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Prostate Development in Girls with Congenital Adrenal Hyperplasia:

Effect of *In Utero* Androgen Exposure or Inadequate Postnatal Hormonal Control?

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Division of Endocrinology, Hospital das Clínicas, School of Medicine, Sao Paulo University, Brazil

The changing of fetal external genitalia into male or female external genitalia basically depends on the presence or absence of androgen action, respectively. In males, the testosterone starts to be produced by the testis around 8 weeks of gestation, and it is transformed into a more potent androgen in the peripheral tissues, called dihydrotestosterone. This latter androgen induces the transformation of the fetal external genitalia into male external genitalia, developing the penis, scrotum, prostatic urethra and also the prostate gland¹. Therefore, the male prostate gland has the same embryological origin as the external genitalia and also depends on androgen action for its development².

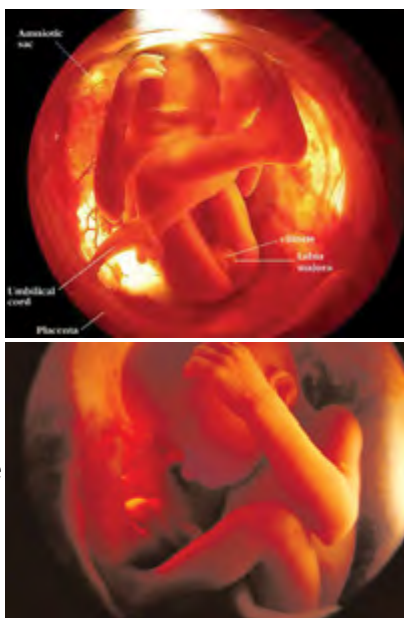
In girls affected with classical forms of congenital adrenal hyperplasia (CAH) due to 21-hydroxylase deficiency, the impaired

synthesis of cortisol leads to an over-stimulation of the adrenal glands and to an increased androgen secretion, which begins at the 7th week of gestation. This androgen production induces virilization of the female external genitalia, ranging from only mild clitoral enlargement to male appearance of external genitalia, which frequently results in errors of sex assignment at birth.

Although the prostate tissue has the same embryological origin as the external genitalia, the detection of this tissue

in CAH girls had been limited to two case reports^{3,4} until a recent study that identified its presence in approximately 16% of Brazilian CAH girls by magnetic resonance imaging⁵. Normally, girls have paraurethral tissues called Skene's glands that are homologous to the male prostate gland, which begin to development around the 10th week of gestation. Like the male prostate gland, the Skene's glands are made of columnar epithelial tissue, secrete prostate specific antigen (PSA) and express the androgen receptor, a protein necessary for the androgen action⁶. Hence, we can suppose that high testosterone levels observed in CAH girls could stimulate the

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Message from Executive Director

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Dear Friends,

It's been a while since we published our last newsletter. We are pleased to catch you up on our work with a new edition of *CARES Connections*.

Strategic Planning Initiative

Last March, under the direction of our new President, Jessica Hall Upchurch, CARES Foundation embarked on its first strategic planning initiative.

The year-long project included teams comprised of Board members, medical professionals, patients, parents, as well as other friends of CARES. The group addressed the future needs of the CAH community including specialized medical care through centers of excellence for CAH, medical and patient education, research and tools for better living with CAH, as well as the funds necessary to implement the recommendations. This initiative set the stage for our work over the next three years.

On behalf of the CAH community, we thank all of you who played an integral part in this process.

Regional Conferences

CARES Foundation is pleased to host its next regional conference on Saturday, November 17 at Children's Hospital Los Angeles. The conference will cover CAH Through the Lifecycle. We look forward to seeing you there.

Earlier this year, we hosted another conference at New York Presbyterian Weill Cornell Medical Center in New York. More than 100 individuals attended the conference.

Comprehensive Care Centers

We are pleased to announce that we have received four applications for Comprehensive Care Centers for CAH. The applicants are Children's Hospital Los Angeles, University of Michigan, University of Oklahoma and New York Presbyterian Weill Cornell.

The pilot center, which will be selected among these four institutions, will be announced by the end of October.

Everyone CARES Gala

In March, CARES Foundation honored its past president Gregory Kraff, for his leadership and continued commitment to the organization and the CAH community at large. Other honorees included Dr. Deborah Merke for her pioneering research, and Wilson & Son Jewelers for their years of financial support to CARES.

Get Connected

Join CARES Foundation on Facebook, Twitter and YouTube.

Personal Stories

Many of our newsletters have included inspirational personal stories about living with CAH. If you'd like to share your experience with the rest of our community, please send your story, with a picture or two, to me at Dina@caresfoundation.org. We look forward to reading it!

We hope you enjoy this edition of *CARES Connections* and welcome your feedback as we work to better serve your needs.

Warm regards...

Dina

transformation of Skene's glands into prostate tissue. However, some other questions arise: what is the crucial moment for female prostate development, the prenatal or the postnatal period? Why is prostate tissue not identified in all female CAH patients? Could genetic factors be involved in the presence or absence of prostate tissue among CAH girls?

Scientific studies showed prostate-like tissue development in female mice exposed to testosterone injections during fetal life and this effect was dependent on the amount of testosterone⁷. In humans, the two previously described CAH females with prostate tissue detected by magnetic resonance^{3,4}, also had severe degrees of external genitalia virilization at birth, which suggests a prenatal androgen exposure effect as a causal factor. It is known that other factors besides testosterone concentrations in the blood can influence the severity of virilization in CAH patients. We have observed that alterations in the gene that produces the androgen receptor (the protein necessary for the androgen action) also affect the degree of external genitalia virilization in CAH females⁸. Considering these above-mentioned data, we speculate that inter-individual genetic alterations related to androgen action could also influence the prostatic tissue development in CAH girls.

The finding of prostatic tissue in 16% of Brazilian CAH girls was probably due to the systematic investigation by the sensitive radiological method, magnetic resonance⁵. Future studies searching for the presence of prostate tissues in CAH girls and comparing these findings with the severity of external genital virilization may elucidate the role of prenatal androgen action on the prostate tissue development in female patients. Additionally, we can not rule out that prostate growth is stimulated by high androgen exposure during postnatal life,



either due to late diagnosis in simple virilizing girls (from countries where CAH newborn screening tests are not performed) or due to the lack of treatment adherence, resulting in inadequate androgen control.

In addition, a scientific study showed an increased proliferation of prostate tissue in adult female mice that received testosterone injections, similar to the prostate tissue of male mice⁹. Therefore, these data reinforce the hypothesis that postnatal hyperandrogenism could also influence the development of prostate tissue in CAH girls. The diagnosis of CAH in the patient previously described by Subramanian et al.⁴ was performed only at 14 years of age and the long exposure time to increased androgen levels could have contributed to the prostate tissue growth.

Since magnetic resonance is an expensive diagnostic tool, it should not always be performed in all CAH patients. It was suggested that the PSA (prostate-specific antigen) measurements in blood may be a good predictor of the presence of prostate tissue in CAH females⁵. However, it is important to note that PSA levels can be detected in up to 10% of normal women, because it is also expressed in other kinds of tissue. Until there is definitive proof, we recommend that the use of PSA

measurements, as screening tool for detecting the presence of prostate tissue, must be restricted to research centers since the finding of detectable PSA in CAH girls may be a false-positive result and can lead to an unnecessary anxiety in the families.

We can conclude that prostate tissue in CAH girls may be common, especially in those extremely virilized patients at birth and in those with poor treatment adherence. These findings reinforce the importance of adequate hormonal control throughout life, aiming to achieve normal androgen levels, adjusted for age and sex, in order to avoid prostate tissue proliferation. We can speculate that inadequate hormonal control may increase the rate of prostate hyperplasia and maybe cancer, but these risks still need to be determined in CAH women.

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Robust Global Survey of People with Adrenal Insufficiency Complete

DuoCort, a wholly-owned subsidiary of ViroPharma Incorporated, conducted a web-based patient survey in people with adrenal insufficiency (AI) between September and December 2008 in collaboration with patient organizations in the US, UK and Australia. The objective of the survey was to gain more insights about unmet needs in the area of replacement therapy and with the hopes of being able to provide patients with a better treatment that addressed those needs.

The survey generated great interest and AI sufferers from other countries such as Canada, France, Sweden and Denmark also completed the survey. In total, there were over 1200 respondents—the majority from the US—making it the largest patient survey ever done in adrenal insufficiency.

The majority of respondents suffer from primary adrenal insufficiency or Addison's disease.

Hydrocortisone is used by most of the respondents—the majority of which are on twice or thrice daily dosing.

Many of the respondents are dissatisfied with their current treatment and the majority report an impacted quality

of life due to their illness. Many AI sufferers need to alter their physical activity, social life, work life and family life due to their illness. The level of impact on social life is in line with data from another international survey conducted in 2003 across the UK, Canada, Australia and New Zealand with 850 respondents with one third reporting that their condition affected their ability to participate in social activities. In the same study over 10% reported they were unable to work through disability or illness, which is also in line with our survey results. Apart from the reported impact on quality of life, a majority of responders were also concerned about long-term side effects of their treatment. Osteoporosis is what worried responders the most, followed by obesity, fatigue and cardiovascular problems.

A majority of responders experience fatigue in the morning or the afternoon or both. This is in line with data from the above-mentioned international survey where nearly two-thirds experienced fatigue. Even more people with secondary insufficiency said they suffer from fatigue in our survey.

People with secondary adrenal insufficiency seem to suffer more from their adrenal insufficiency over all. Compared to people with primary adrenal insufficiency they report

- more illness
- more worry about long term problems with their treatment
- more activities they do not do due to their illness
- that they are less fit to work and
- more absenteeism from work

When people in the survey were asked if they could change anything with their current therapy, a common theme was that a medication that is given once a day would enable them to be able to lead a more normal life. Some quotes from a few of the respondents illustrate this:

"It is difficult to maintain a consistent level of energy. I have peaks and valleys, times when I feel energetic, and times when I feel extremely fatigued. It makes it difficult to function, especially at work."

"I would love a medication that made me feel more like a normal person who doesn't have Adrenal Insufficiency"

"I find the whole timing thing very difficult, once daily would be better than twice"

Some of the results of this survey were presented this September at 15th Congress of the European Neuroendocrine Association in Vienna Austria

For more information, please visit www.viopharma.com.

Preoperative Genitogram May Not Be Necessary

In the interest of limiting invasive procedures in young children with CAH, a recent article brings into question the utility of the preoperative genitogram. A genitogram has traditionally been performed on females with CAH who are born with ambiguous genitalia in order to evaluate internal anatomy prior to surgery. The procedure is a special X-ray test that involves placing a catheter into the urethra and injecting an opaque dye, which helps to delineate the urogenital sinus (fusion of urethral and vaginal openings) and bladder. In the recent article by Vanderbrink et al (2010),¹ the authors reviewed the records of 40 female patients with CAH who underwent genitograms prior to feminizing genital surgery. The genitogram revealed complete anatomy in only 30 cases (72%), whereas the rest of the studies were incomplete. In no case did the genitogram reveal anatomy that was not visible via endoscopy or at reconstruction. The surgical technique was based on endoscopic and intraopera-

tive findings, not on genitogram. If the genitogram has limited value and does not influence the surgical approach, the practice of routinely performing genitograms in females with ambiguous genitalia should be reconsidered.

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Updates from the NIH Clinical Center

Carol Van Ryzin, R.N., C.P.N.P. and Deborah Merke, M.D., M.S.

Thanks to generous support from CARES Foundation, we have had an ongoing Natural History Study of CAH at the NIH Clinical Center since October 2005.

The NIH Clinical Center is the ideal place in which to carry out this study and is one of the few places in the world that facilitates the conduct of long-term studies of rare diseases. To date, recruitment has been very successful with 267 (194 classic, 73 nonclassic) CAH patients, ages 6 months to 66 years, and 250 parents evaluated as part of this study, Protocol # 06CH0011, Natural History Study of Patients with Excess Androgen (ClinicalTrials.gov Identifier #NCT00250159). Detailed clinical evaluations have revealed great variation in treatment approaches of referred patients, with only 30% of patients receiving therapies resulting in acceptable disease control. Abnormal growth and development of children, short stature in adults, cardiovascular risk factors, reduced bone mineral density and adrenal and testicular tumor formation are common. Clearly new treatments are needed. An overview of the clinical findings of this large group of patients is currently in press in the *Journal of Clinical Endocrinology and Metabolism*.

As part of the Natural History Study, our group is analyzing new aspects of the genetics of CAH. We showed that the widely used method to evaluate the CAH gene in 21-hydroxylase deficiency failed to detect mutations in 10% of patients, which is more often than expected.

This is because this method only screens for common mutations¹. Large deletions of the CAH gene are thought to be associated with the salt-wasting form of CAH. Our group also reported that 4 percent of large gene deletions are associated with a mild clinical presentation; the breakpoint in the deletion can be clinically important².

Parents have also been evaluated as part of this study. Ten parents (4 percent) were found to have the mild nonclassic form of CAH unknowingly. These parents underwent a complete medical examination. Men did not have symptoms but women often had a history of infertility and other mild symptoms of excess androgens³. We found that parents of a child with CAH have a 1:25 risk of having nonclassic CAH; therefore if the mother of a child with CAH has infertility, an evaluation for nonclassic CAH is indicated.

Genes neighboring the CAH gene are also being evaluated and this has led to some interesting findings. One gene that lies next to the CAH gene, complement protein C4, is important in the immune system. We found that the most common mutation (V281L) seen in individuals with nonclassic CAH is associated with higher number of C4 genes and increased complement levels. Higher complement levels are known to be protective against autoimmune disease. This association leads to an interesting hypothesis that certain mutations seen in CAH carriers or affected individuals may have an evolutionary advantage⁴.

An important goal of the Study is to follow a large population of patients for referral to future treatment

studies. Diurnal Limited recently finalized an agreement with NIH to study a newly formulated modified release form of hydrocortisone named Chronocort®. This form of hydrocortisone is designed to mimic the natural biorhythm of cortisol secretion. Many of the complications of CAH treatment at the present time, such as obesity, insulin resistance, short stature, and mood alterations, may be due to our current inability to mimic the natural biorhythm of cortisol secretion. A few years ago a study comparing Chronocort® to conventional hydrocortisone was carried out at the NIH Clinical Center⁵. This study showed that Chronocort® closely mimicked normal cortical secretion overnight and was effective in controlling nighttime hormone levels, but was not optimal during the day. Chronocort® has since been reformulated and studied in healthy volunteers. In the new study, Chronocort® will be given twice daily. The study protocol is currently under review by NIH. Once approved, adults with classic form of CAH will be invited to participate in a 6 month study. Another way to mimic the natural biorhythm of cortisol is by using an insulin pump to administer hydrocortisone. We are also planning a study using a pump.

We are very excited to report that we recently expanded our research team. Dr. Ashwini Mallappa completed her fellowship training in Pediatric Endocrinology at the University of Oklahoma and joined our group in July 2012. She will be working on these upcoming projects.

We are still recruiting patients of all ages with CAH (both classic and nonclassic) to the Natural History Study. The current wait time for an appointment is 3 to 4 months. Participants will be seen as outpatients at the NIH Clinical Center in Bethesda, Maryland and may be seen for a full evaluation and up to four

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RESEARCH *Research Studies* continued

visits, and sometimes for ongoing care. Patients seen for a limited number of visits will have a full report sent to their private physician. All testing is free of charge and will include:

- Genotyping (patients with 21-Hydroxylase deficiency only)
- Hormonal evaluation including evaluation for insulin resistance
- Bone age (growing children), ultrasound
- Bone density (patients 8 years and older)

For more information or to volunteer, please contact Suzanne Collier at 301-496-0610.

We gratefully acknowledge the enthusiastic participation of our patients and their relatives, without whom this work would not have been possible.

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Other Research Opportunities

To learn more about other research opportunities, please visit our website: <http://www.caresfoundation.org>

EDUCATION

LA Conference

CARES Foundation, in conjunction with Children's Hospital Los Angeles, will hold a patient education conference entitled **CAH Across a Lifetime on Saturday, November 17, 2012**. Topics will include: Newborn Screening; Genetics & Genetic Counseling; Pregnancy; Consensus Guidelines & Controversies; Surgery; Adults & CAH; and New Research Developments. Participants will explore Emergency Issues, Urological & Reproductive Issues, Genetic Counseling, Mental Health & Nutrition during small-group breakout sessions. Injection training and School/Camp Packet review will also be offered throughout the day.

This will be an opportunity to interact with CAH experts and to connect with other patients and families. Spanish translation services will be provided.

To register or for more information, visit our website at <http://www.caresfoundation.org/productcart/pc/events/CHLA2012/CHLAEvent2012.html>.

New York City Conference

On Saturday, April 21, 2012 dozens of parents, teens, and adults affected with CAH attended the **CAH Education Day** at New York Presbyterian Weill Cornell Medical Center in New York City. Presentations were given by many of the top CAH experts in the country. Attendees learned about a range of topics of interest to patients and caregivers. Training on Solu-Cortef injection administration was also

offered, along with a discussion of the CARES School/Camp Packet.

Attendees who came from the East Coast and from as far away as South Carolina met others with CAH, some for the first time in their lives. It was an enriching and inspiring day for many.

Here are some comments from those who attended:

"We have attended the conference in the past, and this was just as good, if not better...we plan to continue to attend each year..."

"I thought the conference was extremely informative and enjoyed discussions with people that are knowledgeable of CAH. Thank you CARES!"

"As a parent of a child with CAH, this conference was so refreshing. It was so valuable and positive meeting other parents."

Many thanks to New York Presbyterian Weill Cornell for hosting the event and to the volunteers and healthcare professionals who gave their time to make this day a rousing success. We are grateful for their commitment.

THE DOCTOR'S IN

When to Give Injectable Hydrocortisone (Solu-Cortef)

If you have classic CAH or have non-classic CAH and are being treated with glucocorticoid therapy, then you are at risk for an adrenal crisis, and it is absolutely essential that you know when and how to stress-dose with Solu-Cortef.

What is an adrenal crisis?

In times of physical stress or illness, the body's normal response is to make more cortisol (the "stress" hormone), which aids the body in fighting infections, maintaining adequate blood pressure, and preventing low blood sugar. Patients with CAH (or other conditions causing adrenal insufficiency)

do not produce sufficient cortisol, nor can they mount an appropriate stress response with a rapid increase in cortisol. When not enough cortisol is produced during periods of acute illness or trauma, an **adrenal crisis** can occur.

Signs and symptoms of an **adrenal crisis** include:

- Lethargy
- Shock
- Profuse sweating
- Shakiness
- Headache
- Dizziness
- Confusion

If an adrenal crisis is not treated promptly with rapid-acting cortisol, it can lead to heart failure, coma and death.

Solu-Cortef

Solu-Cortef is the injectable form of hydrocortisone, which is structurally the same as cortisol. It has rapid onset of action and must be given if stress dosing cannot be given orally, e.g. severe vomiting and diarrhea or shock/unconsciousness. It should also be given in the event of a severe traumatic injury, particularly those resulting in profuse bleeding or change in mental status.

If there are any signs of adrenal crisis (see above), call your physician and go to the nearest emergency room immediately (or call 911). **DO NOT WAIT** to give Solu-Cortef!! Ambulance services may not be able to administer Solu-Cortef, and there may be a delay in treatment in the emergency room.

Guidelines for the initial Solu-Cortef bolus:

- 25 mg IM or IV for children under 3 years of age
- 50 mg IM or IV for children 3-10 years of age
- 100 mg for children >10 years or adults

If you do not have Solu-Cortef or do not know how to administer it, please speak to your physician immediately so that you are prepared in the event of an emergency.

For instructions on how to administer Solu-Cortef, you may also go to our website for Emergency Instructions: www.caresfoundation.org.

Flu Season is Upon Us

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

Please 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. Back to school means time for cold and flu season. Don't be caught without your Solu-Cortef!

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

ADVOCACY

What the Health Care Reform Law Means to You

History—Patient Protection and Affordable Care Act

Back in 2010, we faced urgent challenges relating to health care and our economy. Despite spending more on health care than any nation on earth, we had 50 million uninsured citizens and mediocre health results. Families, businesses, and government were all struggling under the burden of rising costs. Between 2000 and 2009, premiums doubled. Insurers could cap your coverage, raise your rates, or even cancel your coverage with no accountability. And for the 129 million Americans with a pre-existing conditions such as CAH, cancer or even asthma, there was a good chance of being locked or priced out of the market altogether.

To address those challenges, **the Patient Protection and Affordable Care Act (aka Health Care Reform) was signed into law on March 23, 2010.** The Affordable Care Act puts people back in charge of their health care. The law's first principle is very simple: if you have coverage, you can keep it. So for the 250 million Americans with insurance today, the main change is that they'll get new protections not available before.

It is the law of the land now that:

- Children under age 19 can no longer be denied coverage because of pre-existing conditions. That will be true of adults beginning in 2014.
- Young adults up to age 26 can stay on their parents' plan. More than 3 million young adults in our nation have gained insurance coverage as a result of the health care law.
- Key preventive care is covered without co-pays or deductibles in private insurance and Medicare.
- Insurance companies can no longer drop people from coverage when they become sick because an error in the application
- Lifetime limits on insurance payments for services will be eliminated.
- Insurers must now spend at least 80 percent of your premium on health care services, not marketing or profits, or they must repay the money. That's right: insurance companies will actually be sending money BACK to their customers! Because of this 80/20 rule, nearly 13 million people across the nation with private insurance coverage will benefit from over one billion dollars in rebates from insurance companies this year.
- The law has new rules that require insurance companies—for the first time ever—to publicly justify any rate increase of 10 percent or more.

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ADVOCACY continued

And it gives states new resources to review and block these premium hikes.

For adults with pre-existing conditions the law created a bridge plan to provide them with affordable coverage until 2014.

To learn more about the Affordable Care Act visit: <http://www.healthcare.gov>.

Special thanks to Dr. Jaime R. Torres—*Regional Director of the U.S. Department of Health and Human Services, serving New York, New Jersey, Puerto Rico and the US Virgin Islands for his contribution to this article.*

EMS Update

CARES staff, board members and parents met with the District of Columbia's EMS Medical Director earlier this year. As a result of that meeting, DC has adopted protocols for the administration of Solu-Cortef. DC EMS personnel are being trained on adrenal insufficiency and injection administration with resources provided by CARES.

In New Jersey, CARES has had numerous meetings with legislators about protocol adoption. As a first step, a bill was passed to declare June as CAH Awareness Month. Currently, CARES is working with the Department of Health and Senior Services to provide training information and resources for EMS. We continue to advocate for adoption of protocols.

In California, we are working with the state's EMS department to further educate regional EMS medical directors on the importance of protocols providing for the administration of Solu-Cortef and stocking the medication on ambulances. At present, EMS personnel are only allowed to assist with the administration of the injection.

In Minnesota, the Department of Health patterned guidelines on hypotension

gathered from the CARES website when meeting with the Medical Directors State Advisory Committee. As a result, a protocol for hypotension will be added to the Emergency Medical Services for Children (EMSC) pediatric guidelines and CAH will be listed as one of the causes of shock.

We have ongoing campaigns in many states including: Colorado, Alabama, Arkansas, Connecticut, Florida, Illinois, Indiana, Kansas, Louisiana, Missouri, New York and Wisconsin. Campaigns have been re-invigorated or started in Arizona, Georgia, New Mexico, North Carolina, Virginia and Utah.

Thank you to all of our members, family advocates, and others with adrenal insufficiency who are leading the charge in their local communities. We cannot do it without you.

If you would like to start or join an advocacy campaign in your community, please contact Karen Fountain at Karenf@caresfoundation.org or 1-866-227-3737.

CAH AROUND THE WORLD

Australia

Newborn Screening Advocacy

Congenital Adrenal Support Group of Australia (CAHSGA) is seeking government support for the inclusion of in the NSW/ACT Newborn Screening Register and then support for the rest of the Australian states. It is a slow process, but the group is meeting with government officials about the importance of screening and the challenges faced by CAH patients who suffer due to the absence of routine screenings.

To lend your voice to this important effort, contact Michelle Hoare, President CAHSGA via president@cah.org.au. By working together, the CAH community can make a difference in the lives of so many.

Other News

CAHSGA held its family conference in Sydney on the 9th of September. With more than 60 adults and 20 children on hand, it was a huge success.

The event was a great opportunity for CAH families from around Australia to connect with each other and to learn from specialists in the CAH field. So much information was shared and new friendships made that it left participants eagerly awaiting the next meeting.

Vietnam

In July at the National Hospital of Pediatrics (NHP) in Hanoi, Vietnam, 350 CAH families came together for support and educational updates. With thanks to the support of the fantastic team at NHP—led by Dr. Vu Chi Dung—and in collaboration with CLAN (Caring & Living As Neighbours—www.clanchildhealth.org), Associate Professor Maria Craig of Children's Hospital Westmead (CHW) and Ms Irene Mitchelhill, a specialist CAH nurse from Sydney Children's Hospital, the day was a huge success. A special focus this year was building the financial capacity and independence of the CAH Club in Hanoi as well as its members. Financial burdens are a major problem for the parents of children with chronic health conditions in resource-poor countries, and as the 5th pillar of CLAN's strategic framework for action, is a key priority for CLAN.

Mr. Jim Willett, a volunteer working with CLAN and sponsored by AusAID through the Australian Business Volunteers (ABV) program, also attended the meeting, and stayed on afterwards for a month, traveling to CAH families' homes and learning more about potential solutions we can all work towards for the benefit of the children and families.

With thanks to C3 Vietnam—a brilliant team of film makers based in Hanoi—a fantastic film was created on the day



The CAH Club Meeting Hanoi, Vietnam

of the CAH Club meeting (please visit www.clanchildhealth.org for more.) CLAN sincerely hopes this will prove to be a powerful tool, bringing the stories and voices of the members of the Hanoi CAH community and their supporters to the attention of the broader international CAH community. CLAN is extremely grateful to CAH Support Group Australia for agreeing to share the video at their upcoming meeting in Sydney on 9 September. If we work together, nothing is impossible, and the health and well-being of our neighbours' children who are living with CAH in less fortunate circumstances can become a tangible priority that we can all focus on.

MAKING CONNECTIONS

Ask the Expert!

"Ask the Expert" is a new service that allows our community 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!

Our Blog!

The purpose of our 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.

Physician Referral

Do you have a doctor or other health care professional who has been caring for you or your child that you would like to recommend to others? We are looking to build our database of qualified and caring professionals across the United States and around the world. So, if you would like to recommend someone, please let us know. Send an email with the professional's name, contact information (including email and phone number), and location (city, state, country) to: Dina@caresfoundation.org.

Thank you for helping us make the connection.

facebook twitter

New Ways of Communicating

Do you use Facebook and Twitter ? So do we!! <http://bit.ly/9HkukY>

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.

Opportunities to Meet CAH patients and families

Email, Facebook, and texting are all great methods of communication, but there's nothing as valuable as a face-to-face meeting. So, we have some exciting opportunities to bring CAH patients and families together.



CARES Foundation's CAREing Hearts Walk for CAH Sunday, October 28th

This inaugural event will take place at the Wild Duck Pond Park in Ridgewood, NJ. It's the perfect opportunity to meet others affected by CAH. Ask family, friends, neighbors and colleagues to join you on the Caring Hearts Walk for CAH Awareness.

Children are invited to wear their costumes for a special Trick-or-Treat.

For more information or to register, click here: www.caresfoundation.org/walk.

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MAKING CONNECTIONS *continued*

The Harlem Wizards Trick Hoopz & Alley Oops Game

Sunday, December 2nd

Worried about kids suffering from cabin fever on a cold December Sunday? Why not join us for an afternoon of fun and games at Livingston High School in Livingston, NJ, guaranteed to heat things up. The CARES home team will join the Harlem Wizards on the hardwood.

You and your family can cheer on the home team while raising awareness for CAH. For more information, contact us at www.caresfoundation.org/events.

CAH Families Benefit from Free Camps

We have had exciting developments for our CAH families this year. At present, four camps are accepting our CAH children into their **FREE** medically-supervised recreational and therapeutic programs for those with serious illness. Two of the camps are programs of the **Dream Street Foundation** and the other two are a part the **Serious Fun Network** that was founded by the actor Paul Newman. Serious Fun Network Camps accept children ages 6-16 from all over the world.



Dream Street Foundation

Dream Street offers a week in the summer in Ojai, California

for children ages 4-14. Each year a theme is chosen and activities reflect the theme. Other activities include horseback riding, swimming, playing sports, arts and crafts, zip line,



archery, martial arts, campfires, bounce houses, dances, outdoor movies, scavenger hunts and much more.

Dream Street also has a program for young adults ages 18-24 at Canyon Ranch, the spa and resort in Tucson, Arizona. The week includes daily focus groups for sharing personal challenges; lectures on healthy lifestyle choices and other life issues, swimming, tennis, golf, weight training, exercise classes and more. The goal is for the campers to share their experiences and create a bond with others. It is an intimate, mature and developmental experience.



Double H Ranch founded by philanthropist Charles R. Woods, along with Paul Newman, is located in Adirondack Park outside of Lake George, NY in Lake Luzerne. Activities include swimming in indoor and outdoor pools, high ropes course, archery, horseback riding, costume/dress-up with stage area, arts & crafts, boating, fishing, nature exploration and more.

A CAH mom shared with us: "The

counselors were great. My daughter can't believe she went to camp. I think the entire experience seems unreal to her. She has been talking about it all day on and off. She did miss home a bit, but definitely had fun. She said that the counselors were very good about making sure she had enough water. I guess last night she was light headed and her stomach felt weird. In addition to making sure she had enough water she said they were also very sweet and caring. What a great place! They sang a song to her and hugged her as we were picking her up and I just started crying. One of the counselors gave me a big bear hug and told me how great my daughter was. Thanks so much for connecting us with Double H! Even though I missed her, it was great to know she was having fun at camp and in good hands also."

Double H also has a **Winter Adaptive Sports Program**. A few of our CAH families were able to attend this past winter. They participated in Alpine skiing, snowboarding instruction, and snowshoeing lessons. One mother said, "I can't begin to tell you how much I enjoyed myself. My daughter (age 11) was a pig in mud. She actually said to me: It is worth being sick to come here! She is now a skier, and I am trying to find a place to bring her this weekend to keep at it."

Victory Junction is in Randleman, North Carolina located on 84 acres donated by Richard Petty, the racecar driver, and his wife Lynda. Activities include sports in a full gymnasium, arts & crafts, boating &

Current Participating Camps:

Double H Ranch, Lake Luzerne, NY	ages 6-16
Dream Street Foundation, Ojai, CA	ages 4-14
Dream Street Foundation, Canyon Ranch, Tucson, AZ	ages 18-24
Victory Junction, Randleman, NC	ages 6-16

For more information on camp opportunities, contact Karen Fountain at Karenf@caresfoundation.org.

fishing, archery, a maze where counselors move the labyrinth walls daily, pony rides, bowling alley, mini-golf course and sleeping outside in a tree house.

Another unique experience is Adam's Race Shop which provides a look at the world of NASCAR. Campers "suit up" in a racing suit and actually strap into an authentic NASCAR racecar. In this safe and adaptable program area, campers can change a tire, play Wii, arcade games and much more.

CARES is constantly working to expand camp offerings.

We have submitted an application for our children to attend the **Roundup River Ranch** in Colorado. We are also collaborating with **The Painted Turtle Camp** in Northern California to create protocols and guidelines to allow CAH children to attend next year. We will continue to keep you informed about these and other opportunities via email, Facebook and Twitter.

Please contact each camp for specific information on travel assistance. These camps are the perfect place to let your child explore independence and experience joy in a safe highly supervised environment with a full medical staff.



Support Group Corner

Support Network Restructured

We are pleased to share that we have restructured our support groups. Previously, we focused on providing support regionally. Our specialized network now includes leaders who address specific topics related to CAH. Those looking for support can connect with a leader who lives in the same state, but also another leader who has dealt with the specific issues they are facing.

Individuals will still be able to stay connected with others affected by CAH in their state via their local support group leader. They will continue to gather for meetings, special events and fundraisers.

If you would like to support others in a specific area, please contact Karen at Karenf@caresfoundation.org to become a specialized support group leader.

Our new specialized areas of support are:

- Family Planning
- Pregnancy & Dexamethasone
- Newborns
- Surgery
- Children with Classical CAH
- Children with Non-Classical CAH
- Teens with Classical CAH
- Teens with Non-Classical CAH
- Adults with Classical CAH
- Adults with Non-Classical CAH

Welcome New Support Group Leaders

Our support group leaders are a family of committed, caring individuals who dedicate their time to others by sharing their concerns, experiences and knowledge. We extend a heartfelt welcome to those who recently joined this extraordinary family.

- Wendy Thornley
Connecticut
- Michelle Wanamaker
District of Columbia & DC area
- Jennifer Goleis
Utah, Idaho, Montana, Wyoming
- Erica Callam
Indiana, Kentucky, Adults with Classical CAH (women)
- Eden & Jeff Lord
Kansas
- Maura Roll
Kentucky
- Brett Steckler
Missouri
- Anne McDonough
Virginia & West Virginia

Susan Aycock (Mississippi) and Julie Adams (Colorado) have become specialized leaders in the area of Teens with Classical CAH.

A special thank you goes out to those who recently stepped down from their positions:

- Renee Beard (*Kentucky*)
- Jennifer McLeod (*Pennsylvania*)

We appreciate their years of dedication and commitment to CAH families.

Leaders Needed

We need dedicated individuals to provide support to patients and families in the following states and topics:

- Alaska
- Colorado
- Maine
- Minnesota
- Mississippi
- New Hampshire
- North Dakota
- Rhode Island
- South Dakota

- Men with Classical CAH
- Men with Non-Classical CAH

Activities

California

One of our Southern California support group leaders Kelly Fisher organized a CAH Parent Support Meeting at Children's Hospital of Orange County, on April 28. Dr. Lien Trinh was the guest speaker. She spoke with parents and answered specific questions they had. It was an educational social success! Thank you Kelly!

Oklahoma

The SUCCEED Clinic and Traci Schaeffer, our Oklahoma support group leader & SUCCEED nurse, hosted a CAH Support Group dinner on April 20. Families enjoyed dinner, each other's company and a presentation on "CAH & Urology" by Dr. Palmer. Dr. Laura Chalmers also participated.

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Pennsylvania

On Saturday, August 11, Pennsylvania Support Group Leader, Debbie Ham held a bowling fundraiser at the ABC North Lanes & Lounge in Harrisburg. Debbie and her cousin, Diana Johnson, worked tirelessly to secure door prizes, raffle items and other donations. Everyone had a great time and Debbie raised \$300! Thank you for all of your hard work, Debbie!

Texas

Our Dallas–area leader, Erika Hagenbeck held two events this past spring. The first was a Memorial Day Picnic at Allan Shivers Park at Texas Scottish Rite Hospital for Children. Families were able to gather for fun and companionship! The second was a gathering organized by Erica and Lindsay Lauber for women with CAH at a local restaurant on June 30th in North Arlington. This was a wonderful opportunity to relax and enjoy time together!

Thank you to all of our leaders for connecting our CAH families!

Next SGL Meeting

The next Support Group Leader conference call will be held the beginning of October. We hope leaders participate to hear about upcoming events, share what you’ve been doing and get some ideas from others.

The Circus Came to Town

America’s Original 3-Ring Circus was kind enough to offer the CARES Foundation free tickets to their spectacular show. Many CAH families in Texas, Illinois, Nevada and Wisconsin were able to enjoy a fun-filled afternoon this past spring. Thank you to the support group leaders who coordinated in their states!



The circus is heading back to Texas and over to Tennessee and up to Minnesota this fall. We will be sending an email to all families in those states regarding tickets. Stay tuned.

LA Fiesta

On January 13, the Children’s Hospital of Los Angeles endocrinology clinic sponsored a Congenital Adrenal Hyperplasia Fiesta Day from 10am-3pm. Dr. Mimi Kim and Dr. Mitchell Geffner, along with help from Kelly Fisher, our Southern California support group leader, and staff members, created a wonderful fun-filled event for families. Almost 40 children and their parents/ caregivers enjoyed games; a photo booth; arts & crafts; food; Emergency & Resource booth; a speaker session along with Question & Answer forum with the CAH Medical team.



**Haylie’s Hope
Our Journey from
SWCAH Diagnosis
to Today**

By Angela Lake

First of all...DON’T PANIC!

I know it’s easier said than done, but when your child has been diagnosed with a relatively unknown to you (and almost everyone else) disease, that is most definitely your first instinct. I wish everyone in the first few days after diagnosis could have a mirror that lets him or her see into the future.

The day Haylie was born, my husband and I went into the chapel at the hospital before being admitted, just as we had done with our first daughter. With Katie, I sat and calmly prayed that all would be well and our surgery would be smooth and she would be great and we would have a great recovery together. With Haylie, somehow, the whole time I was pregnant, though I didn’t allow it to overcome me, I just instinctively knew something was different. When Teddy and I went to the chapel before being admitted for Haylie’s c-section, I sobbed; I completely broke down and released all that pent up unknown nervousness that had been in the background for 9 months. I was just petrified, but didn’t really knowing why. I think God allows us instincts and insight into our futures if we listen with our hearts, not our ears. Somehow I knew I would have a precious child I’d have to fight for, I’d always known. I never knew the circumstances, but I had dreams, sometimes nightmares of fighting tooth and nail for a child. I’d wake up; glad it was dream, yet knowing that God was preparing me for something. I knew this little angel and I were going to be fierce warriors together.

Our Haylie was born in September of 2005, weighing in at 9lbs, 15oz. thanks to a healthy dose of gestational diabetes throughout my pregnancy with her. In addition to being a big, BIG bundle of baby love, she was, by all accounts (and still is by my account), PERFECT... 10 fingers, 10 toes, rosy cheeks and bright blue eyes!

We had no indication there was anything to be concerned about until the morning after she was born, when our pediatrician and another doctor came into the room looking very serious. They said that there may be some issue with Haylie. They went on to explain that she showed some urogenital abnormalities, but they spoke so quickly, about ultrasounds to check for internal female organs and chromosomal testing that I wasn't able to understand fully what they said or what they were implying.

HUH? WHAT? I had just given birth to a beautiful little girl...why would they question her chromosomes? I think all that I remember is the calm shock that took over, knowing this was what God had been preparing me for...the what if's...the feeling of being very protective of her no matter what circumstances lay ahead. They came back a short time later to say they'd done the ultrasound and she had a uterus and ovaries, so they were sure she was correctly identified, but they would be 100% certain chromosomally when the other tests came back later in the day.

I don't know why I didn't feel more uptight about it, but I knew in my heart she was my second daughter and there was no need to worry, yet I still let the thoughts randomly creep into my head. What if we find out she's not a girl? What do you tell everyone who thought you had a little girl yesterday and today you have a boy? How do you help that child to understand the circumstances surrounding their birth and all the pictures of pink balloons and dolls? Still, I knew instinctually that she

was my Haylie, my daughter, thoroughly, chromosomally, in every way, my little angel girl, and my second miracle. She has always been my little girl and I really never doubted that for a second, not one second.



After all the testing showed that she is in fact a girl, we asked the pediatric endocrinologist about what Congenital Adrenal Hyperplasia was and what the lifelong repercussions, if any (ha!), there were. He explained in very simple terms that she would require medication for life and that we should think of it the same way one would think of taking a vitamin supplement every day. It was a VERY simplified and not at all thorough version of the truth of CAH, but he probably wasn't prepared for me to have a meltdown in his presence. At the time, I was still very confused and longed to get my hands on a computer, but took his "no big deal" attitude with guarded optimism. I could tell he was trying to simplify it for me, but I wanted the whole truth...I wanted to know what to expect, how to help her, what to look for, things to worry about, what to do, EVERY SINGLE speck of information I could find, but it was not going to happen in the hospital waiting for my c-section to begin to heal!

I felt the need to leave the hospital and flee with my new love, so 1 ½ days after my c-section, I asked to be cleared to

go home. Everything was fine. I think in the hospital I was on autopilot a bit, but not overly concerned. She was (and is) such a bundle of love and sweetness that I watched her and gazed lovingly at her every movement, just as any new parent would. My sense of protection over her was much stronger though, knowing that somehow, we were entering uncharted territory together, and I had to be the captain of her ship for a while, so I was scared for her, for us, for whatever was to come, the unknown future.

When I got home, what I read astounded and scared me to death. The endocrinologist hadn't mentioned anything about adrenal crisis or possible death, or any of the other parts of this disease that wake parents up at night. I decided I was going to arm myself. I sat at my computer and while my girls slept, I absorbed an entire arsenal of knowledge. Every possible reaction, sign, symptom to look for, EVERYTHING, or what was on the Internet about it at the time (which wasn't much).

Besides being a very colicky baby, which at the time, I believed was a direct result of her reading my anxiety, Haylie had a virtually normal first few months of life. Now I realize that she was probably having stomach pain associated her hormone levels until her body was able to build up what was needed and sustain the necessary amount of cortisol. In the meantime, the stores in our area got richer from my buying every baby soothing product, toy and musical thing they had.

We dissolved her medicine into a liquid medicine dispenser with a nipple attached that we bought at Walgreen's. You can find it online at www.walgreens.com for \$2.99 or purchase it at the store. For some reason, that is the only store in our area that carried it and we probably went through 20 of them. It's

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PERSONAL STORY *continued*

made by “Munchkin” and it’s called “The Medicator”. Very serious title for a measuring cup with a nipple attachment. I’d break up her cortef or florinef, whatever pill or combo she was taking and I’d add ¼ tsp. of very hot water, let the pills completely dissolve, then fill the rest of the cup with formula.

We were very lucky in that her first year was completely non-eventful, except for going to the pediatric endocrinologist every 3 months and having blood drawn. We found out so early that she has SWCAH, that she was on medication for it by her 2nd day of life, therefore, we didn’t ever have to face an early health crisis as so many do, especially boys born with SWCAH that have no physical evidence of the disease. She began rolling over when she was about 2 ½ months old, crawling by 4 months old and walking when she was barely 10 months old. In all, she remained with or just a bit ahead of her milestones when compared with other children. She’s always been a big talker and never had any speech delays as our older daughter Katie experienced for a while.

We tiptoed very carefully through her first year, trying to keep her away from anyone who we knew was ill (we still do that). If we go to a store and hear someone cough or sneeze, I turn on my heels and run the other way, which is not always met with understanding by the cough-ee. I’ve had people bring their sick kids around Haylie (knowing about her CAH) and say, “Oh, it’s no big deal, it’s just a cold!” Well, a cold/fever can cause my child to go into adrenal failure or shock, so to me, it’s a HUGE deal, period.

Her first crisis came when she was almost 13 months old. It was cold and flu season (late October) and she went to bed the night before feeling fine, and then woke up with a fever and vomiting uncontrollably. Her fever was quite low-

grade, but she wouldn’t stop vomiting. Well, up until that point, I’d never read anything that said vomiting could be a sign of a crisis, so I didn’t think that was what was happening. I thought she’d gotten a stomach bug. She was limp and lethargic and we quickly took her in to see her pediatrician. On the way there, we called her pediatric endocrinologist and left an urgent message for him to call back. I still was not aware she was in the middle of an adrenal crisis, but since it was her first illness, I was taking all the precautions.

Her pediatrician prescribed an antibiotic and medication to try to settle her stomach. As we were leaving the pediatrician’s office, her endocrinologist returned our call and said that we needed to give Haylie her solu-cortef injection IMMEDIATELY. I’d only ever had one dose prescribed and it was at our home, about 30 minutes away, which I explained to him. At this point, I sensed urgency in his voice and though we had been waiting at the pharmacy to pick up her prescriptions, we decided to head home as fast as we could and give her the injection.

If you’ve never had to do this, the first time is all nerves and fear. I was scared out of my mind trying to make sure that I was following directions to a ‘t’ that I’d printed out from the CARES Foundation website. I’d practiced in my mind, but this was the first time I’d be injecting my daughter in her thigh. It can be a very scary experience—it’s not in our inherent nature to inflict pain on our children--but it doesn’t have to be frightening. First, take a deep breath and try to remain as calm as possible.

For directions on how to administer the injection, go to www.caresfoundation.org, or you can order a pamphlet or two to keep with your injection supplies.

It’s not necessary, but it makes it much easier if you have someone who will be able to hold your baby/child on their

lap (my husband reluctantly did—he was scared too!). Just the thought of injecting your child is going to be unnerving, so repeat this mantra to yourself, “My baby needs this to live, my baby needs this to live,” and just do it. Again, not an easy thing at all to do, but you CAN...you MUST do it!

The first 2-3 years when your child is unable to tell you how they’re feeling or call out to you in the middle of the night are the hardest, by far. Since Haylie seemed to always begin to get sick at night, I slept very little during those first years.

In the same way that you get to know what your child likes to eat, or what makes them smile, you’ll naturally get to know what signs and symptoms to look for in your own child. While we’ve learned to navigate this illness for our daughter, every child is different, as your child will certainly be in regards to CAH. Every child presents the beginning of an adrenal crisis in varying ways. We are lucky that for Haylie, vomiting is the first sign, one that we and everyone else cannot overlook. I know of parents whose children present an adrenal crisis in more subtle ways. If you have ANY doubt about your child’s state of health, call your doctor, take your child to the emergency room (make sure you tell them she has an adrenal insufficiency) and/or give your child the solu-cortef shot. You must educate yourself AND everyone who cares for your child so they are never in a situation where they are unable to get a Solu-Cortef shot should the need arise.

SURGERY OR NO SURGERY?

When Haylie was 1 year old, we started to seriously think about corrective urological and reconstructive surgery for her. I did extensive research and kept going back to one doctor we’d met with at a CARES Foundation Conference in the fall of 2006. At that time and it continues today, there was lots of debate and varying research about the ‘proper’ time to do surgery, whether to do surgery at all and

who was most qualified with the best surgical outcomes.

Dr. Dix Poppas did a presentation at the conference and my husband and I were very impressed with not only his expertise, but his careful consideration and the way he spoke about the subject matter. While much of it was uncomfortable to hear, he covered most of the parental concerns and spoke with compassion and expertise; while certainly an able presenter, he was not up there speaking as a storied clinician or reading off of cue cards. He wanted to make a difference and had worked diligently for children around the world.

After his presentation, my husband and I went to talk with Dr. Poppas and asked some questions about insurance and age recommendations from his experience. He took the time to answer all of our questions and gave me a card to call his office and find out more about the insurance details.

I had already researched CAH surgeons and there were 2 we seriously considered, Dr. Poppas being our first choice. He was always the first choice because he is a pediatrician, urologist and a reconstructive plastic surgeon. Every other doctor we found had "teams" of people who could each do aspects of the surgery, but he was the only one we could find that could do the varying aspects of the surgery in one go. He also had amazing result statistics with preserving nerves bundles and alleviating the prospect of an outcome of incontinence for the children he treated. The bonus when we met him was that we genuinely liked him. He's not flashy (although handsome; he had many of the mom's swooning behind his back), but he's astute and professional. The final straw was that during his presentation he stated, "If my child had CAH, I would perform this surgery in the exact same way and feel completely confident with my results." Afterward, I asked him if he had any daughters and he stated he

did and that he'd meant what he said.

And he did.

It took us 1 ½ years of fighting with the Medicaid system in our state, visits and phone calls with law makers and even a letter writing campaign to the president to get Medicaid to pay for Haylie's surgery. Dr. Poppas' staff jumped through hoops; writing letters for us to present to lawmakers and were generally a great partner in our fight for our daughter. It wasn't about money, as I'm sure when all was said and done, Dr. Poppas was paid a pittance compared to what he's used to and deserves to be paid for his expertise. They just care and knew how important it was to us; it really was that simple.

When we finally had all the paperwork and legalities in place, we had two months to figure out how we would pay for our trip to New York and the approximately 2 weeks we needed to be there. We held a karaoke fundraiser which was a great success.

My faith, though never broken but often shaken during my struggles with bureaucracy, was so rejuvenated and God's mercy was evident everywhere leading up to the fundraiser! As a bonus, many folks, strangers to us before that day, showed up to support us at the fundraiser. The most touching was a man who had seen one of my flyers and called to offer me airline tickets for the follow-up visit we would need to take Haylie to in November. He had a beautiful family and in addition to the tickets, they all showed up to support us at the fundraiser as well. Another man saw a sign in a convenience store that he frequented and decided to go. When the silent auction was about to end, he signed up and bested all the bids to give us an optimum amount for each item. He was a stranger before that day that chose to make a difference...inspiring doesn't sum it up!

Somehow a small group of people

banned together and helped create an amazing fundraiser so our little girl could get the best of care—God has blessed us and shone so brightly over Haylie's life.

In retrospect, it almost seems unreal, as though it was a dream. The amount of work and around-the-clock effort and generosity put forth by so many people assisted our little angel and we are forever indebted to all who gave of themselves be it by a donation or time, or even a hug and encouragement. We raised enough to get Haylie to New York for her initial visit and almost enough to pay for her follow-up.

I have NEVER regretted the decision to choose Dr. Poppas to be Haylie's surgeon and he didn't disappoint in any way. He treated Haylie so tenderly and after she went for her follow-up in November of 2008, he stated that her healing was remarkable and that she'd healed "perfectly." While most post-surgery patients need a follow-up every 2 years or so, her healing was such that she won't need to go back until she's 12 or 14 years old. Yes, God is GREAT!

FAST FORWARD

Our Haylie is now 7 years old and just goes with the flow, even at the doctor's office (after a few tense visits between age 3 and 4). She is such a light in our lives. She knows that she has a small part of her belly that doesn't work the way it should, so she has to take medicine to make sure she feels good. She now swallows her medicine like a grown up and has a very basic childlike understanding, but in so many ways is very wise beyond her years.

Thank you for sharing in her story. It is my hope and intention in writing this to be as honest as possible for the sake of other parents of children with CAH, but at the same time, preserve Haylie's dignity and modesty. I pray I've accomplished that.

Blessings ALWAYS,
Angela

FUNDRAISING

No-Sweat Run for a Cure

Are you in the running? If not, it's not too late.

Our 2012 No Sweat Run for a Cure is well underway, but if you haven't started, there's still time. It will run through September 30th. This virtual event provides an opportunity for the CARES community to raise awareness of CAH and funds to advance CARES' mission. And you don't even have to break a sweat!

To compete in our annual No Sweat Run for a Cure, form a team and ask your friends, colleagues and neighbors to join it. The goal is to raise as much money as you possibly can. For each \$500 raised or donated, you will be entered into a drawing for an Ipad 3 and other prizes.

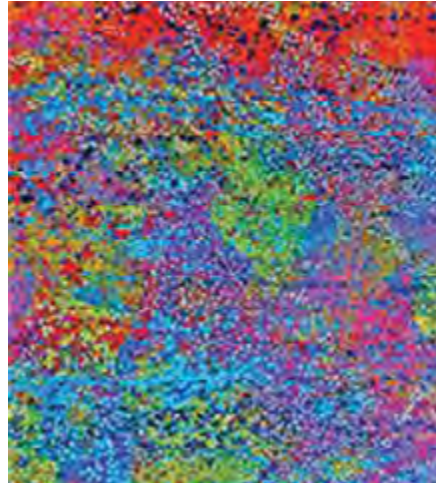
Donating is easy. We provide you with many ways to reach out to your friends. We will send you No Sweat invitations to mail out or you can set up your own No Sweat team page with Kintera, an online fundraising site. You set up your team page, encourage others to donate to it and then you can track your team's progress. Go to <http://CARES.kintera.org/2012-NoSweat> to get started.

This is also a wonderful opportunity to engage your children in raising funds for CAH research. Encourage them to form teams with their friends and classmates. They can choose to organize an event, such as a car wash, basketball game, lemonade stand, etc. to raise money for their team.

Your family and friends can celebrate a special occasion such as a birthday, anniversary, bar or bat mitzvah in the life of a loved one by contributing to No Sweat Run for a Cure.

As we get ready for the opening of our pilot Comprehensive Care Center for CAH, your support of CARES is more important than ever.

For more information, please contact Dina@caresfoundation.org.



Global Spring

Evoking feelings of renewal, hope, and the potential for good in the world, Global Spring was created by noted Texas artist Marianne Howard to benefit CARES Foundation. This limited edition print will truly enhance your home, office, conference room or waiting room, as well as providing a wonderful opportunity to spread awareness about CAH and the importance of research, education and support. Global Spring is also the perfect gift to celebrate a birthday, anniversary, graduation, new home or other special occasion.

Each 28 1/8" x 36 1/8" giclee print, specially priced for CARES Foundation at \$500, will be numbered, individually signed by the artist and mailed to you, within the US, at no additional cost. Your acquisition of this beautiful work of art will help CARES Foundation fund Comprehensive Care Centers, Emergency Medical Care for Adrenal Insufficiency, CAH Awareness, Education and Research. And...for those who've never heard of CARES or CAH, Global Spring gives you the perfect opportunity to explain that because of CARES,

their children, grandchildren, nieces and nephews were screened for CAH at birth.

To place your order for Global Spring and for more information about the Global Spring Project, please contact Dina Matos at 1-866-227-3737 or visit www.caresfoundation.org.



About the Artist

Marianne Howard finds inspiration for her work through the pursuit of her passions, including music, art and science, business and technology,

food, wine and travel. Her extensive worldwide travel has allowed Marianne to explore the power and cultural transcendence of visual images.

Marianne studied drawing, painting, printmaking and photography at Wittenberg University, Springfield, OH, and the School of the Art Institute of Chicago, Chicago, IL. Her work has been exhibited and published nationally and is held in private and corporate collections internationally. An active community and CARES Foundation supporter, Marianne is a frequent conference panelist and guest speaker.

For additional information about the artist, visit www.mariannehoward.com.



Everyone CARES Gala

More than 150 guests including members, families, friends and medical professionals joined WCBS-TV news anchor Chris Wragge, who served as master of ceremonies for the 4th annual Everyone CARES Gala on Thursday, March 1, 2012 at 230 Fifth in NY City.

The evening event recognized the remarkable contributions of three distinguished honorees: Gregory Kraff, immediate past president of CARES Foundation; Deborah Merke, MD, MS, a pediatric endocrinologist and researcher at the National Institutes of Health in Bethesda, MD; and Wilson & Son Jewelers, a luxury jewelry store in Scarsdale and Mt. Kisco, NY who are long-time supporters of CARES.



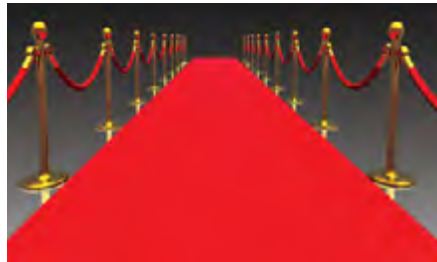
Honorees Gregory Kraff (Pioneer Award), Dr. Deborah Merke (Visionary Award) and Matthew Wilson of Wilson & Son Jewelers (Corporate Partner Award) share their moment in the spotlight.

The vision, dedication and commitment of the honorees have led CARES Foundation to establish itself as an essential resource for families and healthcare professionals in the areas of CAH research, education, advocacy and support. That's why it was important to recognize them in the presence of those on whose behalf they work so hard.

The Everyone CARES Gala is our signature event to raise awareness of CAH and funds for research, education and support while bringing patients and families together. Often, this is the only opportunity for patients and their caregivers to connect with others facing similar challenges. It also provides a forum to inform the community about the latest research, and programs and services available to them.

Attendees who traveled from as far away as Texas, were thrilled to have the

opportunity to meet one another. For some, it was the first time that they met other patients. It was an especially moving event for the children as it was a chance for them to get to know and even play with others who also have CAH. It was a heartwarming experience to witness the realization that they are not alone.



Are You Ready for Your Red Carpet Moment?

Our 2013 Everyone CARES Gala is coming to Hollywood. Mark your calendars now!

Saturday, May 4, 2013
Montage Beverly Hills Hotel
Honoring: Dr. Mitchell Geffner,
Gretchen Alger Lin
and Micato Safaris.

To join the event committee or for more information, please contact Dina@caresfoundation.org.

We look forward to meeting you on the red carpet!

A Look Back at 2011

After two years of hosting the Everyone CARES Gala in New York City, CARES Foundation felt it was important to take the event to different communities it serves. The first stop on the journey to communities outside of CARES backyard was Fort Worth, Texas.

On March 3rd more than 250 patients, families, health care professionals and friends attended the 3rd Annual Everyone CARES Gala at the Omni Fort Worth Hotel to honor the contributions of three distinguished honorees;



2011 Honorees Brad Therrell, PhD, Richard Auchus, MD and Jessica and Matthew Upchurch of Virtuoso.

Dr. Richard Auchus, Dr. Brad Therrell and Virtuoso. The event celebrated the contributions of the honorees to the CAH community and served as an occasion for those affected by CAH to connect with each other. For many, it was also an opportunity to learn about CAH and CARES.

We thank all who contributed to the huge success of the event.

Other Opportunities to Give

Many of you have been incredibly generous in your support of CARES over the years. Others are looking for ways in which to support our mission, but may not know where to start. Here are some ideas:

An easy way to raise money for CARES at no cost to you!

TD Bank-CARES Affinity Program
 Do you have an individual or business account at TD Bank? If you do, please tell TD Bank you want to join CARES Foundation's Affinity Program (#A2332). Raising funds for CARES does not get any easier than this!

By joining the Affinity Program, CARES will receive an annual contribution from TD Bank simply because you bank there! Joining TD Bank's Affinity Program for CARES Foundation is easy!

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FUNDRAISING continued



Call or stop into any TD Bank office (toll-free customer service number: 888-751-9000). Tell a bank representative that you want to join the Affinity Program for CARES Foundation (#A2332). Give them your name and account numbers*.

If you do not currently bank at TD Bank, any bank associate can help you open an account and join the Affinity Program. Any TD Bank customer can join the Affinity Program benefitting CARES Foundation, so ask your friends, relatives, and business partners with TD Bank accounts to call 888-751-9000 and join too. **There is absolutely no cost to you.**

* TD Bank will keep all of your information strictly confidential.

How does the TD Bank Affinity Program work? TD Bank will make an annual contribution to CARES Foundation if 50 accounts are linked to the CARES' Affinity Program. The amount of TD Bank's contribution is based on the average annual balance in the account of the customers who join the Affinity Program. Joining the program does NOT alter the terms or condition of your TD Bank accounts, and none of your funds or personal information will be given to CARES.

http://www.caresfoundation.org/productcart/pc/TDBank_CARES.html

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 [Good-Search.com](http://www.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](http://www.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 an example of how much we can earn:

Number of Supporters	Average Searches Per Day	Estimated Revenue/ 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! Searching has never been better!

Here's the web site:
<http://www.goodsearch.com>

Combined Federal Campaign (CFC) #10933



If you or someone you know works for the federal government, use this opportunity to make the pledge to support CARES. Each year, federal employees and military personnel raise millions of dollars for charity by choos-

ing to donate a portion of their payroll through CFC.

The campaign period is September 15 through December 15. Simply designate Congenital Adrenal Hyperplasia Research Education & Support Foundation, Inc. (CARES Foundation) by including our CFC #10933 and EIN # 22-3755684 in the space provided.

United Way Campaign

Many companies offer their employees the opportunity to give to charity through their local United Way



campaign. Why not select CARES Foundation as your charity of choice? Ask your Human Resources Department for information.

Matching Gifts
Does your company offer a matching gifts program? If so, it's a great way to increase the impact of your giving to CARES Foundation. Every \$1 you give, can turn into a \$2 donation. Contact your Human Resources Department for more information.

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.



Thank You For Supporting Our Mission

Small, often family-sponsored fundraisers are a wonderful opportunity to create awareness of CAH. We want to extend a very special thank you to the following individuals and/or companies for hosting small fundraisers to support our mission.

Melissa Boer
California Pizza Kitchen
Debbie Ham
Brooke Hamblet/Indigo Yoga
Lee Family
Lisa Maples
Polland Family
Amy Price
Chelsea Wilson
Rachel Roussel-Wilson

A very special thank you to the Upchurch Foundation for their generous gift.

If you are interested in hosting your own small event, whether it's a garage sale, bowling tournament, cake sale or other, we will be happy to help with ideas and to spread the word. Contact Dina@caresfoundation.org for more information or assistance.

WELCOME ABOARD!

New Additions to Board of Trustees

CARES extends a warm welcome to Roslyn Allen, Chad Lapp, Traci Schaeffer and Matthew Wilson. Please join us in welcoming them.



Matthew Wilson

Matthew Wilson lives in New York with his wife and two teenage daughters. After graduating from the University of South Carolina with a retail

business degree, he attended the Gemological Institute of America, attaining the title of Certified Gemologist. He is now a partner and the fourth generation in a family-owned full service 106-year old retail jewelry business with locations in Scarsdale and Mt. Kisco, NY.

Matthew and his family have been active in supporting local hospitals including White Plains Hospital, Northern Westchester Hospital, Westchester Medical Center, Blythdale Children's hospital and the Maria Ferrari Children's Hospital. Other organizations they have supported are the American Cancer Society, the March of Dimes, many breast cancer organizations and — very enthusiastically—CARES for the last ten years!



Chad Lapp

A sales and marketing professional with nearly 16 years of television syndication experience, Chad Lapp has a strong background in

presentation, negotiation, ratings interpretation, business and programming strategies, communication and customer service. Detail-oriented and capable of managing multiple priorities simultaneously, he is known for meeting deadlines

and working efficiently!

As the Executive Director, Eastern Sales for Disney-ABC Domestic Television in New York, Chad strategizes and implements the launch of television shows and movies into broadcast syndication, including *LIVE! With Regis and Kelly*, *MILLIONAIRE*, *Grey's Anatomy*, *LOST*, *Desperate Housewives*, *Alias*, *According to Jim*, *My Wife and Kids* and *Scrubs*. He also manages 25 television markets, negotiates license fees, cultivates and maintains more than 150 client relationships throughout the Eastern U.S., teaches the station's sales teams the most efficient way to sell Disney-ABC products, works closely with the research department in developing customized local market pitches, travels extensively to make presentations and build relationships, and created a reference guide of the competitive off-net landscape that is now utilized across the sales division.

Prior to affiliating with Disney-ABC Domestic Television in New York, Chad served as an Account Executive and Director of Eastern Sales for Hearst Entertainment, New York. He is a graduate of Ohio University, Athens and holds a Bachelor of Science degree in Communications.



Roslyn Allen

As Vice President of Merrill Lynch's Global Wealth Management Marketing area, Roslyn Allen served in several

marketing capacities. Subsequent to the firm's acquisition by Bank of America, Roslyn assumed responsibility for strategic marketing in the Northeast Division, supporting the needs of 30+ multi-office sales complexes. This year, her marketing contributions were recognized by Bank of America via a

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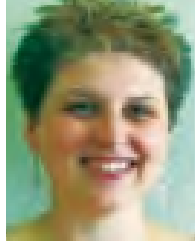
WELCOME ABOARD! *continued*

Global Recognition Award. Prior to her association with Merrill Lynch, Roslyn was employed at TIAA-CREF and the TIAA-CREF Institute in New York, where she created the Hamilton Research Fellowship to honor the life and legacy of Dr. Ruth Simms Hamilton.

Roslyn and her family were featured in the CARES Foundation & CAH Informational Video. She has served on the Professional Advisory Board of the Sisters Network of Central New Jersey, participates in the American Cancer Society 5K fundraising run in Hopewell, NJ and the Sisters Network 5K Walk/Run and Health Summit.

A graduate of Brown University holding dual bachelor's degrees in Management & Organizational Behavior and African-American Studies, Roslyn has also done graduate work at Harvard Extension School and Teachers College, Columbia University. Additionally, she and her husband, licensed lay ministers, pioneered several faith-based ministry mentoring programs for social, relationship, career and spiritual enrichment. Currently, they are marriage support leaders within their local church, provide couples relationship coaching and address national conferences on building strong marriages and families.

Roslyn lives in Central NJ with her wonderful husband Dr. Aberdeen Allen, Jr., a phenomenal daughter, in her 2nd year of gender studies and philosophy at Rutgers University, her pre-teen son, a brilliant scholar-athlete-musician at Rutgers Prep, who has SV-CAH, and a nutty 5 year-old black lab named Zeke.



Traci Schaeffer, RN

Traci Schaeffer is a Pediatric Endocrine Nurse Specialist at Oklahoma University Children's Physicians in Oklahoma City.

In her position, Traci provides long-term follow-up of patients identified as having congenital adrenal hyperplasia (CAH) or congenital hypothyroidism through newborn screening. She is also responsible for educating families, community physicians, hospital staff, child care facilities, and schools about CAH and the needs of affected children, including emergency management.

Traci provides case management of children with CAH through age 21, addressing barriers to care and coordinating a multidisciplinary team to manage patients with CAH, Turner Syndrome (TS), and disorders of sex development (DSD) in SUCCEED Clinic. She is also responsible for the development of educational content for SUCCEED Clinic website. Prior to joining the CARES Board of Trustees, Traci served as support group leader for Oklahoma—a position she still holds. Before joining OU Children's Physicians, Traci was a hematology/oncology nurse at Children's Hospital at OU Medical Center.

New Additions to Scientific and Medical Advisory Board

CARES extends a warm welcome to Dr. Saroj Nimkarn and Dr. Ian Marshall. Please join us in welcoming them.



Saroj Nimkarn, MD

Pediatric Endocrinologist
Dr. Nimkarn currently is Assistant Professor of Pediatrics, Pediatric Endocrinology Department, Weill Medical

College of Cornell University, New York. Previously, he held assistant professor positions at Mount Sinai School of Medicine of New York, Medical College of Wisconsin, and Siriraj Hospital, Mahidol University, Thailand.

Dr. Nimkarn is certified in Pediatrics and Pediatric Endocrinology by the American Board of Pediatrics and holds multiple awards both domestically and abroad for his research work in endocrinology. A frequent presenter on endocrinological issues throughout Asia, he has spoken by invitation in his native Thailand as well as China, Korea and Japan. Extensively published, his work has appeared in numerous peer-reviewed publications including the *Journal of Clinical Endocrinology & Metabolism*; he has also published several books on congenital adrenal hyperplasia and related conditions. Dr. Nimkarn received his medical degree from Ramathibodi Hospital, Mahidol University in Bangkok, Thailand, graduating with honors, and then went on to complete an internship and residency at the University of Illinois, Chicago Medical Center.



Ian Marshall, MD

Chief, Division of Pediatric Endocrinology
Assistant Professor of Pediatrics
UMDNJ-Robert Wood Johnson Medical School

Under Dr. Ian Marshall's direction, the Division of Pediatric Endocrinology specializes in the treatment of all pediatric endocrine disorders including diabetes, disorders of the adrenal and ovarian glands, growth, puberty, bone, calcium, and vitamin D deficiencies.

Prior to assuming his current responsibilities, Dr. Marshall was attending physician at New York Presbyterian Hospital-Weill Cornell Medical College

in New York City, and at the University Medical Center at Princeton, NJ.

Dr. Marshall received his medical degree from University of Cape Town Medical School, Cape Town, South Africa in 1991. He interned at Groote Schuur Hospital in Cape Town, and later completed his residency in Pediatrics at Schneider Children's Hospital, New Hyde Park, NY in 1999. In 2002 he completed his fellowship in Pediatric Endocrinology at New York Presbyterian Hospital-Weill Cornell Medical College.

An acclaimed author, presenter and teacher, Dr. Marshall was named to *New York Magazine's* Best Docs for 2008, 2010, and 2011 and *Inside Jersey Magazine's* Top Doctors for 2010 and 2012.

New Additions to Staff

A warm welcome to:



Karen Fountain,
*Program
Manager*

Karen Fountain brings a breadth of experience to her position at CARES.

She has been a teacher; a women's health clinic counselor; coordinator of community health services; and most recently, a consultant in the international division of Planned Parenthood Federation of America.

Karen graduated from the University of Richmond. She later earned a Masters in Public Health from the University of Medicine and Dentistry of NJ, and an elementary education certificate from Southern Connecticut State University.

As a mother of a child diagnosed with both a seizure and autoimmune disorder, she appreciates the challenges faced by families coping with a child requiring ongoing medical care.



Cindy Rogers
*Director
of Finance and
Operations*

Prior to joining CARES in May, Cindy was Director of Finance and Human Resources for the Alzheimer's Association, Greater New Jersey Chapter.

A graduate of King's College, Wilkes-Barre, PA, she is currently finishing her studies for an MBA from Montclair State University.

Cindy is an active volunteer in her community and serves as Co-Leader

for Girl-Scout Troop 1200. She is the mother of two young girls.



Brendan Faria
Intern

As a college intern, Brendan designs electronic communications for the CARES community and maintains web tools for fundraising events.

He recently entered his sophomore year in college and is an active volunteer with his church.

NEW DIRECTIONS



Comprehensive Care Centers for CAH

The first Center of Excellence for CAH is on the horizon. Our Board of Trustees is in the process of selecting the first Comprehensive Care Center (CCC) for CAH. The center of excellence will manage the care of the CAH patient from birth or diagnosis throughout their lifecycle. The initial applicants competing for the opportunity to be the pilot center include Children's Hospital Los Angeles, New York Presbyterian Weill Cornell Medical Center, Oklahoma University Children's Physicians and University of Michigan Health Systems.

The Comprehensive Care Center project has been a multi-year endeavor that began with the development of guidelines for the centers which involved CAH experts from around the world, as well as patients and parents. The guidelines project was funded with support from NYMAC, HRSA and NBSRC. These guidelines will serve as the foundation for the provision quality care in a medical home setting.

"We are thrilled about this next phase of medical care for CAH patients," said Jessica Hall Upchurch, President of CARES Foundation's Board of Trustees.

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“The CAH Comprehensive Care Centers will provide the level of care that CAH patients need and deserve. With the creation of these centers, patients will no longer have to question where they go to receive the highest quality care, provided by the most experienced, caring professionals regardless of age or severity of their condition. Families and patients will have access to a multi-disciplinary team of experts who will work together to improve their quality of life, as well as a support team to help with everyday challenges. Another exciting aspect of the CCC is the opportunity for more research which is critical for the development of better treatments and one day, a cure for CAH. This is our heartfelt desire for our community. We are most grateful for everyone who has been part of this journey and welcome those joining us to create brighter tomorrows.”

New Posts

Two of our **Scientific and Medical Advisory Board** members have accepted new posts.

Dr. Richard Auchus, formerly with the University of Texas South Western Medical Center in Dallas is now Professor and Fellowship Program Director, Division of Metabolism, Endocrinology & Diabetes at the University of Michigan Health System in Ann Arbor.

Dr. Scott Rivkees has left Yale University to become Chairman of the Department of Pediatrics at the University of Florida College of Medicine in Gainesville.

We wish them both well in their new roles.

Good News for TRICARE Beneficiaries

If you’re a TRICARE beneficiary, rest assured that Solu-cortef is still covered under your insurance plan.

We received a response to our letter of concern regarding non-coverage of Solu-Cortef by TRICARE.

Thomas McGinnis, Chief of Pharmaceutical Operations Directorate assured us that “TRICARE has not made any recent policy changes affecting the coverage of Solu-Cortef. That medication continues to be covered by the medical benefit and under the pharmacy benefit when it can be self-administered.”

He goes on to say that claims for pharmaceutical agents provided by physicians and other appropriate clinicians are processed by the Managed Care Support Contractors (MCSC). When Solu-Cortef is to be self-administered, payment for it moves from the medical to the pharmacy benefit. A newly revised home infusion policy allows the MSCS to grant prior authorization for self-administration, which then enables a patient to obtain Solu-Cortef from an approved TRICARE network pharmacy. The prescribing physician must certify with the MCSC that the patient is able to self-administer Solu-Cortef.

He notes that beneficiaries should contact the regional TRICARE Managed Care Support Contractor for more information about the process.

CARES Brochure Revised and Available For the First Time in Spanish

Our general services brochure has been revised and translated into Spanish for the first time thanks to a generous grant from the New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC).

The brochure serves as an introduction to CARES and CAH for those newly diagnosed, newborn screening professionals, school nurses and organizations serving the Latino community.

Solu-Cortef’s National Drug Code (NDC)

Since the NDC number for Solu-Cortef was changed, some pharmacies are unable to find the product in their computer systems, resulting in erroneously informing people that it is no longer available.

The product is available, but with the following new code: 0009001103



If your pharmacy is having trouble obtaining these products, please instruct them to call Pfizer’s Customer Service at 1(800) 533-4535.

Other contact numbers for Pfizer are 1(800) 821-7000 or patient services at 1(888) 691-6813.

Products to help you manage CAH on a daily basis

Managing CAH on a daily basis takes planning and organization; here are some products we offer to make your life easier and give you some peace of mind.



Shot Kit Bags

Perfect for school, camp, clubs, sports, and leaving with the baby sitter! 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

The *Getting Ready for School/Camp* packet assists you 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 Clings

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 and can be easily removed.

"Adrenal Insufficiency" Shoe Tags
Great for children who have trouble wearing a medic alert bracelet! In case of an emergency, this shoe tag will alert emergency medical staff that your child has adrenal insufficiency. Attach it to your child's shoe lace and other laced items.



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

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.

Disclaimer: Any communication from CARES Foundation, Inc. is intended for informational and educational purposes only and in no way should be taken to be the provision or practice of medical, nursing or professional healthcare advice or services. The information should not be considered complete or exhaustive and should not be used

in place of the visit, call, consultation or advice of your physician or other healthcare provider. You should not use the information in this or any CARES Foundation, Inc. communication to diagnose or treat CAH or any other disorder without first consulting with your physician or healthcare provider. The articles presented in this newsletter are for informational purposes only and do not necessarily reflect the views of CARES Foundation, Inc.

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