


MEMSCIS
Midwest Emergency Medical Services for Children
Information System

An integrated approach to emergency care planning
for patients with heritable conditions


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**On behalf of the
Region 4 Genetics Collaborative**




Emergency Planning for Children with Special Health Care Needs: A National Priority

- ◆ CSHCN face unique concerns in an emergency
- ◆ Rare conditions, or complex conditions with multisystem involvement
- ◆ Paper charts: Unavailable, voluminous, outdated, incomplete
- ◆ Electronic charts: Not designed well for emergency use
- ◆ Improved methods of communication with Medical Home are needed



Emergency plans: where are they now?

- ◆ There is a spectrum:
 - Organized strategies and widely accepted protocols exist for some heritable conditions (SCD)
 - No widely accepted consensus on others (many IBEM, CAH)
- ◆ Most plans currently based on clinical and family experiences
- ◆ Most IBEM treating centers have plans
- ◆ Most are paper based: “emergency letters”



Region 4 and Emergency Care Planning

- ◆ Approximately 730,000 births per year (estimated 250 new babies born with special health care needs due to IBEM alone each year)
- ◆ Ideal opportunity for multistate-multicenter collaborations to better define and implement coordinated plans of emergency care for patients with rare and complex conditions.
- ◆ *Goal: Expanding usage of the MEMSCIS system to children with heritable conditions requiring emergency plans in a large geographic area (Region 4) will test the robustness and flexibility of the system with a large number of patients with a variety of health concerns.*

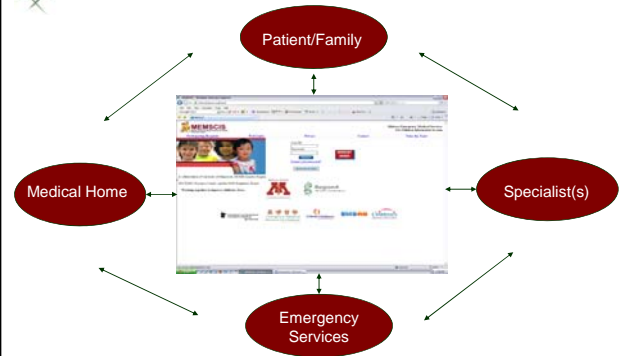


MEMSCIS: make an approved EIF available as a web-based tool for families

- ◆ AAP and AAEM have agreed on elements ideal for emergency information
- ◆ Paper form available
- ◆ Adaptation of elements on paper form to web-based entry



MEMSCIS: A web-based communication tool



MEMSCIS as a priority for Region 4 Genetics Collaborative

- ◆ Available to any clinical center in Region 4
- ◆ **NO COST TO PATIENT/FAMILY OR PARTICIPATING R4 CENTER**
- ◆ Appropriate for any patient with special health care needs who requires an emergency plan
- ◆ MEMSCIS Liaison coordinates with each Region 4 center
- ◆ Can be tailored to center-specific needs (templates, permissions)



Goals for MEMSCIS in R4

- ◆ 50% of patients enrolled in IBEM-IS will also be enrolled in MEMSCIS
- ◆ Facilitate interoperability between MEMSCIS and IBEM-IS
 - Obtain more objective data about emergency encounters
 - Correlate that information with other measures of care
- ◆ Facilitate electronic sharing of care plans among families, medical home, specialists across Region 4
- ◆ MEMSCIS expanded to other conditions beyond IBEM in Region 4



The planners in R4? Care Coordination Workgroup

- ◆ Reviewed literature, center-specific and other existing plans for emergency care planning
- ◆ Identified elements that all agree are essential and that should be done uniformly (all in line with EIF as available through MEMSCIS)
- ◆ Survey of Medical Home, ED, Family, Specialists regarding emergency care needs for patients with heritable conditions in Region 4
- ◆ MEMSCIS Workgroup
 - Liaison

Anticipate National Advisory Group



The Emergency Information Form (EIF)

EIF created by the American Academy of Pediatrics (AAP) & the American College of Emergency Physicians (ACEP)

Blank form available anywhere in the world where there is internet access (not tied to any one medical system)



MEMSCIS Critical Components: Web-based entry for EIF

- ◆ Data: ease of entry from point of service (home, clinic, ED, traveling)
- ◆ HIPAA-compliant, secure, web-based with option of paper and pdf versions
- ◆ Access at varying levels (controlled by patient/family)
 - Patient/Parent/Guardian
 - Medical Home
 - Specialty Providers
 - Emergency Services (911, ED Providers)
 - Other (dietitian, pharmacy, inpatient teams, home care, care coordinators...)



MEMSCIS Web site components

- ◆ Real-time editing/management and access
- ◆ Broadly useful even when:
 - Participants do not have internet access in the home
 - Language other than English is primary language
 - Participants receive specialty and emergency care across borders



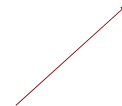
A critical attribute:
Not based on location

Disaster preparedness:

- Reporting functions enable use by and identification of patients by geographic area or resource needs in event of disaster
- Information not dependent on location of data



The Emergency Information Form



- Patient/Family Controls Data
- Click button for "Emergency Access"
- New security measures implemented



Emergency Information Form Data



Updated by Parent



Updated by Medical Staff



Updated by Administration

- Date/time/user marked authentication system fully implemented
- Data stored and backed up in 2 different cities



Transitioned to a clinical tool

- In the beginning: consent process done in person
- Transition to a CLINICAL tool: IRB approval to transition MEMSCIS to a web-based self-enrollment process (expands availability to patients of any age who are affiliated with a MEMSCIS-participating center).
- Enrollees will be asked to consent to allow future contact.

USE OF THE WEB-BASED EIF IS NOT RESEARCH.



MEMSCIS is open for your use

- ◆ “Host” that uses Web-based technology is not tied to any one particular health care system
- ◆ **Ready to expand as Centers sign up and are prepared to assist families with enrollment.**

Go to www.memscis.org and click on **Take the Tour!**



Current status in R4

- ◆ No need to reinvent the wheel: Emergency Information Forms well studied and developed by the AAP and ACEP; MEMSCIS utilizes the EIF
- ◆ A flexible, child/disease specific, detailed yet user friendly web-based communication tool is *AVAILABLE* for patients with special health care needs, their families, their medical homes, their specialists, and emergency care providers.
- ◆ The price is right: Professional and IT support, coordination of MEMSCIS-related research initiatives and materials available at no cost to families or Region 4 participating centers as part of our base funding!



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