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Mail

EMSC Family Advisory Network Newsletter

Spring/Summer 2011 Issue

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On Monday, May 2, during a special luncheon at the 2011 State Partnership Program Managers Meeting, grantees will get a first hand look at the EMSC National Resource Center's (NRC) newest video "EMSC Family Advisory Network: Helping to Improve Pediatric Emergency Care." This 14-minute video captures the compelling stories of nine Family Advisory Network (FAN) representatives and highlights the work they are doing to improve pediatric emergency care at the local and state levels.

As many FAN members may call, more than eight hours of interviews were filmed during last year's Annual EMSC Program Meeting in Bethesda, MD. All FAN members who volunteered to be interviewed are included in the final video. The EMSC Program would like to extend their appreciation for your participation. Your passion

and commitment to children and to EMSC is well reflected in this video.

Each State Partnership program manager will receive a DVD copy of the video to share with his or her FAN representative. FAN representatives are free to duplicate the video. Beginning May 3, the video will

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Pictured above is a clip from "EMSC Family Advisory Network: Helping to Improve Pediatric Emergency Care," a 14-minute video that captures the compelling stories of nine FAN members.

Save the Date: EMSC Day 2011 is May 18

Each year, the federal EMSC Program partners with the American College of Emergency Physicians to celebrate Emergency Medical Services (EMS) Week. The Wednesday within EMS Week is designated as EMSC Day. This year EMSC Day will be held on May 18, 2011.

FAN members can help celebrate EMSC Day in their community by engaging local organizations and medical personnel to raise awareness about the need for specialized emergency care for children. For

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EMSC's FAN Membership Continues to Grow

The EMSC Program is happy to welcome its newest Family Advisory Network (FAN) members:

Arizona FAN representative **Elizabeth Bryant** is the mother of three children: Alyssa, age 11; Robby, age 9; and Addisyn, age 2. Elizabeth's youngest daughter, Addisyn, was born at 28 weeks and spent three months in the Neonatal Intensive Care Unit. Addisyn was diagnosed with tracheomalacia and had a tracheotomy tube until she was 18 months old. Her prematurity has also caused her to have chronic lung disease.

Elizabeth's passion for involvement in EMSC began shortly after Addisyn was born. Elizabeth's mother, an employee with the Arizona Department of Health, was

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

FAN Mail is distributed semi-annually 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 Gayathri Jayawardena at gjayawar@childrensnational.org.

asked if there were any family members that might be interested in filling the family advocacy position. She immediately thought of her daughter because of her experiences with Addisyn through the hospital system.

Formerly a Marine Corps and Air Force Reserves veteran, Elizabeth is currently a stay-at-home mom awaiting reply for admission into a nursing program. She had left the Air Force a year ago in order to tend to Addisyn's special needs.

Robyn VanHemelryck is the newest FAN member to join the Montana EMSC program. Robyn and her husband Dean are the proud parents of three children: Kylee, age 15; Shelby, age 11; and Carson, age 8.



Robyn VanHemelryck

Robyn's passion for EMSC stems from her own experiences with her daughter, Shelby. Shelby was born with a Ventricular Septum Defect, a congenital heart defect. Beginning at age 5, Shelby endured a series of heart surgeries, first to repair the hole in her heart then to repair a leaky aortic valve. Despite these healthcare setbacks, Shelby continues to be involved in sports; her favorites are softball and golf. The EMSC Program is excited to have Robyn and her family join the EMSC community.

Tiffany Holland will serve on the North Carolina EMSC Advisory Committee as the family representative. She is spearheading an effort to get kids with hemophilia enrolled in North Carolina's KIDBase, a program designed to identify children with special health care needs in the community and register their medical information with the local EMS agency.



Tiffany Holland

EMSC National Resource Center Establishes Social Media Presence

The EMSC National Resource Center (NRC) is excited to announce its expansion into the social media arena. Over the past few months the NRC has developed pages on Facebook (<http://www.facebook.com/emscnrc>) and Twitter (<http://www.twitter.com/emscnrc>) in an effort to expand its reach to the EMSC community. The pages will provide a new avenue to connect, educate, and inform different categories of grantees (State Partnership, Targeted Issues, and the Pediatric Emergency Care Applied Research Network), members of the Family Advisory Network (FAN), and the general public about EMSC's priority issues, hot topics, and program accomplishments. In addition, it will provide a venue for information sharing and cross collaboration between these groups.

The NRC's YouTube channel (<http://www.youtube.com/emscnrc>) offers a variety of training and educa-

tional videos, like the iPEMS podcasts (targeted to medical students, residents, and fellowship trainees) that focus on pediatric medication safety issues in the emergency setting. It also features the NRC's newest video "EMSC Family Advisory Network: Helping to Improve Pediatric Emergency Care." This 14-minute video captures the compelling stories of nine FAN representatives and highlights the work they are doing to improve pediatric emergency care at the local and state levels.

Want to join? Visit the NRC's Facebook or Twitters pages and its YouTube channel to connect or "friend" each site. This is a fantastic opportunity to post information, pictures, and videos about local activities and events, upcoming trainings, recently released products and resources, presentations, or even funny tidbits about state FAN programs.

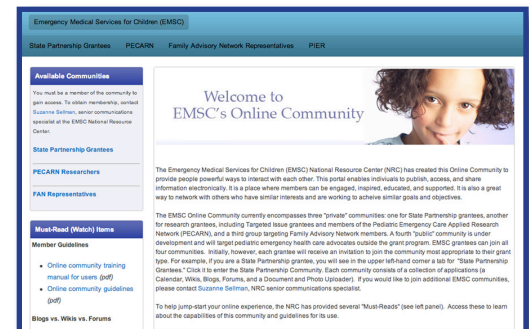
EMSC Builds Online Community; New Technology to Foster Collaboration, Knowledge Sharing

The EMSC National Resource Center (NRC) is piloting its newest social media application, the EMSC Online Community. The community serves as an interactive online portal providing grantees and members of the Family Advisory Network (FAN) powerful ways to interact with each other in real time, electronically.

Through the use of community wikis, blogs, and forums, FAN members can ask questions, discuss their state's current activities and accomplishments, share strategies for helping their state implement the EMSC performance measures, and offer support and guidance to other members within the group. The community

also allows members to upload and share documents and photos, and post events to a community calendar.

Sound interesting? FAN members will soon get their opportunity to be a part of this new technology. The FAN Online Community will be released in summer 2011. EMSC State Partnership grantees will have access to their community in May, following the State Partnership Program Managers Meeting in Annapolis, MD.



EMSC Resource Centers Team Up with PA FAN Member to Present at AMCHP

EMSC National Resource Center Director Ian Weston, National EMSC Data Analysis Resource Center Director Mike Ely, and Pennsylvania Family Advisory Network (FAN) Member Monica Liebman presented at the 2011 Annual Conference of the Association of Maternal & Child Health Programs, which took place February 12-15, in Washington, DC. Their session "Strengthening Communities, Children, Youth and Families with Collaborative Initiatives" examined the utilization of Maternal and Child Health Bureau

funded resource centers (RC) to support federal and state goals and performance measures.

Both Ian and Mike provided a brief overview on how their centers support and enhance the work of state programs and how they encourage and cultivate collaborations with parents and families. Monica provided a brief overview of the history of FAN; its purpose, successes, and ongoing involvement in the activities of EMSC.

Alabama Moves Forward with Hospital/EMS Survey

The Alabama EMSC program, in partnership with the National EMSC Data Analysis Resource Center, has completed their survey of hospitals and EMS agencies in the state. Recently, the Alabama EMSC team and their EMSC Advisory Committee reviewed the results of the data collected to determine next steps to assure that: pediatric medical direction is available to EMS providers 24/7; recommended pediatric equipment items are on all BLS and ALS patient care units; and transfer guidelines and agreements include pediatric components necessary to transfer a child to the appropriate medical facility.

The group also intends to: (1) evaluate its pediatric medical recognition system for both medical emergencies and trauma, (2) discuss the pediatric education requirements prior to the recertification of BLS and ALS providers and (3) determine its status toward establishing permanence of the EMSC Program in their state. For more information, contact Katherine Hert at Hert@adph.state.al.us or Ann Klasner, MD, at aklasner@pediatrics.uab.edu.

Kentucky EMSC Holds Special Meeting to Discuss MCHB Performance Measures

State Partnership grantees have recently learned that they will be participating in a new Maternal and Child Health Bureau (MCHB) performance measure survey designed to assess the populations served by grants and the mechanisms in which these efforts are being accomplished. On February 10-11, 2011, EMSC Program representatives attended a special meeting of the Kentucky EMSC program to review the new MCHB Discretionary Grant performance measures (7, 10, 24, 33, and 41). Meeting Organizer Mary Fallat, MD, invited key stakeholders in the state to review the performance measures and to evaluate whether current state activities incorporated elements of each measure. To their surprise, they learned that in some instances the state is already incorporating key elements of these measures into their current EMSC state trauma program activities.

Note: The federal EMSC Program presented the webcast "A Review of the New MCHB Performance Measures" (<http://webcast.hrsa.gov/postevents/archivedWebcastDetail.asp?aeid=547>) on February 28,

2011. Specific examples of activities that states can undertake to meet the new measure were discussed.

EMSC PIER Region to Host Second Regional Meeting in April

EMSC program managers and partners from the islands of American Samoa, Guam, Hawaii, and the Commonwealth of the Northern Marianas, who collectively make up the Pacific Islands EMSC Region (PIER), will meet in Hawaii, April 18-22, to finalize the development of a white paper which addresses the multiplex of issues affecting inter-facility/inter-island transfer of patients needing specialty resources.

The group has met regularly during the last year to improve the transfer of pediatric patients from the territories to specialty medical centers in Hawaii and the continental United States. Since these islands are geographically isolated from one another, as well as from the Continental U.S., health care resources on these islands are often limited. The critically ill and injured or those requiring specialty care, often need to be transferred to access needed services. Improving these guidelines and agreements will have direct positive patient health outcomes of all Pacific Island residents.

For more information, contact Hawaii EMSC State Program Manager Dwayne Lopes at Dwayne.Lopes@doh.hawaii.gov.

Idaho FAN Member Launches Poster Contest to Promote Traffic Safety

Through her People Against Impaired Driving (PAID) non-profit organization, Family Advisory Network (FAN) Member Pat Tucker sponsored the Idaho Falls' Traffic Safety Poster Contest for students in kindergarten through grade 12. Nearly 500 entries were submitted. Winners for Most Effective Vehicle Safety Message, Most Effective Positive Message, and Most Effective Bicycle Safety Message will be honored at an awards ceremony on April 9. The schools with the most individual winners also will receive monetary awards. Event sponsors include Mutual of Enumclaw, Saab, AAA, Battelle Energy Alliance, and CH2M-WG Idaho.

PAID's mission is to promote greater awareness of the tragic consequences of driving impaired, and of

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the myriad forms of impairment, such as distracted driving or driving while emotionally overwrought, driving while under the influence of alcohol or drugs (both medical and illegal), or driving with physical or mental challenges often associated with the elderly.

“Virtually every vehicle crash is preventable,” Pat said. “[My daughter] Cady would be alive today, if that driver had remembered four words: ‘Not fit? Don’t drive.’”

Pat’s only child, 11-year-old Cady, was killed on August 15, 2002, by a driver with out-of-control blood sugar who drove 10 feet over the center line of the narrow two-lane Montana highway. To make matters even worse, the EMT assigned to Cady was told by a bystander that “she’s already gone.” The EMT turned around and walked away. Cady was not given cardiopulmonary resuscitation. An automatic external defibrillator was not administered, nor was she given any medical treatment whatsoever.

For more information about Pat’s story, watch the video “EMSC Family Advisory Network: Helping to Improve Pediatric Emergency Care” to be released May 3, on <http://www.youtube.com/emscnrc>. For more information on the poster contest, visit Cady for Safety (<http://www.facebook.com/pages/Cady-for-Safety/130374523651456>) or email Pat at CadyTucker@hotmail.com.

Washington FAN Member Creates Website for Sports Concussions

Jean Rickerson is the FAN representative for the state of Washington. In 2008, her 16-year-old son suffered a traumatic brain injury during a high school football game. It had taken more than four-months for her son to fully recover from his injury. Unable to find the resources she needed, Jean created SportsConcussions.org, a website dedicated to educating parents, athletes, and coaches about the dangers of sports-related concussions.

Jean recommends that FAN representatives ask local school boards about their concussion policy for contact sports. Contact sports include football, soccer, baseball, hockey, among others. According to Jean, only 26 states comply with the National Federation of State High School Associations (NFSHSA) concussion policy. Therefore, several states still have no regulations for contact sports. “It is important to educate parents, coaches, players, and prehospital providers to ensure compliance with NFSHSA or to

ensure some type of school policy is in place,” Jean said. Among the more than 38 million boys and girls who participate in organized youth sports in the U.S. today, concussions are one of the most commonly reported injuries.

Jean’s advisory board includes members of the NFL concussion committee, the president of the National Athletic Trainers Association, top researchers from Boston University, University of Illinois, and more. The website has educated and reached more than 100,000 people to date.

EMSC NRC to Establish Online Disaster Clearinghouse

The rise in major disaster declarations over the past two decades highlights the need to improve the gaps in preparedness, response, and recovery policies that should specifically address the needs of children. With this in mind, in 2008, the White House formed the National Commission on Children and Disasters (NCCD). In their final report to the President and Congress in 2010, NCCD outlined a number of recommendations to fill those gaps. One recommendation was to create a pediatric disaster resource database, a single online portal that would house and provide resources on a variety of topics related to preparedness and response.

Last year, the NRC embarked on the development of this ‘clearinghouse,’ compiling hundreds of resources from throughout the country. This disaster clearinghouse will bring together resources from a wide variety of sources (federal, state, and local government agencies; professional associations; non-profit entities; educational institutions; and health care organizations) to assist parents; day care providers; and school personnel; as well as prehospital professionals; acute care providers; and local, state, and federal agency staff in incorporating pediatric concerns into their disaster response plans.

For families, the home and community resources found on the Clearinghouse are likely to be of special interest. Families will be able to find information on how to prepare for disasters at home, such as what to include in a disaster kit and how to prepare an

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Family Representatives Role in the Public Policy Process

The goal of the EMSC Program is to reduce child and youth mortality and morbidity resulting from severe illness or trauma. Standardizing pediatric emergency care protocols, offering public and professional education throughout the continuum of care, or encouraging the development and use of evidence-based practices can achieve this. To affect permanent change on both a local and national level, however, individuals and organizations with a stake in pediatric emergency care must promote EMSC-related issues and priorities among public officials.

Family representatives' participation in the public policy process can raise the profile of EMSC and generate enthusiasm and support for system improvements. Often, a family representative can speak very personally of the benefit of improved pediatric emergency care. Such personal stories often are more compelling than statistics.

Before taking on any activities to educate and inform policymakers about EMSC, family representatives should work with their EMSC project manager to craft a message and ensure compliance with state/federal advocacy rules and regulations. In addition, if a family representative plans to identify him/herself with their employer or as a member of a particular professional organization (e.g., Family Voices or the Parent-Teacher Association) while speaking to a state or federal policymaker, be sure to notify the employer or organization. They will make sure the legislative activities do not conflict with their rules and priorities.

For more information, consult the EMSC National Resource Center's (NRC) Public Policy Primer: A Guide on the Legislative Process and Impacting



Change at the Federal, State, and Local Level (http://www.childrensnational.org/files/PDF/EMSC/PubRes/Public_Policy_Guide.pdf). It provides an overview of the public policy process; suggests ways to educate lawmakers; and includes information on how Congress is structured, how a bill becomes law, how the EMSC Program fits into the decision-making process, and most importantly, how family representatives can directly affect change through this process. In mid-summer, the Advocacy and Education Online Training program will also be available through the NRC website (see ad on page 8).

Disaster Clearinghouse, from page 5

emergency communication plan. Other resources will help families understand how to prepare for and respond to specific emergencies, such as the flu season. The Clearinghouse will also contain resources to help parents respond to a child's behavioral and emotional needs following a disaster. Specific information for special needs children will also be available. Finally, interactive resources designed to teach children about preparing for and recovering from a disaster, mainly in the form of games and coloring exercises, will be available.

Members of the Family Advisory Network are encouraged to submit resources and to provide feedback on the site's functionality. Comments and suggestions should be sent to Jessica Necheles at jnechele@childrensnational.org or Ian Weston at iweston@childrensnational.org. The site's 'go-live' date is schedule for late summer 2011.

EMSC Day, from page 1

ideas on ways to celebrate this special day, download a copy of the EMSC Day Planning Toolkit (http://www.childrensnational.org/EMSC/Events/NEM-SC_Day.aspx). The toolkit includes an assortment of promotional materials, such as downloadable Save-the-Date postcards, camera-ready clipart, animated website banners, and much more!

Don't forget to share the fun! Please use the EMSC National Resource Center's Facebook and Twitter pages and its YouTube channel to post creative ideas, photos, or video about EMSC Day activities or submit an update to Gayathri Jayawardena at gjayawar@childrensnational.org. She can post the updates on your behalf.

Family Presence During Pediatric Trauma Activation: Measuring the Effects of a Multidisciplinary Approach to Patient-family Centered Care

In addition to State Partnership grants, the federal EMSC Program also funds competitive Targeted Issue (TI) grants. These grants are awarded to schools of medicine to identify new approaches in providing the best possible emergency care for children throughout the nation. TI projects usually result in the development of a new resource or demonstrate the effectiveness of a model system component or service of value that would have applicability across borders.

EMSC Partners with General Federation of Women's Club

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. More than 100,000 members in affiliated clubs in every state and more than a dozen countries work in their own communities to support the arts, preserve natural resources, advance education, promote healthy lifestyles, encourage civic involvement, and work toward world peace and understanding.

In 2002, the Oconomowoc Junior Woman's Club (OJWC), a local chapter of the national GFWC, and the Wisconsin EMSC Advisory Board identified a gap in pediatric EMS care. Noting a lack of pediatric equipment on ambulances in certain areas of Wisconsin, the two groups created a strategic partnership to fund and place pediatric "Jump Kit" bags on every ambulance in Waukesha County, WI. Today, the partnership has raised more than \$300,000, and approximately 65% of the states EMS agencies have access to the bags.

During the past year, the EMSC National Resource Center (NRC) and GFWC have developed a national strategic partnership to encourage and market the Wisconsin model to other states and territories in an effort to produce similar outcomes. The NRC encourages Family Advisory Network members to work with their EMSC program managers to develop the partnerships within their state. This collaborative effort can assist EMSC programs throughout the nation to acquire missing pediatric equipment for their local EMS agencies.

Family-centered care has long been advocated as part of the EMSC mission and a focus of many current and past TI grants. For example, TI Grantee Karen O'Connell, MD, (Children's National Medical Center, Washington, DC) is leading a multi-site study to evaluate the effects of family presence on the timeliness and effectiveness of care during pediatric trauma team 'activations.' Her study also seeks to assess families' and providers' attitudes and experiences related to family presence. The multi-site study is currently being conducted at Children's National Medical Center, Dallas Children's Hospital, and Children's Hospital of Philadelphia.

Approximately 1,200 injured children, ages 18 and younger, and their families have enrolled in the study thus far. The study may lead to additional opportunities, as well as to new tools that further perfect family-centered pediatric care.

A number of TI grant projects have a family centered-care component. To learn more about these projects, contact Diana Fendya at dfendya@childrensnational.org.

Select Goals of Children's National TI Grant

- Compare specific measures of timeliness and effectiveness between two cohorts of patients, those with family presence and those without.
- Evaluate patient safety during family presence.
- Describe the experiences and attitudes of family members who did and did not experience family presence.
- Describe the experiences and attitudes of health care providers who have experienced pediatric trauma care both with and without family presence.
- Develop and disseminate a toolkit to assist emergency departments with the implementation of family presence procedures in their hospitals and more.

Ever Wonder How EMSC is Funded at the Federal Level?

The U.S. Congress, which is comprised of the U.S. House of Representatives and the U.S. Senate, plays an important role in ensuring the continued existence of the EMSC Program. For a federal program like EMSC to exist, Congress must approve its authorization as well as its annual federal appropriation. Legislative committees are responsible for authorizing legislation related to the agencies and programs under their jurisdiction. The appropriations committees of the House and Senate have jurisdiction over appropriations (funding) measures.

Authorizing Legislation. Authorizing legislation establishes a federal agency or program and provides guidance regarding the appropriate amount of funds to carry out the activities of the agency or program. Although a funding level is set, authorizing legislation does not provide the funding or guarantee that the funding will be at that level.

Authorizing also delineates what a program is allowed to do and what it is not allowed to do. This is often referred to as a program's scope of authority. For example, the legislation authorizing the EMSC Program defines the entities eligible to receive EMSC grants (states/territories or academic medical centers), the duration of each grant, and how many EMSC grants a state may receive at one time.

The EMSC Program was first authorized under the Preventive Health Amendments of 1984 (PL 98-555).

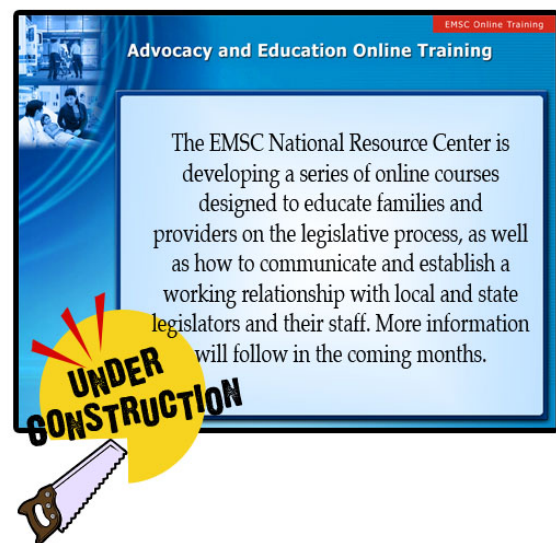
Federal programs are usually authorized to exist for a finite amount of time, typically three to five years, at which time Congress must renew the program's authorization through the legislative process. As such, Congress must renew the EMSC Program every few years. This is commonly referred to as "reauthorization." Congress can make changes to a program's scope of authority when it is reauthorized.

Federal Appropriations. Again, while authorizing legislation sets general funding levels for federal agencies and programs, an indicator of how much funding Congress thinks the program should receive, it does not provide funding itself. Actual program funding is accomplished through the federal budget and appropriations process.

Congress must complete the budget and appropriations process each federal fiscal year (October 1 through September 30). This means that, as a general

rule, federal agencies and programs receive funding one year at a time. If, however, all of the appropriations bills are not signed into law by the beginning of the fiscal year on October 1, Congress may pass a continuing resolution (CR). A CR funds agencies and programs, usually at the previous year's level, for a defined amount of time or until the appropriations bills are enacted.

The amount of funding a program receives can change from year to year, depending upon how much money Congress decides to allocate to it. Based upon federal policy and budget priorities, a program may receive a funding increase, a funding decrease, or level funding. In theory, federal agencies and programs must be authorized in order to receive an annual appropriation. In practice, however, Congress regularly appropriates funding to programs whose authorization has expired. It may take Congress several years to reauthorize a program through the legislative process; during this time, Congress often chooses to continue funding the program, despite the fact that its authorization has lapsed.



FAN Video, from page 1

also be available through the EMSC YouTube channel at <http://www.youtube.com/emscnrc>.

Note that this year's State Partnership Program Managers Meeting is being held in lieu of the Annual EMSC Program Meeting. The meeting will be held May 2-4, at the Westin Annapolis in the beautiful city of Annapolis, MD. It is anticipated that a full EMSC Program Meeting will resume in 2012.