

21 EMRC Newsletter

European Medical Research Councils (EMRC)

December 2012

Editorial

Thank-you for the privilege of being the Chair of EMRC for the last six years. It has been a positive experience serving together with all the great people in the core group, the standing committee and the biomedical sciences unit at ESF in Strasbourg. Thank-you to all of you for your collaboration, a great job done and for personal friendships developed.

Our last core group and standing committee meetings were held in Prague on 4-5 October 2012, hosted by Professor Josef Syka, core group member, at the Czech Science Foundation. Thank-you for a fine meeting.

The EMRC White Papers I and II, describing the strategy of biomedicine in Europe and abroad, have helped to strengthen the area of biomedicine in Europe and globally. Our strategy and policy advice in the form of Science Policy Briefings

and Forward Look reports on basic, translational and clinical research and implementation have facilitated biomedical research and it is widely acknowledged that biomedical research can help answer the challenges in health and healthcare in Europe and globally.



The future strategy and policy work on medical research in Europe will be in the hands of Science Europe and the new medical committee there, chaired by Professor Richard Frackowiak. This summer, in July, I hosted a very successful meeting with Professor Frackowiak, Stephane Berghmans (ESF) and Kirsten Steinhausen (ESF) in Copenhagen. I am convinced that our EMRC strategic agenda will be in good hands in the future, as it is now handed over to Science Europe. It is important for all players on the European research policy arena that we secure one strong voice. A connection with the Biomedical Alliance representing all the medical researchers in Europe and a link to EU DG Research Health will be crucial for improving biomedical research in Europe in the future, also for Science Europe.

For the future, I hope that Europe will engage in personalised medicine and make this an important strategic area for the European Research Area (ERA) with Horizon 2020 and other research programmes funded by the national research performing and funding organisations and private charities.

Open access to all medical publications and emphasis on education and training are important recommendations from me. For those who are privileged living in countries with a high research profile and a stable economy, we ought to work for less inequality and better conditions for research and healthcare in all societies all over the world. Let us join and see the big picture from the helicopter view so that we can work together to strengthen the position of biomedical research with a true emphasis on implementation. It is important to obtain new knowledge, but even more important to implement this knowledge to create better lives for patients and better welfare for societies.

A warm thank-you to all of you, and do take good care of Europe. I will be following up European research funding and research policy as Chair of The Danish National Research Foundation (DNRF) from January 2013.

Lotte

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Biomedical Sciences Unit

Since our last newsletter there have been many changes at ESF. Following the departure of Stephane Berghmans in July, I took over his responsibilities to lead the biomedical sciences unit. In October, I accepted a position at Furtwangen University. I will continue to work for ESF as a consultant. Maria Manuela Nogueira has taken over the role of Senior Science Officer and is now leading the biomedical sciences unit in Strasbourg. During recent months, the whole team has done an enormous amount of work to finalise our strategic reports before the work of EMRC came to an end and the EMRC Standing Committee was disbanded at its final meeting in October 2012 and officially closed at the ESF General Assembly in Brussel (BE) on 23 November 2012. I would like to express my sincere thanks to each member of the team for their hard work and continuing professionalism during this difficult period and the EMRC members for their highly valued advice and support.

The very important Forward Look report, 'Personalised Medicine for the European Citizen' has just been published. The report is the result of many workshops with different European experts from very different fields and we had an extremely active scientific committee supporting this activity. Because of the importance of this topic we will continue to follow-up and implement the recommendations outlined in the report and connect to other activities. We will now be concentrating on a wide dissemination of the report and a launch and dissemination event is being planned to take place in Brussels on 28 January 2013 to which Science Europe will be invited.

Another very important publication is the Science Policy Briefing, 'Open Access in Biomedical Research'. This too is the result of intensive discussions between excellent experts in the field who have concluded that all research stakeholders should work together to support the extension of Europe PubMed Central into an actual Europe-wide PubMed Central. In addition, the Science Policy Briefing, 'Medical Research Education in Europe' was published in September 2012 and provides recommendations on how to improve research careers in the medical field. Dissemination is now underway. Finally, the Science Policy Briefing, 'Implementation of Medical Research in Clinical Practice' was published in September 2012 providing ideas for implementing the recommendations of the previously published Forward Look of the same name launched in May 2011.

Following the closure of the EMRC Standing Committee, a new Scientific Review Group (SRG) for the Biomedical Sciences has now been set up to follow-up the remaining running activities of EMRC such as Research

Networking Programmes, EUROCORES, Exploratory Workshops and the dissemination and implementation of the recommendations of our strategic reports. This group will consist of the scientific members of the EMRC Core Group and will be chaired by Professor Stig Slørdahl. Thank-you to all of you for accepting to take on this very important role to ensure the continuity of our activities.

The SRG will be coordinated by Maria Manuela Nogueira, Janet Latzel and me and we are looking forward to our continuing collaboration on these activities.

Finally a big thank-you to Lotte for her incredible support, especially during the last months which have not been easy for the ESF staff. Her always positive attitude and strong leadership has been very important for us and we hope to meet again in the future!



Professor Dr Kirsten Steinhausen
ESF Consultant,
Professor at Furtwangen University

Highlights

Forward Look



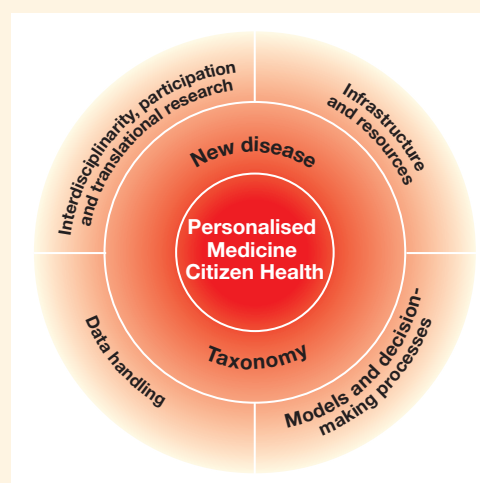
iPM – Personalised Medicine

Following the final Stakeholder Conference in April 2012 in Rome (IT) the final report was drafted and discussed again by different stakeholders. The report was then reviewed by scientific experts and approved by the different ESF Standing Committees. It provides a summary about the main issues in the area of personalised medicine and concludes with 80 recommendations culminating in a ‘personalised medicine target’ (see figure “circle”) representing the different topics which are relevant for personalised medicine. A launch and implementation meeting with different stakeholders is planned on 28 January 2013 in Brussels (BE).

The Forward Look initiative was presented at the COST Conference, ‘Personalised Medicine: Better Healthcare for the Future’ in Cyprus in June 2012, at the European Health Forum in Gastein (EHFG) in Austria in October 2012 and at the meeting of the European Society of Public Health in November 2012 in Malta. Furthermore, a special issue of the journal *Personalized Medicine* and a review article in the journal *New Biotechnology* were published in late spring 2012. Further publications are planned for winter 2012-2013.

In addition, ESF was asked to participate in different similar European activities for personalised medicine, e.g. the European Alliance of Personalised Medicine and the main ideas of the Forward Look report were presented at DG Research on 11 September 2012.

The activities of this Forward Look have been very strongly supported by the scientific committee, Professor Stephen Holgate (Medical Research Council (MRC), School of Medicine, University of Southampton, UK), Professor Aarno Paalotie (Institute for Molecular Medicine Finland (FIMM) and University of Helsinki, FI), Professor Barbara Prainsack (Deputy Director, Centre for Biomedicine and Society (CBAS), Sociology and Communications, Brunel University, UK), Professor Angela Brand (Center for Public Health Genomics, University of Maastricht, NL) and Professor Hans Lehrach (Professor, Vertebrate Genomics, Max Planck Institute for Molecular Genetics, DE).



Science Policy Briefings

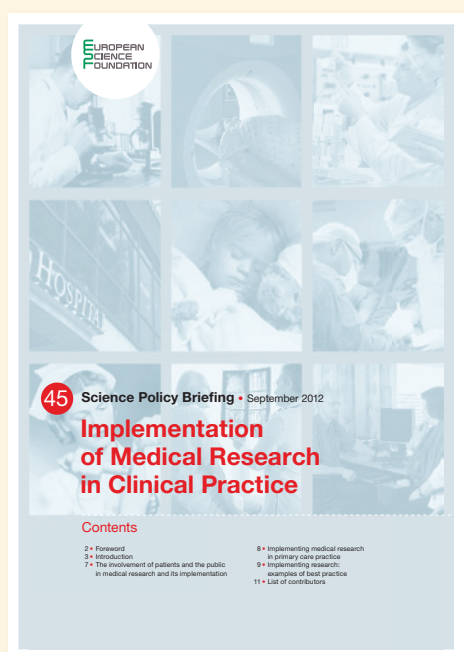
Open Access in Biomedical Research (no.47)

The Science Policy Briefing (SPB), ‘Open Access in Biomedical Research’ was launched on 19 October 2012. It concluded that there is a moral imperative for open access, that individual agencies must work together to raise awareness of this imperative and that all research stakeholders should work together to support the extension of Europe PubMed Central into an actual Europe-wide PubMed Central.

The SPB was largely disseminated during the Open Access Week organised by SPARC Europe from 22 to 28 October 2012. It was also disseminated at the UKPMC Funders’ Engagement Workshop on 28 September 2012 in London (UK), at the Global Research Council regional meeting on 22 October 2012 in Brussels (BE), at the UNESCO Headquarters on 25 October 2012 in Paris (FR), at the European Parliament Science and Technology Options Assessment (STOA) meeting on 22 November 2012 and at the 10th League of European Research Universities (LERU) anniversary conference on 30 November 2012 in Brussels (BE).



In the future, the SPB should be presented at the 2013 Global Summit meeting in Berlin (DE) on 27-29 May 2013. A multi-disciplinary, geographically broad Science Europe working group on open access is now developing a common policy and action plan after defining open access as a key priority for strengthening the ERA.



Implementation of Medical Research in Clinical Practice (no. 45)

The Forward Look Report, 'Implementation of Medical Research in Clinical Practice' was launched in May 2011 with dissemination to over 2,000 organisations and indi-

viduals throughout Europe and it has been extremely well received. An implementation expert group was then set up and chaired by Professor Liselotte Højgaard (EMRC Chair). Three working groups were then created in the areas of Public and Patient Involvement; Primary Care Practice, and Knowledge Generation and Transfer. The recommendations of these working groups have been summarised in the Science Policy Briefing 'Implementation of Medical Research in Clinical Practice' which was published in September 2012.



Medical Research Education in Europe (no. 46)

The Science Policy Briefing (SPB) 'Medical Research Education in Europe', prepared under the chairmanship of Professor Giovanni Pacini (EMRC Core Group) was published in September 2012. This policy report analyses current challenges in MD PhD programmes across Europe and provides recommendations to different stakeholders on how to overcome them, focusing on:

- Recruitment and career development.
- Curriculum design.
- Harmonisation, overarching quality control and common standards.
- Research infrastructures and allocation of resources.
- Geographical and trans-disciplinary mobility.
- Cooperation between universities, research organisations, healthcare centres and other public or private agents.

The report focuses on 11 countries (Austria, Croatia, Czech Republic, France, Germany, Italy, Norway, Portugal, Spain, The Netherlands and United Kingdom) and includes 5 case reports on the United Kingdom, Nordic Countries,

Central and Eastern Countries, France and Australia. This study was done in consultation with 18 key international experts, and endorsed by the 30 members of the ESF-EMRC Standing Committee.

This science policy activity links with key stakeholders and platforms in this field, such as the Innovative Medicines Initiative (IMI), the European Medicines Research Training Network (EMTRAIN), PharmaTrain, and the Organisation of PhD Education in Biomedicine and Health Sciences in the European System (ORPHEUS). The report is currently being disseminated and has been presented in Brussels in November 2012 at the IMI LifeTrain Workshop. Further dissemination will take place in 2013.

Research Networking Programmes

EUROcleftNet: Network for orofacial clefts research, prevention and treatment

Chair: Professor Peter Mossey (UK)

A group of experts on birth defects had a consultation with Members of the European Parliament (MEPs) in Brussels (BE) on 9 October 2012 to address significant issues in the field of birth defects and the debate highlighted in a succinct and very powerful way the extent of this problem, not only



as a European but a global issue with Europe showing tremendous leadership in (a) identifying the problems and related health inequalities and (b) through cutting-edge infrastructure and research expertise, finding cost-effective ways to address these problems. The major highlights included:

- Birth defects affect 1 in 50 births – around 13 million families across Europe.
- Health inequalities across Europe are well documented, but healthcare 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 healthcare 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 Organization (WHO) is 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 focused 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 with awareness being raised throughout Europe to achieve this. In addition EUROcleftNet is preparing an FP7 proposal.

EUROCORES

ECT–Pan-European Clinical Trials

EURAMOS Project Leader: Professor Stefan Bielack, Klinikum Stuttgart, Olgahospital, Germany.

PROFIDYS Project Leader: Professor Philippe Orcel, Assistance Publique Hôpitaux de Paris, France

ECT was launched in January 2005 and featured only 2 Collaborative Research Projects (CRPs) that are investigator-driven clinical trials (IDCTs) on rare childhood diseases, EURAMOS and PROFIDYS. At the time of the launch, there was a near lack of cross-border funding opportunities for pan-European clinical trials in rare diseases, hence the added value of this programme. Both CRPs have yielded positive results in terms of quantitative (publications, training, activities, etc.) and qualitative (interaction among researchers, discussion of new ideas, etc.) outputs. The ECT Final Report was published in September 2012 and is available from:



<http://www.esf.org/research-areas/medical-sciences/publications.html>

ECT has been a unique programme that coordinated funding for pan-European, non-commercial, investigator-driven clinical trials addressing questions that have a strong impact on the quality of life, morbidity and mortality of the European population and has provided a framework for the implementation of pan-European clinical trials in compliance with Good Clinical Practice (GCP) and current national legislation and European regulations. By promoting and supporting networking, the ECT programme has fostered synergies with other European and international initiatives.

EURAMOS (Maintenance treatment with interferon-alpha following intensive multi-agent chemotherapy and surgery for high-grade osteosarcoma) addresses questions evaluating therapeutic strategies in a rare disease, including the use of old drugs in a new indication. Patients with osteosarcoma, a rare bone cancer of primarily young people, are evaluated for risk-based treatment strategies adapted to the response of the primary tumour to pre-operative induction chemotherapy. This is being done in an international setting, as the rarity of the disease would otherwise preclude obtaining meaningful results. EURAMOS is led by Professor Stefan Bielack (DE) and features 13 associated partners. The programme embodies a unique collaboration between the European and the American Osteosarcoma Study Groups. EURAMOS officially began in January 2005 and ended in May 2012, with an extension granted of one additional year. It involves over 300 clinical centres in 20 countries worldwide (13 European countries, USA, Australia, New Zealand, Bahamas, Puerto

Rico, Guatemala and Canada) and at the time of reporting had recruited 2260 patients, which is far above any other previous osteosarcoma clinical study in the world. Further information can be found online by searching under the official registration number NCT00134030 on the www.clinicaltrials.gov website.

PROFIDYS (Prevention of bone morbidity using a bisphosphonate in fibrous dysplasia of bone) is a randomised placebo-controlled trial designed to assess the safety, tolerability and efficacy of an oral bisphosphonate in the reduction of bone pain and osteolytic lesions in patients with fibrous dysplasia of the bone, a rare congenital bone disease characterised by replacement of normal bone by fibrous tissue. PROFIDYS is led by Professor Philippe Orcel (FR) and involves 5 clinical centres in 3 European countries (France, Belgium and The Netherlands). The PROFIDYS final report was submitted in the form of a progress report, since the Project Leader intends to recruit patients until the end of 2014. More details may be retrieved online, searching under the official identifier number NCT00445575 on the www.clinicaltrials.gov website.

Events 2012-2013

- **RNP ERNI-HSF**
Orienting of attention: Neural implementation, underlying mechanisms and clinical implications
Tübingen (DE), 2-3 November 2012
- **RNP ERNI-HSF**
Brain oscillations in health and diseases
Budapest (HU), 8-10 November 2012
- **RNP ESF-ELN**
EWALL Meeting
Frankfurt/Gravenbruch (DE), 16-17 November 2012
- **Innovative Medicines Initiative (IMI) EMTRAIN meeting**
Brussels (BE), 20-21 November 2012
- **STOA – Science & Technology Options Assessment meeting**
European Parliament, Strasbourg (FR), 22 November 2012
- **RNP ESF-ENS@T**
Steering Committee meeting
Madrid (ES), 23 (tbc) November 2012
- **RNP ESF-ENS@T**
11th Scientific meeting
Madrid (ES), 23-24 November 2012
- **Exploratory Workshop**
Gene-Environment interactions and the distribution of Periodontitis in Europe
Aarhus (DK), 26-27 November 2012
- **League of European Research Universities (LERU)**
10th anniversary conference
Open Horizons – A Revolution in Open Science
Brussels (BE), 30 November 2012
- **RNP EUMYONET**
Pathology Diagnosis of Idiopathic Inflammatory Myopathy
The Netherlands, 30 November – 2 December 2012
- **RNP ESF-ELN**
ELN Recommendation Meeting
Atlanta (US), 6 December 2012
- **RNP ESF-REMEDIC**
3rd EACTS Meeting on Cardiac and Pulmonary Regeneration
Berlin (DE), 13-15 December 2012
- **Scientific Review Group**
Biomedical Sciences
First meeting, *date and venue to be decided*
- **RNP REFLECTION**
Steering Committee meeting
Aarhus (DK), 17-18 January 2013
- **Forward Look: Personalised Medicine for the European Citizen**
Launch and implementation meeting
Brussels (BE), 28 January 2013
- **RNP EUMYONET**
Steering Committee meeting
Stockholm (SE), 30 January 2013
- **RNP EUMYONET**
3rd Annual EuMyoNet workshop
Stockholm (SE), 30-31 January 2013
- **RNP ESF-ELN**
10th Annual Symposium of the European LeukemiaNet
Mannheim (DE), 5-6 February 2013
- **Exploratory Workshop**
State of the Art in Diffuse Intrinsic Pontine Glioma
Amsterdam (NL), 28 February – 1 March 2013
- **RNP FFG**
6th ESF Workshop on Affinity Proteomics
Alpbach (AT), 11-13 March 2013
- **BIOVISION The World Life Sciences Forum**
Lyon (FR), 24-26 March 2013
- **RNP REMEDIC**
Steering Committee Meeting
Vienna (AT), 2 May 2013 (*tbc*)
- **RNP REMEDIC**
Workshop on Safety Assessment of New Medical Methods
Vienna (AT), 2-4 May 2013 (*tbc*)
- **Exploratory Workshop**
Early Diagnosis of Cancer in Primary Health Care
Gumslöv (SE), 6-8 May 2013
- **RNP ESF-ENS@T**
4th International Symposium on Adrenal Cancer (FISAC)
Paris (FR), 22-23 May 2013
- **2013 Global Summit Meeting**
Berlin (DE), 27-29 May 2013
- **World Research and Innovation Congress – Pioneers in Healthcare**
Brussels (BE), 5-6 June 2013
- **Exploratory Workshop**
Noise in Decision Making: Theory Meets Experiment
Barcelona (ES), 13-14 June 2013
- **RNP FFG**
Systems Biology of Infection
Monte Verità (CH), 23-27 June 2013
- **ESF-EMBO Research Conference**
B Cells: from Bedside to Bench and Back Again
Polonia Castle Pultusk (PL), 2-7 September 2013
- **ESF-FENS Research Conference**
Neurobiology of Synapses and Rare Dysfunctions
Stresa (IT), 13-17 October 2013
- **ESF-FENS Research Conference**
Neurobiology of Action Control
Stresa (IT), 20-24 October 2013

ESF

The European Science Foundation (ESF) is an independent, non-governmental organisation, the members of which are 72 national funding agencies, research performing agencies and academies 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 and in 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) has been the membership organisation for the medical research councils in Europe since 1971. The mission of EMRC has been to promote innovative medical research and its clinical application towards improved human health. EMRC has offered authoritative strategic advice for policy-making, research management, ethics and better health services. Through its activities, EMRC has served as a voice for its Member Organisations and the wider European scientific community and thus has played an important role in the development of medical research in Europe, working together with the European Commission, research funding organisations, research performing organisations, academies and learned societies, university networks and medical centres, both throughout Europe and internationally. EMRC has disseminated knowledge and promoted the socio-economic value of medical research to the general public and the decision-makers. EMRC has been one of the five scientific standing committees of ESF and has been actively involved in biomedical science policy over the past 41 years.



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