

FAN Conference Call

June 16, 2010 4:00 pm -5:00 pm EDT

Led by:

EMSC National Resource Center
8737 Colesville Road, Suite 400
Silver Spring, MD 20910
202-476-4927

www.childrensnational.org/emsc

Participating Grantees:

Debbie Brown, CARES Foundation
Petra Connel, VA
Julie Eckerson
Joe Hansen, MT
Elaine Hime, TX
Mark Johnson, AK
Cynthiana Lightfoot, DC
Raj Maskay, AK
Greg Natsch, MO
Jean Rickerson, WA
Pat Tucker, ID
Lisa Ward, CO
Donna Westlake, CA
Myra Wood

NRC Staff: Jocelyn Hulbert, Gayathri Jayawardena, Theresa Morrison-Quinata, and Ian Weston

CARES FOUNDATION

Debbie Brown, RN, discussed the purpose and goals of the CARES Foundation, a nonprofit organization committed to improving the lives of families and individuals affected by Congenital Adrenal Hyperplasia (CAH). Recently, the EMSC National Resource Center entered in to a collaboration with the Foundation to help educate EMS agencies about the critical and timely importance of treating CAH patients with the appropriate medication while in route to the hospital. The Foundation hopes to move this initiative forward, in part, by revising EMS protocols to ensure EMS providers are educated about the disease and the implications of delayed medication.

What is adrenal insufficiency?

A group of conditions whereby affected individual's adrenal glands do not produce an enzyme called 21-hydroxylase. Without this enzyme, the adrenal glands are unable to produce cortisol, a hormone necessary for life.

Cortisol is a steroid produced by the adrenal glands that our bodies need to: (1) deal with physical and emotional stress and (2) maintain adequate energy supply and blood sugar levels.

Adrenal insufficiencies include (but are not limited to):

- Congenital Adrenal Hyperplasia (CAH)
- Addison's Disease
- Patients with pituitary gland problems, including growth hormone deficiency, tumor, ACTH deficiency due to pituitary tumor or trauma
- Patients that are on long-term steroids for other conditions such as rheumatoid arthritis and organ transplant recipients

Nearly 1 in 1,500 people suffer from adrenal insufficiency. Classical Congenital Adrenal Hyperplasia is a potentially life-threatening condition characterized by insufficient cortisol and aldosterone production coupled with androgen excess.

- Autosomal recessive genetic disorder
- Affects males and females equally
- Before about 1950, there was no medical treatment for CAH
- Every child born in the United States is tested for CAH at birth!
- No cure for CAH at the present time

CAH-affected individuals are always at risk of adrenal crisis, which requires the immediate administration of glucocorticoids in a timely manner. A treatment option for those with an adrenal crisis is to use an injectable hydrocortisone known as Solu-Cortef®.

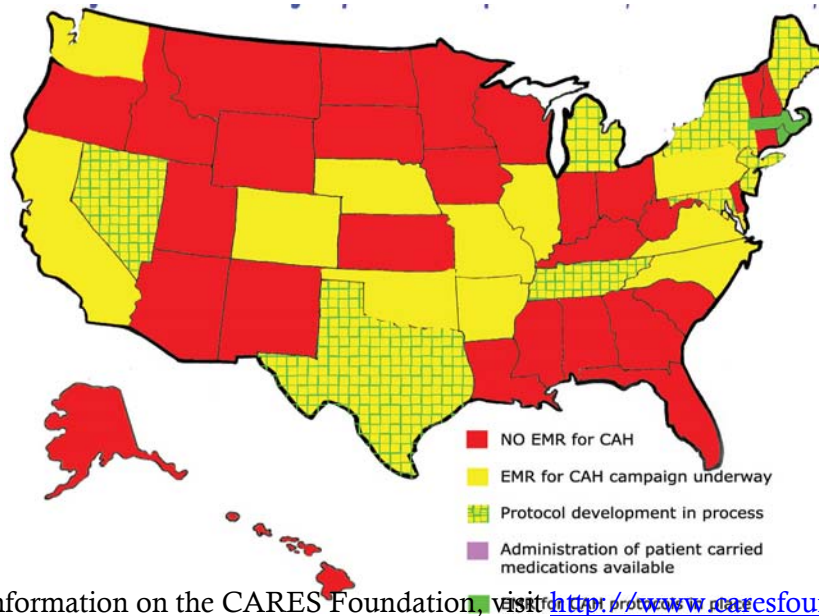
An adrenal crisis can be brought upon by many factors, such as: infection, a virus, a fracture, traumatic injury and surgery. Signs of adrenal crisis may include dizziness, headaches, lethargy, abdominal pain, vomiting, nausea, hypoglycemia, hypotension, shock, heart failure and possible death.

The CARES Foundation is not asking prehospital providers to diagnose children with an adrenal crisis but rather enhance an identification process either through a medical piece of jewelry or through a family member that can ensure the patient receives the best appropriate care.

The Foundation recommends that all individuals with CAH or any form of adrenal insufficiency carry some type of medical identifier to alert emergency responders; in addition to carry a letter from their physicians when traveling. Families are also asked to carry an injection, which has a long shelf life.

How has EMSC assisted in the campaign?

Prior to 2008, not a single state in the country had protocols in place to address adrenal insufficiency in the prehospital setting. In Spring of 2008, Rhode Island became the first state in the nation to add Solu-Cortef® to their formulary and put adrenal insufficiency treatment protocols in place. By the end of 2008, the CARES Foundation had begun campaigns in New York and Nevada. In 2009, CARES presented their appeal at the EMSC Annual Program Meeting held in Washington, DC. Today, adrenal insufficiency protocols are in place in Rhode Island, Massachusetts, and parts of New York and Texas.



For more information on the CARES Foundation, visit <http://www.caresfoundation.org>.

GENERAL FEDERATION OF WOMEN’S CLUBS

Founded in 1890, the General Federation of Women's Clubs (GFWC) is one of the world's largest and oldest nonpartisan, nondenominational women's volunteer service organizations. Since 2002, GFWC has worked with the Wisconsin EMSC program to fund the development and distribution of Pediatric Jump Kit bags for ambulances.

The EMSC National Resource Center encourages program grantees to partner with their local GFWC chapters. Several states have already begun forming partnerships, including Arizona, Indiana, Florida, Illinois, Michigan, North Carolina, and Wyoming. In August, the EMSC Program will be providing more information on this partnership for State program managers and FAN members.

For more information on the global mission and local chapters, visit: <http://www.gfwc.org/gfwc/default.asp?SnID=964740991>.

PAT TUCKER

On August 15, 2002, Pat Tucker’s 11-year-old daughter, Cady, was involved in a head-on motor vehicle crash. The other vehicle was being driven by an out of control diabetic. An LPN with an expired license happened to be at the scene of the accident. When the responding unit arrived, the LPN told the EMT that Cady was gone. The EMT immediately turned away without providing any care or assessment.

Overwhelmed with grief and disappointment, Pat began an education campaign to teach others about the importance of seatbelt and driver safety. In 2009, Pat pushed for legislation which was passed in Montana that assured that unintoxicated drivers that are a danger to other citizens on the road be held accountable for their actions. In addition, Pat wanted to ensure that every child trauma victim received at least five minutes of emergency care for a final chance. Pat continues to promote “at least five minutes” because four minutes is where permanent brain damage can begin to set in if there isn’t a flow of oxygen to the brain. This may allow for chest compression, CPR, AED action, etc.

Pat would like the EMSC Program to build bridges, network, and increase communication to assure that every child is granted at least five minutes of immediated medical care and assessment. She also would like to push for every adult to be CPR-AED trained.

COMMENTS

Based on a recent SurveyMonkey results, most FAN members preferred conference calls to occur on Wednesdays between noon and 3:00 pm EDT/EST.