



Hello there,

And welcome to the latest edition of the EPF newsletter. July has been another busy and exciting month for the EPF community, especially in terms of projects. Read on for more info!

The highlights of this month include the second edition of the [EPF Summer Training Course for Young Patient Advocates](#), which was a great success according to the really positive feedback we got from all participants!

Our project team were very engaged at the [DIA 2018 Global Annual Meeting](#) in Boston to discuss patient engagement, and the [COMPAR-EU workshop](#) in Berlin where patients and healthcare professionals debated in depth preferred patients' outcomes.

We are pleased to share with you some updates on the [EPF Capacity Building Programme](#). We keep working to build a strong and influential patient community, and the new module of Leadership and Positive Governance is already yielding results.

The [EPF Youth Group](#) has been extremely active lately! In addition to participating in the EPF Summer Training Course, they also held their annual meeting in Vienna, where they welcomed three new members and brainstormed on future priorities. They also shared with the group the activities in which they have been involved individually, and Youth Group member Jana told us about [her inspiring experience in the EURORDIS Summer school](#).

Finally, we invite you to read the blog [post written by our partner Tourettes Action](#), an organisation from the UK, that explains to us more about this condition and all the barriers patients living with it face at the workplace.

The EPF Newsletter will be back in September; in the meantime enjoy the summer and a well-deserved break!

Enjoy the reading!

Projects

[EPF Summer Training Course: Campaigning for Count Us In! →](#)

Forty young participants got together to share experiences and learn leadership, advocacy and campaigning skills with one main objective: to get ready to become the next generation of patient advocates!

[DIA 2018 GLOBAL ANNUAL MEETING: Towards Meaningful Patient Engagement →](#)

The DIA 2018 Global Annual Meeting took place in June in Boston and gathered over 6,000 professionals from more than 50 countries. The event was designated 'Patients Included' and "patient engagement" was one of the main themes of the meeting.

[COMPAR-EU: Discussing Preferred Patients' Outcomes →](#)

In July, the COMPAR-EU face-to-face workshop took place in Berlin.

researchers and clinicians, and to analyse the challenges that these different perspectives pose with regard to defining relevant outcomes for different chronic conditions.

EPF Members & Youth Group

[EPF Capacity Building Programme: Enabling Leadership and Positive Governance](#) →

Patient organisations and its leaders are becoming more visible actors and influencers in the healthcare arena. This is an important and positive change but it also brings challenges linked to knowledge-building, know-how sharing and leadership within organisations.

[\(BLOG\) EPF Youth Group Meeting: Brainstorming the Future](#) →

This year's EPF Youth Group spring meeting was held in beautiful Vienna. Three new members were welcomed, and the group had interesting and fruitful discussions about the future activities of the group.

[\(BLOG\) EURORDIS Summer School: A Week of Inspiration](#) →

In June, Jana Popova from the EPF Youth Group participated in the professional Expert Patients and Researchers Summer School, organised by EURORDIS in Barcelona. Read her experience at this training opportunity.

Partners

[\(BLOG\) Employment and Tourettes](#) →

Tourette Syndrome is a neurological condition estimated to affect over 300,000 children and adults in the UK. The main symptoms are physical and vocal tics, which typically develop in childhood. What you see on the outside is usually just the tip of the iceberg, with much more happening beneath the surface.

Events



European Society for Clinical Nutrition and Metabolism (ESPEN) Conference

3 September 2018 / Madrid, Spain

EPF speaker: Nicola Bedlington

Early Intervention Toolkit launch

11-12 September 2018 / Brussels, Belgium

EPF attendance: Nicola Bedlington

12th EMA Stakeholder Forum on the Pharmacovigilance Legislation

24 September 2018 / London, UK

EPF speaker: Kaisa Immonen

EU Patient Task Force on Nutrition

25 September 2018 / Brussels, Belgium

EPF speaker: Katie Gallagher

EFPIA Think Tank

26 September 2018 / Brussels, Belgium

EPF attendance: Nicola Bedlington & Katie Gallagher

European Diabetes Patient Advocacy Summit

27 September 2018 / Brussels, Belgium

EPF speaker: Nicola Bedlington

Publications



[EPF Transparency Guidelines](#) →

What are the actual rules that a patient organisation should respect, and what are the processes to implement and



monitor them in your organisation? This publication tries to answer these and other questions, and it provides information and resources to guide you in fostering transparency within your own organisation.



[Employment and Chronic Conditions - EPF's initiatives](#) →

Have a look at the latest initiatives we've developed for the inclusion of people living with a chronic disease in the workplace.

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