



# European Alliance for Personalised Medicine

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## New challenges ahead for 2018

Welcome to the first EAPM newsletter of 2018 - and Bulgaria's first ever EU Presidency, of which more below.

All of us at the Alliance hope that you enjoyed some quality time off over the festive period and that you greet the new year with renewed vigour and determination after a hectic 2017.

Those of you who live and/or work in Brussels may have seen that December in the city was the darkest since 1934, with a mere 10.5 hours of sunlight.

Let's hope for much more light during 2018!

But it certainly wasn't all dark last year. Alongside all the regular work undertaken by our various Working Groups, and our SMART Outreach events across Europe, the Alliance hosted a fifth annual conference, a second TEACH Summer School for healthcare professionals and a first-ever Congress in Belfast.

Upcoming 2018 events will be highlighted later in this newsletter. Meanwhile, a Congress report from the Belfast event is online now, [here](#).

### **Bulgarian Presidency of the EU**

Bulgaria took over the EU Presidency last week, on the first of January, succeeding Estonia. Unfortunately, healthcare is not a huge priority for Sofia, but let's make the most of what is on offer in our field.

Bulgaria does, however, zoom in on a few specifics that it will hope to accomplish during its sixth-month stint at the EU helm.

When it comes to access to medicines, the new presidency has said that it aims to promote an active debate on the topic of medicinal products.

This it says, is "in order to find solutions to the problems related to the shortage of medicinal products for economic reasons, parallel exports and the need to provide medicines that are proven to be effective and at affordable prices."

Sofia also stated that it aims to promote entrepreneurship and social innovation in various industries. To a greater-or-lesser extent, this will include healthcare.

Meanwhile, in early February, in the country's capital, a meeting will be held on *Better eating - children's health and curbing obesity*, while June's Food 2030 conference in Plovdiv will address research and innovation in nutrition.

### **In the pipeline for 2018**

- **27-28 March: 'Personalised medicine and the Big Data challenge', Sixth Annual EU Presidency conference, Brussels**
- **Second quarter: 'Lung Cancer Screening - Moving forward towards guidelines', Sofia**
- **19-22 June: Third TEACH Summer School for healthcare professionals, Warsaw**
- **26-28 November: Second Annual EAPM Congress, Milan**

As ever, EAPM will be working hand-in-hand with the Presidency wherever appropriate and possible.

### **Estonia Council Conclusions**

The Alliance has now been involved in two sets of Council Conclusions that will have an impact on the future of health in general and targeted treatments and diagnoses in particular.

The first of these was, of course, the landmark Luxembourg conclusions on access to personalised medicine two years ago. These came about in no small part due to EAPM's influence and involvement, not least at a major conference on the topic at the start of the Luxembourg presidency, organised by the Duchy's health minister Lydia Mutsch and her team.

As part of those conclusions it was noted with concern that not all patients have access to innovative methods of better-targeted prevention, diagnosis and treatments and that a significant challenge for Member States consists in promoting appropriate uptake in healthcare systems.

Now we have Estonia's 'Council conclusions on Health in the Digital Society - making progress in data-driven innovation in the field of health'.

Many of these conclusions echo those reached at EAPM's several conferences and particularly at the inaugural congress, held as part of the Estonia presidency.



The Alliance has played a major role in many of the sections, not least regarding genomics, and the conclusions note that new opportunities are arising from big data and improved data analytics capabilities, as well as from personalised medicine, use of clinical decision support systems by health professionals and use of mobile health tools for individuals to manage their own health and chronic conditions.

New knowledge and skills are needed in the health sector to be able to utilise this potential.

The Conclusions invite the Member States and Commission to build on the existing national and EU initiatives and public-private partnerships, and "consider creating decentralised data networks and common platforms to enable data integration and analysis in a secure environment".

EAPM will place a focus on these Conclusions during the coming year, not least in the context of the MEGA initiative outlined below.

#### **MEGA news**

The Million European Genomes Alliance - dubbed the MEGA project - is aimed at linking gene sequencing efforts across the European Union.

MEGA's goal is ultimately to compile a database of a million genomes for clinical research purposes, using a coalition of the willing Member States, as well as for stimulating the life sciences economy, and improving patient care across the EU.

Next-generation gene sequencing technologies provide physicians with the ability to make educated diagnoses based on a patient's genome which will lead to better health outcomes. With rising healthcare costs an increasing challenge, genomics has the potential to reduce costs by ensuring that patients receive the right information and the right treatment at the right time.

The Alliance firmly believes that MEGA is a viable project. It is just as much a vehicle for advancing personalised medicine as it is for bringing together actors from Member States to overcome a fragmented research environment.

MEGA could serve as a flagship for dealing with issues that have prevented European cooperation to date.

In the end, it is all about the patients. And the MEGA project will certainly benefit them hugely down the line.

#### **Coming up in 2018**

EAPM has several key events and programmes planned for this year, with plans for the **sixth annual Presidency conference** already in place for 27-28 March.

The '*Personalised Medicine and the Big Data Challenge*' event will be held under the Bulgarian Presidency of the EU.

Taking place close to the Brussels seat of the European Parliament, the conference will feature plenary sessions in the afternoon of Day One, followed by a dinner in the parliament that evening and a day-long event on Day Two.

Given the European Parliament elections, which will by then not be much more than a year away, a key goal will be to raise awareness of personalised medicine in respect of current MEPs who will be standing again, and potential new Members.

An agenda will be circulated at the end of this month, at which point registration will also open. We hope to see you there.

#### **Pioneering work**

EAPM has won the right to lead an area of the Pioneer Project under the second stage of IMI2 JU Call 10. The Alliance's proposal was evaluated positively by independent experts and the Governing Board of IMI2 JU.

Pioneer stands for **Prostate Cancer DiagnOsis and TreatmeNt Enhancement through the Power of Big Data in EuRope**

Pioneer's vision is to re-orientate the management and clinical practice of PCa across all disease stages towards a more outcome-driven, value-based, and patient-centric healthcare system.

The goal is the best possible care for all European men living



European Alliance for  
Personalised Medicine



# EAPM

## 6<sup>th</sup> Annual Conference

# BRUSSELS

Plans for the sixth annual Presidency conference of the Brussels-based European Alliance for Personalised Medicine are already in place for 27-28 March 2018.

The 'Personalised Medicine and the Big Data Challenge' event will be held under the Bulgarian Presidency of the EU, which runs from 1 January to 30 June.

Taking place close to the Brussels seat of the European Parliament, the conference will feature plenary sessions in the afternoon of Day One, followed by a dinner in the parliament that evening and a day-long event on Day Two.

The conference will revisit the prestigious Bibliothèque Solvay in Parc Leopold.

The effect on healthcare of Big Data, across many disciplines, will certainly mean that clinical researchers and other healthcare stakeholders and professionals will need to develop new expertise and a different approach. Ongoing training will be vital, but there are many other issues to be discussed.

Given the European Parliament elections, which will be not much more than a year away at the time of the conference, a key goal will be to raise awareness of personalised medicine in respect of current MEPs who will be standing again, and potential new Members.

**We would be delighted to have you join us in Brussels.**

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with PCa using sustainable solutions. It is thus a prime time to use available 'big data' to provide 'effective and sustainable' solutions, which will ultimately lead to better disease outcomes.

More details will follow in due course regarding the Work Package that EAPM will lead.

#### **Summer School, Warsaw (pictured above)**

EAPM's third annual Summer Summer School will be held in partnership with the Polish Alliance for Personalised Medicine. It will take place in Warsaw from 19-22 June, 2018.

Once again, 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 faculty has been chosen from medical academic, clinical, communication and research specialists.

Among the reasons that EAPM has chosen to organise this school in Eastern Europe is in order to take into account the need for educated young HCPs who can bring the latest innovations directly to patients outside of the larger, and often richer, EU Member States.

This also dovetails with our **Smaller Member states And Regions Together (SMART)** outreach programme.

Day three of the Summer School will see a focus on lung cancer, a topic that EAPM events have covered intensively (not least on the subject of screening) and will continue to do so.

As we all know, lung cancer is the leading cause of cancer deaths worldwide. In advanced stages of the disease survival rates are sub-optimal. There is an unmet need in development of new and innovative compounds.

For several years improvements in diagnostic surgical and molecular procedures have been taking place, as well as an increasing role for immunotherapy, although identification of predictive factors for immunotherapy is still required.

Meanwhile, imaging has become increasingly important in the evaluation of response to lung cancer therapy and is necessary for determination of disease progression during conventional chemotherapy or/and molecular targeting therapy, especially in the era of personalised medicine.

Radiological response criteria evolve continuously in parallel with the advances in lung cancer treatment.

Aside from the TEACH event, EAPM will continue to place a focus on prevention and early diagnosis, specifically in connection with lung-cancer screening.

#### **Screening conference, Sofia**

The Alliance is working on organising a conference on lung-cancer screening in the Bulgarian capital of Sofia in the second quarter of this year.

The provisional title of the conference is '*Lung Cancer & Early Diagnosis: The Evidence Exists for Screening*' and will be run in association with national affiliate the Bulgarian Alliance for Precision and Personalised Medicine.

The Bulgarian Alliance has taken a lead in putting access and earlier diagnosis as a top priority in its own region as well as in the Balkans.

Sofia sees it as a very important priority to focus on screening and prevention, especially in respect of such a killer disease.

More news on this proposed event will be made available in due course.

#### **Annual Congress, Milan**

Similarly to the inaugural 2017 Congress in Belfast, the second Congress in Milan will be a pan-European, multi-disciplinary event specific to the fast-moving field of personalised medicine and will take place from 26-28 November.

# EAPM

## 2<sup>nd</sup> Annual Congress, **MILAN**

The European Alliance for Personalised Medicine (EAPM)  
is already planning a second major,  
personalised medicine Congress in Milan  
on November 26–28, 2018.

Similarly to the inaugural 2017 Congress in Belfast, this will be a pan-European, multi-disciplinary event specific to the fast-moving field of personalised medicine and will take place from **26–28 November 2018**

EAPM and its stakeholders believe that Europe needs to build better healthcare systems for its current 500 million citizens, and the generations to come.

A key aim of the Congress is to allow cross-fertilisation between the different disease and policy areas, allowing delegates to gain a greater depth of knowledge into barriers in the field of personalised medicine.

It is also geared towards offering up valuable evidence and stakeholder opinion on which policy makers can base their decision making on how better to integrate personalised medicine into the EU's healthcare services.

For more information, please contact the EAPM Office:

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The event will provide the biggest 'space' to date to allow for such a meeting of minds and expertise, and EAPM is building a one-stop-shop for top-level discussion and the formulation of real action plans. So be sure to come.

Once again, the Congress will bring together the different streams (including scientists, industry, regulators, patients and more) in order to allow decision makers to understand changes that are required, now and down the line.

The Congress will pull together leading experts in the arena of personalised medicine drawn from patient groups, payers, healthcare professionals plus industry, science, academic and research representatives.



# world diabetes day

## 14 November

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Once again Congress will bring together the different streams (including scientists, industry, regulators, patients and more) in order to allow decision makers to understand changes that are required, now and down the line. Below are some of the tracks that will be integrated into the Congress programme.

**Public Health:** This track will cover all aspects of public health including legislation, regulation, smart use of resources, cross-border healthcare, the collection, storage and sharing of data, and more.

**Patients - Value, Access, Diagnostics:** Featuring complex inter-related topics that will embrace thinking on the need for improved health literacy (patients, HCPs and regulators), and ongoing training for HCPs.

**Translational Research - Brining Innovation into Healthcare Systems:** European researchers have been at the forefront of major scientific healthcare discoveries in areas such as cancer, cardiovascular disease, genetic disorders, and infectious disease.

The challenge is how best to translate this knowledge and expertise into advances that improve outcomes for patients.

**Pricing and Reimbursement/Access:** The price of new treatments may cause problems in all countries that provide state-based healthcare assistance to their citizens. What is needed is a form of collaboration: pharmaceutical companies have a right to make profit, the state - and therefore its citizens - has a right to obtain access to effective treatments at an acceptable price.

**Education:** This is specific to the education of HCPs in 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. It is more important than ever to bring Europe together in a way that improves the already significant skills that HCPs possess to enable codecision making which will effectively empower the patient.

**Diabetes:** According to the World Health Organization, the number of people with diabetes rose from 108 million in 1980 to 422 million in 2014. It is a major cause of blindness, kidney failure, heart attacks, stroke and lower limb amputation.

It is an epidemic of truly global proportions. This track will explore ways to significantly reduce these numbers.

**Genomics:** Our understanding of genomics has increased substantially since 2000, by which point the majority of the genome had been sequenced as part of the Human Genome Project.

Research since then has greatly improved understanding of the genome's implications for health. These advances have been matched by a revolution in technology, including the development of next-generation sequencing in which a rapid reduction in costs are making the technology more available for clinical applicability.

**Incentives for Innovation:** The question is how to fully integrate Europe's brilliant research into national healthcare systems, especially as the 'system' of getting efficacious, innovative drugs and treatments affordably to those who need them is no longer fit for purpose.

The fact that a new medicine or innovative product usually takes more than a decade to get from bench-to bedside is not only undesirable but is unacceptable in the 21st century.

### *A note on our Working Groups*

EAPM has several Working Groups and will be reaching out to members to finalise key activities for these groups for 2018. Here are a few lines on the policy asks for each.

**Research Roadmap for PM:** Chaired by Queen's University Belfast, this group asks 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.

**Regulatory Affairs Taskforce:** Chaired by EORTC, the group's asks are for a responsive regulatory environment that responds to the needs of all stakeholders whilst ensuring patient safety, with the end result of ensuring development of treatments for patients.

Also needed is easier circulation and sharing of personal data, appropriately balanced with personal privacy and greater

