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]
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 website and following us on Twitter to read our Contact Us page. Our offices received thousands of people across the globe who are always eager to learn and help educate others about CAH.

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 ESM 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 CAH Awareness: Trick-Or-Treats with CAH-Awareness. Trick-Or-Prop 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.

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 meet-ings via teleconference. The meetings are held via conference call on the second Monday and Thursday of each month. For the next call 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 to provide, we will be happy to let you 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,
pregnancies after the diagnosis was made. Other researchers have also observed that miscarriage rates seem to be lower when pregnancy does occur even in-vitro fertilization (IVF or the 'test-tube baby' procedure) may be needed. Additionally, if the couple is young, they should be referred to a gynecologist (unless menstrual cycles are very irregular). Hormone treatment is also safe and recommended in trying to ensure there are no other problems that may be causing infertility (just because you have NCAH does not mean there are no other reasons for fertility problems).

Possibly, we may be able to improve long-term fertility by the early hormone screening and pregnancy outcome in NCAH by treating patients promptly and hopefully as early as possible with adequate androgen suppression or progestogens to prevent the baby from 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 begin trying to conceive, the only treatment that could result in their baby being born with classic CAH, an in-depth discussion with a genetic counselor is in order. Potentially, the use of IVF with pre-implantation genetic diagnosis (PGD, or testing the embryo's genetic defects before it is placed into the patient's womb) may be used. Experimental therapy with demetha- sone (which crosses the placenta) in early pregnancy may prevent masculinization of the genitalia in females with NCAH. 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 demethasone therapy can be discontinued.

In most patients with treated adrenal hyperplasia, the levels of these hormones to normal when treating infertility in patients with NCAH. This therapy, if considered, should be used. Experimental therapy with dexamethasone continued until the sex of the baby is known; if the fetus is a male, high dose dexamethasone therapy can be discontinued.

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.

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 partner choose to have a child, and (b) how to treat the NCAH patient whose progestogens remain high despite adequate corticosteroids.

Regarding fertility, there are small reports suggesting that sperm production might be affected by the process of androgenizing pro- genitors, or by the presence of testicular adrenal rest tumors (bids of adrenal tissue) that might remain to enlarge by the increased ACTH found in men with adrenal hyperplasia, prin- cipally with nonclassic CAH. Overall, there appears to be little convincing data that fertility in men with NCAH is affected to any measurable extent by their disease. More research is obviously needed in this area. So what can we do about infertility (or sub- fertility) in NCAH? It certainly looks as though the earlier we can diagnose and treat patients with NCAH, the better, in terms of fertility, pregnancy outcome, and maybe even in terms of ovulatory function. Therefore, implementing the routine screening of all patients that have androgenizing syndromes is important. Screening can be done by a simple blood test measuring the baseline level of 17-hy- droxyprogesterone (17-OHP).

Patients with NCAH should be counseled about the risk of having a child with classic CAH, and prenatal diagnosis should be consid- ered; 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, during early puberty can accelerate bone growth and cause of 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 less 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 height.

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My colleagues and I conducted a phase I open-label, multiple-dose, intrasubject, sequential dose-escalation study that enrolled 6 women with androstenedione >1.5× normal. At 100 mg/d AA, androstenedione normalized in 58% of participants, with a decrease 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 58% (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 88 ng/dL to a median of 28 ng/dL, 6 fold 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 Contact Information
For patient-related and scheduling questions, email: cctpatient@mail.nih.gov

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 Alenstatini Nelli, 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://clinicaltrials.info.nih.gov/wasb/0b/032001/p/AA_17-CH-0121.html#congenital/adrenal.

NIH Studies Effectiveness of Pump in Administering Medication
The National Institutes of Health is studying the effectiveness of a new pump that 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

NIH Clinical Center

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 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, MBBS, 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 (babystretest.org) that provides educational and family support 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 for Adults
• Treatment Options for CAH in Children & Teens

• New Non-Invasive Method for Prenatal Diagnosis of CAH

Breakout sessions:
• Adult women

• Surgical Considerations for the Adult Population

• Living with CAH: Issues of Gender and Romance for Women

• Monitoring CAH in Children & Teens

• Surgical Considerations for the Pediatric Population

• Genetics and Counseling

• Treatment for Adults with CAH

• 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/new/miami13/cart/pc/events/Miami13.html

Re: Breakout sessions

CARES CONNECTIONS
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 vaccine is a good first line of defense.

ADVOCACY

EMC 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 EMACO Scope of Practice Committee approved a draft Orange County policy enabling paramedic use of prescribed, patient-carried drugs outside of the 24-hour period 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 making sure they are aware of the protocol passage.

Connecticut
On April 6, one of our CT support group leaders, Wendy Thorney, and her family held a 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, Thorney family!

Pennsylvania
On August 10, one of our PA Support Group leaders, Debbie Ham, held her second meeting. Debbie was recently appointed as the new PA Support Group Leader and will be hosting the monthly Newborn Support Group to address the needs of parents who have been diagnosed with CAH.

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 providing such a great experience for your community in Nevada!

Thank you! Many thanks to Stephanie Rose, our Women with CAH support group leader of many years. We are also grateful to Tara Hackett and Chad M. Fostet. 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.

Top: Fred Thorney and his former kindergarten teacher at Bingo Night for CARES in Connecticut. Bottom: Debbie Ham and family at their 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.

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 Baroni and her colleagues who have been tireless in their efforts to make screening a reality.

Vietnam: New CAH Club Provides Support 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 less aided by many great CAH communities all over the world. Thank you very much.”

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. Glucocorticoids (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 hypernatremia (dangerously low sodium) does not occur. In certain situations, it may be appropriate to give extra fluid/scotomors por 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 “Get 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.

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 developed 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 these early 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 Karen@caresfoundation.org for more 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 Bzace – Northern California
• Celestine Quirino – Florida
• Courtney Tolbert – Illinois
• Stacy Holmgen – Minnesota
• Melissa Asex – Washington
• Chana Lewis for Women with NCAH (nationwide)
• Roberta Bacheguy for Women with SWCAH 40+ (nationwide)
• Michele Basso for Newborns (nationwide)
• Karen Brewer for Young Adults with NCAH (nationwide)
• Rosa Loui – South Africa

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Endless thanks to our support group leaders!
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 7th Annual CAREing Hearts Walk for CAH Awareness at Lincoln Park in Galesburg, IL. The mile-long walk for CAH Awareness will include a walk around the park, trick or treating stations, and a costume contest.

To register or for more information, visit our website or contact us at contact@caresfoundation.org.

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+

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.

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 Dinia@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, Dreamstreet Camps and Camp Soaring Eagle offered children ages 4-24 years the opportunity to forget about medicalization, shots and hospitals and just be kids. For the first time, Double H Ranch in Lake Luzerne, NY, hosted a CAH session June 26-29. Our Connecticut camp, 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 teen volunteers, and 15 adult volunteers. There was fishing, archery, crafts, and cooking.

Two of the teen volunteers were Cadette Girl Scouts who planned a Silver Award during camp. One was in charge of planning three science experiments and helping the kids see them come 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 Schwoerer, CAH Aware 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:
• Dreamstreet, Ojai Valley, Calif.
• Dreamstreet at Canyon Ranch, Tucson, Ariz.

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

A PERSONAL STORY

Life with CAH

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

When people ask me, “How do you live with Congenital Adrenal Hyperplasia (CAH)?” I normally take a second or two to think about what to say. Not because I am nervous about how to respond, but because, in my case, living with self-managing CAH has been just that, “living.” In my situation, living with CAH has come 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 pediatrician notes 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 being her 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 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. The neonatologists promoted emergency care and tests that would eventually diagnose him with CAH. (Babies were not treated 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 to be three hours of motionless x-rays, which is now 20 minutes), the MRIs, and the infa-

mous bubble test, we were there for each other through it all. Even when we had fights, like all siblings do, one of the parent 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 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 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 first that used to be three hours of motionless x-rays, which is now 20 minutes), the MRIs, and the infa-

mous bubble test, we were there for each other through it all. Even when we had fights, like all siblings do, one of the parent 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 mole hill.

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So far, it has been just that, “living.” In my situation, living with CAH has come easier to manage with ME. 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 Dinia@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, 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 26-29. Our Connecticut camp, 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 teen volunteers, and 15 adult volunteers. There was fishing, archery, crafts, and cooking.

Two of the teen volunteers were Cadette Girl Scouts who planned a Silver Award during camp. One was in charge of planning three science experiments and helping the kids see them come 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 Schwoerer, CAH Aware 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:
• Dreamstreet, Ojai Valley, Calif.
• Dreamstreet at Canyon Ranch, Tucson, Ariz.

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

A PERSONAL STORY

Life with CAH

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

When people ask me, “How do you live with Congenital Adrenal Hyperplasia (CAH)?” I normally take a second or two to think about what to say. Not because I am nervous about how to respond, but because, in my case, living with self-managing CAH has been just that, “living.” In my situation, living with CAH has come easier to manage with
there were instances when we were horsing around the house, my parents dealt lowing us to get involved in lacrosse. If you are "by accident." blank range directly into the eye of the other on the scene" for the more serious ones. This built a solid core of support throughout my parents, looking back on it, was that my and knowledge about CAH, the most physical and fast-paced game on two feet. We, with a very serious medical condi- m in Miami and making me realize the value of making even better choices when on my antics in Miami and the 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 ask me to do something, I was told to eat something, feed us with intravenous fluids and run a few tests. After a while, the doctor would say, "okay, try to eat something." I have always been told, "okay, try to eat something," but never before this time I asked for a cheeseburger and the doc- tor 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 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 applications charged to it. My parents knew the key to the success of studying abroad is being open to communication. Growing up, 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 medi- cal condition ... without parents/it’s never perfect and you can’t plan for everything, but I assure you that if my brother and I (as the rock star and active as we can be) can handle it and have laughs along the way, you can, too. So, just live with CAH! My parents ... did not allow me to use my medical condition as an excuse to allow life to pass me by. the outside world. If the shot does not stop the vomiting, then we make a quick “day trip” to the hospital to get rehydrated. It became an ongoing family idea that throughout 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." 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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 12-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 don’t 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.

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+. Any 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 shoppers 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!

Talk It or Walk It 2013
Two ways to support CARES!
Sweat or No-Sweat…
Talk It or Walk It
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/host/YourOwnEvent. 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:
• Bike 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

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

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

CARES CONNECTIONS 14
FUN-RAISING

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

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

$10,000–$24,999 – Advocate
Anonymous
Mitz & Bill Davis
Rhonda & Gregory Kraf
Sandra & Chad Lapp

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

*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/Well Cornell Medical Center in New York.

Community Fundraisers Made a Difference
You don’t have to host a huge gathering to make a difference. 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 companies for hosting fundraisers to support our mission:
Fairleigh Dickinson University Students
Deborah Ham
Luz & Family
Kaitlin & Jonathan
Sue Shirey
Wendy Thorney

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 devastated the East Coast. Dozens of patients, families and supporters from four states (NJ, NY, CT, and PA) came together in support and awareness of CAH. The 3K walk was followed by children’s activities, a trick or treat, 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 Cliffto, and Sari Friedman Lee.

Alexandra’s eight-year-old son has CAH.

Carol Cliffto
As Vice President of Revenue Cycle Management for Pinnacle III, a development, management and billing company for ambulatory surgery centers, Carol Cliffto 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 Legs & Sleep Foundation and a board member of the Epilepsy Testing 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.

Alexandra’s professional experience includes director of marketing of communication and account support for management consulting corporations where she managed a range of direct marketing, developed online market- ing plans and led the planning and advertising for new product introduction.

Sandra Dubois is also an active vol- unteer 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.

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 the MEISMS 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.

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Sandra Dubois is also an active vol- unteer 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.

Well 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 Vagazza, MD is the center’s medical director and Dari 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 lifestyle 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; and counseling and prenatal testing, and nutritional support.

The Center will also be providing educational programs and connecting research opportunities.

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

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 holiday season? CARES has developed a travel guide: Traveling with CAREing Hearts/Adrenal Insufficiency. The packet includes tips on what to carry, what to do before you leave, and after your trip: what and how to pack; sample forms to use and more! Be prepared on your next trip and have! Thank you to the CARES store to download the packet for free – http://www.caresfoundation.org/products.

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 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.

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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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