

CARES FOUNDATION Inc.

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Congenital Adrenal hyperplasia Research, Education & Support

Volume 1
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CARES Foundation, Inc. Announces Alliance with *Exceptional Parent Magazine*

The CARES Foundation Inc. has forged a strategic alliance with *Exceptional Parent Magazine*, the nation's leading magazine for families and professionals involved in the care and development of children and young adults with disabilities and special needs.

"We are honored to have the mentorship of *Exceptional Parent's* president, CEO and publisher and the founder of the *Exceptional Parent Foundation for Education Inc.*, Joseph Valenzano," said CARES Foundation founder and executive director, Kelly Leight, "and we look forward to our new alliance."

The goal of the CARES/*Exceptional Parent* collaboration is to educate the public about congenital adrenal hyperplasia (CAH). To that end, the magazine featured CARES Foundation Inc. in the "Organizational Spotlight" in its March 2002 issue [copies of that article are available on the CARES Foundation web site].

Joint undertakings by the CARES Foundation and *Exceptional Parent Magazine* will include the creation of a monograph on CAH to be composed of articles that will appear in the magazine. The monograph will be designed for distribution to families, physicians and the media and

(Continued on page 6)

Family Workshop Houston, Texas April 27th

We hope families in the vicinity of Houston, Texas will be able to attend our family workshop on April 27th from 1-5 pm at the Meyer Building, 1919 S. Braeswood, Houston, TX (Major cross street is Greenbriar). The featured speakers are: Dr. Maria New, Professor and Chairman, Department of Pediatrics, Chief, Division of Pediatric Endocrinology at Cornell-Weill New York Presbyterian Hospital; Dr. Sheila Gunn, Assistant Professor Diabetes and Endocrine Center at Texas Children's Hospital; and Dr. Sheri Berenbaum, Professor of Psychology at Penn State University, and CAH researcher.

This event is free of charge, but we do ask that you RSVP in advance to: *Sandra Billings--by email to billprop@aol.com or by phone at (281) 861-6043.* You may also call Sandra or CARES Foundation for more information. Hope to see you there!



CAH Parent Support Group in Phoenix, Arizona

Please join us for a small, informal gathering of Arizona parents of children with CAH for discussion over dinner (no host). Our goal is to form a network of Arizona families that we can draw support from as our children grow. We hope you can attend! The meeting will take place at *Valle Luna Mexican Restaurant at 4910 E. Ray Road on Friday, May 17th, 2002, from 7:30pm - 9:30.* Baby-sitting will not be available.

Please RSVP to Michelle May either by email michlmay@aol.com, or by phone at 480/759-0870 or to Kelly Leight, Executive Director of CARES at 866-227-3737 or email Kelly@caresfoundation.org.



Newborn Screening Update

**SENATORS DODD and DEWINE URGE
REVIEW OF STATE NEWBORN SCREENING**

**Recent Press Release,
February, 2002:**

Washington, D.C. — Seeking to improve critical detection of potentially life-threatening genetic disorders in infants, Senators Chris

Dodd, D-Conn., and Mike DeWine, R-Ohio, called for a study of each state's

newborn screening programs in a recent letter to the General Accounting Office (GAO). The letter from Dodd, Chairman of the Senate Subcommittee on Children and Families, and DeWine, requested the GAO to report on individual state's efforts; how they test for disorders; the coordination among families, physicians, and laboratories involved; and the procedures and quality of data. The letter also asks for a report on how states protect the privacy of this sensitive and critical health information.

"A child's health shouldn't be influenced by a line drawn on a map," said Dodd. "Newborn screening is a valuable tool in efforts to treat children's health problems, and - as such - we need to better explore how it is being implemented nationwide. This is one test where failing shouldn't be an option."

"Newborn screening programs have unlimited potential. This is an excellent example of preventative medicine at its best and families in all

states should be able to reap the benefits," said DeWine. "Clearly, detecting and treating disorders early in life produces tremendous benefits--by both decreasing the cost of care and increasing the quality of a child's life."

"Newborn screening is a valuable tool in efforts to treat children's health problems, and - as such - we need to better explore how it is being implemented nationwide. This is one test where failing shouldn't be an option."

About 3,000 infants screened each year are identified

with having health conditions that could be harmful in the future. A few of the conditions that can be detected and potentially treated include hypothyroidism, phenylketonuria (PKU), and biotinidase deficiency. Some of the disorders can be treated simply by a change of diet or increase in certain vitamins, as long as the condition is caught at an early stage.

Currently, each state develops and administers their own plan to check for disorders and the programs can vary greatly between states. At this time, there is no comprehensive data on the initiatives of each state.

CARES Foundation has been in touch with Senator Dodd's office about their efforts and will be working with them to ensure that any national plan includes Congenital Adrenal Hyperplasia. **CF**

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STATE Update

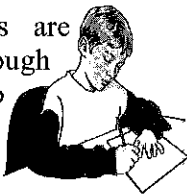
Many thanks to the states that began newborn screening for CAH in January: Virginia, Arizona and Mississippi. However, some states that were supposed to begin newborn screening for CAH over the last couple of months have been delayed. Now, New York and Oregon are scheduled to begin in July. Missouri began screening on March 1st has had 3 true positive cases of CAH in 6 weeks! Montana has added the option of CAH newborn screening for a charge of \$4.00. Ohio has delayed their meeting to discuss adding CAH newborn screening to sometime in June. Any Ohio parents who are willing to write letters or speak to the Health Department should contact CARES Foundation for more information. We may need you to help us be prepared for that June meeting.

In California, the state has no plans to add CAH newborn screening for at least one year. Sadly, approximately 40 CAH babies will be born in CA over the next year and will risk adrenal crisis and even death. Any California parents willing to write letters to the Governor urging him to make newborn screening a priority to save these babies lives will really help. It is an election year and he cares about what people think. Tell him your story about the birth of your child in CA without newborn screening. Tell him how important newborn screening for CAH is. Consider reaching out to your local paper about doing an article on CAH newborn screening. You CAN make a difference! For information on how to contact the Governor, see to the box to the left. **CF**


Teen Pen Pals

The teen years are difficult enough without having to cope with having a life-long illness. Teenagers are so adept these days with email that we decided to try to put together a pen pal program for teens. This way, they can connect with other teenagers experiencing some of the same issues. You or your teen can sign up by emailing me at Kelly@caresfoundation.org. Tell me how old your teen is, whether they want to be contacted by email or telephone, whether they want a male or female pen pal. We must also have the parents' permission and must be able to speak to the parents over the phone to obtain this permission. No private information will be released until all parties agree to the arrangement.


We hope that this will help our kids to weather some of the bumps of adolescence knowing that they are not alone. 

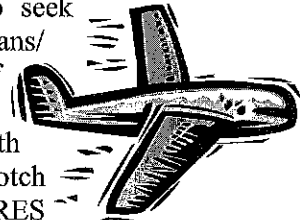


Helmsley Hotel Offers Special Rates for CARES Families

The Helmsley Hotel on 42nd Street in New York City has offered to give reduced rate rooms to CARES Foundation families traveling to the area for specialist care. The rates are only available when the family/individual is coming to NYC for medical purposes. You must have an introduction from CARES Foundation before booking the special rate. Please contact CARES Foundation for more information. 

CARES Foundation, Inc. Offers Financial Assistance to Families Needing to Travel for Specialist Care


Small grants are available through CARES Foundation to assist in the costs of travel when families must travel to seek specialist care. Often, the most experienced physicians/surgeons are at a great distance from the homes of CAH patients and seeing them requires travel and lodging expenses. In order to assist families with legitimate financial need and improve access to top notch medical care for families in all income brackets, CARES Foundation is offering small grants to families to help cover the costs of travel for this purpose. Financial need must be demonstrated. Contact CARES Foundation for more information. 




EMLA Cream—Pain-Free Shots for Kids

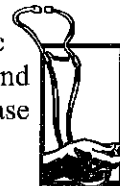
My 9 year old daughter, Alyssa, **M**used begin crying one week before her appointment with the endocrinologist anticipating the shots necessary for the blood work. I hated seeing her so upset, but did not know how to ease her mind. A friend recommended EMLA cream and it has worked wonders! EMLA cream is a numbing agent applied topically to the skin about 2 hours before the blood is drawn. You apply the cream thickly to the area where they take the blood and cover it with Saran wrap taped down on

the edges or the special plastic cover/bandage that comes in the kit. The nurse removes the plastic, cleans the skin and then takes the blood. The area is completely numb and the child does not feel the shot. Now, Alyssa is much more relaxed about her appointments. She loves the EMLA. I only wish I had known about it before.

EMLA is available by prescription only. Ask your doctor if it is appropriate for your child. 

Physician Listings Available from CARES Foundation

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



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 health-care 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 health-care 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. Any referral to physicians is provided as a courtesy only. CARES Foundation, Inc. does not specifically endorse or recommend these physicians.

CARES Foundation SCIENTIFIC and ADVISORY BOARD

Meet our wonderful, internationally renowned advisors...

MARIA I. NEW, M.D.
Pediatric Endocrinologist

Dr. Maria New is Professor of Pediatrics and Chief of Pediatric Endocrinology at the Weill Medical College of Cornell University. Dr. New holds an endowed Chair in Pediatric Endocrinology and Metabolism and is Program Director of the Children's Clinical Research Center of Cornell University. She has been Chair of the Department of Pediatrics for more than 20 years but plans to step down in the near future to concentrate exclusively on care and research in Pediatric Endocrinology, including developing gene therapy for CAH.

DIX P. POPPAS, M.D., F.A.A.P., F.A.C.S.
Pediatric Urologist

Dr. Dix Poppas is Chief of Pediatric Urology at the Children's Hospital of New York - Weill Medical College of Cornell University. He is the Richard Rodgers Associate Professor of Pediatric Urology in the James Buchanan Brady Department of Urology at Weill Medical College. He holds joint appointments as Associate Professor of Pediatrics and Associate Professor of Plastic and Reconstructive Surgery at Weill Medical College.

Dr. Poppas' practice is limited to pediatric urology with special interest in genital reconstruction, laparoscopy and intersex disorders. He serves as Director of the Laboratory for Minimally Invasive Urologic Surgery.

PHYLLIS W. SPEISER, M.D.
Pediatric Endocrinologist

Dr. Phyllis Speiser is Director of

Pediatric Endocrinology for the North Shore-Long Island Jewish Health System in New York and Professor of Clinical Pediatrics at New York University School of Medicine. Dr. Speiser is an internationally recognized expert in congenital adrenal hyperplasia (CAH). Her research has mainly focused on genetic and clinical correlations among patients with adrenal disorders. She is a Medical Advisor to the National Adrenal Diseases Foundation.

DANIEL GUNTHER, M.D., M.A.
Pediatric Endocrinologist

Dr. Daniel Gunther joined the endocrinology team at Children's Hospital and Regional Medical Center of Seattle, Washington, in August, 1998. Dr. Gunther's areas of interest in the field of endocrinology include Turner's Syndrome, intersex disorders, growth and puberty. In addition to working full-time at Children's Hospital, Dr. Gunther holds outreach clinics in Olympia six times a year and in Yakima twice a year.

BRADFORD L. THERRELL, M.S., Ph.D.
Bio-Chemist/Director of national Newborn Screening Center

Dr. Brad Therrell is a Professor in the Department of Pediatrics at the University of Texas Health Science Center at San Antonio (UTHSCSA), and Director of the National Newborn Screening and Genetics Resource Center (NNSGRC) located in Austin, Texas.

Dr. Therrell previously served for almost 30 years as Director of Chemistry at the Texas Department

of Health, where he was responsible for the world's largest newborn screening laboratory. It was under his direction that congenital adrenal hyperplasia (CAH) was added to the newborn screening panel in Texas in 1987.

GARRY WARNE, M.D.
Endocrinologist

Dr. Garry Warne is an Associate Professor and Senior Endocrinologist at the Royal Children's Hospital, Melbourne, Australia, author of the book "Your Child with Congenital Adrenal Hyperplasia". Dr. Warne's work has included laboratory studies on the androgen receptor and its gene, and clinical research on CAH, androgen insensitivity syndrome and Turner's Syndrome. He is currently part of a multi-disciplinary team conducting a long-term follow-up study of patients who had genital surgery early in life. He has helped found a number of support groups in Australia, as well as a CAH support group in Hanoi, Vietnam. He travels regularly to a number of countries in Asia, especially India and Vietnam.

SHERI A. BERENBAUM, Ph.D.
Psychologist

Dr. Sheri Berenbaum is a Professor in the Psychology Department at Penn State University. Dr. Berenbaum's research focuses on the development of individual differences in cognition and social behavior from a neuroscience perspective. Her research has been supported by the National Institutes of Health since 1985.

(Continued on page 5)

SCIENTIFIC and ADVISORY BOARD
(Continued from page 4)

Dr. Berenbaum is an editor of the journal, *Behavior Genetics*, and a member of the editorial board of the journal *Brain and Cognition*. She currently serves on committees concerned with the medical and psychological treatment of children with ambiguous genitalia, including the North American Task Force on Intersexuality.

SUSAN BAKER, Ph.D.
Psychoendocrinologist

Dr. Susan Baker is a Research Associate in the Department of Pediatrics, Division of Pediatric Endocrinology at New York Presbyterian Hospital/Weill Medical College of Cornell University.

Dr. Baker joined the Cornell staff in 1977. Dr. Baker and her colleagues have investigated cognitive strengths and weaknesses in CAH, as well as the effects of prenatal treatment on the condition.

Dr. Baker is the author of the article, "Psychosexual Quality of Life in Adult Intersexuality: The Example of Congenital Adrenal Hyperplasia (CAH)," in "The Therapeutic Outcome of Endocrine Disorders: Efficacy, Innovation, Quality of Life" (pp. 200-208, Springer Verlag, New York, 2000). [CF]

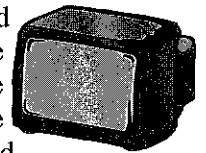
Getting Ready For Summer: Adrenal Crisis

Summer is the time that kids often try new things, take new risks. For the CAH child, this brings with it a need to be prepared to deal with the possibility of physical emergencies, such as heat stroke or a broken bone. Now is a good time to check that you have all of the tools available. First, MAKE SURE you have a good letter of instruction from your doctor on what to do when your CAH child has an emergency. While all parents should already have such a letter on hand along with Solu-Cortef, this letter is especially important to give to camps and summer programs. This letter should spell out in detail all the steps that should be taken in the event of a broken bone, bad sprain or heat stroke, or other physical emergency. If your child is going to camp or a summer program, it should list all of your contact numbers, the contact numbers for your doctors and the name of the hospital you want your child brought to. You should also consider asking your doctor for an extra prescription for Solu-Cortef solution and medication to be left with the Camp Nurse in case they need to use, along with explicit directions on when and how to use

them and what constitutes an emergency for CAH kids. We need to make sure that the nurses at these programs can properly care for our kids when they are out of our care. This way, the kids can have fun and try new things while we can have peace of mind. [CF]

48 Hours Television Program on CAH

The television show, *48 Hours*, is producing a one-hour special on CAH. It will begin filming soon and should air sometime next year. The producers are sensitive and kind and seem genuinely interested in giving a full view of all aspects of this disease, including the need for newborn screening and the need to educate the public about the very common non-classical form. Many thanks to those who responded to our inquiries for families willing to be interviewed. We will keep the CAH community informed about the progress of the filming and the date the show will air. [CF]



To all our CAH Adults and Families:

We are trying to create a workable database with the full names and addresses of the CAH community. *Please help us to help you.* For many of you we only have a first name and email address. If you haven't already done so, *please register on our database at:* <http://www.caresfoundation.org/form.html>.

What Do You Mean *It's Not Covered?*

As many of our families can tell you, the challenge of getting medical coverage for a chronic disease, such as CAH is often frustrating and extremely stressful. Tricia and Calvin Luker, from Michigan, who are parents of a child with a metabolic disorder, have written two excellent articles on how families can best approach these financial concerns. Below highlights some of the important points that they raise.

To get the most out of your insurance company you need to develop a thorough understanding about your policy. If you have frequent claims, you should consider the following:

Withhold payment of the medical bill until you receive insurance payments if you are on a tight budget. Discuss your financial situation with your doctor. Generally, you only have to make a small payment every month to ward off bill collectors.

Work directly with one particular claims examiner. When they get to know you and your family's medical situation, often they are better able to assist you. Make sure you keep notes on who you spoke with and when.

Submit claim forms carefully and methodically. Have a separate "Claims Submitted" folder for each member of the family with copies of all claims, bills and correspondence. Your copy is important protection in the event the paperwork is lost or replaced or needed for future reference. Also, include a reference list of prescription numbers with the names of the drugs in your folder.

Check your claim carefully before submitting to ensure that it is not delayed because of incomplete information; don't claim too many different types of items on one form. If one is rejected, it may delay the processing of the entire claim.

If you were denied coverage and believe that you are entitled to payment under your plan, these are some steps that you can take:

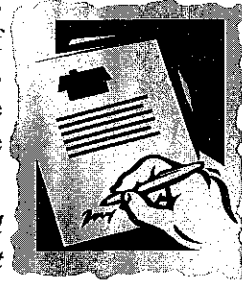
Appeal your denied claim to your health insurance company at least twice.


If you are not reimbursed after these appeals without adequate explanation, contact your state's Department of Insurance and ask to speak with someone in the Office of Consumer Affairs regarding a health insurance problem.

Send the person you speak with a written description of the problem and any literature from your insurance company that supports your case that the service should be covered, and any additional information you feel is important. Give the Department of Insurance two weeks to respond. If you receive no response, call them again and speak to the person you originally contacted. Wait another two weeks. If you still get no satisfactory response and the amount is sizable, consider talking with an a lawyer to resolve your case.

The Lukers' articles also include explanations on how to seek out other financial sources if your medical insurance is not sufficient to meet your needs and

professionals who can assist you in this search. Some of the financial sources they suggest include: tax-supported government programs at the local, state and national levels; voluntary health agencies; and charitable organizations.



To read the original "What Do You Mean It's Not Covered?" articles in their entirety, logon to the CARES Foundation website at: www.caresfoundation.org. 


Exceptional Parent

(Continued from page 1)

will become a useful informational tool at scientific conferences and CARES Foundation and Exceptional Parent events.

Exceptional Parent will also assist in the free distribution of the CARES Foundation video, "Living with CAH." The video, which is now in the planning stages, will be featured in the "Exceptional Parent Library" section of the magazine.

Finally, Exceptional Parent and the CARES Foundation will work together to develop seminars and conferences on CAH. The magazine has significant experience in this area, having created resource materials on epilepsy, ADD/ADHD and Universal Newborn Screening.

For more information about Exceptional Parent Magazine, please consult the magazine's Web site at <http://www.eparent.com>, or call, toll-free, 877-372-7368. It is a great resource for our parents and we strongly recommend subscribing. 

Book Review

Children: Growth and Puberty--A Parents' Guide

By Ze'ev Hochberg. M.D., D.Sc.

Early puberty and sub-optimal growth are common medical issues confronting children with all forms of congenital adrenal hyperplasia. Many parents will be called upon to consider delaying puberty with drugs and/or boosting growth with growth hormones. Dr. Hochberg's book explains growth and puberty in language that is easy for laymen to understand. This book, while it only touches very briefly on CAH, explains the various factors that create impediments to optimal growth in children and the causes of early puberty. As a parent now confronting medical intervention in these areas for my daughter with non-classical CAH, I found the book very helpful in understanding the growth process and its interrelationship to puberty. I feel better prepared to make an educated decision on these therapies for my daughter.

This book is available through the web site, www.1stbooks.com as an electronic book for \$4.95 or in paperback for \$16.50. CF

VOLUNTEERS NEEDED!!

We need volunteers from the Tri-State (NY, NJ and CT) and Greater Los Angeles areas to help organize CAH Family Workshops in those areas. If you are willing to help, please contact CARES Foundation. If you would like to organize a support group or workshop in another area, please contact us as well. CF

New Report on Pregnancy and Non-Classical (Late-Onset) CAH--An Abstract From PubMed

Ned Tijdschr Geneeskd 2002 Feb 9;146(6):268-70

van den Akker ES, Stikkelbroeck MM, Menheere PP, Roumen FJ, Otten BJ.

Atrium Medisch Centrum, afd. Verloskunde en Gynaecologie, Postbus 4446, 6401 CX Heerlen.

In an 18-year-old woman non-classic 21-hydroxylase deficiency was diagnosed and dexamethasone treatment was instituted. Ten years later, she became pregnant for the first time; at 37 weeks unexpected intrauterine foetal death was found to have occurred. A second pregnancy ended with a spontaneous abortion following a 12-week period of amenorrhoea. At the third pregnancy, the medication was replaced with hydrocortisone as it was suspected that the use of dexamethasone may have played a role in the intrauterine foetal death and the spontaneous abortion. The patient gave birth to a healthy, but dysmature, daughter. Female patients with non-classic congenital adrenal hyperplasia present with signs of androgen excess. Treatment with glucocorticoids reduces the symptoms and restores the menstrual cycle and fertility. Preconceptional advice by a clinical geneticist is recommended, because of the risk of an affected child. If there is no risk of having a child with congenital adrenal hyperplasia, hydrocortisone or prednisone is the treatment of choice during pregnancy as neither cross the placenta.

This report brings up issues that women with NCCAH who are pregnant or considering pregnancy should discuss with their physicians. CF

"The Gift of Faith"

Kaye Collelo, mother to Christianna, age 11 months, has begun writing a book about her experience as the mother of a daughter with salt-wasting CAH. Here is a short excerpt from "The Gift of Faith":

"They found a uterus". Those were the words that divided our lives into two different planes in this universe of ours. Like bugs trapped in drops of water, my husband and I became suspended in a chamber of round walls that we could not crawl out of. Our bodies stunned and shocked, it was as if we had gone into a form of suspended animation that we could not escape from. "They found a uterus", words that will forever echo in the back of our minds, those words that initially evoked terror, fear, horror and shame at what they actually meant.

We all anxiously await the finish of this book that will tell "our" story. Good Luck, Kaye! CF



To make your tax deductible contribution to CARES Foundation, please fill out this form and include your check or credit card number. You may also make donations via our website at: <http://www.caresfoundation.org>

Name: _____

Address: _____

Phone #: _____ email: _____

Your Tax Deductible Contribution:

\$1000 ___ \$500 ___ \$250 ___ \$100 ___ \$50 ___ Other \$_____

Matching Gift Program Available? Name of Company _____

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*Mail to: **PO Box 264, Short Hills, NJ 07078***

For credit cards: MC _____ VISA _____ AMEX _____

Card Number: _____ Exp. Date: ___/___/___

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**DO NOT DELAY
MEETING NOTICE**

Address Service Requested