

18 EMRC Newsletter

European Medical Research Councils (EMRC)

May 2011

Editorial

Advances in biomedical research pose new ethical challenges: Ten years of the human genome

Several important ethical problems arise mostly in connection with the rapid way in which we acquire knowledge of the human genome these days. In 2001 the first sequencing of the human genome was published by the groups of Venter and Collins. A decade later, on the verge of the era of personalised medicine, we have to be prepared to have the right answers. For example, many people worldwide, sometimes unknowingly, share their DNA with researchers, and even if the DNA was offered to study a specific disease, it may surrender many other secrets. If a study participant is at a high risk of breast cancer or cystic fibrosis, do we have a duty to let him or her know? Genetics is not the first field to come up against so-called incidental findings. Magnetic resonance imaging scans of the brains of adult healthy volunteers performed with the aim of understanding cognitive functions turned up an unexpected abnormality in around 10% of cases. The researchers receive little public guidance as to how to handle such incidental findings.

A similar ethical problem that we are facing now is the unprecedented possibility to test foetal DNA abnormalities using maternal blood. Approximately 5-10% of the "cell-free" DNA in pregnant women comes from the foetus. Cheap and sensitive sequencing techniques nowadays allow researchers to examine this DNA and to analyse the state of the foetal genome. Obviously, serious counselling based on knowledge and wisdom is expected to follow. Fears of eugenics will appear as such testing moves from fatal diseases to non-medical characteristics.

Continuous ethical discussions are accompanying research on embryonic stem cells and their use in the therapy of serious diseases. Embryonic stem cells can divide through mitosis and differentiate into diverse specialised cell types as explained in a recent EMRC Science Policy Briefing (www.esf.org/hscr). Once a great hope, replacing embryonic stem cells with so-called induced pluripotent stem (iPS) cells has turned out not to be as easy a solution as was originally expected. iPS cells are generated through the reprogramming of differentiated adult stem cells and can be directed to develop into many cell types, including germ cells, which opens new issues on human cloning. However, several recent reports have indicated that the reprogramming and the subsequent cell culture processes can induce genetic and epigenetic abnormalities in these iPS cells. The studies show that genetic abnormalities are already

inherited from the cells used for reprogramming. In principle, iPS cells display more genetic and epigenetic abnormalities than do embryonic stem cells. This does not mean, however, that scientists are abandoning the possibility of using reprogrammed adult cells in future clinical therapy; only the way how best to achieve this goal confronts more obstacles than originally envisioned.

Sequencing the human genome was a historical development that has made possible many goals, but still it has generated more questions than it has effectively answered. Knowledge has increased steadily but handling and understanding it is a complex issue and a challenge at the beginning of the 21st century.



Professor Isabel Varela-Nieto,
EMRC Core
Group member



Professor Josef Syka,
EMRC Core
Group member

We would first like to thank Professor Varela-Nieto and Professor Syka for their contribution to the EMRC Newsletter but more importantly for their active participation in the Core Group of the EMRC. Like the other EMRC members, their involvement is the key reason in today's success and impact of the EMRC.

This month only has seen new major achievements for the EMRC as a new Forward Look report on the 'Implementation of Medical Research in Clinical Practice' was officially launched (www.esf.org/imrcp) and was followed also in Berlin by the last meeting of the OECD Global Science Forum (GSF) on the facilitation of international non-commercial clinical trials – a GSF that EMRC helped trigger more than a year ago together with the German and Spanish governments.

The OECD will now share its recommendations on international clinical research in a report to be published in the fall. These will be instrumental to help implement recommendations from our previous report on 'Investigator-Driven Clinical Trials' (www.esf.org/idctreport), and draft the new EU Clinical Trials Directive. We only hope that with your help, the new Forward Look which has already been given a wide echo in the press will have a similar long-term impact.

Kind regards,
Lotte,
Professor Liselotte Højgaard, EMRC Chair
Stephane,
Dr Stephane Berghmans, Head of Unit

Highlights

Research Networking Programmes (RNPs)

REFLECTION – Researching complex interventions for nursing

REFLECTION was launched on 14 March 2011 and will run for five years. Through summer schools and seminar programmes this RNP aims to disseminate important methods for the development of evidence-based nursing. It will focus on three activities: 1. Develop an interdisciplinary European faculty network of researchers in nursing; 2. Share knowledge and expertise by running summer schools for early stage researchers; 3. Develop programmes of translational research in nursing directed at improving evidence-based nursing to meet European health and social care concerns.

► **More at** www.esf.org/reflection

ELN – European LeukemiaNet

The 8th Annual Symposium of the European LeukemiaNet was held on 1-2 February 2011 in Mannheim (DE). In total, 425 participants from 34 countries attended the 2011 Symposium including invited speakers from Europe and the USA. The session “New developments around the Clinical Trials Directive (CTD)” preceded the symposium where EMRC gave a presentation about current issues. Challenges and new directions in leukemia research and related disease entities were highlighted during the meeting in three consecutive sessions. Important activities include European clinical trial platforms, consensus decisions in clinical study endpoints, the set up of patient registries for all leukemias, common standardisation procedures and classification systems in diagnosis and follow-up (molecular monitoring, cytogenetics, minimal residual disease assessment) but also harmonisation in data evaluation and reporting.

► **More at** www.esf.org/esf-eln and www.leukemia-net.org

EUROCORES

EuroSTRESS – Stress and Mental Health

The Symposium on ‘Early life stress, brain development and ageing: the use of different methods in measuring cognition and brain function throughout life’ was held in Tilburg (NL) on 2 March 2011. At this symposium, international outstanding experts in the field of cognition and brain function presented and discussed how human brain development/ageing and cognitive function can be

measured from foetal life until old age. Topics included specific methods that can be used in smaller or large cohort follow-up studies within or outside a clinical context as well as empirical evidence of lifelong programming of human brain development/ageing and cognitive function by (early) life stress in interaction with (epi)genetic factors. This symposium promoted the lifespan view that is believed to be vital in developmental programming research.

► **More at** www.tilburguniversity.edu/research/social-and-behavioral-sciences/life-stress/

Forward Looks

Gene Environment Interaction in Chronic Disease (GENESIS)

On 15-16 March 2011 the Consensus Stakeholder Conference for the ESF Forward Look GENESIS was held at the Harnack Haus in Berlin (DE). In addition to high-level scientists representing diverse areas of research in chronic disease, the conference was attended by representatives from relevant industries (food and pharma) and patient organisations as well as ESF Member Organisations. The consensus plenary discussions prioritised the recommendations in the three central topics of the Forward Look: intrinsic and extrinsic mechanisms of chronic diseases as well as therapy and interventions. The Consensus Conference therefore served a quality and filtering function that led to the identification of 12 overarching recommendations.

The Forward Look Scientific Committee has already published some of its conclusions in an article in *Nature Immunology* in April 2011 (doi:10.1038/nio411-273). Next steps now include the finalisation of the Forward Look report that will include the recommendations. Further, a launch event will be held in Brussels in September to ensure the highest impact for this foresight activity.

► **More at** www.esf.org/genesis

Exploratory Workshops

Multidisciplinary consortium on the development of effective, but non-toxic drugs against MDR-TB and XDR-TB

This Exploratory Workshop was held at the Institute of Hygiene and Tropical Medicine, Universidade Nova de Lisboa, Lisbon (PT) on 1-3 December 2010. It was organised with the intent of providing an atmosphere where discussions were to be encouraged and collaborations between the participants would be facilitated. The number of participants totalled 23 and came from Argentina,

Austria, Denmark, France, Germany, Holland, Hungary, Ireland, Portugal, Spain, Turkey and the UK. Of these, 20 provided 30-minute presentations on their interests, work and involvement in studies of multi-drug resistant tuberculosis (MDRTB) infections, therapy, drug discovery and descriptions of expected collaborative work with identifiable participants. The main objective of this workshop was to provide the platform for interaction of European scientists from a variety of disciplines for the formulation of a plan that may result in the creation of effective anti-MDR/XDR TB. The rates of active pulmonary TB in certain parts of Europe continue to rise though this is only the 'tip of the iceberg' with respect to the impact of this serious infection. A far greater and more significant threat to the health status of Europe is the rising advent of MDRTB infections despite intense attention from the health authorities in European countries. The results of the 3-day meeting indicated that the main objective of this Exploratory Workshop could be readily satisfied with follow-up collaborations made possible by proposals to be submitted to the ESF or the EC for Research Networking Programmes, Networks of Excellence, FP7 or FP8, and possibly a COST Action.

► **More at** www.esf.org/index.php?eID=tx_nawsecure&file=fileadmin/be_user/ew_docs/09-007_Report.pdf&t=1306491351&hash=3dc5ef6f8638b09bce8e255781cad3

Events 2011

- **EUROCORES – ECT / EURAMOS: European Musculo-Skeletal Oncology Society (EMSOS) meeting**
Ghent (BE), 18-20 May 2011
- **RNP REMEDIC: Tissue engineering in the auditory system: Paving the way from basic science to clinical practice**
Royal Society, London (UK), 2 June 2011 – royalsociety.org/ and www.earfoundation.org.uk/education/articles/644
- **RNP EUROLeftNet: Kick-off meeting**
Strasbourg (FR), 9 June 2011 – www.esf.org/eurocleftnet
- **ESF Research Conference: B Cells and Protection**
Sant Feliu de Guixols (ES), 12-17 June 2011
www.esf.org/conferences/11366
- **Exploratory Workshop: Image-Guided Laparoscopic Therapies**
Cáceres (ES), 15-17 June 2011
imageguidedtherapies.ccmijesususon.com
- **RNP TRACE: Kick-off meeting**
Antwerp (BE), 16 June 2011 – www.esf.org/trace
- **ESF Research Conference: 3rd European Summer School in Nanomedicine**
Wittenberg (DE), 19-24 June 2011
www.esf.org/conferences/11367
- **EUROCORES – EuroSTRESS: Symposium on Stress and Mental Health**
Umea (SE), 20-23 June 2011 – www.esf.org/eurostress
- **Council of Europe/Bioethics Division: 40th Plenary Meeting of the Steering Committee on Bioethics**
Strasbourg (FR), 21-23 June 2011 – www.coe.int/bioethics
- **ESF Governing Council**
Lisbon (PT), 22-23 June 2011 – Chief Executive's Office
- **RNP REFLECTION: The doctoral students' summer school in nursing**
Lund (SE), 27 June – 8 July 2011 – www.esf.org/reflection
- **Exploratory Workshop Early Modern Veterinary Beliefs and Practice In Europe: C. 1500-1800**
Winchester (UK), 7-9 July 2011
- **RNP REMEDIC: 8th IBRO (International Brain Research Organisation) World Congress of Neuroscience**
Florence (IT), 14-18 July 2011 – www.ibro2011.org
- **RNP REMEDIC: Summer School 2011 'Regenerative Medicine: from basic research to orthopaedic applications and beyond' and 4th Steering Committee meeting**
La Magdalena Palace, Santander (ES), 25-29 July 2011
www.esf.org/remedic
- **EUROCORES – ECT / EURAMOS: International Meeting – Integration of clinical trials with tumour biology**
Leiden (NL), 29-30 July 2011 – www.esf.org/ect
- **ESF Research Conference: Natural Products Chemistry, Biology and Medicine IV**
Acquafredda di Maratea (IT), 28 August – 2 September 2011
www.esf.org/conferences/11371
- **RNP FFG: 4th European Conference on Chemistry for Life Sciences**
Budapest (HU), 31 August – 3 September 2011
www.esf.org/ffg and www.functionalgenomics.org.uk
- **Exploratory Workshop: Invitro Meat: Possibilities and Realities for An Alternative Future Meat Source**
Göteborg (SE), 31 August – 2 September 2011
- **Exploratory Workshop: The Future of Research in Sport Participation in the Lifespan**
Rome (IT), 14-17 September 2011
- **RNP ESF-ENS@T: 3rd International Symposium on Pheochromocytomas and Paragangliomas (ISP3)**
Marne-la-Vallée (FR), 14-17 September 2011
www.esf.org/esf-ensat and www.ensat.org
- **EUROCORES – EuroEPINOMICS: Kick-off and 1st Scientific Committee Meeting**
Strasbourg (FR), 19-20 September 2011
www.esf.org/euroepinomics
- **Forward Look Personalised Medicine: iPM Technology Workshop**
London (UK), 19-20 September 2011 – www.esf.org/ipm
- **RNP REMEDIC: 5th UHMWPE International Meeting**
Philadelphia (USA), 23-24 September 2011
www.esf.org/remedic and www.uhmwpe.org
- **EMRC Core Group and Plenary Meetings**
Strasbourg (FR), 28-30 September 2011 – www.esf.org/emrc
- **EMRC White Paper: Launch Event**
Strasbourg (FR), 29 September 2011

ESF

The European Science Foundation (ESF) is an independent, non-governmental organisation, the members of which are 78 national funding agencies, research performing agencies, academies and learned societies from 30 countries.

The strength of ESF lies in its influential membership and in its ability to bring together the different domains of European science in order to meet the challenges of the future.

Since its establishment in 1974, ESF, which has its headquarters in Strasbourg with offices in Brussels and Ostend, has assembled a host of organisations that span all disciplines of science, to create a common platform for cross-border cooperation in Europe.

ESF is dedicated to promoting collaboration in scientific research, funding of research and science policy across Europe. Through its activities and instruments ESF has made major contributions to science in a global context. ESF covers the following scientific domains: Humanities; Life, Earth and Environmental Sciences; Medical Sciences; Physical and Engineering Sciences; Social Sciences; Marine Sciences; Materials Science and Engineering; Nuclear Physics; Polar Sciences; Radio Astronomy; Space Sciences.

EMRC

The European Medical Research Councils (EMRC) is the membership organisation for all the medical research councils in Europe under the auspices of the ESF. EMRC's mission is to promote innovative medical research and its clinical application towards improving human health. EMRC offers authoritative strategic advice for policy making, research management, ethics and better health services. In its activities, EMRC serves as the voice of its Member Organisations within the European scientific community. EMRC disseminates knowledge and promotes the socio-economic value of medical research to the general public and decision makers.

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May 2011 – Print run: 300