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Stem Cell Research in Europe – The Patient's View

Brussels – Charlemagne Building 15-16 December 2005

A conference to stimulate informed debate on stem cell research in Europe, its ethical, religious and political aspects. The particular aim of the conference was to allow patients (and others) to learn more about all aspects of this sensitive issue and to make their views known.

Introduction

In recent years, most debates on stem cell research have taken place in isolation from one another, with scientists talking to scientists, politicians to politicians, ethicists to ethicists, etc. So far, the patients – the people for whom these matters hold most importance - have not been involved. This means that decisions have already been taken by researchers and policymakers across Europe, without any real knowledge of the views of the very large section of the public which would be most affected by potential stem cell therapies.

The European public generally is not well-informed about stem cell research, and many policymakers need a clearer understanding about the science and the actual positions of ethicists and religious leaders. Politicians also need to know the views of their constituents – the voters. During the political discussions which will take place in the years ahead, politicians and civil servants will need accurate information so that appropriate policies can be tabled and debated to produce decisions which will really benefit European citizens.

European Commission

With these aspects in mind, the European Commission – D-G Research - opened 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. EFNA and its partner decided to apply with a proposal whose concept was to bring together representatives of all stakeholders, including a majority of patients, to air and discuss all views and, especially, for the patients' views to be heard. The application was successful and the Commission provided a grant of €500,000 for the project, plus a further amount which covered the travel and accommodation costs of a number of people who attended the conference from the 10 countries which had recently become members of the EU. Further substantial funding for the staging of the meeting was required and was raised by EFNA from a number of sources.

EFNA

EFNA is 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. European Parkinson's Disease Association, European Multiple Sclerosis Platform, Alzheimer Europe, Stroke Association for Europe and others at one end of the scale work in partnership with much smaller groups such as European Dystonia Federation, Euro-Ataxia, European Network for Research into Alternating Hemiplegia, and Retina Europe at the other. The aim of EFNA is to find ways of improving 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 Programme - Mary Baker, as EFNA President, opened the conference with Janez Potočnik, European Commissioner for Research. Messages of support for EFNA's initiative were received from Tony Blair, Prime Minister of the UK which held the EU Presidency at the time, and from the famous athlete and Parkinson's patient Muhammad Ali.

The conference covered the following themes:

1. ***The story of stem cells*** – History and scientific background
2. ***Science meets medicine*** – How stem cell research has been and may be applied therapeutically
3. ***The patient's perspective*** – What the possibilities actually mean for patients and their families
4. ***Stem cell research and society*** – Cultural, ethical, legal, gender and religious perspectives on stem cell research
5. ***Politics and the media in Europe*** – How much do politicians and the media actually understand? What influence and control do they have on the stem cell debate and to what extent do they reflect the views of the other stakeholders, including the public?
6. ***The way forward*** – How can the views of patients be accommodated within the political process? How can patient groups 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? How to close the gap between patient expectations and scientific reality?

The Conference

This was a conference "with a difference". No podium. 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. No 'breakout' sessions for parallel discussions on separate topics. On this occasion, all stakeholders were given the opportunity to take part fully in a moderated and serious debate.

Format - The meeting was organised as a televised debate, with pre-recorded videos of the views of various experts and patients, plus footage of actual research work. Throughout all six sessions, the speakers made short statements rather than presentations and were interviewed by an experienced moderator - a well-known UK television broadcaster - who invited the audience to question and interact with the experts. The aim was to give high-quality, accurate scientific information about stem cells, alongside the views of representatives from politics, religion, ethics, media, etc., then find out what European patients actually think about this important area of research. Simultaneous translation was provided in 7 languages. The latest in voting keypad technology was 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.

The audience – Almost five hundred attendees (approximately 60% patients or patient representatives) came from all 32 countries in the European Research Area and beyond, with a sizeable proportion from the countries which had recently joined the European Union. Additional funding was provided by the European Commission facilitating participation of all the EU-10 and accession countries.
Several thousand invitations had been issued to patient, scientific, medical, 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 stem cell debate were also well-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 very broad cross-section of attendees from all of the areas of illness and disability which might be affected by stem cell research.

Last, but not least in importance, were the politicians and all 732 Members of the European Parliament were invited. However, as the Parliament was sitting in Strasbourg that week, none was able to attend although one or two sent their assistants.

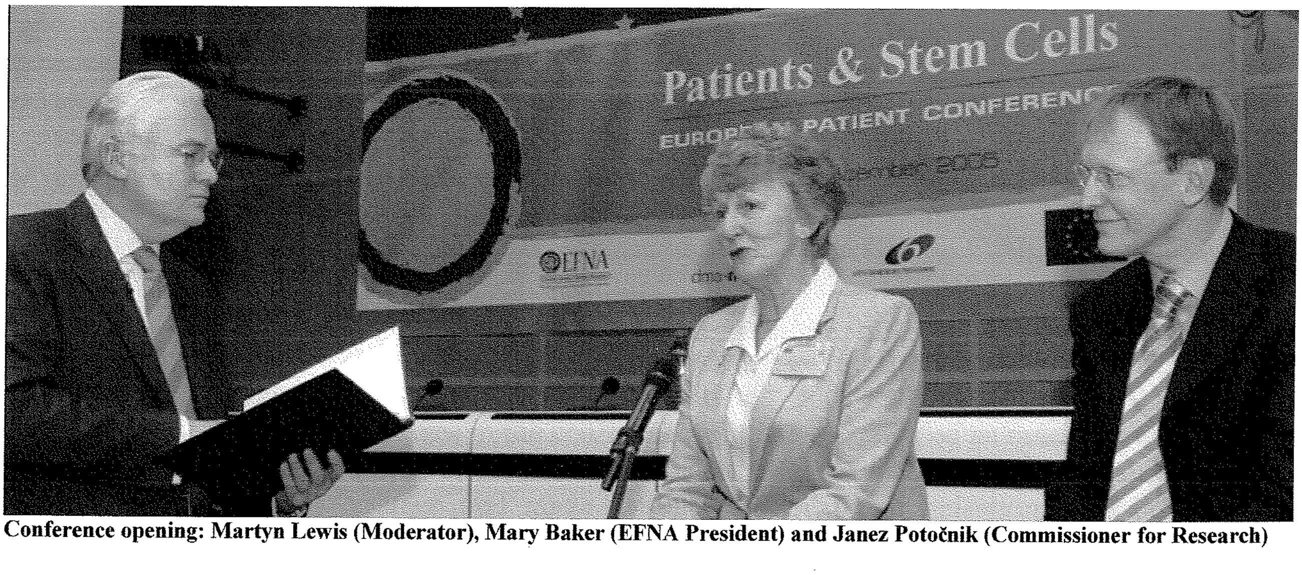
International survey of patients' views

A large-scale survey of over 17,000 patients in 19 countries across Europe was organised alongside the conference. This received a response of more than 34%, which provides the results with a very high level of credibility, and these were sent to all MEPs. The aim of the survey was to assess the level of understanding of stem cells by patients, and their attitudes to the main issues surrounding the research and the application of potential therapies.

Conclusions of the conference

- Stem cell research has considerable potential in many areas of medicine, including neurology.
- Although it was agreed that disappointments may occur in the research results, and we must be careful not to raise expectations of 'miracle' cures, the huge majority of delegates also wanted to allow research to develop further.
- Some people in the audience held sincere ethical or religious views on aspects of stem cell research which prevented them from supporting the majority on some issues, and a number of speakers on all sides pleaded for determined efforts to reach a consensus as the wider debate develops.
- There is a need for national and European regulation
- Stem cell research should be considered as part of a broader biomedical research approach
- Bridges need to be built for clearer understanding between patients, scientists and clinicians and religion, politics and media
- The EU could do much more to enable citizens and politicians to understand the issues more clearly

The event was judged to be a great success, and gave 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.



Conference opening: Martyn Lewis (Moderator), Mary Baker (EFNA President) and Janez Potočnik (Commissioner for Research)