

Course Outline/Bibliography

Ethical Issues in Genetic Testing in Adoption (CE)

Hypothetical Scenarios discussed with Dr. Emily Todd:

- A pregnant woman has made an adoption plan and adoptive parents have been identified. Shortly after birth, doctors are concerned that the child looks like he has Down syndrome. The potential adoptive parents want confirmatory genetic testing before proceeding with the adoption.
- A newborn baby is available for adoption. The birth mother has a history of schizophrenia and depression. The potential adoptive parents would like the baby tested for psychiatric diseases before proceeding with the adoption.
- A pregnant woman has made an adoption plan. When recording her family history, she notes that her father died at 45 years old from a heart attack and her maternal grandfather died at 62 years old from Alzheimer's disease. The potential adoptive parents would like to test the baby to see if he is at increased risk for either heart disease or Alzheimer's. They would like to know this information so that they may make "healthy choices" for the child including diet and exercise modifications.
- A Jewish couple is looking to adopt. They have made this decision after losing their biological child to Tay-Sachs disease. They would like to have the child they are considering for adoption to be tested to see if they are a carrier for "Jewish genetic diseases" as they do not want their child to be a carrier of these genetic diseases and have to make difficult reproductive decisions.
- A pregnant woman has made an adoption plan. The potential adoptive parents have met with her but have

some concerns and would like some “general genetic testing” on the baby at birth before proceeding with the adoption. When asked to clarify their concerns, the potential adoptive parents say they feel like the birth mother is “flighty, irresponsible and immature”. They didn’t like that she was late to the appointment because she couldn’t find her keys and had to call “some guy she knows” to give her a ride. They felt she was too loud and said too many swear words. They are concerned that the child may have inherited some of these undesirable personality traits.

- A 20-year-old birth mother in active labor. Although her mother has been very active in the prenatal care and in the adoption process, she is not present in the delivery room. Upon inquiry, the birth mother reveals that her mother is in the early stages of Huntington’s Disease and is having a “bad day” so couldn’t be at the delivery. This is the first time a family history of HD has been mentioned. Upon further inquiry, the birth mother does not know her own status with regard to HD. The adoptive family wants the baby tested before going through with the adoption.
- Adoptive parents contact you to let you know that their 16-month-old adopted son has just been diagnosed with Tay Sachs. They remember that the birth mother had recently delivered and made an adoption plan for that child as well. They opted not to adopt that child but thought that the other adoptive parents should be aware. What is the most important thing you need to know?
- A 3-year-old boy adopted at birth was just diagnosed with Fragile X Syndrome. He has a paternal half-brother and a maternal half-sister. The girl is with another adoptive family. The boy is being raised by his paternal grandparents. Who gets tested?
- A 4-year-old adopted boy was just diagnosed with

- Duchene's muscular dystrophy (x-linked recessive). His maternal half-sister is with another adoptive family in another state. Should his half-sister be tested?
- A birth mother calls to tell you that she did one of those "spit kits" and she has the breast cancer gene. She wants you to let the adoptive parents of her biological daughter know that the daughter should have a double mastectomy ASAP or she's going to get breast cancer. What do you do?

Resources referred to in this interview.

- Creating a Family Online Course: [Inherited Traits and Disorders](#)(with genetics researcher, Dr. Danielle Posthuma, with the large study mentioned in this course: Meta-analysis of the heritability of human traits based on fifty years of twin studies)
- Importance of Genetics in Determining Who We Are. Summary of [an exhaustive meta-analysis of all the twin studies published in the last 50 years](#), including an hour long interview with one of the lead study authors, Dr. Danielle Posthuma, Head of Department of Complex Trait Genetics at the Center for Neurogenomics and Cognitive Research at the Neuroscience Campus in Amsterdam, The Netherlands. In total they looked at 17,804 traits over 14 million twin pairs across 39 different countries. Researchers are now able to give a specific percentage of how much a trait is controlled by genes.
- [Genetic Testing and Genealogy for Adoptees](#). Interview with 3 genetic genealogists that specialize in working with adoptees.
- [Are Kids Exposed Prenatally More Likely to Abuse Alcohol & Drugs](#) (Expert Q&A)
- [Genetics vs. Environment: Which Affects Us Most](#) (Audio interview with Dr. Matt McGue, a behavioral and

- quantitative geneticist and director of the Minnesota Twin Study; and Dr. Kerry Jang, a Professor with the UBC Department of Psychiatry.)
- [Genetics vs. Environment: Which Affects Us Most](#) (article)
 - [Are Genetics or Environment Most Important in Determining Who Our Kids Will Be?](#) (audio interview with Sally Ann Rhea, the study coordinator for 25 years for one of the most renown adoption research projects in the world, the Colorado Adoption Project, focusing on investigating genetic and environmental influences on human behavior; and Dr. Alexandra Burt, Associate Professor of behavioral genetics with affiliation with the Michigan State University Twin Registry and a research focuses on the role of genes and the environment interplay in the development of anti-social development.)
 - List of Creating a Family resources on [Nature vs. Nurture](#).

Ethical and Policy Issues in Genetic Testing and Screening of Children

COMMITTEE ON BIOETHICS, COMMITTEE ON GENETICS, AND, THE AMERICAN COLLEGE OF MEDICAL GENETICS AND, GENOMICS SOCIAL, ETHICAL and AND LEGAL ISSUES COMMITTEE

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Technical report: ethical and policy issues in genetic testing and screening of children

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ASHG/ACMG STATEMENT Genetic Testing in Adoption

The American Society of Human Genetics Social Issues Committee and
The American College of Medical Genetics Social, Ethical, and Legal
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