



European Alliance for Personalised Medicine

EAPM Bulletin: Issue 32, November 2017

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Alliance set to give Europe's innovators a 'HI-5'

Welcome to EAPM's November newsletter. The main event for the Alliance and stakeholders this month is obviously our inaugural Congress, from 27-30 November in Belfast, which will also play host to the first HI-5 Awards.

Details of the Congress follow elsewhere in the newsletter, but here's some information on those awards...

HI-5 Awards

Linked to the Presidency Gala Dinner on 28 November, the awards will be given in five categories and will be known as the Health Innovation Five, or HI-5 Awards.

The awards will be contested on an annual basis and, in order to decide the winners, EAPM has brought together a committee of five experts for each award - so, 25 people in total. The five committee members in each category were then tasked with identifying and evaluating the possible candidates before eventually deciding the winner in their own section. Part of the sponsorship for each award will be given to a charity decided by the recipient.

Categories and nominees:

EU-based Minister or politician who has best support health innovation in personalised medicine

- Jevgeni Ossinovski, Minister of Health, Estonia
- Chris Fearne, Minister for Health, Malta
- Lydia Mutsch, Minister of Health, Luxembourg
- Maggie De Block, Minister of Health, Belgium
- Beatrice Lorenzin, Minister of Health, Italy
- Simon Harris, Minister of Health, Republic of Ireland
- Marisol Touraine, Minister of Health, French

EU-based region that has done the most to support innovation

- Auvergne-Rhône-Alpes
- Baden-Württemberg
- Catalonia
- Lombardy
- Bratislava
- Danish Capital Region

In the pipeline

- **27-30 Nov: EAPM Congress, 'Personalising Your Health: A Global Imperative, Belfast**
- **28 Nov: Inaugural HI-5 Awards, Belfast**
- **27-28 March, 2018: 'Personalised medicine and the Big Data challenge', EU Presidency conference, Brussels**
- **16 May, 2018: Lung Cancer Screening - 'Moving forward towards guidelines', Sofia**
- **19-22 June, 2018: TEACH Summer School for healthcare professionals, Warsaw**

EU-based research centre for innovation in personalised medicine

- Cambridge Cancer Centre
- German Cancer Research Centre & National Centre for Tumor Diseases
- Gustave Roussy
- Karolinska Institute
- Netherlands Cancer Institute
- Vall d'Hebron Institute of Oncology
- Queen's University Belfast

Best EU-based hospital for integrating personalised cancer medicine

- Tartu University Hospital
- Humanitas
- The Leeds Teaching Hospital
- Uniklinik Köln
- UniversitätsKlinikum Heidelberg
- University Hospitals Birmingham



Best company to promote personalised healthcare

- Roche
- Novartis
- Merck
- AstraZeneca
- Pfizer
- Shire
- MSD

MEGA project

The Million European Genomes Alliance (MEGA) initiative is moving forward after EAPM's engagement with the European Commission and certain Member States.

Better use of our increasing understanding of the genome is recognised as being one of the main determinants of future improvement in healthcare as part of personalised medicine and is already being increasingly deployed in routine clinical practice.

Sequencing of the all the genetic material of an individual, whole genome sequencing, is becoming an affordable and achievable test for clinical use and creates a powerful resource for research.

This MEGA project will take into account that every country has bigger or fewer resources, but the stunning concept would ideally see a linking together of the efforts in order to reach the one million figure.

A number of genome sequencing initiatives at scale in the last few years to try and capitalise on this potential. Within the EU the UK has led the way with the 100,000 Genomes Project. MEGA would take this much further.

In the EU, of course, healthcare is a national competence, but we have floated the idea that each Member State (or at least a 'coalition of the willing') should develop a genome project proportionate to their populations.

HARMONY general assembly

The HARMONY GA took place on 23-24 October in Berlin. The meeting's agenda has a strong scientific focus and emphasised the seven HM Pillars.

The event allowed all HARMONY partners and associated members to come together to discuss and reach agreement on existing and forthcoming bench-to-bedside projects and more. As part of its involvement, EAPM produced a framework document.

At the meeting EAPM executive director Denis Horgan emphasised the need to harmonise rules in order to implement the General Data Protection Regulation and that this depended on the willingness of Member States to collaborate.

Aspen Healthcare Forum

The Alliance took part in the Aspen Healthcare Forum, under the title of '*Healthcare as an investment, from cost to social efficiency*', also held in October, in Bucharest, Romania.

Up for discussion were multiple possible policy approaches fostering better access to medicines for the population of Romania as well as the wider Central and Eastern Europe region.

Also discussed was mapping Romania's healthcare services needs in order to find adequate responses and identify integrative health solutions, as well as a session on access to new technologies and the next steps in the development of an innovation-based health system.

Among those present were Dr. Laszlo Attila, president of the Committee for Public Health in the Romanian Senate, Oliver Groene, a senior lecturer in Health Services Research at the London School of Hygiene and Tropical Medicine, EAPM's Denis Horgan and Prof. Dr. Cristian Vlădescu, director at the National School of Public Health, Management and Professional Development.

Speaking after the event, Horgan said: "This forum was yet further proof that smaller countries, in this case Romania, are key in setting the agenda when it comes to personalised medicine.



"Issues such as integrating innovation and access to medicines affect everyone and there is a growing movement in Romania and other countries to overcome barriers in this emerging field."

Sofia PM conference

EAPM was also present in Bulgaria's capital on 26-27 October to take part in the first PM conference to be held in the Balkans.

The objective of the two-day event was to outline the stage of development, challenges for implementation and future trends in personalised medicine in the Balkan region.

The conference focused on the presentation of scientific projects, clinical, diagnostic and organisational methods, integrated approaches, real-world-evidence, real-world data and experience in the field of precision and personalised medicine.

Jasmina Koeva-Balabanova, chair of the board of the Bulgarian Alliance for Precision and Personalised Medicine, spoke about the need to share best practice around educational issues for HCPs and patients with neighbouring countries in the Balkan regions.

EAPM, meanwhile, pushed forward the issue of early diagnosis and the need to have frameworks in place, for example in lung cancer, complete with attendant screening guidelines.

Data protection/innovative payment schemes

Last month (23 October) also saw a meeting on the General Data Protection Regulation run by the European Commission and including EAPM's input.

On the 25th, meanwhile, a meeting on innovative payment models for high-cost innovative medicines saw representatives of healthcare payers and national health authorities discuss concrete, short-term solutions on how to pay for expensive drugs. This gathering was also organised by the Commission.

Attendees heard that there are currently no mechanisms that could meet the objectives of all payers and governments.

Big in Japan

The Alliance went further afield than usual when its executive director gave two presentations at the International Association for the Study of Lung Cancer (IASLC) in Japan.

Denis Horgan took the opportunity to highlight the role of early diagnosis, treatment and need for screening, referencing an [EAPM report](#) and saying that the Alliance has made lung-cancer screening and effective guidelines one of its main priorities going forward.

Said Horgan: "Figures show that lung cancer causes almost 1.4 million deaths each year worldwide, representing almost one-fifth of all cancer deaths. Simply within the EU, meanwhile, lung cancer is responsible for almost 270,000 annual deaths - some 21%.

"It is at the very least surprising that the biggest cancer killer of all does not have a solid set of screening guidelines, or globally introduced screening programmes. . This must change and quickly."

Preventable blindness White Paper

MEP Cristian Silviu Buşoi hosted an eyesight workshop in the Brussels European Parliament ahead of World Sight Day (12 October).

The workshop took place on the 11th, and a [White Paper](#) on blindness (with involvement from EAPM) was launched to highlight that eye disease and its prevention is a major issue in Europe today and will only become bigger as the 500-million-plus population ages (and the incidence of, for example, diabetes grows).

Buşoi was joined by fellow MEPs Alojz Peterle, Marian Harkin, and Soledad Cabezon Ruiz.

Ian Banks, the chair of the European Forum Against Blindness (EFAB), alongside European Alliance for Personalised Medicine (EAPM) executive director Denis Horgan, gave overviews of the White Paper, before a stakeholder discussion.



Also present at the workshop were Caroline Klaver, Professor of Epidemiology and the Genetics of Eye Diseases at Erasmus MC, Rotterdam, who spoke about myopia and eye problems.

She was joined by Carel Hoyng, Professor of ophthalmology, Department of Ophthalmology, Radboud University Medical Centre, who covered the topic of age-related molecular degeneration. Olivier Arnaud, Senior Director, European Research, JDRF, whose topic was 'Seeing eye disease through the diabetes lens', and Christopher Brittain, Senior Medical Director, Ophthalmology Clinical, who spoke about ophthalmology research and development.

Further topics discussed focused on easing access to prevention and innovative treatments, including patients in preventable blindness policy formation, and promoting research into blindness.

The workshop heard that there are some 39 million blind people in the world, but 80 per cent of blindness can be cured or prevented. So, in effect, 31.2 million people are blind when they needn't be.

Meanwhile, studies suggest that eye disease costs society in Europe some €20 billion, causing a significant economic burden. The number of blind people in the EU population (aged more than 50) is around 1.3 million, with in the region of a further 10 million living with medium-to-severe visual impairment.

Economic consequences of visual impairment in Europe include direct medical costs due to treatment and diagnosis, treatment of potential future health consequences (which includes an increased risk of falls or other accidents), and direct non-medical costs.

Loss of productivity due to an inability to work is also a huge factor, and this often includes the patient's carer.

MEP Marian Harkin said: "The substantial costs are more than likely to increase in the future and much better use of already-available cost-effective prevention and treatment tools would reduce the fiscal burden."

"Investment in screening programmes, earlier (and better) diagnoses and adequate treatment of retinal conditions, can lower the economic burden and bring about improved quality

of life, and therefore a more productive population," added the Irish MEP.

Belfast Congress

As mentioned earlier in this newsletter, EAPM is now closing in on the First Annual European Personalised Medicine Congress, to be held from 27-30 November in Belfast, Northern Ireland.

The majority of speakers have now been confirmed and a substantial number of scientific abstracts have been received with a wide range of stakeholders represented.

It is rapidly approaching the last chance to book your place for what will be a one-stop-shop for discussion about the fast-moving world of personalised medicine.

The Congress will act as a bridge and a 'point of excellence', bringing researchers, scientists, policy makers, patients, healthcare professions together with a view to advancing conclusions regarding necessary actions, reached by consensus, to politicians at regional, Member State and EU level.

The Congress website, the abstracts portal, current programme and online registration are all available. (See links on Page 5.)

Key areas that the Congress will include:

- **Patients** - Modern-day patients are better informed than ever before and are demanding to share in co-decision making about issues affecting their treatments. They are also hugely in favour of being able to share their own private health data (under strict ethical and privacy provisions) for the benefit of fellow patients and future generations.

- **Education & Training** - Healthcare professionals (HCPs) are falling behind with front-line knowledge as developments in personalised medicine move swiftly. Europe must put programmes in place to bring, and keep, these HCPs up to speed.

- **Regulation** - Proponents of personalised medicine believe that much legislation governing aspects of healthcare is out-of-date and not fit for purpose in these fast-changing times. Regulations and directives must be brought up to modern levels



through a consensus of experts and key actors, including patients.

- **Research & Development** - EAPM has always promoted state-of-the-art research, and this will be a focus of the Belfast Congress which will be held at The Waterfront venue (above).

Useful Congress links

[Congress Programme](#)

[About the Congress](#)

[Session formats](#)

[Sessions styles](#)

In the news: EAPM articles

[#EAPM: Recent innovations in the healthcare arena](#)

[#EAPM: Diabetes and blindness in India and beyond](#)

[#EAPM: Lung-cancer screening – who should take the lead?](#)

[#EAPM: Screening for lung and other cancers in EU](#)

[#EAPM: EU must open its eyes to preventable blindness](#)

[#EAPM: EU focus on eye diseases central to European Parliament White Paper](#)

[White Paper on Blindness to launch in European Parliament](#)



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About EAPM

The European Alliance for Personalised Medicine (EAPM) , launched in March 2012, brings together European healthcare experts and patient advocates involved with major chronic diseases. The aim is to improve patient care by accelerating the development, delivery and uptake of personalised medicine and diagnostics, through consensus.

As the European discussion on personalised medicine gathers pace. EAPM is a response to the need for wider understanding of priorities and a more integrated approach among distinct lay and professional stakeholders.

The mix of EAPM members provides extensive scientific, clinical, caring and training expertise in personalised medicine and diagnostics, across patient groups, academia, health professionals and industry. Relevant departments of the European Commission have observer status, as does the EMA. EAPM is funded by its members.

**Contact: Denis Horgan
EAPM Executive Director
Avenue de l'Armee/Legerlaan 10, 1040 Brussels
Tel: + 32 4725 35 104
Website: www.euapm.eu**