

## Regulating Stem Cell Research in Europe

a report by

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In December 2005, a conference was held in Brussels to stimulate an informed debate on stem cell research in Europe and the ethical, religious and political aspects of such research. The particular aim of the conference was to allow patients (and others) to become better informed on all aspects of this sensitive issue and to make their views known.

For some years, the debate on stem cell research, and its actual and potential uses, has been led by scientists, ethicists, politicians and the media. Unfortunately, most of these debates have taken place in isolation from one another, with scientists talking to scientists, politicians to politicians, ethicists to ethicists, etc. Thus far, the patients – the people for whom these matters hold most importance – have not been involved. This means that a number of decisions have already been taken by researchers and policy-makers across Europe, without any real knowledge of the views of the very large section of the public that would be most affected by potential stem cell therapies.

To emphasise the inequity of this position, it has become clear that not only is the public insufficiently informed about stem cell research, but many policy-makers also fail to understand the science and the actual positions of ethicists and religious leaders. A matter of even greater concern is the fact that politicians at the national and European levels are also badly informed about the views of their constituents (the patients). During the political discussions that will take place in the years ahead, politicians and their civil servants will need accurate information so that appropriate policies can be tabled and debated to produce decisions that will really benefit European citizens.

### The European Commission

This situation prompted the European Commission (EC) Directorate-General for Research to open a call for a Special Support Action in its 6th Framework Programme to organise a one-day conference 'by patients for patients' to allow debate on the issues surrounding European stem cell research. The concept was to bring together representatives of all stakeholders, including a majority of patients, to allow all views to be discussed and, especially, for the patients' views to be heard. The European Federation of Neurological Associations (EFNA) was awarded a grant of €500,000 to help bring this concept to life. Further fundraising proved necessary and EFNA rose successfully to this additional challenge.

### EFNA

EFNA is a union of pan-European federations of national patient advocacy organisations in the field of neurology. Its members, in terms of numbers of patients, range from the very large to the very small. The European Parkinson's Disease Association (EPDA), the European Multiple Sclerosis Platform (EMSP), Alzheimer Europe, the Stroke Association for Europe (SAFE) and others at one end of the scale work in partnership with much smaller groups, such as European Dystonia Federation (EDF), Euro-Ataxia, European Network for Research into Alternating Hemiplegia (ENRAH) and Retina Europe, at the other end. The aim of EFNA is to contribute to the advancement of neurology and related areas to improve the quality of life of people living with neurological conditions by working with medical and other associations in a 'Partnership for Progress'. Bringing together the energies of many groups on a clearly understood area of

medicine such as neurology can often be a more effective way of making the patient's voice heard. The 'Partnership' approach lends itself well to organising a wide-ranging conference involving a large number of different stakeholders.

### Debate and Policy

The Brussels conference was one with a difference. There was no podium and no long presentations of complicated scientific or ethical topics with a lack of real opportunity for the audience to question and debate points with the speakers and other audience members, nor were there any 'break-out' sessions for parallel discussions on separate topics. Previous meetings on stem cell research have mainly been organised by scientists for scientists or among ethicists but on this occasion, all stakeholders were given the opportunity to take part fully in a moderated and serious debate.

The meeting was organised as a televised debate, and pre-recorded videos of the views of various experts plus footage of actual research work were shown. Throughout the conference, there were live interviews with the speakers (who made short statements rather than presentations) by an experienced moderator – a well-known UK television newsreader – who walked among the audience, inviting them to question and interact with the experts. The aim was to give accurate scientific information about stem cells, alongside the views of representatives from politics, religion, ethics, media, etc., and then find out what European patients actually think about this important area of research. Simultaneous translation was provided in seven languages. Voting keypads were also used,

to allow the anonymous opinions of the audience to be canvassed on the most important topics emerging from the discussion and to measure any overall changes of view as the debate progressed.

### Representatives

Almost 500 attendees (whereof approximately 60% patients or patient representatives) came from many countries in the European Research Area and beyond, with a sizeable proportion from the countries that had recently joined the EU. Several thousand invitations had been issued to patient, scientific, ethical, religious and other organisations across Europe, and the resulting audience constituted an excellent cross-section of background and opinion. Many patients and their representatives took full advantage of the opportunity to debate with the experts, and the moderated aspect of the proceedings ensured that all were heard in a constructive forum.

The other stakeholders in the wider stem cell debate were also represented, with speakers from the Jewish and Muslim faiths, as well as the Roman Catholic, Protestant and Orthodox churches. Ethics was given full expression by several influential experts and the media – as public opinion-formers – were also fully involved, as was the pharmaceutical industry. Patients were represented by a broad cross-section of attendees from all areas of illness and disability that might be affected by stem cell research.

The conference had hoped to involve European politicians, and all 732 Members of the European Parliament (MEPs) had been invited. However, none actually attended, although the former Research Commissioner Philippe Busquin (MEP, Belgium) and Pia Locatelli (MEP, Italy) registered their support for the meeting and its aims. As this was the first patient-led conference ever funded by the EU, it was unfortunate that no elected representative could be there to hear their constituents' views on such a sensitive topic and learn more of the facts about stem cells.

### The Way Forward

Mary Baker, as President of EFNA, opened the conference with Janez Potocnik, European Commissioner for Research, and

messages of support for EFNA's initiative were received from Tony Blair, Prime Minister of the UK (which held the EU Presidency at that time), from the UK Health Minister Jane Kennedy and from the famous boxer and Parkinson's patient Muhammad Ali.

The conference covered the following themes:

- the story of stem cells – history and scientific background;
- science meets medicine – how stem cell research has been and may be applied therapeutically;
- the patient's perspective – what the possibilities actually mean for patients and their families;
- stem cell research and society – cultural, ethical, legal, gender and religious perspectives on stem cell research;
- politics and the media in Europe – discussing how much politicians and the media actually understand, what influence and control they have on the stem cell debate and to what extent they reflect the views of the other stakeholders, including the public;
- the way forward – debating how the views of patients can be accommodated within the political process, how patient groups can relate to the media to reflect the views of their members, how to provide a forum in which patients and their representatives can participate meaningfully in the societal debate surrounding stem cells and research, and how the gap between patient expectations and scientific reality may be closed.

### High-quality Science

EFNA was careful to ensure the highest possible level of scientific information, with contributions from Nobel Laureate Professor Olle Lindvall and a number of other respected researchers in this field in Europe.

### International Survey of Patients' Views

A large-scale survey of more than 17,000

patients in 21 countries across Europe was organised alongside the conference and was funded by GlaxoSmithKline. This received a response of more than 32%, which will provide the results with a very high level of credibility. The results are being professionally processed and are being submitted for publication in the *British Medical Journal*. The aim of the survey is to assess the level of understanding of stem cells by patients and their attitudes to the main issues surrounding the research and application of potential therapies from this technology. The initial results of the survey appeared to be closely in line with the keypad responses of the attendees at the conference.

### Conclusions

During the conference, it became clear that stem cell research has considerable potential in many areas of medicine, including neurology. Although it was agreed that some disappointments may lie ahead in the research results, and that caution must be taken not to raise expectations of 'miracle' cures, the huge majority of delegates also wanted to allow research to develop further. However, some people in the audience held sincere ethical or religious views on certain aspects of stem cell research that prevented them from supporting the majority, and a number of speakers pleaded for determined efforts to reach a consensus as the larger debate develops.

The event was judged to be a great success and an exciting example of how to bring science closer to society. The patients' views on such a sensitive issue, expressed in lively but serious debate and through the results of the extensive survey, have the authority to inform future discussions and help to guide the scientific and political decision-making processes. ■

### About the Author

Alistair M Newton is Secretary-General of the European Federation of Neurological Associations (EFNA) and Executive Director of the European Dystonia Federation (EDF), the presidency of which he held for eight years. He also holds the post of Acting Treasurer of the European Brain Council (EBC), is an observer on a number of committees of the European Federation of Neurological Societies (EFNS) and a member of the Ethics Committee and the International Patient Advisory Board of the *British Medical Journal* (BMJ). His work on a number of projects brings him into regular contact with Members of the European Parliament and the European Commission, as well as many eminent members of the scientific community.