Resolution on Genetic Privacy and Paternity Testing

Introduction

Michigan and Wyoming have enacted statutes to protect genetic privacy by regulating both sample and record retention. These statutes appear problematic to the process of reliably establishing parentage utilizing genetic testing. Further, the statutes are contrary to federal mandates, laboratory accreditation requirements, and potentially will result in conflicts between state and federal laws. There are also compelling reasons to maintain records that outweigh any risk to genetic privacy. Of note, the genetic testing used in parentage testing has no medical or employment significance and as such these laws were not needed, nor has any instance of abuse been sited.

THEREFORE, NCSEA resolves that:

1. State legislation mandating return or destruction of genetic records and samples upon final paternity determination be opposed.
2. The federal Office of Child Support Enforcement (OCSE), in cooperation with others (NCSEA, National Council of State Legislators, National Governor's Association, etc.), advise states of this conflict between state and federal laws, as well as good science. States are cautioned not to pass such laws until study on a national level is complete and balanced legislation can be recommended.
3. OCSE establish a joint workgroup consisting of representatives of State IV-D Directors, NCSEA, OCSE and the American Association of Blood Banks' (AABB) Parentage Testing Standards Program Unit to review current laws and make specific recommendations as to the need for laws and language of laws governing genetic privacy and the retention of samples and paternity records.
4. Protections for samples be incorporated in state law, such as the language included in the 2002 and 2017 editions of the Uniform Parentage Act: An individual commits an [appropriate level misdemeanor] if the individual intentionally releases an identifiable specimen of another individual for any purpose other than that relevant to the proceeding regarding parentage without a court order or the written permission of the individual who furnished the specimen be supported.

Background

Federal law 42 U.S.C. 666(a)(5)(F) requires states to use genetic testing labs approved by an accreditation body. Many states require IV-D agencies to follow American Association of Blood Banks (AABB) accreditation standards. AABB and the federal Clinical Laboratory Improvement Act (CLIA), which also governs laboratories, require record retention for several years. Violation of the CLIA regulations may result in

prohibition against shipping specimens across state lines, thus precluding Uniform Interstate Family Support Act (UIFSA) cases. As federal funds are utilized for parentage testing, the laboratories must maintain records, including final reports, for possible audits.

The Deoxyribo Nucleic Acid (DNA) testing results from paternity evaluations do not have diagnostic or prognostic value in health or employment. Further, the results, unless ordered by a physician for parentage evaluation, are not part of one's medical history. Thus, state laws mandating return or destruction of genetic records would violate federal rules and their own state rules specifying compliance with accreditation standards. Leaving genetic markers off of the report is not a good solution. If a tested party wants the report reviewed by another expert, the expert has nothing to review. Laboratory errors may be detected because the genetic markers are on the report and other experts can easily review them. This destruction and expunging requirement is contrary to all national standards that require the maintenance of records for at least five years.[1]

Cases have been seen where the excluded man turns out to be an imposter. Without records the laboratory could not verify that the imposter (or any other person) actually appeared. Another problem that has occurred involves cases where the mother (or another person) alters the report, issued as an exclusion, so the man appears included. There are several cases of these altered reports making it through the court systems causing men who were actually excluded to pay child support. Without laboratory records, these alterations would not be detectable and could not be investigated. Exclusion is the expected result if there is an error either in chain of custody or in the testing. By destroying the samples and records it becomes impossible to investigate to see if a potential error has occurred. There are cases where a non-excluded man has challenged the excluded man's paternity results. If there are no records, an expert cannot testify to the validity of the testing.

Adopted by the NCSEA Board of Directors on August 11th, 2001

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[1] For example, in the American Association of Blood Banks, Standards for Parentage Testing Laboratories, 4th ed. (1999) Standard 6.300 Record Retention. The laboratory shall retain the following records for 5 years, or as required by applicable law: 6.310 Records related to each parentage case.