



Dear readers,

On behalf of the EPF Secretariat we would like to wish everyone a very happy and prosperous new year ahead! We are pleased to send you the first newsletter of the new decade.

The new year already got off to a running start, with a fruitful meeting with the EU Commissioner for Health and Food Safety Stella Kyriakides. With the new Parliament and Commission, this year will be of crucial importance for the successful continuation of our work on health policy and advocacy, and our focus on the patient perspective will remain on the forefront of all emerging health initiatives and activities.

We have also opened activities for our yearly Capacity Building Module on Empowering Leadership and Positive Organisational Governance and our fourth edition of STYPA – Summer Training Course for Young Patient Advocates.

We wish you an excellent reading!

The EPF team

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## The EU Cancer Plan will be meaningful and fully patient-centric, says EU Commissioner Stella Kyriakides



On 7 January EPF met with the new Commissioner for Health and Food Safety Stella Kyriakides. The Commissioner, who invited EPF for a meeting around the theme of the forthcoming EU Cancer Plan, we are pleased with the outcome of this productive meeting, which we hope will be the start of a long-term fruitful collaboration with the Commission and other health and patient organisations.

[Read more](#)

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## State of Universal Healthcare Coverage in Europe: EPF's view on Médecins du Monde's recent report



On 11 December, EPF was honoured to be invited to moderate a panel at an event in the European Parliament organised Médecins du Monde (Mdm).

On this occasion, Mdm launched its [2019 observatory report](#) on the state of universal healthcare coverage in Europe, which sheds the light on healthcare exclusion experienced by people in vulnerable situations such as homelessness, migration and poverty especially for children – a situation which is unacceptable in EPF's view.

[Read more](#)

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## Involving patients in the development and review of lay summaries: good practices



The upcoming [Clinical Trial Regulation](#) expects the development and dissemination of Lay Summaries of clinical study results.

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content of Lay Summaries, there is no guidance on how best to handle the development process and how best to ensure reliable dissemination to **increase of clinical research transparency, and both the patients' and the public's understanding of clinical research.**

[Read more](#)

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## Data Saves Lives: Why health data matters



Data  
Saves  
Lives

Europe is facing major healthcare challenges due to its ageing population and the rise of chronic diseases. There is an urgent need for more effective and smarter medicine to deliver better care to patients. New opportunities are arising for treatment through genetics. Better decision-making is possible using algorithms and artificial intelligence. Yet, all this needs to be delivered within the same healthcare budgets. Learning more from health data can lead to discoveries that will show us how to make these improvements.

[Read more](#)

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## **Empowering Leadership and Positive Organisational Governance module**

*Applications are now open for our 2020 Capacity Building module on Empowering Leadership and Positive Organisational Governance until 16 February!*

Patient organisations and patient organisations' leaders are becoming more and more visible actors in the healthcare arena. This is an important and positive change. Nevertheless, it also brings new and bigger challenges:

- Organisations leaders exchange more frequently and more intensively with several stakeholders at the same time;
- Instable political situations and rapid changes in governments put extra pressure on patient organisations;
- The growth in visibility is not linked to a growth in financial and human resources of patient organisations, therefore they face more challenges and increasing demands from external stakeholders with small teams, mostly of volunteers and limited financial resources.

This module will address such challenges and opportunities, by offering a high quality and tailored training for leaders of all patient organisations, or similar.

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Please find more information and instructions on how to apply [here](#).  
Please apply before **16 February 2020**.

## SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES

### Shaping the future of Patient Advocacy

#### Summer Training Course for Young Patient Advocates

*Applications for STYPA are officially open until 30 March 2020.*

The Summer Training Course for Young Patients Advocates (STYPA) – Leadership Programme is an exciting and unique opportunity offering a tailored high-quality training to young patient advocates or representatives, who have the motivation to learn more about advocacy and maximise their leadership potentials in a real environment.

Our vision for STYPA is to create a platform where young patient advocates would empower, inspire, and learn from each other on an annual basis.

If you know of any young patients, who would like to improve their advocacy skills then do not hesitate to spread the word!

Find our more about the format of the training, more information and how to apply [here](#).

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The launch of the *Young Coalition for Vaccination and Prevention Manifesto: Let's step up for Vaccination*, was held on 21 January at the European Parliament, in Brussels. As partners of the Coalition, EPF attended the launch representing the patient perspective with Executive Director Dr. Usman Khan as a key speaker at the event, and other staff members. MEP Brando Benifei (S&D) and Isabel de la Mata, Principal Adviser for Health and Crisis Management at the European Commission hosted the event and officially launched the Manifesto.

[Read more](#)

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**PARADIGM project - 7 months til the end: are we on track?**



PARADIGM is an atypical project by its nature and its duration – very short and most of the tangible achievements are due at the end of the project. The project was built in two phases, the first one to be able to capture the data, identify gaps and see what is missing to make patient engagement in pharmaceutical R&D the norm. The second phase focuses on the creation of tools to facilitate patient engagement for all the stakeholders.

[Read more](#)

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## EPF Youth Group | Blog contributions



### **Youth Group blog XLH Alliance Meeting**

*Blog by EPF Youth Group Member Sally Hatton*



THE XLH Alliance is an international alliance of patient groups supporting individuals and families living with XLH (X-Linked Hypophosphatemia), a rare metabolic disorder in which the body wastes phosphate it needs for healthy bone development. In November, I was lucky enough to attend my first meeting of the Alliance held in Malmo, Sweden, as a representative of XLH UK.

[Read more](#)



## **IFSBH Event on Sexuality**

*Blog by Marcus Ward*

From 5-6 October 2019 I travelled to Varese in Italy to attend a youth conference on sexuality for people with spina bifida and hydrocephalus. The conference was organised by the IFSBH (the International Federation for Spina Bifida and Hydrocephalus) and

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Group, of which I am a member.

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