Title: Intellectual Developmental Disability Biobanking (IDDB)



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Proposal

Biobanks or banks of biological products can be defined as "any repository of biological samples identified, identifiable, anonymized or anonymous, or their derivatives, with a limited or unlimited storage time, obtained from material previously or prospectively collected, whether as a component of a routine health care consultation, a screening program, or a research project".

Biobanks are being implemented for a multiplicity of research purposes. In 2009 the Organisation for Economic Cooperation and Development (OECD) released the document: "Recommendation on Human Biobanks and Genetic Research", in which the importance of Biobanks and linked databases of genetic and genomic data is recognized. This article provides guidelines for the establishment, operation, structure, management, access, use and discontinuation of Biobanks. Several Biobanks with linked genetic databases, either public or private, have been implemented in different countries. In this regard, various suspicions related with the informative power of DNA are being discussed, particularly ethical questions concerning sample mishandling and confidentiality loss. Aiming an overview of the experience of these Biobank holders' it is our pleasure to invite you as an expert on this subject, to submit original research or a review article to our special issue on Intellectual Developmental Disability Biobanking to be published in Journal of Intellectual Disability - Diagnosis and Treatment.

Potential topics include, but are not limited to:

- 1. A legislator point of view;
- 2. Multicenter and multinational Biobanks;
- 3. What about European public investment?
- 4. Neonatal screening as a Biobank;
- A Portuguese geneticist perspective;

We would appreciate if you send us title and abstract by as soon as possible. Further you are requested to forward this invitation among your colleagues who are specialized in this field.

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