



Dear readers,

We hope you have had a relaxing summer break: we are delighted to welcome you back to our newsletter!

Preparations for our much awaited EPF Congress 2019 are in full swing! Under two months to go now until the very first European Congress on patient involvement driven by patients. This edition features an update on our special ambassador Hans Kluge, who has just been nominated as Regional Director-elect of the WHO European region; one of our keynote speakers, Tessa Richards, senior editor at the BMJ; and an update from the Youth Group. Remember to [register](#) if you have not already done so!

featured new Board Elections, and our recent Leadership module under EPF's Capacity Building Programme. Under the same programme, we have also released a trailer showing highlights of our Summer Training Course for Young Patient Advocates.

The opportunities offered by a new European Commission and Parliament feature prominently in the thinking of the EPF Board and Secretariat. At EPF we always aim to develop and expand our multi-stakeholder network across the health spectrum, in order to fully represent the patient voice over the next mandate. To this end, a recent statement issued jointly with EPHA warmly welcomes the nomination of Stella Kyriakides as the EU Commissioner for Health.

We are also pleased to inform you that our Transparency Guidelines are officially out and available for your download.

Happy reading!

[Usman Khan, EPF Executive Director](#)



EPF Capacity Building Programme: Enabling Leadership and Positive Governance

The final part of EPF's second [Capacity Building](#) Module was held in Sofia, Bulgaria on 7-8 September 2019. This year the topic of the module was about Leadership and Positive Governance.

The module aimed at strengthening patient organisations by enhancing their leaders' leadership skills and consequently enabling positive governance in their organisation. The overall objective is to support patient organisations in positioning themselves as legitimate

[Read more here](#)

Summer Training Course for Young Patient Advocates 2019: trailer out now!

Becoming #Advocates4Health

*Are you thinking of becoming a patient advocate?
Interested in what the summer training course for young patient advocates is all about?*

Take a look at the highlights of this year's edition in our recently released trailer [here](#).

You can find more information about the programme [here](#).

News about EPF Congress

An important message on the Congress from our Youth Group.

Listen to this message from the Youth Group: what will the surprise be? There is only one way to find out! Stay tuned for more updates, and (you heard them) [register](#) and spread the word about our much awaited Congress.

[Youth Group Trailer](#)

Who should attend our session on patient safety, and why.

Since 17 September is officially #WorldPatientSafetyDay, it is timely that this is one of the topics chosen for the parallel working sessions

the EPF Congress is dedicated to patient safety, and the role of patients and families. The session builds on previous work by EPF and shows how patients can contribute to improving safety, what barriers exist and how they can be overcome. You will hear from the patient perspective what is missing today; learn about new initiatives to measure patients' experiences and patients' reports of safety incidents; implementation of partnership approach in a hospital setting; and bringing together patients, families and healthcare managers to change culture.

[Read more here](#)

EPF Transparency Guidelines now available!

Patient organisations are under increasing pressure to demonstrate transparency and good governance. They deal with health, which is a highly sensitive topic. They also operate in a complex external environment which includes relationships with regulators, healthcare professionals, and industry with high potential for real or perceived conflicts of interest. This calls for a high degree of integrity and accountability.

EPF is proud to announce that our Transparency Guidelines are now available online for your download, absolutely free. These guidelines aim at providing guidance on sound and ethical practices in the following fields: governance, cooperation with industry, membership, and communications.

Take a look at the Guidelines [here](#) and feel free to spread the word!

Policy Update

EPF welcomes election of Hans Kluge as new Director of the WHO European region!

international experience across several WHO regions with numerous health policy stakeholders allows him to truly understand the needs of patients as well as healthcare professionals. We do not doubt that he will ensure that healthcare needs are adequately met across Europe.

[Read more here](#)

Health makes the cut of the new European Commission

The European Public Health Alliance (EPHA) and the European Patients Forum (EPF) welcome Ursula von der Leyen's effort to reflect people's everyday concerns by retaining a Commissioner for health in her new team. **Stella Kyriakides'** knowledge of the European-level health field and understanding of patient-advocacy is a strong base for future collaboration between the Commission and civil society in the interest of public health.

[Read full joint statement here](#)

European health community says don't let a no-deal Brexit put patients across Europe in danger

As the prospect of the UK leaving the European Union without a negotiated deal remains a real possibility, European patient groups and health sector organisations have spoken out about the need to take urgent steps to protect patients across the EU.

[Read more here](#)

EPF responds to the EMA's public consultation on electronic medicines information

At the end of July, EPF submitted a response to the European Medicines Agency's public consultation on key principles regarding electronic product information on medicines (e-PI).

organisations, was submitted via online questionnaire, and will be published by the EMA. In the meantime [you can read it here](#).

For more background information about the consultation, [click here](#).

You may also read our take on the opportunities and challenges of electronic medicines information [here](#).

EPF Members & Youth Group

Portuguese Parliament supports patients' initiative on public participation in health

(Article by Margarida Santos and Sofia Crisostomo - MAIS PARTICIPAÇÃO melhor saúde)

The [Charter for Public Participation in Health](#) was approved by the Portuguese Parliament in July, with 85% of MPs voting in favour of the legal initiative. The Charter was initially developed by the [MORE PARTICIPATION better health](#) initiative – a group of Portuguese patient and health service user organisations. The group also collected more than 4000 signatures for the Charter to be discussed at the Parliament.

[Read more here](#)

EPF Youth Group Fall Meeting 2019 – Elections and powerful start to a new project

By Jana Popova and Borislava Ananieva (Members of EPF Youth Group)

This year's EPF Youth Group Fall Meeting took place from 6 to 8 September in the beautiful city of Budapest, Hungary. The meeting started with an official welcome to all members. In the afternoon the Group kicked off with a discussion on their favorite initiative: Work and Youth Strategy (WAYS) project.

[Read more here](#)

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