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The Patient Perspective

January 2021



Reflections

Welcome to 2021!

We're happy to announce the **SAVE THE DATE** for our **EPF Congress 2021**, taking place virtually on 26-29 October. The second edition of our patient-led event will focus on the digital transformation of healthcare. More info on it below.

Our **Policy** team has been busy with several important consultation opportunities that will be fundamental to shape better health policy in the EU for the patient community. this month, we also launched our new Patient Guide "Let's Talk About Vaccination" in an online event to fill in the information and awareness gap and strengthen knowledge. You'll find further information below in our Policy and Advocacy Corner.

Our **Projects Portal** features some new announcements and updates from several of our ongoing projects, including a Call for User Advisory Group members for the Gravitare Health Project. You can stay up-to-date on all ongoing matters by visiting our website [Projects Page](#). Some of our members have important announcements and updates that you will in the **Member Focus** section.

There are several events, webinars and virtual conferences happening in February so please 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.

Stay safe and enjoy the weekend!



News From the Secretariat

updates from the inside

SAVE THE DATE
EPF Congress 2021: Digital Transformation of Healthcare
26-29 October 2021

Join us for a 4-day virtual event to explore the digital transformation of healthcare driven

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new technologies, and why it is critical to successful innovation.

Registration will open in April with Programme Details to follow.

Visit [<u>epfcongress.eu</u>>>](https://epfcongress.eu)

Listen to [EU Patients' Podcast #3 - EPF Congress 2021<u>>>](#)



SHOT CALLERS: A Virtual Event on COVID-19 Vaccines 28 January 2021

The COVID-19 pandemic has led to the development and approval of new vaccines in a much shorter time-frame than usual. As a result, there are still several questions that patients and civil society need to be answered. On 28 January, EPF gathered credible experts in the field of therapeutics and vaccines to shed light and answer these questions.

EPF Special Advisor Nicola Bedlington moderated a lively and informative discussion with: Prof. Jean-Michel Dogne, Member of WHO Global Advisory Committee on Vaccine Safety, Prof. Guido Rasi, former Executive Director of European Medicines Agency (EMA) and Marco Greco, President of European Patients' Forum.

Watch [Shot Callers Recording<u>>>](#)

[EU Patients' Podcast #2 – On COVID-19 Vaccine Approval<u>>>](#)

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A VIRTUAL EVENT ON COVID-19 VACCINES

JANUARY 28, 2021 | 15:00-16:15 CET

Moderated by:

Nicola Bedlington
Special Advisor
European Patients' Forum



Speakers include:



Marco Greco
President
European Patients' Forum



Prof. Jean-Michel Dogne
WHO Global Advisory Committee
on Vaccine Safety



Prof. Guido Rasi
former Executive Director
European Medicines Agency



Chiara Boni joins EPF as Communications Officer

Chiara Boni joined the EPF team in January 2021. As Communications Officer, she manages EPF's digital communications channels and she creates communication content for all the organization channels. Chiara holds a Bachelor's Degree in Communication Sciences and a Master's Degree in Journalism from the University of Verona, Italy. Before joining the EPF, she worked for the European Parliament, as a Web Content Creator for the Italian non-profit organization Impactscool, and as a Journalist for an Pantheon Magazine, focusing on gender issues and human rights.



Juan Jose Fernandez Romero joins EPF as Policy Assistant

Juan Jose joined EPF in January 2021. As Policy Assistant, he is in charge of regularly monitoring of intelligence and updates on policy developments, carrying out background research for EPF's policy briefs and position statements, and assisting the policy team on membership issues. He has a background in European policies and public affairs. Prior to joining the EPF, he has worked for other Brussels-based policy organizations, the European Medicines Agency, and for the Spanish diplomatic corps. He holds an MA degree in European Studies obtained at the University of Gothenburg (Sweden).



Policy and Advocacy Corner

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

January in Review

2021 kicked off with several important consultation opportunities for EPF and for the broader European patients community, attesting once again how the coming 12 months will be fundamental to shape better health policy in the EU.

On **Digital Health**, the European Commission is seeking input on the [Data Governance Act](#) and on the Roadmap/Inception Impact Assessment for the [European Health Data Space](#). The Data Governance Act will serve as an horizontal framework for the different sectorial Data Spaces while the Roadmap/IIA for the EHDS represents the first step of a year long consultation processes on the Data Space dedicated to healthcare. EPF has worked with its Digital Health Working Group to prepare dedicated responses, which will be submitted and published on our website in early February.

The EU is also looking at **reinforcing the mandates for two of its agencies**: the [European Centre for Disease Prevention and Control \(ECDC\)](#) and the [European Medicines Agency \(EMA\)](#). EPF will share its views on these two crucial elements of the European Health Union initiative, with a particular focus on ensuring better engagement with stakeholders and the public and more effective actions tackling key healthcare issues.

Finally, the EU is also planning to **review two key regulatory frameworks of crucial importance for European patients: the Cross-Border Healthcare Directive and the Blood, Tissues and Cells legislation**. On the Cross-border, the European Commission published a roadmap for the evaluation of cross-border healthcare and patient rights, and is now collecting feedback via the Have your say portal [at this link](#). Feedback collection will be open until 11 February 2021. A more wide-ranging consultation will follow in Q2 2021. On the Blood, Tissues and Cells legislation, the Commission has therefore launched two public consultations to gather opinions on the proposed policy options for revising the directives on blood and on tissues and cells: [an online general public consultation and a targeted consultation](#), aimed at organisations that are directly involved in, or impacted by, the BTC legislation. **The two consultations are currently open until 15 April 2021.**

EPF will actively engaged in these consultation process in the coming weeks. Keep following our communication channels or reach out at policy@eu-patient.eu to know more!

For regular updates on EU consultations, visit <https://www.eu-patient.eu/Members/consultations/>

Launch of our Patient Guide "Let's Talk About Vaccination"

Vaccine hesitancy, misinformation and distrust are among the top threats to global health. On 14 January, we launched our Patient Guide "Let's Talk about Vaccination" in a virtual

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We hope the Guide will be useful to anyone who wishes to strengthen their knowledge on and their confidence in having meaningful conversations about vaccination.

View the Patient Guide ['Let's Talk About Vaccination'>>>](#)

Launch Event of ["Let's Talk About Vaccination" recording>>>](#)



WORKSHOP INVITATION
VAC-PACT Regional Workshop #1
Thurs, 11 Feb 2021 (10:30 - 15:00 CET)

The Vaccination Confidence – Patients' and professional Awareness Communication and Trust (VAC-PACT) is hosting the first of three regional workshops to enable us to engage and work with representatives at national levels within the **CEE region, Southern and Western Europe**.

It will be the first patient led and focused health event on vaccination of its kind to be held in Europe, and EPF particularly welcomes your participation gathering patients, supporting communities and healthcare professionals from at least three countries within each region.

Each workshop will take place over one day and will follow the principle of active engagement of the participants, with plenary sessions and parallel workshops to enable interactive debate and reflections, focusing on concrete and workable outputs and recommendations.

The format of the sessions will be designed to enable participants to transmit the knowledge afterwards to their communities, and to support effective use of a toolkit, as well as dissemination through participants' networks. The event will bring together over 60 participants, including healthcare professionals, patients and supporting communities, in addition to vaccination and patient empowerment experts.

These events are geared towards people from **Bulgaria, Romania and Hungary** specialising in **Diabetes, Respiratory, Immunocompromised, Organ transplant and cancer**.

[Register here>>>](#)

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Vaccination Confidence – Patients' and Professionals' Awareness, Communication & Trust (VAC-PACT)

The Pilot Project received funding by the European Union's Health Programme under the SANTE/2019/C3/013-SI2.820639 Service Contract.

REGIONAL WORKSHOP #1

LOCATION: CENTRAL AND EASTERN EUROPE (CEE)

DATE: 11 FEB 2021



Projects Portal

briefings on EPF's ongoing projects

EPF begins Gravitate Health Project

On 16 November 2020, the European Patients' Forum joined 39 partners to kick-off the Gravitate Health Project. Gravitate Health is a 5-year research project that aims to improve access and understanding of health information for the safe use of medicines, risk minimization and improved quality of life. Currently, patients primarily receive their medicines information in the form of a paper leaflet provided with medications; this can present several challenges to understanding. The project aims to develop a digital information tool that will share approved medicines information in an understandable and trustworthy format.

EPF is co-leading the work on Capacity Building and Multi-Stakeholder Engagement, in particular issues related to health literacy for patients, citizens and healthcare professionals. We will also provide our expertise on accessibility, and developing educational materials for the digital tool.

Gravitate Health is a project of the [Innovative Medicines Initiative 2](#) (grant agreement No. 945334), which receives funding from the European Union and from the European Federation of

Call for interest - User Advisory Group members

EPF is pleased to announce a call for representatives for a User Advisory Group (UAG) for the Gravitate Health Project. We are searching for a group of maximum 20 individuals. The group will play a major role in identifying and understanding the key user needs of the Gravitate Lens G(-Lens) platform that will be developed during the project and will contribute to validate the tools

The UAG will inform Gravitate Health activities from a user perspective and identify mechanisms for meaningful patient and public involvement and input throughout the project. Participants will receive compensations during the time of commitment.

We believe multi-stakeholder engagement at the heart of Gravitate Health activities will be key to the success of this project.

To learn more about the timeline and selection process, application form and documents go to [our website](#).

[Apply Here>>>](#)

Gravitate Health

The [@DSL.DataSavesLives](#) initiative has a new Facebook page

Click below to **follow** Data Saves Lives and stay up to date on the latest health data topics across Europe! You can learn more about #DataSavesLives at datasaveslives.eu or on our [projects page](#).

[Follow DSL on Facebook>>>](#)

Save the Date – Data Saves Lives tweet chat

The live chat will feature experts in health literacy, health advocates, patient leaders and other umbrella organisations.

On 19 February 2021 at 13:00 CET the Data Saves Lives will host its first tweet chat of the year. The focus will be on how we can improve health data literacy among patient communities.

Anyone can participate in the tweet chat: just log on to twitter at the chat time, set your search to 'latest' and find the conversation using the hashtag #DSLChat. To join the conversation, tweet your questions using the #DSLChat via the DSL twitter at:

twitter.com/DataSaves_Lives

Data Saves Lives is a multi-stakeholder initiative that aims to raise wider patient and public awareness about the importance of health data and to improve our understanding of how it is used.

[Data Saves Lives website>>>](#)

#DataSavesLives

PharmaLedger Project now on the EPF website

In January 2020, EPF joined 29 other partners for the kick-off meeting of the PharmaLedger project. The consortium members of the project come from across leading Industry companies, to Universities and patient organisations.

The goal of PharmaLedger is to **drive the early adoption of blockchain-based technology** by working together with partners to build a complete solution for improving the quality of healthcare, and explore how blockchain technology can help us tackle real-world health challenges. This will help to increase the speed of innovation, while ensuring the security of patient's health data and secure data sharing, ultimately benefitting the whole healthcare ecosystem – patients and manufacturers.

EPF will work together with project partners to deliver a **Collaboration Platform** to support the engagement of patients and of people that support patients (like carers). EPF will support the exchange of knowledge and know-how on the design of the platform, sharing ideas, problems or issues raised by patients, and others.

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Agreement No.65599), which receives funding from the European Union and from the European Federation of Pharmaceutical Industries and Associations.

[PharmaLedger website>>>](#)



PharmaLedger

BLOCKCHAIN ENABLED HEALTHCARE

EUPATI Open Classroom

EUPATI Open Classroom is a brand new e-learning platform featuring a flexible and on-demand learning catalogue and allows patients, patient representatives and other stakeholders from anywhere in the world to take courses in medicines research and development.

There are currently 4 Topics ('Modules') available; Getting started, Introductions to Medicines R&D, Pre-Clinical Development and Clinical Development. Two more Topics will be added by May 2021: Regulatory affairs and HTA. Each Topic contains several 'Courses' (Training Units) which a learner can complete online and receive a certificate for (for 8 EUR/Course).

You can become a EUPATI Fellow by completing all online courses in the programme. The total cost is estimated to be EUR 232 (incl. VAT) to complete 29 courses which make up the EUPATI Patient Expert Programme. Access it: <https://learning.eupati.eu/>



Member Focus

highlights from our member organisations



The [European Federation](#)

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EMSP is looking for a qualified Community Manager to join its team. If you are a tech-savvy professional, have experience in community building and engagement, social media, PR and promotional events, they would like to meet you. Deadline to apply is 29 January.

[apply now>>>](#)



EFNA has developed a series of elearning modules for patient advocates. These open-access courses aim to upskill participants on how they can effectively advocate in a virtual world by identifying and engaging key stakeholders, hosting successful online events and developing and disseminating key advocacy messages. The courses are video-based and divided into sections that can be watched independently at times that suit you. Each module includes supporting notes and the option to receive a personalised certificate of completion.

[start learning here>>>](#)

competition on the theme 'Me and my brain'. The public were invited to create a drawing, painting, collage or digital illustration representing their relationship with their brain, through artwork that explores their hopes, frustrations, or the day to day impact a neurological disorder has on their life. The winner is **Stacy Hart**, for her entry 'Marshmallow Head'. Stacy, who lives with Myalgic Encephalomyelitis (ME) explains "It often feels like my brain is a wall of marshmallow and the thoughts I have and the words I want to speak are somewhere right at the back, behind it all."

[see the winners>>>](#)



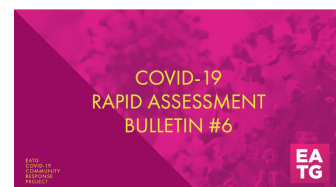
Mental Health Europe (MHE) is looking for an Advocacy and Policy Officer. The Advocacy and Policy Officer will support MHE's advocacy work and its work in the field of mental health across different policy fields and projects.

[apply now>>>](#)



Alzheimer Europe continues to develop and improve its **Clinical Trials Watch (CTW)**, an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in a least one European country. The service provides information on phase II and III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer's disease (AD). In January 2021, two new Phase II trials have been added to the service: The purpose of the **GRADUATION study** is to evaluate the effects of once weekly administration of Gantenerumab in participants with early (prodromal to mild) AD. The **VIVIAD study** is aiming to evaluate the safety, tolerability and efficacy of PQ912 in people with mild cognitive impairment and mild dementia due to AD.

[more information>>>](#)



EATG COVID-19 Rapid Assessment Bulletin #6 This bulletin draws the project to a close by looking to 2021 and beyond.

[read RAB #6>>>](#)

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initiatives, stories and events from our most budding members

'Let's Talk about Vaccination' – The young patients' perspective

by Jana Popova

On 14 January, EPF organised its first webinar to launch its Patient Guide 'Let's Talk About Vaccination.' This event gathered together experts in the field of vaccination and patient advocacy. The event provided an opportunity to discuss the vaccination process in Europe and to present the vaccination strategy, composed by the major European institutions in the healthcare sector. Noël Wathion highlighted that vaccine hesitancy is one of the biggest ongoing challenges in the COVID-19 pandemic and presented different options for engagement of patients and healthcare professionals. He provided tools for information on COVID-19 vaccines, presented EMA's transparency policy and the fact that we should listen and understand public's concerns about vaccination and search for information from reliable sources,

The Patient Guide "[Let's Talk about Vaccination](#)" consists of basic information about what we need to know to make informative decisions and contains useful tools, which patient advocates may use individually or in different discussions on the topic. As a young patient, for me the key message from the webinar was that now we should focus more than ever on transparency, good communication and reliable information sources, so we could take the best decision for our health.



Inside the Bubble

updates, stories and events around EU healthcare

European Commission authorises second safe and effective vaccine against COVID-19

The European Commission has granted a conditional marketing authorisation (CMA) for the COVID-19 vaccine developed by Moderna, the second COVID-19 vaccine authorised in the EU. This authorisation follows a positive scientific recommendation based on a thorough assessment of the safety, effectiveness and quality of the vaccine by the European Medicines Agency (EMA) and is endorsed by the Member States. The Moderna vaccine is based on messenger RNA (mRNA). mRNA plays a fundamental role in biology, transferring instructions from DNA to the cells' protein making machinery. Moderna, with whom the Commission signed a contract on 25 November, will deliver the total amount of 160 million doses between the first and the fourth quarters of 2021.

Commission launches consultation on blood, tissues and cells legislation

The European Commission has launched a public consultation on the EU's legislation on blood, tissues and cells, following a 2019 review that found the directives to be outdated. The central issue that has divided discussion on plasma donation in Europe is whether donors should be paid. Currently, only several EU countries pay for plasma donations. The public consultation is open until April 15.

Commission urges AstraZeneca to give answers on vaccine supply cuts

The European Commission is pressing British drugmaker AstraZeneca to provide immediate answers on the announced reduction of coronavirus vaccine deliveries to the EU. Frustration about AstraZeneca's announcement is running high because the vaccine — which could receive its market approval by the European Medicines Agency as early as the first week of February. The EU agreed last August to purchase 300 million doses with an option to purchase an additional 100 million of the Oxford/AstraZeneca jab, although the deal is based on quarterly deliveries. EU leaders on Thursday voiced new urgency about

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"There is one consolation in being sick; and that is the possibility that you may recover to a better state than you were ever in before."

- Henry David Thoreau



Calendar of Events

3 February

[Launch of Europe's Beating Cancer Plan](#)

[visit our website](#)

4 February

[World Cancer Day](#)

[contact us](#)

5 February

[HIVE-33 Mini-Series - Episode 3 ft. EPF's Elena Balestra](#)

11 February

[Vaccination Confidence – Patients' and professional Awareness Communication and Trust \(VAC-PACT\) Regional Workshop #1](#)

19 February

["14 Million Reasons to Discuss Life after Cancer: Implementing the Right to be Forgotten across Europe"](#)

28 February

[Rare Disease Day](#)

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