

“OECD Guidelines Roadshow” Report

EuroGentest’s aim is to improve the standards of genetic testing and its delivery throughout Europe. This involves not only the laboratory, clinical, counselling and public information services but, importantly, gaining the understanding and support of policy makers and the wider public for the provision of the resources necessary. For EuroGentest to succeed in its aim it is therefore crucial to reach and influence them. Consequently it decided to use the publication by the Organisation for Economic Cooperation and Development (OECD) on 10 May 2007 of its authoritative guidelines¹ for genetic testing as the basis for a series of sessions in appropriate key scientific conferences across Europe inviting policy makers and journalists to attend – entitled the “*OECD Guidelines Roadshow*”.

The majority of scientists see the need for such political and media activities but are often hesitant for quite understandable reasons, especially priority of research, publication, funding and assessment coupled with lack of familiarity, experience and training with these efforts. Encouragement and guidance is often needed together with, importantly, practical support in organising such events, providing media facilities and attracting policy-makers and journalists to attend and to take up the issues involved. This is being provided for the “*OECD Guidelines Roadshow*” by Dr David Bennett giving guidance on the organisational and policy matters and Richard Hayhurst on the media relations. The former has a great deal of experience in organising these kinds of events and the latter as a public relations professional in the biomedical field.

The first “*Roadshow*” was held during the 2nd Polish Congress of Genetics, 17-20 September 2007 in Warsaw, a conference organised every three years by the Polish Society of Genetics and the Polish Society of Human Genetics. The discussion panel “*EuroGentest and its European implications*” was organised by Professor Michal Witt, the Polish EuroGentest participant, from the Institute of Human Genetics in Poznan and the International Institute of Molecular and Cell Biology in Warsaw. The panel brought together four EuroGentest speakers and two presenting Polish data together with panelists taking part in the final discussion.



Programme :

- 9.00-11.00 DISCUSSION PANEL: “*EuroGentest and its European implications*” (Session host - WITT M.)
- 9.00-9.10 WITT M. *EuroGentest ? how it helps to harmonize genetic testing across Europe*
- 9.10-9.30 KENT A. (UK). *Quality of the information on genetic testing for patients*
- 9.30-9.50 BARTON D. (Ireland). *The OECD guidelines for quality assurance in genetic testing*
- 9.50-10.10 KAARIAINEN H. (Finland). *Guidelines for quality genetic counselling related to genetic testing*

¹ <http://www.oecd.org/dataoecd/43/6/38839788.pdf>

- 10.10-10.20 LATOS- BIELENSKA A. (Poland) *Current status of genetic care for children with congenital malformation in Poland*
- 10.20-10.30 MIDRO A. (Poland) *From genetics to parents, from parents to genetics - Polish experience*
- 10.30-11.00 General discussion: M. Mazurczak (President of PSHG), G. Wegrzyn (President of PSG), M. Krajewska-Walasek, D. Hoffman-Zacharska, A. Sobczynska-Tomaszewska and others.

Before the Congress Dr Bennett visited Professor Witt in Warsaw on 30 July 2007 to plan the “Roadshow” event with him and Professor Tomasz Twardowski, a leading scientist and experienced science communicator in Poznan, by teleconference. They discussed the details for the session, arrangements for a press briefing session and the invitation of Polish politicians and journalists. Professor Witt and Dr Bennett visited the Congress venue to assess its facilities and their suitability, and discussed the event with the Congress organiser, Professor Monika Rakoczy-Trojanowska. Richard Hayhurst provided advice on press relations, drafted a press release for circulation to journalists before the event and designed a Powerpoint template for speakers in the session to use for their presentations.

The “Roadshow” event was a plenary session on the third day of the Congress, 20 September 2007 and attracted an audience of some 200 people. The general conclusion of the discussion was that the network of Polish clinical genetic centres works very professionally and efficiently, however the genetic care system requires higher level of legislation for proper functioning (for example the EU Convention on Human Rights and Biomedicine of 1997 has not been ratified by the Polish Parliament since 1999, when it was signed). The other danger identified was the uncontrolled activity of various unlicensed laboratories offering a variety of genetic tests with no further proper counselling. The efforts made towards licensing of genetic diagnostic centres by the Polish Society of Human Genetics were described in detail. Participation in European quality control activities was encouraged.



As Professor Witt reported to Professor Cassiman, EuroGentest coordinator, in an email of 9 November 2007:

Dear J-J,

I was sorry not to have a chance to talk to you in San Diego. However, I wanted to inform you (what you probably already know) that the EuroGentest roadshow in Warsaw went smoothly and attracted quite a lot of attention. The session itself gathered about 200 people - in the scale of this meeting this was a lot! Media were present although not very interested: no flashes, no juicy details, no NEWS... A bunch of leading Polish geneticists was there and this might cause something good in the future. No politicians/decisionmakers obviously (they never come) but I was already asked to participate in the ministerial commission on bioeconomy (whatever it means) to deal with problems of genetic diagnostics - I should be on a first meeting probably in a month or so (currently I have no idea if this is of any importance). To my knowledge, relations with OECD in this matter are being planned.

EuroGentest presenters were excellent. I am going to present EuroGentest guidelines at my Institute in Poznan during a regular seminar in December.

Anyway, this was fun to organize such a session and I'll be happy to disseminate EuroGentest spirit in future, too. In fact I consider this as my duty, being the EuroGentest participant.

Best wishes,

Michal

Further “*OECD Guidelines Roadshow*” events will be held during the final two years of the EuroGentest project in order to help ensure the improvement of the standards of genetic testing and its delivery throughout Europe by reaching out to policy makers and, via the media, to the wider public. Appropriate key national and international scientific conferences will be identified and their organisers supported in holding the “*Roadshow*” events with speakers from EuroGentest and guidance by Dr Bennett on logistical arrangements and Richard Hayhurst on press relations.

Annexes:

Press release

Powerpoint presentations

FOR IMMEDIATE RELEASE		Ref	07EGT04
Project Enquiries	Professor Jean-Jacques Cassiman Leuven Tel +32 16 34 58 60 Email: jean-jacques.cassiman@med.kuleuven.be		
Media enquiries	Richard Hayhurst, Hayhurst Media Tel +44 (0) 7711821527 Email: richard@hayhurstmedia.com		

EuroGentest calls on Poland to lead the way in adopting OECD guidelines on genetic testing

Key stakeholders attend special meeting in Warsaw

Leuven, September 20, 2007: Genetic testing technology and services are developing at an incredible speed. However, it is often difficult if not impossible for politicians and health officials to keep track of the implications for both professionals and patients. In June this year, the OECD approved new guidelines to provide a framework for countries seeking to develop their genetic testing services. EuroGentest, a major EU-funded project dedicated to harmonising genetics testing services across Europe, will hold today in Poland the first of a series of roadshows aimed at encouraging EU member states to implement the new OECD guidelines.

Poland is an ideal starting point for a variety of compelling reasons, according to roadshow host and leading Polish geneticist, Professor Michal Witt: "Firstly we have a scarcity of legal regulations in Poland regarding genetic testing, matched by a reluctance of politicians and legislators to get involved in what is admittedly a difficult area. We also have the contrast of highly professional state-funded clinical genetics centers being challenged by a growing number of commercial labs, clinics and companies offering genetic testing with no further interpretation of results or counselling. And of course there is a growing interest in and demand from the public for genetic testing. We therefore hope that this EuroGentest-sponsored meeting will encourage Polish politicians to commit to being one of the first countries to fully implement the OECD guidelines as soon as possible."

The key messages are being delivered to an audience of geneticists, healthcare professionals, politicians and other stakeholders by leading European authorities. Dr David Barton, Chief Scientist at the National Centre for Medical Genetics in Dublin,

Ireland who was personally involved in drawing up the OECD guidelines, will stress the importance of proper quality assurance schemes being in place for genetic testing to ensure public confidence in results. Helena Kääriäinen, Research Professor, the National Institute of Public Health, Finland will explain that: "genetic counselling is an integral part of genetic testing, as patients should understand why the test is offered and what are the implications of the result to the individual and the family." She also pointed out that the Council of Europe is preparing an additional protocol on genetic testing to its Bioethical Convention; which all members are expected to adopt. Finally, Alastair Kent from leading patient interest group GIG will talk on the need to consult with patients when devising services: "Testing needs to deliver information that is comprehensive and accurate in a timely, user friendly way if patients are to be able to make informed decisions that they can live with afterwards."

Following the roadshow in Poland, EuroGentest intends to hold similar meetings across the EU and associated member states.

-Ends-

Notes to editors

Professor Michal Witt is head of the Division of Molecular and Clinical Genetics, Institute of Human Genetics, Polish Academy of Sciences in Poznan and a member of the Board of Directors of both the Polish Genetics Society and the Polish Society of Human Genetics

EuroGentest is an EU-funded project (10 million Euro for 5 years) that aims to establish an NoE (Network of Excellence) in genetic testing. Started in January 2005 the project is coordinated by Professor Jean-Jacques Cassiman, an acknowledge world expert in CF testing who holds the Arthur Bax and Anna Vanluffelen chair of Human Genetics at the Center for Human Genetics in Leuven, Belgium. The project is divided into 6 units each with a number of working parties.

More information is available at www.EuroGentest.org