years. The conference will cover topics of interest to parents as well as adult patients and health care professionals. We look forward to seeing you in Miami.

Education extends to our website and outlets such as YouTube. We have created a new stress dose video available on our website, and a training video on recognizing the signs of an adrenal crisis. This video is aimed at educating emergency department staff including doctors and nurses.

Patient Resources

A diagnosis of CAH can be frightening, overwhelming and certainly life-changing. As parents, you have many questions about what to expect now and throughout your child's life. We want to help you sort through the onslaught of medical information, cope with the feelings you are experiencing, and answer your questions. So, we've established monthly support group meetings via teleconference. The meetings are held via conference call on the second Monday and Thursday of each month. We invite you to participate. Contact us for call-in information.

In our efforts to continue improving the lives of CAH patients, we have created a *Guide to Traveling with CAH and Adrenal Insufficiency* which provides valuable information on how to prepare for a trip – what to do before, during and after your travel. This guide is available on our website through product cart.

If there are other resources you would like us to provide, please let us know what they are and we will do our best to respond to your requests.

Personal Stories

Inspirational personal stories about living with CAH are always welcomed by families and patients. If you'd like to share your experience with our community, please send me your story with a picture or two at dina@caresfoundation.org. We look forward to reading your story!

Let us know what you think about this edition of *CARES Connections*. Your feedback will help us better serve you in the future.

Wishing you a fun-filled and healthy end of the summer,

Dina

[*continued from page 1*] and/or facial male-like hair growth (i.e. hirsutism), acne, and less frequently, male-patterned scalp hair loss (i.e. androgenic alopecia).

• The excess male hormones also frequently result in irregular ovulation, which causes NCAH patients to have irregular, infrequent or absent menstrual periods and to have diminished fertility.

The excess male hormone production from the adrenal causes irregular ovulation by two main mechanisms. Firstly, the excess androgens affect the ovaries directly. It is harder for normal ovulation to occur in the ovary in an environment with too many male hormones.

Secondly, the excess male hormones affect the parts of the brain that control the hormonal signals that determine normal ovulation and normal ovarian function, namely the hypothalamus and the pituitary gland (also called hypophysis or 'master gland') right below it. The excess male hormones tend to cause irregularity in this signaling, and consequently irregular ovulation, although the exact manner by which excess androgens do this is still unclear.

In addition to excess male hormones, the adrenals in patients with NCAH overproduce progesterone type hormones (a.k.a. progestogens), including progesterone itself and 17-hydroxyprogesterone (17-OHP) (the level of which is generally used to screen for and diagnose NCAH). Patients with NCAH also overproduce other progesterone-like hormones, although in smaller quantities, such as 17-hydroxypregenolone.

The excess progestogens have a number of effects that diminish the fertility potential of women with NCAH. Firstly, these hormones also affect the function of the hypothalamus and the pituitary, contributing to the irregular brain-to-ovary signaling and the consequent irregular ovulation of patients with NCAH.

In addition, even if ovulation occurs, the excess progestogens diminish fertility by causing the lining (endometrium) of the womb (uterus) to be thinner and less receptive to a pregnancy than it should be at the time of ovulation. Doctors often call this a prematurely decidualized or luteinized endometrium. The excess progestogens can cause the mucus at the neck of the womb (cervix) to be thicker and cloudier than it usually is at the time of ovulation, thus making it harder for sperm to penetrate and get to the inside of the uterus (and eventually fertilize an egg or ovum).

We generally treat the excess production of androgens and progestogens by the adrenal by giving NCAH patients corticosteroids – hydrocortisone, prednisone, or dexamethasone. In brief, the corticosteroids (also called glucocorticoids) reduce the need for the adrenal to produce cortisol, and hence also reduce the amount of androgens and progestogens produced by the gland.

However, excess androgen and progesterone production from the adrenal is not the only cause of infertility in women with NCAH. Over years, the detrimental effects of these hormones on the function of the ovary becomes more permanent, and women with NCAH begin to develop a self-perpetuating abnormality of ovarian function, similar to what is found in women with polycystic ovary syndrome (PCOS). This similarity is another reason why we should strive to always distinguish women with true PCOS from those with NCAH by screening any woman with symptoms suggestive of hyperandrogenism for NCAH using baseline levels of 17-OHP.

In this event, the ovaries become somewhat larger and are covered in small cysts, which result from egg-containing follicles that never ovulated. They produce an ovarian picture that we call "polycystic ovaries." The ovaries in these NCAH women also overproduce male hormones, often in quantities greater than that produced by the adrenal itself.

What is more worrisome is that the ovarian condition in these women with NCAH often becomes self-perpetuating. Even if we reduce the amount of male hormones produced by the adrenal by using corticosteroids, the ovaries of these women continue to overproduce male hormones and to ovulate irregularly.

What we don't know is how long it takes for women with NCAH to develop PCOS-like ovaries. Moreover, can this scenario be prevented?

In fact, we are currently undertaking a study of this exact question, funded in part through a generous grant from CARES Foundation.

It has been my experience, having seen or studied hundreds of women with NCAH, that patients diagnosed early in life (before the age of 20 years) and treated with corticosteroids demonstrate relatively regular ovulation while on treatment, while women that are older when first diagnosed do not resume regular ovulation, even when treated with corticosteroids.

> Most patients with NCAH will be successful in their quest for fertility and a family of their own, although early diagnosis and careful pre-pregnancy counseling ... will increase the odds of a healthy outcome.

Therefore, we are doing a study to see if this impression is correct. Firstly, we are studying the records of the women with NCAH that I, and a few colleagues, have already seen for clues to the answer. Secondly, also with the help of colleagues from around the world (many of whom formed part of the 'NCAH Multicenter Study Group'), we will try to identify women with NCAH when they are diagnosed for the first time and study what their ovulation does in response to corticosteroid therapy alone.

Perhaps our results will indicate that early diagnosis and treatment solely with corticosteroids will result in life-long regular ovulation in the majority of women with NCAH. We hope to have some preliminary results later this year or early in 2014.

What about pregnancy outcome in patients with NCAH? A number of years ago, with members of the NCAH Multicenter Study Group, we completed a large study of over 200 women with NCAH who had conceived. We found that, of 203 pregnancies studied, almost 70% occurred prior to the mother's diagnosis of NCAH. Spontaneous miscarriages occurred in one-quarter of pregnancies occurring prior to the mother's diagnosis of NCAH, but in only 6% of

pregnancies after the diagnosis was made. Other researchers have also observed that miscarriage rates seem to be lower when women with NCAH become pregnant when on corticosteroid treatment.

Our study also indicated that 2.5% (or less than 3 per 100) of the 162 live-births observed were diagnosed with classic congenital adrenal hyperplasia (CAH) at birth. This small risk of classic CAH in the children of women with NCAH likely occurs because about two-thirds of women with NCAH carry at least one severe gene mutation that can determine classic CAH if the father also happens to carry a severe mutation. In addition, about 15% of children of mothers with NCAH also have NCAH. Both these risks were much higher than initially estimated, likely because mothers with NCAH (like most of us) tend to marry within their ethnic groups, which increases the chances that they will be having a child with a partner that also carries a mutation in the 21-OH gene.

The results of this study suggest that diagnosis (and likely treatment) before a woman with NCAH becomes pregnant may help reduce the chances of a miscarriage if pregnancy does occur. The results also suggest that appropriate preconception (pre-pregnancy) counseling of patients with NCAH, regarding their risk for having a child with NCAH and classic CAH, should be done. The assessment of risk will require genetic testing of the patient and her partner. If both individuals carry a severe mutation, there is a risk of having a child with classic CAH, and prenatal diagnosis should be considered; although still experimental, high dose corticosteroid treatment in early pregnancy can reduce virilization in a female offspring affected with classic CAH.

A few words about the effects of NCAH in male patients. In general, males with NCAH also have the same excess production of androgens and progestogens by the adrenal as women with NCAH do. The excessive production of these hormones, particularly androgens, early during puberty can accelerate bone growth and cause some of these boys to have shorter adult stature than they would otherwise have. Anecdotally, male patients with NCAH seem to be hairier and to be more likely to have scalp male pattern hair loss than non-affected men. However, considering the vastly greater (and more potent) amounts of androgens being normally produced by the testicles relative to that produced by the adrenal, I think it is unlikely that NCAH in males causes much difference in body hair growth.

> Not all REI experts fully understand the impact or ramifications of NCAH on fertility, so it's best to check ahead as to whether the physician has ... experience in treating infertility in patients with NCAH.

Regarding fertility, there are small reports suggesting that sperm production might be affected by the excess androgens or progestogens produced, or by the presence of testicular adrenal rest tumors (bits of adrenal tissue in the testes which are stimulated to enlarge by the increased ACTH found in many men with adrenal hyperplasia, principally those with CAH). Overall, however, there appears to be little convincing data that fertility in men with NCAH is affected to any meaningful degree by their disorder. More research is obviously needed in this area.

So what can we do about infertility (or subfertility) in NCAH? It certainly looks like the earlier we can diagnose and treat patients with NCAH the better, in terms of the pregnancy outcome, and maybe even in terms of ovulatory function. Therefore, implementing the routine screening of all patients that have hyperandrogenic signs or symptoms (e.g. those with persistent acne, irregular menstruation, or hirsutism) for NCAH is important. Screening can be done by a simple blood test measuring the baseline level of 17-hydroxyprogesterone (17-OHP).

Patients with NCAH should be counseled about the risk of subfertility and, when possible and feasible, they should consider beginning to attempt conception at an earlier age (not as a teenager, of course, but before age 35 years!). There is no need to make things more complicated by unnecessarily adding in the natural decline in fertility that occurs with age. They should also be counseled about the possible benefits of therapy and about the possible need for genetic testing of her and her partner before attempting pregnancy.

Additionally, if the couple is young enough, they should be counseled to be patient (unless menstrual cycles are very irregular). However, an evaluation may be necessary to ensure there are no other problems that may be causing infertility (just because you have NCAH doesn't mean there are no other reasons for fertility problems).

Possibly, we may be able to improve long-term ovulatory function and pregnancy outcome in NCAH by treating patients promptly and hopefully as early as possible with corticosteroids. If corticosteroids alone fail to cause regular ovulation (which needs to be verified by checking ovulation not just by checking the menstrual function), then the use of ovulatory agents like clomiphene or even gonadotropins (a.k.a. menotropins… the 'shots') may be necessary. Occasionally, even in-vitro fertilization (IVF or the 'test-tube baby' procedure) may be needed.

Two of the most difficult issues to deal with in the treatment of fertility in NCAH patients are: (a) what to do when the NCAH patient and the father-to-be carry genetic defects that could result in a baby being born with classic CAH, and (b) how to treat the NCAH patient whose progestogens remain high despite adequate corticosteroids.

When the NCAH patient and the father-to-be both carry severe mutations of the 21-OH gene that could result in their baby being born with classic CAH, an in-depth discussion with a genetic counselor is needed. Potentially, the use of IVF with pre-implantation genetic diagnosis (PGD, or testing the embryos for genetic defects before being placed into the patient's womb) may be used. Experimental therapy with dexamethasone (which crosses the placenta) in early pregnancy may prevent masculinization of the genitalia in female offspring with classic CAH. This therapy, if considered, should be initiated before nine weeks gestation and continued until the sex of the baby is known; if the fetus is a male, high dose dexamethasone therapy can be discontinued.

In most patients with NCAH treated with adequate doses of corticosteroids, the levels of progestogens in the blood will decrease to close to normal. However, in those patients with NCAH whose endometrial lining (lining of the womb) never fully develops (generally judged by its thickness as seen by ultrasound in the days immediately before ovulation) and who continue to have high levels of progestogens (progesterone or 17-hydroxyprogesterone), higher doses of corticosteroids may be used to fully decrease the levels of these hormones to normal when attempting to conceive.

One final word about seeking medical care for infertility related to NCAH. While many general gynecologists do perform basic infertility evaluation and therapy, it is probably best that NCAH patients seek the advice of a board-certified infertility expert (called 'reproductive endocrinology & infertility' or REI specialists, which are certified as such by the American Board of Obstetrics & Gynecology). However, not all REI experts fully understand the impact or ramifications of NCAH on fertility, so it's best to check ahead as to whether the physician has an interest and, more importantly, experience in treating infertility in patients with NCAH. Co-consultation with a medical or pediatric endocrinologist with expertise in the treatment of NCAH may also be appropriate.

Overall, most patients with NCAH will be successful in their quest for fertility and a family of their own, although early diagnosis and careful pre-pregnancy counseling, preparation, and therapy with the right physician will increase the odds of a healthy outcome. 💔

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RESEARCH (continued)

Abiraterone Acetate Added to Physiologic Hydrocortisone and Fludrocortisone Normalizes Androgens in Adult Women with Classic 21-Hydroxylase Deficiency

Richard J. Auchus, MD, PhD, University of Michigan

My colleagues and I conducted a phase 1 open-label, multiple-dose, intrasubject, sequential dose-escalation study that enrolled 6 women with classic 21-hydroxylase deficiency and serum androstenedione >1.5× normal (>345 ng/dL), who were taking 20 mg/d hydrocortisone plus fludrocortisone. Abiraterone acetate (AA) is a potent inhibitor of CYP17A1 (steroid 17-hydroxylase/17,20-lyase), an enzyme required for androgen synthesis, and AA tablets are FDA-approved for treating prostate cancer. The AA oral suspension was taken for 6 days, starting at 100 mg QAM with dose escalations after ≥7-day washouts, until >80% of participants had normalization (<230 ng/dL) of the morning androstenedione. After the last dose, we measured androgens every 2 hours for 8 hours. Janssen Pharmaceuticals sponsored the study.

Of 14 subjects taking 20 mg/d hydrocortisone and fludrocortisone screened, only 6 women had an androstenedione >1.5× normal. At 100 mg/d AA, androstenedione normalized in 50% of participants, with a reduction from a median baseline androstenedione of 764 ng/dL to 254 ng/dL. The primary end point was met at 250 mg/d AA, as androstenedione normalized in 5/6 (83%) participants, with a decrease from a median baseline of 664 ng/dL to 126 ng/dL (81% fall). After the Day 6 AA dose, androstenedione fell further to a median nadir of 66 and 38 ng/dL by 8 h at 100 and 250 mg/d, respectively. Serum testosterone and urine testosterone metabolites fell in parallel to androstenedione. At 250 mg/d AA, testosterone decreased from a median baseline of 89 ng/dL to a median of 28 ng/dL (69% fall). AA was safe and well tolerated, without significant adverse events.

AA appears to be a promising addition to current therapy for treating the androgen excess of 21-hydroxylase deficiency.

NIH Studies Effectiveness of Pump in Administering Medication

The National Institutes of Health is studying the effectiveness of a new pump which delivers missing adrenal hormones in a manner more closely matching release by the adrenal glands.

The study is limited to individuals with classic congenital adrenal hyperplasia (CAH). Soon after birth, infants with the disorder have such symptoms as lack of appetite, vomiting, lethargy, and salt wasting—elimination of sodium through excessive urination. Treatment for CAH involves taking pills containing hydrocortisone, a synthetic form of the hormone cortisol, which their bodies fail to produce. The pills deliver a single large dose of the medication rather than a continuous small dose. Large doses may be required to treat some CAH symptoms. Too large a dose, however, can lead to abnormal weight gain and obesity, accumulation of fat in liver, diabetes, low bone mass, and bone fractures.

"We hope that the pump represents a new treatment that more closely matches the body's production and release of cortisol, and reduces the current risk of side effects associated with taking a single large dose of medication," said Aikaterini Nella, MD, of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), a part of NIH. The researchers will conduct the study at the NIH Clinical Center in Bethesda, MD. Participants may qualify for reimbursement for travel and lodging expenses.

To be eligible, men and women with classic congenital adrenal hyperplasia must be 18 years of age or older, must have high androgen levels, and must be diagnosed with one or more of the following: obesity, fatty liver, increased risk for diabetes, low bone mass, or inability to tolerate cortisol pills.

Study participants will be evaluated free of charge by NIH physicians four times over six months. Each visit at the NIH will last three to five days. Patients will be asked to provide blood and urine samples, and will undergo magnetic resonance imaging scans and other tests. Additional information about the study is available at http://clinicalstudies.info.nih.gov/cgi/wais/bold032001.pl?A_13-CH-0121.html@congenital@adrenal.

NIH Contact Information

For patient-related and scheduling questions, email: ccdmpatient@mail.nih.gov

CHASE Study Update

Richard J. Ross, MD, Sheffield University, UK

In the UK, we have been following up on a cohort of over 200 patients with CAH who are now adults. In the original publications, we found that patients had an increased instance of obesity and associated problems in addition to impaired quality of life. We have now analyzed this in further detail. In a paper published in *JCEM* earlier this year we looked at the relationship between genotype of patients with CAH compared to the problems they had in adult life. What we found was that health outcomes such as obesity and poor quality of life were not related to the genotype, suggesting that they might be related to treatment. In a second paper published in the *European Journal of Endocrinology* again this year, we looked at the relationship between quality of life and treatment. We found that increased adiposity and insulin resistance were associated with the use of prednisolone and dexamethasone and with impaired quality of life. Of course, what we don't know is whether or not patients who have a worse quality of life get put on different drugs or whether the different drugs may result in adiposity and impaired quality of life. This will require future study.

EDUCATION

Educational Videos

We have introduced new learning tools that can be found on our website and YouTube.

Congenital Adrenal Hyperplasia & Stress Dosing educates parents, teachers, school nurses, family and caregivers on when and how to give a stress dose injection. We are grateful to Louise Fleming, MSN, RN and UNC-Chapel Hill School of Nursing for the development of this essential video.

Adrenal Crisis in the Emergency Setting educates emergency department doctors, nurses and other personnel on the signs of adrenal crisis and how best to treat it. Special thanks to our medical director, Dr. Karen Lin Su, and Matthew Krayton of Fairleigh Dickinson University.

These videos cannot be reproduced without written consent of CARES Foundation.

NYMAC Introduces Baby's First Test

The New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC) has launched a clearinghouse website (babysfirsttest.org) that provides educational and family support and services information, materials, and resources about newborn screening at the local, state, and national levels. Here you will find:

- Basic facts about newborn screening and what to expect from the screening process
- State-specific newborn screening program information for parents and health professionals
- Condition-specific information
- Social media feature
- An interactive blog

2013 EDUCATION CONFERENCE

CAH: A Comprehensive Approach to Patient Care (Classic and Non-classic)

Our annual education conference will be held on Saturday, October 19, 2013 at Miami Children's Hospital in Miami, Florida. The conference covers a range of topics for pediatric and adult patients and features some of the nation's top experts in CAH, including Drs. Richard Auchus, Alejandro Diaz, Maria New, Dix Poppas, and Scott Rivkees, among others.

Topics include:

- Diagnosis of CAH/NCAH for Adults
- Treatment Options for CAH/NCAH in Children & Teens
- Surgical Considerations for the Adult Population
- Living with CAH: Issues of Gender and Romance for Women
- Monitoring CAH/NCAH in Children & Teens
- Surgical Considerations for the Pediatric Population
- Genetics and Counseling
- Treatment for Adults with CAH/NCAH
- New Non-Invasive Method for Prenatal Diagnosis of CAH

Breakout sessions:

- Adult women
- Dermatological Issues
- Emergency Issues
- Parents of Adolescents
- School/Camp Packet Overview

This is an excellent opportunity to interact with CAH professionals and to connect with other patients and families. Spanish translation and sessions will also be provided.

The conference is not for patients only. Caregivers and health care professionals will benefit from the program.

To register or for more information, visit our website at: www.caresfoundation.org http://www.caresfoundation.org/product-cart/pc/events/Miami13/.html

THE DOCTOR'S IN

Back to School and Sports

It's that time of year again. Keep these health tips in mind as the kids get back into the swing of the school year:

1) Sports
Extra snacks and fluids are particularly important for patients with CAH during strenuous exercise. Water alone does not provide adequate replenishment for what is lost during copious perspiration. Gatorade (or similar) provides electrolytes and glucose along with fluid replacement, but it may not contain enough sodium for salt-wasters who are sweating profusely. In these cases, salty snacks will also be necessary to make sure that hyponatremia (dangerously low sodium) does not occur. In certain situations, it may be appropriate to give extra fludrocortisone prior to a particularly strenuous activity in extreme heat, but do not do so without speaking to your endocrinologist first.

2) Flu Vaccine
Early fall is the time to start thinking about immunizing your child against the influenza virus, which causes the "flu." Because any severe illness can precipitate an adrenal crisis in individuals with CAH, it is better to be protected ahead of time. Speak to your pediatrician about when the flu vaccine will be available for administration.

3) School
In order for your child to remain safe during school, it is important to prepare ahead of time. If applicable, speak to the school nurse about any medications your child requires during the day as well as when Solu-Cortef® should be administered. Provide the school with a letter from your doctor to keep on file. Also make sure that sports and physical education personnel understand the precautions detailed above under "Sports."

Please see our "Getting Ready for School" packet for additional information.

4) Trauma
Trauma can occur at any time. Be prepared by wearing Medical Alert Identification and making sure Solu-Cortef® is easily accessible at all times.

Remember to check the expiration date on all Solu-Cortef® Act-O-Vials. All households should check their Solu-Cortef® prescriptions and ask for new prescriptions if necessary. Expired Act-O-Vials can be used to train teachers, school nurses, caregivers, family and friends on how to administer an injection.

If you would like a copy of CARES' Emergency Instructions, please call (toll free) 866-227-3737 or email info@caresfoundation.org.

See our "Adrenal Insufficiency" tags and shot kit bags, available in the CARES Shop.

FLU SEASON IS HERE!

Don't forget to get flu vaccinations early (either by injection or nasal mist). Children and adults with CAH require special care during illness, and the vaccination is a good first line of defense.

ADVOCACY

EMS Campaign Update

Progress continues to be made in our efforts for the inclusion of treatment protocols for adrenal insufficiency by EMS providers.

Arizona
On November 21, we will present before the EMS Protocols, Medication and Devices Committee at the Bureau of EMS and Trauma. This committee makes recommendations for protocol changes to the state EMS medical directors covering 80 EMS agencies in Arizona.

California
The EMDAC Scope of Practice Committee approved a draft Orange County policy enabling paramedic use of prescribed, patient-carried drugs that are outside of the state scope of practice. The Orange County medical director is working on expanding paramedic education to include addressing adrenal crisis.

Colorado
Protocols have been approved for all Advanced Life Support (ALS) ambulances to carry and administer Solu-Cortef®. Local ALS ambulance services should be contacted in order to ensure they are aware of the protocol passage. Basic Life Support (BLS) services may apply for a waiver so that they may also administer Solu-Cortef. Marshall Cook, of Lamar Ambulance Service, was very instrumental in these positive developments in Colorado.

Connecticut
Protocols are being drafted addressing adrenal crisis and will be presented to the regional EMS medical directors for approval.

New York (Suffolk County)
Protocols have been approved for all of the 84 Advanced Life Support (ALS) departments. Prior to this, specialized protocols were sent to the ALS department where someone with adrenal insufficiency was identified.

Vermont
Statewide protocols are being drawn up and are expected to be approved in the fall of 2013.

Campaigns are continuing in Alabama, Arkansas, Arizona, Florida, Georgia, Illinois, Indiana, Kansas, Louisiana, Missouri, New Mexico, North Carolina, Oregon, Virginia, Utah, Washington and Wisconsin.

Your Support Is Important
Your support will help advance our cause. If you would like to start or join an advocacy campaign in your community, please contact Karen Fountain at Karenf@caresfoundation.org or 1-866-227-3737.

Visit Your Firehouse
It's always a good idea to visit your local firehouse/ambulance association to alert them to your household member with CAH. You can also offer to help with adrenal insufficiency training. Call us for more details.

MAKING CONNECTIONS

Support Group Center

Monthly Newborn Support Group Meetings
Finding out your child has been diagnosed with CAH is overwhelming, frightening and raises many questions. In order to assist new parents and caregivers, we have started a monthly Newborn Support Group to address issues that arise during this intense time period. Our Newborn Support Group leaders are available during these calls to help navigate those first doctor's appointments and provide resources for more information.

The meetings are being held via teleconference on the second Monday of the month at 11am (Eastern Time) and second Thursday of the month at 9pm (Eastern Time). Contact the office at 866-227-3737 or Karenf@caresfoundation.org for the call-in information.

Welcome New Support Group Leaders
Our support group leaders are an invaluable resource to new members and others looking for answers and an understanding ear. We'd like to welcome our newest support group leaders:

- Kristen Guzman Brazie – Northern California
- Celestine Quiroga – Florida
- Courtney Tolbert – Illinois
- Stacy Holmgren – Minnesota
- Melissa Axtell – Washington
- Chana Lewis for Women with NCAH (nationwide)
- Janice Blaszczyk for Women with SWCAH 40+ (nationwide)
- Michele Bacus for Newborns (nationwide)
- Kendra Borzio for Young Adults with NCAH (nationwide)
- Rosa Louw – South Africa

Thank You!
Many thanks to Stephanie Rose, our Women with NCAH support group leader of many years. We are also grateful for Tara Hackett and Chad M. Foster. Tara has helped us for a number of years as our Northern California support group leader and Chad has been a great help to our members in Michigan. Thanks for your commitment to those affected by CAH.

Connecticut
On April 6, one of our CT support group leaders, Wendy Thornley, and her family held a Benefit Bingo Night for CARES. It was a full house with Wendy's husband Fred calling all the games. The fun event raised more than $2,000! Thank you, Thornley family!

Nevada
On August 4, Julie Tacker held a Nevada Support Group event at her home with swimming, barbecue, and fun for the kids. Thanks for gathering our Nevada community!

Pennsylvania
On August 10, one of our PA Support Group leaders, Debbie Ham, held her second annual Bowling Fundraiser at the ABC Lanes & Lounge in Harrisburg, Pennsylvania. It was a great night which brought together older and younger people affected by CAH.

Top: Fred Thornley and his former kindergarten teacher at Bingo Night for CARES in Connecticut. Bottom: Debbie Ham and family at their second annual Bowling Fundraiser in Harrisburg, Pennsylvania.

Next SGL Meeting
Our next Support Group Leader teleconference will be held October 16 and 17. We are looking forward to hearing about issues being raised in our community and how we can better help. It's always great to hear what other leaders are doing around the country.

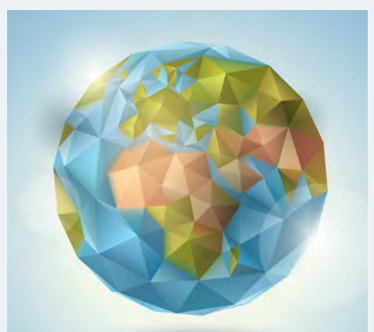
Endless thanks to our support group leaders!

CAH AROUND THE WORLD

Brazil: Newborn Screening
On May 9, 2013, Brazil's Ministry of Health published an ordinance authorizing the first of four states to start testing newborns for CAH. The states are São Paulo, Minas Gerais, Mato Grosso do Sul and Paraná. Advocates hope that by the end of this year, five more states will begin testing.

We applaud the efforts of Dr. Tânia Bachega and her colleagues who have been tireless in their efforts to make screening a reality.

Vietnam: New CAH Club Provides Suppport to CAH Patients
We applaud CLAN and the CAH community in Vietnam for their work to improve the lives of CAH patients through the formation of a new CAH Club in Hue, Vietnam. CARES Foundation is proud to have supported its founding with a donation. Dr. Yen-Thanh Mac, CLAN Vietnam Program Manager expressed his gratitude with this note, "I can say that I found that Vietnamese CAH community was surrounded by many great CAH communities all over the world. Thank you very much."



CAREing HEARTS WALKS FOR CAH

New Jersey and Oklahoma
Patients, health professionals, families and friends will gather in New Jersey on September 28th and Oklahoma on October 12th for the 3-mile CAREing Hearts Walk for CAH. The Walks will also include a Kids Fun Run and other activities for children. Registration starts at 9am and the Walks kick-off at 10am. There will be music and raffle prizes, including the chance to win an Ipad Mini.

Illinois
Saturday, October 26th – Lincoln Park – Galesburg, IL

Join CAH families and members of the community for the 1st Annual CAREing Hearts Walk for CAH Awareness at Lincoln Park in Galesburg, IL. The Halloween-themed Walk will include a walk around the park, trick or treating stations, and a costume contest.

To register or for more information, visit our website at www.caresfoundation.org or go directly to: http://caresfoundation.kintera.org/walkit2013. Those who prefer not to walk can support the event by making donations and spreading awareness. More details are available on our website.

Proceeds from the walks will benefit CARES' programs, including patient and medical education, research, centers of excellence, EMS protocols for adrenal insufficiency and other programs to benefit the CAH community.

Ask the Expert

Do you have questions about medication, treatment, nutrition, etc.? Then "Ask the Expert" is for you! It's a service that allows our community to ask our Medical Director a question that has not been answered on our site. If you have concerns, this is a great way to have your mind put at ease. Dr. Karen Lin Su responds to you directly. Several of the questions and answers are posted on our blog for the benefit of others who may have similar questions or concerns. Ask the expert to get involved and join the conversation!

Our Blog

The purpose of our blog is to build a community, to increase awareness and advance communication. We encourage you to read, search, and join the discussion. Topics we cover include: "Ask the Expert" questions, Personal Stories, EMS Campaign Updates, Parent Tips and more. If you have a personal story, parent tip, or a question that would benefit others and you would like to share, please email us at contact@caresfoundation.org. Make sure to take a look at our blog and click the subscribe button to get notifications and updates.

Get Connected

Do you use Facebook and Twitter? So do we! And in addition to Facebook and Twitter, we now use LinkedIn, Pinterest, and Google+.

We are striving to keep you updated on all the latest topics concerning CAH in real-time. Social media is a great way to stay connected with us and the CAH community.

Physician Referral

Do you have a doctor or other health care expert who has been caring for you or your child that you would like to recommend to others? We are continuously updating our database of qualified and caring professionals across the United States and around the world. If you would like to recommend anyone, please let us know so we can share it with others. Send us an email with the professional's name, contact information (including his or her email address and phone number), and location (city, state, country) to Dina@caresfoundation.org.

Thanks for helping us create the connection.

CAH Families Benefit from Free Camps

Once again this spring and summer our children were invited to attend medically-safe camps. SUCCEED Clinic, Serious Fun Network Camps, Dreamstreet Camps and Camp Soaring Eagle offered children ages 4-24 years the opportunity to forget about medication, shots and hospitals and just be kids. For the first time, Double H Ranch in Lake Luzerne, NY, hosted a CAH Session June 28-July 3. Our Connecticut support group leader, Wendy Thornley, was one of the volunteer nurses. Wendy's husband, Fred, was also a volunteer counselor that week.

SUCCEED Camp, now in its fifth year, held a CAH weekend May 18-19 with 23 kids, six teenage helpers, and 18 adult volunteers. There was fishing, archery, crafts, and cooking.

Two of the teen volunteers were Cadette Girl Scouts who completed their Silver Award during camp. One was in charge of planning three science experiments and helping the kids carry them out. The other scout planned and led a sensory hike that engaged all five senses. They did research beforehand to ensure their planning was developmentally appropriate for our 4-11 year olds.

Traci Schaeffer, CARES board member and camp organizer, said, "My favorite part of camp is watching the kids meet other people, young and old, who have the same story. "You take medicine, too?" The connection is immediate and, at this age, intense."

Below are the programs that were open to our community this year:

Succeed Camps:
- Camp Dakani, Oklahoma City, Okla.

Camp Soaring Eagle, Phoenix, Ariz.

Free Serious Fun camps:
- Painted Turtle, Lake Hughes, Calif.
- Camp Korey, Carnation, Wash.
- Double H Ranch, Lake Luzerne, NY
- Victory Junction, Randelman, NC

Free Dreamstreet Camps:
- Dreamstreet Ojai Valley, Ojai, Calif.
- Dreamstreet at Canyon Ranch, Tucson, Ariz.

For information, contact Karen Fountain at Karenf@caresfoundation.org or 866-227-3737.

A PERSONAL STORY

Life with CAH

The Normalcy of a Life-Threatening Medical Condition
by Marc Pollack

When people ask me, "How do you live with Congenital Adrenal Hyperplasia (CAH)?" I normally have to take a second to actually think about what to say. Not because I am nervous about how to respond, but because, in my case, living with salt-wasting CAH has been just that, "living." In my situation, living with CAH has become easier to manage with time. Not that I am judging anyone else, but for me, my parents have knocked it out of the park. To begin my story, I refer back to when my parents first brought me into this world. With my father, standing 6' 4" tall and my grandmother at 5" 10", the expectation that I would be tall was unanimous.

A rough start
I was born on June 6, 1991. When I was an infant, my parents would bring me to the pediatrician carrying along eating charts and, pardon me, throw up charts, because my mother knew something was wrong. Each doctor's appointment, my mother knew something was off. I didn't take down food at all (it actually turned into a running joke which ended up with me getting a plastic bib to save on the clean-up time), and I simply did not look healthy. This pattern continued for my first year of life. I gravitated to salty foods much more readily than sugary foods. I was known as "Marc-y Mouse."

Then, I began to progress rapidly. I shot up in height and began puberty before I was three years old. For those outside of the CAH community, this would seem odd, but for those trained in the CAH field, this would be a tell-tale sign. This was not the case for my inexperienced pediatrician who blamed my mother's worry on her being a first-time parent. Time and time again, my parents brought me in hoping that a light would go off in my doctor's head which would trigger some more tests. Nothing ever came of it.

This was the routine until my brother Jacob was born three years later. Unlike myself, he crashed within a few weeks of birth, thus promoting emergency care and tests that would eventually diagnose him with CAH. (Babies were not screened for CAH at birth back then.) As rare as it is to have two siblings with the same condition, my mother had me tested. If there was ever an "I told you so" moment that I would want to witness, it would have been when the hospital physician told my parents that I also had CAH.

The bond of brotherhood
I am sure that it was both a relief and a blow to my parents to know that not only was one of their children sick, but both were. Looking back, it was a blessing in disguise. To have someone else with me to go through the process of first figuring out the treatment course, then travel to the National Institutes of Health (NIH) and, as mundane as it might sound, take medicine three times a day, was simply a godsend. There were times when one of us was simply scared of the tests, and to have that person related by blood right there was something not many people have. Whether it was standing together at the same time for the two-hour standing test or turning the task of 24-hour urine collection into a competition, it made the journey easier knowing my brother was with me. One time it got so competitive that he accidentally fumbled his entire container in the rest stop on the way down to NIH; needless to say, I won that competition.

This medical condition, as devastating as it might seem, helped us bond and become closer than any duo. From the countless times we had to be stuck with needles, to the bone density tests (the test that used to be three hours of motionless x-rays, which is now 20 minutes), the MRIs, and the infamous bubble test, we were there for each other through it all. Even when we had fights, like all siblings do, one of the patent lines from him was, "If I wasn't born, you wouldn't have been diagnosed," which I took as him saying that I am basically indebted to him until he thinks I've made up for it. This is all brought up for the simple reason that no matter how tough the diagnosis might be at first, having your family as a support system can make any mountain seem like a minor mole hill.

> No matter how tough the diagnosis might be at first, having your family as a support system can make any mountain seem like a mole hill.

Good sports
Growing up, my brother and I were always involved in sports. Yes, that's right, someone with this condition was not only involved in sports, but contact sports as well. My father

playing basketball at the University of Georgia and my mother always being involved in athletics and cheerleading, it was almost a no-brainer that we would be partaking in at least one sport per season. A lot of parents out there think that this simply cannot be done because of all of the possible outcomes there are, but my parents saw past that. My parents knew what kind of kids we were, especially being boys. They quickly came to the conclusion that keeping us inactive was simply not an option. It started with soccer in pre-K and developed into adding baseball or, at that age, T-ball, to the roster of sports. As we got older, we wanted to play more and more. Eventually, we enrolled in the local basketball programs for the winter season and then briefly dove into the football realm.

What made all of this a lot easier for my parents, looking back on it, was that my father was the coach for most of our teams. This built a solid core of support throughout the minor injuries, and a stable first hand "on the scene" for the more serious ones. Honestly, whether we were playing sports, or horsing around the house, my parents dealt with injuries of varying degrees our entire lives. We are boys, and brothers, so obviously there were instances when we were playing outside and one came in crying. I'm not pointing a finger about the time one of the brothers launched a lacrosse ball at point blank range directly into the eye of the other "by accident." These things just happen; there's nothing anyone can do to prevent them. I guess that is a huge hurdle that my parents got over pretty quickly.

What I really give my parents credit for is allowing us to get involved in lacrosse. If you are not familiar with what this sport entails, to put it simply, you run around and hit each other with both your body and a stick. This is probably the most physical and fast-paced game on two feet. We, with a very serious medical condition, played it from young elementary school age all the way through high school.

Support system

Throughout all of this, as easy as I may have made it out to be, the truth is, it is not. When I was younger, it was very important for both my parents and myself, to set up a routine for taking the medications. I cannot tell you how many times my medicines have changed – both the type and dosage. As a kid growing up, the last thing I wanted to do each morning was take pills, but my parents had me do that every single morning. I would wake up at 6:00 am, and by 6:10 am would have taken my medicine. My parents were good at letting me take the pills my own way. For example, I used to have to take about 20 or so pills a day. Swallowing all of them individually was a chore, so in came the apple sauce. It came to be that every family member of mine had a jar of apple sauce in their house in case I slept over. Again, the support system and having everyone informed and prepared made the journey a heck of a lot easier.

Then there was the hassle of being taken out of school lunch a few minutes early for medicine. It really did not bother me that much and, in fact, there were times when I purposely scheduled it to my advantage. I'd go *after* lunch so that I had a few extra minutes of freedom before going back to class. The school nurses made sure I was taking my medication and staying hydrated. There were always Gatorades in the fridge for whenever I needed one or two. My support system included not only family but others in my life as well. I was able to enjoy school field trips, both day and overnight.

As I got older, my support system grew to people I wanted it to include. My high school friend, Carolina, for instance, was there every step of the way, for the ups and downs, dealing with my frustrations and for anything else that I needed during any medical situation. I couldn't have asked for a better friend in her. One of my teachers, Ms. Alice Jenevier, turned out to be there for me when very few people were. In my town, people complain about a broken toe or the car that their parents got them wasn't the one they wanted, and here I was having real issues and very few people understood that. Ms. Jenevier did, and it was in her that I found one of my first adult confidantes that truly helped shape me into who I am today. I have done a poor job of communicating this to her over the years, but I really could not have developed into who I am now without her in my corner.

This trust, and knowing who is good for me, found its way into my current relationship. My girlfriend Suzie may not have been there from the start, but she has certainly been there for my antics in Miami and making me realize the value of making even better choices when on my own. Overall, my parents were very upfront with me about what I needed to do, and what the consequences were for my body if I did not. That in itself made me more responsible than the other kids in my grade.

Taking control

As I got older, my parents began letting me take the reins over my condition. Of course, they were still very hands on, but they began to let me take control of myself, which helped me believe that I could handle my condition as I went to high school. I began making my own medicine kits (with their supervision), going out late (or what I considered late, at the time), and just in a general sense making my own decisions. It began being my responsibility to be on top of this condition and that boosted my self-esteem. I was able to see for myself that this condition, as scary and hard as it is to handle at times, *can* be managed.

Thankfully, my parents were big supporters of going away to college. Not knocking any school in New Jersey, but their motto was that "there is a college for everyone in another state." I had a few offers from Division 3 colleges to play lacrosse and, as awesome as this was, it took a lot for my parents to allow me to make my own decision. Eventually, I chose Curry College, a small private college in Milton, Massachusetts. Nearby, I had the two best relatives I could have ever asked for to support me. After all, I was a college freshman and just like every other kid out there, there were incidents that landed me in the hospital. However, because I had trust in my body, and knowledge about CAH, paired with having relatives 20 minutes away with knowledge of my condition, I was able to overcome the minor setbacks.

Tune ups

Overall, I think the scariest medical incident I ever had directly related to CAH was the stomach virus. With CAH comes the threat of severe dehydration which messes with everything in your body, and when you can't keep anything down, there is a process. First goes the extra meds in the form of pills. If I can't keep them down, there is a six inch intramuscular injection waiting for me. As weird as it may sound, this might be one of the funniest experiences of growing up with CAH. The first time I required an injection, my father was out of town and my mother was alone with me and my brother at the shore. I accidentally let the glass medication bottle roll off the table and it broke! We had to go to the local hospital for another injection. Finding the humor in the incident brought levity to a situation that looks more serious

> My parents ... did not allow me to use my medical condition as an excuse to allow life to pass me by.

to the outside world. If the shot does not stop the vomiting, then we take a quick "day trip" to the hospital to get rehydrated. It became an ongoing family joke that throughout all of Jacob's and my broken bones, sports injuries and stomach viruses, we had our own VIP suite in the emergency room at our hospital. It may sound serious, but I assure you that it becomes a quick page in history and a laugh at the kitchen table as time progresses.

We referred to these mini emergency trips as "tune ups." We would go in, the doctor would give us something to stop the vomiting, feed us with intravenous fluids and run a few tests. After a while, the doctor would say, "okay, try to eat something." I remember one time I asked for a cheeseburger and the doctor said, "sure, why not?" My mom looked at him like he had two heads, but she went and got the cheeseburger from the McDonald's restaurant that was in the hospital. All good to go, we headed for home.

Transitions

From Boston, I decided that I wanted to transfer schools. Imagine my parents' faces when they received the credit card bill with 15 college transfer application charges and none of them being close to family and/or close to New Jersey. That conversation was one for the books. Eventually, I persuaded them to allow me to transfer to the University of Miami in Florida. I also convinced them to allow me to live in an apartment off campus with three other guys who were already down there. I must say that I am indebted to my mom's best friend who, as I learned through the years, has been her sounding board for everything that has come into our lives. It was Kim who helped my mother realize that I could handle this move in my life.

I decided to play lacrosse there and – wouldn't you know it? – during my first practice I ended up breaking my forearm. I am hoping that whoever reads this will show it to their child and learn to go to the doctor when your father, or the soon-to-be doctor in your apartment, thinks you should. I didn't, and it ballooned to the point where I had to go to an emergency orthopedic clinic. Everything turned out okay, but that was an instance when I was trying to be a hero by waiting a couple of weeks as opposed to just going to the doctor.

A year went by without any major issues. Then I wanted to study abroad. Yes, that's right, in another country. I sprung this idea on my parents, and to my pleasure they were 100% okay with me going. With this came the added responsibility of communication. Just because they let me go didn't mean that they did not worry every day I was there. Any parent would be naïve to not have concerns about their child living abroad for six months in a country where they had no contacts. (My dad did contact CARES Foundation for the names of specialists and hospitals with knowledge of CAH, in case I got sick.) I was in London and am now back in the States, safe and sound.

The key to the success of studying abroad is being open to communication. Growing up, even when I wanted to separate from my parents in the way that all teens do, I knew I had to answer the phone call, the text or email. If not, I could visualize my mom flying an F-16 fighter plane to check on me. I hear that as a parent that feeling never really goes away. That's why it was my job to assure them that they did not have to act on that feeling and could trust me enough to take care of myself.

A full life

This journey has not been easy, especially in the beginning. My parents acknowledged that I have a serious medical condition and will take medication for the rest of my life. They did not allow me to use my medical condition as an excuse to allow life to pass me by, even when we got some crappy news from NIH – such as learning of the presence of adrenal rest tissue that can affect the ability to have children, or the realization that my brother and I were just not going to be as tall as my father. The point is that we were raised with the mentality to fight and say, "Yeah that does suck, but what do we do now?" We push through the stuff that would normally tear people apart.

CAH is a condition, not a death sentence. I have lived a normal, healthy, active life that made me into the man I am becoming. Sure, I made mistakes, but I was knowledgeable about my condition, enough to be able to go off on my own and handle it whether my parents were down the street or an eight-hour flight away.

If I were to have a child now, I would absolutely take advantage of all of the camps that the Cares Foundation offers. It's an ideal place to meet kids who have the same medical condition … *without parents!* It's never perfect and you cannot plan for everything, but I assure you that if my brother and I (as off the rocker and active as we can be) can handle it and have laughs along the way, you can too. So, just *live* with CAH!

FUN-RAISING

A Night to Remember

The 2013 Everyone CARES Gala, A Night at the Montage was a wonderful celebration of the CAH Community. The event, held on Saturday, May 4th at the Montage Beverly Hills, was highlighted by a spirit of dedication, commitment and generosity. The evening recognized the remarkable contributions of three distinguished honorees: Dr. Mitchell Geffner, a renowned CAH expert and physician at Children's Hospital Los Angeles; Gretchen Alger Lin, a tireless advocate for the CAH community; and Micato Safaris, an organization dedicated to helping orphaned and vulnerable African children and adults affected by the HIV/AIDS pandemic. Their vision, dedication and commitment have allowed CARES Foundation to establish itself as a global resource for families and health care professionals in the areas of CAH research, education, advocacy and support.

More than 260 guests joined the evening's emcee Stephanie Erb, a television, film and stage actress who has been featured in recurring roles on shows such as *True Blood* and *Weeds*, and is the mother of an 11-year-old with CAH. Erb has spent many years helping new CARES members adjust to the demands, fears, and questions that arise when parenting a child with CAH. One of this year's Gala honorees, Dr. Mitch Geffner, has been a crucial part of Erb's child's medical care, and she and her family are forever grateful to him.

The honorees and guest speaker LA Councilman Bill Rosendahl, whose family is also affected by CAH, highlighted the importance of educating others and raising awareness of the disorder through the sharing of personal stories. These stories create a connection with others that develops into an understanding of the effect CAH has on people's lives. Gretchen Alger Lin encouraged the crowd to tell their stories to others "because you never know who is affected by CAH. You do not know how your experiences may help others cope with CAH." Dr. Geffner spoke of the importance of research, education and quality medical care which can significantly improve the lives of CAH patients in the absence of a cure. Anna Pinto, representing Micato Safaris, noted the importance of raising awareness. "I had never heard of CAH until I learned that dear friends were personally affected." Many of the evening's guests were only introduced to CAH and CARES when they were invited by the event's co-chairs, Jessica Hall Upchurch and Anna Pinto.

The Gala was magical in other ways, too. For some, it was the first time they met another patient with CAH. Families were able to meet other families for the first time and share their stories, challenges, fears and triumphs. The evening was filled with a real sense of community – the feeling that those affected by CAH are not alone.

The event, which included a cocktail reception, dinner, and awards ceremony as well as live and silent auctions, raised more than $250,000 for research and education – *our most successful gala yet!* We are exceedingly grateful for the extraordinary generosity of all who supported the Gala and for the hard work and dedication of event co-chairs Jessica Hall Upchurch and Anna Pinto without whom the evening would not have been possible.

Top: Montage Beverly Hills. Midde left: Dr. Mitchell Geffner with family and friends. Middle right: Executive Director Dina Matos greets guests. Bottom left: Honorees Anna Pinto (Micato Safaris), Dr. Mitchell Geffner and Gretchen Alger Lin. Bottom right: A red carpet moment.

25 Reasons to CARE

In April, leading up to the Everyone CARES Gala, we launched our 25 Reasons to CARE campaign aimed at raising awareness and educating individuals about CAH.

For each of the 25 days, CARES revealed a new reason to CARE with postings in social media outlets including Facebook, Twitter, LinkedIn, and Google +. Many of the reasons described how CARES' efforts have changed the lives of those living with CAH. Others provided facts about the condition.

Why 25? The goal was to raise $25,000 in 25 days for CARES to receive a matching $25,000 gift. Thanks to the generosity of our community, we reached our goal.

A Gift of New Technology

Thanks to the generosity of Jessica Hall Upchurch, Board of Trustees President, our office is now equipped with brand new laptops. Her donation also included other technology upgrades. This new technology allows us to be more efficient and provide the CAH community with better service.

We are grateful for her continued commitment to CARES and our community. Thank you!

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!

GoodSearch

In addition, shop through their online shopping mall, GoodShop.com – where you can shop at 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 web site: 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

Talk It or Walk It 2013

Two ways to support CARES!
Sweat or No-Sweat …
The Choice Is Yours
July – October

Join our new TALK IT or WALK IT Campaign (formally No-Sweat). You can "Talk It" by launching an online campaign with your own web page and invite friends, family and colleagues to donate, or you can "Walk It" by joining one of our walks or hosting your own fundraising event.

TALK IT (No-Sweat)
Not quite ready for the challenge of a full-scale event? Then start an online fundraising campaign with your very own team web page. It's quick and easy to do, and you never have to leave the comfort of your favorite sofa or lounge chair. Start your campaign by setting up a web page at: http://caresfoundation.kintera.org/talkit2013.

WALK IT (Break a Little Sweat)
Ready to break a little sweat? Raise funds and CAH awareness by:

Joining one of the following CAREing Hearts Walk for CAH locations:

Ridgewood, New Jersey
September 28, 2013

Mustang, Oklahoma
October 12, 2013

Galesburg, Illinois
October 21, 2013

To register, go to: http://caresfoundation.kintera.org/walkit2013.

Or host your own event! Start a campaign by setting up a team web page at: http://caresfoundation.kintera.org/HostYourOwnEvent. Pick your event, set a date, make an invitation list, and collect donations. Not sure what kind of event to run? Give these ideas a try:

- Hike or Walk
- Pool Party or Block Party
- Yard, Sidewalk or Garage Sale
- Bowlathon or Mini-Golf Tournament
- Lemonade Stand
- Barbecue
- Picnic
- Birthday, Anniversary, Bar or Bat Mitzvah or Quinceañera
- And … we predict a hot time will be had by all at a chili cook-off!

CAREing Hearts Society

We are pleased to introduce CARES Foundation's CAREing Hearts Society, launched in April 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 welcome the following charter members of the Society and thank them for playing an integral role in the success of CARES.

***$100,000+ – Pioneer**
Jessica Hall & Matthew Upchurch

$50,000–$99,999 – Visionary
Anonymous
Kelly & Adam Leight

$25,000–$49,999 – Champion
Cindy & Alan Macy
Heather McDonald
Marc & Marjorie McDonald
Meridith & Daniel Taylor

$10,000–$24,999 – Advocate
Anonymous
Mitzi & Bill Davis
Rhonda & Gregory Kraff
Sandra & Chad Lapp
Susan & Ernest Mendes
Deborah & Richard Pendino
Sandra & Mack Rose
Dr. Diane Snyder & Albert Steren
Drs. Karen & Edwin Su

$5,000–$9,999 – Friend
Anonymous
Susan & Carl Aycock
Sondra & Michael Brunone
Pamela Chiles
Alexandra & Christian Dubois
Leah & Jeffrey Kronthal
Vivian Altman & Rodrigo Quintanilla
Hope & James Raphalian
Dr. Richard Rink
Stephanie Rose
Dr. Peter Schlegel
Vicki & Kenneth Upchurch
Barbara & Matt Wilson
Katherine Fowler & Doug Zehner

**These amounts reflect cumulative giving since 2006.*

Volunteer Your Services

Do you have a special skill? Perhaps you are a good writer, social media expert, graphic designer, website designer or other IT professional. If so, we can use your help for newsletters, brochures, our website and more. You can also help with projects if you are near our New Jersey headquarters or volunteer for a special event such as a conference, family gathering or other events.

If you'd like to help, please contact Dina@caresfoundation.org.

Thanks for Supporting Our Mission

The Deena Jo Heidi-Diesslin Foundation Supports CARES with Generous Gift
On behalf of CARES Foundation and the entire CAH community, we extend our deepest gratitude for a $25,000 donation from the Deena Jo Heidi-Diesslin Foundation. This very generous donation will help fund our upcoming patient education conference in Miami, and a new research initiative at our Comprehensive Care Center at New York Presbyterian/Weill Cornell Medical Center in New York.

Community Fundraisers Made a Difference
You don't have to host a huge gathering to make an impact. Small, often family-sponsored fundraisers are a great way to raise awareness of CAH. We want to extend our gratitude to the following people and/or companies for hosting fundraisers to support our mission:

Fairleigh Dickinson University Students
Deborah Ham
Lurz Family
Kaitlyn Percle
Sue Shirey
Wendy Thornley

Katherine Fowler, CARES VP and Chair of the Fund Development Committee, accepts a generous donation from Dave Diesslin.

Harlem Wizards

More than 800 people attended our Harlem Wizards event in Livingston, NJ, emceed by talk show host Wendy Williams. The event raised over $12,000 for CARES Foundation, and more importantly introduced hundreds of people to the CAH community. Special thanks to Sari Friedman Lee for coordinating the event and to all the volunteers and supporters who helped make it a huge success.

A Look Back at Our 1st Annual CAREing Hearts Walk for CAH

Our first annual CAREing Hearts Walk for CAH Awareness was held on October 28, 2012, in Ridgewood, NJ, one day before Superstorm Sandy slammed the East Coast. Dozens of patients, families and supporters from four states (NJ, NY, CT, and PA) came together to raise awareness of CAH. The 3K walk was followed by children's activities, a tricky tray, music and socializing. Many families had their first chance to meet others with CAH and parents were able to discuss their successes and challenges with other parents. It was a day of fun and camaraderie.

We look forward to you joining us for this year's CAREing Hearts Walk for CAH! You'll find more information on page 10.

WELCOME ABOARD

New Additions to the Board of Trustees
CARES extends a warm welcome to Alexandra Dubois, Carol Ciluffo, and Sari Friedman Lee. Please join us in welcoming them!

Alexandra C. Dubois
Alexandra C. Dubois of Hingham, Massachusetts, has served as a volunteer Support Group Leader for CARES Foundation since 2009. She was also instrumental in the implementation of EMS Treatment Protocols for Adrenal Insufficiency in Massachusetts and New Hampshire.

Alexandra holds a BA from the University of Pennsylvania and has held various leadership positions in marketing and communications.

Alexandra's professional experience includes director of marketing communications and account supervisor for several corporations where she managed a range of direct marketing, developed online/offline marketing plans and led the planning and advertising for new product introduction.

Alexandra Dubois is also an active volunteer with East Elementary School PTO, Rosie's Place, and Reach Out and Read, where she directs and serves families. Alexandra's eight-year-old son has CAH.

Right: Drs. Dix Poppas and Maria Vogiatzi are joined by CARES Executive Director Dina Matos, Program Manager Karen Fountain, CARES trustees Sari Friedman Lee and Chad Lapp, former board president Gregory Kraff, medical director Dr. Karen Lin Su, and New York Presbyterian Hospital/ Weill Cornell Medical Center staff to cut the ribbon for the Comprehensive Care Center for CAH.

Carol Ciluffo

As Vice President of Revenue Cycle Management for Pinnacle III, a development, management and billing company for ambulatory surgery centers, Carol Ciluffo is responsible for day-to-day operations of the centralized billing office. She is a graduate of Colorado State University where she earned a BA in marketing. Her expertise includes budgeting, billing/collection analysis and reporting. Carol has also served as National Advisory Board Member for the Restless Leg Syndrome Foundation and as a board member of the Epilepsy Foundation of Colorado for nine years.

Sari Friedman Lee, Esq.
Sari Friedman Lee is owner and manager of Livingston, New Jersey based Little Lawyers, LLC which provides enrichment classes to children of all ages in public speaking, debate, mock trial, conflict resolution and negotiation. Sari is also an adjunct professor of Political Science and Law at Montclair University in Montclair, NJ. Sari has held positions at Invesco Institutional, Inc., and Milkbank, Tweed, Hadley & McCloy LLP, where she was responsible for drafting, negotiating and reviewing various corporate documents.

Sari Lee holds a BA from the University of Pennsylvania and a JD from New York University School of Law. She is the mother of a seven-year-old with CAH.

NEW DIRECTIONS

Comprehensive Care Center for CAH

We are pleased to announce that the first CARES-designated comprehensive care center is now open at New York Presbyterian Hospital/ Weill Cornell Medical. The official opening of the Comprehensive Center for Congenital Adrenal Hyperplasia took place on April 19, 2013, with a ribbon-cutting ceremony. Maria Vogiatzi, MD is the center's medical director and Dix P. Poppas, MD is the surgical director.

The Center offers a multi-disciplinary team of experts in the diagnosis and management of CAH for pediatric and adult patients. Services include medical treatment and lifelong follow-up care for patients with classical and non-classical CAH from birth to adulthood; surgical consultations and treatment; transition care for adolescents; psychological support; genetic counseling and prenatal testing, and nutritional support. The Center will also be providing educational programs and conducting research.

For appointments, call 212-746-3975 or visit the website is nyp.org/komansky/cah.

Tell Us about Your Visit
If you had a consultation at the Comprehensive Care Center since April 19th, please email Dina@caresfoundation.org and let us know.

TIDBITS

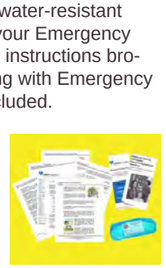
Traveling with CAH/ Adrenal Insufficiency

Planning a fall getaway or thinking ahead to the holidays? CARES has developed a travel guide: *Traveling with CAH/Adrenal Insufficiency*. The packet includes tips on what to do before, during and after your trip; what and how to pack; sample forms to use and more! Be prepared on your next trip and have a *great* time! Head to the CARES store to download the packet for *free* – http://www.caresfoundation.org/productcart.

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.

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.

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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