

# Newsletter EPF - October 2019

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The European Patients' Forum newsletter – October 2019

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2019 **EPF**  
Congress

*It's nearly time for*  
**EPF Congress!**



Dear readers,

There are only two weeks to go now until the very first patient designed and led European Congress on Patient Involvement. This edition features an exclusive interview with Special Ambassador Hans Kluge, recently nominated as Regional Director-elect of the WHO European region.

We are all very much looking forward to discussing issues which range from patient involvement in research, to patient-led innovation, patient safety, digital health and much more over three content filled days at our [EPF Congress!](#) We are very grateful to our Advisory Board and Congress Speakers who have been drawn together from academia, health policy and management, patient advocacy and international organisations. Remember to tune in our live updates by following the hashtag **#EPFCongress19**, and don't forget that we will be livestreaming the plenary sessions on our Youtube channel!

We also have updates from our policy and projects teams, our members and last but not least from our Youth Group, whose activities and work in the field of young patient advocacy are getting valued recognition every day.

Happy reading!

*[Usman Khan, EPF Executive Director](#)*





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## News about EPF Congress



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## **EPF Congress 2019: Interview with Hans Kluge**

We asked Dr. Hans Kluge, WHO Regional Director nominee for Europe, a few questions about his role as ambassador to our Congress: here is what he replied.

*What made you agree to become an Ambassador to our Congress?*

I was very honoured to receive this request and in fact, it was a 'no-brainer' to accept because formerly I was a GP and a family-oriented doctor. Although right now I am on the policy side with my academic experience and education, I worked closely with patients, which gave me a lot of satisfaction. Growing up with my sister in Flanders, Belgium with a father who was a traumatologist who held consultations at our home and my mother being the 'nurse', the patients were always seen as the VIP. In fact even when we would plan something with my sister it would be cancelled at the last minute because a patient would come in and everything would stop, in order to really put patients' needs at the centre.

[Read full interview here](#)

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**EPF brings together initiatives for the future of patient engagement**





“Inspiring”, “exciting”, “engaging”, “stimulating” and “promising” are among the key words used by participants to describe the [Patient Engagement Open Forum \(PEOF\)](#), co-organised by [PARADIGM](#), [EUPATI](#) and [PFMD](#) in Brussels on 18 and 19 September. These three initiatives have been very active in the field of patient engagement in medicines research and development, and the event served as the ideal opportunity to align their work. The forum aimed to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation and silos belonging to the field.

For two days, more than 200 participants deep-dived into patient engagement activities in sessions covering topics ranging from tools and recommendations for effective patient engagement, methods for monitoring and evaluation of impact and outcomes in patient engagement activities, and fair market compensation for patient input, to interactive sessions on assessing good practices in patient engagement.

The results of the forum were impactful and nurtured by the participants representing patient advocates and organisations, regulatory bodies, healthcare industry and non-profits that are working together to make patient engagement the norm through tools, education, recommendations, good practices, framework and capacity

...assessment, recommendations, good practices, monitoring and capacity building.

Check out this [summary video](#) to understand the present and future for involving patients at every step of medicines development.

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## EPF participates in international guidance for patient involvement



### CIOMS Working Group XI meets in Geneva, 16-17 October 2019

In principle, the importance of involving patients in all aspects of medicines development and use is recognised – but what about practice? Despite progress in the EU and some other regions of the world, where patients' perspectives and preferences are more or less incorporated into medicines research, regulatory evaluation and monitoring, patient involvement in many other regions is patchy and there is little awareness of existing best practices.

CIOMS is an international organisation based in Geneva that has over decades produced globally applicable guidelines on topics ranging

from medical ethics to clinical trials and medicines safety. Until now, the role of patients in CIOMS guidelines was defined primarily by other stakeholders – regulatory authorities and pharmaceutical companies, rather than by direct involvement of patients.

In April 2018 CIOMS marked an important milestone by launching a new **Working Group XI on Patient involvement in the development and safe use of medicines**. The group includes representatives from patient organisations, industry, regulatory bodies and academia. EPF, EURORDIS and EATG were among the “founding” members of the group at its first meeting, but we soon realised that to ensure meaningful representation in a work of such a large scope, global application, and workload, a much wider range of diverse patient perspectives would be needed.

So far the group has met four times: in April 2018 in Geneva, in October 2018 in Berlin, in April-May 2019 in Geneva and in October 2019 in Basel. We will aim to complete our work by the end of 2021. While it has been challenging to find people with the right profiles who also have the time and ability to commit themselves to the work, today the group includes patient representatives from countries including the United States and Uganda.

### ***Why does CIOMS guidance matter?***

The CIOMS WG XI is an extremely important initiative because the results will not be only theoretical but will serve as an important tool to support the practical application of patient involvement in medicines development and use everywhere in the world. The new book will give a comprehensive overview of present knowledge and existing initiatives on patient involvement, and will give regulators, industry and other stakeholders guidance and tools to address the remaining

Other stakeholders guidance and tools to address the remaining challenges and practice gaps. The book will also be an important advocacy tool for patient organisations.

- We are still looking for interested patient representatives who could contribute to this work especially from regions outside the European Union and North America. Please do not hesitate to contact EPF at [policy@eu-patient.eu](mailto:policy@eu-patient.eu)
- All documents relating to the working group are publicly available on the [CIOMS website](#)

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## COMPAR-EU: how we promote self-care and self-management by patients



### What is COMPAR-EU and why does it matter to patients?

It is important to develop effective strategies for supporting self-care and self-management by patients. Self-management is something patients already do most of the time, but often they do not receive enough support for this from the healthcare services. Governments seek to develop healthcare systems that guarantee high-quality care with a special focus on ageing population, and on tackling the rise in



chronic diseases. Technologies that enable and support self-management can provide a solution. COMPAR-EU is an EU-funded project that is looking to identify such technologies and provide insights to help patients and healthcare professionals find the best solutions for managing with chronic condition.

### ***How is EPF involved in COMPAR-EU?***

As part of the [COMPAR-EU project](#), last year EPF identified patients' priorities for the core outcomes of the project. This year, EPF began to summarize and 'translate' key project outcomes to adapt them and make them accessible and understandable for patients EPF has also set up a *patient panel* – a group of patients who will be involved in the project throughout its full duration. The patient panel meets once a month online and brings a real-life perspective that helps us ensure that our contribution to this project aligns with patients' needs and priorities.

On 30 September and 1 October, EPF and all other COMPAR-EU project partners gathered in Ioannina, Greece for the second project consortium meeting, to report on 2019 project progress and plan the next year's steps for this important project.

In 2020, EPF has planned very exciting activities, including face-to-face meetings of the patient panel, developing lay summaries for major project outputs that will be of interest to patients and their families, and online webinars. All these activities will keep the patients' participation and their interests central to the development of COMPAR-EU.

For more information on the project please contact Lyudmil Ninov at [lyudmil.ninov@eu-patient.eu](mailto:lyudmil.ninov@eu-patient.eu)

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## EPF Youth Group



### New Members of the EPF Youth Group!

We are very excited to inform you that following recent elections, we have recently welcomed three new members to our Youth Group! We look forward to engaging them into our activities and projects lined up for the EPF Congress, and beyond!

Firstly, from Cyprus we welcome Anastasia Sofia Semaan, youth ambassador of the Pancyprian Association of Rare Genetic Diseases called **'Μοναδικά Χαμόγελα' (Unique Smiles)**, which is a member of the Pancyprian Federation Of Patients' Associations and Friends.

Our second addition is Marcus Ward from Ireland, a member of the **International Federation for Spina Bifida and Hydrocephalus (IF)** Youth Group, and member of International Federation for Spina Bifida and Hydrocephalus, Ireland.

Our third new member is Nikola Kumović, Vice-President of the [Serbian Haemophilia Society \(Udruzenje Hemofilicara Srbije\)](#) since it was founded, and a youth member of the Board.

Last but not least, Sally Hatton is joining us from the UK! She is a member of Metabolic Support UK, a volunteer at [XLH](#) UK and also a member of the [Patient Engagement Committee for Find A Cure](#).

Find more information about the EPF Youth Group [here](#).

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## **Nordic Youth Camp in Iceland**

*Blog by EPF Youth Group Member, Magdalena Doragrip*

On 12-15 September a group of young adult patients with primary immunodeficiencies gathered in Iceland for the Nordic Youth Camp. As an EPF Youth Group member I gladly attended the camp both as a participant and a speaker. I told the group my story, as well as what you can do for your organisation to truly make a difference. On that topic, I also got the opportunity to present some information about the WAYS project – a project aimed at fostering inclusion and non-discrimination of young patients with chronic conditions in the workplace.

The camp was filled with visits to great attractions, such as geysers and beautiful waterfalls, which Iceland is known for. In between those great attractions the programme was filled with lectures to get more young adults involved and interested in becoming more active in their national organisations.

The lectures were all highly informative and inspiring: and I especially enjoyed a lecture by a life coach that focused on helping us find what we prioritise in life and what we can do to change or keep that. However the most important experience during this camp was the networking. This is what I find is the most important thing for such an event: getting to know people, exchanging experiences, and constantly learning from each other.

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## EPF Members



### **COPAC project for rare disease associations wins the 2019 PAL Award Grant**

*Article by Luminita Valcea*

The Coalition of Patient Organisations with Chronic Diseases in

Romania (COPAC) is one of the five recipients of the [Patient Advocacy Leadership \(PAL\) Award Grant](#), provided by Sanofi - Genzyme in 2019.

The grant is meant to help patient organisations create unique projects for patients living with lysosomal storage disorders (LSDs), a group of rare diseases that can cause debilitating health problems.

The grant was offered for the project "Building capacity for new rare disease associations", and it will enable COPAC to fund a leadership training for 10 patient representatives across three newly established LSD associations, with the aim of strengthening the capacity building of these associations.

The project created by COPAC in collaboration with [The National Alliance for Rare Diseases](#), will include a training programme for the 10 LSD patient representatives on themes such as capacity building, healthcare policies and system organisation, communication, writing projects and documents. In addition it will fund a six-month mentoring programme for the 10 participants, a project contest, and it will ensure pro bono legal services to each organisation, with the goal of supporting people with LSDs. Therefore, the project has a strong practical component, by encouraging the participants to directly apply their new knowledge.

The participants will be rewarded with a good practices exchange at EPF. They will also be encouraged to apply for EPF's yearly module on [Empowering Leadership & Positive Organisational Governance](#).

The 3 LSD associations will be supported to continue the information

exchange with COPAC's remaining 19 members. They will continue to be supported by COPAC and the National Alliance for Rare Diseases. They will also be invited to participate to all the trainings on capacity building that COPAC will organise in the future.

three representatives from each LSD association will be invited to participate at the National Forum for Patient Associations and at the EUROPLAN conference to speak about their progress and about the problems that their members are facing.

**COPAC** is an umbrella organization which includes 19 Romanian associations representing several pathologies (HIV, rare diseases, cancer, diabetes, etc). The organisation's main goals are to protect the Romanian patients' rights regarding access to treatment and medical services, to support capacity building of new organisations, to maintain the quality of the healthcare system, and to support patients after their diagnosis.

The **Romanian National Alliance for Rare Diseases (RONARD)** is one of COPAC's members, and was established as an initiative of the Romanian Prader Willi Association (RPWA) through a project funded by the CEE Trust in August 2007 with the main goal of bringing together patient organisations for different rare diseases in Romania and improving the capacity of representation and advocacy for the rights of patients and making their voice heard. RONAR won a PAL award in 2017 and the "URC - Understanding rare challenges" project is in implementation.

[www.eu-patient.eu](http://www.eu-patient.eu)





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