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THE EPF PATIENT PERSPECTIVE

European Patients Forum

MARCH 2024

EDITORIAL

Dear readers,

March brought significant milestones in two of the most debated legislative initiatives in the European healthcare landscape: the pharmaceutical legislation and the European health data space (EHDS).

On March 15th, the negotiations on the European Health Data Space (EHDS) between the European Parliament and the Council finally reached an end. The provisional text agreed by the co-legislators introduces several clauses for both secondary and primary use of health data. These provisions, for which **EPF has advocated since the proposal of the EHDS regulation** in 2022, are set to make the regulation more patient-centered by giving greater control to patients over their health data. However, in order to thoroughly assess the impact of the changes that have been made to the text initially proposed by the Commission, we need to wait for the final publication of the agreed text. The formal adoption of the text by the Council and Parliament is expected in April.

Four days later, the European Parliament's ENVI Committee adopted the reports on the Directive and Regulation revising and replacing the existing EU pharmaceutical legislation. Throughout the revision process, **EPF has played an active role**, contributing to discussions and advocating for a patient-centred revision. As such, we were happy to see that many of EPF's wordings have been incorporated into the final texts and the improvements made to the legislation increase patient involvement throughout the regulatory process, including the management of shortages, and accessibility to information for patients.

With two months to go until the European Elections, our **#Vote4Patients campaign** is gaining more traction, with support from many of our members and endorsement from MEP's and candidates. Earlier this month, MEP **Radka Maxová was the first one to join our cause**. Our Board member and treasurer, Radu Gănescu spoke about our Manifesto in an interview for Romanian media. We're sharing an excerpt below, as part of our ongoing campaign updates.

As always, this issue of the newsletter will bring plenty of updates from our members and news from ongoing projects!

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CAMPAIGN UPDATES

Patients Must Be Seen as Dialogue Partners in the Healthcare Debate

by Bogdan Guță

[Except from an interview with Radu Gănescu, EPF Board Member and treasurer]

At European level, patients face a number of country-specific problems. What should patients/patients' associations in Romania do to make sure that their problems are heard as well as those of patients/patients' associations in Germany, France, the Netherlands or Belgium, for example?

Indeed, this is a complex challenge. Every country is different, both in terms of legislation and participation in the democratic process. There are countries where, through their democratic tradition, the participation of civil society has become customary. In the case of Romania, we still have ground to make up. The EPF campaign advocates, among other things, for the participation of patients' organisations in health policies based on solidarity, equity, mutual trust, sustainability and accountability. This is why I think it is important to act at national level, in the context of the Euro-parliamentary elections. By establishing early cooperation with future Romanian MEPs, we will have the opportunity to interact more easily during their term of office when it comes to health. At the same time, building a relationship of collaboration and trust between civil society and the authority is the key to success, we are a young country in terms of democracy and we need to increase the collaboration of all actors in health. Often our problems are heard and listened to, the next step would be to build both short and long term so that these problems disappear and are not perpetuated in a system stuck in time.

What is the the Patient Organisations' Manifesto and what is its vision?

The Patient Organisations Manifesto is a roadmap for everything that means involvement, at European and national level, of patients and their representative organisations. The document was first presented at the EPF's 20th anniversary event last year. It expresses the EPF community's vision of patient involvement in health policy. Among the key messages of the manifesto I would mention the need for meaningful and sustainable involvement of patient organisations, identifying effective channels and mechanisms in collaboration with patients. The campaign calls on policy makers to enable patient organisations to actively participate at all stages of policy making, ensuring that their voice is heard and taken into account. For this to happen, there is a need to institutionalise participatory processes and formalise patient participation in any decision-making body on health and related policies. In this way, patient organisations become key partners in the decision-making process. Last but not least, there is a need for patient organisations to be able to access long-term, unrestricted operational funding.

This interview was taken by Bogdan Guță for *Revista Politici de Sănătate* (Health Policies Review). It's fully available in Romanian **here**.

SECRETARIAT NEWS

EPF Received the Outstanding Contribution to Health Award at DIA Europe 2024

11th March, 2024: During the DIA Europe 2024 Gala dinner in Brussels, a moment of triumph unfolded as the European Patients' Forum (EPF) was presented with the prestigious Outstanding Contribution to Health Award. Receiving the award on behalf of our team was Marco Greco, EPF President, in acknowledgment of EPF's dedication to advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, and empowerment.

of organisations that have made significant and innovative strides in promoting healthcare on a global scale. Marco Greco, graciously accepting the award on behalf of the EPF team, expressed profound gratitude, emphasising the collective commitment to fostering equitable, person-centred, accessible, and sustainable healthcare systems across Europe.

STYPA 2024 - ANTIMICROBIAL RESISTANCE (AMR)

The Skills Training for Young Patient Advocates (STYPA) is back in 2024! STYPA is an exciting and unique opportunity offering a tailored, high-quality course for young patients or representatives of young patients, aged between 18-30 years old.

The topic of STYPA 2024 is **Antimicrobial Resistance** (AMR). Many people do not know that antibiotics do not cure infections caused by viruses, such as colds or flu, or that it is important to take antibiotics exactly as prescribed and not to self-medicate to safeguard their efficacy. Similarly, patients are not informed about the rates of resistant bacteria and healthcare-associated infections in hospitals and measures to address them. Good health literacy and patient empowerment can therefore contribute to the fight against AMR effectively, along with increased focus on vaccination, hygiene, and proper disposal of medicines.

When and where?

- Introduction webinar - June 2024;
- The face-to-face meeting of STYPA will be held from 4 to 7 July, in Brussels, Belgium at the Radisson Red Hotel;
- Follow up workshop webinars - September and October 2024;
- Closing Celebration webinar - November 2024.

How to apply?

You can apply by completing **this application form** (deadline 1st May). If you have any additional questions or issues with your application, please contact the EPF Staff at **stypa@eu-patient.eu**.

UPDATES FROM THE EMA

Multi-Agency Report Highlights Importance of Reducing Antibiotic use

Countries that have decreased their consumption of antibiotics in both animals and humans have seen a reduction in antibiotic-resistant bacteria. This is according to the fourth joint report on the integrated analysis of the consumption of antimicrobial agents and occurrence of antimicrobial resistance (AMR) in bacteria from humans and food-producing animals (JIACRA IV), published by the European Centre for Disease Prevention and Control (ECDC), the European Food Safety Authority (EFSA), and the European Medicines Agency (EMA).

Taking a **One Health** approach, which recognises the connection between the health of people and animals, the report presents data primarily collected between 2019 and 2021 on antibiotic consumption and AMR in Europe.

Full details about the project and the 4th joint report are available **here**.

YOUTH GROUP UPDATES

europeanpatients'forum Youth Group

Welcoming Voices: The Fresh Faces of Our Youth Group

Blaz Urbanc

As the seasons change, so does the image of our vibrant Youth Group. With each new who bring with them the spirit of youth and the promise of tomorrow. We asked them to give us a reflection of their first in-person Spring Meeting, which we held at the beginning of March in Brussels, during which we progressed on our current 'Young Patient Involvement in Patient Organisations' project, planned our next steps for the upcoming months, and got to know each other and our new members on another level as a team.

Anna Revilla Bruñol is actively involved in advocacy activities within the European Multiple Sclerosis Platform - Young People's Network. She described her experience within the Youth Group in-person Spring Meeting as follows:
"When I got into the EPF youth group, I was really thankful for the chance. But after our spring meeting, I felt even more grateful. Collaborating with the team in person on our project was incredibly empowering. Plus, getting to know the members of the group on a deeper level was a real highlight. The spring meeting really inspired me to keep working for a better future for those who we are living chronic conditions."

Eimear O'Rourke is a medical student and working in allergy research and policy at both a national and a global level. She described our common spent weekend as an "*incredible experience. Meeting fellow members face-to-face and collaborating on the projects in person was really enjoyable. It was a great opportunity to engage with other members and learn about their impactful work with their own patient organizations which was incredibly inspiring to hear about. The weekend was great fun, the whole group were extremely welcoming and I'm really looking forward to seeing everyone again at the next fall meeting."*

Amina Berbić is a dedicated patient advocate with a focus on improving the lives of young patients facing pulmonary hypertension in Serbia and Bosnia and Herzegovina. Her first-hand impressions of our Youth Group atmosphere and ongoing projects are as follows:
"One of the aspects I cherished most during the Spring Meeting was the sense of camaraderie and shared purpose among attendees. Despite everyone coming from diverse backgrounds and disciplines, there was a palpable sense of unity in our commitment to driving positive change. From the lively discussions in breakout sessions to the late-night brainstorming games, every moment was filled with passion and dedication to our collective mission."
In addition to that Amina also thought that: *"The ongoing projects presented at the Spring Meeting were nothing short of impressive. It was evident that each team member had poured their hearts and minds into their work, resulting in innovative solutions and tangible progress. What struck me the most was not just the quality of the project but also the collaborative spirit behind them. Despite the challenges posed by diseases and cultural differences, the team worked seamlessly together, showcasing the true power of global collaboration."*

Do not forget to follow us on our social media platforms, including **Facebook**, **X**, **Instagram** and **LinkedIn** to find out more about our new members, for more interesting content from our Youth Group, for our progress on our projects, and how you can get involved and support our team, or email us at **youthgroup@eu-patient.eu** with any questions!

PROJECTS PORTAL

Join this year's edition of the Patient Engagement Open Forum (PEOF)!

This year’s Patient Engagement Open Forum (PEOF) will take place from 21 to 23 May 2024, in Baveno Italy. PEOF is a multi-stakeholder event organised by EPF, EUPATI, and PFMD.

This year EPF is organising several on-site and online sessions:

- A dedicated session on **early feasibility studies for medical devices, introducing HEU-EFS.**
- **Another session will discuss the ongoing project IDERHA,** with a focus on inclusive decision-making and patient engagement in institutional and organisational policies for data use in research.
- A virtual session happening on 25 April from 14:00 to 15.30 pm will introduce **Gravitate Health.** Through an interactive booth, EPF and its Consortium partners will be presenting the MVP2 of G-Lens.
- Last but not least, there will be a separate session on **Health Technology Assessment** (HTA).

Don’t miss out: find more information **here**!

LEARNING | Read the Latest From the First EUCAPA Extended Training!

The first EUCAPA Extended Training was a success!

EUCAPA hosted their first in-person training session at **UMIT TIROL** University, in Austria, to provide patients with the skills to engage in Health Technology Assessment. From technicalities in defining the trade-offs in HTA to communication techniques to confidently advocate for patients' rights, the participants had the opportunity to dive deep into HTA's ins and outs.

Are you a patient or patient representative and do you wish to engage in HTA? Follow their social media (**LinkedIn**, **X**) and take a look at their courses!

- **Fast-Track Training**: In this comprehensive 8-hour online training programme, patients and patient representatives will learn the skills, tools, insights, and expertise they need to engage in joint clinical assessments and scientific consultations within the EU HTA regulation.
- **Extended Training:** A 3-Day in-person training program in HTA for patients and patient representatives at **UMIT TIROL - University for Health Science and Technology**, in Austria. An in-depth training program designed to deepen your knowledge of the principles and methods of HTA, health decision sciences, and patient involvement. You will learn about communication and personal skills, such as presenting and discussing patient-relevant topics!

📚 **Enrol in the Fast-Track Training**
📚 **Enrol in the Extended Training**

EUCAPA's programmes are mainly designed for cancer and rare disease patients, but also other patient categories will be considered! Attending the Fast-Track training is a prerequisite for participation in the extended training.

EVENT | H2O on a National Scale: the Austrian Chapter

On March 8, we participated in the "**H2O** in Austria - Putting Patients at the Center" event, in Vienna. We were engaged in insightful discussions regarding the significance of patient-centred healthcare and the role of initiatives like H2O in transforming healthcare provision.

The Health Outcomes Observatory (H2O) project aims to establish patient-centric pan-European and national observatories to amplify the patient voice in their healthcare and within healthcare systems. This project is currently setting up digital tools for patients to report their health outcomes in a standardised way while retaining control over their data and access permissions.

Key highlights from the event discussions included:

- **Patient Empowerment**, participants emphasised the importance of empowering patients to actively participate in their healthcare decisions, underscoring H2O's role in providing patients with the tools and resources to take charge of their health outcomes.
- **Data Privacy and Control**, concerns surrounding data privacy and patient control over their health data were thoroughly discussed, with participants recognising the significance of ensuring patients retain autonomy over their data while benefiting from its utilisation in improving healthcare outcomes.
- **Collaborative Healthcare**, the event highlighted the collaborative nature of the H2O project, emphasising the need for multidisciplinary collaboration between patients, healthcare providers, and policymakers to drive positive changes in healthcare delivery.

resources, Data Saves Lives aims to harness the potential of health data to improve healthcare outcomes and save lives.

- **Future Directions**, participants expressed optimism about the future of patient-centred healthcare, envisioning a healthcare landscape where patient voices are central to decision-making processes, and initiatives like H2O play a pivotal role in shaping this future.

This event served as a platform for meaningful dialogue and collaboration towards advancing patient-centred healthcare in Austria. Through initiatives like H2O, stakeholders are poised to drive positive changes that prioritise patient experiences and outcomes in healthcare delivery.

Do you want to read more? Visit the official **website**!

MEMBER FOCUS

Patient representation in the German healthcare system with **BAG SELBSTHILFE**

For citizens, both with and without a migration background, it is important to understand how their rights as patients are represented. So far, there has been a lack of information about the German healthcare system in English. BAG SELBSTHILFE aims to address this issue by providing a new video in English about the opportunities and responsibilities of participation in patient representation in the Federal Joint Committee (G-BA).

The video "Patient representation in the German healthcare system with BAG SELBSTHILFE" (with **subtitles** | with **audiodescription**) explains how the Federal Joint Committee (G-BA) is composed, which decisions regarding the German healthcare system are made there, and the role that self-help groups and patient representatives play in determining essential components of statutory health insurance.

In patient representation, it is important for people with a migration background to for all affected individuals. If people with a migration background are not represented in these important bodies, their interests cannot be adequately represented.

An important task of BAG SELBSTHILFE is to inform patients about the various aspects of the healthcare system and self-help work. It is important that this information is as accessible as possible, with few barriers. In order for people who do not speak German to access these information, videos in English are increasingly being published on the BAG SELBSTHILFE **YouTube channel** as part of the project "**Engaging People with Migration Backgrounds in Self-Help Exchange.**

EU agreement on air quality legislation: exposure remains but information, justice and compensation are reinforced

The **European Federation of Allergy and Airways Diseases Patients Associations (EFA)** has been working for the last three years on advocating for updated EU ambient air quality standards to match the latest science to protect lung health. While the final agreement reached fails to adapt to the 2021 WHO guidelines, the upcoming EU legislation foresees better public information, access to justice and compensation for health damage caused by ambient air pollution. Read more on **the EFA website**.

The cardiovascular patient community unites to create the first global manifesto calling for early detection and diagnosis of cardiovascular disease

Global Heart Hub has united the cardiovascular disease (CVD) patient community with global thought leaders to create the first global manifesto calling for early detection and diagnosis of CVD: "*Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change*." The first-of-its-kind manifesto was developed via a multi-stakeholder approach, bringing together 125 patient advocates including 40 CVD patient organisations, key opinion leaders and multidisciplinary experts from leading organisations including World Heart Federation and the European Society of Cardiology.

Learn more about the manifesto here >>>

EA TG European AIDS Treatment Group

Updates from European AIDS Treatment Group

EATG announces Nicoletta Policek as new Executive Director

After a diligent recruitment process, the Board of EATG is happy to announce the organisation's new Executive Director
The Board of EATG announces that Nicoletta Policek, an HIV activist with a longstanding academic career, will step into the role of the Executive Director (ED) starting 8 April. This decision comes after a recruitment process that began in August 2023.

EATG Statement for Zero Discrimination Day: Our Rights, Our Health

1st of March marked Zero Discrimination Day and EATG underlines this year's focus to '**protect everyone's health, protect everyone's rights**', as equity and inclusion are central to a successful response to HIV/AIDS and related epidemics. EATG calls for systemic changes to enable access to essential services, ensuring that people can seek and receive care in a safe environment free from prejudice, as well as enjoying equal rights.

affected by HIV/AIDS can lead a fulfilling life.

Community Breakfast Club at CROI 2024 conference

EATG reports from Community Breakfast Clubs at **#CROI2024** are available online:
Session 1: Spotlight on Social and Behavioural Science at CROI 2024

Session 2: Living with HIV for a Lifetime – It's Complicated

Session 3: Research Roundup: Scientists and Advocates Offer Fresh Perspectives and Seasoned Analyses of CROI 2024 Research

The Community Breakfast Club is brought to you through a collaboration including the CROI Community Liaison Subcommittee, AVAC , EATG and other groups.

Civil Society Forum on Drugs: Position Paper on Decriminalisation

EATG endorsed the **Position Paper on Decriminalisation** issued by the Civil Society Forum on Drugs in Europe, to which we contributed along with other participating organisations.

International Women's Day: Our voice matters. Our stories are important.

On International Women's Day EATG shared the **inspirational words of EATG's women.**
Nicoletta, Eliane and Elena-Andreea talk to all of us about the realities they face, small and bigger battles and the insights they have gained living with HIV.

Patients say NO to extending the duration of intellectual property protection for medicines

EATG **co-signed a common statement** from Health Civil Society on the EU regulation of pharmaceuticals.

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