

Congenital Adrenal hyperplasia Research, Education & Support

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**Endocrinologic and Psychological Evaluation of
21-Hydroxylase Deficiency Carriers**

Deborah P. Merke, M.D. and Julie Hardin, B.A.

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Everyone has two 21-hydroxylase genes (one from their mother, one from their father). In autosomal recessive conditions, like CAH due to 21-hydroxylase deficiency, the disease state occurs when both genes are impaired. The carrier state is when a deletion or mutation is present in one of the two genes (one gene is impaired and the other gene is functioning normally). Typically the carrier state is a benign healthy state that goes undetected. Previous studies have shown that carriers of 21-hydroxylase deficiency have subtle differences in the control of their adrenal glands.

The 21-hydroxylase enzyme is important in the production of cortisol. Cortisol is not an independently acting hormone; it is dependent upon a cascade of hormones that precede it in a pathway initiated by the hypothalamus, a brain structure. The hypothalamus is responsible for the production of corticotropin releasing hormone (CRH), which is produced in response to many types of stress. Once released, CRH travels from the hypothalamus to its target, the pituitary gland, where it in turn stimulates the release of adrenocorticotrophic hormone (ACTH).

As the name implies, ACTH is responsible for stimulating the outside region of the adrenal gland (the cortex) in order to produce cortisol, which is then released into the bloodstream. Cortisol is able to disrupt this linear pathway of hormone stimulation and release by feeding back to the hypothalamus and pituitary to inhibit the production of CRH and ACTH. Thus, this cortisol pathway is self-regulating. If there is an excess amount of cortisol, it will essentially "tell" the hypothalamus and pituitary to quit releasing CRH and ACTH until cortisol levels return to normal.

Previous studies of carriers have found that after ACTH is stimulated, there is an increase in the concentration of substances that build up to cortisol like 17-hydroxyprogesterone. This indicates that many carriers may not be efficiently synthesizing cortisol and may compensate by producing excess amounts of CRH. Oversecretion of CRH has been found in states of anxiety and depression. We recently studied carriers of 21-hydroxylase deficiency in order to obtain both an endocrine and psychologic profile of these individuals and to investigate associations between the adrenal

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Time is Running Out!!

Sunday, October 24, CAH Conference – New Jersey



If you haven't already registered to attend our CAH conference in Summit, New Jersey, fill out our registration form on page 19 in this newsletter or register via our website at: www.caresfoundation.org. Admission is free to all individuals and families affected by CAH. For more information, turn to page 18 in this newsletter. We also welcome nurses to our conference and will provide 7.3 contact hours for attendance. Contact us for more information.

A Message from the Executive Director:



Dear Friends,

As CARES celebrates its 3rd anniversary, I marvel at how far we have come in such a short time. Every day, I am overwhelmed by the enthusiasm of our members, by your willingness to help spread the word and to be active participants in our CAH community. Our phenomenal staff, Meryl Stone, Laurie Hitzig, Pam Knight and Robin Levan amaze me with their dedication to making CARES a successful organization and to serving the needs of our community. We have been blessed with terrific a Board of Trustees and Scientific and Medical Advisory Board, who give so much of their time and resources. In my wildest dreams 3 years ago, I could not have imagined that CARES would be where it is today.

Since CARES began, the number of states screening for CAH has doubled, due in large part to the advocacy efforts of members. Our recent victory in California illustrates the power of our grassroots message, "Save Our Babies". We set out to educate the California legislature and Governor about the benefits of newborn screening and succeeded. Now, over half a million more babies will be screened at birth for CAH and about 40 other life-threatening disorders in California. I cannot thank all of you enough. It seems everyone helped—whether you distributed Pink Postcards, wrote letters, made phone calls, visited legislators or just talked about the importance of comprehensive newborn screening to educate your friends. Now, only 10 states remain

that don't screen for CAH: Arkansas, Kansas, Kentucky, Louisiana, Montana (limited pilot program only), Nebraska, New Hampshire, South Dakota, Utah, and West Virginia, along with the District of Columbia. We are expanding our efforts now to Canada and Puerto Rico. Over the summer, Idaho and Wyoming began screening for CAH as well.

We have been active participants in research for a better understanding of and better clinical treatments for CAH. Research into various aspects of CAH has expanded in recent years as a result of our encouragement and involvement. We have given funds for research and expect to raise more money as we grow. Perhaps some day, with your continued support, we can help to develop a cure for CAH.

When I visit with other CAH families, there is an instant connection. We share a common bond, a common experience. I began CARES quite selfishly—because I wanted to connect with others going through the same things with their kids and because I wanted to learn as much about CAH as I could. I have gotten so much out of CARES and am so gratified to see that others are benefiting as well. I get so excited about our conferences and support group get-togethers with the prospect of meeting so many of my new email/telephone friends and

seeing familiar faces. Our upcoming conference on October 24th, promises to be a phenomenal day. We have a great line-up of speakers and panels. I hope you will all try to come, learn and connect. We are trying, at this

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Executive Director's Message

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conference, to provide information for CAH, NCAH parents and adults—a tall order. So, please come!

Welcome to Pam Knight, formerly a Board member, who just joined our staff. You can learn more about Pam on page 9. We also welcome Laurie Ember from Los Angeles who just joined our Board. We are honored to have them working with us.

Board Member Jami Abell Patterson is planning a major fundraiser for CARES on March 10, 2005 in Los Angeles. Read more about this exciting event on page 16 and PLEASE offer to help! We really want to make this a success, but cannot do this without you.

Have a wonderful fall!

Warmly,
Kelly

Northern California Family Picnic – June 19, 2004



Family Day in Middlebury, Connecticut - July 25, 2004



Dr. Judson Van Wyk

We are sad to report the passing this summer of Dr. Judson Van Wyk. Dr. Van Wyk was a good friend to CARES and to the CAH community. He trained so many of the pediatric endocrinologists who care for CAH patients during his many years at the University of North Carolina, Chapel Hill. Most recently, he studied the results of adrenalectomy in CAH and wrote an article summarizing his research for our newsletter last year. His dedication to the CAH community and his contributions to the field of pediatric endocrinology will be remembered, and his kind ways will be missed. We send our deepest condolences to his widow, Persis and to the rest of his family.

CF

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This newsletter is published 3 times a year.

Evaluation of 21-Hydroxylase Deficiency Carriers

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cortex response to CRH stimulation and psychologic characteristics.

Our Study

Thirty-four consecutively seen parents of children with the classic form of CAH and 23 parents of children with other chronic endocrine disorders were interviewed for entry into the study. The group of control subjects was comprised of parents of children with Turner Syndrome, Cushing disease, and one adoptive parent to a child with CAH. Parents of patients with CAH were excluded from the study due to an associated medical or psychiatric condition more often than the controls (see Table 1). Overall, 18 carriers of 21-OH deficiency (six males and 12 females) were included in the study, along with 16 healthy subjects (five males and 11 females). Because this study is looking at potential vulnerability to stress and anxiety, it was important to have a healthy control group that had also experienced the effects of having a child with a chronic endocrine disorder. None of the subjects that completed the study had a family history of mental illness, were taking medication for a psychiatric problem, or medications that influence the hypothalamus, pituitary gland, or adrenal gland.

The hormonal evaluation included two 24-hour urine specimens to measure urinary free cortisol. On day three of the study, CRH was administered via IV and blood samples measuring ACTH, and 17-hydroxyprogesterone (precursor to cortisol) were collected at -5, 0, 15, 30, and 45 minutes after CRH stimulation.

In terms of the psychologic evaluation, we employed five standardized questionnaires to obtain a psychologic profile of each subject. The assessment included the State-Anxiety Inventory, the Beck Depression Inventory, the Profile of Mood States (POMS), the Symptom Checklist 90-R, and the Temperament and Character Inventory.

Our Findings

The results of the endocrine tests showed that carriers of 21-OH deficiency had significantly lower mean 24-hour urinary free cortisol excretion than the control subjects, but higher ACTH and 17-hydroxyprogesterone levels after CRH stimulation (see Figure 1). The analysis of the psychiatric surveys did not reveal any significant differences between the carrier and control groups.

Because the purpose of this study was to examine associations between hormonal findings and psychologic profiles, we used statistical methods to determine correlations. In carriers of 21-OH deficiency we found a negative correlation between the mean urinary free cortisol excretion and obsessive compulsive behavior, novelty seeking, and reward dependence, meaning that the lower the 24 hour cortisol excretion, the greater the tendency for such behaviors. Likewise there was also a negative correlation between the peak 17-hydroxyprogesterone levels and anxiety and hostility. One should note, however, that these are relationships based on associations, not on cause and effect. For the control subjects, we found a positive correlation between the urinary free cortisol excretion and traits such as anxiety

and paranoid thoughts, meaning that as the concentration of urinary free cortisol increased so might the tendencies for these behaviors. The associations observed in the controls were in line with previously established correlations between cortisol production and stress-related behaviors.

General Observations and Conclusions

Parents of patients with CAH were more likely to be excluded from participating in the study than parents of children with other endocrine conditions. Exclusion was based on having a medical or psychiatric condition that would interfere with the testing. In the subjects studied, carriers of 21-OH deficiency had significantly lower 24-hour urinary free cortisol levels and had significantly higher ACTH and 17-hydroxyprogesterone response after CRH stimulation. These findings suggest that in carriers, the hypothalamus is mildly compensating for the low levels of cortisol by producing more CRH and ACTH. Such a finding is of interest as previous studies have shown that an overactive hypothalamus, excessive secretion of CRH, and low cortisol production have behavioral effects. Oversecretion of CRH has been documented in states of anxiety and depression. Chronic low cortisol production has been associated with several disorders, ranging from depression, chronic fatigue syndrome, fibromyalgia (persistent pain), and the postpartum period. Therefore our findings suggest that carriers of 21-OH deficiency may be genetically vulnerable or predisposed to the development of emotional or anxiety disorders upon exposure to adverse environmental factors.

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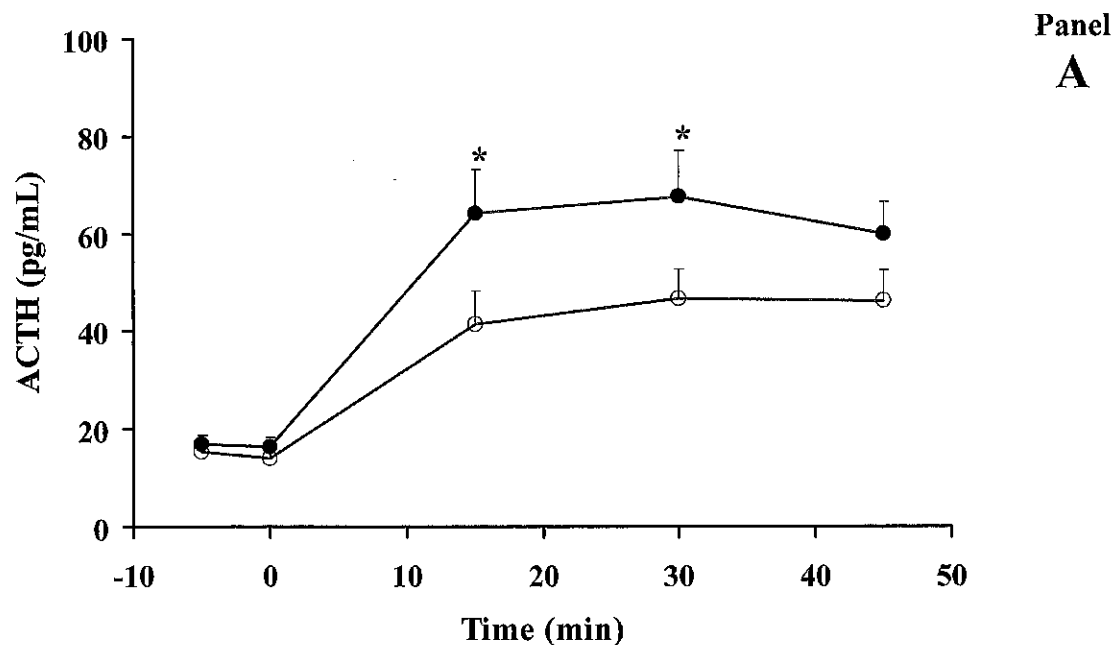
Evaluation of 21-Hydroxylase Deficiency Carriers

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Table 1: Populations screened, included and excluded subjects

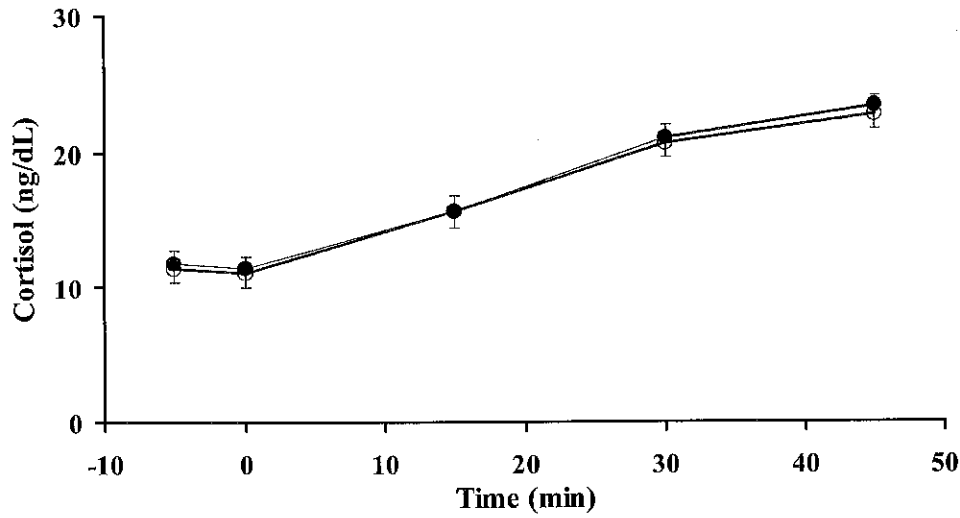
	Carriers	Normal	P value
Screened	34	23	
Included in the study	18	16	
Excluded from the study	16	7	
Excluded from the study because of associated medical pathologic conditions	16	5	0.05
Reasons for exclusion:			
Diabetes Mellitus type 1 (adult onset)	1		
Diabetes Mellitus type 2	2	1	
Breast cancer	2		
Hypertension	2		
Depression	7	4	0.6
Treatment with glucocorticoids (Systemic lupus erythematosus, Multiple sclerosis)	2		
Pregnancy		1	
Hormone replacement therapy		1	

Figure 1: Baseline and CRH-stimulated responses of ACTH (Panel A), cortisol (Panel B) and 17-hydroxyprogesterone (Panel C) in carriers of 21-hydroxylase deficiency (dark circles) and healthy controls subjects (open circles). Panel D shows mean 24-hour urinary free cortisol excretion in carriers of 21-hydroxylase deficiency and healthy control subjects. Carriers had significantly higher CRH-stimulated ACTH (P=0.04) and 17-hydroxyprogesterone (P<0.001) concentrations and lower mean 24-hour urinary free cortisol excretion (P=0.03) than healthy control subjects (from Charmandari E, et al. J Clin Endocrinol Metab 89:2228-2236, 2004; with permission)

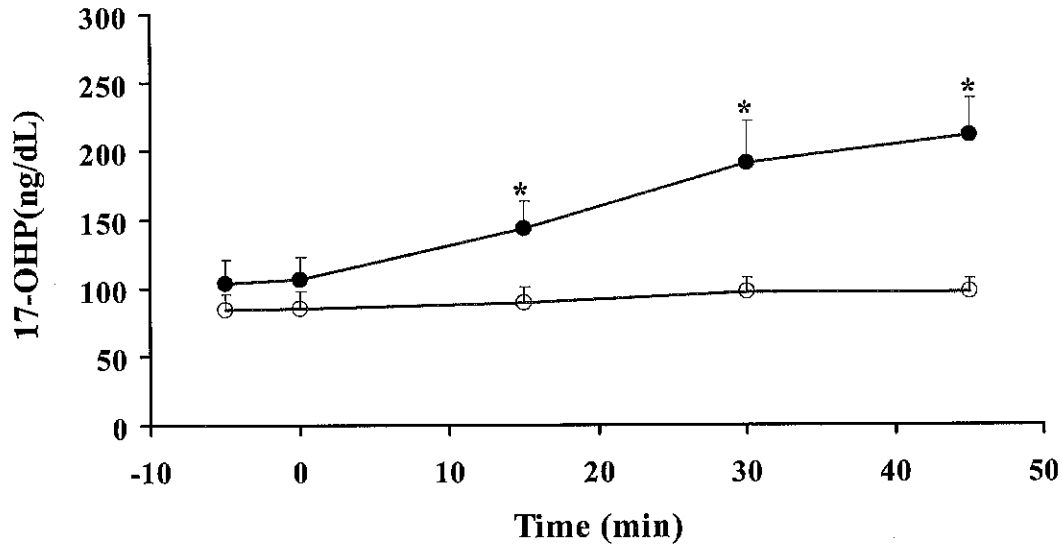


Evaluation of 21-Hydroxylase Deficiency Carriers

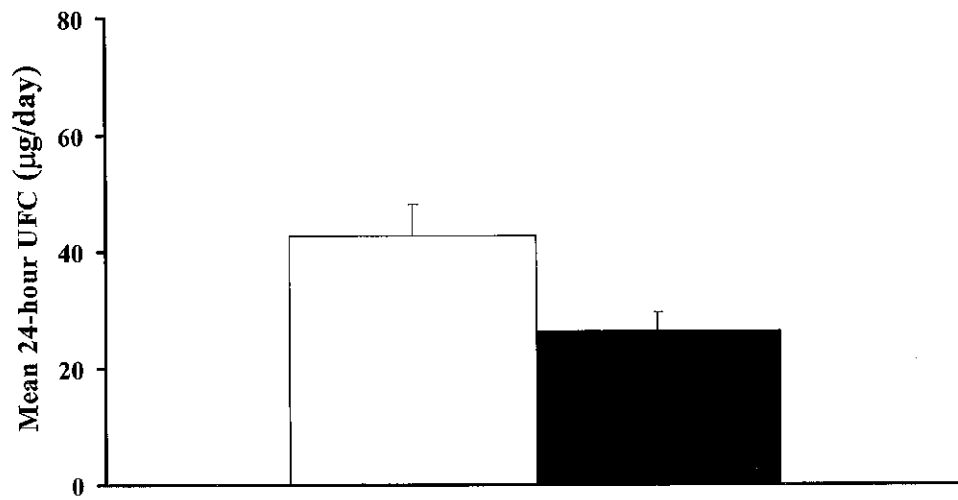
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Panel B



Panel C



Panel D

CF

Extra Hydrocortisone Is Not Beneficial in Patients with CAH Undergoing Exercise

Deborah P. Merke, M.D. and Julie Hardin, B.A.

As we described in the Spring/Summer edition of the Cares Foundation Newsletter, the most severe form of CAH (classic) has not only been linked with abnormalities in the adrenal cortex, but also abnormalities of the adrenal medulla. This association is significant because the adrenal medulla is responsible for producing the stress hormone epinephrine (also known as adrenaline), which helps regulate blood glucose (sugar) levels. As the *Exercise Study of Patients with Classic CAH* article described, a normal increase in blood glucose levels in response to exercise was not observed in CAH patients and this result is most likely caused by the insufficient adrenaline response. Furthermore, since CAH patients sometimes complain of decreased endurance during exercise, some practitioners recommend taking extra doses of hydrocortisone to combat fatigue during sustained exercise. Given this information, we recently carried out a study to examine whether an extra dose of hydrocortisone would increase blood glucose levels and exercise tolerance in patients with CAH during short-term, high intensity exercise.

Our Study

The study subjects included nine healthy patients with the classic form of CAH who demonstrated good hormonal control and nine healthy volunteers matched for gender, age, and body mass index. Each subject completed three exercise tests over three days, including a test to

determine fitness level and two standardized tests. CAH patients received their normal morning dose of hydrocortisone and fludrocortisone an hour before exercising as well as either an additional dose of hydrocortisone or a placebo (inactive substance) before the standardized tests. The hydrocortisone and placebo pills looked the same, so patients did not know which one they were taking. After the series of three exercise tests was completed, the CAH patients were asked during what session they believed they had received the extra dose of hydrocortisone.

Our Findings

Although the additional morning dose of hydrocortisone resulted in about a doubling of blood cortisol levels, these levels decreased over time. Furthermore, the stress dose of hydrocortisone did not appear to affect blood glucose levels, adrenaline, or other glucose-regulating hormones (glucagon, insulin, growth hormone), exercise capacity or perceived exertion during exercise. Instead, glucose and adrenaline concentrations in CAH patients with and without a double dose of hydrocortisone remained lower than the levels observed in matched, healthy controls. Also, as described in the previous exercise article, the normal exercise-induced rise in glucose was not observed in the CAH subjects. Interestingly, only one patient was able to correctly

guess which day he had received the stress dose rather than the placebo.

While administering extra hydrocortisone during a period of physical stress such as in illness or injury has been shown to be beneficial, our data suggest that patients with the classic form of CAH do not benefit from extra hydrocortisone during short-term, high-intensity exercise. In addition, unnecessary and excessive use of hydrocortisone can actually cause a myriad of adverse effects on the skin, bones, body composition and heart. Because the benefits of stress dosing before exercise have not been supported by research and the potential side effects are detrimental, the regular use of extra hydrocortisone with exercise is not recommended. At the National Institutes of Health Clinical Center in Bethesda, Maryland, we are currently studying CAH patients undergoing 90 minutes of exercise and will soon have additional information regarding longer-term exercise in patients with CAH.

CF

*If you want to re-read Dr. Merke's article, "Exercise Study of Patients with Classical CAH" from our Spring/Summer newsletter, go to our website at: www.caresfoundation.org/news_letter/ or click on **Newsletter Archives** from the home page.*

Psychological Adjustment in CAH

Sheri A. Berenbaum, Ph.D.

Departments of Psychology and Pediatrics, The Pennsylvania State University

There are several reasons to wonder whether children and adults with CAH have more psychological difficulties than do people without CAH. CAH is a chronic illness that requires lifelong medication and, in some cases, frequent hospitalizations. It's reasonable to wonder whether these stresses result in psychological problems. Further, cortisol is a "stress hormone" and there have been questions about whether individuals with CAH have more difficulty managing stress than do individuals without CAH. (This was discussed by Dr. Merke in the last newsletter.)

Questions about psychological adjustment have most often been asked in the context of the virilized genitalia of girls with CAH. For many years, early surgery to "normalize" the genitalia of girls with CAH was considered necessary to promote the development of normal female gender identity and overall psychological health. But now, some are suggesting that the surgery, rather than preventing problems, actually produces them. Both physical and psychological problems have been suggested to result from surgery. Physical problems might include reduced genital sensation because of damage to the nerves and blood supply to the clitoris, and pain during intercourse because of scarring from vaginal surgery. These physical problems are then suggested to result in sexual problems, such as dissatisfaction with and avoidance of sex. Although the focus of this article is not on genital or sexual function, it is important to note that there is very

little good evidence about these outcomes in women with CAH. What little evidence there is shows that some women with CAH are satisfied with their sexuality and some are not, but satisfaction does not appear to be related in a simple way to the surgery that was done. Perhaps this is not surprising, given that there is a lot of variability in sexual satisfaction in women *without* CAH. There are other ways in which virilized genitalia might result in psychological problems in females with CAH. These include, for example, repeated genital examinations (which have been likened to sexual abuse), or shame and stigma associated with a girl's physical appearance (either with or without surgery).

Despite the abundance of *speculations* about the consequences of being born with virilized genitalia and having surgery to correct them, there has been surprisingly little *evidence* about psychological outcome in females with CAH. A few older studies found females with CAH to have good overall psychological adjustment, but those studies need to be repeated because they did not use very good measures (so they might not have been able to detect problems), and it is not clear how well they can be generalized to girls diagnosed with CAH today.

My colleagues and I studied psychological adjustment in two groups of people with CAH. Joining me in this work were Dr.



Stephen Duck, a pediatric endocrinologist at Evanston Hospital in Illinois, Susan Resnick, a psychologist at the National Institute on Aging, and Kristina Bryk, a social worker and research assistant who has worked with me for many years and who conducts most of the home testing visits. The study participants were also key collaborators in this work.

The first group of participants we studied includes boys and girls with CAH and their unaffected siblings who participate in our ongoing longitudinal study. (Other published results from this group reported previously in the newsletter and at CARES Foundation meetings show that most girls with CAH play with boys' toys but identify as girls.) The second group of participants includes adolescent and young adult females and males with CAH and their unaffected siblings studied in collaboration with Dr. Resnick and others when we were at the University of Minnesota. (Other published results from this group show females with CAH to have higher spatial ability than their sisters without CAH.) We measured psychological adjustment with widely-used and accepted measures. In the first group, parents reported on their children's behavior, and teenagers reported on their own feelings and behavior. In the second group, all participants reported on their own feelings and behavior.

Results from both groups show that individuals with CAH have good adjustment. This applies to

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Psychological Adjustment in CAH

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females and males with CAH, in childhood, adolescence, and adulthood. In both groups of participants, people with CAH were not different from their siblings without CAH on the measures we used. Both patients with CAH and their siblings had scores that were similar to scores of people in the general population.

We also looked at the association between adjustment and aspects of CAH, especially details of genital appearance and surgery. We were only able to do this in the first group, relying on medical records to get this information. Dr. Duck carefully extracted information from the records about genital appearance at birth and details of medical and surgical treatment. We wondered if, as originally believed, adjustment was better in girls who had had surgery early in life or, as some now believe, that adjustment was better in girls who had later (or no) surgery. We found that adjustment was not associated with the age at which the surgery was done or with how virilized the genitalia were when the girls were born. So, it looks like it doesn't matter how old the girls were when the surgery was done, at least as far as the outcomes we measured. But, there is an important caveat to these results – most girls did have surgery early in life (the typical age at clitoral surgery was between 1 and 2 years of age, the typical age at vaginoplasty was between 2 and 4 years of age), so we could not really compare those with surgery in infancy to those with surgery in adolescence. We also were unable to examine whether other factors related to genital appearance and function might affect adjustment, so we do not know if there is an effect on

adjustment of the number of surgical procedures, the quality of the surgery, or the number of genital examinations. So, we do advocate more studies to explore the association between psychological adjustment and genital virilization or surgery.

Our findings of good psychological adjustment in patients with CAH might be surprising given complaints from intersex activists and assumptions about the consequences of having CAH or an intersex condition or any chronic illness. But, intersex activists are probably not representative of the population of individuals with intersex conditions, particularly CAH. Further, there's quite a lot of scientific evidence that shows that unfortunate life events (such as cancer and spinal-cord accidents) have only temporary effects on adjustment. (It's also true that really pleasant events, such as winning the lottery, often have short-lasting effects). It's also true that people are not very good at predicting what will make them (or others) happy, because they attend only to causes that are right in front of them and ignore other factors that might be relevant.

So, what do our results mean for you and your family? They mean that CAH and its treatment are not generally a cause of psychological problems. They also suggest that genital appearance and age at surgery are not big contributors to adjustment in girls and women with CAH, but, again, we note that we have only begun to look at this. We also emphasize that we only looked at broad indicators of adjustment. It may turn out that females with CAH have problems in specific areas, such as body

image, or that both males and females with CAH are more responsive to stress than those without CAH. We are currently exploring these possibilities.

This means that you can expect your child with CAH to be pretty similar to your children without CAH in overall adjustment. Of course, there are some people with CAH who do have psychological problems, just as there are people without CAH who have problems. And it may turn out that CAH causes problems for people who are reactive, but if they didn't have CAH, then something else might trigger their problems. But problems do *not* appear to be more common in CAH than in the general population. Nevertheless, if your child does have a problem, don't ignore it – there are many good health professionals and treatments available to help you and your child.

CF

Pamela Knight: New Director of Development

Pamela Knight, our new Director of Development, has worked as a medical writer for 18 years. She became interested in CARES while writing for its newsletter, and served on the Board of Trustees from 2002-2004. Pam's main roles at CARES are fundraising and media relations. She recently attended a class on writing grant proposals at the Foundation Center of New York, and is eager to apply her journalism background to craft effective grant applications, fundraising materials, and press releases. In addition, Pam will help coordinate our volunteers' regional fundraising efforts. You can contact Pam at 866-227-3737, or e-mail her at: pam@caresfoundation.org.

My Vietnam Experience

by Michele Konheiser

When I was first approached about travelling to Vietnam with the Royal Children's Hospital International team, I asked myself one question, "What could I possibly offer to doctors and families in Vietnam that would be valuable to them?" I felt that I had nothing much to contribute. I was finally convinced by others that what I could talk about would be helpful – my experiences with CAH as a mother, in my role as a committee member for CAHSGA for the last 6 or so years and as a 'sounding board' to many CAH parents and patients with whom I'd spoken to in my role as a family contact.

My role in Vietnam was to present a talk to doctors, specialists and nurses about how a team of people helps to provide the best care for CAH patients, as well as a presentation to the families of the Vietnam CAH club. Our team consisted of Prof. Garry Warne, a paediatric endocrinologist and the director of Royal Children's Hospital International; Dr Sonia Grover, a gynaecologist and obstetrician who has worked with many CAH women; Elizabeth Loughlin, a social worker who frequently sees CAH girls and their families, and also me. Each member of the team would discuss their own role and how we all work together and often refer to each other to help the patients and families live well with CAH.

My talks were translated into Vietnamese, but it was hard for me to gauge the impact of my talk to the doctors and professionals. I talked about our family story of diagnosis,

my role in the support group, in general what families are concerned about, and also the benefit of having experts to refer to. As one of the only a few non-medical/professionals in the room I was sometimes overwhelmed with the technical descriptions of CAH. I felt most uncomfortable when the doctors showed photographs of children and their genitals in relation to CAH sexual development. Some of these patients were named on the screen. I worried for the patient and their family. How would they feel if they were sitting in this room? The issue of the patient's feelings did not arise during the medical staff presentations. It seems to be a cultural issue that feelings aren't often discussed with the patients. I cannot ever consider not being able to talk to our doctor about how I feel.

I guess a small breakthrough for me was during a coffee break. A doctor told me how he spoke to a family whose child had been diagnosed with a chronic condition. The family was very worried for the child and so the father stayed home from work, as did the uncle and aunty etc. In the home, they did not make any noise around the 'sick' child. I thought to myself that happens in Australia too. When we were told about CAH, I worried about our child dying every single day. After I contacted the support group, I understood it was OK and normal to feel like that. In the long term, it's not good for the child or family. Talking through my feelings with a support group member

helped me get over that. So things were not so different in Vietnam after all. In Australia, we have more opportunity to talk about things that worry us or resources to contact a social worker. But, these Vietnamese families don't have resources to ask those questions. I wondered where they hid all those emotions.

Vietnamese CAH Family Day

It's not often that I've experienced something that's changed my life. This day was one of those events. I met with Giang the past CAH club president the day before at the doctors' conference. She's a wonderful young woman in her 20's who is passionate about improving life for CAH patients in her country. I believe that I will always have a connection with her. When she met my daughter with CAH there was an instant bond between them. She also welcomed my husband and son like we were old friends.

There were somewhere between 150 – 200 people in the auditorium when the meeting began. I started out with my story again about the diagnosis of CAH in our daughter and how we felt at the time. The parents seemed to listen, but I was not quite sure if anything in my speech was helpful to them. Then the new club president stood up and told his story of his son's diagnosis. He spoke about when his son asked why the other children in the family didn't take medication for CAH and how it broke his heart as a father to answer that question. I addressed the club members and asked them to tell me their stories as well. I was not

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My Vietnam Experience

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prepared for what followed. A few parents stood up and asked questions as well as telling their stories. One lady stood next to me and spoke of her concerns for her daughter. She'd had one operation and was worried that she'd need another. She broke down in tears and I found myself in tears as well. She had so much grief inside her. Many comments seemed to focus around the culture – it's very important to be married and have children in the Vietnamese people's eyes. They worried for their children's ability to be accepted by a partner and be able to conceive-- not unlike many Australian parents who've felt the same.

The main difference between our countries is the medication. I heard stories of parents giving their child one tablet every few days as they couldn't afford daily medication. The government of Vietnam will not yet import the drugs regularly. So families often resort to giving their child prednisolone or whatever else is available. I spoke to a few parents in

the coffee break who spoke English. One father told me he pays anywhere from \$10.00 to \$30.00 for 1 bottle of medicine for his daughter. His monthly wage is about \$50.00 for the entire family. The supply is unreliable. Sometimes they just can't get the medication. The black market can therefore charge whatever it likes for the tablets. As a parent, what choice do they have but to pay the asking price? When dealing with your child's life, priorities are quickly put into perspective.

I felt so lucky and yet so guilty about not having to make those sort of choices for my daughter. This added a new level of admiration and understanding for these people. The sacrifices that they make in order to keep their children alive and well astounded me. I truly appreciate what I have in our country now.

The physical symptoms of unreliable treatment were obvious. A 16 year old girl stood next to my daughter who is almost 8. They were about the same height. The

other girl had no breast development or physical appearances to indicate her 16 years. Many of the patients were also quite short. Our patients in Australia were obviously managed so much better. In Vietnam, they don't have blood tests to monitor hormone levels, but what good would they be if you can't regularly take medication anyway?

I left the meeting with a heavy heart. These people were really disadvantaged. I wished for regular medication for them – an affordable, reliable supply that will allow their children to grow up and reach their full potential in life-- something that I've taken for granted for the last 8 years as I've watched my child grow into a happy, healthy and intelligent little girl. I intend to tell everybody about this problem in Vietnam. Maybe somebody will then do something about it. *CF*

*Michele Konheiser,
Special Projects Officer
CAHSGA Inc.*

Australian CAH Support Group



CAH Vietnam Club

The State of Children and Teenagers with CAH in Vietnam

Vietnam is a country I know very well. Since 1995, I have visited Vietnam seventeen times as an Endocrinologist and as Director of an international cooperation program between the Royal Children's Hospital Melbourne and the National Hospital of Pediatrics (NHP) in Hanoi. On most visits I have seen patients with CAH and I have conducted many clinical workshops and given many lectures on the subject. In 2000, I spent a month in Hanoi, interviewing patients with a range of intersex conditions, including CAH, and their families. My former Fellow, Dr Vo Thi Kim Hue (Lily) established the CAH Club and two other former Fellows, Bui Phuong Thao and Vu Chi Dung are endocrinologists at NHP. Since 1997 the number of CAH patients being treated at NHP has more than doubled, to 214. The fact that over 200 parents and children from all over Vietnam attended the Annual Meeting of the CAH Club is testimony to the desperate need for support. We in developed countries have to some extent lost sight of how devastating a condition CAH is. In good centres such as ours, children with CAH look normal, they grow normally and they go through a normal puberty. Adrenal crises are relatively uncommon and death is unlikely because we educate people on what to do.

In Vietnam, many parents cannot afford to buy the drugs their children need. One family told us that to buy one bottle of tablets cost the equivalent of 16 bags of rice. Other families were forced to spend one-third of the total family income to buy drugs to keep their child with



*Vietnam CAH Club Meeting June 1, 2004
(L-R) Endocrine Nurse, Mrs Hoa, CAH Club President, Ms Giang, Dr. Gary Warne and Mr Trung, a CAH patient*

CAH alive. If a child needs an operation, it is done free until the age of 6 years but after that, the parents have to pay. Blood tests are all charged for. Travelling to the Center for a consultation takes the family away from their work, therefore they do not earn, and it costs money for transport and accommodation in the city. When the average monthly income for a rural family is about \$US30, these costs create great hardship. Not surprisingly, parents sometimes resort to rationing the medications, giving it every other day or even less often. Patients perish from adrenal crises at the rate of several per year. Laboratory testing is behind the times and has not changed in the 9 years I have been visiting. There is no 17-hydroxyprogesterone assay in Hanoi, even though it is available in Ho Chi Minh City.

Many girls are seen with advanced virilization which can be seen in their overall appearance and on closer examination of the genitalia. Some have gross enlargement of the clitoris. As part of the service to those who attended the meeting of the CAH Club, my colleague Dr Sonia Grover examined over 40 girls with CAH in one

afternoon. Many had had very good surgery but this was not universal by any means. Some had urinary incontinence. Vaginal dilatation seems to be almost unknown.

With money donated by CAH groups from Australia, the United States and the U.K., supplemented by a donation from RCHI, I was able to prescribe medications through my own hospital pharmacy for all of the patients. Altogether I took 12,840 20 mg tablets of hydrocortisone and 17,000 tablets of Florinef and these were distributed to the families on the day of the meeting. They were overjoyed to receive them.

Our Social Worker, Elizabeth Loughlin, also attended the meeting in Hanoi. There is a very great need for social and emotional support for these very distressed families but mental health services are underdeveloped in Vietnam. Michele Konheiser, together with her husband, her daughter with CAH and her unaffected son, also journeyed to Hanoi for the meeting of the Club and their gesture of support was much appreciated by the Vietnamese families.

Families of children with CAH in Vietnam have urgent needs almost beyond imagination. Those of us in more fortunate circumstances have a duty of care to them and I feel passionate about wanting to make a difference.

What can you do to help?

CF

*Garry Warne
Senior Endocrinologist
Royal Children's Hospital
Melbourne, Australia
Garry.warne@rch.org.au*

Many Thanks to all our Wonderful Artists...

We sincerely appreciate all the terrific entries for our new symbol of support for CAH and CARES Foundation. We received so many wonderful entries! We are currently reviewing the designs and will let you know the results soon. We are thrilled to have so many talented and committed members in our organization.

CF

Physician Listings Available from CARES

CARES Foundation has compiled a large list of pediatric endocrinologists, some adult endocrinologists, urologists and psychologists with experience in treating CAH/NCAH patients. Please contact CARES Foundation for more information.

DID YOU KNOW???

All of our newsletter articles are archived on our website. If you miss an issue or misplace it, you can always find it at: www.caresfoundation.org/news_letter/ or click on **Newsletter... Archives** on the home page.

CF

States Directed to Inform Parents of All Screening Options

After forceful parent testimony at a recent U.S. Health Resources and Services Administration (HRSA) meeting, state health departments have been told to promote awareness of all available newborn screening tests, even those not yet required by state law.

Parents and others speaking at the June 2004 meeting of HRSA's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children argued that state newborn screening programs need to do more to inform parents-to-be of the lifesaving potential of comprehensive newborn screening tests, including ones that parents may need to seek out and pay for on their own.

Following this meeting, HRSA's Maternal and Child Health Bureau (MCHB) officially recommended that state newborn programs create a way to make new parents aware of all available screening options.

In a letter to state health officials, maternal and child health directors, newborn screening programs, and directors of agencies for children with special health care needs, Dr. Peter van Dyck of the MCHB noted that, "in the past few years, the possibilities for screening

newborns have greatly expanded. And while not all states may be utilizing these new technologies, parents need to know about the full spectrum of options available for newborn screening."

Van Dyck quotes a recommendation by the American Academy of Pediatrics' Newborn Screening Task Force that "each state or region should, with input from families who have children with special health care needs and/or parent information centers, develop and provide family educational materials about newborn screening."

Trish Mullaley, President of the National Coalition for PKU & Allied Disorders, notes that the MCHB letter "shows that the message from newborn screening advocates was loud and clear. This letter will be a good tool when advocating in your state," she adds. "It can be used to help generate expansion, whether through the state or birthing hospitals. Every pregnant mother needs to have access to this information."

CARES Foundation thanks Save Babies Through Screening Foundation (www.savebabies.org) and Trish Mullaley for sharing this update with us.

CF

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Pink Postcard Victory for Newborn Screening in California

Thanks to the personal efforts of CARES families and other advocacy groups including the California March of Dimes, the Golden State passed legislation in August mandating expansion of newborn screening to cover 41 inherited conditions, including CAH.

Expanded screening is expected to save an estimated 140 babies per year in California from death or disability. Our California members, including Kristen Guzman, Larie Hall, Natalie and Alyssa Ackenheil, and Kelly Horton, have been tireless in promoting this cause in California, and we commend them all for their successful efforts. So many of our members participated and it really made a difference.

Prominent among these efforts was our Pink Postcard campaign urging Gov. Schwarzenegger to "Save Our Babies" by supporting the statewide comprehensive newborn screening. CARES Foundation launched this mail-in campaign last October, distributing over 10,000 neon-pink postcards addressed to the Governor. In addition, our Executive Director, Kelly R. Leight, and local

CARES family members met with state legislators, telling their personal stories to the leaders who would be making this important decision.

"CARES volunteers have been terrific in terms of making themselves available for visiting their representatives and talking with committee members about their personal experiences," says Keith Nash, director of Public Affairs for the California March of Dimes.

The comprehensive screening test is sensitive, simple, and inexpensive. It involves taking a few drops of blood from the heel of a newborn at birth. The blood is screened using a technique called tandem mass spectrometry (MS) that can test for many different inborn conditions at once.

The provision for expanded newborn screening was included in a Budget Health Trailer Bill attached to the California state budget signed on August 1, 2004. Originally sponsored by Dede Alpert (D-SD), it requires the State



Department of Health, under its Genetic Disease Branch (GDB), to expand statewide health screening of newborns to include screening for CAH, as well as for many inborn disorders of fatty acid oxidation, amino acid, and organic acid metabolism, and to provide information with respect to these disorders and testing resources to all California women receiving prenatal care and admitted to a hospital for delivery.

In choosing to expand newborn screening, California becomes the 40th state in the U.S. to adopt this life-saving measure. Currently, the U.S. has no uniform standards for newborn testing, but more states are expanding their newborn screening.

This trend is not only humanitarian, but practical. The California GDB estimates that for every dollar spent on expanded screening, \$2.59 is saved in average lifetime costs of medical and supportive care.

As you can see, our efforts are making a difference. We are saving babies, one state at a time!

CF

CAH Volunteers Needed for Exercise Study

Catecholamine Reserve and Exercise Tolerance in Subjects with CAH and in Healthy Controls

Principal Investigator: Dr. Deborah Merke M.D., Pediatric Endocrinologist and Chief of Pediatric Services at NIH

At the National Institutes of Health in Bethesda, Maryland, we are currently investigating the effects of sustained exercise over 90 minutes in patients with classic CAH. Participants will be paid \$300 upon completion of the study.

In order to participate in this study volunteers must:

- ✓ have the classic form of CAH (21-hydroxylase deficiency);
- ✓ be between 12 to 22 years old;
- ✓ demonstrate good clinical control defined by: 17-OH-progesterone level between 100 and 1500 ng/dl, plasma renin activity within the normal reference range, normal growth rate (children), and no new signs of excess androgens;
- ✓ not be on other medications besides their CAH-related medications.

The study consists of 4 visits over 5 days and includes a screening visit (physical examination, family history, pregnancy test, and electrocardiogram), an exercise test to obtain fitness level, and two 90-minute standardized exercise tests. Travel is paid by the NIH. For more information or to volunteer, please contact Julie Hardin at (301) 496-6909.

CARES Family Support Groups in North America



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Contact Tonya Judson
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Laurel Meier

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Are you interested in starting a support group in your state? Contact the CARES office and we will get you started.

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Fundrai\$ing Corner


How We Help CARES

When Austin was diagnosed with CAH we felt overwhelmed, lost, alone, and scared. Brad spoke with Kelly long before I did. He kept telling me "call her and talk to her it will make you feel better". One day she called and the machine picked-up. I knew it was her so I answer the phone. I wish I had spoken with her so much sooner. I think deep down, talking to Kelly was going to make Austin having the CAH so much more real. I really didn't want to accept it. But thanks to God, CARES, Kelly, Dr. Pamela Thomas and staff, and our family & friends, we have accepted it.

Now we are trying to do what we can for CARES and other CAH families through fundraising. We started brainstorming for fundraising ideas. Our first was a bake sale at a nearby Wal-Mart. It was really successful! I can say that because I expected to make a couple hundred dollars and ended up with a couple thousand. We listed names of family and friends to ask to bake for us and the outcome was unreal. By noon the first day I called my mom to tell her we need more bake goods could she make a few calls. At the end of the second day we had a few things left over which sold the next day at the place where I use to work.

We had a local newspaper, The News-Sun, write an article about CARES, CAH, and the bake sale. That article did so much! It was in the paper the day before we started. Some people drove up, handed us money, and drove away. I even had one person who bought stuff, that offered to bake. The next day she

showed up with a big box of stuff. It was such an emotional experience. It was wonderful.


We have shared and received fundraising ideas with other people in our community who do it for causes of their own. We have gotten some good ideas. Don't assume a particular idea isn't good. We've had a couple we thought would be really successful and weren't, but we've had more that did really well. It all helps...every dollar and every penny. I am amazed at how much awareness has been raised in our area for CAH and CARES Foundation. With the help of our family, friends, and community, we have raised money and awareness. There are no words to thank them, but may God bless each and every one of them because we could not do it without them. "And thank you Kelly Leight...where would all of us CAH families be without you having started the CARES Foundation. God bless you." 

*Tina Smith
Albion, Indiana*

Upcoming California Fundraiser – We need your help!!


I am excited to inform you that we now have a date, location and time for the very first CARES Fundraiser in Los Angeles - March 10, 2005 at the Skirball Cultural Center - Ahmanson Hall from 10:00am-3:00pm. That leaves us 5 months to pull off a very, very successful event - and I know it can be done. Obviously, there is much to be accomplished in this period of time and I am hopeful that I may count on your support and involvement in making this happen, as your involvement on any level is welcomed.

Please contact me if you are interested in volunteering to be on our event committee. With your help, I know this fundraising event will be a huge success.

Many thanks. 

*Jami Abell Patterson
Jami@caresfoundation.org
(818) 906-8668*

CARES First Annual Golf Outing Indiana

On Sept. 19th, 2004, Jenny Hendricks, grandmother of Cody, hosted the first CARES Golf outing at the Valle Vista Golf Club in Greenwood, IN, just outside Indianapolis. It was a fun day for all, enjoying the golf while raising awareness about CAH and funds for CARES. We send Jenny and her committee our deepest thanks for organizing this terrific event. We also thank our sponsors and the players for their support. Next years' event committee will be even bigger and better. Please contact CARES if you would like to be on the Golf Committee for next year. 

Garage Sale Success!

My son Jake, has salt wasting CAH. As a member of the Board, I try my best to assist in fundraising. To help raise money for CARES Foundation, I decided to organize a garage sale. I contacted family and friends to donate items to be sold at my garage sale, letting them know that all proceeds would go to CARES. With car loads of items showing up at my door daily, we had more than enough items to have a productive sale. I made posters and stickers stating that all of the money raised would benefit CARES. A lot of customers asked about CARES, and what the organization does. Some people even over paid on items, just because they knew the money was going to charity.

Overall, the sale was a huge success and raised \$350.00 to be donated to CARES. The event was successful not only in raising money, but it helped a lot of people clean out their attics and basements, including my own. This was a wonderful way to raise awareness about CAH and CARES while assisting CARES in raising money. CF

*Michelle Cascarelli, NJ
Metuchen, NJ*

Candle Sale Raises Over \$4,000

Many, many thanks to **Terry Rowe of Avilla, Indiana and Gold Canyon Candles (Chandler, AZ)** for organizing a fundraiser that netted CARES \$4,300. Terry, whose grandson has classical CAH, decided to raise money for CARES after learning that Gold Canyon Candles would donate 40% of proceeds from a candle sale fundraiser to the nonprofit organization of her choice. She and her distributorship partner Bev Grate added to this amount by kicking in their sales commissions, as well as more from their own pockets, to bring their contribution up to a nice round number.

Asked about the secret of her success, Terry revealed the key elements: motivated sellers, good timing, and calling on local businesses to donate goods and services. Having an attractive product didn't hurt, either.

Terry and Bev started by asking local businesses to donate prizes for the top candle sellers. They motivated their 55-person salesforce to focus on the three-week fundraising event by offering gift certificates for the Holiday Inn in Fort Wayne, Applebee's in nearby Kendallville, a local bank, a

supermarket, a pizza shop, and a home decorating business.

Then, the two obtained permission from local businesses to set up sales tables during times when a lot of people would be present. Community State Bank in Avilla let them sell there on the first Friday of the month, when many people come in to cash government checks. A brand new Wal-Mart in Kendallville let her set up shop the day after its Grand Opening—when it was packed with customers. The food market told her Saturdays were probably their busiest time, and invited her to sell then.

Terry says that organizing the event was easy and fun. "I just started making calls, explaining what CARES does, and people just started giving," she reports. "I was so excited every time a company agreed to donate a prize for our top salespeople during the event."

Anyone who would like to explore the possibility of holding a CARES fundraiser in their town can receive a copy of our Fundraising Guide (after we update it with Terry's hints!) from the CARES Foundation office. You can also get help preparing written materials for distribution or publication from Pam Knight, whom you can reach at the main CARES phone number, or email at pam@caresfoundation.org. CF

Attention Arizona Shoppers!! Bashas' Supermarket will Donate to CARES !

Bashas' Supermarket is starting up its annual fundraising program: "*Thanks A Million For Friends and Neighbors*". As a non-profit organization, CARES will benefit when patrons link their Bashas' Thank You Cards to our organization. Every time you make a purchase at Basha's, the supermarket will donate 1% of your



total to CARES Foundation. It costs you absolutely nothing – Basha's makes the donation on your behalf!

Just link the **CARES group ID number: 29261** to your Basha's Thank You Card. Each time you make a purchase, Basha's will credit our account with the

donation. *Make sure to check your receipt after your purchase to see CARES Foundation listed-- this will ensure that the donation has been properly credited. This program will run from **September 1, 2004 – April 30, 2005**. Please consider shopping at Basha's during this time period and encourage your family and friends to do the same.* CF

**You are invited to attend the
2004 Conference on Congenital Adrenal Hyperplasia
hosted by CARES Foundation, Inc.**

**When: Sunday, October 24th, 2004
9:00 AM to 5:30 PM**

Where: Wallace Auditorium at Overlook Hospital
99 Beauvoir Ave, Summit, NJ 07901
Telephone: 908-522-2000
http://www.atlantichealth.org/cons/hospitals/at_OH/overview.html

**Cost: There is no charge to attend this event,
but your tax-deductible donation is greatly appreciated.**

Financial assistance is available for travel expenses to the conference for those in need.

This event is intended for adults and older children. Snacks/ lunch will be provided.
A recreation room will be available which will be supervised by teenage volunteers.

TOPICS:

- ◆ New Advancements in CAH Treatment & Future Trends in Research
- ◆ Behavioral and Psychological Aspects of CAH
- ◆ Monitoring & Treatment of CAH/NCAH
- ◆ Prenatal Therapy
- ◆ Pregnancy & Reproduction in CAH/NCAH
- ◆ Surgical Reconstruction in CAH
- ◆ Panel Discussion: Impact of CAH on Family & Siblings
- ◆ Transition to Adult Care & Adult Healthcare Issues
- ◆ Panel Discussion: Adults with CAH/NCAH
- ◆ Breakout Groups for Children with CAH and for Adults with CAH and NCAH
- ◆ And much more.....

We give special thanks to Atlantic Health System, Overlook Hospital for their support of this event.

CARES Foundation, Inc. (Congenital Adrenal hyperplasia Research, Education and Support) is a tax-exempt, education 501c(3) organization. Its purpose is to educate the public and physicians about all forms of Congenital Adrenal Hyperplasia, its symptoms, diagnostic protocols, treatment, genetic frequency, the necessity for early intervention and benefits of newborn screening. It is also dedicated to providing support and information to affected individuals and their families. The CARES Foundation website can be viewed at www.caresfoundation.org and CARES can be reached by telephone, toll free, at (866) 227-3737 or email to info@caresfoundation.org.

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New items added all the time... check the website!!

Don't wait... it could protect and save your child's life! It saved Cody's life! We also carry many more items. A portion of all profits will go to CARES Foundation, Inc.

Help Wanted!!

We are in need of the following skilled help:

- **Spanish Translator** to help us translate our CAH materials for Spanish-speaking families.
- **Video Specialist** – who can adapt film to create a webcast of our last conference on our website and develop DVD's for our members who were not able to attend.
- **Strong Writer** – who can help us prepare emergency care documents.

🏠 *Have you recently moved, changed your phone number or email? Please make sure to let us know, so we can keep our information current. ☒*



ZIMMER