PROJECT IDENTIFICATION:

Project Title:	**Genetics Services Program**
Project Number:	**H46 MC 00196-02**
Project Director:	**Carmen B. Lozzio, MD, FACMG, Professor and Chair, Department of Medical Genetics**
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Project Period	**6/1/2001 to 5/31/2003**
Total Amount of Grant Awarded:	**$150,000.00**

ABSTRACT

PURPOSE**:** To develop a comprehensive statewide genetics plan that ensures that the State Newborn Genetic Screening (NBS) and Newborn Hearing Screening (NHS) Programs have an adequate public health infrastructure and are coordinated with other programs for children with special health care needs (CSHCN).

PROBLEMS: Several different state departments were providing services for CSHCN. There was a need to develop a system that would allow multiple service providers to coordinate care and to facilitate access to those providing services.

GOALS: 1) Early identification of children with genetic disorders and special health care needs; 2) Integration of the systems of early identification with those of early intervention; 3) Development of a system for retrieval of this information by case managers and primary care providers; 4) collaboration between public health programs, early intervention services and between those programs and community health professionals, and the public.

PROGRAM ACTIVITIES: Coordination of services at the state level was accomplished by creating a Statewide Genetics Planning Committee (SGPC) of 29 members with representatives from programs within the Tennessee Department of Health and other members from the Tennessee Department of Education, Department of Mental Health and Developmental Disabilities, and the Division of Mental Retardation as well as consumer organizations. The members of this committee

participated actively in the development of the Tennessee Genetics Plan through frequent conference calls and the reports of seven subcommittees that addressed specific goals and objectives of this program. The Information Technology (IT) infrastructure was expanded to create a Child Health Profile. Focus groups were conduced to identify areas of concern for parents of CSHCN.

RESULTS/OUTCOMES: The Tennessee Genetics Plan and an Information Technology (IT) Plan were developed. Recommendations were made to expand the NBS Program and by the end of 2003 Tennessee will be screening for the nine disorders recommended by the March of Dimes and about 98% of all infants born in the state will receive a newborn hearing screening (NHS). The NBS and NHS programs have been coordinated at the state and local levels and a comprehensive follow-up plan has been developed.

ANNOTATION:

The purpose of this project was to develop a comprehensive genetics plan for the State of Tennessee. The problems addressed were the lack of coordination of services. The goals and program activities addressed the need to coordinate services to expand the Newborn Genetic Screening (NBS) and Newborn Hearing Screening (NHS) programs and to develop the Information Technology (IT) infrastructure needed to coordinate the follow-up services. The major achievements of this project are, the development of a comprehensive Genetics Plan, the Information Technology (IT) Plan, and the expansion of Newborn Screening (NBS) and Newborn Hearing Screening (NHS) services.

KEY WORDS: State Genetics Plan, Expanded Newborn Genetic Screening (NBS), Interagency Cooperation