



Euro-Ataxia is an association who's members work together to give people with hereditary ataxia as normal a life as possible. We do this by building a strong organisation that represents people with hereditary ataxia's throughout Europe, by encouraging scientific research into causes and treatments, and by campaigning for treatments to be made available.

## EDITORIAL

*Marco Meinders*

This issue of the Newsletter tells you about *euro-Ataxia's* upcoming general membership meeting, an upcoming research conference in the United Kingdom, and gives you a summary of the European conference on patients and stem cells of last December in Brussels.

This is the last issue of the Newsletter that will appear on paper. Starting with the next issue, we will distribute the newsletter, in PDF-format, by e-mail. If you want to receive the newsletter by e-mail, all you have to do is send a message to [newsletter-subscriptions@euro-ataxia.org](mailto:newsletter-subscriptions@euro-ataxia.org). Publishing the newsletter this way saves us valuable time and money. We will, of course, continue to publish our newsletter in PDF-format on our website ([www.euro-ataxia.org](http://www.euro-ataxia.org)).

Previous issues were edited by Daniela Iser (Zürich). She took over from Michael Morgan (Belfast) and did a wonderful job! I am bridging the gap to the next newsletter, which will be edited by Michael Morgan. So, if you have information from the science front, politics and legislation, or if you have information about activities from patient support groups, please feel free to inform Michael. He will gladly consider publishing your articles.

The next issue will most likely provide you with an update of various types of ataxia and the efforts made by Euro-Ataxia and it's member organisations to boost scientific research.

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### Lay out

Marco Meinders

## WHAT IS EURO-ATAXIA?

*From Euro-Ataxia's Daily Management*

Do you remember when you first heard of Euro-Ataxia? And did you wonder what Euro-Ataxia is? Time to put together a short summary. It helps us focus on what we want to achieve and to inform scientists and policy makers about who we are and what we do.

### Policy

Euro-Ataxia is an association who's members work together to give people with hereditary ataxia as normal a life as possible. We do this by building a strong organisation that represents people with hereditary ataxia's throughout Europe, by encouraging scientific research into causes and treatments, and by campaigning for treatments to be made available.

### Key strategies

- Compliance with Belgian law and legislation
- Representing all people with a hereditary ataxia in Europe
- Perfect financial management

### Other strategies

- Publishing at least two newsletters a year
- Enough volunteers to realise our activities
- Enough funds to realise our activities
- Supporting research
- Lobbying for research and availability of treatments

These strategies will be updated as we progress. ?

## AMENDMENTS TO EURO-ATAXIA'S STATUTES

*From Euro-Ataxia's Daily Management*

Due to new legislation in Belgium, where Euro-Ataxia is registered as an "international association without the objective of making a profit", we have had to our statutes. The changes are minor: they do not affect our objectives or activities. The process of amending the statutes has been overseen by a solicitor. The amended statutes will be presented to the members at the upcoming general membership meeting.

One other amendment is foreseen: a change of our statutory seat to another address in Belgium. At present, we are still using the address of our former secretary-general, Dagmar Kroebe. At the upcoming general membership meeting, the members will be asked to agree to this amendment. ?

## EURO-ATAXIA'S GENERAL MEMBERSHIP ASSEMBLY 2006

Saturday 16th September 2006,  
University of Hertfordshire, Hatfield, UK

*From Euro-Ataxia's Daily Management*

This year, euro-ATAXIA's general membership assembly is hosted by Ataxia UK. They have found an excellent meeting place at the De Havilland Campus of the University of Hertfordshire in Hatfield, about 20 miles north of London, London Luton airport and London Stanstead airports.

This campus, opened in September 2003, is named after the De Havilland Aircraft Company and cost £120 million. This new, state-of-the-art campus is the home of the Business School, the School of Humanities and the School of Education.

The items on the (provisional) agenda are promising. During the morning session, the daily management will present audited accounts for the years 2003, 2004 and 2005. It will also present the activity report of 2005 and an amendment of the statutes as a result of changed legal requirements (see the article elsewhere in this newsletter).

In the afternoon, we will have two presentations. One will be about the latest developments in patient funding for Friedreich's Ataxia, the other will be about the way in which the European Federation of Neurological Associations works. This will be followed by a discussion around the key issue "How can euro-ATAXIA be more effective".

In the evening, Ataxia UK has organised a tour of London by night. After all the business, this will be a good opportunity to get to know our board members and the representatives of our member organisations. ?

## ATAXIA UK RESEARCH CONFERENCE 'DIAGNOSIS AND POTENTIAL NEW TREATMENT FOR THE ATAXIAS'

### Ataxia UK

Ataxia UK is organising a research conference with a focus on the diagnosis and potential new treatment for the ataxias on Friday, 15 September 2006. The conference will be held at the De Havilland campus of the University of Herefordshire.

### Program

10 – 10.30 Registration and coffee

### Morning sessions 10.30 -12.15

Welcome – Dr Barry Hunt, Chair of Ataxia UK's Scientific Advisory Committee

Research update on the ataxias – Professor Massimo Pandolfo, Service de Neurologie, Hôpital Erasme, Brussels

Sporadic ataxia: how much of it is truly idiopathic? – Dr Marios Hadjivassiliou, Department of Neurology, Sheffield Hallamshire Hospital, UK

From basic research to establishing potential treatments for dominant ataxias– Dr Antoni Matilla, Institute of Child Health, University College London, UK

LUNCH (12.15 – 1.15)

### Afternoon sessions 1.15 – 4.30

Potential treatments for Friedreich's ataxia

- Idebenone trial for Friedreich's ataxia – representative from Santhera pharmaceuticals
- Cytokine recombinant human erythropoietin (rhuEPO) as potential therapy for

Friedreich's ataxia – Dr Barbara Scheiber-Mojdehkar, University of Vienna, Austria

Rehabilitation for the ataxias – Dr Ewout Brunt, University Hospital Groningen, The Netherlands

Specialist Ataxia Centres: a model of care for people with ataxia – Dr Paola Giunti, National Hospital for Neurology and Neurosurgery, London, UK

The potential for stem cells as future treatments for the ataxias – Dr Stephen Ray, Ribostem, UK

Conclusions

## EURO-ATAXIA JOINS THE EUROPEAN ORGANISATION FOR RARE DISEASES

By Marco Meinders

Earlier this year, euro-ATAXIA has joined Eurordis. We want to benefit from their expert knowledge and contacts with science and politics. Some of our member organisations are also member of Eurordis, namely the Rare Neurological Diseases/Finnish MS Society, the Association Française de l'Ataxie de Friedreich (AFAF), Connaître les Syndrômes Cérébelleux (C.S.C.), the ADCA-Association of the Netherlands and the Federación de Ataxias de España (FEDAES).

Eurordis is the only European organisation for rare diseases. It is a non-governmental, patient-driven alliance of patient organisations working in the area of rare diseases. It has 260 member organisations in 29 countries. Its mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives.

By becoming a Member of Eurordis, we have joined an active Pan-European rare disease community of dedicated people facing similar issues. Also, we strengthen the voice of people living with rare diseases in Europe: the more members in the

network, the broader the range of diseases and countries represented, the more legitimate our movement and the larger our impact.



Member of  
**EURODIS**  
Rare Diseases Europe

**Benefits of Eurordis' membership**

- Be listed on the Eurordis website with a direct link to your website
- Receive the monthly Eurordis e-newsletter, available in six languages
- Receive information on designated orphan drugs
- Share best practices and experience with other patient organisations and the Rare Disease community in Europe
- Post information of interest to you and other patient organisations (conferences, seminars, tenders...) in the Member News & Announcements section of the Eurordis website
- Take part in the European decision making process to influence European and national legislations
- Participate in the Annual Membership Meeting, Conference and workshops on RD specific issues
- Participate in regular training sessions

- Be represented at key European Institutions, such as the European Medicines Agency (EMA) and the Committee of Orphan Medicinal Products (COMP)

**We can**

- Take part in some of Eurordis' projects
- Attend the Annual Membership Meeting (including a conference and workshops)
- Contribute to Eurordis' strategic orientations through its position papers, Committees and Policy Task Forces
- Put forward patients or medical experts on your disease for EMA or European Commission's requests to Eurordis
- Be a candidate for the Eurordis Board of Directors

More information on EURORDIS can be found at their website: [www.eurordis.org](http://www.eurordis.org)?

**PATIENTS & STEM CELLS**

*Mary Kearney, secretary*

On the 15<sup>th</sup> and 16<sup>th</sup> of December 2005 and with support of the European Commission, an European conference was organised in Brussels by the European Federation of Neurological Associations (EFNA), of which **euro-ATAXIA** is a member. Dr. Mary Kearney represented **euro-ATAXIA**.

The aim of the conference was to inform, initiate and promote a meaningful dialogue on issues relating to stem cell research. Patients and their representatives, from 34 countries, were invited to engage with scientists, physicians, religious and political representatives as well as the media to contribute to an informed and balanced debate. The conference explained the different types of stem cells. There was a particular focus on the impact of research on patients.

There is a diversity of legal regimes regulating stem cell research and in particular embryonic and foetal stem cell research in Europe. There is uncertainty as to the legal scope of the "moral exclusion" clause in article 6 of Directive 98/44EC of 6th July 1998 on the legal protection of biotechnological inventions. Clarification on the scope of the Directive is essential to foster research and investment into stem cell research in Europe. Research is a must and clear ethical limits must be specified taking into consideration the concerns of the society.

**The Story of Stem Cells**

Stem cells are cells which are unspecialised cells in the body and have the ability to become specialised cells. They maintain and repair tissues and organs in the body. Adults have stem cells but they are more accurately named tissue stem cells. Tissue stem cells while still at an early stage of development retain the potential to turn into different types of cells of that tissue or organ. In bone, tissue stem cells, i.e.

bone marrow stem cells, give rise to all kinds of blood cells.

During pregnancy, cells from bone marrow of the developing baby can find their way into the umbilical cord and placenta. Research suggests that umbilical cord blood stem cells, are less mature than those from adult bone marrow and may be induced to turn into non-blood cells. The only cells that can evolve into any cell in the body are found in a few day-old fertilised eggs, blastocysts, and are called embryonic stem cells. In-vitro-fertilisation (IVF) involves the sperm fertilising the egg in the laboratory to create an embryo. The embryo can then be implanted into the womb, hopefully normal pregnancy will follow. Currently most of these embryos are destroyed if not used to achieve a pregnancy.

**Types of stem cells**

1. adult stem cell; more accurately known as tissue stem cells
2. umbilical cord blood stem cells
3. embryonic stem cells are usually collected from IVF clinics
4. Foetal stem cells -cells collected from abortions- At 12 weeks of development in the uterus the embryo is recognisable as a human and is called a foetus. Foetal stem

**How can stem cells be used?**

1. they give a clear understanding of how organism under healthy and disease conditions develop
2. to develop new families of drugs and new therapies
3. to treat cancer – Stem cells from bone marrows have been used for the last 30 years in bone marrow transplant operations for cancer

4. to repair injured organs or to fix degenerative disease – they are injected into the body often after being modified. Embryonic stem cells offer the prospect of developing new therapies for serious or life threatening diseases.
5. to build new tissues outside the body. Hopefully this new idea will develop.

**Dr. Stephen Minger, London** is involved in stem cell research at molecular level. He stated that there are over 300 articles in the medical and scientific journals on stem cell research. Some of the research articles referred to the use of umbilical cord blood. He uses all types of stem cells in his research department. He has students, who come from Germany to study in England with him. German law on the use of embryonic, foetal and cord stem cells is strict.

In-vitro-fertilisation (IVF) involves the sperm fertilising the egg in the laboratory to create an embryo. This is then implanted into the womb, hopefully to develop into a normal pregnancy. German law and Catholicism only allow 3 embryos to be developed so that no spare one is available. Currently, there is a school of thought whereby spare embryo could be used for research rather than destroyed. UK law allows these unused embryos to be used for research. It also allows: rather unusually: embryos to be created for stem cell research.

Another Scientist contributing to this session was **Dr Giuseppe Testa, Milan**. He works as a scientist in Milan in the area of stem cell renewal. **Prof Jonathan Brotchie, Toronto, Canada**, with a particular interest in Parkinson's disease presented us with new ways to treat this difficult disease. He is collaborating with a movement disorder clinic involved with clinical trials. **Prof Matjaz Jeras, Slovenia** works in the area of blood transfusion and genetics and has a lot of experience using stem cells in this area.

### Science meets medicine

Recently new major expectations concerning stem cells have emerged

1. developing new stem cell therapies towards an increasing diverse range of illnesses such as heart disease, stroke, Parkinsons and diabetes
2. new medical products which would help restore the function of damaged or diseased cells
3. an increase in our understanding of a wide range of diseases including cancer

**Prof Olle Lindvall, Lund, Sweden**, a neurologist, said that adult (tissue) stem cells are of no value in the treatment of neurological illnesses. Embryonic, foetal and umbilical cord stem cells can differentiate into neurones. The brain is very complex. Parkinson's disease is a progressive and currently incurable neurological disorder. It is caused by the degeneration of specific nerve cells in the midbrain, called dopaminergic neurones. It was stated that it would be very difficult to get these "dopaminergic neurons" repaired with stem cells. There are trials in progress at present using foetal stem cells for Parkinson's disease. On a different note, he mentioned that

"Deep brain stimulation" is being used successfully in treatment of Parkinsons. He highlighted that stem cells could over-produce dopamine in Parkinsons or could cause tumours.

**Prof Francois Pattou, Lille, France** is an endocrinologist who said he had used stem cell therapy successfully in diabetes. The story was continued by a lady, a qualified nurse, from the audience. She told us of how she had stem cell treatment for her insulin dependent diabetes 6 months earlier and it has "given life back to her". She had been having significant, uncontrollable, hypoglycaemic episodes as a result of her diabetes prior to stem cell therapy. These have improved and she is off insulin and caring for a similar diabetic sufferer who hopes to receive stem cell treatment soon. Since receiving stem cell treatment she is on immunosuppressant treatment.

### The Patients Perspective

The burden of illness and suffering has a tremendous impact on patient and carer. Rare diseases are also increasingly being considered as a public priority and many patients and families affected by rare diseases need support and action.

**Alistair Vinden, London UK** spoke as a patient who had several medical problems. He was in his 30s. He was almost dead due to his heart problems, when his friend saw an article in the paper regarding stem cell treatment in Germany. With considerable help he traced the clinic in Germany. He had stem cell treatment there. It has saved his life and as a result, has been able to attend December '05 conference in Brussels.

A young girl in the audience reported on how she lost the sight in her eye. She has epilepsy and had a fit in the shower which resulted in visual loss. A doctor, whom she met by accident at a hospital visit recommended her to a centre for stem cell treatment 3 months ago. Within 2 months she noted some improvement in her vision from seeing nothing to being able to see sufficiently well to count her fingers.

**Michael Griffith, Dublin, Ireland**, is chairman of Medical Research Charities group. He advised all that we should listen to each others opinions. He hoped that we could support research, to proceed in a non confrontational way and yet benefit those who need it.

A carer in the audience expressed a view after hearing these testimonies, that stem cell treatment is very helpful. So we can go forward optimistically into the field of stem cell research.

### Stem Cell Research and Society

This session aimed to show how cultural, ethical, legal and religious perspectives were impacting on this new scientific stem cell development.

**Prof Kristina Hug, Sweden** posed the question – Where does human life begin? There are five stages from conception to

embryo to foetus.

- Step 1. Fertilisation 0-24 hours
- Step 2. As the fertilised egg passes down the fallopian tube towards the uterus, it undergoes a series of divisions in a process called cleavage day 1-4
- Step 3. Formation of a blastocyst (day 4-8), its inner cell mass is used to make embryonic stem (ES) cells
- Step 4. Gastrulation (week 3-4) In this stage the cells in the inner cell mass move and arrange themselves in 3 layers. The first evidence of a nervous system is seen at this stage.
- Step 5 . Organogenesis (week 4 – week 12) is the term used to describe the formation of all the organs that will be needed for the embryo to develop into an adult

Does human life begin at fertilisation, or when the embryo is implanted in the uterus, or at organogenesis? The morning after pill, mirena intrauterine coil and some forms of oral contraception may work on the fertilised egg. One would expect opponents to stem cell treatment to be opposed to these forms of contraception. She asked that opponents to stem cell treatment be consistent in their arguments. Prof Hug's proposals were put forward to strengthen the argument in support of stem cell research.

A member of the audience asked if there was a parallel between using organs donated from dying patients to help people in need and using unwanted embryos or umbilical cord blood to help treat disease?

**Mrs Peggy Maguire**, an Irish woman representing the **European Institute for Women's Health**, suggested broadening the debate as she wanted to inform the public about stem cell treatment and its implications. She felt the "ordinary public should be involved" in the European Commission decision making process concerning the future of stem cell treatment

**Margaret Jacobi** – represented the **Jewish** perspective on stem cell treatment. She told us that in the Jewish tradition that the embryo did not have "life status". She went on to say research has potential to save human life and that is very important. Israel does allow stem cell research. In principal every one "is signed up for it" but there is some disagreement on making human embryos for research.

**Mona Siddiqui**, from the **Islam** faith prefaced her remarks by telling us that not all Muslims agree on everything. "Religion in general does not have a monopoly on ethics". In the Islamic tradition Ms Mona Siddiqui stated that human life does not start until after the blastocyst (day4-8) stage, even if life is existent or potential life is existent prior to day 4. Islam would therefore be happy to allow embryonic research.

**Rev. Donald Bruce**, a **Protestant** church minister from **Edinburgh, UK** stated that Protestants live with range of views. In particular he told us that his faith did support the principle that spare embryos from IVF should be used for research rather than destroyed.

**Dr. Matthias Beck**, a Roman Catholic doctor from **Vienna** said that Roman Catholic (RC) belief had been leading debate against this particular problem in Germany. The German constitution's position on this issue is like that of the RC church. Dr Beck has a doctorate in Theology and medicine. The strict RC position is that from the moment of fertilisation the embryo needs to be protected. When 46 germ cells come together to make an embryo, it is a living entity.

Dr Beck felt that at the time of in-vitro-fertilisation only 3 embryos should be made and all should be implanted to achieve a pregnancy. In this way there would be no spare embryos available. The R C church supports stem cell research except embryonic or foetal stem cell research. Creation of embryonic stem cells for research would also be unethical.

Dr Beck reminded us of the often quoted phrase "Do unto others as you would have done unto yourself". In reply to this, a 68 year old German man, from the audience said, he would have been willing to give his life for another when he was a baby. He went on to tell us that he had to do exactly that, when he fought in World War II.

Further questions were presented to the assembled delegates on what most influences the ethical debate on stem cells. It appeared that less than 50% were influenced by their religion. After more questioning, there seemed a greater number less influenced by religion. This shows more information on stem cell treatment and research is needed. When the assembled delegates was asked if they would you refuse personal treatment if it involved using a human embryo, an overwhelming majority said no.

The recommendations from this session were

1. Allow each country have its own laws,
2. Concentrate efforts on non controversial therapies,
3. Let each country fund its controversial research,
4. Try to avoid wasting umbilical cord blood (There is an umbilical cord blood bank in Dusseldorf).

Dr Beck concluded by telling a thought provoking story about a fire in a laboratory. The laboratory had 2 exit doors. An embryo was at one door and a baby was at the other. The person in the laboratory could only exit by one door. Which one would be chosen to be save, the embryo or the baby? He felt we should think about the answer to this question before making a final decision. Dr Beck concluded by asking delegates if they would you support or allow embryonic stem cell research or treatment?

### Politics and the Media

At the opening of this session a question was posed for the delegates Are newspapers, radio, TV , government reports and specialised reports given equal credit for informing the public about stem cell research. At the closing of this session the same question was posed. The majority of people seem to indicate that it is newspapers which influences the debate most.

Participants felt that the media tells us much of what we know about the stem cell therapy. It was felt that the media should avoid sensational headlines about the benefits of treatment.

**Dr Thomas Stuttford, Primary Care Physician & Journalist, from London** stated that a writer has not the final say on the headline of any article. Dr Stuttford felt that the writer needed overall control on medical article headlines.

**Roland Marchal – a former MEP**, and now suffering from Parkinsons. He stated that he wanted laws passed which would favour the patient. He was disappointed that there was no current MEP present. However there was a budgetary meeting ongoing in another building at that time and the audience appreciated how difficult it was for MEP to be present.

**Dr Carlos Lima, Lisbon, Portugal**, is a **Neuro-pathologist**. He has been using stem cells from the nose in surgical treatment of spinal cord lesions with some success. He expressed the view that it is difficult to be fully informed of the full extent of research taking place worldwide. He encouraged scientists worldwide to share the results of stem cell treatment as it would further development and save duplication of research.



**James Lawford Davis, London** is a **Solicitor** specialising in law relating reproductive technology. He felt that a European directive was needed to regulate application of therapies derived from stem cell research. With this in place, then each country, could further regulate for itself and be responsible for its own research programme.

With the growth of the internet, people have become their own doctors. Unverified information is available on internet. Negative results from stem cell treatment should be published. If therapies are available in other countries people will cross borders to avail of them. He was concerned about follow-up for sufferers travelling to different countries for stem cell treatment. Education is a priority for patient organisations.

### The Way forward

The closing session summarised events to date. The issues raised were

1. stem cells can improve health
2. the issues surrounding stem cells are complex and how is one to cope with the gap between patient expectations and scientific reality
3. how the cultural diversity within Europe can be accommodated

**Prof Trevor Jones, Managing Director of Neurone**, a pharmaceutical company, is hopeful that stem cell treatment will contribute in a meaningful way to health both directly and indirectly through drug development. He hoped that scientists should not exaggerate the value of stem cell treatment.

**Dr Matthew Menken, Princeton, USA** contributed to the debate that has always existed between science and religion.

**Prof David Vodusek, Neurologist, Ljubljana, Slovenia**, supported EFNA, who organised the conference, in their efforts to seek common ground. He felt education and dialogue through patient organisations was important. He thanked the EU for the contribution they made towards the conference.

**Mary Baker, President, EFNA, London** thanked this distinguished gathering of speakers and listeners who had come together from various parts of the world. She felt that we could in December 2005 disperse on a note of optimism. She felt that the way forward was to look at the family unit and show respect for the views of different members within it. Similarly Europeans must respect different countries because of their values, history and culture.

**Audrey Craven, Vice President, EFNA, Ireland**, in her closing reminded delegates that, "All that makes evil develop into the world is that good people do nothing". ?

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