

Ethical and legal aspects of medical genetics

Medical genetics is a very specific medical branch that connects the science and routine practice. Medical genetics touches not only the issues of general laws but it also has to follow the ethical laws in biosciences. The particular laws will be different all around the world, however we may mention some common principles.

Legal aspects

The national laws usually touches those issues:

- **Termination of pregnancy** (local laws may modify if the procedure is legal or not, what are the possibility/diagnoses when mothers can opt for the termination, what is the gestation week threshold).
- **DNA analysis** (DNA is considered delicate biological sample. DNA analysis and its possibilities/limitations are often subject to special regulation).
- **Personal information safety** (Genetic examination is especially delicate and its results are not to be distributed to anyone, not even to close family members of the proband wishes otherwise)

Ethical aspects

Biomedicine is quite special branch of science regarding the ethical issues. While the most important issues will be again different all over the world we provide some general overview.

- The right of being informed (proband shall have the right to opt for targeted analysis regarding genetic diagnoses, even of the information is not useful for further treatment/management).
- The right of being NOT informed (proband shall have the the right to refuse any kind of diagnostics/further information regarding genetic diagnoses that he does not wish to have. Even the diagnostics of another members of his/her family shall not touch this right of particular individual). This right shall be especially considered in children (normally - the legal representatives decide about the genetic examination in children, but regarding the late onset diseases (Huntington disease, Hereditary cancer syndromes) the diagnostics itself shall be postponed to the time, when the child will have its own right to decide about accepting/refusing targeted molecular genetic examination.
- The right of being fully informed: The proband shall get all the information regarding genetic testing (s)he wishes to have. This information can include the details regarding the diagnostic procedures itself, alternative methods, risk for diagnostic failure, risk of obtaining non-informative or partial-informative results, risk of obtaining of variants of unknown clinical significance.
- Termination of pregnancy (pro-life vs. pro choice): Possibly one of the most controversial issues overall touches significantly the issues of prenatal diagnostics. In the end - the possibility of the termination of pregnancy for the selected fetal anomaly depends on the local law (see above) the ethical issues are much wider. Basically, the medical geneticist shall not question/judge decision of the probands, (s)he shall only fully inform about all legal possibilities and help the proband to fulfil her or his wishes.