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## CARES Foundation: An EMSC National Resource Center Interview with Suzanne Levy

### Inside this Issue

#### Page 2

Program News: FAN Updates in District, VA, and WI

#### Page 4

Catalyst Center Provides Financing Options for CYSHCN

National Infant Immunization Week

#### Page 5

FAN Education and Networking Opps

Earlier Vaccinations Could Reduce Cases of Whooping Cough

In 2008, the Emergency Medical Services for Children (EMSC) National Resource Center (NRC) interviewed Suzanne Levy, acting executive director of CARES Foundation, to learn more about how and why the foundation was established.

In 2000, founders Kelly and Adam Leight's child was diagnosed with non-classical Congenital Adrenal Hyperplasia (NCAH), a family of inherited disorders affecting the adrenal glands. The most common form of Congenital Adrenal Hyperplasia (CAH) is 21-hydroxylase deficiency (21-OHD), which is inherited in severe or mild forms. The severe form, called Classical CAH, is usually detected in the newborn period or in early childhood. The milder form, called NCAH, may



Suzanne Levy

cause symptoms at anytime from infancy through adulthood. NCAH is a much more common disorder than Classical CAH. CAH is potentially life threatening if not identified, treated, and managed with the required medication.

As the Leights searched for information about CAH, they discovered that a centralized location for families to share and learn more about the disease did not exist and the non-endocrine medical community lacked resources and guidance. Recognizing the lack of centralized coordination, the Leights decided to create CARES (Congenital Adrenal Hyperplasia Research & Education Support) Foundation.

*Continued on page 4*

## Senate Appropriations Committee Chairman Steps Down, Daniel Inouye Successor

In December 2008, Senator Robert Byrd (D-WV) announced that he would step down as chairman of the Senate Appropriations Committee in the 111th Congress, which began January 2009. He served as committee chairman for the last 10 years. Senator Daniel Inouye (D-HI) is the new

committee chairman. Recall that Senator Inouye spearheaded the efforts to establish the EMSC Program in 1984 and is the sponsor of S 60, which will reauthorize the federal EMSC Program.

*Continued on page 4*



### DC Recruits Third Family Representative

In December 2008, the District of Columbia EMSC Program recruited its third family representative, Doreen Hodges. Doreen's son "King" Titus was born with [Down Syndrome](#) and, at age 4, was diagnosed with [Pervasive Developmental Disorder \(PDD\)](#).



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*FAN Mail* is a publication of the EMSC National Resource Center, located in Silver Spring, MD.

*FAN Mail* is distributed quarterly to an alliance of family representatives from states, territories, and the District of Columbia who actively support state emergency medical services for children (EMSC) program initiatives. The Federal EMSC Program is supported by the Health Resources and Services Administration's Maternal and Child Health Bureau. FAN members work with their state EMSC managers to ensure that family-centered care (FCC) is incorporated into prehospital and hospital healthcare systems across the nation.

Family representatives may contact the EMSC National Resource Center for FCC-related resources to excel in their leadership roles and to guide in their efforts to implement FCC in their area.

*FAN Mail* welcomes articles on people, programs, and activities related to family representative participation in emergency medical care of children activities. All manuscripts, artwork, and photography should be submitted to Therese Morrison-Quinata at [tmquinat@cnmc.org](mailto:tmquinat@cnmc.org).

Titus learned to communicate using American Sign Language (ASL). However, he often became frustrated with the inability of others to understand ASL. Later, Titus began to exhibit multiple behavior problems in school. Out of concern for her son's welfare, Doreen decided to home school Titus in August 2004 and resigned from her job as a legal secretary. This, however, left Doreen's family without medical insurance to cover Titus' growing healthcare needs.

Through research, Doreen learned about the Children's Health Insurance Program (CHIP), DC Healthy Families. She was elated to learn that Titus qualified for coverage under the program regardless of his disabilities. After homeschooling Titus for two years, Doreen and her husband returned to the workforce and found an employer that offered partial insurance benefits for Titus. Whatever is not covered through the employer-based plan, is paid through the CHIP Program.

Doreen is now the executive director for Family Voices of DC, a local chapter of a national grassroots network of families and friends, advocating for health care services for children and youth with special health care needs and/or disabilities.

CHIP is a combination of Medicaid and the State Children's Health Insurance Program (SCHIP) and is open to families with incomes up to twice the poverty level and to children and pregnant women with income up to three times the poverty level.

Family Voices of DC is a federally funded project managed by the Family-to-Family Healthcare Information Center (F2FHIC). F2FHIC offers information, training, support, resources, and options for informed decision-making by families of children and youth with special health care needs and the professionals who serve them.

**American Samoa Welcomes New Family Rep**  
Mary Taufete, a long time supporter of EMSC, is now the program's family representative in American

*Continued on page 3*

## Program News, from page 2...

Samoa. Mary currently chairs the EMSC Advisory Committee, is an elected legislative official, and a child advocate always seeking opportunities to improve services to children and youth in American Samoa. Welcome aboard Mary!



ceived many accolades and awards, including the 2006 EMSC National Heroes Award for Community Partnership. GFWC clubs in North Carolina and Florida have replicated the project, with clubs in other states requesting project start-up information.

In 2006, the Wisconsin state chapter of GFWC selected the Pediatric Jump Kit bags as its state project, and appointed Elizabeth as the project chairman. All Junior Women's clubs within the state were asked to work with an EMS department to fund and equip its ambulances with the pediatric bags. As project chairman, Elizabeth serves as a liaison between the EMS agencies, Junior Women's clubs, and other community clubs. She also searches for alternative funding sources to help EMS agencies that do not have a sponsoring club. Under her leadership, more than 50% of Wisconsin's 446 EMS agencies now carry Pediatric Jump Kit bags, and funding to support the project now exceeds \$230,000.



### Wisconsin Family Rep Named Chair of State GFWC Project

In 1993, Elizabeth Davy – a mother of two active boys who manages an engineering and survey-

ing firm – joined the Oconomowoc Junior Woman's Club (OJWC), a local chapter of the national General Federation of Women's Clubs (GFWC) that focuses on youth helping youth. In 2002, she was named co-chair of OJWC's newest committee, the EMSC Committee. Working with the local EMS and the Wisconsin EMSC Advisory Board, this new committee created and funded Pediatric Jump Kit bags – specialized kits that put critical pediatric emergency supplies in one place to help EMS respond to pediatric calls with organized, easily accessible, and properly-sized equipment – for ambulances in Waukesha County.

In 2002, four pediatric bags were in use in Waukesha County. By 2006, more than 75 pediatric bags had been purchased. Currently, all ambulances in the county now carry the pediatric bags.

In 2005, OJWC was asked to present a report about the Pediatric Bag project at the GFWC Annual International Convention. Since then, the project has re-

### Why is pediatric bag project so vital?

According to Elizabeth, Wisconsin has 1.1 million children younger than age 14. "A pediatric call could be anything from a premature infant to an injured teenager; their size and needs are completely different," Elizabeth said. "Yet most of our ambulances were not set up with all the appropriate sized equipment to treat pediatric emergencies easily, efficiently, and effectively. By providing the right tools, in the right place, to our EMS we can positively affect the outcome of these children in need – more than 26,000 transported children per year in Wisconsin." This project potentially impacts every child in Wisconsin, their families, and the dedicated EMS who serve them.

"Support and involvement from the state EMSC project is critical to community service groups like GFWC; groups that chose to donate time and money to make a difference in children's lives," Elizabeth continued.

Elizabeth accepted the Wisconsin family representative position in the summer of 2008 after working with the state EMSC project since 2002.

## Suzanne Levy, from page 1...

Many states did not screen newborns for CAH in 2000, resulting in misdiagnoses and delays in obtaining the most appropriate medical care. Over the past eight years, CARES Foundation has focused its efforts to educate others about CAH, the importance of early detection and proper treatment, and the need to centralize the medical knowledge available and experiences of those afflicted with CAH for future research purposes. Today, every state ensures that newborn screening include testing for CAH.

In addition, CAH-affected individuals are always at risk of adrenal crisis, which requires the immediate administration of glucocorticoids in a timely manner. CARES Foundation is now focusing its efforts to 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.

*CARES Foundation is dedicated to improving the lives of families and patients affected by CAH through pro-*

*actively advancing research for a cure, educating the public and healthcare professionals about all forms of CAH, advocating for universal newborn screening, and providing support services and resources vital to the CAH community worldwide. For more information not available on the Foundation's website, contact Suzanne Levy at [Suzanne@caresfoundation.org](mailto:Suzanne@caresfoundation.org) or Gretchen Alger Lin at [gretchen@caresfoundation.org](mailto:gretchen@caresfoundation.org).*

## Study Indicates Earlier Vaccinations for Whooping Cough Could Reduce Illness

A study appearing in the November 2008 issue of *Pediatrics* (Vol. 122 No. 5) indicates that accelerating the pertussis vaccine (whooping cough) for infants could prevent about 1,236 illnesses and seven deaths a year. Researchers analyzed national data to determine the effects of immunizing infants two weeks earlier than normal, at six weeks of age instead of two months. Rates of pertussis have been increasing in the U.S. and can be fatal to infants; in 2003 there were 13 fatal cases of pertussis in children.

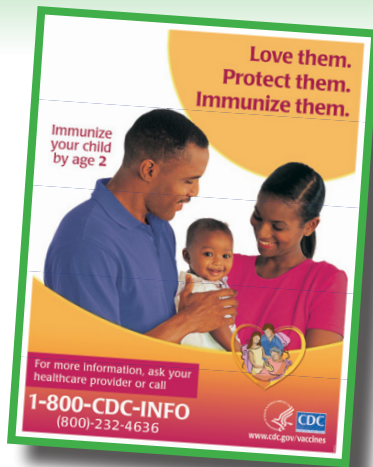
## Inouye Successor, from page 1...

In addition to Sen. Inouye, the leaders listed below serve on congressional committees of importance to the EMSC Program. Note that, at time of publication, some positions had yet to be selected.

1. Senator Thad Cochran (R-MS), Ranking Member, Senate Appropriations Committee
2. Senator Tom Harkin (D-IA), Chairman, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
3. Senator Arlen Specter (R-PA), Ranking Member, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
4. Senator Edward M. Kennedy (D-MA), Chairman, Senate Health, Education, Labor, and Pensions Comm.
5. Senator Michael Enzi (R-WY), Ranking Member, Senate Health, Education, Labor, and Pensions Comm.
6. Congressman Dave Obey (D-WI), Chairman, House Appropriations Committee and House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
7. Congressman Jerry Lewis (R-CA), Ranking Member, House Appropriations Committee
8. Congressman Todd Tiahrt (R-KS), Ranking Member, House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
9. Congressman Henry A. Waxman (D-CA), Chairman, House Energy and Commerce Committee
10. Congressman Joe Barton (R-TX), Ranking Member, House Energy and Commerce Committee
11. Congressman Frank Pallone, Jr. (D-NJ), Chairman, House Energy and Commerce Subcomm. on Health
12. TBD, Ranking Member, House Energy and Commerce Subcommittee on Health

## Mark Your Calendars: National Infant Immunization Week

The Centers for Disease Control and Prevention (CDC) has celebrated **National Infant Immunization Week** (NIIW) annually since 1994 as a way to highlight the importance of protecting infants from vaccine-preventable diseases and to celebrate the achievements of immunization



programs and their partners in promoting healthy communities. This year NIIW will be held April 25-May 2, 2009. The commemoration serves as a call to action for parents, caregivers, and healthcare providers to ensure that infants are fully immunized against 14 vaccine-preventable diseases.

### *Are multiple immunization shots safe?*

According to the CDC website (see [CDC Common Questions Parents Ask](#)), studies show that children, including infants, can handle many shots at once. "Having several vaccines at once is safe, even for a newborn."

### *Are combination vaccines effective?*

Combination vaccines protect a child against more than one disease with a single shot. This reduces the

number of shots and office visits a child needs. This is good news since a greater number of shots are recommended/required now than a few years ago. As science advances, additional vaccines may be added to protect children against other diseases.

## FDA Releases Statement Regarding Voluntary Change of Cough and Cold Medication Warnings for Children

The Food and Drug Administration (FDA) released a [statement](#) in October 2008 regarding the voluntary change of cough and cold medication warnings for children. The Consumer Healthcare Products Association (CHPA), which represents most makers of over-the-counter (OTC) cough and cold medicines in children, recently announced that its members are voluntarily modifying the product labels to state "do not use in children under 4 years of age." The FDA statement describes its support for the measures by the CHPA and discusses its continuing assessment of OTC medications; it further recommends that parents and caregivers adhere to dosing instructions.

## FAN Education and Networking Opportunities

### **FAN Webinars**

The EMSC National Resource Center (NRC) hosted part one of a three-part series of web-based educational seminars (webinars) on January 8, 2009, designed specifically for state EMSC family representatives. The goal of the webinars is to educate family representatives about the significance of the EMSC performance measures and how their involvement may help to achieve each measure.

We encourage all family representatives to participate in the upcoming webinars scheduled for February 20, and May 20, 2009. All training sessions will be held from

3:00 pm to 4:00 pm eastern time. More information about each webinar may be found on the [NRC website](#).

### **Annual EMSC Program Meeting**

The next Annual EMSC Program Meeting (formerly referred to as the Annual EMSC Grantee Meeting) will be held June 9-12, 2009, in Alexandria, VA. The EMSC National Resource Center (NRC) will host a FAN Reception from 7:00 pm to 9:00 pm on June 10.

Mark your calendars and look for updates regarding the meeting in NRC's weekly *QuickNews* or online at: [www.childrensnational.org/emsc](http://www.childrensnational.org/emsc).