



European Alliance for Personalised Medicine

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Banishing lung cancer (if not snakes...)

Welcome to our March newsletter. As most of you will know, this month features Saint Patrick's Day, the celebration of the death of the patron saint of Ireland (17 March).

During the same month, the EAPM team will be holding its fifth annual conference in Brussels (on 28 March - although there will be less Guinness available at the latter event!).

Entitled *'Innovation, Guidelines and Screening: The Case of Lung Cancer'*, the conference will once again take place at the historic Bibliothèque Solvay, close to the European Parliament. More details are available [here](#).

Ireland, if not St Patrick himself, has had a connection down the years with lung-cancer prevention - of which smoking is, of course, a major cause - not least through the Alliance's co-chair, David Byrne.

A one-time Attorney General of Ireland, David was, from 1999-2004, the European Commissioner for Health and Consumer Protection.

During his time in the Berlaymont, he was a major driving force behind tobacco control legislation, including directives banning tobacco advertising and regulating tobacco products.

While Saint Patrick allegedly banished Ireland's snakes, more than a millennium-and-a-half later David worked hard at the highest level to lay the foundations for getting rid of his country's (and Europe's) culture of smoking in pubs, restaurants and more.

Smoking in workplaces in the Emerald Isle was banned on 29 March 2004, and made Ireland the first country in the world to institute an outright ban in this regard.

While David Byrne is unfortunately not able to be present in Brussels on the day of the conference, the event will build on solid foundations.

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

In the pipeline

- **7 March: EAPM Working Groups meeting**
- **27 March: Polish Alliance for Personalised Medicine, annual conference, Cracow**
- **28 March: EAPM 5th conference, Brussels**
- **27-30 June: HCPs Summer School, Bucharest**
- **27-30 November: EAPM Congress, Belfast, Northern Ireland**

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

Within the EU, meanwhile, lung cancer is the biggest killer of all cancers, responsible for almost 270,000 annual deaths. 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.

Th EAPM conference will attempt to address this large gap for the benefit of EU patients.



Meeting of EAPM Working Groups

On 7 March, the Alliance's Taskforce on Regulatory Affairs, and Working Groups on Access, Big Data and Research will get together in Brussels. Here's a little more information:

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

- **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."

- **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.

As well as the working group for the **Education and Training of Healthcare Professionals**, 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.

Also on the agenda that day will be Country Specific Focuses for the upcoming Congress, more of which below:

Belfast Congress

During the coming months, EAPM will be focusing on and developing the policy asks that will be set out in this First Annual European Personalised Medicine Congress, to be held across four days (27-30 November) in Belfast, Northern Ireland (pictured above).

The Congress website, the abstracts portal, and online [registration](#) have been launched and the current programme is available to view [here](#).

Key areas that the Congress will focus on 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, while improving their interaction skills with patients.

• **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. Despite health largely remaining a Member State competence, regulations and directives must be brought 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. The Alliance's stakeholders have engaged often with IMI and the European Commission (for example, Horizon 2020) to discuss incentives for industry, patients and academics in the area of R&D.

The Congress will see 35 parallel sessions plus ten presidential sessions. During the coming months, EAPM will be working with the session leads to ensure translation into the key policy objectives that the Alliance will focus on going into the upcoming election cycles for MEPs.

There will also be many opportunities for EAPM members and the broader stakeholder community to get involved in terms of proposing speakers and adding suggestions about policy areas.

Here is a further link that readers should be aware of: to submit abstracts, click [here](#)

Further action for 2017

In the near future, a mid-term briefing for MEPs will be launched

and distributed by the Alliance. This will concentrate on several areas that include the following:

- **What value do we put on health?**
- **Personalised medicine and the European Parliament**
- **Changing times in healthcare**
- **Aligning laws for personalised medicine**
- **Priorities for the European Commission**
- **Patient power on the rise**
- **Managing expectations**
- **The role of carers**
- **Prevention measures**

Aside from this, EAPM will continue to engage with MEPs to ensure that they are aware of the issues that concern citizens in the era of personalised medicine.

Also, the Alliance will be following and engaging with its national members, in particular those Member States that, as already mentioned, have upcoming elections. The idea is to set the terms of the priorities that EAPM wants to pursue.

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

Meanwhile, on 27 March, the Polish Alliance for Personalised Medicine will hold its annual conference in Cracow (pictured above) and EAPM will be present.

TEACH Summer School

Further down the line, the second Summer School for healthcare professionals will build on the success of the first such school held in July 2016 in Cascais, Portugal.

This year, the concept will be taken east to Bucharest, Romania, and run from 27-30 June.



As it was in 2016, 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 news

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

[An investment in knowledge pays the best interest](#)

[Juncker through the looking glass...](#)

[Charlie and the Medicine Factory](#)

[Commission must bring healthcare to the fore](#)

[Rare cancers: A headache for policymakers](#)

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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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