



## *The challenges of health inequalities in the treatment and prevention of birth defects in Europe*

**An information workshop for MEPs and NGOs at the European Parliament, Altiero Spinelli building.**

**Tuesday 9 October 2012, 15h00-16h30: *Room ASP 5E3***

One in 50 Europeans have some kind of congenital birth defect - that's around 13 million people Europe-wide. This is not a marginal group but a significant number of people who in most cases can lead life to the full with the right care, support and treatment.

For example, a child born with a congenital cleft lip and palate in one member state will go on to lead a full life and realise their potential yet in another, perhaps neighbouring, state they may end up in an orphanage and ultimately be seen as a burden to society. These children have lost their human rights.

This workshop highlighted some of the key discrepancies in treatment, care and prevention of birth defects throughout Europe and make a case for a coherent European health strategy dedicated to congenital anomalies. There is clear need for an EU-wide approach – from expert collaboration to formulating social and economic strategies. It is not simply about resources but about joined up care, clinicians, politicians and patients talking and listening to each other and working together to improve the circumstances for all children born with a congenital abnormality in the EU.



## Scientific Abstract / Outcome

Having had this amazing opportunity presented to us, and having had the discussions in the European Parliament, we now have an opportunity to capitalise and maximise the benefits. One strategy would be to have a message transmitted from an MEP to officials in DG research, with a view to having birth defects placed on the European Framework programme agenda in 2014 through what is described as the Horizon 2020 initiative.

The main messages arising out of the presentations and engagement with MEPs were as follows:

- Birth Defects affect 1 in 50 births - around 13 million families across Europe
- Health inequalities across Europe are well documented, but health care and health and social service inequalities remain a major challenge
- Children with certain birth defects in Eastern Europe are still institutionalised and deprived of their basic human rights
- Birth defects are emerging as a major cause of both mortality (mainly in the developing world) and morbidity
- Europe leads the world in birth defects surveillance and registration
- Clinical trials have revealed much more cost effective and less burdensome treatments for birth defects but many of these have not yet been implemented
- There is scope for a massive reduction in health care costs for the treatment of birth defects
- Genomics research in birth defects in Europe is leading the rest of the world and there is a need to remain at this cutting edge, which requires further funding
- Patient groups are heavily involved in our birth defects research and make a very meaningful contribution
- There is a massive swing in the emphasis towards primary prevention in Europe and strategies with respect to lifestyle and behavioural change are being piloted and implemented.

In addition to this the World Health Organisation (WHO) are taking a special interest in birth defects and disabilities research in Europe and Dr Mario Meriardi, Director of Reproductive Health and Research at WHO issued the following statement: **“initiatives such as that presented today in Brussels are extremely important in shaping the post millennium development goals agenda. After 2015, we expect to see an expansion of the interest of maternal and child health to move beyond an agenda focussed on survival of mothers and infants to a comprehensive life course approach on early child development (including pre-natal development). In the context of this new global health agenda, prevention and treatment of birth defects and disabilities will represent a major line of action”**.

The consensus agreement was that it is crucially important for Birth Defects to be included in the Horizon 2020 agenda, and we must raise awareness in the right places in Europe to achieve this.

All contributors allowed their presentations to be transmitted as part of the meeting report, and these are attached. This message will also serve as a succinct bullet point summary of some of the key outcomes of the discussions and I am circulating this message among our group for further comments.

Professor Peter A Mossey (EUROcleftNet Convenor / University of Dundee)

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## PROGRAMME

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- 15:00** Introduction: **Seán Kelly, MEP** and **Peter Mossey, Chair**
- 15:05** **Alastair Kent**  
**“Patient and Family Expectations and Response of the Health Care System”**  
Director of Genetic Alliance UK: Alastair works to promote development of the understanding of genetics in health and disease and is particularly interested in rare diseases and transfer of knowledge into improved services and support for treatment of genetic diseases. He has a good understanding of the issues surrounding health inequalities and issues concerning voluntary organisations, health policy, service development and disability.
- 15:13** **Ysbrand Poortman**  
**“All babies born healthy; dream or reality”**  
Biologist by education, a promoter of patient initiatives, a founder of patient alliances, a bridge builder between expertise from science and industry and the people in need for this, a promoter of genetics, genomics and biotechnology as instruments for early detection, accurate diagnosis, prevention and treatment of serious/chronic/genetic disease. Based in The Netherlands but influence across the EU as a partner in major international projects, an adviser in many committees and an author of a variety of publications.
- 15:21** **Michel Grupper**  
**“Birth Defects and rare diseases – surely prevention is better than cure ?”**  
Experienced in private – public health issues and is well positioned to comment on and provide advice on health economy in relation to prevention of polygenic multi-factorial disorders such as cleft lip and palate (but also perhaps a range of other diseases or disorders). Michel is also involved in Resurgens, has become a friend of the European Cleft Organisation (ECO) and in the past he has also worked for organisations such as the World Health Organisation, the World Bank and DFID.
- 15:29** **Mario Meriardi**  
**“Infant mortality and maternal health in the MDG – our responsibility”**  
Mario Meriardi is Head of Reproductive Health and Research in the WHO in Geneva. His research interests are focusing on issues related to the reduction of maternal and newborn mortality worldwide. He is a strong supporter of the need to foster international research collaborations between researchers from developing and developed countries.
- 15:37** **Bill Shaw CBE**  
**“Reducing the burden of care in Europe through evidence based research”**  
Professor of Orthodontics at the University of Manchester, UK. Bill has a long track record in European and international craniofacial research and would be able to provide a high impact presentation on things like evidence base for clinical practice and the delivery of best practice – hence addressing a couple of major issues – economic benefits and reducing health inequalities.
- 15:45** **Martin Persson**  
**“The psychosocial consequences of disability”**  
Martin is a Psychologist and Project Manager, Lifecourse Epidemiology and Population Oral Health, University of Bristol, UK, and in his role as a clinical and health psychologist will provide an overview of some of the challenges of health psychology and disability and aspects such as quality of life, cognitive function, health inequality and early mortality.
- 15:50** **Gareth Davies**  
**“The ultimate cost of health inequalities - doing nothing is not an option”**

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In his role as CEO of the European Cleft Organisation he will comment specifically from personal experience the tremendous problem of health inequalities between Western and Eastern Europe and quote experiences from Bulgaria and Romania. He will also comment on efforts to produce minimum standards of care for Europe.

15.58

**Rhonda Curran**

### **“Birth Defects surveillance with a view to prevention”**

Rhonda represents the EUROCAT (European Surveillance of Congenital Anomalies) registry, and as such she is currently involved in project managing the latest EUROCAT programme - “EUROCAT Joint Action 2011-2013” that aims to facilitate the reduction of the public health burden of congenital anomalies by epidemiological surveillance through the European network of congenital anomaly registries.

16:05

**Presentation and Panel discussion:** After hearing from the guest speakers, there will be a five minute presentation by a mother from Bulgaria, **Dani Markova**, who will be accompanied by her son **Donni** who was born with a cleft, and she will share her experiences of having a child born with a disability. There will then be an opportunity to put questions to the panel, and this will be facilitated by Professor Peter Mossey. Participants in the discussion will include MEPs, families, scientists, health advisors.

16.30

Close of meeting

For further information contact Nicholas Mackie [n.mackie@dundee.ac.uk](mailto:n.mackie@dundee.ac.uk) +44 (0)7891 554982 or Peter Mossey [p.a.mossey@dundee.ac.uk](mailto:p.a.mossey@dundee.ac.uk) +44 1382 (0) 381643 Mobile: +44 (0) 7900 897560

***Tihomara’s baby (right) was put in an orphanage at the advice of health professionals. Only with the intervention of a UK-trained specialist cleft nurse was she able to persuade the orphanage to let her bring her baby home***



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