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Building partnerships to promote healthy lives for everyone impacted by genetics

Genetic Alliance
Statement on Newborn Screening
Senate Committee of Health, Education, Labor, and Pensions
Subcommittee on Children and Family
June 14, 2002

As the largest coalition of genetics consumers and professionals worldwide, the Genetic Alliance applauds the commitment demonstrated by the Senate Health, Education, Labor, and Pensions Subcommittee on Children and Families in facilitating today's hearings on newborn screening. The Genetic Alliance knows first-hand that comprehensive newborn screening saves lives. Current advances in technology and healthcare have made it feasible to detect and to treat a large range of congenital disorders within days of birth. Without early diagnosis and treatment, many of these disorders will cause chronic illness, mental retardation, physical disabilities, or even death. When these conditions are detected at an early time, treatments are available that will drastically improve the quality of a child's life. However, public health policy is lagging behind the times, and we are deeply concerned about the inequities found from state to state in newborn screening programs.

Increased funding is clearly necessary to assist the public in taking advantage of the new technologies afforded and The Genetic Alliance is prepared to spearhead efforts to give every newborn in the United States equal access to comprehensive screening and follow-up medical care. We support the right of an infant's parents to receive current and accurate information about the newborn screening procedures the state provides as well as locations where they can obtain additional testing through a private facility. Our goal is not only to educate consumers about the merit and availability of comprehensive newborn screening, but to give them a voice that can bring about life-saving changes in policy on a state-by-state basis. Educated consumers, with reasonable demands and a vested personal interest, constitute a powerful force in public health policy. With over 300 disorder-specific organizations in our membership, as well as professionals, and patient and parent advocates, we are uniquely positioned to champion the cause of newborn screening.

The guiding principles driving our newborn screening campaign are as follows:

- Every child born in the United States deserves equal access to comprehensive newborn screening, regardless of zip codes or state lines.
- Every child diagnosed with a congenital disorder as a result of comprehensive newborn screening deserves equal access to the most effective treatment regimens, regardless of income or insurance status.
- Newborn screening programs must include resources to provide follow-up care and counseling to families in the event that a child is diagnosed with a congenital disorder.
- The disorders included in newborn screening panels must be amenable to clinical interventions that improve health outcomes.
- Newborn screening technology must be accurate and reliable.



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- The responsibility of newborn screening lies first and foremost with the doctors and hospital staff to which we entrust our children. If they do not implement the required screening, the government must step in and require it.