

### EURADIA Spring Meeting

London, Heathrow, 3 June 2013

EURADIA members came together on 3 June 2013 at Heathrow for their Spring Meeting in order to review future plans. A welcome was given by new Chairman Prof Michael Stumvoll, University of Leipzig, Germany followed by an update on current status of the office, finances and application to the UK Charity Commission. Application for membership by the European Society for Paediatric Endocrinology was unanimously approved.

The meeting progressed with information about the FP7-funded InterConnect project introduced by the Project Coordinator Prof Nick Wareham, University of Cambridge, UK. EURADIA will be responsible for two work packages in this project, dealing with networking and communications, both of which EURADIA is well placed to do given the extensive network of the Alliance. Prof Philippe Halban, Honorary Chairman, then informed members about the European Commission new Research Framework Programme Horizon2020. The timetable to the start of the programme, along with the efforts of EURADIA to ensure that chronic disease (of which diabetes was a prime example), was highlighted. An overview of the Knowledge Innovation Communities (KICs) was given by Board Member Dr Volker Lodwig who described the European Institute of Technology (EIT) strategic agenda including a strand on 'Healthy living and active ageing'; the intention of the KICs is for projects to become self-financing with the ultimate aim of delivering products and services.

DIAMAP, the Road Map for Diabetes Research in Europe was a successful first of its kind activity (at European level) and is again to be a priority project for EURADIA. It was agreed that DIAMAP should be updated under the name DIAMAP2020. The European Platform for Clinical Research in Diabetes (EPCRD) intended as a platform to reduce the costs and to streamline the process of clinical research in diabetes, and to launch an expert advice and communications network, was reviewed during the meeting. Finally, Prof Clifford Bailey took the participants on a journey through EURADIA's mission and priorities for the next few years. The Spring Meeting concluded with participants looking forward to the plans becoming a reality.



Read more on: <http://www.euradia.org>

## EURADIA Alliance News

### New Alliance member: European Society for Paediatric Endocrinology (ESPE) Improving care of children with endocrine diseases by promoting knowledge and research

The European Society for Paediatric Endocrinology (ESPE) is a truly international membership organisation aiming to promote the highest levels of knowledge, research, education and clinical practice of paediatric endocrinology and metabolism throughout the world. Since being founded in 1962, when the first annual scientific meeting was held in Zurich, the Society has increased in both size and scope, becoming the leading international scientific community of paediatric endocrinologists.

Underpinning all ESPE activities is benefit to children and adolescents and the Society is dedicated to serve both its members and the international scientific community. It is also actively involved in promoting the interests of the general public and in advising on European health policy in the area of paediatric endocrinology. ESPE is committed to welcoming and supporting colleagues and young paediatric endocrinologists from around the world, as well as establishing close relationships with other scientific societies.

EURADIA extends a warm welcome to new member ESPE and looks forward to working together in the future.

Read more on: <http://www.eurospe.org>

### **The right prevention and treatment for the right patient at the right time** **Outline Strategic Research Agenda for a biomedical research public private partnership under Horizon 2020**

#### **Summary of press release from EFPIA - July 10, 2013**

EFPIA and its specialised groups, Vaccines Europe and European Biopharmaceutical Enterprises, announce the European Commission launch of the IMI2 research funding initiative, which will build upon the success of the Innovative Medicines Initiative in a continued effort to bring innovative solutions to patients. IMI is a public-private partnership between the European Commission and EFPIA, the European Federation of Pharmaceutical Industries and Associations. Under the new EU framework programme Horizon 2020, IMI2 will carry on the collaborative spirit of IMI by bringing together the pharmaceutical industry, European government, and health research partners and patients to advance scientific research and development for a healthy European society.

IMI2 aims to advance trends in personalised medicines; to further R&D in areas of unmet medical need; and to address the regulatory context in hopes of speeding translation from research to innovation.

Following the example of IMI success stories, IMI2 aims to address R&D challenges in areas of unmet medical need. An IMI2 Strategic Research Agenda (SRA) was developed to pinpoint key areas of engagement that can be best tackled together by stakeholders and that will ensure the most relevant results for society. Following further consultation, a finalised SRA is anticipated this autumn.

Máire Geoghegan-Quinn, European Commissioner for Research, Innovation and Science, stated: "Chronic and degenerative diseases are placing a growing burden on our health systems. The second more ambitious phase of the Innovative Medicines Initiative will help develop the next generation of cost-efficient vaccines, medicines and treatments that Europe desperately needs".

#### **EURADIA contribution to the EFPIA consultation can be read here:**

[http://www.euradia.org/uploads/EURADIAresponseEFPIA\\_April2013.pdf](http://www.euradia.org/uploads/EURADIAresponseEFPIA_April2013.pdf)

#### **The full press release can be read here:**

<http://www.efpia.eu/mediaroom/112/43/IMI2-Launch-to-Further-Innovative-Medicines-Initiative-Success-Right-Prevention-and-Treatment-at-the-Right-Time>

#### **New version of the Agenda is now online and available at the following link:**

[http://www.efpia.eu/uploads/Modules/MCMedias/1373296554546/IMI2%20Strategic\\_Research\\_Agenda\\_v%208%20July%202013.pdf](http://www.efpia.eu/uploads/Modules/MCMedias/1373296554546/IMI2%20Strategic_Research_Agenda_v%208%20July%202013.pdf)

#### **The dedicated IMI2 EFPIA website:**

<http://efpia.eu/topics/innovation/innovative-medicines-initiative/innovative-medicines-initiative-2>

### **Useful links and websites**

#### **Linkedin**

There are several useful sites and forums to help become informed and prepared for Horizon 2020; however, you do have to register for LinkedIn to gain access. All the sites mentioned here are external and EURADIA has no control or influence over their content.

#### **Horizon 2020 News and Views**

[http://www.linkedin.com/groups/Horizon-2020-News-Views-4270510?home=&gid=4270510&trk=anet\\_ug\\_hm](http://www.linkedin.com/groups/Horizon-2020-News-Views-4270510?home=&gid=4270510&trk=anet_ug_hm)

#### **Horizon 2020, Framework Programme for Research and Innovation**

<http://www.linkedin.com/groups/Horizon-2020-Framework-Programme-Research-164166/about>

#### **"Horizon 2020": Framework Program for Research and Innovation**

<http://www.linkedin.com/groups/HORIZON-2020-Framework-Program-Research-3731775/about>

#### **HorizonTap – tapping into the knowledge of project managers of EU-funded projects/networks**

<http://www.linkedin.com/groups/HorizonTap-tapping-into-knowledge-project-4891076/about>

### Horizon 2020

#### Conclusion of negotiations on Horizon 2020: Summary of articles reporting developments

On 17 July, the Committee of Permanent Representatives (Coreper) endorsed the agreement reached in three-way talks that took place in June on Horizon 2020, which will pave the way for a formal agreement at the European Parliament, on 22 October, and then at the Council. Now Horizon 2020 looks set to start on time in January 2014. The new funding programme will have a budget of around 70 billion euros for the seven year period, thus making Horizon 2020 the world's largest research programme. The previous multi-annual programme FP7 had a financial allocation of 53 billion euros.

The current budget allocation can be found at

[http://www.consilium.europa.eu/uedocs/cms\\_Data/docs/pressdata/en/intm/138118.pdf](http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/intm/138118.pdf) where **38.53% of the budget has been allocated to the third pillar on Societal challenges with 9.70% going to health, demographic change and wellbeing**. This would amount to €25.9 billion according to the website Horizon 2020 projects. Horizon 2020 will include the framework programme for competitiveness and innovation and the European Institute of Innovation and Technology (EIT). The European Parliament has been arguing for the R&D programme to be opened to applications that are closer to the market.

#### Three Pillars

The Horizon 2020 programme is divided into **three pillars**, each with a fundamental objective:

- **Excellence in science**: includes financing from the European Research Council (ERC), Marie Curie actions, research infrastructures and emerging technologies
- **Industrial leadership**: lays down specific support for innovative SMEs and for industrial technologies
- **Societal challenges**: covers the specific actions programmes financed under the FP7, such as energy, transport, climate and research into problems linked to the ageing population and deterioration of the environment.

#### Rules for Participation

Rules for participation and financing have been simplified in Horizon 2020. The agreement reached in three-way talks and endorsed by Coreper lays down a single reimbursement rate for eligible costs, which is set at 100% for basic research and 70% for innovation programmes that are close to the market (except not-for-profit organisations, which will continue to benefit from full reimbursement). Lastly, the agreement lays down reimbursement of indirect costs at a rate of 25% of the total eligible costs.

#### Ethics and Stem Cells in Horizon 2020

Horizon 2020 will maintain the main ethical principles that apply under the current FP7. These principles are sporadically being challenged by stem cell researchers, who feel they are being held back by national laws. Stem cell research - adult and embryonic - will therefore continue to be financed according to the legal framework of the member state involved. Under the agreement, no financing can be granted to research activities that are banned in all the member states.

For more information:

<http://www.sciencebusiness.net/news/76212/Any-questions-A-guide-to-Horizon-2020>  
<http://ec.europa.eu/research/index.cfm?pg=newsalert&year=2013&na=na-250613>

### Findings by the European Court of Auditors on FP7 research funding Summary of press release 7 June 2013

The European Commission has taken a number of steps to bolster its management of the Seventh Framework Programme for Research (FP7), according to a new report from the European Court of Auditors (ECA). However, researchers seeking FP7 funding are faced with unnecessary inconsistencies. The ECA also found that FP7 processes are geared to ensuring that funding is invested in high quality research, but with less focus on efficiency. The most efficiency gains can be made by developing better grant management tools, reallocating human resources, shortening processing times and aligning the financial control model with the risk of errors.

Read full report on: <http://eca.europa.eu/portal/pls/portal/docs/1/22494827.PDF>

### Innovation Investment Package

#### Summary of speech by Máire Geoghegan-Quinn

An innovation investment package, worth more than 22 billion euro over the next seven years was unveiled by Máire Geoghegan-Quinn European Commissioner for Research, Innovation and Science. The intention is to "strengthen our economy, they are an investment in a better quality of life". Overall, a proposed 8 billion euro investment from the next EU research and innovation programme, Horizon 2020, will secure 10 billion euro from industry, and 4 billion euro from EU Member States.

The contribution from the EU budget is more than doubled and the commitment from industry has increased even more.

This investment will be anchored by five public-private partnerships, called Joint Technology Initiatives.

The five Joint Technology Initiatives are:

1. The Innovative Medicines Initiative to develop new antibiotics and other critical treatments.
2. Clean Sky will help develop cleaner, quieter aircraft with 30% lower CO2 emissions.
3. Bio-based Industries will seek to replace fossil fuels and fossil fuel based products with those from biological resources and waste.
4. Fuel Cells and Hydrogen will find new ways to store and transport energy.
5. Electronic Components and Systems will boost Europe's electronics manufacturing capabilities.

In addition, the package includes four public-public partnerships between the European Commission and EU Member States focused on:

1. support for high tech SMEs
2. new treatments against poverty-related diseases
3. measurement technologies for industrial competitiveness, and
4. solutions for the elderly and disabled to live safely in their homes.

These partnerships are focused on areas where the market alone has not been able to find a solution quickly, often because the return on investment is not guaranteed. But solving these challenges will improve our quality of life, reduce the burden on our societies and create markets for exciting new products and services.

Read full speech on:

[http://europa.eu/rapid/press-release\\_SPEECH-13-624\\_en.htm?locale=en#PR\\_metaPressRelease\\_bottom](http://europa.eu/rapid/press-release_SPEECH-13-624_en.htm?locale=en#PR_metaPressRelease_bottom)

### Calls for tenders and applications

Call for tender No SANCO/2013/CI/004 concerning a pilot project for developing and implementing successful prevention strategies for type II diabetes

(published June 2013, no deadline given) Timetable: Execution of tasks shall not exceed 24 months

[For more information click here.](#)

Diabetes Research and Wellness Foundation DRWF application for diabetes research projects and proposals

Deadline for applications 23 August 2013

<http://www.drwf.org.uk/Research/ResearchNews/tabid/707/View/true/ParentId/451/Default.aspx>

### Global Alliance for Chronic Diseases

#### Members of GACD to fund landmark research initiative to reduce impact of diabetes

From Press Release 26 July 2013

Diabetes is now one of the most common non-communicable diseases (NCDs) globally. With the burden of this chronic non-communicable disease ever increasing, members of the Global Alliance for Chronic Diseases (GACD) will issue a call for research proposals that address the prevention and treatment of type 2 diabetes. The focus will be on implementation and intervention research in low- and middle-income countries, vulnerable populations in high-income countries and indigenous populations in Canada and Australia.

Over the past twenty years, the global death rate from diabetes has doubled [1] and the World Health Organization (WHO) is predicting that this will increase by two thirds by 2030. It is currently estimated that 347 million people worldwide suffer from diabetes, with more than 80% living in low- and middle-income countries. Of those suffering from diabetes, type 2 comprises 90% of this population around the world [2]. The WHO has identified halting the rise of diabetes as a global NCD target and Member States are required to consider it.

The GACD was established in 2009 to support clear priorities for a coordinated research effort that will address chronic non-communicable diseases, a growing health crisis now reaching epidemic proportions globally.

Last year, the GACD funded research projects on hypertension (high blood pressure) prevention and control in 15 low- and middle-income countries (LMICs). The first coordinated funding effort among GACD members, this initiative included 15 community-based research projects that will focus on implementing effective approaches to control high blood pressure.

The GACD member agencies include:

- Chinese Academy of Medical Sciences (CAMS)
- Canadian Institutes of Health Research (CIHR)
- Research & Innovation DG, European Commission (EC)
- Indian Council of Medical Research (ICMR)
- Medical Research Council, UK (MRC)
- National Heart, Lung and Blood Institute (NHLBI)
- National Health and Medical Research Council (NHMRC)
- Medical Research Council, South Africa (MRC)

The International Development Research Centre of Canada will also contribute funding to this initiative.

**Press Contact:** Rosie Bartlett, Communications Manager, GACD at: [r.bartlett@ucl.ac.uk](mailto:r.bartlett@ucl.ac.uk).

[1] [Lozano et al; The Lancet, Dec 2012, Vol 380, Issue 9859](#)

[2] <http://www.who.int/mediacentre/factsheets/fs312/en/index.html>

To read full article:

<http://www.gacd.org/homepage/news/gacd-fund-landmark-diabetes-research>

### Diary Dates

18 Sept 2013 Innovations in Diabetes: European Action Summit 2013 (IDEA Summit). Lund, Sweden

<http://www.ideasummit2013.se/>

19-21 Sept 2013 18th FEND Annual Conference. Barcelona, Spain

<http://www.fend.org/>

23-27 Sept 2013 49th EASD 49th Annual Meeting. Barcelona, Spain

<http://www.easd.org/>

24-27 Sept 2013 Int Pancreas and Islet Transplant Association 14th World Congress. Monterey, USA

<http://www.ipita2013.org/>

27-29 Sept 2013 Beta-cell Regeneration and Genome Regulation. Sitges, Barcelona, Spain.

<http://www.isg2013.org/>

# European Forum for Good Clinical Practice (EFGCP)

## Annual Conference 29-30 January 2013

### Virtual Future: the ethical dimensions of emerging technologies in clinical trials and research

As a member of the EFGCP, EURADIA finds these meetings provide a useful overview of current thinking in clinical research. The EFGCP has a track record of picking up topics not approached by anyone else in a similar way. The conference took place over two days with 14 plenary sessions covering issues related to emerging technology and healthcare: such as conducting clinical trials on the internet; the perspectives of patients; improving consent; the clinical trial process; e-research, and fraud and misconduct.

The conference began with two sessions laying out the scope of e-health (also called mHealth, connected health and cybermedicine), which focuses on the use of information and communications to inform decisions and actions by professional staff and by the public at large. There are many health social networking sites of interest. One of these, 'PatientsLikeMe' has already conducted a trial into the use of lithium in patients with ALS (motor neurone disease). The trial - "one of the first examples of a really genuine citizen study in which patients decided on and designed the study" - showed no difference in progression, and prompted later randomised clinical trials. Also noted was the possibility for people to meet up via FaceBook, decide on a research question, define their own eligibility criteria, randomise themselves, obtain drugs from online pharmacies, measure and record end-points, collaborate on data analysis and publish online prompting the question - it was asked then: "where does that leave Good Clinical Practice"? Citizen science has pros and cons. On the plus side, it promises faster, wider reach in recruitment, enthusiasm and real patient-related outcome measures. The results are likely to be rapid and focused, and to be adopted quickly. It is also less expensive, and can ask new questions. But there are some cons: reliability, bias and the risk of contamination. But there is potential to engage with patient-led studies to overcome some of these problems.



EFGCP Conference Report picturing the Chair, Dr Ingrid Klingmann

The Joseph Hoet lecture on ethics in clinical research was given by Prof Silvio Garattini from the Mario Negri Institute for Pharmacological Research, Italy, who attacked what he called the widespread misuse of clinical trials. "Today a drug can be approved if it shows quality, efficacy and safety. But we need to add three

more words: "therapeutic added value", said Garattini.

During a stimulating and enjoyable meeting in addition to the plenary sessions there were eight workshops covering issues such as: recruitment and new technologies; consent and new technologies; privacy, confidentiality and electronic media; conducting clinical trials on the internet; preparing for the future: training needs analysis; how should ethics committees review e-research? *Really* involving the public in research using new technologies: citizen science - which included an impressive example of a project from Cancer Research UK.

**EURADIA members may contact Sarah Hills for the full conference report and the presentations. More information on the EFGCP may be found at: [www.EFGCP.eu](http://www.EFGCP.eu)**

For more information or to contribute to the EURADIA newsletter contact Sarah Hills on:

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