**Method:** Summaries of relevant empirical and conceptual studies.
**Results:** The speaker will summarize the key findings from studies of decision-making capacity and proxy consent and place these in the context of day-to-day clinical care and research that involves persons with cognitive impairments. The speaker will discuss the potential clinical and policy impacts of changing concepts of Alzheimers disease.
**Conclusion:** Substantial progress has been made to improve the science of measuring decsional capacity and in understanding the ethics of proxy consent. More work needs to be done to identify relevant cross cultural differences. The science of capacity assessment provides clinicians and researchers concrete steps to improve how they communicate with patients and their families. Pending changes in how we define Alzheimers disease may have substantial impact on clinical practice and health care policy.

**IN18-MO-02**
**End of life decisions**

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Recent therapeutic advances provide significant help to severely affected neurological patients. However, curative treatment strategies still remain unfulfilled goals. In case of terminal prognosis, palliative care is required and the end of life decisions need to be made. This approach incorporates clinical, psychological und ethical aspects, which may vary according to the specific disorder and the individual needs of the patient. This presentation focuses on end of life decisions concerning patients suffering from severe stroke. Advances in acute stroke management (e.g. thrombolysis, neuroradiological interventions, stroke units) have significantly increased the chances of survival after severe cerebrovascular incidents as well as reduced the ensuing neurological deficits. However, survival with permanent and substantial impairment may be the clinical outcome. Therefore, survival after severe stroke is not necessarily compatible with advance directives or the presumed wishes of affected patients. Therapeutic decisions are further complicated by the fact that patients may not be able to communicate and by economical restrictions Despite these difficult circumstances, the following practical approaches to end of life decisions in critically affected stroke patients will be proposed and discussed: (1) Physicians should critically consider the aims of therapeutic options. (2) The clinical situation should be clearly explained to the relatives, allowing them to contribute to a decision which is compatible with the wishes of the patient. (3) The decision to omit or withdraw life supporting treatment should be specified concerning medication and nutrition. (4) An individual concept of palliative care should be establishes in order to control distressing symptoms. It ist important to emphasize that palliative care in severe stroke does not represent "medical capitulation" but is a valuable therapy for a sub-group of patients facing an unfavourable prognosis.

**IN18-MO-03**
**Is somatic cell gene therapy ethical?**

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Any science, research and treatment of patients needs ethical requirements and ethical regulations. Ethics as a branch of philosophy is based on the rules of morality and bioethical principles. Occidental ethics, the "Christian Ethics", have the roots in the Greek philosophy, modified by the Christian philosophers Saint Augustinus and Thomas Aquinas. Western ethics cannot be inoculated in other religious and cultural ideologies. The transcultural intentions for global ethical laws have to be worked out.
Ethical demands are the basic needs of all types of cell therapy. Somatic cell gene therapy is defined as the repair or the replacement of defective gene within somatic tissue. A clear distinction between somatic gene therapy with DNA-transfer to a normal body tissue and the germ line gene therapy, the DNA transfer to cells producing eggs and sperm, is necessary. The somatic cell gene therapy is restricted to the actual patient and not to a next generation.
The technology of cell gene therapy has gone through great progress, but is till now unpredictable, even if the target disease was cured. The germ line gene therapy for use in human is unethically in the recent time. Somatic germ cell therapy would need more detailed examination mostly on primates including the high responsibility in such a research program. There is a principal decision to interfere in a human genome, even if this is disturbed.
After a note of the Royal Pharmaceutical Society of Great Britain the high hopes for the translation of medicine through genetic testing, gene based drugs, stem cells, gene therapy and other new developments are the result of hype rather than realistic expectation. Biomedical innovation is designated as a slow and incremental process. Adverse media reports or excessive regulations hold back the development of new medicines. The merchandise backed influence brings great danger in the evolution of any kind of cell therapy.

## Tuesday 27th October

### IN19 – Multiple sclerosis 1

**IN19-TU-01**
**The relationship of clinically isolated syndromes and MS**

G.C. Ebers, *University Dept of Clinical Neurology, University of Oxford, John Radcliffe Hospital, Oxford, United Kingdom*

The relationship of clinically isolated syndromes (CIS) to MS has drawn considerable attention. The factors involved in the progression or lack thereof must hold important clues to pathogenesis and in many ways CIS can be seen as an ideal control for studies of MS.
The baseline epidemiology of the 2 conditions is strikingly similar, for prevalence, for sex ratio, for age of onset and even for MHC associations. Cementing a very close relationship over and above the obvious fact that most cases of MS begin as CIS, is the finding of truly isolated ON in the families of MS.
Optic neuritis has been studied much more systematically than other CIS forms. The rate of conversion of ON to MS seems to differ markedly between ophthalmological and neurological series suggesting some kind of ascertainment difference which will be discussed.
Several genetic loci have now been implicated in MS pathogenesis and these can now be examined in isolated ON. We have studied these and these data add another perspective to the place of ON and CIS in the MS spectrum. By far the most important of these is the MHC where multiple epistatic interactions are clearly important both in susceptibility and in outcome. In addition outcome loci are emerging and the application of these to the ON question will be discussed.
The predictability of conversion to MS has been substantially helped by MRI and these results will be reviewed.

**IN19-TU-02**
**Natural history of multiple sclerosis**

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The general evolution of multiple sclerosis is now well known at the population level and results are consistent among studies worldwide. Improvements in modern statistical techniques and in the quality and representativity of epidemiological studies have lead to a better knowledge of the prognosis. Recent papers have challenged our vision of MS natural history. Some report a better global prognosis. Others present characteristics of relapses in the first years of the disease and the occurrence of a progressive phase as the

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