

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

Workgroup 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**
- **Revise Emergency Information Forms to facilitate electronic sharing of care plans**

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

Region 4 Progress Review for MEMSCIS Project with Inborn Errors of Metabolism

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). Funding for the MEMSCIS Pilot Project was awarded as part of the base funding grant for Region 4 and implementation began in June 2007. The Minnesota MEMSCIS project had previously been funded by the USDHHS MCHB and implemented in Minnesota for three years.

MEMSCIS is fully implemented at the University of Minnesota Children's Hospital, Fairview for use in children with 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. Several participants do not have internet access in the home. Other participants have a primary language other than English. Some participants are involved with multiple health care systems across state borders.

Negotiations are in process to expand MEMSCIS availability to the University of Illinois at Chicago for use by patients with sickle cell disease. Indiana is considering the use of MEMSCIS for their patients with inborn errors of metabolism. A teleconference is planned in October 2008 to demonstrate MEMSCIS to researchers at Northwestern University in Illinois.

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 us to collect more objective data on emergency encounters for patients with inborn errors of metabolism and correlate that information with other measures of care.

MEMSCIS Enrollment Expansion

The Region 4 Care Coordination Workgroup Emergency Subcommittee reviewed literature, Region 4 center-specific plans, and other existing plans for emergency care for children with special needs and determined that the MEMSCIS program meets the essential elements of such 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 Physicians. 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. Reporting functions enable use by, and identification of patients by, geographic area or resource needs in event of disaster.

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. Many more children are born in Region 4 each year with other heritable conditions and those children also face unique concerns in an emergency. Both populations of children with special health care needs would benefit from coordinated plans of care that are created in collaboration with their medical home and specialty health care providers

Recommendation to the Region 4 Genetics Collaborative (as represented by the 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 Care Coordination Workgroup further recommends:

- **Restructure the MEMSCIS Advisory Board to reflect a broader group of Region 4 stakeholders (disorder specific, role, etc.).**
- **Implementation of a series of stakeholder surveys to obtain information to assist in:**
 - **Adapting MEMSCIS to better meet the needs of the users**
 - **Identifying and developing strategies to address barriers to implementation of Emergency Information Forms; specifically MEMSCIS**
 - **Promoting MEMSCIS as the EIF of choice for clinicians in Region 4.**