

FAN MAIL



MARCH 2004

EMSC FAMILY ADVOCACY NETWORK (FAN)

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**NEXT ISSUE:
EMSC FAN Regional
Representatives from
IRECC, New England, and
Red River.**



The Emergency Medical Services for Children (EMSC) Program is designed to ensure that all children and adolescents – no matter where they live, attend school, or travel – receive appropriate care in a health emergency. EMSC is jointly administered by the Health Resources and Services Administration’s Maternal Child Health Bureau and the National Highway Traffic Safety Administration.

The EMSC NRC was established in 1991 to assist the Federal EMSC Program. The NRC works with states to reduce child and youth disability and death as a result of severe illness or injury. Guided by the EMSC Program, the NRC helps states identify resources needed to organize and implement a range of activities. These include providing guidance in securing funding, developing injury prevention plans, building coalitions, shaping public policy, training prehospital and hospital providers, producing educational materials, and promoting family-centered care.



Family-centered care

Family-centered care is premised on planning, delivery, and evaluation of health care that is achieved by engaging interactive involvement of mutually beneficial partnerships between health care providers, patients, and families. Family-centered care applies to patients of all ages and may be practiced in any health care setting.

FAN Advisory

In February 2004, the FAN Advisory Group was formed. The Advisory Group consists of FAN representatives from each of the eight EMSC regions. The Group strengthens communication as it links parent advocates across the nation to the EMSC NRC. They work closely with the EMSC NRC and inform parent advocates of national and regional progress made towards achieving EMSC initiatives. They also engage in information-sharing meetings and teleconferences to discuss family-centered care issues and the learning needs of parent advocates to effectively support EMSC initiatives in their states.



FAN – linking families and providers

Integrating family-centered health care is a continuous process. Its success is contingent upon an institution's interest and willingness to learn from the experience and knowledge families and professionals can provide. As such, the EMSC NRC is committed to sustaining an effective collaboration between providers and families through the ongoing partnership-building efforts of the Family Advocacy Network (FAN).

EMSC Regions and Scheduled Symposiums

Center of America Regional EMS for Children (CARE)

Member States:

Illinois, Indiana, Michigan, Missouri, Ohio, and Wisconsin

Regional Symposium:

October 18-20, 2004, Madison, Wisconsin

Heartland EMS for Children Coalition (HECC)

Member States:

American Samoa, Iowa, Kansas, Minnesota, Nebraska, North Dakota, and South Dakota

Regional Symposium:

September 16-18, 2004, Two Harbors, Minnesota

Intermountain Regional EMS for Children Coordinating Council (IRECC)

Member States:

Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Northern Marianas Islands, Utah, and Wyoming

Regional Symposium:

October 28-29, 2004, Las Vegas, Nevada

Mid-Atlantic EMSC Region

Member States:

District of Columbia, Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, and West Virginia

Regional Symposium:

November 3-5, 2004, Rehoboth Beach, Delaware

New England EMSC Region

Member States:

Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont

Regional Symposium:

November 20-21, 2004, Newport, Rhode Island

Pacific Regional EMSC Partnership (PREP)

Member States:

Alaska, California, Guam, Hawaii, Oregon, and Washington

Regional Symposium:

January 2005, Seattle, Washington

Southeast EMS Regional for Children (SERC)

Member States:

Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, Puerto Rico, South Carolina, Tennessee, and Virgin Islands

Regional Symposium:

September 4, 2004, Atlanta, Georgia

Red-River EMSC Region

Member States:

Arkansas, Louisiana, Oklahoma, and Texas

Regional Symposium:

August 5-6, 2004, New Orleans, Louisiana

Meet Your FAN Regional Representative



PREP
Regional Representative

Marlene M. Carbullido
Guam

PEPP Provider/Nurse Supervisor
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Marlene Carbullido is the Family Advocate for the island of Guam. She is married to Paul A. Carbullido and has three children - Christopher is 13, Cassandra 10, and Christiana is 4 years old.

Ms. Carbullido received a Bachelor of Science in Nursing and is licensed in Guam and California. She is a California Certified Public Health Nurse, AHA Pediatric Advanced Life Support (PALS) Provider, Pediatric Education for Pre-hospital Professionals (PEPP) Provider, Certified Lactation Educator, GMHA Staff, and Community Health Nurse Supervisor.

“Four years ago, our youngest child Christiana was born with vocal cord paralysis. The experiences that my family and I faced, and continue to face today, have inspired me to contribute what I can through my professional nursing and daily experiences as a mother. Advocating through the EMSC program, I can help improve the lives of other families who have children with special health care needs. When I heard about the new Special Needs Identification Project (SNIP), I was so excited that I put all my extra energy into promoting the program. The SNIP program addressed all my concerns with Christiana regarding pre-hospital providers. The Guam Department of Public Health & Social Services, EMSC and MCH Coordinators who initially organized the project, invited me to go on local radio stations to promote the program. The calls from families with concerns were really touching and it was then that I decided to start the family support group “Christiana Cares.” It is a network of families with different medical conditions where I provide professional and personal support. In this, I link families to other families with similar conditions, and refer them to other sources of medical, social, and emotional support.”



MID-ATLANTIC
Regional Representative

Cynthiana Lightfoot
District of Columbia

EMT-P/EMS Instructor
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Cynthiana Lightfoot has been the Family Advocate for the District of Columbia (DC) since 1998. The former elementary school teacher began volunteering at Children's National Medical Center (CNMC) in 1990 and has devoted much of her time to the pediatric patients there. Cynthiana is a nationally registered paramedic. She teaches Pediatric Advanced Life Support (PALS), Pediatric Education for the Prehospital Providers (PEPP), Special Children's Outreach and Prehospital Education (SCOPE), First Aid, CPR for Healthcare Providers, and EMT- Basic and Intermediate courses. Cynthiana helped the DCFD/EMS department develop community outreach programs involving child carseat fitting stations and senior citizen wellness. She also advocated for Automated External Defibrillator (AED) and DNR legislation. In addition, Cynthiana is a certified Child Passenger Safety Technician that teaches parents how to properly install car seats.

As an educator of prehospital care and injury prevention, Cynthiana has positively impacted the lives of DC's children. She is a respected community advocate who is knowledgeable of each phase of the EMSC continuum of care. Cynthiana brings both personal and professional experiences in her service as the Chairman of the Community Advisory Board (CAB) for the Chesapeake Applied Research Network for EMSC. She also serves as a representative of the City Council in various public health venues, including the development of the Trauma Plan and the Medical Control Advisory Committee. Recently, Cynthiana helped compile the Mayor's Transitional Report on EMS.



MID-ATLANTIC
Regional Representative

Beth A. MacDonald
Delaware

Family Voices Coordinator
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Beth MacDonald is the Family Advocate for the State of Delaware. She was an educator for 18 years – teaching first grade for 11 years and art for 7. Beth’s experience with her family and daughter Liz, who is now 14 years old, inspired her to get involved with prehospital care. Liz was hospitalized for the first 10 months of her life and was ventilator-dependent for 4 years. She was the first child sent home on a ventilator in the State of Delaware. This motivated Beth to begin working with families, educators and medical professionals to address the medical needs of children with special health care needs.

Beth has built state partnerships and established relationships with Delaware’s congressional members and staff. She has been a member of the DE Interagency Coordinating Council Birth to Three (ICC) since 1994 and Chair for more than 5 years. She has worked with the Delaware Medical Home Program since the initial planning began and has supported its implementation and ongoing educational training activities.

“Through my participation in various projects I present at state, local, regional and national conferences during the year. I am quite comfortable presenting information to families, CSHCN youth, and state and medical professionals. I have a passion to make sure our families and CSHCN have the best resources and services available to them, and that they have community and family support at every changing level of need. It is my dream that EMSC will be a vehicle to provide in state and intra-state support for families in our area as they find the need to use and be transported to the Children’s Hospitals in our Region. EMSC services should be a comfort zone for families as they find the need to cross-state lines for emergency and critical care issues. “



SERC
Regional Representative

Conni Wells
Florida

Executive Director
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Conni Wells is a member of Florida’s Emergency Medical Services for Children (EMSC) Advisory Committee. She serves as Florida’s parent representative for various local, state, and national initiatives. Conni is the Executive Director of Florida’s Institute for Family Involvement and was the first recipient of the EMSC National Parent Volunteer of the Year Award.

Conni advocates for children with special health care needs (CSHCN) on a statewide and national level. She supports community involvement in the development of family-centered community based systems for individuals with special health care needs. Ms. Wells is a tireless advocate whose many accomplishments are a direct result of dedication, talent and hard work. She contributes to EMSC publications, promotes and presents on pediatric emergency care at conferences and meetings, and provides ongoing consultation regarding family-centered care.

Conni’s primary activities for 2003 include: State EMSC Advisory Committee and Subcommittee for CSHCN, Family CAFÉ (statewide conference held for CSHCN and their families), Florida KidCare Outreach Coalition, Georgetown University National Cultural Competency Advisory Committee, Florida Substance Abuse and Mental Health Board of Directors, EMSC Southeast Region Conference, Florida Children’s Medical Services Telemedicine Project, Florida Exceptional Student Education Advisory Committee, and FL Department of Health Quality Showcase Award for Disaster Planning and Preparedness for Special Populations. She also presented at the World Congress on Disability Disaster Planning and Preparedness for Special Populations in the workplace, State Safety Expo, Children’s Mental Health Seclusion and Restraint statewide training, and Statewide Bioterrorism work group.



CARE
Regional Representative

Stephen Brock
Indiana

EMT-P / PALS Instructor
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Stephen "Steve" Brock is the Parent Advocate and EMSC Advisory Council Representative for the State of Indiana. He has been married to Stephanie for 17 years and has two children: Lucas is 8 and Kara is 6 years old.

Steve is the EMS Director of Brown Township Fire and Rescue in Martinsville, IN and is the co-Founder and President of the Morgan County EMS Association. He is a certified AHA Advanced Life Support, AHA Pediatric Advanced Life Support (PALS), and AHA Basic Life Support Instructor. Mr. Brock is also a certified Paramedic in the State of Indiana.

Steve has always been an advocate for children, especially for children with special health care needs. He grew up assisting in the care of his developmentally challenged sister who is now 47 and married. In Steve's spare time, he enjoys camping, traveling, and being with his family.



HECC
Regional Representative

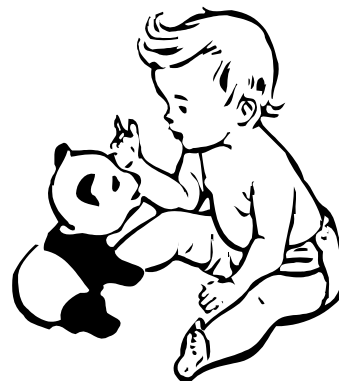
Donna Habrock
Nebraska

EMT/EMS Instructor
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Ms. Donna Habrock is the Parent Advocate for the State of Nebraska and is from Madison City.

"I'm a single parent of three. My daughter Laura is 18, my oldest son Lance is 16, and my youngest son Taylor is 4. He keeps me young and on the go."

"I've been an EMT and EMS instructor for the state of Nebraska for 15 years. I've worked on both volunteer and paid EMS systems, along with working in the emergency room for 5. I've been actively working with law enforcement personnel in communities to educate families about the dangers of teenage drinking and driving. I've helped local rescue squads with documentaries and been involved with public awareness of pediatric care by speaking at EMS conferences. I'm a member of Nebraska's Critical Incident Stress Management team where I've seen the effects of pediatric trauma on pre-hospital providers. I am looking forward to serving as a Family Advocate for EMSC and contributing my experiences as a single parent and EMS provider/instructor."



EMSC FAN Regional Representatives

The FAN Regional Representatives from the IRECC, Red-River, and New England Regions will be featured in the next EMSC FAN Newsletter. Currently, **IRECC** has selected **Melody Mesmer** (Colorado EMSC) and **Shauna Hatton-Ward** (Utah EMSC).

On March 9, 2004, FAN members and EMSC NRC staff met during a teleconference. In attendance were: Stephen Brock, Marlene Carbullido, Shauna Hatton-Ward, Conni Wells, Debbie Smades Henes, John Susa, Tom Manglona, Jeanette Shipley, Theresa Morrison-Quinata, and Ken Allen. Discussions included a brief explanation about the need for an advisory group and suggested topics for the 2004 Annual Grantee Meeting.

FAN members continued discussions during another teleconference on April 13, 2004 at 3:00PM EDT. In attendance were Conni Wells, Melody Mesmer, Thom Danenhowe, and Theresa Morrison-Quinata (NRC).

On **May 5, 2004 at 3:00PM EDT** NRC EMSC staff will conduct another teleconference with FAN members. An agenda will be distributed prior to the meeting. To join the conference, please dial: 1-888-847-0297 and enter 707-620-0933# when prompted for an access code.

EMSC would like all parent advocates to attend a special focus group session with the NRC and Children's Safety Network staff on **June 28, 2004 at 4:00PM**. The session will be held during the 2004 Annual EMSC Grantee Meeting in Washington, D.C. More information will be announced later.



Technical Assistance Team

For resources, guidance, and support, please feel free to contact the Technical Assistance Team.

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**IRECC & PREP
Regions**

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**CARE, HECC &
NEW ENGLAND
Regions**

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**MID-ATLANTIC
& RED-RIVER
Regions**



Advocacy Resources

Below is a list of publications and websites that may be helpful to you in your advocacy efforts:

(reprint from last issue)

- Johnson, B.H., Thomas, J., and Williams, K. (1997). Working with Families to Enhance Emergency Medical Services for Children. Emergency Medical Services for Children National Resource Center, Washington, DC.
- Thomas, J. and Jeppson E.S. (1997), Words of Advice: A Guidebook for Families Serving as Advisors. Institute for Family-Centered Care, Bethesda, MD.
- Thomas, J. and Jeppson E.S. (1997), Essential Allies: Families as Advisors. Institute for Family-Centered Care, Bethesda, MD:
- Wertz, E (2001). Emergency Care for Children. Delmar Thomson Learning, Albany, NY.
- "Family Information" section of EMSC web page: www.ems-c.org
- The Institute for Family-Centered Care: <http://www.familycenteredcare.org/>. Provides a forum for families who have experienced emergency care.
- Family Voices: Families and Friends Speaking on behalf of Children with Special Health Care Needs: <http://www.familyvoices.org/>: Offers information about Family Voices, resources for families with children with special health care needs, advocacy materials, related links, etc.
- National Parent Information Network (NPIN): <http://www.npin.org/about.html>. Contains information about the NPIN. It is a project of the ERIC system administered by the National Library of Education in the U.S. Department of Education. The virtual library may be found at <http://ericps.crc.uiuc.edu/npin/books.html>.
- National Parent Teacher Association (PTA). <http://www.pta.org/apta/index.htm>. Provides information about the national PTA, resources, and links to state PTA offices, and national standards for family involvement programs.
- Georgetown University's Child Development Center: <http://www.georgetown.edu/research/gucdc/mmcan.html>. Offers information about the "Communities Can" Program and family-centered care.
- Federation of Families: <http://www.ffcmh.org/>. Includes information about the Federation of Families for Children's Mental Health. It is a national parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families.



Question & Answer Section

Do you have questions regarding advocacy, family-centered care, etc.? Well, chances are other parent advocates may have the same question. Send us an email and we will post your question in the next newsletter.