

# FAN Mail

## EMSC Family Advisory Network (FAN)

Distributed by the Emergency Medical Services for Children

National Resource Center (EMSC NRC), 8737 Colesville Road Suite 400, Silver Spring, MD 20910



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*FAN ... an alliance of family representatives from states, territories, and the District of Columbia who actively support state EMSC program initiatives. Members work with their state EMSC Managers to ensure that family-centered care (FCC) is incorporated into pre-hospital 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 guide in their efforts to implement FCC in their area.*



*If you a question or have information you would like to share with FAN members, please send via e-mail to [tmquinata@emscnrc.com](mailto:tmquinata@emscnrc.com).*



*(pictured from left to right) Lizzy MacDonald, Samantha Donnelly, Beth MacDonald, Alex Moore, Faith Moore, and Cynthia Lightfoot.*

EMSC FAN Liaisons, Ms. Beth MacDonald (Delaware) and Ms. Cynthia Lightfoot (District of Columbia) were invited to share their story at the Mid-Atlantic's Regional Symposium in Rehoboth Beach, Delaware in November 2004. They were joined by Lizzy, Samantha, Alex, and Faith. Much was learned from this dynamic group, as they shared their life and how it led them to the EMSC Program.

Cynthia and Beth are community leaders and educators working to help improve our nation's emergency medical services system by educating the public and providers.

### Dates to Remember

#### **EMSC Annual Grantee Meeting – April 11-13, 2005**

*Hyatt Regency Hotel, Bethesda, Maryland*

#### **Childhood Depression Awareness Day - May 3**

*Childhood Depression Awareness Day (CDAD) offers Mental Health Associations, partners, like-minded organizations and child advocates an opportunity to come together to focus on childhood depression. This year, the National Mental Health Association has expanded the observance to include other serious childhood mental health problems such as bipolar disorder, anxiety disorders and attention-deficit hyperactivity disorder. Go to <http://www.nmha.org/may/CDAD/index.cfm> for more information.*

#### **Emergency Medical Services Week .... May 15-21, 2005**

*Emergency Medical Services Week brings together local communities and medical personnel to publicize safety and honor the dedication of those who provide the day-to-day lifesaving services of the medical "front line." EMS Week is sponsored by the American College of Emergency Physicians. Organizational sponsors include The National Highway Traffic Safety Administration and the Emergency Medical Services for Children program. More information may be found at <http://www.acep.org/1,32538,0.html>*

#### **Emergency Medical Services for Children Day - May 18, 2005**

# The Power of Networking



## Christiana ... One of the Youngest EMSC program Advocates

Written by: Marlene Carbullido, PREP Regional FAN Liaison

Christiana was born with meconium aspiration and required mechanical ventilation. After two weeks of unsuccessful attempts to extubate her, she was transferred over 3,800 miles to the nearest Children's Hospital in Hawaii -- over 3800 miles away where a tracheotomy was performed.

When Christiana was 18 months old, Dr. Robin T. Cotton at the Children's Hospital in Cincinnati, Ohio performed surgery to lateralize Christiana's vocal cords. She has had many respiratory illnesses since and her vocal cords are still paralyzed, but with speech therapy, medical follow-up, and natural growth and healing, she has a great chance of managing this chronic health condition.

Christiana receives special education services offered by the Guam Department of Education and is enrolled in the Emergency Medical Services for Children's Special Needs Identification Project (SNIP). Because of Guam's remote location, medical care is not always optimal and families are not always aware of available healthcare services. For this reason, I started a support system of family and friends. This network of information sharing and support may simply involve making a telephone call or sending an email to get more information for families. As the network began to grow and more families inquired, we decided to call ourselves "Christiana Cares".



Recently, I was contacted by the parents of Baby Jewel (pictured with Christiana). They were given the SNIP Brochure and when they discovered that Christiana had a similar medical condition, they began to look for me. Christiana and I visited Jewel and as she carried her on her lap for pictures, I could not help but feel so much emotion in that brief moment of just how fortunate and happy we are that Christiana is here today. I could see the glimmer of hope in Jewel's family, as they too needed to know that there is a tomorrow and things will get better -- one day at a time.

It is just so important for parents of children with special health care needs to reach out to each other. The Family Advisory Network is very important. Parents gain strength and learn from one another. I encourage families to reach out and get involved in whatever way possible.

Thank you to the folks at the EMSC National Resource Center for making this Family Advisory Network possible.

## Resources:



**Coping with Chronic Illness: Tips from Parents and Families:** The Center for Infants and Children with Special Needs at Cincinnati Children's Hospital Medical Center provides a holistic approach to the care of children and young adults with significant chronic illness. For more information, go to <http://www.cincinnatichildrens.org/about/patient/coping/>

**Growing up with medical problems:** The Band aides and Blackboards website contains information about growing up with medical problems. Its purpose is to help people understand what it's like, from the perspective of the children and teens. These kids have become experts at coping with problems that most have never heard of. Information can be found in three different ponds; one for kids, one for teens, and one for adults. The site contains pages designed and arranged by Joan Fleitas, Ed.D., R.N. Associate Professor of Nursing, Lehman College, Bronx, New York 10468. The website is found at <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>

**Advances and changes in Pediatrics:** The American Academy of Pediatrics (AAP) is looking back at the advances and changes in pediatrics since 1930. There will be special events, community outreach, and promotional items to commemorate their 75<sup>th</sup> year. The AAP will continue to provide accurate online information parents and pediatricians need to keep kids healthy. Check out this website regularly -- <http://www.aap.org/>

## *Technical Assistance Team*

For resources, guidance, and support in the following regions and for resources in expertise areas, you may contact the Technical Assistance Team:

### **IRECC & PREP Regions, and Disaster Preparedness & Mental Health**

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