



The Patient Perspective

November 2020



Reflections

It has been a whirlwind month for EPF!

Some good news! The European Parliament and Council agreed on an increased ambitious **EU4Health** budget of 5.1 billion to protect European patients and citizens. EPF also welcomed the outcome of the Plenary Vote on the EU4Health programme which is supportive of many of EPF's proposals. We have engaged in ongoing triologue negotiations supporting the Parliament's positions on an inclusive governance framework, with direct participation of patient organisations and civil society along with sustainable resources for financial support to NGOs.

The Commission also presented a package of proposals laying out important building blocks for an **EU Health Union**, to enhance European resilience towards future health crises and reinforced mandates for the ECDC and EMA. We consider this as a starting point to build better healthcare for the benefits of all Europeans. The **EU Pharmaceutical Strategy**, another important building block of the EU Health Union, focuses on competitiveness and innovation, access to affordable medicines and tackling shortages. You can view our response below.

Our programme team has been extremely busy, especially with the launch of the latest project in which we are partnering - **PERISCOPE**. We've shared some exciting communication materials for our work with **CHRODIS PLUS**, including a video and leaflet for the Workbox on Employment and Chronic Conditions. Meanwhile, there several webinars and virtual conferences that will be taking place in December, including **EUPATI's Open Classroom**.

Our Youth Group launched its **Work and Youth Strategy (WAYS) Report** with an interactive webinar launch ending with key recommendations to accommodate the needs of young patients in the workforce. Our members were also really busy with the recent EU developments and their own initiatives, which you can catch up on below.

There are several events, webinars and virtual conferences happening in December so we strongly recommend you visit our **Calendar of Events section** at the end of the newsletter to register. Don't forget to check our [COVID-19 Resource Point](#) on a weekly basis.

As we approach the last month of the year, we would like to congratulate all of the institutions on their efforts to work towards closing gaps exposed by COVID-19 and

Stay safe and enjoy the weekend!



News From the Secretariat

updates from the inside

Elisabeth Kasilingam appointed as EPF's interim Executive Director

The EPF Board is pleased to announce the appointment of Elisabeth Kasilingam as Acting Executive Director on a part-time basis, following the departure of Usman Khan, until the recruitment of a new Executive Director.

Serving EPF as Board Member and Treasurer, and being the CEO of the European Multiple Sclerosis Platform, Elisabeth has extensive experience and knowledge of the patient organisations, including operational management, strategic planning, financial management, European advocacy and health policy fields. Elisabeth has supported the EPF Secretariat as liaison with the Board since April 2020.

We are excited that Elisabeth has agreed to serve in this capacity as we continue to implement our transition plan to find a new Executive Director. Elisabeth's role as EPF Board Member will resume after the recruitment. In the meanwhile, she will sit on the Board in her role as Acting Executive Director. EPF is committed more than ever to pursue its mission to advance the interests of patients and patient communities by strengthening our collective impact across Europe through effective advocacy, education, empowerment, and partnership.



Last Chance to Apply for European Health Parliament (EHP6)!

The European Health Parliament is a space for the voice of patients. We are looking for patient advocates to bring their knowledge to this initiative, this is your chance to reach the key EU policy makers on issues that matter to you! Apply to [#EHP6](#) now.

[Apply Here>>>](#)



"Participating in the EHP was a great experience that I strongly recommend to health professionals, advocates and young and ambitious individuals that are interested in health policy. It is a unique chance to boost your knowledge about key healthcare topics, meet great people from across Europe and have your say on the future of health in Europe!"

Michele Calabrò,
EHP3, Committee on a European Vaccine Initiative
Policy Adviser, European Patients' Forum



Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues





EPF's Welcomes Europe's new Pharmaceutical Strategy

EPF welcomes the Commission's new pharmaceutical strategy for Europe, presented earlier this week. In our view, a main strength of the strategy is that it is centred around patients' needs, with accessibility and affordability of medicines at the core.


Our position is based on the premise that health is a fundamental right and a critical investment in society. Medicines are not consumer goods like any others; and patients' lives cannot be measured in purely economic terms. This strategy signals the Commission's understanding that medicines should be considered an essential public good and a core element of health policy.

[Read Full Statement>>>](#)

THE PHARMACEUTICAL STRATEGY FOR EUROPE

<p>Innovative & affordable medicines</p> 	<p>Addressing unmet medical needs</p> 
<p>Enhancing preparedness & reducing shortages</p> 	<p>Strengthening EU competitiveness</p> 

#EUPharmaStrategy #EUHealthUnion



EPF Patient Survey

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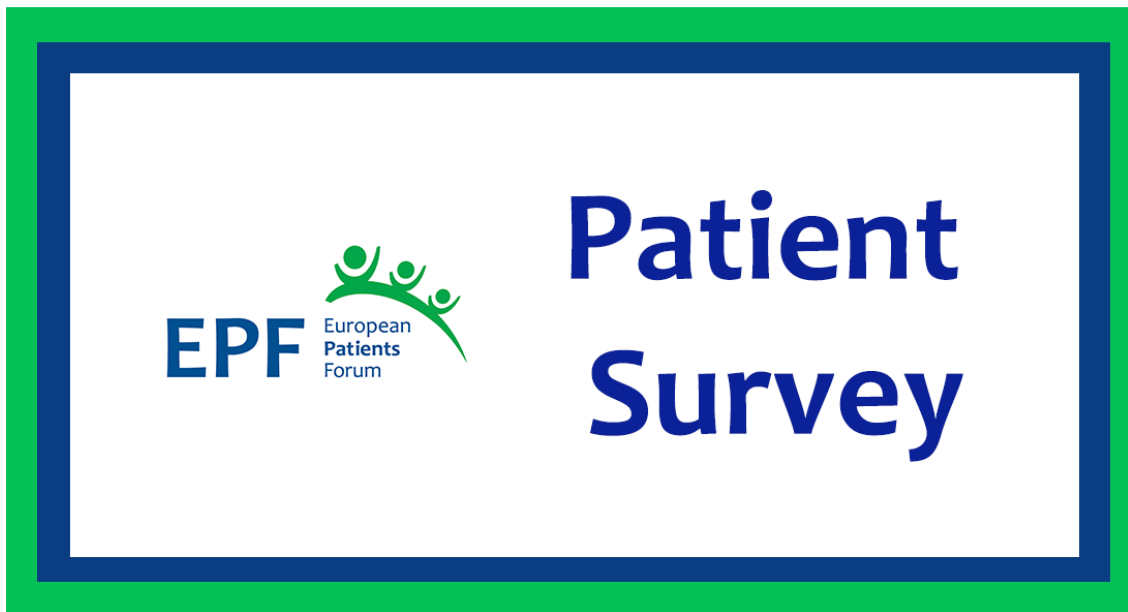
Patient organisations role in shaping the basic and continuing education of professionals has until now been unrecognised and underused. Patients can be involved in professional education in many ways.

Through **this survey** we hope to gain a better understanding of how common it is for patients (individual patients or patient organisations) to participate in continuing professional development / continuing medical education (CPD/CME) activities, what kind of activities they participate in, and what their experiences are like, as well as get patients' recommendations on how to improve this.

The survey is meant for individual patients, patient advocates and experts, family members, informal caregivers, or representatives of patient organisations.

The **deadline** for completing the survey is **January 15 2021**.

[Take the Survey>>>](#)



EPF joins European Alliance for Value in Health

This month, EPF along with 10 associations formed the European Alliance for Value in Health. The Alliance represents a broad group of European associations representing patients, scientific and professional societies, healthcare managers, hospitals, regional health authorities and life-science industries.

[Read Press Release>>>](#)

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“It is essential that the patient's perspective is at the heart of how value of healthcare is defined, and that patients are involved as partners in policy debates and implementation strategies at all levels. This is why the European Patients' Forum is pleased to be a partner in this new Alliance”

Kaisa Immonen, Director of Policy
European Patients Forum



Shaping a European Health Union that Delivers a New Deal for Patients and Civil Society

The European Patients' Forum (EPF) welcomes the 'EU Health Union' proposal package, presented on Wednesday 11 November by the European Commission.

The project for an impactful EU Health Union should go beyond crisis preparedness and cross-border threats. A true EU Health Union should be built on a broader framework, equipped with the right resources and instruments to address **systemic challenges such as access to quality care, inequalities, healthcare digitalisation and tackle non-communicable and communicable diseases alike**. Civil society organisations should be welcomed as partners in shaping Europe's new health agenda. To enable them to play this role effectively and independently, **co-production** should be built into all EU-level health-related initiatives.

[Read Full Statement](#)>>>



Latest Plenary Vote on EU4Health

EPF welcomes the outcome of the EU Plenary Vote, and we wholeheartedly agree with the focus of placing more attention on the importance of adequate resources, offering a stronger role for patient organisations and civil society through an inclusive EU4Health Steering Group, as well as accessible and affordable person-centred care and better integration within health systems. The outcome of the vote is particularly welcome as it

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EPF looks forward to engaging with EU institutions during the triogue negotiations to further help design a patient-centred EU4Health programme.

A blue banner featuring the European Union flag and the European Commission logo. The text reads "EU4Health programme for a healthier and safer Union" and includes the hashtags "#EUBudget" and "#EU4Health". The background shows a blurred image of a child and an adult.

EU4Health programme
for a healthier and safer Union

#EUBudget #EU4Health



Projects Portal

briefings on EPF's ongoing projects

EPF begins the PERISCOPE Project

PERISCOPE (PAN-EUROPEAN RESPONSE TO THE IMPACTS OF COVID-19 AND FUTURE PANDEMIC AND EPIDEMICS) is a large-scale research project that brings together 32 European institutions and is coordinated by the University of Pavia. PERISCOPE is a Horizon 2020 research project and will investigate the broad socio-economic and behavioral impacts of the COVID-19 pandemic, to make Europe more resilient and prepared for future large-scale risks.

EPF, along with the other partners of the consortium, will carry out theoretical and experimental **research to contribute to a deeper** understanding of the **short- and long-term impacts of the pandemic and the measures adopted to contain it.** **Such research-intensive activities** will allow the consortium to propose measures to prepare Europe for future pandemics and epidemics in a relatively short timeline.

[Learn more>>>](#)



EUPATI Open Learning Classroom

Discover the brand new EUPATI Open Classroom, a flexible on-demand platform – a new version of the EUPATI Patient Expert Training Course. As part of the EUPATI Reload project, this platform will give the opportunity to patients, patient representatives and other stakeholders to access this training not just in Europe but from around the world.

[Register Now for 16 December Launch>>>](#)



CHRODIS+ Final Conference on Chronic Diseases Making Europeans happier, healthier and more active by implementing good practices

On 27 October 2020, the CHRODIS PLUS project held its [closing project conference](#). Over its 3-years, the aim of the CHRODIS PLUS Joint Action (2017-2020) was to support countries in overcoming the burden of chronic diseases by promoting policies and practices that have proved successful in the previous edition of the project: CHRODIS. Further refinement and EU cross-border sharing of these tested policies and good practices, as well as implementation has been the core idea behind this pan-European project. The recordings of the keynote speeches and roundtable discussions are available via the link below.

This Final Conference illustrated the impact that CHRODIS PLUS has had on public health systems across EU member states over the past 3 years. It focused on showing how the good practices, models and tools implemented by the project can be tailored to various

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Sandrine, EPF Senior Policy Adviser, participated in the session on challenges of employment and chronic diseases; and Valentina Strammiello, Senior Programme Manager, moderated the roundtable discussion on the implementation of mHealth tools for improving quality of care for people with chronic diseases.

EPF participated in CHRODIS PLUS to provide the patients' unique perspective and experience, emphasizing on the importance of patient empowerment and the creation of supportive work environments for patients. We contributed to work in communication & dissemination, piloting the implementation of the Integrated Care Model for multi-morbidity, fostering quality of care of chronic diseases and finally employment and chronic diseases tools development.

[Learn More>>>](#)



CHRODIS PLUS Workbox on Employment and Chronic Conditions

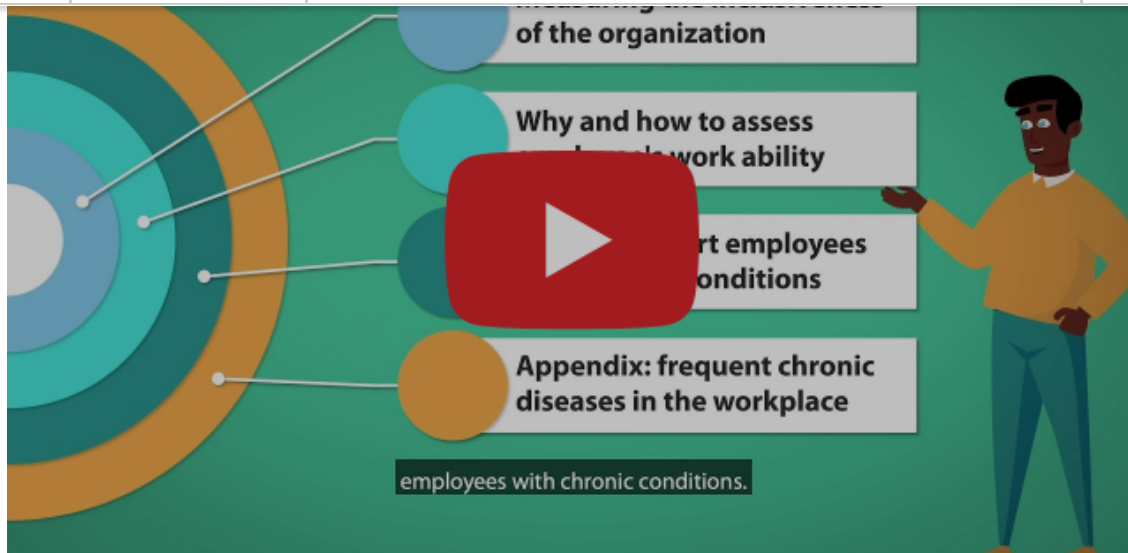
EPF, along with 17 other partners from 11 EU countries, worked together to develop and pilot the CHRODIS PLUS Workbox on Employment and Chronic Conditions. The CHRODIS PLUS Workbox supports EU member states and their workplaces in creating working conditions that foster wellbeing, health, and work ability; prevent the development of chronic diseases; and help individuals with chronic health problems to continue working. The Workbox brings thus benefits for employees, employers, and the entire society.

The CHRODIS Plus Workbox on Employment & Chronic Conditions is composed of 2 tools:

1. The Training Tool for Managers promoting inclusiveness of people with chronic diseases at work
2. The Toolkit for Workplaces offering 127 means to foster employees' wellbeing

To understand how the CHRODIS+ Workbox functions, EPF created a **short animated video** (see below) and [Leaflet](#).

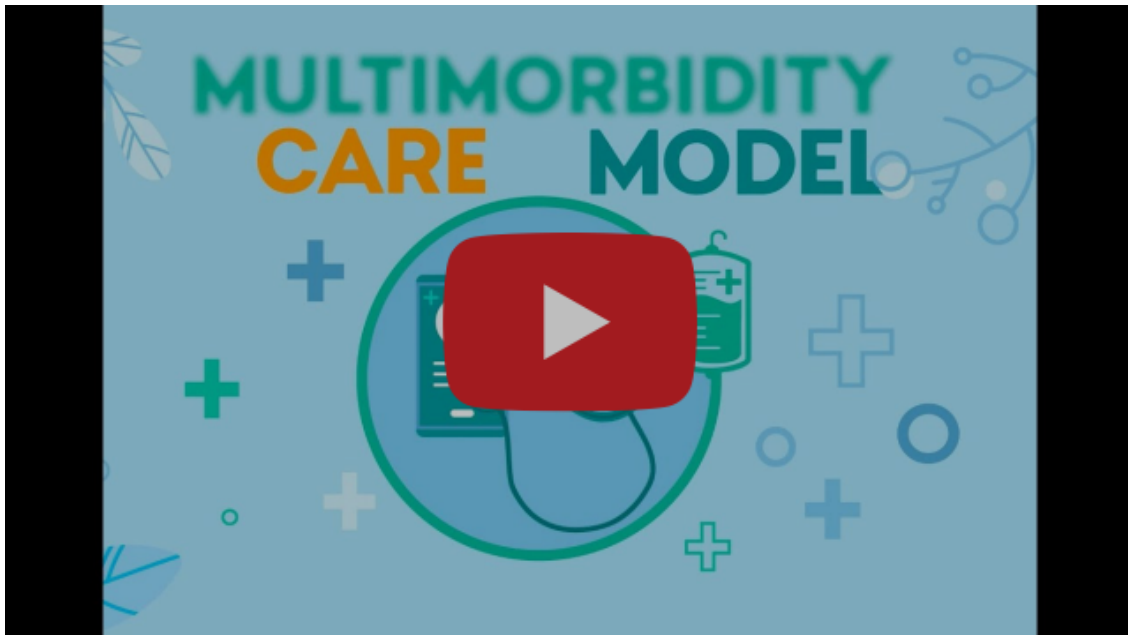
To use the CHRODIS PLUS WORKBOX, please visit <https://workbox.chrodis.eu/>

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CHRODIS+ Workbox on Employment and Chronic Conditions

CHRODIS PLUS Multimorbidity Care Model

Due to an ageing population and improved detection and treatment of diseases, many people now have more than one illness. A patient with multimorbidity presents a unique constellation of needs, disabilities or functional limitations to the health care system. Care for people with multimorbidity is complicated because different conditions and their treatments often interact in complex ways. Despite this, the delivery of care for people with multiple long term conditions is still often built around the individual conditions, rather than the person as a whole. As a result, care is often fragmented and may not consider the combined impact of the conditions and their treatments on a person's quality of life. The **CHRODIS PLUS Integrated Multimorbidity Care Model (IMCM)** aims to overcome many of the issues related to fragmented care. Find out more in this video.



CHRODIS+ Video on the Integrated Multimorbidity Care Model

Register for the end of year DSL Workshop

Join the Data Saves Lives team for an exploration of the successes and learnings from 2020 and how the initiative plans to have an even bigger impact in 2021. Register now to take part in the closed workshop event that will give you the opportunity to **shape a**

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projects. EPF's near exclusively from internationally renowned speakers on how 2020 has been a tide-changing year for the conversation on the value of health data.

[Register Here>>>](#)

A graphic for a workshop event. It features a blue background with a magnifying glass over a globe. The text 'Data Saves Lives' is inside the magnifying glass. Below it, the text reads 'Under the magnifying glass: 2020 in review and looking to 2021'. An orange box on the right says 'WORKSHOP EVENT'. At the bottom, an orange bar contains the date and time: 'DATE: 9th December' and 'TIME: 11:30 – 14:45 CET'.

EATRIS+ Patient Advisory Committee kick-off meeting

On 19 November 2020, the EATRIS-Plus Patient Advisory Committee (PAC) held its kick-off meeting with seven patient representatives from a diverse range of disease areas and European countries. The meeting featured guest presentations from Toni Andreu, Scientific Director of EATRIS; Alain van Gool, Head of the Radboudumc Translational Metabolic Laboratory; and EPF member EATG (European AIDS Treatment Group), who has been brought on board the project to support the coordination of the PAC.

The PAC will inform EATRIS-Plus activities from a patient perspective and will identify mechanisms for meaningful patient involvement and input throughout the project. PAC members will attend key project meetings and will contribute to the development of a patient involvement toolkit for translational researchers, as well as other key deliverables of the project.

EATRIS-Plus will deliver innovative scientific tools to the research community and will reinforce EATRIS' leadership in the European Research Area, particularly in the field of Personalised Medicine research and development. This can have a big impact for patients, as it can reduce trial-and-error treatments, enable better decisions about which medicines may be more effective, and it can help to manage rising healthcare costs.

[Learn More>>>](#)

eatris+

DHE Consortium Meeting

On 12-13 November, the DigitalHealthEurope (DHE) consortium held its last annual meeting. Colleagues from 17 collaborating partners dialled in to share the work done so far, and discuss the exciting upcoming activities to foster the digital transformation of health and care, ahead of the project's conclusion in the Summer 2021.

The European Patients' Forum participated in the meeting and focused in particular on the key learnings of its [5-6 October Multi-Stakeholder Workshop](#) on Digital Tools for Patient Empowerment and Person-Centred Care. EPF shared how the insights gleaned during this two-day event will shape our main output in DHE: the White Paper on boosting active cooperation between patients & health and care providers, and our communications activities in the final months of the project. Another pivot point was the further collaboration and exchange among partners and conducting detailed plans on how this can be achieved. DHE strongly depends on cross-cutting activities within the project.

DHE is a Horizon 2020 initiative that aims to provide comprehensive, centralised support to the digital transformation of health and care priorities of the Digital Single Market.

[Learn More>>>](#)



European Health Data Space virtual conferences

On 10 November 2020, the Data Saves Lives (DSL) initiative participated in the [virtual conference](#) Health Innovation – the European Health Data Space and Real-World Evidence, co-hosted by the RWE4Decisions and German Presidency of the Council of the EU.

DSL hosted a digital booth, focusing on the importance of health data, understanding how it's used, establishing a trusted environment for dialogue, and key recommendations for responsible use and good practice. Robert Greene, Advisory Board Member of DSL also participated in the virtual roundtable on using cancer as a case study for the use of real-world evidence. During his interventions, Robert highlighted the need to involve both citizens and patients in conversations about health data – **'in our lifetime, we will all be confronted in one way or another with cancer' he said; by involving all citizens in health data discussions, we can have a broader conversation.** The

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On 18 November, Gözde Susuzlu, DSL Project Coordinator, spoke at an event hosted by [APCO Brussels](#) on making data governance models more patient centric. During her interventions, Gözde focused on the patient vision of data sharing and the ideal European Health Data Space (EHDS), as well as debunking the myth that patients are opposed to sharing their data. **'Patients expect the European Commission to create a solid, trustworthy and useful EHDS,'** she shared. Gözde further elaborated on patient views on addressing digital literacy, and the potential for digital tools to help address health inequalities. The panel discussion also featured interventions by Andrzej Rys, Director at DG SANTE, and Cornelia Kutterer, Senior Director at Microsoft.



Health Innovation - the European Health Data Space and Real-World Evidence

Hosted by:

RWE4Decisions multi-stakeholder initiative

An event hosted under the associated programme of the Federal Ministry of Health within the German Presidency of the Council of the EU 2020



Member Focus

highlights from our member organisations

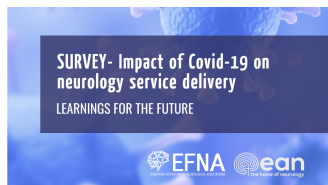


EMSP is organizing a webinar to draw stakeholder attention to the International Convention on the Rights of Persons with Disabilities by presenting the highlights of the latest edition of the **Multiple Sclerosis (MS) Barometer**. MS Barometer provides the context of the current challenges faced by people affected by MS in accessing health and social care. This will be an opportunity to identify potential collaboration avenues with other



Applications to **EFNA's 2021 Advocacy Awards** must be made by Friday, December 4th. We are looking for entries from both organisations and individuals whose work takes action against stigma. Winners will each receive a prize of €2,000 to assist with their work, so be sure to consider making an application.

[apply now>>>](#)



EFNA are currently running a survey in



AT WHAT COST THE ECONOMIC IMPACT OF STROKE IN EUROPE



New research by the **Stroke Alliance for Europe (SAFE)** shows projected future costs of stroke care in Europe could increase to €86 billion in 2040 if we fail to invest in stroke prevention, treatment and rehabilitation. SAFE's Report **At What Cost - the Economic Impact**

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positive changes within the European health and social systems.

[register now>>>](#)

Cancer leagues say

Employers should identify strategies to address stigma and workplace discrimination which hinder reintegration of their employees affected by cancer.

How to manage Cancer at Work
A handbook for employers, HR professionals, managers,
business organisations



#CancerAtWork ECL: EUROPEAN CANCER LEAGUES

The **European Cancer Leagues** has launched a **new Handbook** for employers illustrating how managers, supervisors and HR departments can best support their employees affected by cancer and minimise the impact of cancer (and other chronic diseases) on their organisations and everyone involved.

[read the ECL Handbook>>>](#)

Neurology (EAN) to assess the impact of Covid-19 on neurology service delivery across Europe. The deadline has been extended to next Monday 30 November, so please take a few moments to respond.

[take the survey>>>](#)

to help reduce the burden of stroke and future proof healthcare services at the time when COVID-19 has amplified the problem and exposed already overstretched and failing healthcare systems.



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

[share the call>>>](#)



Youth Group

initiatives, stories and events from our most budding members

Recap of the Webinar Launch of Work and Youth Strategy (WAYS) Report

By: Erato Markantoni

The EPF Youth Group's Work and Youth Strategy (WAYS) report findings officially launched on the 18th of November. The results and findings of the report were presented in the webinar, alongside real testimonials of patients in the workforce. The idea was initiated back in 2016, where the Youth Group identified that emotional and physical symptoms of chronic conditions, along with the stigma associated with chronic conditions caused a real struggle for young patients searching the job market. The initial aim was to present evidence from patient's real experiences and find solutions to the problems and limitations that surfaced, both general and tailored to each unique condition.

To achieve this, an online survey was published in December 2018, that had 62 respondents across 21 EU countries. A high 35% of participants admitted that they would not disclose any 'invisible' condition under any circumstances, supporting further the 44% of respondents who admitted to the challenge of finding a job. Some of the WAYS key findings that were highlighted during the webinar included the long-term effects of missing out on education due to a chronic condition, as well as the negativity and stigma associated with the abilities of young patients, creating fear of discrimination among them.

Throughout the report, we recommend flexible working policies, such as adjustable hours and working remotely, to accommodate the needs of young patients, as well as training

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During the webinar, fruitful discussions between young patients and EPF members revealed the struggles young patients often endure, with a personal touch from each speaker and unique ways of how they have resolved problems that came their way. The Youth Group strives to make its findings more accessible, and we made sure that the human right to be integrated into the society as an equal was a core principle that was highlighted throughout our report and webinar.

[Watch the Webinar>>>](#)

[Read the WAYS Report>>>](#)



The screenshot shows a webinar interface. At the top, there are four video thumbnails of participants: Anastasia Semaan, Marlou Schenk, Ivett Jakab, and Erin Davies. Below the thumbnails is a presentation slide with the following content:


“WAYS” LAUNCH WEBINAR
YOUNG PATIENTS AND EMPLOYMENT –
BARRIERS AND RECOMMENDATIONS

18 November 2020
Brussels, Belgium

@weareEPF
@EPFYouth

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

EPF European Patients Forum

The EPF Youth Group is looking for new members!

- Are you a young patient advocate?
- Are you between the ages of 18 and 30?
- Are you passionate about building a better future for young patients?

Then you have what it takes to advocate on behalf of all young patients to ensure the youth perspective is provided within patient organisations at both the European and national level. [Register Here>>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

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agenda, which covers November 24 through December 23, no longer mentions the plan.

BioNTech/Pfizer and Commission reach vaccine deal

BioNTech and Pfizer confirmed that they completed a deal for the European Commission to purchase up to 300 million doses of their front-runner coronavirus vaccine. The Commission agreed to purchase 200 million doses of the vaccine, with the option to purchase an additional 100 million and will be manufactured in both Pfizer's Belgian and BioNTech's German production sites. The company hopes to manufacture 1.3 billion doses in 2021. The companies announced their vaccine was found to be 90 percent effective earlier in the month.

Moderna says its coronavirus vax is more than 90 percent effective

U.S. biotech company Moderna announced that its coronavirus vaccine is more than 90 percent effective, according to preliminary results from a late-stage U.S. trial involving more than 30,000 people.

The results are on par with those announced by BioNTech and Pfizer, which reported that their coronavirus vaccine is more than 90 percent effective. Both Moderna and BioNTech/Pfizer employ mRNA technology for their jab. The EU hasn't signed a deal with the American company yet.

AstraZeneca, Oxford: Coronavirus vaccine is 70 percent effective

A coronavirus vaccine from Oxford University and AstraZeneca is 70 percent effective, according to interim analysis from a large scale clinical trial. The announcement Monday combines data from two different dosing regimens. When the vaccine was given as a half dose and then a full dose, it had an efficacy of 90 percent. When given as two full doses, it showed 62 percent efficacy.

"I have chosen to be happy because it is good for my health."

– Voltaire



Calendar of Events

2 December

[EFNA Webinar: 'Improving access to care and treatment for HD patients and families: what role for policymakers?'](#)

[visit our website](#)

[contact us](#)

3 December

[EMSP Webinar: "Towards equitable access to quality health and social services and a supportive environment across Europe for people affected by MS"](#)

4 December

[HIVE-33 Mini-Series - Episode 1 ft. EPF's Elena Balestra](#)

9 December

[Data Saves Lives Workshop Event](#)

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[Conference on Neuromuscular Disorders \(NMD\)](#)

11 December

[EMA Stakeholder Meeting on Development and Authorisation of safe and effective COVID-19 vaccines in the EU](#)

16 November

[EUPATI Open Classroom Launch](#)

24 December

[Christmas Eve](#)

25 December

[Christmas Day](#)

31 December

[New Years Eve](#)

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