

## American Society of Human Genetics Social Issues Committee Report on Genetics and Adoption: Points to Consider

*This publication is the only, final officially approved "Genetics and Adoption" statement of The American Society of Human Genetics (ASHG). Previous versions were drafts and were not intended for circulation, attribution, or citation.*

*These "Points to Consider" are designed to stimulate discussion about an important policy matter. They are published with the understanding that the ASHG is not rendering medical or other professional services. Individuals involved with adoption should rely on professional judgment or on consultation with appropriate authorities.*

The following statement concerning the collection of genetic information on children being placed for adoption was endorsed at the 1990 Annual Meeting of The American Society of Human Genetics (ASHG). The proposal was brought by the Social Issues Committee to the attention of the Board of Directors following its study of problems faced by adopted persons in gaining access to important biological facts about themselves.

In recent years health professionals and adoption agencies have become increasingly aware of the importance of obtaining a genetic history as part of the adoption process. Recent changes in adoption laws and increasing knowledge about the genetic component of human physical and mental health made this a timely topic for review.

In 1986 the Social Issues Committee formed a subcommittee to determine (1) whether genetic information should be collected on the biological parents of and the adopted child and shared with the adoptive parents, (2) whether the collection of such information should be required by law, and (3) whether there was a need to develop genetic education programs for social workers and others working for adoption agencies.

In 1987 subcommittee members conducted two surveys that studied (1) state requirements for obtaining genetic information and (2) what public adoption

agencies collected as genetic history. During 1988, opinions were elicited from the same agencies as to (1) whether legislation should be mandated to collect such genetic information and (2) whether genetic education programs should be developed and implemented for adoption-agency staff. An article summarizing these activities was recently published in the *Journal* (Plumridge et al. 1990).

The 1987 survey determined that Wisconsin was the only state in which a statute clearly mandates the collection of genetic information on children being placed for adoption. That law requires that in appropriate circumstances adoptive parents and/or adopted persons be furnished with "the medical and genetic history of the birth parents and any medical and genetic information furnished by the birth parents about the child's grandparents, aunts, uncles, brothers, and sisters. The Social Issues Committee decided that it would be helpful to analyze the impact that this law has had on adoption work in Wisconsin. Subcommittee members Diane Plumridge and Joan Burns conducted this study, which will be submitted for publication.

In 1990 the Social Issues Committees, after reviewing a recommendation made by the Subcommittee on Adoption, endorsed a statement concerning the importance of including a genetic history as part of the adoption process. The statement was then reviewed, redrafted, and approved by the ASHG Public Policy Committee. Finally, it was reviewed and endorsed by the ASHG Board of Directors. The text of the statement approved by the board is as follows:

Address for correspondence and reprints: Philip Reilly, M.D., J.D., Shriver Center, 200 Trapelo Road, Waltham MA 02254.  
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1. Every person should have the right to gain access to his or her medical record, including genetic data that may reside therein.
2. A child entering foster care or the adoption process is at risk for losing access to relevant genetic facts about himself or herself.
3. The compilation of an appropriate genetic history and the inclusion of genetic data in the adoptee's medical files should be a routine part of the adoption process.
4. Genetic information should be obtained, organized, and stored in a manner that permits review, including periodic updating, by appropriate individuals.
5. When medically appropriate, genetic data may be shared among the adoptive parents, biological parents, and adoptees. This should be done with the utmost respect for the right to privacy of the parties. The sharing of information should be bidirectional between the adoptive and biological parents until the child reaches an appropriate age to receive such information himself or herself.
6. The right to privacy includes the right of any party to refuse to enter into or cease to participate in the process of gathering genetic information.

It is the hope of the Social Issues Committee and the Board of Directors that this statement may encourage

state and private agencies to collect helpful genetic histories. This policy statement was also endorsed by the Alliance of Genetic Support Groups on November 11, 1990, and by the Council of Regional Networks for Genetic Services on November 19, 1990.

### **Acknowledgment**

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The Social Issues Committee wishes to acknowledge the efforts of the Subcommittee on Genetics and Adoption. Diane Plumridge, M.S.W., led this effort. Joan Burns, M.S.W.; Lynn Fleisher, Ph.D., J.D.; Seymour Packman, M.D.; and Philip Reilly, M.D., J.D. served on the subcommittee.

### **Reference**

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Plumridge D, Burns, J. Fisher NL (1990) Heredity and adoption: a survey of state adoption agencies. *Am J Hum Genet* 46:208-214