

# **Education Plan for Uniform, Comprehensive Newborn Screening in Military Treatment Facilities**

Version 2.2

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Newborn Metabolic Screening Integrated Project Team

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## **Introduction**

On 24 June 2005, the Tricare Management Activity chartered the Military Health System Newborn Metabolic Screening Integrated Project Team (IPT) to “promote and facilitate the execution of a comprehensive, expanded, and uniform newborn metabolic screening program.” In this charter, emphasis was placed on training those physicians responsible for oversight of newborn screening within each Military Treatment Facility (MTF). The IPT developed an understanding, however, that an essential element of creating an effective newborn screening (NBS) program would be a broader emphasis on education. This education plan would necessarily encompass all clinicians who implement or utilize NBS. In addition, parents, nursing and laboratory personnel, subspecialty consultants, and policymakers require information that explains this new plan for NBS within the Military Health System (MHS). Because NBS will continue to change, our educational materials and strategies must remain responsive to these changes through ongoing review and revision.

## **Methodology**

An IPT subcommittee comprised of three members, Col Melissa Fries (USAF, Obstetrics and Medical Genetics, USUHS - retired from active duty March 2006), Ms Kathryn Camp (Pediatric Nutrition, WRAMC), and COL Scott McLean (USA, Pediatrics and Medical Genetics, BAMC and WHMC), formulated this educational plan from June 2005 through October 2006. The IPT recommended the development of a general policy to promote the application of a uniform, comprehensive approach to newborn metabolic screening throughout the MHS that would be consistent with the recommendations of the American College of Medical Genetics Expert Group under contract to the Health Resources Services Administration. Education Subcommittee reports were reviewed by the IPT monthly. Source material and input included those available through the National Newborn Screening & Genetics Resource Center (NNSGRC), the March of Dimes, the American Academy of Pediatrics, and the Secretary’s Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. The Newborn Screening Performance Evaluation and Assessment (PEAS), available through the NNSGRC, has provided important guidance for this process.

## **Strategy**

Because newborn and pediatric public health care within the MHS differs from that within the civilian community, some variation from state-oriented educational plans for NBS has been anticipated. For instance, military beneficiaries generally have ready access to primary care providers who, in turn, have access to a global network of communication, medical transportation, emergency and critical care, and subspecialty services. However, the fundamental educational focus has remained on the Medical Home, the partnership of parents and the primary care manager to optimize health care outcomes.

## Mission Statement

The Military Health System Newborn Metabolic Screening Program will provide comprehensive education for parents, primary care providers, and members of our health care community who support them. The educational program will be accessible worldwide, across all military services, will enable rapid provision of state-of-the-art evaluation and treatment, and will foster a supportive and pro-active medical home.

## Goals and Objectives

1. MTFs throughout the Department of Defense (DoD) will use a uniform, core curriculum that will be consistent with national guidelines and DoD Policy.
2. The curriculum will utilize a variety of educational materials and will be tailored to the needs of specific stakeholders, who will include parents, nursing personnel, laboratory personnel, primary care clinicians, specialty care clinicians, and policymakers.
3. Parental educational materials will be linguistically and culturally appropriate for each family.
4. Educational materials for those clinicians who care for newborns and infants will include didactic information that explains their critical role in the larger picture as well as point-of-care information to facilitate the timely management of newborns with positive screening results.
5. The Education Program will undergo annual review and update by a multi-disciplinary group with Triservice representation.
6. Parents will have formal opportunities to provide input.

## Identification of Stakeholders

The Military Health System's NBS education program will focus on primary care providers and parents. However, a number of other individuals with supporting roles will benefit from familiarity with the overall process and will require periodic education and/or training in order to integrate their particular skills with the screening system.

Stakeholders include:

- Newborns, whose interests are represented by their parents; by clinicians whose professional roles include advocacy, responsibility, and oversight; and by administrative and policy experts with a duty to promote the public health.
- Parents

- Primary Care Providers, whose interests begin prenatally and end when newborn screening data is no longer clinically relevant. This time frame is incompletely understood, since some conditions may become clinically apparent well into childhood or even, in some rare cases, in adulthood. Clinicians who care for children as old as 24 months, even on a first encounter, will be targeted.
  - Obstetricians
  - Neonatologists
  - Pediatricians
  - Family Physicians
  - Advance Practice Nurses, who may see infants and toddlers
  - Physician Assistants, who may see infants and toddlers
- Pediatric Subspecialists caring for newborns who have had an abnormal newborn screen and require confirmatory testing and/or urgent management.
  - Pediatric Endocrinologists
  - Pediatric Hematologists
  - Child Neurologists
  - Pediatric Pulmonologists
  - Pediatric Gastroenterologists
  - Clinical Geneticists
  - Biochemical Geneticists
- Other care providers
  - Cystic Fibrosis Center personnel
  - Pediatric Nutritionists
  - Social Workers
  - Nursing Personnel
    - Inpatient
      - OB
      - Neonatology
      - NICU
      - Pediatrics
    - Outpatient
      - OB
      - Pediatrics
      - Family Medicine
- Laboratory Personnel
  - Laboratory Directors
  - Laboratory Managers/Administrators
  - Laboratory Technologists/Technicians
    - Collection
    - Processing
    - Shipping
    - Result reporting
- MHS Informatics
  - Local
  - Global
- Education Coordinators

- Nursing
- Undergraduate/Medical Student
- Graduate Medical Education
  - Residency Directors
    - Obstetrics
    - Pediatrics
    - Family Medicine
    - Pathology
  - Fellowship Directors
    - Neonatology
    - Pediatric Hematology/Oncology
    - Pediatric Endocrinology
    - Pediatric Gastroenterology
    - Developmental Pediatrics
    - Child Neurology
    - Maternal-Fetal Medicine
- Dietetic Education
  - Dietetic Internship Directors
  - Dietetic Masters Program Director
- Policy makers and advisors
  - TMA
  - Service-specific clinical and laboratory consultants to the Surgeons General
  - Offices of the Services Surgeons General
  - Public Health
  - Legal Counsel
  - Medical Ethicists
  - TRICARE Health Benefits Advisors
- Local Administrators
  - Department Chiefs
  - Hospital commanders
- Newborn Screening Public Health Officials
  - NNSGRC/HRSA
  - State Newborn Screening Coordinators
- Military NBS Program Advisory Committee Members

### **Parent Education Plan**

Numerous opportunities for parent education can be leveraged during the prenatal, perinatal, and postnatal periods. Ideally, these might form a continuum of information. However, because health care visits might occur intermittently or might occur outside the MHS, each educational presentation should be independently capable of communicating the full message of what newborn screening can offer to newborn children and their families. Elements of the parental education program should include

- The principles behind screening in the immediate newborn period
- The conditions included in the newborn screen
- The importance of newborn screening
- Limitations of newborn screening
- Point of contact to ask questions
- Resources available for more in-depth information
- Understanding of how to obtain NBS results

All communication with parents at each contact and through each modality should be in language that is clear, appropriate to their educational background, and culturally appropriate.

During the prenatal period, the outpatient Obstetrics or Family Medicine Clinic will begin the prenatal education process. Passive measures might include clinic posters, bulletin boards, and brochures. A number of federal, state, and private agencies have already developed various media for this purpose, such as:

- The American Academy of Pediatrics and HRSA have developed a brochure, *Newborn Screening Tests – These Tests Could Save Your Baby’s Life* [**Appendix A**], that is available without charge in the public domain and should be adapted for MHS use.
- The March of Dimes has created a low-cost DVD titled “A Parents Guide to newborn Screening” available in both English and Spanish, which might be useful for prenatal classes or in waiting areas.

In addition to these passive measures, newborn screening should be directly discussed – either during one-on-one prenatal visits or in group settings. A potentially useful time might be when prenatal cystic fibrosis counseling occurs, already a standard element for many MHS obstetric practices. Recent research ([Davis TC, et al. \*Pediatrics\* 2006;117\(5\):S326](#)) indicates that parent education, using both oral and written materials, during the third trimester is most effective.

Parents often learn about newborn screening when the nurse or technician draws blood from the baby’s heel and the parents ask, “Why are you doing that?” Written information should be provided in the immediate postnatal period. In addition, a conversation about newborn screening should occur well enough in advance of the heel-stick blood collection to allow parents to understand the nature and intent of this procedure. These written materials should include the first well baby clinic appointment, 7 -14 days after birth , at which time newborn screening test results will be disclosed. Written materials should also direct parents to authoritative internet resources, to include the March of Dimes and the NNSGRC parent web sites.

At the first well-baby visit, parents should be informed about the NBS test results for their child. If results are not available, arrangements should be made to inform parents telephonically as soon as results are available.

In the event that a newborn screen is positive for one or more of the tested conditions, parent education becomes an important aspect of the integrated management of the potentially affected child. It is incumbent upon the primary care giver to provide reassurance and support and yet clearly articulate the degree of urgency, the nature of the suspected condition, the necessary steps for clinical evaluation, laboratory confirmation, empiric treatment, and expert consultation. Much of the information that will guide the primary care giver will be available via ACTION sheets that are available via the NNSGRC web site. These have links to fact sheets that have been created specifically for parents. The primary care provider in many cases will simultaneously make contact with a subspecialty consultant who, in the case that the infant is referred, will provide in depth parental education.

### **Nursing Education Plan**

At the time that a NBS blood sample is obtained from the baby after birth, parents usually learn about newborn screening from the infant's nurse. Recent research (Davis TC et al. Recommendations for effective newborn screening communication. *Pediatrics* 2006;117:326-340.) found that parents typically remember very little about newborn screening during the short hospital stay. Nursing personnel on the Mother/Baby inpatient service should receive an initial orientation to the MHS NBS Program via an appropriate modification of the Core Curriculum (see below). Nursing and medical providers should communicate to ensure that their parental education activities are complementary and not in conflict. Nurses may have responsibility for providing the MHS NBS Brochure (Appendix A) and should verbally reinforce, using language with which the parents are comfortable, the seven points recommended for parental discussion (see Appendix B):

1. All newborns should be tested for some rare disorders before discharge.
2. Babies with these disorders may look healthy at birth.
3. Serious problems can be prevented.
4. We will take a few drops of blood.
5. We will get the test results. Your baby's provider will tell you about them at the first check up.
6. Some babies need another test. If this is the case, it is important to get re-tested quickly.
7. If you have questions, call your baby's primary care provider.

In addition, nursing personnel are frequently responsible for collecting the filter paper blood sample, accurately entering information on the attached data form, and delivering the specimen to the hospital or clinic laboratory. Each of these initial elements, if not executed in a timely and precise manner, may undermine the entire NBS process. Consequently, these activities must be scrutinized by every level of supervisory personnel in a continual effort to maintain the highest level of quality.

## Primary Care Provider Education Plan

For the purpose of NBS, the primary care provider (PCP) will be considered the credentialed provider who bears primary responsibility for newborn care in the hospital at the time of delivery until discharge. In addition, the PCP is also the responsible clinician who provides routine outpatient well child care, ideally with consistency and in the context of the Medical Home, during the first 24 months of life. These individuals may be neonatologists, pediatricians, family physicians, advanced practice nurses, or physician's assistants.

All PCPs must be familiar enough with the NBS program in order to effectively educate parents. They must therefore review the parental curriculum and resources carefully. See **Appendix B**

(<http://www.medicalhomeinfo.org/screening/Screen%20Materials/Newborn%20screening%20disorders.pdf>).

### *Core Curriculum*

Under different conditions, PCP educational needs will vary significantly. Ideally, each licensed clinician will have received didactic and clinical graduate training that addressed the principles and practice of NBS. However, many PCPs indicate that they lack confidence in this area, especially when NBS utilizes tandem mass spectroscopy. (See Gennaccaro M et al. The knowledge gap in expanded newborn screening: survey results from paediatricians in Massachusetts. *J Inherit Metab Dis* 28 (2005): 819-824.) Consequently, a standard, core curriculum and a selected bibliography that focus on fundamental issues should be available for all providers and will include the following elements:

- History of Newborn Screening
  - What drives NBS?
  - Military-specific challenges
- Principles of Population Screening
- Elements of a Newborn Screening Program
  - Parent and vider Education
  - Access to the screening test
  - Sample acquisition, handling and shipping
  - Laboratory Testing
  - Transmittal and Documentation of Test results
  - Communication of test results to parents
  - Management of Positive Results
    - Clinical evaluation
    - Confirmatory testing
    - Referral to Subspecialist
- Follow-up
- Quality assessment
- Policy oversight

Descriptions of each screened condition

- Incidence
- Inheritance
- Natural history
- Clinical diagnosis
- Screening test
- Confirmatory test
- Management
  - Emergency Intervention
  - Pharmacologic Treatment
  - Subspecialty Referrals
  - Prognosis
  - Genetic Counseling

Internet and Support Group Resources

Effective Communication

Missed Screens and other limitations

Best Clinical Practices

- Universal screening
- Speed
- Communication
- Reassurance
- Follow-up
- Referral

**Appendix C** is an annotated PowerPoint presentation that incorporates many of the points above. Brief descriptions (ACTion Sheets) of each condition currently recommended by ACMG/HRSA are available for review via the NNSGRC website.

Effective use of this core curriculum may employ several options. Because military and civilian clinicians who work in the MHS are sometimes overburdened with numerous duties, it would seem unreasonable to universally mandate yet another training module as a pre-requisite for credentialing. However, when a PCP joins a facility at which he/she will order, evaluate, or utilize NBS, that individual should be made aware that this resource exists. This may be upon initial employment or at the time of a PCS or TDY assignment. The local MTF NBS coordinator, usually the chief of a clinical service or his/her designee, should incorporate educational guidance in their local NBS policy document. Options for use of the core curriculum might include self-study, didactic lectures, and video tele-conferencing.

Annual “refresher” training, especially if there have been changes to the NBS panel, information management, vendor protocols, or in the availability of MHS resources, should be encouraged for all PCPs.

### *“First Responder” NBS Education*

A general familiarity with NBS will serve most PCPs well in daily practice. Because the new MHS NBS Program will significantly increase the number of conditions screened, there will be a proportionate increase in the number of positive NBS results. PCPs will naturally be unfamiliar and anxious in negotiating their way through the unfamiliar territory of distinguishing the true positive from the false positive. In the event that a newborn’s screening test is reported as positive, that PCP must have immediate access to understandable, practical, and comprehensive educational materials. The Newborn Screening Act Sheets and Confirmatory Algorithms developed by ACMG (<http://www.acmg.net/resources/policies/ACT/condition-analyte-links.htm>) will fulfill this need. Additional information will also be available via the genetic counselor who serves as the point of contact at the NBS laboratory contractor. The local State or Regional NBS Program may have the capacity to identify subspecialty consultants, such as metabolic geneticists and nutritionists, who in turn would provide the most authoritative management advice over both the short and the long term. The MHS NBS Program, however, if it does not participate financially in state programs or regional cooperatives, should not assume that their resources will be routinely accessible.

The ACMG Act Sheets are designed to be customized for the needs of specific State NBS programs. The MHS NBS Program will modify these ACT Sheets and make them available to PCPs via a dedicated web site link (to be developed at a centralized MHS website source). MHS NBS modifications should include:

- Information on how to contact the MHS NBS Laboratory and Support Staff
- Links to local State NBS Programs
- Links to MHS Subspecialty Resources
  - On Call Pager Numbers
  - Routine contact phone numbers
  - Email addresses for teleconsultation
    - Pediatric Hematology
    - Pediatric Endocrinology
    - Pediatric Neurology
    - PICU
    - Inpatient Services
    - Metabolic Genetics
    - Pediatric Pulmonary
    - Regional Cystic Fibrosis Centers

### *Obstetrics*

Obstetricians, OB Nurse Practitioners, OB Nurse Educators, Nurse Midwives, Family Physicians, and others who evaluate and counsel women during routine prenatal visits should be aware of the core curriculum and the parent education program.

### **Subspecialist NBS Education Plan**

Within the MHS, numerous subspecialists – both in uniform and civilian contractors – are available as valuable clinical resources. This is one of the unique assets available to the MHS NBS Program and may be effectively cultivated via educational curricula that address each subspecialty area's needs.

Because individual subspecialists will routinely evaluate newborns with positive newborn screening test results, each should be familiar with the scope and range of the MHS NBS Program. In addition, subspecialists should be comfortable with their roles as consultants for the Medical Home. Through service-specific subspecialty leaders and senior clinicians, each subspecialty network should disseminate the standard educational materials for parents and primary care providers in order to develop a consensus approach to handling requests for advanced educational materials. Subspecialists should be encouraged to seek out newborn screening topics when obtaining Continuing Medical Education. They should also be encouraged to focus on screened conditions when asked to provide didactic lectures or grand rounds to colleagues or PCPs.

### **Laboratory Officer and Technologist/Technician Education Plan**

Pathologists and administrative laboratory officers are frequently overlooked elements in the delivery of NBS services. They will provide supervision and oversight of the technicians who will collect, process, and ship the newborn screening samples to the vendor. Laboratory personnel also will have responsibility for receiving NBS results and incorporating them into the electronic medical record. It is incumbent that these individuals grasp the strategic picture and foster effective and timely communication among the health care team. Consequently, at least one key supervisor at each MTF should be expected to be familiar with the parent education materials and the core curriculum.

Because of personnel changes, inexperience, and other factors, the collection and processing of newborn screening samples is often the weakest link in any NBS program. This is amplified in the MHS. Poor collection techniques, logistical impediments to rapid shipping, delayed and/or poor data entry must be minimized in order to maintain adequate overall quality. Education for laboratory technologists/technicians must be given a degree of priority that results in acceptable rates of unsatisfactory specimens.

### **Medical Trainee Education Plan**

Undergraduate and Graduate Medical Education is an integral component of the MHS. Medical students at the Uniformed Services University of the Health Sciences; residents in pediatrics, family medicine, and pathology; dietetic interns and dietitian enrolled in the

DoD Dietetic Master's Program; fellows in pediatric neurology, pediatric endocrinology, and pediatric hematology are already components of the MHS and can be expected to remain in the MHS for a number of years. Consequently, exposing these individuals to the core NBS curriculum as a component of their larger curriculum represents an important opportunity. Program directors should be made aware of the high value of this topic and the considerable educational resources that exist within the MHS. Prepared power point presentations similar to Appendix C will be made available for download and use via the central MHS website. The MHS NBS Program should seek to connect training programs with other regional and national NBS subject matter experts, as well.

### **Administrative and Executive Personnel**

A number of supervisory and advisory personnel will need to be aware of the activities of the MHS NBS Program and will bear some responsibility for understanding whether it is accomplishing its goals. Departmental chiefs, hospital commanders, public health experts, and policy makers within each service and within the TMA should be familiar enough with the fundamental principles of NBS and the MHS NBS Program in particular to make informed decisions on related topics as they arise. The Consultants to each of the Surgeons General, for Pediatrics, Newborn Medicine, Family Medicine, Pathology/Lab Program, Information Technology, and Clinical Genetics, must maintain familiarity with the MHS NBS Program. Representatives who serve in key roles, especially if they serve in an official MHS or TMA advisory capacity, should be encouraged to participate in the ongoing national dialogue of NBS policy development. It will be critical to maintain a DoD representative to the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, who will in turn serve as a key educational advisor to the MHS NBS Program. In addition, national and regional NBS scientific meetings are excellent opportunities for education of MHS NBS Program coordinators.

### **Annual Review**

A committee with Triservice representation will conduct an annual review of the educational program. Input from all stakeholders, including parent representatives, will be requested. Periodic surveys of parents and primary care providers will be developed to ascertain needs, trends, and opportunities for improvement. The education review committee will compile an annual report to be submitted to the chair of the Comprehensive Metabolic Newborn Screening Sub-Working Group. This Sub-Working Group will function as the primary advisory group to the MHS on newborn metabolic screening issues and will report overall progress in the implementation of comprehensive, up to date screening quarterly to the DoD TRICARE Clinical Quality Forum or as needed.