

Newborn Genetic Testing & Parents' Rights

Protect Your Child From Genetic Profiling!

The MN Department of Health takes a sample of every baby's blood at birth for genetic testing and a state DNA databank—without informing parents. You can now opt out!

• **Ethical, Social, Moral & Legal Issues** - Concerns regarding newborn genetic testing include, but are not limited to:

- Parent rights, and right to informed consent.
- Creation of government DNA database.
- Discrimination by insurers or employers.
- Ownership and control of personal DNA.
- Future reproductive restrictions?
- Enduring impact of results in patient record.
- Does newborn genetic testing violate privacy and genetic rights of future adults?
- Impact of testing on other family members.
- Unable to predict with 100% certainty that person will develop the medical condition, or be disabled by it.
- Who bears burden of cost for treating *potential* future medical conditions?
- Testing for preventable and treatable vs. non-preventable or incurable conditions.
- Social/emotional impact of “knowing the future.”

• **Genetic Testing Without Parent Notice** - The heel stick done on a newborn is genetic testing. Most parents are simply told that the heel stick is a blood test for PKU (phenylketonuria) to prevent mental retardation.

• **Mandatory Genetic Testing** - The PKU test was mandated in 1965 for all children except those with a religious exemption. In 1994, the exception was repealed. In 2003, parents were given an opt-out option, however it is often not being offered (*read more below*). Today, newborns are tested for more than 50 conditions.

• **State Bureaucrat Has Sole Authority** – Minnesota's Commissioner of Health, a political appointee, has authority to expand, without legislative oversight or public comment, the number and types of genetic tests conducted in Minnesota. In 2006, children will be tested for cystic fibrosis, a condition without a cure.

• **Genetic Testing by Government** - Hospitals send five (5) newborn blood spots to a state laboratory at the MN Dept. of Health (MDH).

Some of the more than 50 tests are performed by the Mayo Clinic. *Results are reported by MDH to the child's physician, and entered into the child's permanent medical record.*

• **Computerized Database on Citizens** - the MDH maintains a database of all children tested. Genetic test results, *collected since July 1986*, will soon be linked electronically with a child's birth certificate, newborn hearing screening test (*another test reported to the government without parent consent*), and the new state Birth Defects database (*medical data also collected without parent consent*).

• **Government DNA Databank** - About 70,000 children are born each year in Minnesota. Newborn blood spots, considered state property, are a rich source of DNA. MDH has collected newborn blood spots *since July 1997*. Researchers have already been given access, and use by law enforcement is a future possibility.

• **Parents' Right to Protect Child's Genetic Privacy** - As a result of testimony by Citizens' Council on Health Care, the 2003 legislature required all persons and institutions with care of newborn children to inform parents of their right to: 1) refuse to have their child tested, or 2) allow government testing, but require the child's test results/blood sample to be destroyed. *Parents with older children may also direct MDH to destroy retained test results and blood samples.* To exercise these rights, parents must sign a form (*provided at hospital or available at CCHC website*) which is then sent by hospital or parent to MDH.

• **Minnesota Law Ignored** - Most hospitals have not informed parents of their rights and options. Therefore, the 2006 Minnesota legislature heard the **“Parents' Right to Say No Act”** legislation to require explicit informed parent consent for genetic testing, and parent access to private (*non-State*) testing options. The Mayo Clinic, March of Dimes, and the Univ. of MN opposed the bill.

Questions? Contact CCHC at #651-646-8935 or info@cchconline.org

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