



Reduced Final Height Outcome in Congenital Adrenal Hyperplasia under Prednisone Treatment: Deceleration of Growth Velocity during Puberty

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INTRODUCTION

Management of children with congenital adrenal hyperplasia (CAH) is a challenge with regard to growth outcome. Traditional treatment consists of substitution of cortisol to reduce excessive androgen production and its consequences. Undertreatment with steroids leads to androgen excess with advancement of bone age, and reduced final height. In overtreatment, growth is suppressed by growth inhibiting effects of steroids. Further side effects of overtreatment are truncal obesity and osteoporosis. Overtreatment is a greater risk when potent longer-acting glucocorticoids, such as prednisone, or dexamethasone are used. Therefore there is only a narrow therapeutic window in the traditional treatment of CAH with glucocorticoids. Alternate approaches in the treatment of CAH have been investigated recently, including the use of antiandrogens, aromatase inhibitors, and adrenalectomy.



Adequacy of treatment is best evaluated by monitoring growth rate and skeletal maturation. In addition, urinary and serum analysis of steroid hormones and determination of 17-hydroxyprogesterone are used for evaluation of therapy. Reports on long-term follow-up and final height outcome in patients with CAH are still sparse and heterogeneous. There is still controversy on certain factors and on critical periods of growth.

We report on 125 patients with CAH who have reached final height and who have been followed in our clinic since diagnosis of CAH.

RESULTS

In total, 33 patients had been treated with prednisone (two times daily) during infancy and childhood, whereas 92 patients had received hydrocortisone (three times daily) for glucocorticoid substitution only. Patients with salt-wasting (SW) CAH received fludrocortisone in addition. Relative glucocorticoid potency was considered one for hydrocortisone and four for prednisone, so that we use a low-end estimate of hydrocortisone equivalence in our analysis. Since patients were followed at a single center, we present data on a homogenous group of patients with CAH.

CAH continued on page 7

2007 No-Sweat Run for a Cure



A Race to the Finish

Our virtual event was a REAL success!! With over 673 donations, we raised \$87,500. Thank you to all who participated. See page 13 for more details and prize winners. (Note: All prizes were generously donated).

And the Survey Says...

The results are in for the 2007 Membership Survey. See page 4 for details.



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New Addition to Medical Advisory Board

CARES Foundation is pleased to welcome Pediatric Psychologist **David E. Sandberg, Ph.D.** to our Medical Advisory Board. Dr. Sandberg is Associate Professor and Director of the Division of Child Behavioral Health in the Department of Pediatrics and Communicable Diseases at the University of Michigan in Ann Arbor.



A child and adolescent clinical psychologist with expertise in caring for youths with chronic medical conditions and their families, Dr. Sandberg has served as a member of healthcare professional teams caring for youths with various endocrine conditions for more than 18 years. His clinical research program flows from these clinical experiences, including studies of the psychosocial aspects of short stature.

A second focus is the psychological development of children born with a

conditions identified by newborn screening. He has developed a psychoeducational treatment manual for clinicians caring for newborns with congenital adrenal hyperplasia and is designing health-related quality of life questionnaires for patients with conditions affecting sexual or reproductive function, and their parents.

Dr. Sandberg obtained his doctorate from Concordia University in Montreal, Canada and completed postdoctoral fellowships at the University of Miami and at the College of Physicians & Surgeons of Columbia University. He is a member of the Lawson Wilkins Pediatric Endocrine Society, is a Fellow of the American Psychological Association and the Society of Pediatric Psychology, and is on the editorial board of the Journal of Pediatric Psychology.

Letter to the Editor

My son, Adan Cardenas, celebrated his 4th birthday on August 12th thanks to the doctors in the ER at Children's Medical Center, Dallas, Texas. Adan is a SWCAH patient and was careflighted to Children's on his 8th day of life.



He actually died from Potassium attacking his heart on the helipad and the ER doctors recognized his symptoms and saved his life. He is now a thriving 4 year old little boy full of energy and life. We've had several scares but I held my cool and gave him a shot and called 911—and 3 times now he has pulled through.

Never in my life could I have thought that a life was as precious as this. He is the light of our family and will always be the center of our family. Thanks to you, CARES Foundation, for providing our family with important and comforting information regarding CAH. You will forever be in our hearts and minds. You are a blessing. May God bless you and all the staff and supporters.

Sabrina Cardenas

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a message from the President & Founder

Dear Friends,

Our profound appreciation goes to all the families who so enthusiastically participated in our successful 2007 No-Sweat Race for a Cure. Supporters made donations to CARES based on the number of kilometers they



did not run. Teams, comprised of family, friends and colleagues, were motivated beyond our wildest expectations, not only by our mission but by the measurable time and money saved by not training, not purchasing new clothes and running shoes, and not running! See page 13 for race results.

A WELCOME ADDITION

We are delighted to welcome Dr. David Sandberg to the CARES Scientific & Medical Advisory Board.

IN MEMORIAM

One of our beloved medical advisors, Daniel Gunther, MD, passed away suddenly on September 30, 2007. He will be greatly missed. Read more about this dedicated doctor on page 23.

IN RESPONSE...

Last Spring, my daughter Alyssa wrote an essay for school that moved me so much I submitted it for last CARES newsletter. While many people liked the article, others were unfamiliar with Jewish religious practices and thought that CARES edited her essay and used G-d instead of God. A few said they found it offensive. I discovered that many people were unfamiliar with Jewish traditions and did not know that this practice of not spelling out "God" is to show respect and humility.

CARES did not edit her essay: Alyssa always uses G-d instead of God in writing because it is our religious tradition. In Judaism, the name of G-d is

not written out fully by many of those of the Jewish faith. Traditional Jews use "Hashem" (which in Hebrew means "the name") or G-d, instead of "God" to show their respect to God by not taking the name lightly and only using the proper name "God" in prayers. So, it is a sign of the ultimate respect in our religion. While I am not as strict about this in my own personal speech and correspondence and use "God" regularly, my daughter follows these religious traditions more strictly. So, I hope that those wondering about this in her essay now understand a bit more about Judaism and realize that no offense was intended.

May God, G-d, Hashem, Allah, etc. bless you and your families, and keep you all safe and healthy.

SCREENING ACROSS THE NATION

Screening for CAH is now being implemented in all 50 states, and we are thrilled that the word is reaching families across our country.

A FOND FAREWELL

All of us here at The CARES Foundation are wishing the very best to Erin Anthony, our outstanding Program Development, Support and Education staff member who left to pursue her dream of becoming a physician's assistant at Seton Hall University. Erin was personally affected by CAH and her special warmth and professional commitment was always welcomed... and will surely be missed. Our supportive thoughts are with her, and we know she will fabulously successful in her new career.

Warmly,
Kelly

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This newsletter is published 3 times a year.

Results and Findings of the CARES Membership Survey



Recently, the CARES Foundation, Inc. conducted a Membership Survey to help the organization better understand our members' perceptions and needs.

Our goals were:

- 1. To learn more about who members are and what resources they value.*
- 2. To guide CARES in providing services, education, products and activities that truly meet the needs of members.*

The membership survey was offered to certain registered members of CARES Foundation (families and affected individuals only) through the organization's website. The survey was made available from February through July 2007, and members were invited to participate by email and regular mail. The potential survey population was 1534 selected members of which 526 responded for a response rate of 34%.

Key Findings

The response rate was high: over one third of CARES Foundation members responded to the survey. The CARES Foundation membership base seems eager to share opinions about services and programs offered by the Foundation. The survey uncovered key findings within the following areas: membership demographics, organizational programs and services, funding priorities and embryonic stem cell research.

Membership Demographics

CARES Foundation survey respondents represented 24 nations, with 89% of the respondents from the United States. Of the members residing in the United States, those from California, Texas and New York represented over 25% of respondents. These three states account for a significant portion of CARES Foundation members. The vast majority (85%) of respondents were female.

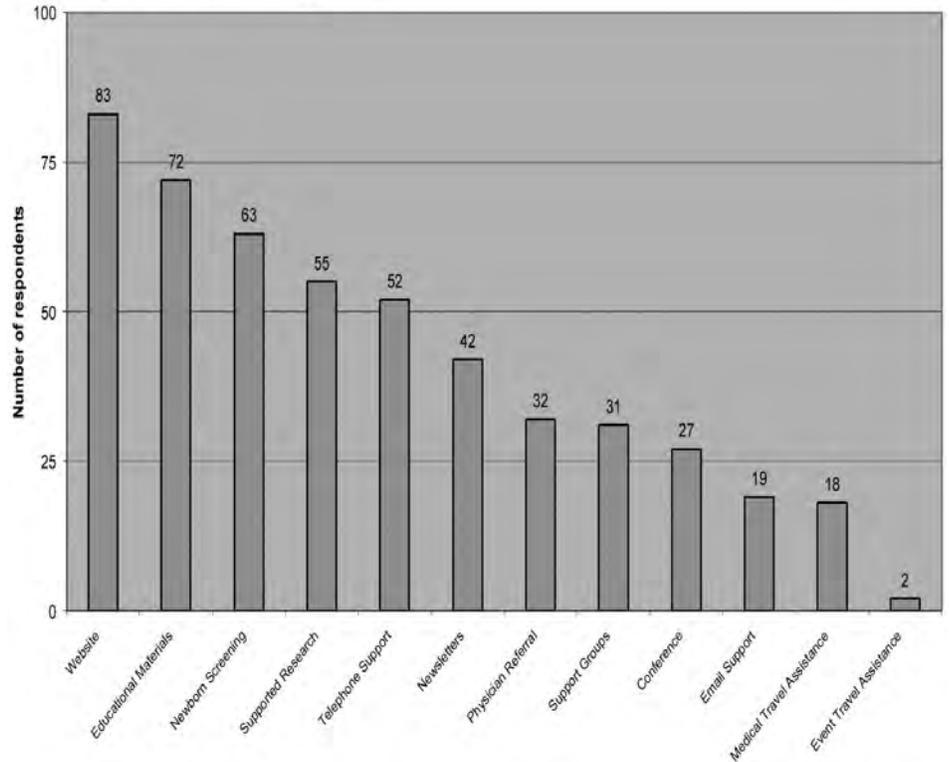
Foundation Programs and Services

The survey asked participants to indicate how they became aware of CARES Foundation. The website and various internet-based modes of communication (CAH message boards, chat groups, email listserv) represented the main sources. According to the survey results, the most used services are the website, newsletter and educational materials. The least used services were medical travel assistance, event travel assistance and support groups.

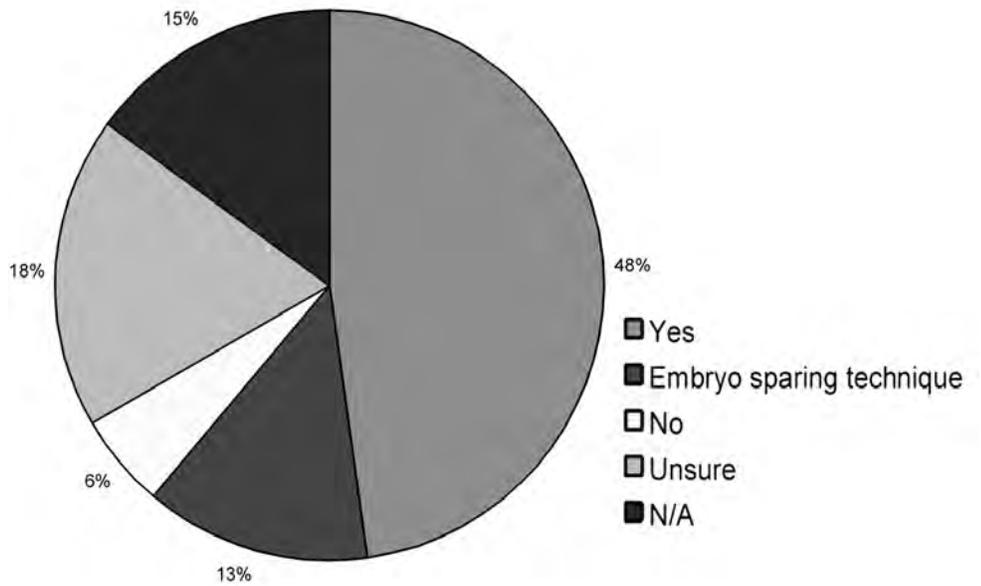
Embryonic Stem Cell Research

Respondents were asked to indicate their support of the embryonic stem cell research for a cure for CAH. The chart (Embryonic Stem Cell Research) below outlines the results of this question. Nearly half of the respondents, 48% (251 respondents) indicated that they support embryonic stem cell research. Another 13% would only support stem cell research if embryo-sparing technique is implemented. Of all the respondents, only 6% did not support embryonic stem cell research. At 18%, nearly one fifth of the survey respondents felt unsure about pursuing embryonic stem cell research. A further 15% left the selection blank, possibly indicating that they felt unsure about this type of research. A conjecture can be made that 1/3 of the survey respondents are unsure about pursuing embryonic stem cell research and 2/3 support it in some capacity.

Most Important Services and Programs



Embryonic Stem Cell Research (n=526)



continued on next page

Funding Priorities

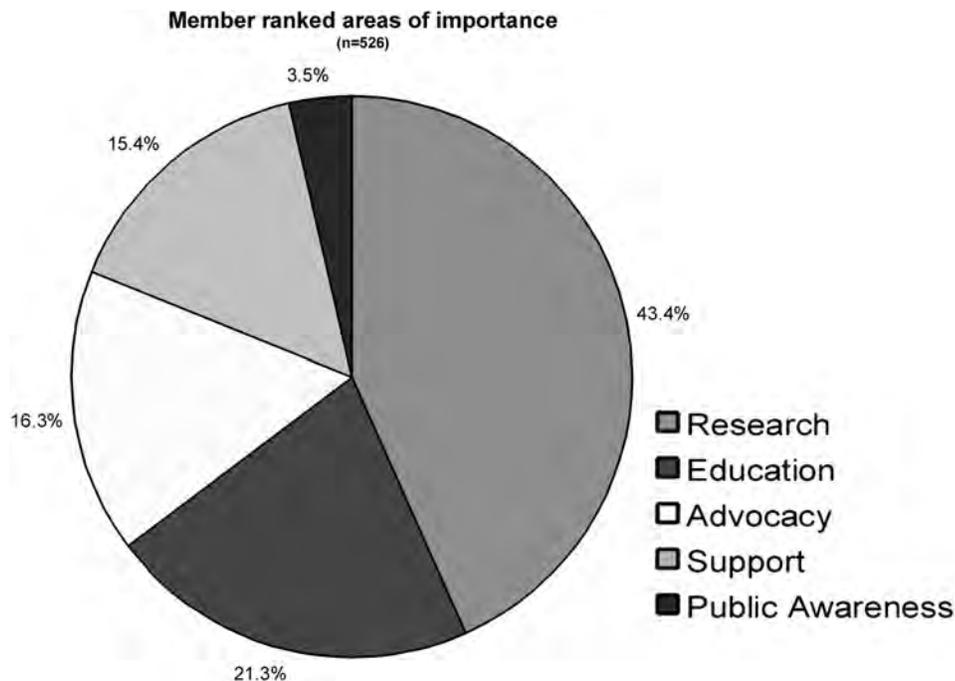
Survey respondents were given the opportunity to select which areas they felt to be the most critical. The five areas to be ranked included:

- CAH research
- education of the public and healthcare professionals about all forms of CAH
- advocacy for universal newborn screening
- support services and resources vital to the CAH community
- * public awareness of CAH

According to the survey, research ranked as the most important funding priority followed by education. Advocacy and support were the next most important funding priorities with public awareness being the least important according to the survey results.

International Demographics

Of the respondents, 89% answered that they resided in the United States, while 11% indicated that they lived outside of the United States. The three countries outside of the U.S. with the highest response rates were Canada, Australia and the United Kingdom,



which accounted for over 46% of international responses. Small numbers of respondents were from the Bahamas, Chile, Columbia, Dominican Republic, former Yugoslavia, Germany, Greece, Hungary, India, Israel, Italy, Jordan, Mexico, New Zealand, Philippines, Poland, Puerto Rico, the Republic of South Africa, Syria and Uruguay.

United States Demographics

Within the U.S. resident respondent group, 47 states and the District of Columbia were represented. The three states with the highest response rates

were California, New York and Texas, which made up over 27% of the national responses.

The membership survey indicated that research for a cure was the highest priority for funding. According to the research results, 48% of respondents felt that CARES Foundation should set research as the top funding priority.

We thank everyone who took the time to fill out the survey. We gained so much useful information from this survey. ❤️

IMPORTANT ANNOUNCEMENT!

Pfizer just announced that all shortages and delays in the production of the 100 mgs vials of Solu-Cortef™ have been resolved. The product should now be readily available at your local drugstores.

Patients with salt-wasting CAH were diagnosed early at a mean age of 0.3 years [range 0-2.7 years, whereas patients with the simple virilizing form were diagnosed at a mean age of 2.2 years [range 0-6 years]. Once the diagnosis of SWCAH had been established, only two patients had suffered from adrenal crisis.

Mean final height in females (n=77) was 158.7±6.3 cm (-1.0±1.0 SDS): females with salt-wasting CAH were significantly taller (160.3±6.4 cm, -0.8±0.9 SDS) than female patients with the simple virilizing form (157.2±5.9 cm, -1.3±1.0 SDS), p<0.05.

In males (n=48), mean final height was 169.8±6.9 cm (-1.2±1.0 SDS): male patients with salt-wasting CAH reached a mean final height of 170.5±6.6 cm (-1.0 ± 1.0 SDS), and males with simple virilizing CAH a final height of 168.0±7.2 cm (-1.4 ± 0.9 SDS). There was no significant height difference between salt-wasting and simple virilizing CAH males (p>0.05), although metabolic control was worst in SV CAH males, indicated by most advanced bone age at onset of puberty.

A total number of 92 patients had been treated with hydrocortisone during infancy and childhood, and 33 patients had received prednisone exclusively during this period.

In the hydrocortisone treated group there were 31 SW CAH females and 26 SV CAH females, and 22 SW CAH males and 13 SV CAH males. In the prednisone treated group 6 females and 8 males were salt-wasters, and 14 females and 5 males had the simple virilizing form of CAH. Hydrocortisone treated patients (Final Height-SDS -0.9±0.9) were significantly taller at final height than patients who were treated with prednisone (Final Height-SDS-1.6±1.0), p<0.01.

Prednisone treated patients did not have better suppression of adrenal androgen secretion. Hydrocortisone equivalent doses were significantly higher in the prednisone treated group at the age of two years (p<0.01) and at the start of puberty (p<0.01). Nevertheless, final height in all 125 patients showed no correlation with the hydrocortisone dose or hydrocortisone equivalent dose given at two years of age (p>0.05), but final height correlated negatively with the dose given at start of puberty (r=-0.3, p<0.05).

Furthermore, patients treated with less than 20 mg hydrocortisone/m² at start of puberty were significantly taller than patients who were given more than 20 mg hydrocortisone/m², p<0.05, irrespective of treatment with hydrocortisone or prednisone.

Mean height SDS at start of puberty was 0.3±1.4 (females 0.1±1.4 SDS and males 0.5±1.4 SDS), and decreased significantly to -0.5±1.2 SDS at the end of puberty (females -0.7±1.2 SDS and males -0.3±1.2 SDS), p<0.01, indicating an insufficient pubertal growth spurt. Total pubertal growth in females was 12.8±7.1 cm and 17.4±6.9 cm in males, which is significantly less than in the reference population of Prader et al with a mean pubertal growth in females 20.3±6.8 cm and 28.2±8.2 cm in males, p<0.01.

DISCUSSION

In our large cohort of homogeneously treated patients with CAH, we found that, with regard to growth, potential puberty is an extremely critical period in the treatment of CAH. Total pubertal growth was significantly decreased in both forms of classical CAH, irrespective of the sex. An explanation for the decreased pubertal growth spurt could be a too tight control of the disease at the onset of puberty, so that the sex

hormones influence on growth is suppressed, resulting in a less profound growth spurt. Accordingly, hydrocortisone dose at onset of puberty correlated negatively with final height. A significant difference in the effect on final height was seen in the corticosteroid used for treatment of CAH. Use of prednisone resulted in higher hydrocortisone equivalent doses and significantly reduced final height. Since hydrocortisone equivalent doses correspond to the anti-inflammatory, and not to the androgen and growth suppressant effects, the meaning of equivalent doses in the context of CAH remain unclear in some aspects.

As experience shows, hydrocortisone is routinely used for treatment of CAH in infancy, childhood and puberty in our days. To our knowledge, this is the first study to prove that treatment with prednisone leads to decreased growth in children and adolescents with CAH. We also conclude from our results that an optimal hydrocortisone dose during puberty should not exceed 20 mg/m² body surface area.

In summary, final height in CAH patients receiving traditional therapy is within the lower range of genetic potential. Total pubertal growth is significantly decreased in this cohort. Treatment with prednisone during childhood results in decreased final height. Accuracy of treatment should not be monitored only by biochemical assessment, but also by careful follow-up of growth velocity especially during puberty. Thus glucocorticoid doses should be adjusted (below 20 mg hydrocortisone or hydrocortisone equivalent dose per m² body surface area) in this rapid phase of growth and GnRH analog or aromatase inhibitor treatment should be considered in patients with advanced skeletal maturation.



CARES Creates Honorary Board

We are pleased to announce that CARES Foundation has created an Honorary Board, to include dignitaries and other persons who can enhance CARES' public visibility. They will act as ambassadors for CARES Foundation and provide advice to the organization as needed.

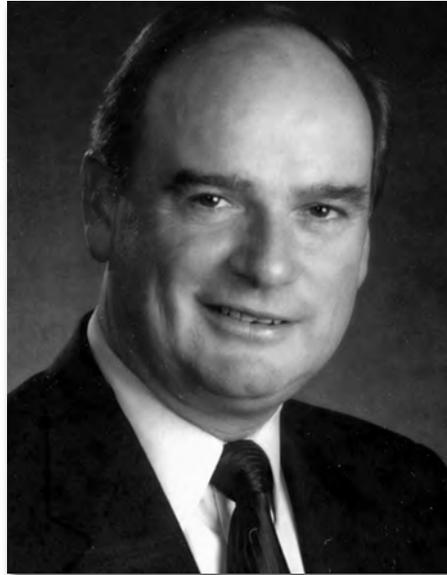
Governor Donald DiFrancesco

New Jersey State Senate President Donald T. DiFrancesco was sworn in as Governor of New Jersey shortly after 11 a.m. on January 31, 2001, succeeding Governor Christine Todd Whitman, who resigned one hour earlier to become administrator of the Federal Environmental Protection Agency.

Mr. DiFrancesco was first elected to the New Jersey State Senate in 1979, was re-elected six times, and served as President of the Senate from January 1992 until 2001. Because Article V, of New Jersey's constitution states that all powers, duties and emoluments of the office of Governor devolve upon the President of the Senate in the event of a gubernatorial vacancy, Mr. DiFrancesco served as Acting Governor at least once every year while Governors James J. Florio and Whitman were traveling out of state for short periods of time.

At the time of his election to the Senate, Mr. DiFrancesco was in the Assembly. He was elected to his first Assembly term in 1975, was re-elected in 1977, and served on the Assembly Institutions, Health and Welfare Committee, as well as on the Banking and Insurance Committee. He was Vice Chairman of the Joint Committee on Ethical Standards.

As Senate President, Mr. DiFrancesco sponsored the constitutional amendment prohibiting unfunded state mandates, the 2000 law that renewed the Transportation Trust Fund, and the 1999 bond act that led to the



establishment of the Garden State Preservation Trust Fund, a \$98 million initiative dedicated to preserving open space, farmlands and historic properties. As Governor, he dramatically increased and improved health and healthcare programs for the children of New Jersey, including creating the NJ KidCare program and expanding newborn screening.

The CARES Foundation honored Governor DiFrancesco in 2006 for signing the 2001 Executive Order that dramatically expanded newborn screening in New Jersey and saved the lives of hundreds of New Jersey babies.

The families and children affected by CAH are forever grateful to the Governor for saving their children and giving them a healthy start at life.

Mr. DiFrancesco was born in Scotch Plains, New Jersey. After graduating from Scotch Plains-Fanwood High School, he attended Pennsylvania State University and Seton Hall Law School. He was admitted to the Bar in 1969, and was Senior Partner in the law firm of DiFrancesco, Kunzman, Coley, Yospin, Bernstein & Bateman in Warren Township, New Jersey from 1992 to January 31, 2001.

After serving the people of New Jersey as Governor, Mr. DiFrancesco rejoined the law firm of DiFrancesco, Bateman, Coley, Yospin, Kunzman, Davis & Lehrer, P.C. In addition to CARES Foundation, Governor DiFrancesco serves on the Board of Directors of Commerce Bank, The New Jersey State Chamber of Commerce and Children's Specialized Hospital of Mountainside, New Jersey. Mr. DiFrancesco and his wife, Diane, have three adult daughters.



Minnesota State Representative Paul Thissen



Paul Thissen serves in the Minnesota House of Representatives representing south Minneapolis and Richfield. He was first elected in 2002, and re-elected in 2004 and 2006.

A graduate of the Academy of Holy Angels in Richfield, Paul attended Harvard University, graduated with high honors in 1989, and earned his law degree from the University of Chicago Law School in 1992. He clerked for the Honorable James B.

Loken of the United State Court of Appeals for the Eighth Circuit and subsequently accepted a position at the law firm of Briggs and Morgan. He has also worked for the Minnesota State Public Defenders Office.

Until his election in 2002, Paul served as Chair of Briggs and Morgan's Pro Bono Committee and was an active participant in programs intended to increase the availability of legal representation to those in our community who cannot otherwise afford a lawyer. Paul served on the Board of the Minnesota Justice Foundation and founded a program for volunteer lawyers called Access for Persons with Disabilities to increase the availability of legal representation to persons with disabilities in the Twin

Cities. He has worked with Minnesota Advocates for Human Rights to represent refugees seeking asylum in the United States. In partnership with the Chrysalis Center for Women, he has also represented women seeking Order for Protection from abusive partners.

Paul resigned as a Briggs and Morgan partner in 2002 when he was elected to the Minnesota House of Representatives. In 2007, he was appointed Chair of the House's Health and Human Services Committee, and also sits on the Biosciences and Emerging Technology Committee, Finance Committee, Health Care And Human Services Finance Division Committee, Rules And Legislative Administration Committee, and Telecommunications Regulation and Infrastructure Division Committee.

Paul was Chief Author of HF 1, the Children's Health Security Act, serves on the Health Care Access Commission and also serves on Governor Tim Pawlenty's Health Transformation Taskforce. Both groups have worked throughout the summer and fall of 2007 to develop plans to reduce health care costs and provide universal coverage in Minnesota by 2011. In addition, Representative Thissen worked to protect Minnesota's newborn screening program from various threats.

In 2006, Paul was named one of "Forty Under 40" top business professionals in the Twin Cities by the *Twin Cities Business Journal*. He and his wife, Karen, were married in 1993 and have three children. His son, Evan, is affected by salt-wasting CAH.



CAH STUDIES

Classical Adult Women's Quality of Life Study

CARES Foundation and Dr. Sheri Berenbaum from Pennsylvania State University have launched a quality of life study of women with classical CAH. It is open to women with classical CAH (Salt wasting and simple virilizing forms) over the age of 18, and entails answering a written survey. If you have questions about the study or want more information, please contact Kelly Leight at 1-866-227-3737 or email kelly@caresfoundation.org.

Los Angeles City Councilman Bill Rosendahl

Bill represents the 11th District, which includes the communities of Brentwood, Del Rey, Mar Vista, Marina del Rey, Pacific Palisades, Palms, Playa del Rey, Playa Vista, Venice, West LA and Westchester. He serves as chair of the council's Public Works Committee, which has oversight of most essential city services, vice-chair of the Commerce Committee, which oversees Los Angeles World Airports, and member of the council's Transportation Committee, Budget & Finance Committee, and Ad Hoc Committee on Homelessness, which he co-founded. He is also chair of the Southern California Regional Airport Authority and one of the city's appointees to the Santa Monica Bay Restoration Commission and the Exposition Light Rail Construction Authority.

A resident of Mar Vista, the largest community in the 11th District, Bill is the first openly gay man elected to the Los Angeles City Council, and is the city's highest-ranking GLBT official.

Prior to his election, Bill served as Distinguished Professor at Cal State Dominguez Hills. He is, perhaps, best known as producer and moderator of the critically-acclaimed public affairs television shows: "Local Talk", "Week in Review" and "Beyond the Beltway." An



advocate of empowering people through information, Bill produced more than 3,000 programs over 16 years, opening the airwaves to all viewpoints and steering thoughtful dialogue on the most complex and controversial issues.

An avid participant in civic life, Bill chaired the California Commission on Tax Policy in the New Economy, served as president of the Los Angeles Press Club, as chairman of the Cable and Telecommunication Association and as a member of the education fund of the Los Angeles League of Women Voters. Prior to his cable TV career, he was a White House appointee to the State Department as Chief of Operations for the U.S.

Trade and Development Program, served as an associate in philanthropic work for John D. Rockefeller, III and worked political campaigns, including Robert Kennedy's 1968 presidential bid.

A Vietnam-era veteran, Bill served in the U.S. Army from 1969-71, spending a year as a psychiatric social worker, counseling troops returning from combat, and is currently a member of The American Legion, Post 283, in Pacific Palisades.

Bill holds a Master of Social Work (MSW) from the University of Pittsburgh, and a Bachelor of Arts in Political Science & Economics from St. Vincent College, Latrobe, PA. A recipient of the Cable Ace Award, The Diamond Award, the Freedom of Information Award, the Los Angeles League of Women Voters Public Service Award and the Beacon Award for Cable's Free Air Time Project, he is also a world traveler who has visited 52 countries.

Bill's nephew, Joey, has salt-wasting CAH.



Insurance Alert!

Battling your insurance company can be an enormous challenge, but you can be successful. If you're dealing with an "uncooperative" company, consider:

1. Get help. Your doctor, hospital business office, and employee benefits office can be a lot more powerful than you are. Plus, there's a non-profit group called the Patient Advocate Foundation (www.patientadvocate.org) which employs 72 case managers to help people work out insurance issues.

2. Be persistent. Appeal again and again and again. You may go through three or four levels of appeals before you get a favorable resolution.

3. Use the right words. Certain words will trigger a denial, according to patient advocacy groups. Insurance companies may refuse to pay for surgeries related to cleft lip or palate, saying it's not necessary. For example, when parents appeal because a child needs surgery for "cosmetic" reasons, the appeal often fails. In reconstructive

surgery for CAH, mentioning problems with urination, menstruation, or infection is more likely to be effective.

4. Ask your doctor to try again. Often a tweak in paperwork will change everything.

5. You may need a lawyer. Steps one to four are helpful, but the threat of a lawsuit (with lawyers cc'd) is often the deciding factor.

Our thanks for this information to Elizabeth Cohen, CNN Medical News.

In Sickness and in Health



A sick child often presents parents with conflicts they never imagined, and the resulting turbulence can turn a sunny day into a cloudy one in seconds. Here are a few suggestions, contributed by way too experienced moms and dads, to help avoid stress, pressure and marital difficulties.

- Before a crisis occurs, talk about who will stay home and who will go to work when a child needs 24 hour care. Maybe mom and dad can each work part-time during a child's illness.
- Arrange for back up if mom and dad both need to be working and an unexpected problem occurs. Share the responsibility by discussing each parent's role and responsibilities.
- Be considerate of your wife's or husband's schedule and work demands. Try dividing up childcare responsibilities and reviewing these responsibilities monthly.
- Have an emergency plan in place; base it on location, availability, and time-off policies.
- Think about hiring help. While this is surely an expensive decision, it may well be worth it if parents of a sick child can once again enjoy each other's company!

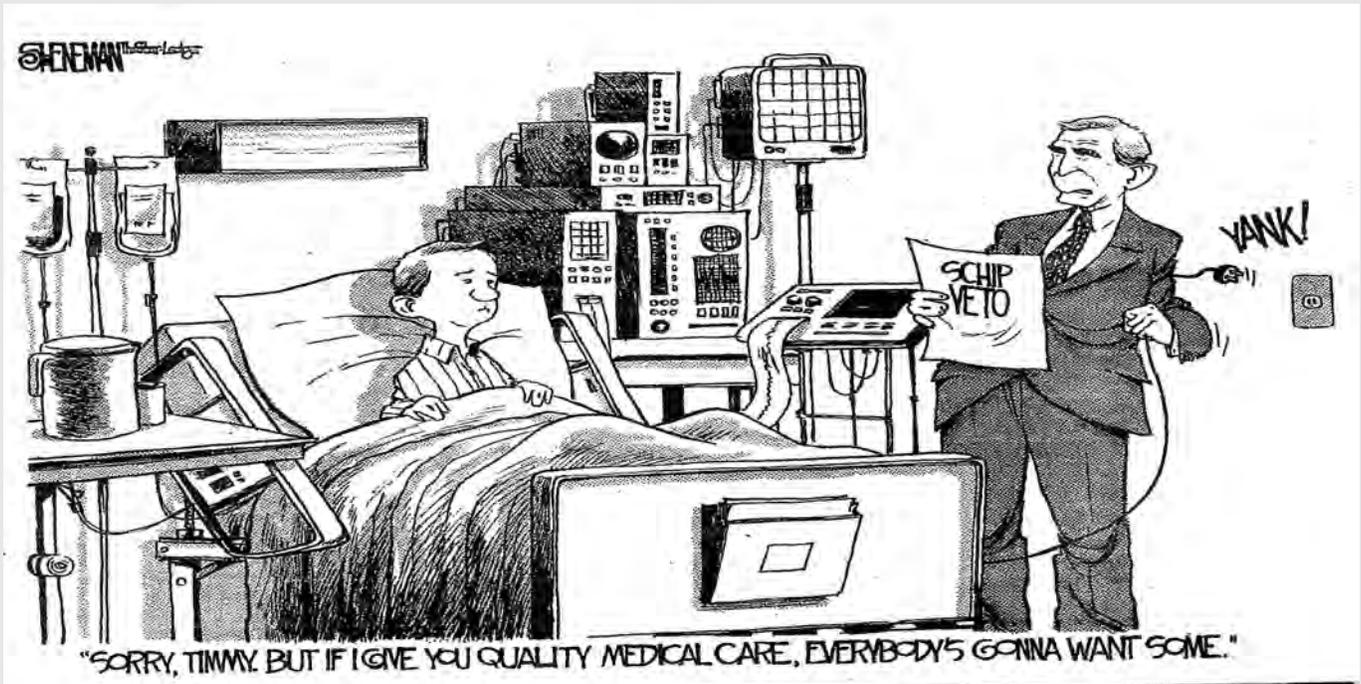
Hike for a Cure Raises \$2700!

When little Wyatt Harper was diagnosed with CAH, his parents, Dawn and Mark Harper of Snoqualmie, WA, turned to the CARES Foundation for support. Enormously appreciative of the help her family received, Dawn Harper and her closest friends, Nan McCutchan and Robin Gray, hiked nearly 40 miles on August 11, 2007 to raise funds for the CARES Foundation's educational and research programs. They raised \$2700.

Wyatt, Dawn is pleased to report, is a healthy, adventurous toddler and she is committed to helping the CARES Foundation continue their outreach efforts.

(Left to right) Robin Gray, Nan McCutchan, Dawn Harper.





Bush Vetoes Health Bill for Kids

On Wednesday, October 3, 2007, President Bush vetoed a bill that would have expanded SCHIP—the State Children's Health Insurance Program which subsidizes health coverage for poor and working-class families—to include an additional 4 million children. Passed by both the House and the Senate, the bill would have been funded by raising the federal excise tax on cigarettes from 39 cents a pack to 61 cents. On October 18, the House failed to override the bill.

Our Federal legislators are currently working to revive this bill. Our kids cannot afford NOT to have healthcare coverage due to their chronic disorder. To advocate for our children, please contact your US Senators and Representatives at www.senate.gov and www.house.gov/writerep.

"Never doubt that a small group of committed citizens can change the world. Indeed, it is the only thing that ever has."—Margaret Mead, anthropologist

Important Info For Residents Of Florida

A new website, www6.bsmv.state.fl.us/dlcheck/findcustomer, is now available through the Department of Highway Safety Motor Vehicles that allows residents to go online and enter two (2) emergency contacts on their Florida Drivers Licenses. The emergency contact information is obtained by law enforcement officials only. If a resident

or a family member is involved in an accident and is unconscious or unable to speak, law enforcement officials may query your driver's license number and obtain your emergency contact information immediately.

Effective October 1, 2006, any child five (5) years or older may be issued a Florida

Identification Card. This will allow your child to be placed in the D.A.V.I.D. program which provides vital information along with a photograph to law enforcement officials having an immediate need for information regarding missing persons, runaways, and abductions.

2007
No-Sweat
Run for a Cure
a virtual event for a real cause

AS OF OCTOBER 5, 2007

FOR MOST MONEY RAISED:

1ST PLACE: 19" LCD HDTV
The Kimura Family—team #1103
raising \$9,818 with 126 donors

2ND PLACE: 3 Piece Designer Luggage
Richard Pendino—team #1224
for his \$5,000 donation

FOR THE MOST NUMBER OF PARTICIPANTS IN THE RACE:

1ST PLACE: Apple Video IPOD
The Racin' Jason team (Lin Family)—team #378
raising \$4,531 with 63 donors

2ND PLACE: David Yurman Earrings
The McLeod Family—team #1359
raising \$1,175 with 30 donors

Our Board of Trustees were also extremely active in this race,
but were ineligible for any prizes.

OUR TOP TWO BOARD TEAMS WERE:

The Upchurch Family—team # 1081 raising \$13,268 with 31 donors
and the
The Abell-Patterson Family—
team #772 raising \$11,000
with 2 donors.

*Jason Lin's team, team
Racin' Jason, collected more
than \$4500 in sponsorships*



A Race to the Finish!

The “non-event” was a smashing success due to the incredible support from more than 100 CARES families who participated. As of this writing, this event has raised over \$87,500! This is the first time we have undertaken a campaign like this and we are thrilled with the financial support for the CAH community.

Thank you to everyone who contributed their money and their time sending out invitations, letters, emails, and making phone calls. Special thanks to the Lin and Harper families who went “one step further” by organizing a walk and a hike respectively.

All of our prizes were generously donated. Thank you to Kelly & Adam Leight for the LCD HDTV; Marj & Steve Bromberg for the designer luggage, Meryl Stone & Michael Cohen for the Video IPOD, and Wilson Jewelers, Scarsdale & Mt. Kisco, NY for the David Yurman earrings.

We plan to make this an annual event and we hope we get even more families involved in the future. If you have any ideas on how we can improve this campaign, please contact Meryl at meryl@caresfoundation.org or call her, toll-free, at 866-227-3737.

Mazel Tov to Joey Feldbaum and his family on his Bar Mitzvah planned for November 17. Joey chose this event as his social action project, and raised over \$1,000, with more checks arriving each day.

Hypertension in Children with 21-Hydroxylase Deficiency

Todd D. Nebesio, M.D.

*Department of Pediatrics,
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Hypertension is the medical term for elevated blood pressure. Until recently, few reports have attempted to characterize and describe hypertension in children with congenital adrenal hyperplasia (CAH) due to 21-hydroxylase deficiency (21OHD). Unlike other forms of CAH, such as 11-hydroxylase or 17-hydroxylase deficiencies, hypertension is not typically mentioned in discussions about 21OHD. However, there are several aspects of 21OHD that may impact blood pressure.

Children with the salt-wasting form of 21OHD are treated with salt in infancy as well as both a mineralocorticoid and glucocorticoid throughout life. Depending on the dose, either of these medicines may potentially cause hypertension (1). Excessive amounts of mineralocorticoid, such as fludrocortisone, may result in hypertension due to salt and fluid retention. If this occurs, a reduction in the dose of mineralocorticoid will often normalize the blood pressure. Excessive amounts of glucocorticoids, such as hydrocortisone, prednisone, or dexamethasone, may also result in hypertension along with many other unwanted side effects, such as growth suppression, bone disease, and weight gain. However, undertreatment with glucocorticoids may result in excessive

male hormone production, which leads to bone age advancement and short stature as an adult. The goal in CAH is to give the minimum dose of glucocorticoid needed to adequately suppress the adrenal glands while avoiding the negative consequences of overtreatment.

*It is well known
that patients with
21OHD are at risk
for increased
weight gain and
the development
of obesity.*

In all children as well as adults, the percentage of those who are overweight in the United States has increased significantly over the last several years (2). If a child is overweight, there is a high likelihood that they will also be overweight as an adult. Similarly, a higher blood pressure in childhood is predictive of hypertension in early adulthood (3). There is a significant association between body mass index (BMI) and blood pressure in all childhood age groups (4). In other words, with an increasing BMI, there is a significant

increase in blood pressure. Therefore, healthy lifestyle choices and regular exercise are important for all children in order to avoid complications associated with obesity, such as hypertension.

BMI is a calculated number which allows one to determine if a person is or at-risk for being overweight or obese. BMI is affected by height, weight, and body composition. Currently, those children with a BMI between the 85th to 95th percentile for age are classified as “at-risk for overweight” and those with a BMI > 95th percentile for age are classified as “overweight”. New pediatric obesity guidelines presented at the 2007 Endocrine Society in Toronto will soon be published. Among the guideline’s new recommendations include changing the old terminology of “at-risk for overweight” to “overweight” and the previous term of “overweight” to “obese” (5).

It is well known that patients with 21OHD are at risk for increased weight gain and the development of obesity. Even in children with 21OHD who are medically well controlled, their BMI tends to increase throughout childhood, which is predominately a result of weight gain due to increased fat mass (6). In one study of 89 children and adolescents with CAH, it was noted that children and adolescents with 21OHD have a higher risk of obesity. Interestingly, glucocorticoid dose, chronological age, advanced bone age maturation, and parental obesity all positively correlated with an elevated BMI. However, the type or form of

glucocorticoid as well as the dose of fludrocortisone were not associated with obesity (7). Researchers have attempted to implement alternative medical regimens in the treatment of CAH to decrease the daily glucocorticoid dose so as to avoid complications of overtreatment, such as obesity. Such regimens include bilateral adrenalectomy (8), the use of anti-androgens and aromatase inhibitors (9), and most recently the use of calcium channel blockers (10). Many of these strategies are experimental and still being studied.

There have been a few prospective studies investigating blood pressure profiles in children and adolescents with 21OHD. In the first study which looked at 38 children from the United Kingdom, the majority had elevated blood pressures as well as loss of the normal, physiologic overnight drop in blood pressure. Blood pressure measurements were not related to laboratory markers of CAH control, such as 17-OHP, androstenedione, or renin. However, hypertension was associated with an elevated BMI, particularly in females (11). In a second study looking at 11 children from Australia, prolonged glucocorticoid treatment was not associated with hypertension (12). In a third study looking at 55 children from Germany, elevated blood pressure was correlated with the degree of overweight and obesity (13). As in the previous studies, there was no correlation between blood pressure and renin levels, which suggests that an excessive dose of mineralocorticoid was not the reason for hypertension.

Recently, we sought to categorize the prevalence of hypertension in our CAH patient population at Riley Hospital for Children in Indianapolis, Indiana (14).

We defined hypertension based on reference values for age and gender, and each child had to be on an anti-hypertensive medication and under the care of a blood pressure specialist. Over the last 20 years, we identified 91 children (54% female) with CAH due to 21OHD. Overall, 6.6% of the children were found to have hypertension. Of these 6 children, one had hypertension as a result of acute renal failure after presenting in an adrenal crisis and shock. Therefore, 5 children or 5.5% had essential hypertension, which means that no identifiable cause for the elevated blood pressure was identified. Three children had salt-wasting CAH, and none had a suppressed renin level at the time of diagnosis of hypertension. Family history for blood pressure problems was negative in all children with 21OHD and hypertension.

We hypothesized that an elevated BMI would be predictive of those who had hypertension. Interestingly, this was not the case. Only one child with essential hypertension had an elevated BMI (Body Mass Index) at the 95th percentile for age. In those children with 21OHD and hypertension, 40% were at risk for overweight and 20% were overweight. In those children with 21OHD and no hypertension, 16% were at risk for overweight and 48% were overweight. Although there were more children with a BMI > 95th percentile for age who were not hypertensive, the difference between the two groups was not statistically significant (14).

In the general population of healthy children, the overall prevalence of hypertension is around 1% (15-17). A more recent study examined the prevalence of hypertension in a

pediatric population where 20% of children were overweight. In this heavier population, the prevalence of hypertension was 4.5% (18). In our study of infants, children, and adolescents with 21OHD, we found an even higher prevalence of hypertension (14). One needs to consider that it is often difficult to measure blood pressure accurately in children in an outpatient clinic environment. However, in children with CAH, other studies have shown that blood pressures obtained in outpatient subspecialty clinics are an accurate and reliable method to detect tendencies of blood pressure elevations (19). It is not clear why our patients had an increased prevalence of hypertension. Animal research suggests that ACTH or abnormalities in glucocorticoid metabolism may contribute to some forms of essential hypertension (20), but additional studies in children with 21OHD are needed.

In conclusion, children with 21OHD are at an increased risk for the development of hypertension. Excessive amounts of mineralocorticoid and glucocorticoids should be ruled out as the cause of elevated blood pressure. Obesity is also prevalent in children and adolescents with 21OHD. Therefore, healthy lifestyle choices and daily exercise are important to decrease the development of complications associated with increased weight gain, including hypertension. However, other undefined factors besides obesity may be at fault for the increased prevalence of hypertension in children and adolescents with 21OHD. This is definitely an area in which more investigation is needed! 

References omitted due to space constraints. Available upon request.

Adverse Effects Of Prenatal Dexamethasone: The Evidence Is Inconclusive

Submitted by Heino F. L. Meyer-Bahlburg, Dr. rer. nat., NYS Psychiatric Institute & Columbia University, and Maria I. New, Mt. Sinai School of Medicine, New York, NY. E-mail: meyerb@childpsych.columbia.edu

Through the phrasing of their paper title and conclusions, Hirvikoski et al. (1) posit as definitive that “prenatal dexamethasone treatment of children at risk for congenital adrenal hyperplasia [adversely] affects cognitive functions”. We certainly welcome that the Swedish team has provided follow-up data on cognitive function in this under-researched area, but the data do not justify their conclusions.

In the absence of randomized clinical trials, the best investigative approach would be a prospective case-control study involving blinded assessments and comparing separately short-term and long-term prenatal dexamethasone treated children to demographically similar non-treated children of the same sex and condition (CAH-affected versus -unaffected), and with comparable participation-refusal rates, all factors to which behavioral outcome data are much more sensitive than endocrinological data. The present study, however, did not use blinded assessments, had no CAH-affected children among the controls, and only 3 long-term treated children, i.e., CAH girls, in the treated group who could not be analyzed by themselves and are grouped with the short-term treated CAH boys (plus one CAH girl who could not be tested because of “low intellectual performance” and only entered group comparisons involving

parent-report data). Moreover, the controls came from two different sources and differed markedly from the dexamethasone-treated group in urban-rural background and in participation-refusal rates. Breaking down the treatment sample into even smaller subsamples is likely to create additional disparities, which should be checked and reported. All of this raises unanswerable questions of sample comparability.



In addition, given the recent publication of a Scandinavian study (2) on impaired intelligence in CAH children, the question arises whether the data showing marginally ($p < .08$) impaired full-scale IQ in the dexamethasone-exposed group reflected CAH effects rather than dexamethasone effects, which in turn might account for some of the significant effects on specific neuropsychological tests.

Another problem is that several of the effects were significant for the comparison of CAH-unaffected short-term dexamethasone-treated children to controls, but not for the CAH-affected dexamethasone-treated children, although the latter combined the short-term treated CAH boys with the long-term treated CAH girls. This is not

only a question of statistical power. For instance, anxiety means for treated unaffected children were shown to be above the means of controls on all 4 scales while the anxiety means for affected children were below those of controls on 3 of the 4 scales. Thus, short-term exposure to dexamethasone during a very early phase of brain differentiation has adverse effects, but long-term exposure from very early through late fetal development is not adverse or even beneficial? This interpretation seems less plausible than confounding effects from inadvertent differences between comparison groups in demographic, sex, and/or disease characteristics. (Unfortunately, the data for the other tests are not reported by subgroup so that one cannot check on the consistency of those findings.)

It would therefore seem premature to make this Swedish study the basis for depriving CAH girls of a prenatal treatment that has very beneficial effects on their genital development and reduces or abolishes the need for genital surgery.



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MORE SUPPORT GROUPS NEEDED!

We need volunteers to help run support groups in the following states:

Hawaii
Massachusetts
Montana
New Hampshire
North Dakota

Rhode Island
South Dakota
Washington
Wyoming

Please contact Gretchen at
gretchen@caresfoundation.org
or (toll free) 866-227-3737
for more information



PICNIC IN THE PARK

A great time was had by all at The 4th Annual Northern California CAH support group picnic, held Sunday, September 16th at Micke Grove Park in Lodi, CA. Many thanks to the organizers, Adria Stoner, Russ and Dina Stoddart and Alesia Pinson.

The most popular gathering places were the playground the Japanese Garden, the zoo, and the museum. And the potluck policy was a total success!



Classical Women's Group

A place for women with classical CAH to talk about the issues that affect them. To join, send an email to <http://health.groups.yahoo.com/group/classicalwomen/>

CAHSisters2

A place for adult women with late-onset CAH. To learn more about this group, go to <http://groups.yahoo.com/group/CAHSISTERS2>.

CARES Spanish Group

A Yahoo Group for the Spanish-speaking CAH community. To learn more and join, go to <http://mx.groups.yahoo.com/group/hiperplasia/>

Greek CAH Groups

Places for Greek speaking families and individuals affected by CAH. To learn more and join, visit <http://groups.yahoo.com/group/cabgreece> and <http://groups.msn.com/cabgreece>



Attention Support Group Leaders!

Send us your photos, updates and event announcements. We will publish them in the next newsletter as well as on the CARES Foundation website.

Please contact Kelly at 866- 227- 3737 or kelly@caresfoundation.org

WOMEN HELPING WOMEN

Would you be willing to help women with CAH by coordinating a support group?

Share information and empower adult women as they conquer CAH. Please contact Kelly for more information at 866-227-3737 or kelly@caresfoundation.org.

EVERY NEWBORN IN THE UNITED STATES TO BE TESTED FOR CAH BY JULY 2008!

Victory in Arkansas and Across the Nation!

On July 11, 2007, the Arkansas Department of Health publicly committed to expanded newborn screening including testing for CAH by July 2008. A huge day for families across the nation, CARES member Gail Blucker appeared on the evening news to share the story of her SWCAH-affected granddaughter and to congratulate the state on making a dream reality: As of July 2008, every baby born in the United States will be tested for CAH at birth. Thank you Gail as well as Governor Mike Beebe, the Arkansas Board of Health, the Arkansas Department of Health and other advocates who worked so hard on this initiative.

Canada Nearly Halfway There

Alberta started screening for CAH in April and British Columbia plans to start soon. Joining those already screening for CAH (Manitoba, North West Territories, the western part of Nunavut and Ontario), now five and a half of the 13 provinces have committed to expanded newborn screening including testing for CAH. If you live in a province that does not currently screen for CAH and would like to join CARES in advocating for expanded newborn screening in Canada, please contact Gretchen Alger Lin at gretchen@caresfoundation.org



*On July 11, 2007,
the Arkansas Department
of Health publicly
committed to expanded
newborn screening
including testing
for CAH by July 2008.*

List of Countries Where CAH Newborn Screening is Available

- ARGENTINA
- AUSTRIA
- BELARUS
- BELGIUM
- BRAZIL
- CANADA
- CHILE
- CHINA
- COLOMBIA
- COSTA RICA
- FRANCE
- GERMANY
- GREECE
- INDIA
- ITALY
- KOREA, REPUBLIC OF
- LUXEMBOURG
- MACEDONIA
- MEXICO
- NETHERLANDS
- NEW ZEALAND
- PHILIPPINES
- PORTUGAL
- RUSSIAN FEDERATION
- SAUDI ARABIA
- SPAIN
- SWEDEN
- SWITZERLAND
- TAIWAN
- THAILAND
- UNITED ARAB EMIRATES
- UNITED KINGDOM
- UNITED STATES
- URUGUAY
- EQUADOR
- GUATAMALA
- ISRAEL
- LIBYA
- PERU
- QATAR
- SOUTH AFRICA

Source: Perkin Elmer

**Newborn Screening
Worldwide**

**WE NEED
YOUR HELP**

While we are celebrating victories for babies across North America, the fate of newborns affected by CAH around the globe remains ominous. Testing is available in 39 countries outside of the United States and Canada with Saudi Arabia being the most recent to begin CAH newborn screening. Screening is being done under a pilot program in Finland and a similar program is in the works for 2008 in Denmark and possibly Australia. Mandated testing for CAH however remains uncommon and often is not universally available even in those countries where testing has begun. For example, in Brazil, only the private sector is offering testing and in the United Kingdom, every infant is not being screened for CAH at birth, nor does the government require it. The time has come to change this. CARES is working on an advocacy plan for these countries: reaching out to our members, professionals and other advocacy organizations. If you would like to join us in our efforts, please contact Gretchen Alger Lin at gretchen@caresfoundation.org

**MAKE SURE YOUR FAMILY IS PROTECTED
AGAINST GENETIC DISCRIMINATION,
TELL THE SENATE TO TAKE ACTION
ON GINA NOW!**

As a part of CARES Foundation's continual advocacy efforts, over the past several months CARES Foundation and our members have been working on initiatives related to the Genetic Information Nondiscrimination Act of 2007 (GINA) and funding for the NIH and State Children's Health Insurance Program (S-CHIP).

WHAT IS GINA?

The Genetic Information Non-discrimination Act of 2007, (S.358) is a bill that will prohibit discrimination on the basis of genetic information by health insurers and employers. (see <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:SN00358:@@D&summ2=m&> for a summary) For 12 years, the United States government has been trying to pass legislation making discrimination based on genetic information illegal.

**HOW DOES GENETIC
DISCRIMINATION AFFECT PEOPLE
WITH CAH?**

Genetic testing is particularly important in families with a history of CAH. Testing in the parents allows for early detection and treatment in the child. However, some people may fear discrimination by health insurers and avoid testing for CAH. The Genetic Non-Discrimination Act of 2007 would prevent insurers from dropping coverage or charging higher rates for families known to carry

mutations for CAH. It also would prohibit employers from making decisions related to hiring, firing, promotions or training based on your CAH status.

WHAT CAN YOU DO?

Right now, GINA is waiting to be brought to the Senate floor for a vote. Legislation like GINA has been introduced again and again over the past 12 years and never passed. It has been approved by the House; we just need the full Senate to vote on the bill to get it to the President's desk! Tell your Senator to help bring GINA to the floor for a vote immediately. Go to www.senate.gov to contact your senator.

Pass it on! Tell your friends, family, coworkers, and other CARES members to take action now. We must make a big impact on this issue, and if every senator is contacted multiple times, we can make it happen!

NIH BUDGET

As an orphan disease, there is very little money available for research for better treatments and eventually a cure for CAH. Without proper funding of the National Institutes of Health, much of the research that is being done on CAH will suffer. Unfortunately, presidential budget requests over the past few years have continually fallen short of prior budgets thereby threatening the very research vital to our community.

STUDY TO TEST INSULIN PUMP USE IN CAH

The purpose of this study is to develop a more physiological approach to the management of children and adolescents with salt wasting Congenital Adrenal Hyperplasia.

The glucocorticosteroid will be administered via insulin infusion pump to see whether this treatment will improve the serum hormone concentrations. In this study, researchers will try to imitate the body's normal hormone production and will give the medication via an insulin pump to see if this treatment method will decrease the male hormones in the blood. This study will help to develop a new and better treatment for children and adolescents.

The study will take place at Texas Children's Hospital Clinic and General Clinical Research Center, Houston, Texas and is open to children with SWCAH, ages 3-18.

If interested in learning more or participating, please contact :

Andrea E Balazs, MD • 832-822-3773

aebalazs@texaschildrenshospital.org

PRENATAL DIAGNOSIS RESEARCH PROJECT TO TARGET WHICH WOMEN SHOULD TAKE DEXAMETHASONE DURING PREGNANCY

We are seeking the help of couples at risk for having an affected child with congenital adrenal hyperplasia to participate in a research project in Boston. As you know, some pregnant women are offered the opportunity to take dexamethasone early in pregnancy to reduce the risk of masculinization of a female fetus affected with congenital adrenal hyperplasia (CAH). The problem is that only 1 in 8 fetuses will be female AND affected, so 7 out of 8 possible fetuses will receive unnecessary treatment. Steroids, while effective, do cause side effects in pregnant women and some children. Our research aims to target dexamethasone treatment to only female fetuses at high risk of having CAH.

The purpose of this research study is to develop a simple prenatal test that will use blood samples from a pregnant woman and her partner. The pregnant woman's blood will be used to determine if the fetus is male or female using cellfree fetal DNA testing. This can be done as early

as 7 weeks following the first day of the last menstrual period. If both parents have different mutations, the partner's blood will be used to test for the presence of his mutation in the pregnant woman's blood, which was inherited by the fetus.

Please note that this is a research study. In the first phase of the study, we cannot release results of fetal gender testing to you. Thus, the results will not affect your clinical care. However, if we get enough patients enrolled, and our study is accurate, our hope is that in the near future this will transition to early fetal gender diagnosis that can be used clinically. The study involves 1-2 blood samples from the pregnant woman and 1 sample from her partner. There is no travel required. We will arrange to have the blood drawn in your hometown.

To find out more information about participating, please contact Helene Stroh Hstrob@tufts-nemc.org or Diana Bianchi, M.D. Dbianchi@tufts-nemc.org

AN INVITATION to participate in a study on mothers of babies with a genetic anomaly or birth defect

Hello! I am a PhD student studying maternal adaptation in women who have given birth to babies who were diagnosed prenatally with a genetic anomaly or birth defect. I need at least 100 mothers 18 years or older to fill out a research questionnaire. This online questionnaire should take approximately 30 to 40 minutes to complete.

If you would be willing to participate, please visit the following website to connect to the survey and get further directions: www.surveymonkey.com/s.aspx?sm=AnmUvT_8gwV7uEUcK1o36fQ_3d_3d

The information that is learned from this study may help us design better nursing care and support for mothers who have babies with a genetic anomaly or birth defect, and their babies.

If you have any questions or need more information after completing the survey, please contact Cynthia M. Little, RNC, MSN, WHNP, School of Nursing, Virginia Commonwealth University at littlecl@vcu.edu. Thank you for considering the invitation to complete this survey.

**In Memoriam:
Daniel Gunther, MD**



Dr. Daniel Gunther passed away unexpectedly on September 30, 2007 at the age of 49. He was a founding member of the CARES Foundation Scientific and Medical Advisory Board. Dr. Gunther was a kind, thoughtful man and dedicated physician. He cared deeply for his patients, going the extra mile to make sure that his patients received the best quality care. He was always available to CARES Foundation staff and its members, often calling members in distant places who were not his patients to offer support and guidance when asked.

Dr. Gunther was born Feb. 21, 1958 in Washington, DC, and grew up in southern California. In 1980 he graduated from University of California Santa Barbara with a BA. After serving in the US Army for 3 years, he received an MA in Educational Psychology from University of California, Berkeley in 1986. Dan then graduated from University of California Davis School of Medicine in 1992. He received specialty training in Pediatrics from University of Rochester, New York, completed in 1995. His Fellowship in Pediatric Endocrinology was at University of North Carolina, Chapel Hill, completed in 1998. At the time of his death, Dan was Associate Professor at University of Washington School of Medicine and was an Attending Physician, Pediatric Endocrinology, Children's Hospital and Regional Medical Center in Seattle, since 1998.

Dr. Gunther leaves behind a large, loving family: his father and father's wife, eight siblings and many nieces and nephews. May he rest in peace.



Weight Loss Through Video Games?

Using a video game to help children increase their activity level and lose weight may seem a bit unusual, but West Virginia University and the West Virginia Public Employees Insurance Agency have paired together to study the benefits to children using the video game Dance Dance Revolution (DDR) to increase activity. DDR is distributed by Konami Digital Entertainment America and consists of a game console, dance pad and software. The player moves his or her feet following a video screen pattern, dancing in time with the rhythm of the music. The game comes in a home version which includes a workout mode that can track the number of calories burned, while maintaining the fun aspect of a video game.

Other academic institutions including Syracuse University and Pennsylvania State University are studying additional physiological effects of children using the game. We'll keep you posted.

**CONGRATULATIONS
& THANK YOU TO
CHRISTINE AND DANNY!**

Wedding bells rang for Danny and Christine Stevens on August 11, 2007 in Colorado Springs, Colorado. Christine has two nephews with CAH, so the couple decided to honor them by making a donation to CARES in lieu of wedding favors for their guests. A rolled vellum card was placed at each table setting, as a favor would be placed. The card read:

Danny & Christine

August 11, 2007

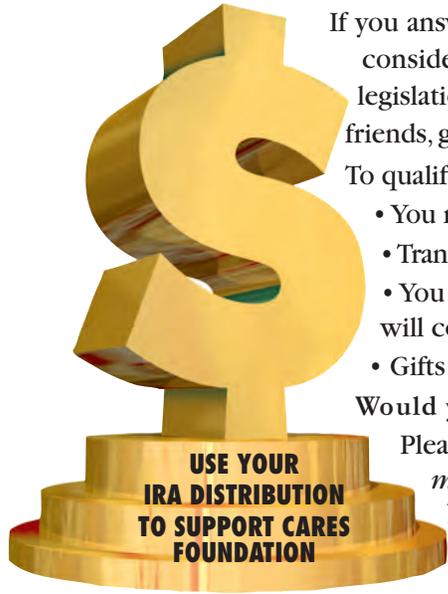
*Thank you for being part of
our lives and our wedding day.*

*In honor and appreciation of our guests,
we have made a contribution
to CARES Foundation.*

The bridal couple now resides in Astoria, New York. We thank them for their generosity and wish them health and happiness as they begin their new life together.



**ARE YOU PLANNING TO TAKE YOUR 2007 REQUIRED IRA DISTRIBUTION?
WOULD YOU LIKE TO SUPPORT CARES FOUNDATION'S PROGRAMS?**



If you answered "yes" to both of these questions, you may wish to consider special opportunities created by recent pension legislation using your IRA funds to make gifts. For many of our friends, gifts from IRAs provide extra benefits.

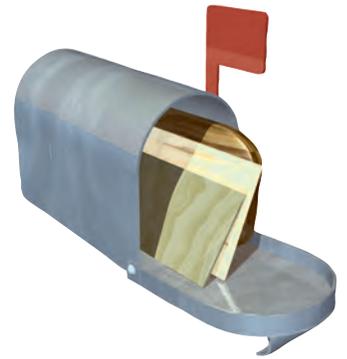
To qualify:

- You must be 70 1/2 or older at the time of the gift.
- Transfers must go directly from the IRA to CARES Foundation.
- You can make gifts up to \$100,000 per taxpayer and the gift will count toward the required minimum distribution.
- Gifts must be outright.

Would you like to know more?

Please contact us today toll-free at 866-227-3737 or meryl@caresfoundation.org to find out how you can benefit from this special opportunity, which may be available only in 2007.

CARES Foundation, Inc. is a not-for profit, 501(c)(3) organization.



Moving right along...

Have you recently moved, or changed your contact information? Please notify Meryl at the CARES office

so we can continue communicating! Office: (toll-free) 866-227-3737

or email:

meryl@caresfoundation.org

CARES Foundation, Inc.
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