

Nutrition Aspects in CAH Management

By Saroj Nimkarn
and Maria G Vogiatzi

Glucocorticoids remain the mainstay of treatment for CAH¹. However, current standard treatment regimens are still not perfect. This article focuses on two health issues that are associated with long term glucocorticoid treatment in CAH: overweight and bone health. Also simple nutritional advice to lower the risks of unwarranted consequences is discussed.

Overweight

Over the past 3 decades, the rates of overweight and obesity have increased dramatically in children and adolescents. This is particularly true for children with CAH, who are found to be at higher risk for obesity than other children. According to certain reports, weight gain starts in CAH early in childhood^{2,3}. Being overweight is likely to have important long term implications. Being overweight may predispose to lipid abnormalities, hypertension and insulin resistance (IR), which is a condition in which normal amounts of insulin are inadequate to produce a normal insulin response. These individuals face an increased risk for type II diabetes and cardiovascular disease later on in their

lives. Finally, insulin resistance in adolescent girls and women is associated with irregular menses and impaired reproductive function in the form of polycystic ovarian syndrome. Polycystic ovarian syndrome may contribute to high androgen levels in adolescents and women with CAH, who are particularly vulnerable to the unwanted effects of elevated androgens.

An increased risk of diabetes^{4,5} and other cardiovascular risk factors, such as increased carotid intima-media thickness⁶, glucocorticoid associated dyslipidemia⁷ and hypertension^{3,8}, have been described in CAH. An additional recent report in a large group of adult CAH patients from 17 endocrine tertiary care centers in Europe supported the idea these patients have

high rates of obesity and cardiovascular complications⁹. Women were more affected by weight problems than men (41% obese, 37% overweight and 10% had metabolic syndrome). Obesity is common in general; the question arises whether this is simply a surveillance effect or whether families of CAH patients also have family incidence of obesity.

The dose and the type of glucocorticoids have both been thought to contribute to the weight gain in CAH. Suppression of adrenal steroids may occasionally be difficult. The physician should avoid over-treatment by titrating the dose to the lowest possible that is required for optimal control. In addition, we cannot also overlook the

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A Message from the Executive Director

Dear Friends:

I am pleased to report that despite the current economic climate, CARES continues to grow to meet the needs of the CAH community. This year welcomed our very first medical director, Dr. Karen Lin Su. Dr. Su has been a wonderful addition to our organization. Her expertise, commitment and dedication to the CAH community is both enlightening and profound. We have also introduced our "Ask the Expert" service and blog to enhance communication and provide you with the latest CAH news.

In addition to these new programs and services, we have made progress in our efforts to ensure that everyone faced with a potentially life-threatening adrenal crisis receives appropriate care in an emergency. Our EMS campaign has resulted in a number of states adopting protocols and adding life-saving medications to emergency vehicles. Active campaigns are ongoing in several states and we will not stop until every state has adopted protocols and trained emergency medical service personnel to provide emergency care to the adrenal insufficient community. Guidelines have been finalized for the creation of CAH Comprehensive Care Centers (centers of excellence) and the project has transitioned to the implementation phase. Excitement abounds with the prospect of bringing together various specialties under one roof to provide a comprehensive approach to caring for the CAH patient. We will keep you informed as we move ahead with this project.

We thank you for your past financial support and ask for your continued support in order to sustain and enhance our services to the CAH community. In



this issue, you will learn how you can help. In addition to raising funds, we need your help in raising awareness of CAH. Please join us on Facebook and Twitter and help us spread the word.

No-Sweat Run for a Cure

The 2010 No-Sweat Run for a Cure is here! There's still time to set up your team, solicit donations or plan to *Break a Little Sweat* with a fund raiser.

For information on starting a team or ideas on small fundraisers, visit our website. No team, no problem. You can support the event by making a donation at www.caresfoundation.org

Ask the Expert/Blog

We are always looking for new ways to stay connected with our community. Our new *blog* and "Ask the Expert" service provide you with the tools necessary to stay current on the latest topics concerning CAH and to get answers to important questions. Why not join the conversation?

Personal Stories

Many of our newsletters have included inspirational personal stories about living with CAH. We would love to be able to include a personal CAH story in each and every newsletter, so I'm inviting you to tell yours. If you'd like to share your experience about living with CAH, please send your story, with a picture or two, to me at dina@caresfoundation.org. We look forward to reading your story!

Thank you for supporting our efforts as we meet the needs of the CAH community.

Warm regards,

Dina

Welcome Aboard!

New additions to Board of Trustees

CARES would like to extend a warm welcome to Susan Crowley and Katherine Fowler. Please join us in welcoming them.

Susan Crowley

Susan Crowley, a recognized expert in private sector interactions with international organizations, is the Founder of Multilateral Consulting, LLC, a firm dedicated to helping organizations navigate the complexities of the United Nations and other bodies engaged in international deliberations. For nearly 30 years, Susan internally promoted and led Merck & Co., Inc.'s engagement with the WHO, the UN and the World Bank, resulting in broad recognition of the company's leadership and its inclusion in a number of high-level discussions with leadership of these agencies. Her expertise relates to technology access, human rights, intellectual property, and promoting market-based solutions. While her specialty is pharmaceuticals, vaccines and biotech products, she has also participated in broad industry deliberations and projects that spanned health technologies, information technologies and telecommunications.



Susan holds a BA in History/Public Affairs with a minor in Economics from Rollins College. She completed graduate management programs at Georgetown University (Lendegger Program in International Business Diplomacy), IMD (International Public Affairs), and Boston University and Harvard Schools of Public Health (International health programs).

Katherine Fowler

Upon completing her residency at Presbyterian St. Luke's Medical Center, Katherine Fowler joined Hospital Corporation of America (HCA). A career hospital administrator, she is a member of the senior management team, as well as Ethics and Compliance Officer, with HCA/HealthONE Swedish Medical Center in Englewood, Colorado. Swedish Medical Center is a 368-bed tertiary care medical center with focus on Level I Trauma, Neurosciences, Women's Services, Oncology, Cardiology, and Orthopedics. Current operational responsibilities include Risk Management, Family Practice Residency (satellite clinic), Communications/PBX, Medical Library, Physician Services, and Continuing Medical Education.



Katherine holds a BS in Health Administration and Minor in Business Administration from Ohio University. She completed her Masters in Health Administration at the Medical College of Virginia Campus of Virginia Commonwealth University. A Swedish Medical Group Board Member as of 2010, she has been a member of the American College of Healthcare Administrators since 1995, Diplomate since 2004, Fellow since 2006. Katherine sat on the Colorado Regents Advisory Council from 2001 to 2004 and has been a member of Colorado Association of Healthcare Executives since 2006. She has served as a mentor at both Metro State Community College and Colorado University MBA with Healthcare. In serving the community, she has worked with the Special Olympics, United Way, Employee Crisis Fund and Race for the Cure.

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Dina M. Matos, Executive Director
Dina@caresfoundation.org

Meryl I. Stone, Chief Operating Officer
Meryl@caresfoundation.org

Odaly Roche, Administrative Assistant
Odaly@caresfoundation.org

Camela Cruz, Intern
Camela@caresfoundation.org

Gretchen Alger Lin, Public Affairs
Gretchen@caresfoundation.org

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This newsletter is published 2 times a year.

**Karen Lin Su, M.D.
Appointed as
CARES' First
Medical Director**



CARES Foundation is pleased to announce the appointment of Karen Lin Su, M.D. to the position of Medical Director.

"Dr. Su has a deep understanding of the treatment and research associated with congenital adrenal hyperplasia," said Gregory J. Kraff, President, CARES Foundation. "She will provide invaluable medical expert input to support group training, review of medical content for our newsletter and website as well as provide guidance for our CAH Comprehensive Care Center initiatives. As CARES Foundation's Medical Director, Dr. Su will provide medical leadership, ensure the organization's publications and statements are medically sound, oversee medical information that is rendered through the organization, and assume leadership responsibility for the medical aspects related to the organization."

Dr. Su currently is a research associate at the Hospital for Special Surgery and voluntary faculty member of the Pediatric Endocrinology Department of Weill Medical College of Cornell, both in New York. Previously, she held assistant professor positions at both Mount Sinai School of Medicine and New York Presbyterian/Weill Medical College of Cornell. She is certified in Pediatrics and Pediatric Endocrinology by American Board of Pediatrics and holds two awards from the National Institutes of Health for her rare disease and health research work. Extensively published, her work has appeared in numerous peer-reviewed publications including the Journal of Clinical Endocrinology and Metabolism and Clinical Pediatrics. She graduated *cum laude* with honors from Yale University and then went on to complete her medical degree at Cornell University Medical College.

Congratulations to Dr. Ricardo Azziz



We extend our congratulations and best wishes to Scientific and Medical Advisory Board member, Ricardo Azziz, M.D., MPH, MBA on being named eighth president of the Medical College of Georgia. Dr. Azziz has been at Cedars-Sinai Medical Center in Los Angeles since 2002 where he holds the endowed Helping Hand of Los Angeles Chair in Obstetrics and Gynecology, and has served as professor and chair of the Department of Obstetrics and Gynecology and director of the Center for Androgen-Related Research and Discovery.

We wish him much success in his new role and look forward to continuing to work with him.



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

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

In addition, shop 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! Here's examples of how much we can earn:

# of Supporters Per Day	Average Searches	Est Rev/per year
100	2	\$730
1,000	2	\$7,300
10,000	2	\$73,000

Number of Supporters	Amount Purchased Per Person/Year via GoodShop	Average % of sale donated	Estimated Revenue
100	\$500	3%	\$1,500
1,000	\$500	3%	\$15,000
10,000	\$500	3%	\$150,000

The sky's the limit! Here's the web site — <http://www.goodsearch.com>
Searching has never been better!

Family Fundraisers are a significant source of support for CARES.

On behalf of our members and the entire CAH community, we want to thank our families for helping us advance our mission by raising much needed funds. Here we highlight some of these events:



Gregory Kravitz, CARES Foundation Board of Trustees president, thanks the Goffmans for their support.



Jenn and Slavik Goffman—event hosts.

CARES FOUNDATION UNCORKS \$25K FOR CAH RESEARCH, EDUCATION & SUPPORT

On the evening of Saturday, June 26, 2010, more than 80 people gathered at the Moore Brothers Wine Company in New York City raising over \$25,000 for Congenital Adrenal Hyperplasia (CAH) research, education and support.

“What an evening! It was an opportunity for individuals, many of whom only recently became familiar with CAH, to support CARES in a meaningful way,” exclaimed Dina Matos, executive director of CARES Foundation.

An awareness and fundraising event, attendees of “Cheers for CARES—Uncork the Future for CAH” enjoyed select wines from the Moore Brothers Wine Company’s extensive collection along with hors d’oeuvres and bid on fabulous silent auction items. The highlight of the night was a live auction featuring a Yankees’ pitcher CC Sabathia signed jersey and a hot air balloon ride. The evening was hosted by Jennifer and Slavik Gofman.

UPCOMING FUNDRAISERS:

CARES Foundation members are hosting/participating in the following events to raise funds to support CARES’ mission.

Family Fun Picnic Day

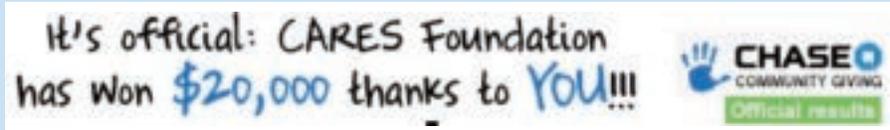
Brady’s Back Yard Picnic for a Cure
August 28th—Vincent, AL
(No Sweat)

Pittsburgh Great Race

September 26th - Pittsburgh, PA
(No Sweat)

Baked Goods Sale

November 5-6
National BBQ Festival, Douglas, GA



WE DID IT! CARES FOUNDATION WON \$20,000 IN THE CHASE COMMUNITY GIVING CAMPAIGN!

Thank you to everyone who voted and solicited other votes on behalf of CARES. Although thousands of non-profits were eligible to compete, CARES Foundation received 1,578 votes—enough to be one of the Top 200 charities to win the contest! **Together**, we’re making a difference!

We thank Chase for their generosity.

YOUR NAME AND PHOTO HERE

We will happily publicize your fundraising event and its success in our upcoming newsletter. (With your permission, of course.) Just email info and photo to: Dina@caresfoundation.org. Creative fundraisers are the key to surviving in this challenging economy. Please keep us posted on your results!

OUR STORY



On October 5, 2006, Morgan Shea Bundy was born with Salt Wasting CAH. Of course we, Jeremy and Katie, her parents, had no clue what it was. They knew even before the testing was done because of her genitalia. We weren't sure whether she was a boy or girl (**she had surgery to correct at the age of 6 months**). She was transferred from the local hospital, where she was born, to Brenner Children's Hospital immediately. Once there, they did an ultrasound, and surely enough, all her "female" parts were there. And of course, we were so glad we didn't have to return all of the "pink" merchandise!

Once we brought her home, she was such a delight! But, that's also when reality had set in. With CAH being new to us as parents, we worried constantly! Always checking her temperature and always on the internet reading up on CAH. Hearing the risks, etc. with this disorder, we were just totally shocked! Having to triple her hydrocortisone when Morgan has a fever, having her blood drawn to check her levels quite often. She is also Salt Wasting CAH. This disease is a very scary thought, but when it all comes down to it, we can't believe that we (parents) found each other (we met on the internet!). A one in a million chance of meeting someone with the exact same impaired gene. But now, we are so much more educated (**thanks to CARES Foundation**) and know what to expect and how to handle it. We don't stress as much anymore! We are both so blessed to have such a beautiful little girl! We also have a wonderful son/step-son named Cole, who is 12, born November 13, 1997. We can't brag enough about "Big Brother." He is absolutely wonderful with Morgan! He is

so protective over her, just as a big brother would be. He is not a CAH child, but he is just as special to us as Morgan. We have chosen not to have any more children. We have a 50%-50% chance of another child having this disorder. We do not need any more anyway. We are blessed enough!

I know a lot of parents question the surgery that females with CAH would need to consider. Morgan was 6 months old when she had the surgery, so of course she wouldn't even remember it at all. We (parents) would not have done anything different. Not only does she "look normal" now, but she will see herself as a "normal" girl. It not only helped her cosmetically, but more medically. Her vagina was connected to her urethra. Morgan needed to have those separated and have an opening made for her vagina. She had such a wonderful doctor (urologist) to do the surgery. We were told that she would be in the hospital for at least a week for recovery. Oh, no, she went home the very NEXT DAY! She was doing so well that the doctor sent her on home. Parents always take it harder than the child when it comes to surgery. Our nerves were beyond shot, but it didn't even faze Morgan. She was such a trooper.

We have been so blessed to have Morgan. She has taught us so much! She is now three years old! Boy, how the time has flown by. We are so thankful for each and every day that we have, and try to live each day like it's our last. We are also so thankful for Cole and how wonderful he is with Morgan.

Thanks for letting us share our story and God Bless,
Jeremy, Katie, Cole & Morgan Bundy
North Carolina

I Do Not Know Her Name. . . . Kelly Leight, July, 2009

Her face haunts me. I see her in my sleep, during quiet times in the day. I see her sweet, weak smile, her sallowness, and rheumy eyes expressing fatigue and pain. Is she still alive? Did she go into crisis? Did her grandmother give her medicine, or did Grandma run out of it again? I feel helpless and sad when I think of her and her situation. She has the life-threatening disease called CAH (congenital adrenal hyperplasia—a form of the same disease affects my daughter) and she lives in extreme poverty. Her chances of surviving childhood are slim. I can't get the memory of her out of my head, and I don't even know her name.

I met this little girl and her grandmother this June in Vietnam at the CLAN (Caring and Living As Neighbors) CAH Club Meeting at the Saigon Children's Hospital. The gathering was remarkable; families traveled for hours, even days by bus from the far provinces of Vietnam to Saigon to attend. They hoped to meet others dealing with CAH and to get a just few months' supply of the precious commodity: Florinef, a medication needed to treat CAH that is not otherwise available in Vietnam.

Children with chronic diseases living in the developing world face a dire situation. Unlike their counterparts in the developed world with better access to treatment and healthcare, these children are certain to suffer. If a disease requires regular medication, therapy or medical monitoring, an affected child's condition will undoubtedly deteriorate as these services are usually out of reach or unavailable to the vast majority of families in the developing world. Vietnam is a low income country [according to the World Bank classification (i)], with a healthcare system that is not yet able to deal with chronic medical conditions of childhood. Its per capita income is very low by world standards, and the burden of a chronically ill child is heavy for all but the wealthiest 1% of Vietnam's families. Many families must choose between treating the illness of one child, and feeding the rest of their children. As a result, treatment is often rationed or unavailable to the chronically ill child. The outcomes for these children are very poor, and death from otherwise treatable illnesses and disorders is common.



Vietnamese CAH Support group

As the CAH Club Meeting was breaking up, I saw the girl lying on the chairs, looking pale and sad. She barely had the energy to lift her head. I walked over to the grandmother and asked whether the child was feeling ill. Grandma replied that she often felt like this, as she tried to force the child to sit up and greet me. I protested that she should let the girl rest and asked whether she had difficulty obtaining medication for the child. Grandma said that

they had run out of medications almost 8 days ago. She told me the girl had been losing a lot of weight during the past week. She did not seem to understand how critical her granddaughter's situation was.

I felt panic. I know that 8 days without medication for a child with salt-wasting CAH is life-threatening. The child was weak and lethargic because she was dying. Without medication entering her system soon, she would go into an adrenal crisis, followed by cardiac arrest. It could happen at any moment. First I tried to get the attention of one of the Vietnamese doctors, but to no avail. I think they may be more immune to these kinds of crises because they see them all of the time and death in children is very common. It is hard to become attached to these kids because often, there is nothing the doctors can do to help.

I sought out Dr. Maria Craig, a pediatric endocrinologist from Australia who was traveling with CLAN and helping to treat children on our trip. We caught up with the grandmother as she was carrying the child on her hip and leaving the building. Maria asked the grandmother about the child's condition and lack of medication. The grandmother had been given medication to take home from the meeting, so Dr. Craig told her to give the child a triple dose of the medication right away and to continue the triple dose for a few days. I fear that Grandma will not do so, given how precious the medication is. She will probably ration it to make it last longer. How I wished I had brought some of my daughter's medication to give away to them. I bade them farewell and said, "May God Bless you." Since the translator had just left, I know they did not understand me, but I meant it so deeply and sincerely. As they walked away, the little girl dozing on Grandma's shoulder, I felt warm tears streaming down my face. After they had turned

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the corner, I broke down and just sobbed for awhile.

CAH (Congenital Adrenal Hyperplasia) is a genetic disease that is relatively common in Vietnam, affecting about 1 in 5,000. Children with this disease do not produce certain essential hormones needed to deal with everyday physical stress and maintain the fluid balance in their bodies. Without replacing these hormones through medications, these children will die. However, the medications are difficult to obtain in Vietnam and other developing nations and are very expensive. CLAN works with the Children's Hospitals and Vietnamese health officials to encourage them to take proper care of patients with chronic diseases like CAH. CLAN helps to train healthcare professionals, helps organize affected families to create support networks, and provides medications to children in need. Right now, CLAN's humanitarian donations of Florinef are the only supply of this medication for those with CAH in Vietnam. Their work over the last couple of years has saved the lives of countless children. In Vietnam alone, CLAN has worked with international partners to identify some of the barriers to access to essential medicine for Diabetes and CAH, and this has encouraged one Children's Hospital to provide free insulin to children with diabetes; ensure that hydrocortisone (another medication necessary to treatment of CAH) is now reliably and affordably available off the black market; and most recently apply for permission to import Florinef into Vietnam. CLAN currently has projects in Vietnam, Philippines, Pakistan, India and Indonesia. With CLAN's help, I hope that the future will be brighter for children like this little girl.

<http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/0,,contentMDK:20421402~pagePK:64133150~piPK:64133175~theSitePK:239419,00.html>

SUPPORT GROUP CORNER

We are looking for a few dedicated individuals to serve as support group leaders in the following states:

Arizona • Idaho • Kansas • Michigan • Minnesota • Missouri • Montana • Nebraska • New Mexico • North Dakota • South Dakota • West Virginia • Wyoming

If you are interested in joining our growing support network, please contact Dina Matos at dina@caresfoundation.org.

Book, Bake, Lemonade & Yard Sale

Support Group Leaders Deborah Ham and Jennifer McCloud hosted a Book, Bake, Lemonade & Yard Sale in Millville, PA on April 30th—May 2nd. The event raised funds to support CARES' mission.

We thank Debbie and Jennifer for their continued support!

Moving Sale

Susan Aycock, our Mississippi support group leader turned her moving sale into a fundraiser for CARES. Susan and her family are moving to a smaller home and had a garage sale to get rid of items they had accumulated over many years. They advertised that the proceeds from the sale would benefit their beloved charity, CARES Foundation, and their neighbors turned out in big numbers. Thank you Susan!



Front row: Paris Hewes
Second row: Summer Hewes, Debbie Ham, Alyssa Frolich, Jennifer McLeod, Peter McLeod
Back row: Tara Hewes, Jason Hewes

NEW SERVICES!

Introducing "Ask the Expert" Service!

"Ask the Expert" is a new service that allows our membership to ask our Medical Director a question that is not already answered on our site. It's a way to put your mind at ease about concerns you might have. Our Medical Director will correspond with you directly. Many of the "Ask the Expert" questions and answers will be published on our blog (they can be found under our "Ask the Expert" tag). *The chances are someone else might be wondering about the same thing!* Join the Conversation!

Introducing our Blog!

Our goal in launching this blog is to build community, increase awareness and improve communication. We welcome you to read, search, and join the discussion. Topics include: "Ask the Expert" questions, Personal Stories, EMS Campaign Updates, Parent Tips and more. **If you have a personal story you would like to share or parent tip that others could benefit from, please email us at contact@caresfoundation.org** Make sure to check out our blog and click the subscribe button to get notified of updates.

importance of lifestyle modification that includes a healthful diet and increased physical activity. For pediatric patients, the role of parents is essential. Parents can model healthful behaviors, and establish good eating and recreational habits for the whole family. To make the most of their visits with their doctor, they can track their child's growth and weight gain during each visit.

They can then discuss their child's progress and develop a plan according to the individual needs of the child. Doing this from a very young age is very important to achieve life-long healthful lifestyle habits and prevent later on weight problems¹⁰. In general, the endocrinologist can provide advice on healthful nutrition according to the age of the patient. Finally, parents or patients may seek the advice of a nutritionist for the development of a detailed and individualized meal plan.

Bone Health

Bone strength, or "Bone mineral density" (BMD) may be affected in CAH and lead in the development of osteoporosis. Today, it is still unclear if osteoporosis is a problem in CAH. Glucocorticoids in high doses are known to lower BMD. On the other hand, androgens may have a beneficial effect on bone. Therefore, the competing actions of androgen excess (from undertreatment) and glucocorticoid excess (from overtreatment) can both occur in a patient at different time points of his life. Unlike other diseases treated with chronic glucocorticoid therapy, the effect of glucocorticoid replacement in CAH on BMD is unclear. Several studies of patients with 21OHD have reported decreased BMD^{11,12}, whereas other studies have reported increased or normal BMD^{13,14}. The discrepancies may be due to differences in age and gender, as well as varying treatment regimens.

Table 1 Recommendations for Healthful Eating Habits

Serve water and low-fat milk at meals; keep tap water in the fridge.

Reduce or eliminate sugar-sweetened beverages

Serve more vegetables and fruits

If juice is consumed at all, limit to 4-6 ounces of 100% juice per day

Eat less fatty food, fast food, and candy. Offer fresh fruit as snacks

Pay attention to portion size. Serve smaller portions of everything except vegetables

Sit down and eat together as a family

Do not watch or allow television viewing while eating meals or snacks

Do not use food as a punishment or reward

*Modified from *Helping Children Reach and Maintain a Healthy Weight* City Health Information vol 28 (5):41-48, August 2009*

Table 1 provides a summary of simple recommendations on lifestyle modification that will help maintain a healthy weight. In general, sugary drinks, large portions and high fat foods constitute the three most frequent problems in the American diet today. Patients with the salt wasting form of CAH may need to consume quantities of salt larger than the general population, and salt should not be restricted in these cases. Beyond this factor, patients with CAH need to follow the same diet as anybody else. For patients with insulin resistance, a diet relatively low in simple carbohydrates and high in fiber (i.e. fruits and vegetables) may be beneficial.

Recommendation to maintain bone health in children and adults includes adequate calcium and vitamin D intake. Other risk factors for bone health should be minimized or eliminated. According to recent studies, the rates of vitamin D insufficiency or deficiency are increasing in the western world. This can be explained in part by the more wide spread use of sun blocks. Additional large scale population studies bear out long-held concerns that low vitamin D levels are associated not only to adverse outcomes on bone health, but also in innate immune and metabolic syndrome¹⁵. For

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these reasons the recommendations for daily vitamin D intake have increased to 400 IU for children and 400 to 800 IU for adults under age 50. However, many physicians believe that this amount may not be sufficient to maintain optimal vitamin D levels. Some individuals may require as much as 2000 IU per day, particularly those who have limited sun exposure. Calcium intake in the range of 800 and 1200 mg per day is considered adequate for children and adolescents respectively. 1000 mg of Calcium per day is recommended in adults up to the age of 50, and 1,200 mg per day for individuals older than 50 years. Patients with CAH should have optimal calcium and vitamin D intake. In general, dairy products are high in Calcium and vitamin D. However, it is very difficult to meet the daily vitamin D requirements only by food intake. For this reason, screening for vitamin D is recommended. This can be easily achieved by blood work and is routinely performed in many labs. According to most recent vitamin D recommendations, adequate blood levels are those above 30 ng/ml. In our program, we include screening for vitamin D as a component of our comprehensive care management for CAH.

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Great Recipe from Cares Family Cookbook

"YOU'RE THE APPLE OF MY EYE" SALAD

Ingredients

- 1 large head of romaine/red leaf lettuce
- 1 head iceberg lettuce
- 1-2 apples, delicious or granny smith (or your favorite)
- 1/4 cup grated locatelli romano or parmigiano reggiano cheese
- 2 packages of Perdue short-cuts ready-cooked & cut chicken breast OR 4 chicken breasts, seasoned with salt & pepper, and grilled, cut into strips
- 1 package (envelope) of Good Season's Caesar dressing (or your choice of dressing, if preferred)

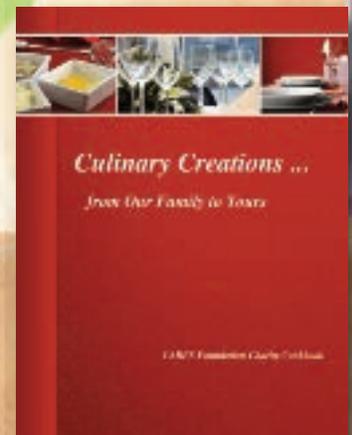
Wash & drain lettuce. Tear into bite size pieces into a large bowl. Peel, core, cut apples into cubes; toss in with lettuce. Heat chicken in microwave (45 seconds or so) until warm, or take chicken right from grill and slice into strips. Add chicken to lettuce, sprinkle grated cheese over all; toss with dressing or serve dressing on the side.

Variations/optional add-ins

Season uncooked chicken with lemon pepper or grill seasoning, (or use your favorite marinade) then grill. You can add lemon juice to the salad. Add pears along with the apples. Try French, Ranch or Creamy Italian dressing instead. Add shredded cheddar or mozzarella cheese (1/2-3/4 cup).

"When both of my children were in nursery school, they each had a day when they were the "Apple of my Eye", so I came up with this salad & they loved it. It's a quick & easy summertime meal, but we really enjoy it year-round, and it's so easy to add or subtract ingredients."

—Lorraine Penoro



Please contact the researchers if you are interested in any of these studies:

Tweens to Teens (T2T) Project @ Penn State

*Principal Investigator: Dr. Sheri Berenbaum
Departments of Psychology & Pediatrics,
Penn State University*

Researchers at The Pennsylvania State University are conducting a study of behavior and feelings in girls with congenital adrenal hyperplasia (CAH). They are recruiting girls with classical and nonclassical CAH who are 10 to 13 years old. Their goal is to learn more about the development of characteristics related to gender development.

At your convenience, researchers will visit your home. Girls will be asked about their activities, interests, thoughts and feelings. They will also be asked to provide saliva so that researchers can examine their hormones and determine their CAH gene mutation. Parents will be asked to complete questionnaires about their activities, interests and their daughter's behavior. Shortly after the home visit, researchers will call girls and their parents on several days to ask about the girls' activities. The home visit takes about 2-3

hours and the phone interviews last about 30 minutes each. Families will be compensated for their participation. If you are interested in learning more about this study, please contact researchers at:

phone or text: (814) 933-6438

phone: (814) 867-2339

e-mail: T2TProject@psu.edu

Cardiovascular Disease Risk Factors Study at Children's Hospital Los Angeles*

The Division of Endocrinology at Children's Hospital Los Angeles is currently recruiting individuals who are at least 9 years old for a research study to determine if there is a risk for heart disease in individuals with classic congenital adrenal hyperplasia (CAH), both salt wasting and simple virilizing forms. For comparison, they are also recruiting healthy siblings of individuals with CAH, and non-siblings. The study will involve up to three visits, and individuals will be offered \$10 per visit for participating. If you have classic CAH, or are a sibling of someone with CAH, and are interested in participating in this study, please contact: Mimi Kim, M.D. at (323) 361-1358, mskim@chla.usc.edu.

How many times have you had to throw out water bottles or glasses of juice that were half full because you didn't know what drink belonged to whom? Those days are over...Order your ID drink bands now!



**CARES Drink ID Bands
"Yours, mine, but never ours!"**

Stay healthy with our reusable elastic Drink ID Bands. Great for kids or adults—Identify your drink and raise awareness! Use them at home, bring them to parties, and buy them as gifts. (Six bands in a package.)

Fits all sizes • Latex Free • Biodegradable

Be sure to check out other items at the CARES Shop:

CARES Coffee Mugs

CARES T-shirts

CARES Charity Cookbook

School/Camp Packet

"Adrenal Insufficiency" Shoe Tags

"Adrenal Insufficiency" Window Clings

NCAH/CAH Stress Study at Children's Hospital Los Angeles*

The Division of Endocrinology at Children's Hospital Los Angeles is currently recruiting subjects for a research study aimed at determining the stress fighting ability of subjects with non-classical congenital adrenal hyperplasia (NCAH) and comparing these responses to those in subjects with classical congenital adrenal hyperplasia (CAH) and those in carriers of either disorder. If you have NCAH, CAH, or are a sibling of someone with either disorder, and are interested in participating in this study, please contact Dr. Bhavan Bali (323) 361-8705 or Dr. Mitchell Geffner at (323) 361-7032.

*Note: Travel to Los Angeles is at parents' expense.



MEETING THE NEEDS OF OUR COMMUNITY

Because one of our most important goals is to meet the needs of our entire community, we invite you to visit our website where you will find important information and frequently asked questions in Spanish.

Announcing...

CARES Foundation's FAQ's in Spanish

Did you know that 1 in 40 Hispanics are affected by CAH? Thanks to a grant from Verizon, CARES Foundation is proud to announce the launch of its Frequently Asked Questions (FAQ's) page in Spanish.

Anunciando...

Preguntas más frecuentes pagina en Español

Sabía usted que 1 de cada 40 hispanos se ven afectados por la CAH ? Alguna vez has querido saber:

1. Que debo hacer cuando mi niño(a) fue detectado por el tamizaje de los recién nacidos? Cuando un niño es detectado por un tamizaje neonatal anormal, el debe ser visto inmediatamente por un médico. [Haga clic aqui para leer mas...]

2. Al pedir una identificación de alerta médica que debo escribir en ella? CARES recomienda conseguir algún tipo de información médica con el símbolo de alerta médica y las palabras "insuficiencia adrenal, dependiente de cortisona." [Haga clic aqui para leer mas...]

3. Cuando le aplico la inyección? Si su niño se torna más enfermo a pesar de la dosis de estrés, es posible que no haya recibido suficiente glucocorticoides, o la absorción no sea suficientemente rápida. En ese caso, doctores recomiendan la inyección. [Haga clic aqui para leer mas...]

Para ayuda adicional contacte a nuestro líder* de apoyo en español: Bernise Sosa-Izquierdo nj2.support@caresfoundation.org. *Los líderes del Grupo de Apoyo ofrecen ayuda a personas y familias con CAH, proporcionándoles información adecuada y apoyo.

Las preguntas más frecuentes (FAQ's) página en español, fue posible gracias a una donación de Verizon.

Regional Conferences/CAH Awareness

Our support network and medical community are working together to provide educational programs and promote CAH awareness.

1st Weill Cornell CAH Conference—New York

The first regional conference, “*New Developments in Congenital Adrenal Hyperplasia: An Update on Classical CAH*”, was held on Saturday, April 24, 2010 at New York Presbyterian Weill Cornell Medical Center. The event drew participants from as far away as Alabama.

The conference featured some of the leading CAH experts. There was also an adult panel discussion and an overview of the school/camp packet. Participants also learned how to give injections.

Special thanks go out to conference organizers and presenters Debbie Brown, Nancy Ginsberg, Drs. Zoltan Antal, Saroj Nimkarn, Dix Poppas, Karen Su and Maria Vogiatzi and adult panelists Ryan Banks, Timothy Kilgannon and Jenny Obando. We also extend our gratitude to Weill Cornell for hosting us.

The New York event was the first in what we hope will be a series of conferences organized by our support group leaders across the country.



New Ways of Communicating

Do you use Facebook and Twitter? So do we!!

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.



Making Informed Decisions

As a patient or parent, at some point you will likely face the need to make important medical decisions, and it is absolutely essential that you have full understanding of the procedure or treatment (and the alternatives) before making your decision. Some examples of medical choices that you could encounter may include whether to undergo a surgical procedure or perhaps participate in a research trial.

Participating in clinical research

Clinical research is crucial to the advancement of medicine, and if you are considering participating in a research trial, you are making a very important contribution to the medical field and to future patients. That being said, it is necessary for you to protect yourself and/or your child. Any treatment that is considered experimental should take place under the auspices of an Institutional Review Board (IRB)-approved protocol.

An IRB is an independent oversight committee within a medical institution, comprised of lay persons as well as health care professionals. Each IRB has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans with the aim to protect the rights and welfare of the research subjects. In the United States, the Food and Drug Administration (FDA) and Department of Health and Human Services (specifically Office for Human Research Protections) regulations have empowered IRBs to approve, require modifications in planned research prior to approval, or disapprove research. An IRB performs critical scientific, ethical, and regulatory oversight functions for research conducted on human subjects.

Any IRB-approved research study must obtain written *informed consent* from all participants (or their legal guardian).

What is informed consent?

Informed consent is a communication process between patients and physicians, such that fully informed patients can participate in choices regarding their health care.

When should informed consent be obtained?

The goal of informed consent is for patients to have an opportunity to be informed participants in their health care decisions. Informed consent should be obtained for participation in all research studies as well as for any experimental or major therapeutic or diagnostic procedure for which disclosure of major risks involved would assist a patient in making a decision whether or not to undergo the proposed procedure.

Written informed consents obtained for research studies are signed by the participant (or legal guardian), the investigator, and a witness. A copy of the signed consent form is given to the participant.

What are the components of informed consent?

Complete informed consent should include a discussion of the following:

- The nature and purpose of the proposed treatment or procedure
- Reasonable alternatives to the proposed treatment or procedure
- The relevant risks, benefits, and uncertainties related to the proposed treatment or procedure and for each alternative
- The risks and benefits of *not* receiving or undergoing the proposed treatment or procedure
- Assessment of patient understanding
- Acceptance by the patient

In order for the patient's consent to be valid, he/she must be considered competent to make the decision at hand and his/her consent must be voluntary. The patient should have an opportunity to ask questions to develop better understanding of the treatment or procedure, so that he/she can make an informed decision to proceed with or to refuse the proposed treatment or procedure.

Assent for older children and adolescents

Health care decisions regarding older children and adolescents should include, whenever feasible, the *assent* of the patient as well as the participation of the

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MAKING INFORMED DECISIONS

continued from page 13

parents and the physician. Though consent must still be obtained from their legal guardian, minors should be given serious consideration within their developmental capacities for participation in decision-making and for their assent.

Assent from a minor should include the following:

- Helping the patient achieve a developmentally appropriate awareness of the nature of his/her condition.
- Describing for the patient at his/her level what to expect with the proposed procedure
- Assessing the patient's understanding of the situation and the factors influencing his/her response
- Obtaining an expression of the patient's willingness to accept the proposed care.

Please check our website for more information on research and treatment considerations.

New Educational Resources on Law Against Genetic Discrimination Now Available

User-friendly materials to help health-care providers and members of the public understand their rights and responsibilities under the Genetic Non-Discrimination Act (GINA) are now available online through **GINA & You**. The Genetic Information Non-discrimination Act (GINA) make it:

1. Illegal for employers to base decisions to hire, fire, promote or train someone on genetic information, and
2. Insurance companies are prohibited from denying coverage or setting insurance rates based on an individual's genetics.

Genetic testing is particularly important to families with a history of CAH. Testing in the parents allows for early detection and treatment in the child. However, some people may fear discrimination by health insurers and avoid testing for CAH. Furthermore, until now the lack of federal legal protections against the misuse of genetic information has restricted individuals' access to health information and clinical trials. Fear of the misuse of genetic information limits access to genetic tests. Refusal to utilize effective genetic tests hinders the ability of individuals to learn important medical information, which they could use to proactively manage their health. Fear of discrimination also causes a large number of people to opt out of clinical trials. This lack of participation in research has a negative impact on researchers, clinicians, and industry, slowing the research and development process for targeted drugs and treatments. With GINA we can now fully promote personalized medicine and the use of genetic information in healthcare.

Visit ginahelp.org to access essential details of this legislation as well as for clear information about what GINA doesn't cover.



Our 2010 No-Sweat Run for a Cure has kicked off and will run through September 20th. The event provides an opportunity for CARES members and supporters to raise both awareness of CAH and funds to advance CARES' mission.

This year we are giving participants a choice to raise funds the "virtual" way, without breaking a sweat *or* to *break a little sweat* by hosting an "actual" fund raiser. Some ideas for an actual event are: a hike or run for a cure, pool party, picnic, party, yard, sidewalk or garage sale, bowl-a-thon, mini golf tournament, lemonade stand or a chili cook-off.

To compete in the 2010 Run for a Cure, form a team and invite family, friends, and colleagues to join it, set up your webpage, make reminder calls or send emails, track your donations and watch your funds grow. To host an event, decide on the type of event, set a date, make your invitation list, collect donations and have fun. Either way, the goal is to raise as much money as you possibly can for CARES. This is also an opportunity to engage your children, friends and neighbors in helping fund CAH research and to celebrate a special occasion such as a birthday, anniversary, bar/bat mitzvah, or quinceanera.

To learn more or sign up, visit our **No-Sweat Run for a Cure** webpage at: <http://cares.kintera.org/2010-nosweat>.

We are pleased to report that progress continues to be made in our efforts for the inclusion of treatment for adrenal insufficiency in EMS protocols across the nation. Thanks to our efforts, adrenal insufficiency treatment protocols are in place in Massachusetts, New York—Suffolk County, in addition to Rhode Island. Administration of patient-carried medications is approved in Maine, Nevada—Southern Region, Texas—Fisher County, and Maryland.

Currently, campaigns are underway in thirteen states and the District of Columbia, and protocols are being developed in three states. In those states where we have on-going campaigns, concerned residents can make a huge impact. Affected individuals and their families can truly help our appeal by getting involved and urging the addition of Solu-Cortef® to EMS formularies and emergency treatment protocols for CAH and other adrenal insufficiencies. Please visit our EMS Campaign webpage for complete current campaign information, to contact a campaign leader, and for sample letters.

California Residents and Visitors

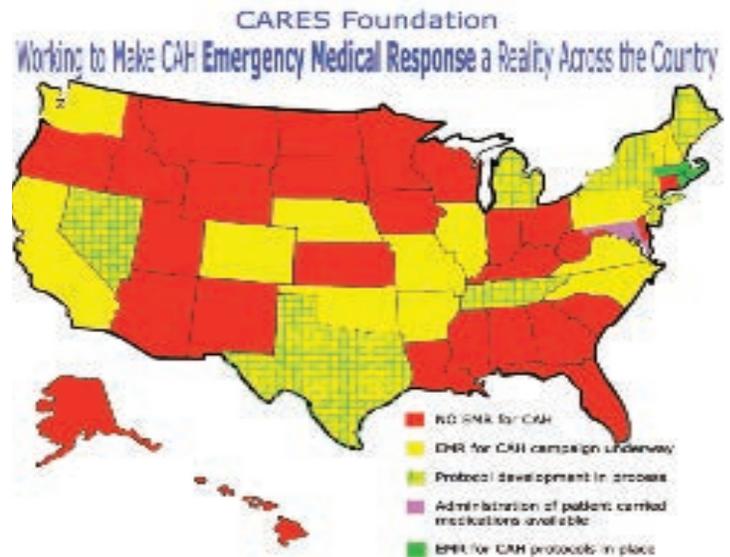
Our campaign in California took a huge step forward recently when CHLA endocrinologists Drs. Geffner and Kim met with the Los Angeles County EMS Director, Dr. Koenig, to discuss Act-o-vial training and protocol change processes with California. All residents of and frequent visitors to California can help by submitting letters of support; a sample letter can be found on our website. Please personalize this letter and send the original to your Regional EMSA (their contact information can be found via the web at www.emsa.ca.gov/EMDAC/members.asp) as well as a copy to the State EMSA Director:

Steve Tharratt, M.D.
 EMSA Director
 EMERGENCY MEDICAL SERVICES AUTHORITY
 1930 9th Street, Sacramento, CA 95811-7043

Also send a copy, via email, to Chuck Young (cbuckyoung@sbcglobal.net) who is coordinating the EMS protocol effort in California.

New York

In New York State, guidelines for regional adoption of protocols approved by the NY State Emergency Medical Advisory Committee (SEMAC) and Solu-Cortef added to statewide formulary! A regional-level implementation campaign now is underway. On August 27, 2010, CARES Foundation will have the unique opportunity to present our appeal before all New York EMS county coordinators during the Vital Signs Conference in New York City. With Suffolk County having adopted protocols and Nassau and



the Western Region having committed to doing so, we are now focusing on encouraging adoption of adrenal insufficiency pre-hospital treatment protocols across the rest of the state. All New York State residents can help by submitting letters of support to their regional EMS leadership. A complete list of regional EMS councils and a sample letter can be found on our website at www.caresfoundation.org.

Centers of Excellence for CAH

We are pleased to announce that the guidelines for CAH Comprehensive Care Centers (centers of excellence) have been finalized. This multi-year project involved CAH experts from around the world, as well as patients and parents. The project was funded with support from NYMAC, HRSA and NBSRC. These guidelines will be used to direct care in a center of excellence setting.

The guidelines were presented at the Endocrine Society’s annual expo in San Diego in June. They will also be published in the International Journal of Pediatric Endocrinology (IJPE) in the fall.

These guidelines are the first step in making comprehensive care centers a reality. Our next step is to identify institutions that are interested in becoming specialized centers and making sure they meet the criteria set forth by the guidelines. We will then work with those institutions to make CAH comprehensive care centers a reality. The centers will manage the care of the CAH patient from birth or diagnosis throughout their lifecycle.

Second Annual Everyone CARES Gala

More than 150 guests, including members, families, friends and medical professionals, attended the second annual Everyone CARES Gala at 230 Fifth in New York City on March 18th. The Gala, marking CARES Foundation's 10th anniversary, recognized the remarkable contributions of distinguished honorees: Kelly and Adam Leight & Family, Maria I. New, M.D. and Perkin Elmer. The Leights, founders of CARES Foundation, were presented with the *Visionary Award* for their foresight and commitment to serving the needs of families and individuals affected by CAH; Dr. New was awarded the *Pioneer Award* for her research and CAH education; and Perkin Elmer received the *Corporate Partner Award* for their support of CARES' education initiatives and newborn screening.

Gregory Kraff, president of CARES Foundation's Board of Trustees and Dina Matos, executive director thanked guests for their support and reminded them of the organization's accomplishments as well as challenges. Greg Kraff reflected on how much of an impact the evening's honorees have had on the success of CARES. Dina Matos noted that while significant progress has been made with newborn screening, advances in treatment and research, there is still much work to do, primarily improving access to quality care throughout the lifecycle and appropriate, immediate medical response for adrenal insufficiency. Both expressed hope for a better future for those affected by CAH.

Guests enjoyed a cocktail reception, dinner, awards ceremony, silent auction and a live auction featuring a 14-



Front row (seated): Kelly Leight, Alyssa Leight, Dr. Maria New
Back row: Adam Leight, Joshua Leight, C. Scott Palubiak
(Perkin Elmer)

day European cruise. The event was an opportunity for many families, advocates and health care professionals to meet and share experiences about living with and caring for those with CAH. The event raised nearly \$100,000 for CAH research, education, advocacy and support.

Please remember

that CARES Foundation has "Gone Green" and that our newsletters are now only available electronically. Please make sure we have your most current e-mail address and contact information to ensure that you receive newsletters and other important information from CARES.

Send your updated information to Odaly Roche at Odaly@caresfoundation.org.

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