NETHERLANDS NEUROETHICS ACTIVITY REPORT 2009

The topic of Neuroethics has been under development in the Netherlands already sionce 1993, when Dr. R. Ravid became Cofounder and co-Chair of the European Brain Bank Network (EBBN). This network of European Brain Banks, was funded by the EU and dealt with the basic guidelines for legal and ethical conduct of recruiting, handling, dessiminating and storig human specimen of the CNS.

In 2009, We still need to identify gaps/needs of the variol scientific/medici organizations and formulate methods to address them.

The new initiatives are present in research and public engagements and there is an urgent need for researchers to be actively involved in international collaboration in Neuroethics.

Currently, an intensive collaboration is ongoing in tyeh following frameworks:

1. Invitro models for research on neurodegenerative diseases (INVITROM; www.invitrom.org).

2. Collaboration with the European Science Foundation (ESF; www.esf.org) on the Neuroethics of Biobanks .

3. International collaboration on Neuroethics of Biobanks and Brain Banks in the framework if various International Tissue repositories.

Funding, training and education are still not present and not being adequately addressed.

Also, there is ample coordination between various groups involved in Neuroethics within the country; These 2 issues form the obstacle to the development of well coordinated and standardized Neuroethics in The Netherlands.

Clinical and basic research on brain diseases are very well developed in The Netherlands and several papers by Dutch researchers have been recently published , indicating the golden standards for Brain Banking and the Neuroethics correlated with it.

We would like to be active in collaboration with the INN to promote an international harmonization of the neuroethical issues correlated with Brain Banking, brain research and the Biobanking needed for brain research and the search for Biomarkers in neurodegenerative diseases.

Dr. R. Ravid set up a consultancy service for scientists /organizations who wish to set up a brain bank / Tissue bank or Biobank. (www.brainbankconsultants.com).

Abstracts presented at the SFN meeting:

1. Ethical and legal issues in European brain banking

Brain Bank organizations are an essential repository for basic scientists ; the growing number of sophisticated neurobiological techniques which can be applied on post-mortem brain increases the pressure on brain banksto supply autopsy material to the scientific community.

European Brain Bank Network has the following objectives:

a. Foster research in clinical and basic neuroscience and serve as a dynamic system with ongoing consultations on the many various daily issues of brain banking.

b. Achieve standardization between banks of commonly accepted criteria for the neuropathological diagnosis and compatibility of protocols for tissue procurement, management and preparation.

c. Facilitate multi-center concordance studies and studies of risk factors in diseases which have genetic end environmental components.

d. Monitor safety measures and secure storage.

e. Abide by ethical and legal codes of conduct; the laws regulating autopsy procedures and the ethical guidelines are significantly different in the various brain banks of the member states of the European Union.

To create and develop the adequate infrastructure for these activities, one should have medico-legal and ethical support according to local legislation. Brain Banks apply the ethical aspects in their daily practice of tissue procurement, tissue management, tissue dissemination, confidentiality, "Financial gain" and genetic testing.

A well functioning international network of brain banks should be recognized as an entity that possesses the legal and ethical approach needed for the procurement and distribution of donated tissues for scientific research. Each Brain Bank should abide by the international discussions being considered with respect to ownership and use of postmortem tissues for scientific research by end-users.

2. Cerebrospinal fluid biomarkers in dementias and neurological disorders

The diagnosis of dementing disorders is severely hampered by the absence of reliable biomarkers that can be measured in body fluids such as blood , urine and cerebro-spinal fluid (CSF).

The search for biomarkers is based on specimens collected from living donors as well as autopsy material collected and store by Biobanks and tissue banks. The validation of biomarkers has to cope with data fluctuation due to the huge variability in biomarkers between individuals and the rapid post-mortem changes. We are currently using amyloid and Tau as early diagnostic markers in the pathology of dementia and in differential involvement in Alzheimer's disease (AD), Lewy Body dementia (DLBD),

Vascular dementia , fronto-temporal lobar degeneration (FTLD) , CJD and non-neurological controls.

Biobanks collect, preserve and type RNA and DNA and proteins extracted from brain /tissue /body fluids specimens in order to update the pathological hallmarks of dementing disorders. These are subsequently incorporated into clinical drug trials and elucidate proposed mechanisms of disease and drug action.

Due to the overlap in pathophysiological hallmarks of the various syndromes, we are currently identifying common markers which are present in blood and CSF.
In our studies we determine CSF-total and phosphorylated tau and CSF-Aß42 in blood and CSF, both in living donors and in rapid autopsy material , in combination with imaging techniques to assist in differential diagnostic procedures.

Although it is presently clear that no single biomarker can absolutely discriminate between AD and other dementias, a judicious combination of several biological markers may substantially increase the sensitivity and specificity of the diagnosis. If the results from a panel of biomarkers are added to the findings derived from a classical work-up, diagnostic accuracy can be further increased between AD and other dementias, a judicious combination of several biological markers may substantially increase the sensitivity and specificity of the diagnosis. If the results from a panel of biomarkers are added to the findings derived from a classical work-up,
diagnostic accuracy can be further increased.

Recent publications related to Neuroethics:

Ravid R – Standard operating procedures, ethical and legal regulations in BTB (brain/tissue/bio) banking: what is still missing? Cell Tissue Bank;9(2):121-37, 2008.

Ravid R and Grinberg LT. How to run a brain bank-revisited. Cell Tissue Bank. 9(3):149, 50. 2008.

Ravid, R -BIOBANKS FOR BIOMARKERS IN NEUROLOGIAL DISORDERS-The DaVinci bridge for optimal clinico-pathological connection. Journal Neurological Sciences, 283, 119-126, 2009.

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