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The Patient Perspective

October 2020



Reflections

October was an action-packed month for the EPF Community!

Our Policy team sent proposals to the co-legislators on **EU4Health Programme** requesting greater patient involvement and an enhancement of coordination amongst member states. They participated at the **European Health Forum Gastein** and several other conferences and launched two surveys, including one on **Artificial Intelligence**, with the deadline ending on 31 October.

October was also an extremely busy month for our project team. EPF was able to present materials on the CHRODIS recommendations and quality criteria (QCR), and a workbox on employment at the **CHRODIS+ Closing Conference**. Our **Digital Health Europe Workshop** was a great success bringing together key stakeholders with an interest in digital tools that can empower patients and foster their collaboration with healthcare professionals. We also took part in the kick-off meeting for our newest project, **H20**, which focuses on Value Based Healthcare. Another major milestone was the launch of the **PARADIGM Patient Engagement Toolbox**. More information on this below.

Our Youth Group has several updates regarding their own Gastein experience and their Autumn meeting and they have just announced the date for the webinar **launch of their Work and Youth Strategy (WAYS) Report for 18 November**. You can register below.

There are many events, webinars, theme days and virtual conferences happening in November so we strongly recommend you **visit our Calendar of Events** section at the end of the newsletter to register. You'll also find some exciting vacancies at EPF and EUPATI, so please feel free to share amongst your network.

Have a great weekend and a Happy Halloween!



News From the Secretariat

updates from the inside

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thought leaders virtually to discuss the challenges that this new legislature is planning to or forced by events to undertake, obstacles that stand in their way as well as the potential ways to tackle them.

EPF's Director of Policy Kaisa Immonen will be participating in the Panel Discussion on 'Coronavirus: Lessons Learned' on 17 November beginning at 4:15 PM CET.

[Register for the Session>>>](#)



EPF is Hiring a New Policy Assistant!

The policy assistant will support EPF's policy and advocacy work, in particular through regular monitoring of policy updates, events and initiatives, research tasks, preparing reports and briefings, and assisting the policy team in its engagement with external stakeholders and members. The policy assistant will also support the policy team's work on projects and communication activities as needed.

The deadline for applications is 6 November 2020 at 23:59.

[See Full Job Posting>>>](#)

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We Are Hiring!

Lamprini Bikou joins EPF as Operations Assistant!

EPF would like to welcome Lamprini Bikou as our new Operations Assistant. The Operations Assistant will have a key role in the Secretariat supporting the Executive Director, Special Advisor and Senior Management Team on administrative tasks, as well as providing support to the Grants & Office Coordinator in office management and administrative tasks. The Operations Assistant will also provide ad-hoc support the rest of the team.

Welcome aboard!



POLITICO's Health Care Systems Post-COVID19 Event

EPF President Marco Greco took part in a fruitful discussion providing the patient perspective during POLITICO's event on health care systems post-COVID.

You can watch the recording here: https://lnkd.in/dnMF_Z4

POST-COVID 19 PRESSING RESET? ⏻



"We are all patients and we will all become patients at some point. And that is why I'm saying that investing in health care is investing in ourselves."

Marco Greco

PRESIDENT,
EUROPEAN PATIENTS' FORUM (EPF)



Policy and Advocacy Corner

*discussing the most relevant patient-centered
policy and advocacy issues*

EPF's proposals to co-legislators on EU4Health

The COVID-19 crisis has highlighted, once again, that patients should be involved in shaping health policy at national and European levels, and why their unique knowledge and expertise, collectively and individually, are vital. We believe that the EU4Health programme represents a unique opportunity to act on this, whilst enhancing European coordination to protect our health.

In the context of ongoing discussions within the Council and European Parliament on the EU4Health programme proposal, EPF has continued to advocate and stress [our proposals for the Programme](#). On 9 October, EPF sent a **letter** to the Heads and Health Attachés of the Permanent Representations to the EU, highlighting concerns with some elements of the Council's compromise text. On 12 October, we shared **voting recommendations** with Members of the European Parliament's Committee on Environment, Public Health and Food prior to their vote on the Parliament's position.

[See our Letter and Voting Recommendations>>>](#)

EPF welcomes the results of the Parliament's Health Committee vote as an important improvement to the Commission's proposal for the Health Programme. In the context of Member States' position on the programme, EPF is concerned that the direction [Council discussions](#) are taking may jeopardise the originally strong proposal from the Commission and further progress brought by the Parliament. In the coming weeks, we intend to further support the European Parliament's work in view of the Parliament Plenary vote, taking place on 12 November. We intend to also engage, together with our members and other civil society organisations, in forthcoming negotiations between the co-legislators, advocating for an ambitious, well-resourced and patient-centred EU4Health Programme.



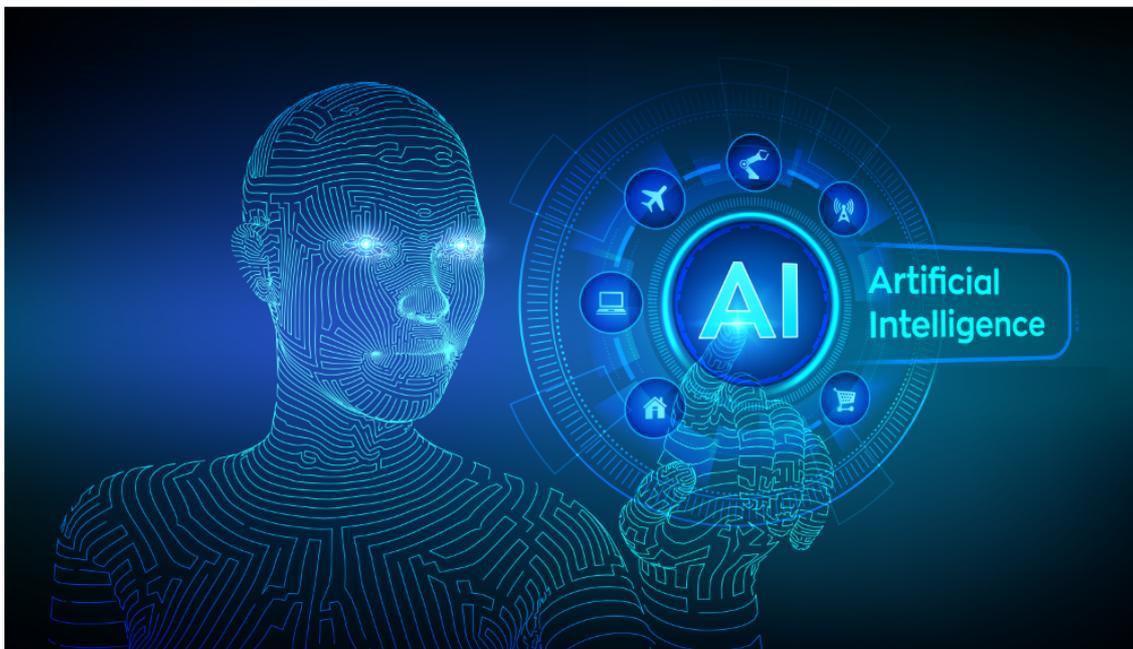
EPF Survey on Artificial Intelligence in Healthcare

Artificial Intelligence (AI), together with big data, has the potential to transform care delivery, and change several aspects of the healthcare value chain: population health, healthcare operations and healthcare-related innovation.

Given this rapid increase of interest in the importance of AI in healthcare and in view of upcoming policy activities, EPF has decided to reinforce its engagement on this matter to ensure that the patients' views will be adequately represented in the future discussion and EU-level debates, starting with this first EPF survey on AI.

The survey report will be published and available for free on EPF website in the coming months. **The survey deadline has been extended to 31 October 2020.**

[Take the Survey>>>](#)



EPF gathers at the Gastein

Earlier this month the health policy community gathered once again in occasion of the European Health Forum Gastein, for the first time taking place fully online. EPF had the chance to join several discussion panels throughout the topics and convey the patients community voice on a wide range of key topics. On Wednesday 30 September, President Marco Greco represented EPF in a [WHO-led discussion](#) to shape a new vision of

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importance of health literacy and health authorities communication to improve trust in the general public.

On Friday 2 October, Senior Programme Manager Valentina Strammiello discussed [evidence-practice gap on NCDs](#) during a dedicated session organised by one of the key EPF projects: Chrodiss+. Finally, EPF Policy Adviser Michele Calabrò, together with EPF Youth Group representatives, joined the workshop '[Young European Voices](#)' on the importance of involving young people, in particular patients, in shaping the future of health systems in Europe



EUROPEAN
HEALTH FORUM
GASTEIN

Q&A: David Somekh, Board Member at CEMPaC

EPF has recently begun working on the CEMPaC project which promotes patient empowerment by offering information and training for both citizens and health professionals. We recently sat down with David Somekh, member of the CEMPaC board to give more information about the project and how EPF members can get involved.

[Read Full Interview>>>](#)



CEMPaC



Projects Portal

briefings on EPF's ongoing projects

Digital Tools for Patient Empowerment and Person-Centred Care – Workshop

On 5 & 6 October 2020, the European Patients' Forum (EPF) hosted a two-day multi-stakeholder workshop under the framework of the [DigitalHealthEurope](#) project. The workshop brought together a breadth of participants including patient advocates, healthcare professionals, policy makers, industry, and other health stakeholders with an interest in digital tools that can empower patients and foster their collaboration with healthcare professionals. It took place over two days of plenary and breakout sessions, enabling all participants to contribute their views and shape the discussion.

[Learn more about the Workshop>>>](#)

Digital Health Europe



EHDEN General Assembly

On 14-15 October, the European Health Data & Evidence Network (EHDEN) held its 4th General Assembly. Over the two days, the consortium shared updates, participating in workshops, reviewing the work of the EHDEN Academy, and diving deeper into the benefits of federated networks for patient outcomes. EHDEN aims to improve patient care by generating high quality evidence from standardised health data.

[Learn more EHDEN on our project page>>>](#)



EUPATI is hiring a Partnerships & Operations Coordinator

EUPATI seeks a candidate ready to take a leading role in managing EUPATI's partnerships with its public and private partners (patient organisations, academic and non-profit organisations and pharmaceutical companies) and their in-cash and in-kind contribution.

[See Full Job Posting>>>](#)

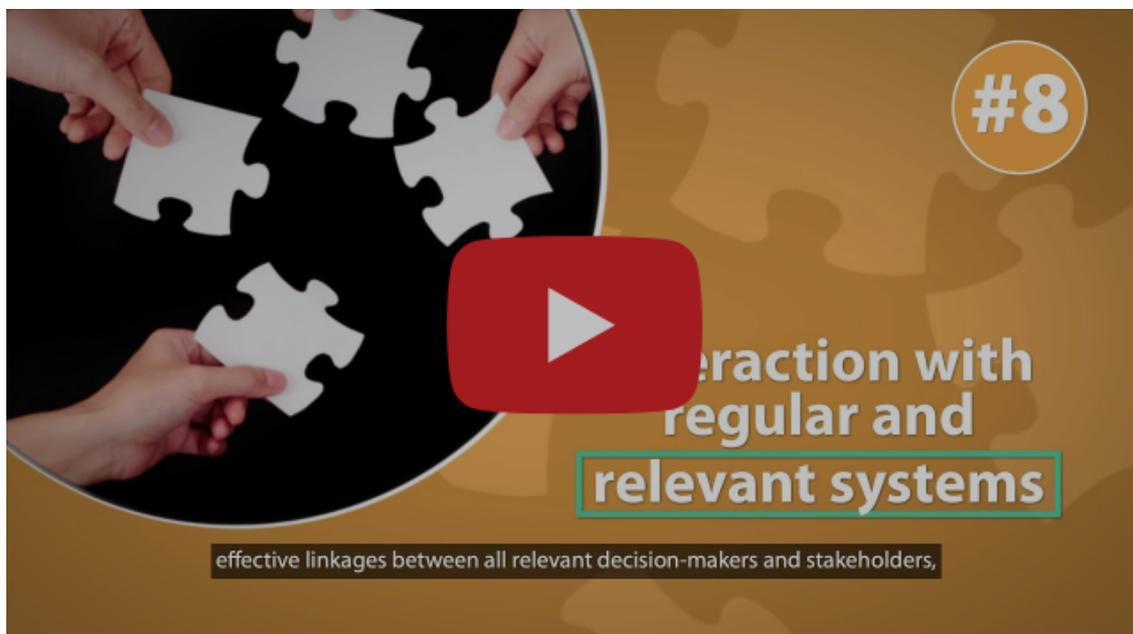


Launch of the JA CHRODIS Recommendations and Criteria (QCR Tool)

The JA CHRODIS QCR Tool was launched this past month at the CHRODIS+ Online Closing Conference on 27 October.

The Quality Criteria and Recommendations (QCR) tool aims to provide high-quality care for people with chronic diseases. The recommendations can be used to develop and improve practices, programmes, This tool was created during the course of Joint Action CHRODIS (2014–2017), the predecessor of CHRODIS+, of which EPF was an active member. The The recommendations can be used to develop and improve practices, programmes, strategies and policies in areas including: Prevention, Care, Health promotion, Education and Training.

You can view the instructional video below or the [trifold brochure here](#).



CHRODIS+ Recommendations and Criteria (QCR Tool)

H2O Kick-Off Meeting

On 12-14 October, the Health Outcomes Observatory (H2O) project held its project kick-off meeting. Over 20 partners dialled in to launch the project, share the overall mission and plan for the first six months. H2O brings together 23 partners and is coordinated by the Medical University of Vienna and Takeda.

The aim of H2O is to empower patients with digital tools to measure their health outcomes in a standard manner in order to improve their care. It will also empower patients to

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resources.

EPF will contribute a strong patient perspective by bringing on board patient advisory boards as the cornerstone of our contribution to the project. Together with the expertise of these patients, we will ensure that there is a strong patient perspective, and that patients are consulted throughout.

H2O has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 945345-2. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation program and EFPIA.



PARADIGM Patient Engagement Toolbox & Tools Q&A sessions for the patient community

The sessions will start with a short presentation of the PARADIGM project and its main outcomes, the PE Toolbox, its accessibility and the tools. It will follow with a Q&A session dedicated to an active interaction between the audience and the lead authors of the tools, with the aim of clarifying concepts and discuss how to best use the tools..

How to get the most of the sessions? As the objective of the sessions is to allow participants to ask questions to the lead authors and facilitate interaction, the tools will not be presented in details during the Q&A sessions.

[Programme Details>>>](#)

PARADIGM Patient Engagement Toolbox

This toolbox centralises all PARADIGM's co-created recommendations, tools and relevant background information to make patient engagement in medicines development easier for all. Browse from the sections below for the tools you might need, hover over to see a quick preview and click on the tool to access all related resources. Let us know how you've used these tools, we'd love to know how they've helped you in your patient engagement activities!

Planning Patient Engagement	Conducting Patient Engagement	Reporting and Evaluation
Raising awareness on managing competing interests in a multi-stakeholder environment: Guidance to patients and engaging stakeholders Learn More	The code of conduct Learn more	Patient Engagement Monitoring and Evaluation Framework Learn more
Enhancement of the EUPATI industry guidance Learn more	Working with Community Advisory Boards: Guidance and tools for patient communities and pharmaceutical companies Learn More	Guidance for reporting and dissemination of patient engagement activities Learn more
Recommendations on required capabilities for patient engagement	Patient Engagement in Early Dialogues: Tools and resources for HTA bodies	

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 highlights from our member organisations

WORLD MENTAL HEALTH DAY 2020

 Mental Health for all:
Greater Investment – Greater Access.
Everyone, everywhere...

This year's **World Mental Health Day** came at a time when our daily lives have changed considerably as a result of the COVID-19 pandemic, writes **MHE's** Polish member Mateusz Biernat in a blog for EPF. For people with lived experience of mental ill-health, this time is an opportunity to reflect on some key points and barriers in the functioning of our mental health systems, such as recovery, human dignity, individual growth and stigma.

[read the blog article>>>](#)

DEMENTIA IN EUROPE
THE ALZHEIMER EUROPE MAGAZINE
Issue 34
October 2020

Alzheimer Europe Report #34 The decision to change to an electronic format was taken earlier in 2020, prior to the publication of issue 33, in light of some of the uncertainties around COVID-19 and its impact on service-providers.



The European Federation of Neurological Associations (**EFNA**), in partnership with the European Academy of Neurology (EAN), has launched a survey on the impact of Covid-19 on neurology service delivery. The survey is open to anyone who is living with a neurological disorder and resides in Europe. It is open until November 20th and is available in 10 languages.

[take the survey>>>](#)



The **EMSP Virtual Conference 2020** aims at gathering the European MS community to provide them with learning and networking opportunities. This year, the event will take place virtually on **19-20 November**.

[see the agenda>>>](#)



The **Duchenne Patient Academy** works in partnership with leading DMD patient organisations to set a strong patient advocacy base for patient organisations and the Duchenne and Becker



On the occasion of Liver Cancer Awareness Month, the **European Liver Patients' Association (ELPA)** joined forces with **Digestive Cancers Europe (DiCE)** organizing, in the framework of DiCE Masterclass series, the webinar 'Deep Dive into Liver Cancer'.

[learn more>>>](#)

SNEAK PEEK

WORLD CONTINENCE WEEK 2020

#SneakPeekWCW20 #ContinenceMatters

World Continence Week (WCW) is an annual initiative with the primary aim to raise awareness about incontinence related issues. WCW is customarily held the third week of June. This year due to the Covid-19 pandemic WFIP postponed WCW20 to align with the ICS annual meeting, WCW20 dates therefore are **16th to 22nd November 2020**.

[learn more>>>](#)



EPDA has launched a new survey focused on drooling (sialorrhoea) – which, although very

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Fertility Week 2020 (2-8 November)

This is the fifth Fertility Week organised by Fertility Europe. In 2018 they launched their five-point Call to Action.

During **European Fertility Week 2020 (held 2-8 November 2020)**, they are promoting the Call to Action to policymakers across the European Union and gathering support to create an MEP interest group on fertility.

[learn more>>>](#)

world, they aim to contribute a unified and strong voice to coordinate the global advocacy strategy of the community. Those interested can complete the application from the link below. **The deadline for submitting applications is November 13.**

[apply now>>>](#)

Parkinson's symptom. This survey is aimed at people with Parkinson's who experience drooling due to their condition, as well as at their family members and carers who may have important insights about the symptom to share.

[take the survey>>>](#)



WEBINAR

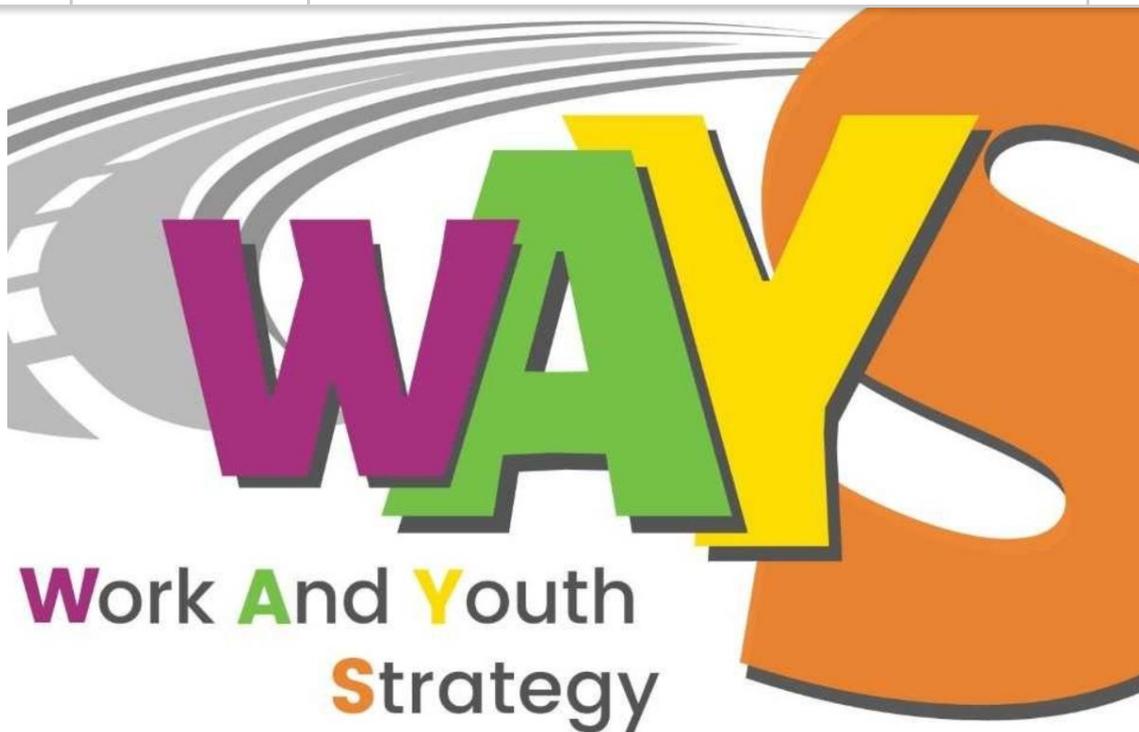
Young patients and employment: Barriers and good practices - Launch of the EPF Youth Group WAYS survey results 18 November (18:30 - 19:15)

The EPF Youth Group raises awareness about the challenges young patients face in their daily lives and advocate for the development of policies to overcome them. On 18 November at 18:30 CET, we invite you to take part in **the virtual launch of the EPF Work and Youth Strategy (WAYS) Report in an open webinar.**

Employment was one of the first topics that we recognised as essential for young patients. Since our first initiative on employment back in 2016, we were approached by other young patients who wanted to share their story, so the idea for the Work and Youth Strategy (WAYS) came up. WAYS aims to gather the opinions of young patients across the EU and use the results to make a valuable contribution towards fostering self-awareness and self-esteem in young people that are looking for employment across Europe.

Join our webinar for a lively discussion and learn key insights and our recommendations to include young patients in the working world.

[Register Here>>>](#)



Another Positive YG Fall Meeting

by Anastasia Semaan, EPF Youth Group Member

During the second weekend of October, the EPF Youth Group held its Fall Meeting. Despite the virtual setting, it was still fun and enjoyable. More than anything this meeting gave us the opportunity to socialize as a group, and to talk through some of the challenges that that we have been facing over the past year. Most importantly, it gave us the chance to set up our goals for the next few months. [Read full article>>](#)



Our Gastein Experience

This year for the first time ever, the EPF Youth Group took an active role at **European Health Forum Gastein**. In the "Young European Voices - The Future of Health Systems Sustainability" session, EPF Policy Advisor Michele Calabrò represented the young patient's voice. Following that, EPF Youth Group members joined the parallel discussions on "Digital health" and "Prevention and sustainable health care systems". The aim of the break-out sessions was to bring together youth representatives from all across healthcare

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EUROPEAN HEALTH FORUM GASTEIN

EHFG 2020: Cancer care, health literacy & COVID-19

Michele Calabrò
Policy Advisor
European Patients' Forum

Evelina Kozubovska
Interconnected Care Committee
European Health Parliament

Signe Ratso
Deputy Director General
DG RTD

Susana Solís Pérez
MEP
European Parliament

YOUNG FORUM GASTEIN *Think Young* **EUROPEAN HEALTH PARLIAMENT** **europatients'forum Youth Group**

one **YEL** Young European Leadership **EU 40** **DIGITALEUROPE** **Young Coalition for Prevention and Vaccination** **europayouthforum**

#UnitedYoungVoices

EHC Virtual Conference 2020

by Ivett Jakab

From 5 October through 9 October, I followed a virtual conference hosted by European Haemophilia Consortium. This year's most important event for people with bleeding disorders brought a variety of speakers from all around wider Europe to discuss novelties. After a warm welcome from Amanda Bok, CEO of EHC, and Declan Noone, President of EHC, all the speakers were given a platform to present their work and also to be a part of panel discussions along with patients.

First session was Talking Pain, since pain is and will be present in our lives and we could understand how important it is that we address pain properly. Although for many years the Von Willebrand Disease was not in focus, things are starting to change as it was the topic for the rest of the first day. The second day taught us the importance of individualized treatment. Women with bleeding disorders was the key topic for day three. Novel therapies such as bypassing agents and gene therapy alongside with safety assessments were reserved for the last two days.

Throughout these 5 days I was able to acquire lots of valuable information, find answers to some incredibly difficult questions and stay up to date with current health crisis. For me personally, it was incredible and encouraging to be a part of an event with all of these wonderful and motivated people, As a patient with chronic illness it gives me a sense of security knowing that we are not alone.

EHC

european haemophilia consortium

Is a Positive Work Environment Exaggerated or Underestimated?

by Katre Trofimov, Board Member of Estonian Coeliac Society

Katre Trofimov examines what is needed to create from upper management and employees alike to create an inclusive, supportive and positive work environment.

[Read full article>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

Sandra Gallina made official DG SANTE head

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particularly suitable candidate to foster the work on numerous health priorities in the current context, including the EU Vaccines Strategy.”

Council affirms countries' health competence in EU4Health stance

EU council are sticking with plans for a limited €1.7 billion budget for the new EU4Health program. In a newly agreed position, EU ambassadors said they will finance the program with €1.7 billion from the seven-year Multiannual Financial Framework (MFF), in 2018 prices (worth €1.9 billion in current prices). The Commission originally proposed spending €9.4 billion on the program, but a €7.7 billion contribution from the EU recovery fund was cut under a budget deal between EU leaders in July. The Council's position did stress strengthening the EU's role in global health, especially with reforming the World Health Organization. The program is due to start January 1, so needs to move to trilogue negotiations quickly. The Parliament's position still needs sign off in plenary, which is expected in November.

Sanofi, GSK to allocate 200M coronavirus vax doses to COVAX

Drugmakers Sanofi and GSK announced a plan to make 200 million doses of their coronavirus vaccine available for COVAX, the global effort to ensure equitable access to coronavirus vaccines. The COVAX facility aims to distribute two billion doses by the end of 2021. Ninety-two higher-income countries have signed up to the facility as "self-financing" members, meaning that they'll pay for the vaccines themselves, while another 92 low and middle-income countries will be supported by the facility.

Commission to buy rapid-result coronavirus tests

The EU is buying €100 million worth of rapid-result test kits to help cope with rising coronavirus infection numbers. The tests will be purchased through the emergency support instrument and then be distributed to member countries. The Commission has issued coordinated testing recommendations to help member countries align their strategies and create a framework for mutual recognition of test results throughout the bloc.

"To ensure good health: eat lightly, breathe deeply, live moderately, cultivate cheerfulness, and maintain an interest in life."

- William Londen



Calendar of Events

2-8 November

[European Fertility Week](#)

[visit our website](#)

4-5 November

[IHf Transforming Health Services ft. EPF's Nicola Bedlington](#)

[contact us](#)

9 November

[PARADIGM Q&A session: Recommendations on required capabilities for patient engagement](#)

[Subscribe](#)[Past Issues](#)[Translate ▼](#)**16 November**

[PARADIGM Q&A session: Patient Engagement Monitoring and Evaluation Framework](#)

17 November

[POLITICO Health Care Summit ft. EPF's Kaisa Immonen](#)

18 November

[WEBINAR: Young patients and employment: Barriers and good practices - Launch of the EPF Youth Group WAYS survey results](#)

19-20 November

[#EMSPVirtual2020 Conference](#)

20 November

[PARADIGM Q&A session: Working with Community Advisory Boards: Guidance and tools for patient communities and pharmaceutical companies](#)

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