

Brief Summary - 4th GFBR meeting

29-30 October 2002

BRASILIA , BRAZIA

The theme of the fourth forum was "Genetics, Genomics and Ethics: Ethics of Genomic Research". Rapid progress in the field of health and biological sciences, especially in the area of the human genome, somatic cell nuclear transfer ('cloning'), and stem cell research has generated great challenges for the research community, civil society and for bioethists.

Genetic researchers working in resource-poor nations face many ethical challenges. The biggest challenge surrounds informed consent, mainly because language barriers between researchers and subjects can diminish effective communication, especially in the translation of genetic concepts. Due to beliefs that genes and genetics can interface with notions of kinship and group identity, the consent of family members, community permission and local authority permission are among the main concerns raised in the issue of gaining informed consent.

Stigmatization, discrimination, and the promulgation of negative stereotypes were addressed in the conference as well. While focusing on this issue, many concerns were raised. For example, if there is wide disagreement amongst community residents, should the research project be given up, or should researchers be permitted to proceed with those people who agreed to participate. How much consensus should be achieved in order to conduct the research? Regarding community permission, whose voice should "trump" the other voices? How best to address the relationship between individual consent and community permission?

Although the database of genetic research might be intended to be made available to researchers worldwide, the trial participants themselves could hardly benefit in the near future, and thus the issue of benefits and burdens to subjects and to the community was raised by the meeting participants. This unfolded through the discussion of what the obligations of researchers are in considering the benefits to the individuals and to the community, how best to promote the benefit, etc.

In conclusion, it became clear that there is seldom right and wrong answer in ethics in international settings. What is important is to build partnerships where researchers can learn from each other and exchange their views on ethics and its interpretation. It is also emphasized that, to achieve excellence in research practice, we need to analyze and interpret norms in a culturally fair context, which not only protects subjects and increases scientific output, but also provides "ethical sustainability" to decisions and proposals aimed at the betterment of scientific enterprise and its relevance to humans.