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SENATE PUBLIC HEALTH, WELFARE & SAFETY
EXHIBIT NO. 6
DATE: 1-31-05
BILL NO. SB 275

Montana's Voluntary Genetics Program
Background Information

The Voluntary Genetics Program was established by the Legislature in 1985 and section 50-19-211, MCA creates the program "…in the department [DPHHS] to offer testing, counseling, and education to parents and prospective parents. The program includes, *but is not limited to*, the following services:

(1) followup programs for newborn testing, with emphasis on the counseling and education of women at risk for maternal phenylketonuria;
(2) comprehensive genetic services to all area of the state and all segments of the population;
(3) development of counseling and testing programs for the diagnosis and management of genetic conditions and metabolic disorders; and,
(4) development and expansion of educational programs for physicians, allied health professionals, and the public with respect to:
   a. the nature of genetic processes;
   b. the inheritance patterns of genetic conditions; and
   c. the means, methods, and facilities available to diagnose, counsel and treat genetic conditions and metabolic disorders."

The following table summarizes how these services are provided.

Program Services	Method of Provision	Provider(s)
1) followup for newborn testing	DPHHS staff	• Public Health Laboratory is responsible for notifying providers regarding NBS testing results • MCH Data Monitoring Section, Family & Community Health Bureau, Public Health & Safety Division is responsible for tracking abnormal results, assuring referrals to services are made, and reporting and monitoring incidence per federal guidelines. • Children's Special Health Services, Children's Health Resources Bureau, Child & Adult Health Resources Division is responsible for assurance of services needed by diagnosed children
2) comprehensive genetic services	Contracted DPHHS staff	• Montana Children's Home and Hospital, Inc AKA Shodair Hospital† • Monitoring of birth defects including genetic abnormalities is the responsibility of the Birth Defects Registry within DPHHS*
3) counseling and testing programs	Contracted	• Shodair Hospital
4) educational programs for physicians, allied health professionals, and the public	Contracted DPHHS staff	• Shodair Hospital provides the primary education to physicians and allied health professionals • Education is also provided to the public by the Birth Defects Program at DPHHS

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† Montana Children's Home and Hospital, Inc. is commonly known as Shodair Hospital
** The Birth Defects Registry has been implemented and maintained through federal grants from the Centers for Disease Control and Prevention.*

In 1987, Section 33-2-172, MCA established a **genetics program fee to** fund the voluntary statewide genetics program established in 1985 in section 50-19-211. The language is as follows: "Except as provided in 33-2-713, for each Montana resident insured under any individual or group disability of health insurance policy on February 1 of each year, the insurer or health service corporation issuing the policy, and the state group health plan provided for in Title 2, chapter 18, part 8, shall pay 70 cents to the commissioner. The fee must be paid on or before March 1 of each year and be deposited in the general fund. The purpose of the fee is to fund the voluntary statewide genetics program established in 50-19-211."

Amount generated and placed in the general fund in response to MCA 33-2-712 Genetics program fee.

Year	Amount (Calendar Year Revenue determined after March 1 of the next year)	Shodair Contract Amt SFY
1999	$579,895	$614,314
2000	$541,498	$578,995
2001	$613,467	$578,995
2002	$569,711	$561,000
2003	$584,816	$561,000
2004	*	$530,000
2005	*	$500,000

* Revenues are summarized on the basis of a calendar year. The final payments to the state for the calendar year are not collected until March of the following year.

Revenues generated from the insurance fee are not considered state special revenue funds, but by statute are deposited in the state's general fund for appropriation to the department for support of the program. The department contracted with Shodair Hospital beginning in the early 1980's for clinical genetic counseling services for Montana. The department has assumed primary responsibility for the newborn screening notification of results, tracking and referral. Shodair, under contract with the state, has provided clinical genetic counseling services. Prior to 2002, generated fees were expended via contract for genetic services. Monitoring, tracking, reporting and referral costs were covered by the state general and special funds for laboratory personnel and by the federal Maternal and Child Health Block Grant for Family and Community Health Bureau personnel follow up activities. Due to decreases in the Block Grant allocations to Montana, in 2002 and 2003 the responsibilities for activities described in the MCA language were reviewed, and it was determined that DPHHS time for designated duties within the law were included in the statewide voluntary genetics program. The funds have helped support portions of three staff salaries and limited birth defects registry system development costs needed to track referrals and monitoring.

An independent audit of the contractor was performed in 1997 by Galusha Higgins and Galusha for fiscal years 1996 and 1997 and attested to the fair representation of the financial condition of the contracting agency and compliance of the contractor with generally accepted accounting principles.

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Due to budget shortfalls, the GF available to support the statewide Genetics Program appropriation was decreased to $538,970 in SFY 2004. In order to clearly describe needed services in light of decreased funding, to comply with state procurement policy, and to ensure equitable access, in May 2004, the department worked with the Procurement Division of the Department of Administration to issue a formal State of Montana Request for Proposal for the provision of these services. The process concluded with awarding of a $500,000 contract with Shodair Hospital in July 2004 for state fiscal year 2005. The contract is subject to annual renewal at the discretion of the department.

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