



# European Alliance for Personalised Medicine

EAPM Bulletin: Issue 15, June 2016

[www.euapm.eu](http://www.euapm.eu)

## First HCP Summer School now in sight

Welcome to the June newsletter. As ever, EAPM has been building on the work undertaken since its formation with recently published reports on two events.

The Alliance's fourth annual Presidency conference took place in April and this was followed swiftly by a series of research roundtables. Both events took place in Brussels and the reports are available by clicking below.

Conference report: ['Taking Stock: Where we are now and the necessary next steps'](#)

Roundtables report: ['Crossing the Research Rubicon - 5 Different Ways: The Stakeholders' Voice'](#)

### Summer School for HCPs

EAPM's first TEACH Summer School will be held in Cascais, Portugal from 3-7 June.

The Alliance, in collaboration with other medical societies under the leadership of the Past President of EHA, Christine Chomienne, is organising a Summer School for young healthcare professionals called TEACH' - which stands for Training and Education for Advanced Clinicians and HCPs - and the goal is to bring young HCPs up-to-date with developments in this exciting field.

Aimed at young healthcare professionals aged 28-40, TEACH will cover topics such as monoclonal antibodies, inhibitory drugs and putting the patient at the centre of his or her own care - all within the context of personalised medicine.

Recognising that the patient at the centre of personalised medicine, the summer school will focus on training in "how to communicate to patients about personalised medicine" and, even more specifically, on "how the treatment they will receive is meant to work", "how was the target of this treatment discovered in research and confirmed in the patient's own samples?" and "what side effects or type of response may be expected considering other diseases/aspects of the patient?".

The training will consist of plenary sessions followed by time spent in small groups focussing on how to communicate in respect of several defined topics over the course of four days.

Tutors (the faculty) have been chosen from medical academic, clinical and research specialties, patient organisations and communication specialists.

### In the pipeline

- **1-2 June: PerMed conference on personalised medicine, Brussels**
- **16 June: SMART Outreach meeting in Romania**
- **27-29 June: EAPM will take part in the Symposium ETH Zurich on personalised medicine**
- **3-7 July: Summer School for HCPs, Cascais, Portugal**

Participating organisations are:

- European Haematology Association
- European Society for Nuclear Medicine
- European Association of Urology
- European Respiratory Society
- European Society of Pathology
- European Society of Pharmacogenomics
- European Institute for Oncology
- Association of Public Health Schools
- European Brain Council
- European Association of Hospital Pharmacists
- European Organisation for the Research and Treatment of Cancer

Over the course of the school, a 20-strong faculty of experts will oversee plenaries, group discussions and interactive role play sessions involving those HCPs enrolled on the course.

Venues for the school are Centro Cultural de Cascais, Museu-Biblioteca dos Condes de Castro Guimarães, Casa das Histórias Paula Rego and Casa de Santa Maria.

The school has its own section on the EAPM website, [click here](#)



# SMART

Smaller Member States And Regions Together

## Personalised Medicine Conference, European Commission

On 1-2 June, at the European Commission's Charlemagne building in Brussels, an EC-led conference will explore personalised medicine through research policy. Europe is a leader in this developing field, an interdisciplinary area which will drive the health research and innovation agenda for years to come in order to improve healthcare.

The conference aims to showcase the current state of the art in the area and explore future research and innovation challenges. It will also introduce a new collaboration among health research funding and policy making organisations called the International Consortium for Personalised Medicine (IC PerMed).

PerMed was launched at EAPM's 2015 conference and the Alliance will be building on this association during the event.

Speakers include: Peter Kapitein, Patient Advocate, Inspire2Live, Amsterdam (Peter spoke at the 'Taking Stock' Conference and will be speaking at the Summer School); Wolfgang Ballensiefen, Project and Programme Manager, German Aerospace Centre (who spoke at the research roundtables); Sabine Tejpar, University Hospital Leuven, (who sits on EAPM's Clinical Trials Working Group) and; Maarten J. IJzerman, Professor, University of Twente, Enschede (who also spoke at the 'Taking Stock' conference).

The agenda is available [here](#)

## Copenhagen Roundtable

The 10 June will see a roundtable meeting at the European

Haematology Association congress: "Crossing the Rubicon from Copenhagen - EHA Leading the way."

Personalised medicine has never been more in the public eye than it is now, and the roundtable aims to reflect this.

America is moving quickly in this field, quickly concluding that health equals wealth and that investment in research and innovation, alongside laws and rules that are fit-for-purpose and reflect the swiftly changing world of medicine, are vital.

Europe needs to grasp these points at every level, for the benefit of the millions of potential patients spread across 28 Member States.

The haematology community has a lot to contribute and has been a leading light to shape the EU policies as evidenced by Luxembourg's Council Conclusions on Personalised Medicine.

At the EHA Congress, 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.

EAPM will, of course, be in attendance.

## SMART Outreach

Romania will, on 16 June, see its first SMART Outreach event. SMART stands for Smaller Member states And Regions Together and aims to see personalised medicine working on the ground, in the nations and regions.

Other successful Outreach events have already taken place in Poland, Austria, Bulgaria and Italy, and all worked towards



formulating a patient-centred strategy involving national decision makers and regulators in the arena of public health.

This is to help facilitate the EU and Member States in contributing to integrating personalised medicine into clinical practice while enabling much-greater access for patients.

The Alliance's June 2015 EAPM conference introduced the 'SMART' concept and, although Brussels-based – which helps to better engage with the European Commission, EU permanent representations and the European Parliament in the 'Capital of Europe' – EAPM aims to expand its work with the multi-stakeholder groups, and nations, that form its membership.

### **Alliance helps shape new IVD rules**

The European Parliament and European Council have reached a political agreement on the Medical Device Regulation and the In Vitro Medical Device Regulation.

The discussions have been ongoing since 2012.

EAPM welcomes the inclusion of many suggestions and recommendations it has made during the process. These were formulated after numerous Alliance meetings and roundtables with key stakeholders.

EAPM is delighted to say that it has contributed hugely to a piece of legislation that saw many amendments to the original draft as it developed and changed.

These new medical device regulations update existing EU

legislation going back to the last millennium and they cover devices ranging from sticking plasters and contact lenses to breast implants and even pacemakers.

The new deal will secure further, more up-to-date, health and safety protection for patients. See the link to an article at the end of this newsletter.

### **Special issue**

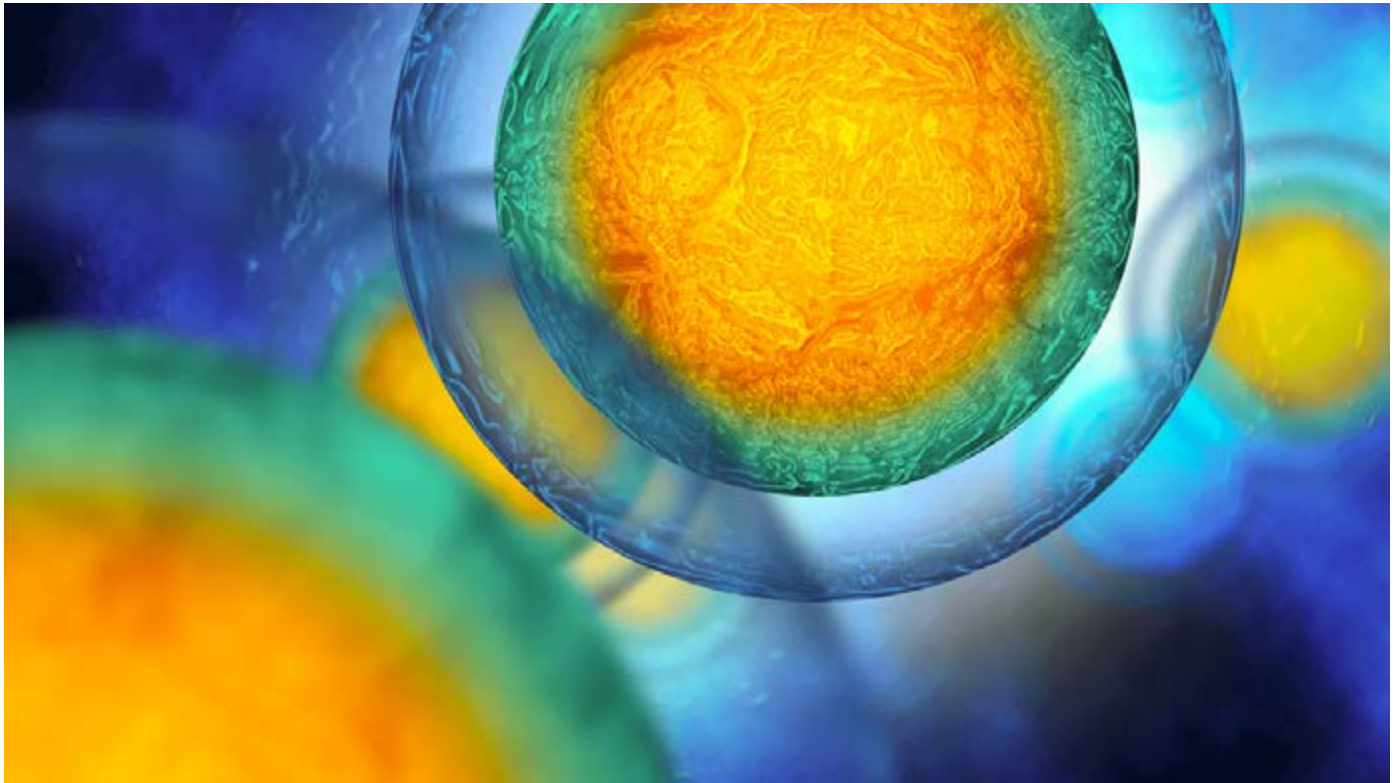
A *Public Health Genomics* special issue on challenges and opportunities for enhanced patient access to personalised medicine in Europe, has been produced by EAPM and will be available online from 1 June.

Co-written by Angela Brand, Mark Lawler and Denis Horgan, the special publication takes into account the Council of the EU issuing its Conclusions on Personalised Medicine for Patients, highlighting how "the development of personalised medicine may offer new opportunities for the treatment of patients in the European Union...allowing healthcare providers to offer better-targeted treatment, avoid medical errors and reduce adverse reactions to medicinal products."

Personalised medicine certainly has the potential to improve outcomes for European citizens, but its undoubted promise must be balanced against a number of highly relevant challenges that may limit its positive impact on 21st century medicine.

Issues such as increasing costs, inequitable access across European countries and regions and the need for an ethical,





regulatory and reimbursement environment are currently undermining the integration at personalised medicine at European and national levels.

Recognising the need to address these important issues, EAPM assembled a multi-stakeholder panel to identify and precisely define the critical barriers that limit personalised medicine uptake, while also developing putative solutions that will enhance patient access across Europe.

The outputs from their discussions are captured through a series of articles in this Special Issue, complementing the activities of the EAPM's Working Group on Access, which is surveying the European landscape and developing policy recommendations in this complex domain.

Click [here](#) from 1 June onwards.

## In the news

As ever, EAPM has had articles published in the media recently. Readers can access these by clicking on the titles below.

[Genetic testing not yet perfect – but its benefits are real](#)

[Italy event flags up needs of cancer patients](#)

[Personalised medicine group helps shape new IVD rules](#)



Follow EAPM on Twitter @euapmbrussels

## 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](http://www.euapm.eu)**