



HRSA Update and Introduction; July 2010

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Genetics Services Branch-Legislation

- Heritable Disorders Program- Public Health Services Act- 2000
- Congenital Conditions- Newborn Screening Saves Lives Act- 2008
- Special Projects of Regional and National Significance (SPRANS)- Title V- Social Security Act
 - Genetic Services
 - Sickle Cell Disease and Newborn Screening- earmark
 - National Hemophilia Program
 - Thalassemia

Congressional Mandates

- Hemophilia-Provide access to hemophilia diagnostic and treatment centers to provide comprehensive care through adulthood
 - **340B Drug Pricing Program**-Provide access to factor at a discounted price and pass the savings on to the consumers or back into services
- Sickle Cell Disease and Newborn Screening- Enhance the sickle cell disease and carrier follow-up services of State newborn screening programs with community-based efforts that provide hemoglobinopathy counseling, education, referrals to primary care providers and comprehensive SCD treatment centers. Funding for a National Coordinating & Evaluation Center
 - **FY 2011**-Formation of 6 regional networks and a coordinating center
 - Align with SCD Treatment Program

Congressional Mandates

- Sickle Cell Disease Treatment Demonstration Program-the development and establishment of infrastructure and partnerships to enhance the prevention and treatment of sickle cell disease. Fund a National Coordinating Center
- Thalassemia- Support implementation of demonstration grants regarding a model system of comprehensive care and medical management for individuals and families at risk for or affected by Cooley's Anemia/Thalassemia-tertiary care

DSCSHN: Program Framework

- “Facilitate the development of systems of services for children, youth, and adults with special health care needs”....(OBRA '89)



Genetics Services Branch Programs

- Heritable Disorders Program
 - Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children
 - Newborn Screening Information Clearinghouse
 - Resources for families, general public and providers
 - Data Repository
 - Effective Newborn Screening and Follow-up
 - Regional Collaboratives
 - Interagency Collaboration

- Hemoglobinopathy/ Blood Disorder Program

- Originally 4 grantees and a NCC; expanded to 6 grantees for Sickle Cell model system of comprehensive care and medical management Treatment Demonstration Project.
- Recently funded 3 Thalassemia projects
 - model system of comprehensive care and medical management
- Recently contracted with SCDAAs to work on NBS educational project
- HHS strategic plan for blood disorders being developed (HRSA, NIH, CDC, AHRQ, CMS)

- Hemophilia Treatment Program

- 12 Regional grants and 130 Hemophilia Treatment Centers
- In 47 states, The District of Columbia, Guam and Puerto Rico
- Funding is for comprehensive care, outreach, collaboration and facilitation of factor replacement
- **FY 2011**
 - Propose formation of 8 regional networks
 - One coordinating center
 - Collaboration with CDC and NIH for monitoring of health outcomes

Newer Initiative

- Early and Continuous Screening through the Medical Home.
 - Improving screening and surveillance practices within the medical home for all children and adolescents.
 - One grantee-NY consortium centered at Albert Einstein

New FY 2010

- **Effective Follow-up in Newborn Screening** (4 years)
 - Use of electronic health information exchange (HIE) to improve the newborn screening system,
 - Attention to both short and long-term follow up.
 - 4 States [NY, CO, UT, IN] funded (and many partners have joined working group)

Prenatally and Postnatally Diagnosed Conditions/ Congenital Conditions (4 yr)

- Allows family support groups working with health professionals, state genetic services programs and Health Resources and Services Administration, (HRSA)/Maternal and Child Health Bureau (MCHB) to increase awareness and educate families (including potential adoptive parents) on prenatally/postnatally diagnosed conditions.
 - *The appropriations language further specified positive test diagnosis for Down syndrome, spina bifida, dwarfism, or other prenatally and postnatally diagnosed conditions.*

Family History for Prenatal Providers.(3 years)

- Develop a family history tool that may be used for taking a woman's health history spanning her life cycle.
- The tool is to be developed for eventual incorporation of history taking tools and accompanying information, educational and decision-making materials into electronic health records.

Newborn Screening Clearinghouse (5yr)

- Existence is legislated
- Focus will be development of a provider and consumer resources
- For next couple of years will be working with HRSA to gather information about what new NNSIS will look like- but will not HOUSE the NNSIS
- **No newborn screening patient information will be linked to this site**

Future Programs

- ICC- Interagency Coordinating Committee on NBS
 - Legislated in NBSSLA
 - Will include all major HHS entities
 - Federal agencies will make up the membership
 - Will provide guidance for Secretary of HHS
 - Will work with SACHDNC
 - Will be shared delegation by CDC and HRSA

Future Programs

- NBS CQE Program
 - Voluntary program to enhance quality of NBS SYSTEMS
 - Collaboration with CDC NBSQAP and PT programs
 - Will include pre and post analytical systems
 - Outgrowth of NNSGRC program evaluation
 - Needs to be shaped by state needs
 - Hope to be able to get certification that impacts CHIPRA and Medicaid reimbursement

Future Projects

- Through Cooperative Agreements, we will continue to explore the issues of the maldistribution of all aspects of genetic service capacity, including many of the policy and education and training issues that will surround us. These issues include such areas as: family health history, emergency preparedness, education of providers and consumers, utilization of telegenetics/telehealth options.
- **Please send project ideas.....**

Patient Protection and Affordable Care Act

A group health plan and a health insurance issuer offering group or individual health insurance coverage shall, at a minimum provide coverage for and shall not impose any cost sharing requirements for—

- ...and
- “(3) with respect to infants, children, and adolescents, evidence-informed preventive care and screenings provided for in the comprehensive guidelines supported by the Health Resources and Services Administration.
- “(4) with respect to women, such additional preventive care and screenings not described in paragraph (1) as provided for in comprehensive guidelines supported by the Health Resources and Services Administration for purposes of this paragraph.

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