



European Alliance for Personalised Medicine

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No slowing down for Alliance in 2017

Welcome to the first newsletter of 2017. EAPM would like to take this opportunity to wish a Happy New Year to all our colleagues, members and associates and we hope that you had an enjoyable and restful holiday period.

This year promises to be as busy as ever for the Alliance, with the fifth annual conference (Brussels) coming up in March, our second Summer School for healthcare professionals, another meeting at the UN General Assembly in New York and a landmark conference planned for Belfast in the autumn.

Alongside all this, we'll be undertaking more SMART Outreach events, continuing to have dialogue with MEPs as they start the second half of their five-year mandate, and meeting with Commission officials on a regular basis.

As well as the aforementioned continued and increased engagement with Members of the European Parliament, the Alliance will also focus on dialogue with Member State governments' representatives in their own home parliaments to further the embedding of personalised medicine in the current EU 28's health systems.

And as it's January, a new Member State has taken over the rotating presidency of the European Union. Step forward, Malta. EAPM would like to wish Malta's representatives all the very best with the country's programme for the next six months.

AGM Brussels

EAPM held its annual general meeting in Brussels, in early December.

Co-chair David Byrne opened the meeting and welcomed all members. The former European Commissioner for Health highlighted the amount of work done over the last several years, which culminated in the Luxembourg Council Conclusions on access to personalised medicine of December 2015, and its implementation at the EU/national level.

Three new board members were elected to represent medical societies, research/universities and industry. These are, respectively, Alexander Eggermont, ESMO Executive Board; Mark Lawler, Dean of Education Faculty of Medicine, Health and Life Sciences, Queen's University Belfast, and; David Boyd, Director European Government Affairs, AstraZeneca. We wish them a warm welcome.

The meeting heard that EAPM has built upon four high-profile EU Presidency Conferences and a series of national events in

In the pipeline

- **16 January: Congress registration opens**
- **17 January: Regulatory WG**
- **24 January: Education WG**
- **26 January (& 21 February): Big Data WG**
- **30 Jan-2 February: Engaging with MEPs**
- **7 February: The Challenge of Precision Oncology & Drug Development Processes**
- **14 February: Orphan Regulation meeting**
- **28 March: EAPM 5th conference, Brussels**
- **3-7 July: HCPs Summer School, Bucharest**

major European cities including Dublin, Brussels, Milan, Warsaw, Copenhagen, Madrid, Sofia, and Athens, culminating in the Alliance's participation in a Sustainable Development Goals session, which took place during September's UN General Assembly meeting in New York.

Those present heard that EAPM has increased its interaction with the media and politicians in a continuous bid to influence policy and regulatory change. Without the ability and effort to engage the press and politicians, many of the key issues surrounding personalised medicine may have passed unnoticed – among the public, politicians and the general policymaking authorities.

This increase in coverage is reflected in the SMART Outreach activities at the national level where EAPM events appeared in national and regional media.

Meanwhile, EAPM has had a regular and strong presence at major events, as well as often holding its own meetings, workshops and roundtables, plus SMART (which stands for Smaller Member states And Regions Together).



SMART

Smaller Member States And Regions Together

The SMART Outreach programme has the following objectives:

- Capacity-building at the national level for personalised healthcare/medicine by connecting high-quality scientific communities in various disciplines, existing networks, patient groups and policy-makers to form EAPM at the national level;
- Coordinating, and contributing to the development of a state-of-the-art action plan dedicated to further implementation of PM in ways that are sensitive to the particular needs, challenges and constraints of different institutional, regional, and national contexts;
- The development and consolidation of a platform for sharing best practices in personalised healthcare, aiming to advise policy-makers and other key stakeholders.

Since its inception, SMART meetings had seen more than 2,220 delegates attending, including patients, medical professionals, healthcare planners, industry representatives, scientists and researchers.

These outreach events epitomised a strategic approach, developing major points and allowing a cross-section of representatives from industry, science and research communities to come together at national level.

Action for 2017

This year, EAPM will extend its activities where SMART outreach meetings have been established as well as widen its outreach in Member States where there is interest from members.

Meanwhile, the second Summer School for healthcare professionals (HCPs) will build on the success of the first such school held July 2016 in Cascais, Portugal.

This year, the concept will be taken east to Bucharest, Romania, from 3-7 July.

As it was this year, the school will be entitled 'TEACH', which stands for Training and Education for Advanced Clinicians and HCPs, and the goal is to bring young, front-line professionals up-to-speed with fast-moving developments in the field.

Aimed at age-range 28-40, TEACH holds to the thesis that, if personalised medicine is to be in line with the EU and Member State principle of universal and equal access to high-quality healthcare, then clearly it must be made available to many more citizens than is currently the case.

The school dovetails with EAPM's call on the European Commission to focus funds to stimulate a Continuous Education and Training Programme for HCPs in the context of personalised medicine.

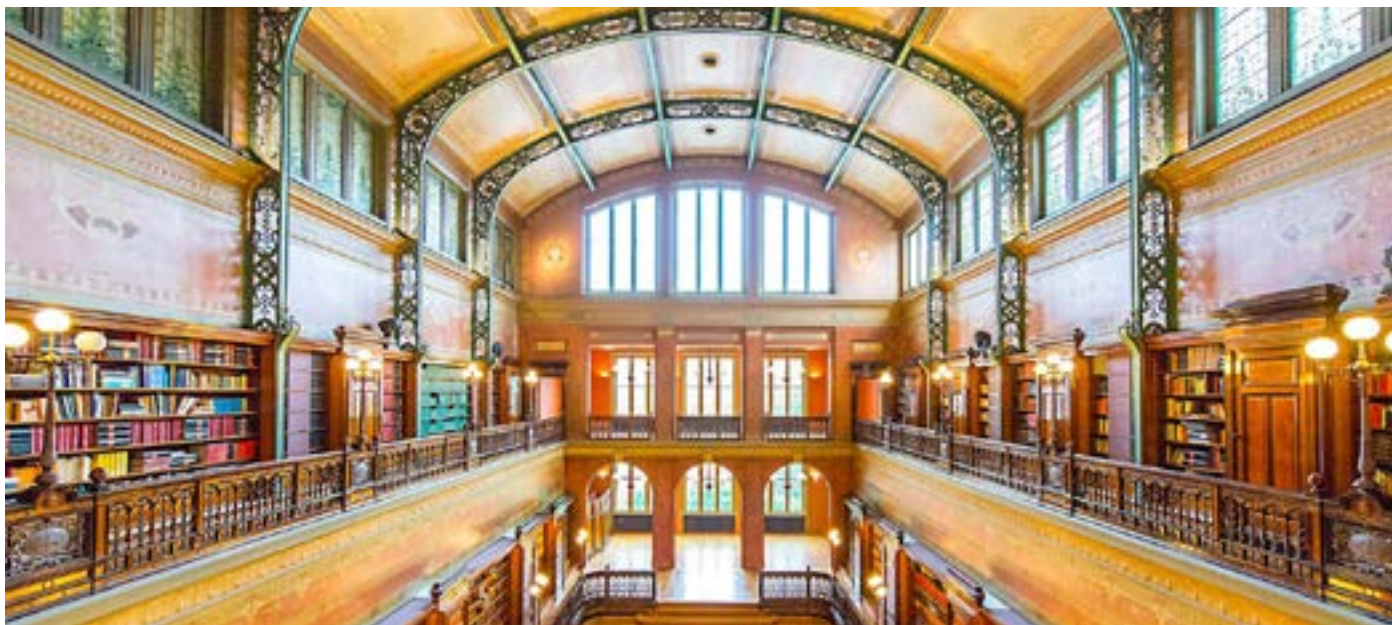
Also set to continue great work in 2017 are the EAPM Policy Working Groups, Committees and Taskforce.

The Alliance has four WGs, plus one Taskforce and all have different activities. These are:

- **Big Data:** Key Policy Ask: "By 2020, the EU should endeavour to achieve widespread benefits for patients and citizens from personalised healthcare by defining and subsequently executing a Data Strategy for Personalised Medicine."

- **Education and Training of Healthcare Professionals:** Key Policy Ask: "By 2020, the EU should support the development of a Europe-wide education and training of healthcare professionals' curriculum for the personalised medicine era. The EU should subsequently facilitate the development of an Education and Training Strategy for HCPs in Personalised Medicine."

- **Early Access and Better Decision Making:** Key Policy Ask: to ensure healthcare resources allocated to development and utilisation of personalised medicine, through acceptance of its long-term cost-effective benefits and also to effect a paradigm shift in pricing and reimbursement to recognise the societal value of a medicine.



- **Research Roadmap for PM:** Key Policy Ask: For the EU to commit to the development of a European Translational Research Platform that enables the efficient translation of research discoveries to innovative diagnostics, therapeutics, products and processes that will benefit European patients, industries and societies.

- **The Taskforce on Regulatory Affairs:** will continue to respond to regulatory issues at national level.

These groups bring together stakeholders in neutral forums to discuss the issues related to their specific area (patients' unmet needs, medical perspectives, research, industry and more).

The goal is to understand any differences, overcome any misunderstandings and to find common ground, leading to a prioritisation of issues.

Activities include parliamentary engagement at the EU and Member State level, research engagement, the writing of policy papers, as well as meetings with institutional representatives.

Achievements within this framework have included key changes to three pieces of legislation (Data Protection, Clinical Trials and In Vitro Diagnostics), supporting research in terms of Horizon 2020 and IMI II legislative proposals, plus putting personalised medicine on the political map through the Luxembourg Presidency's Council Conclusions of late 2015.

Down the line, this newsletter will provide more information about upcoming activities. The Working Group will be engaging in current regulatory and policy themes, shaping them at EU level and following implementation at the national level.

This is geared towards supporting our members and developing an environment for personalised medicine.

EAPM 5th annual conference

EAPM's fifth Annual Conference - *'Innovation and Screening in Lung Cancer - The Future'* - will take place on 28 March at the historic Bibliothèqu Solvay in Brussels (pictured above).

The conference will build on solid foundations and aim to raise awareness among policymakers about the needs of modern-day

patients and how personalised medicine has the potential to change healthcare for the better.

As ever, high-level speakers and attendees will come from a wide range of stakeholder groups including patients, healthcare professionals, academics, industry representatives, politicians and legislators, the media and more.

The conference will be held across one full day, and the aim is to see real and concrete recommendations emerge.

Modern medicine is advancing swiftly and there are many areas trying to play catch up. With the giant leaps in gene sequencing, imaging, data availability and more, a genuine improvement in cooperation is required across all disciplines and all geographical areas.

Much can be achieved with consensus-based guidelines to ensure that all stakeholders are aware of acceptable standards and are effectively all 'singing from the same hymn sheet'.

There is clearly a need to:

- Raise awareness of the need for agreed guidelines over lung-cancer screening
- Improve the knowledge of policymakers and world health agencies so that effective lung-cancer screening guidelines and policies can be formulated on the international stage
- Work across national borders to ensure cooperation and collaboration in respect of much-needed guidelines in the fast-developing field of personalised medicine
- Advance parallel work done by professional groups, patient groups, healthcare funders, pharmaceutical companies and academic institutions to a new level

Figures show that lung cancer causes almost 1.4 million deaths each year worldwide, representing almost one-fifth of all cancer deaths. Within the EU, meanwhile, lung cancer is also the biggest killer of all cancers, 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 across Europe.



2017 Maltese Presidency of the Council of the European Union

In these testing financial times, with expenditure on healthcare rising, it is vital that the benefits of screening are weighed against potential harms (radiation etc) and cost effectiveness.

Patients need to be made aware of potential negatives of screening in their case (as well as the benefits) and thus be able to make a choice. Co-decision making is a core principal of patient groups and others backing personalised medicine.

Belfast Congress

EAPM will be focusing on and developing the policy asks that will be set out in the Congress, to be held in Belfast, Northern Ireland in the autumn.

The Congress website, the abstracts portal, and online registration will all be launched on 16 January.

In the news

As ever, EAPM has been busy in the media. Click the links below to read our more recent articles.

[This is the modern world – Time for regulation to move with the times](#)

[Frustrated patients deserve better health-care strategies](#)

[Democracy – Would you vote for it?](#)

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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.

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