



**Region 4 Genetics Collaborative Care Coordination Workgroup
Recommendation to the Advisory Group
November 17th, 2008**

RE: Midwest Emergency Medical Services for Children Information System (MEMSCIS)

Goal

Promote care coordination for children with heritable disorders

Strategies

- Promote care plans (emergency) for children with heritable disorders
- Implement use of emergency information forms specific to the needs of children with heritable disorders

Workgroup Activities Supporting This Recommendation

There are an estimated 250 babies born in Region 4 each year with inborn errors of metabolism ascertained through expanded newborn screening by MS/MS and many more children are born in Region 4 each year with other heritable conditions. Both populations of children face unique concerns in an emergency and would benefit from coordinated plans of care that are created in collaboration with their medical home and specialty health care providers.

The Region 4 Care Coordination Workgroup Emergency Subcommittee engaged in a process to become familiar with best- and promising practices based on findings in relevant literature, identify existing tools, assessing the identified tools, selecting a tool for adaptation to meet the needs of children with heritable disorders in an emergency situation, and assessing the selected tool for adaptability, feasibility, and resources needed.

A. Identifying and reviewing emergency information forms as clinical tools for improving emergency care for children with heritable disorders.

Several emergency care plans were reviewed and evaluated using a multi-step process. Emergency care plans reviewed included: Individual care plans currently being used by specialists' with Region 4 who treat children with heritable disorders; emergency plans/protocols developed for families and for professionals and promoted by disorder specific support groups; and emergency protocols from other genetic regional collaboratives.

Initially, the committee members reviewed plans according to a basic review tool developed by the Care Coordination Workgroup that directed the reviewer to comment on plan components (information captured), format, ease of use and strengths/weaknesses. Information was summarized so that the committee could compare components found in individual plans and the format in which the emergency information was provided.

B. MEMSCIS

After the review process was completed, the subcommittee reached consensus that the MEMSCIS program meets the essential elements of emergency care plans. MEMSCIS is a HIPAA compliant, web-based communication tool that utilizes the Emergency Information Form (EIF) developed and endorsed by the American Academy of Pediatrics and the American College of Emergency Physicians¹. With permission from the patient/family; the medical home providers, specialty providers, emergency providers, and other parties involved in the child's health care all have input into the content of the EIF and can access that information in an emergency. MEMSCIS is available anywhere in the world where there is internet access, and is not tied to any one particular health care system. The data on the EIF is owned by the patient.² Reporting functions enable use by, and identification of patients by, geographic area or resource needs in event of disaster.³

The MEMSCIS plan captured components of the plans reviewed and organized them in a logical, easy-to-read format. The subcommittee also compared the components of the MEMSCIS plan to information from the Newborn Screening ACT Sheets to ascertain that the MEMSCIS format was compatible to store information from the ACT sheets.

MEMSCIS, although web-based, includes a printer-friendly option that meets the needs of families who need, or desire, to keep the information available in hard-copy as well as accessible on the web.

C. Assessing the selected strategy for feasibility, adaptability and resources needed:

The subcommittee then assessed MEMSCIS according to adaptability, feasibility and resources needed to implement

Feasibility

Previous experience with Region 4 partners demonstrates the feasibility of implementing MEMSCIS. MEMSCIS is fully implemented at the University of Minnesota Children's Hospital, Fairview for use with children who have inborn errors of metabolism, congenital adrenal hyperplasia, and other chronic health conditions. As of September 2008, 233 children with special health care needs requiring emergency care plans were enrolled in MEMSCIS. Of the 233 enrolled, 83 have inborn errors of metabolism, 81 have cardiac conditions, 18 have endocrine conditions (congenital adrenal hyperplasia), and 51 have other chronic health conditions.

Adaptability

Programming of the MEMSCIS system is flexible and can accommodate different types of services and specialties by means of using specific diagnosis, medication list, and condition-specific common presenting problems and plans of care. Negotiations are in process to expand MEMSCIS availability to the University of Illinois at Chicago for use by patients with sickle cell disease.

¹ American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children with Special Health Care Needs. *Pediatrics*. 1999; 4:104. Available at: <http://www.pediatrics.org/cgi/contents/full/104/4/53e>

² Development of a web-based database to manage American College of Emergency Physicians / American Academy of Pediatrics Emergency Information Forms. *ACAD Emergency Med*. March 25, 2005. Vol 12 No 3 Available at: www.aemj.org

³ American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children with Special Health Care Needs. *Pediatrics*. 1999; 4:104. Available at:

Indiana is considering the use of MEMSCIS for their patients with inborn errors of metabolism. A teleconference was held in October 2008 to demonstrate MEMSCIS to researchers at Northwestern University in Illinois who are interested in improving access to vital, disorder specific information at the time of emergency transfer between medical care facilities.

MEMSCIS also is adaptable to meet family needs. Several participants do not have internet access in the home. These users can be given a copy of the EIF printed directly off the MEMSCIS system website. They can keep that copy for their record or when they visit the ED when needed. Other participants have a primary language other than English. A multi-language informational DVD has been made to teach families about MEMSCIS. Languages include: English, Spanish, and Hmong.

Resources

Resources are currently available to support the expansion of MEMSCIS through Region 4 Base Funding. In 2007, the Region 4 Genetics Collaborative agreed to support the expansion of the Minnesota Emergency Medical Services for Children Information System to include all metabolic centers in all seven Region 4 states, becoming the Midwest Emergency Medical Services for Children Information System (MEMSCIS). Later in the grant cycle, MEMSCIS expansion strategies include facilitating interoperability between the web-based server (DocSite) used in the IBEM-IS (Priority 2 activity) and the web-based server (ImageTrend) used in the MEMSCIS project. This will enable the data on emergency encounters for patients with inborn errors of metabolism to be integrated with long-term follow-up data.

Recommendation to the Region 4 Genetics Collaborative Advisory Group

Support, promote and encourage the use of MEMSCIS throughout Region 4 as a clinical tool for improving emergency care to individuals with heritable disorders.

To realize this recommendation, the following next steps will be initiated:

- Restructure the MEMSCIS Advisory Board to reflect a broader group of Region 4 stakeholders (disorder specific, role, etc.) to provide input, oversight, and access to expertise as MEMSCIS is expanded to include additional heritable disorders and a broader geographic region.
- Develop an implement a process to respond to inquires about MEMSCIS to engage interested parties in a timely fashion.
- Develop an implement a marketing plan, including recruiting clinics to enroll their patients.