



Multiple Sclerosis Society

**MOTOR
NEURONE
DISEASE
ASSOCIATION**

Briefing for parliamentarians on MS and MND, medical research and the Human Fertilisation and Embryology Bill, April 2008

A meeting of the All Party Parliamentary Group for Multiple Sclerosis will consider the scientific and ethical aspects of medical research and the HFE Bill at 3pm on Wednesday 23 April, committee room 11. The APPG will be addressed by:

- Dr Stephen Minger, Senior Lecturer in Stem Cell Biology, Kings College, London and member of the UK Gene Therapy Advisory Committee (GTAC)
- Canon Dr Robin Gill, Professor of Modern Theology at the University of Kent and member of the Medical Research Council's stem cell steering committee.

For further information on the meeting, please contact Emily Sam on 020 8434 0829.

Summary

The research provisions of the HFE Bill have great potential importance for research into long term neurological conditions such as multiple sclerosis (MS) and motor neurone disease (MND). There is currently no cure for MS or MND and few effective therapies. It is essential to keep all possible avenues of research open.

The research provisions

The Bill would allow the creation of four types of embryos containing both human and animal DNA and known as human admixed embryos, under licence. This would help overcome the problem of a current shortage of donated human eggs for embryonic stem cell research.

The Human Fertilisation and Embryology Authority (HFEA) will regulate all embryo research as now. The HFEA are an independent regulator. They will only grant the research licence if they consider the proposed use of embryos or human admixed embryos is necessary for the purpose of the research.

The Bill includes strong safety provisions for the use of such human admixed embryos. They may only be created, kept or used with a licence. They must not be kept for longer than 14 days of development. The Bill specifically prohibits the implantation of human admixed embryos in a woman or animal.

A recent poll carried out on behalf of the Times found that 50 percent of people believe human-animal embryos should be allowed for research purposes and only 30 percent felt they should not.

MS and the Bill

Some embryonic stem cell research already shows promise for advances in the treatment of serious diseases; stem cell research is advancing rapidly and it is vital that potential new avenues are kept open. The provision for creating admixed embryos, which in genetic terms are 99.9 per cent human, could overcome the problem of a current shortage of donated human eggs for embryonic stem cell research. If made from the DNA of patients with MS, the cells derived from them could be used to investigate the causes of MS and to develop new treatments.

MS is only one of many conditions which could benefit from this type of research in the future; among others, organisations representing people with cancer, heart failure, muscular dystrophy and Parkinson's disease have all spoken of the possible advantages of such research for such conditions.

MS and ongoing research

Last year the MS Society approved funding of approximately £3.7 million for 27 new research projects ranging from clinical trials, research into the cause, cure and care of MS and projects investigating symptom relief. To date the MS Society has spent £62 million on research and pledges to increase its annual research spend even more in the coming years, including £5.6 million ring-fenced specifically for new research funding this year.

MND and the Bill

MND is a fatal disease that can affect any adult at any time. The cause is unknown and there is no known cure. In this country alone MND affects around 5,000 people and every day five people in the UK die from this cruel disease. It is a rapidly progressive condition in the majority of cases with around half of those diagnosed dying within 14 months.

The MND Association supports medical research that has sound scientific rationale and has the potential to bring us closer to effective treatments for MND. Because of this, we support aspects of the Human Fertilisation and Embryology Bill relating to the use of human-admixed embryos.

At present, there is no viable way of studying living human motor neurones in the laboratory, which is greatly inhibiting our understanding of the disease and the search for effective treatments. Stem cells derived from human-admixed embryos would offer a potential source of motor neurones for research.

Speakers at the APPG for MS meeting

Canon Dr Robin Gill, Michael Ramsey Professor of Modern Theology, the University of Kent

Robin Gill was appointed as the first Michael Ramsey Professor of Modern Theology at the University of Kent in 1992. Previously he was also the first holder of the William Leech Professorial Fellow in Applied Theology, University of Newcastle upon Tyne. He has particular research interests in health care and Christian ethics and in the sociological study of churches.

Since 2001, he has been a member of the Medical Research Council's Stem Cell Steering Committee and from 1999, a member of the BMA Medical Ethics Committee. Between 1993 and 2006, Robin was chair of the Archbishop of Canterbury's Medical Ethics Advisory Group, Lambeth Palace.

Dr Stephen Minger, Senior Lecturer in Stem Cell Biology, Stem Cell Biology Laboratory, Wolfson Centre for Age-Related Diseases, King's College London

Dr Stephen Minger is a Senior Lecturer in Stem Cell Biology Laboratory in the Wolfson Centre for Age Related Diseases at King's College London. Over the last 16 years, his research group has worked with a wide range of tissue-derived stem cell populations, as well as mouse and human embryonic stem (ES) cells.

In 2002, together with Dr Susan Pickering and Professor Peter Braude, Dr Minger was awarded one of the first two licenses granted by the UK Human Fertilisation and Embryology Authority for the derivation of human ES cells. His group subsequently generated the first human embryonic stem cell line in the UK and was one of the first groups to deposit this into the UK Stem Cell Bank.

Dr Minger is the Stem Cell Expert and Member of the UK Gene Therapy Advisory Committee (GTAC) at the Department of Health. Stephen is one of the co-organisers of the London Regenerative Medicine Network, a grass-roots, research-led organisation designed to stimulate clinical translation of cell- and gene-based therapies within London. He is also the Senior Editor of *Regenerative Medicine*, a journal launched in Jan 2006 by Future Medicines, which won the 2006 ALPSP/Charlesworth Award for Best New Journal.

More information

For more information, please contact the MS Society policy and campaigns team on 020 8438 0700, campaigns@mssociety.org.uk, or Donna Cresswell, Director of Communications, Motor Neurone Disease Association, on 01604 611837, donna.cresswell@mndassociation.org.