THE EPF European Patients Forum
PATIENT PERSPECTIVE
JUNE 2024

EDITORIAL

A Roadmap to the Future

How will the future of European healthcare and patient advocacy look over the next five years and beyond? This is a question we at EPF have deeply reflected upon, especially now with the European elections behind us. The new mandate carries the responsibility of implementing the European Health Data Space, engaging in the trialogue for the pharmaceutical legislation, and rolling out the health technology assessment regulation. These legislative initiatives will impact the delivery of healthcare to European Union citizens.

With the introduction of the **Patient Organisations' Manifesto**, we envisioned the next decade of patient advocacy as being truly democratic, participatory, and inclusive. The **Council Conclusions on the European Health Union** brought encouragement by calling attention on the need for ambitious joint action across a wide range of public health challenges. These actions will support more resilient, patient-centred healthcare systems, strengthen investment in health, and address unmet patient needs. However, we call for an increased focus on prioritising health literacy to empower patients and improve health outcomes, achieving a true single market for medical products to enhance patient access, and affirming the key role of civil society organisations, particularly patient organisations, in bridging the gap between institutions and the public.

The HTA Regulation has been a particular focus for us this month. Alongside other patient organisations, we formulated ten key recommendations aimed at improving patient involvement in Joint Clinical Assessments (JCAs) under the EU HTA Regulation. These recommendations are designed to foster a more inclusive, transparent, and patient-centred approach to JCAs. At the same time, **we signaled that elevating the risk of conflict of interest to an exclusion criterion for patient involvement in HTA** jeopardises valuable input: the lived experiences of patients provide essential evidence and guidance for evaluating the clinical effectiveness and safety of health technologies, ensuring that HTA is conducted in the best interests of those directly impacted.

At the same time, we conducted **an analysis of the European Parliament reports on the revision of the EU pharmaceutical legislation**, summarising the main changes

Looking towards the future, we believe that the strength of EPF lies in the strength of our members. To begin with, we initiated a conversation on Antimicrobial Resistance (AMR) through a series of webinars. The first webinar discussed the impact of AMR on different patient groups and what actions are needed to improve advocacy and understanding of this complex issue. In support of this, the **AMR Info Point**, now live on our website, hosts various resources to better prepare the patient community to address AMR.

As we navigate the evolving landscape of European healthcare and patient advocacy, EPF remains committed to building a more inclusive, patient-centred system. By prioritising health literacy, enhancing access to healthcare, and ensuring robust patient involvement in shaping health policies, we can address the challenges ahead. The strength of our organisation lies in the collective power of our members, and together, we will continue to advocate for a healthier, more equitable future for all patients across Europe.

SECRETARIAT NEWS

REFLECTIONS ON THE FUTURE OF THE EUROPEAN HEALTH UNION

EPF welcomes the adoption of the Council Conclusions on the European Health Union. **Read our reflections here ->>**

ANALYSIS OF THE EUROPEAN PARLIAMENT REPORTS ON THE REVISION OF THE EU PHARMACEUTICAL LEGISLATION

On 10 April 2024, the European Parliament adopted the reports on the **Directive** and the **Regulation,** thus formalising the Parliament's official position on the revision of the EU pharmaceutical legislation. **We summarised the main changes proposed by the Parliament that are relevant to the patient community.**

FEEDBACK ON THE DRAFT IMPLEMENTING ACT FOR ASSESSING AND MANAGING CONFLICT OF INTEREST

The Implementing Act for assessing and managing conflict of interest will determine which patients and clinical experts participate in Health Technology Assessment (HTA) cooperation at the EU level. **Read EPF's feedback on the draft Implementing Act here ->>**

10 KEY RECOMMENDATIONS FOR ENHANCING JOINT CLINICAL ASSESSMENTS UNDER THE EU HTA REGULATION

Patient organisations released **10 key recommendations for enhancing Joint Clinical Assessments under the EU HTA Regulation**.

EPF CALLS ON NEW MEPS TO PRIORITISE HEALTH IN THE EU AGENDA

As newly elected Members of Parliament (MEPs) settle into their roles, EPF **recalls the need to place health at the forefront of the EU agenda**.

PROJECTS PORTAL

5 years

Data
Saves
Lives

Launch of #DSL5 - Join the Celebration!

Did you know **Data Saves Lives** (DSL) is celebrating its 5th anniversary this year? To mark this milestone, DSL and EPF have launched a joint communication campaign, #DSL5. Unfolding as a countdown, the campaign is dedicated to highlight the initiative’s milestones and its journey so far.

You can follow the campaign on social media and join the conversation by using the hashtag #DSL5 to share your favorite moment of DSL history.

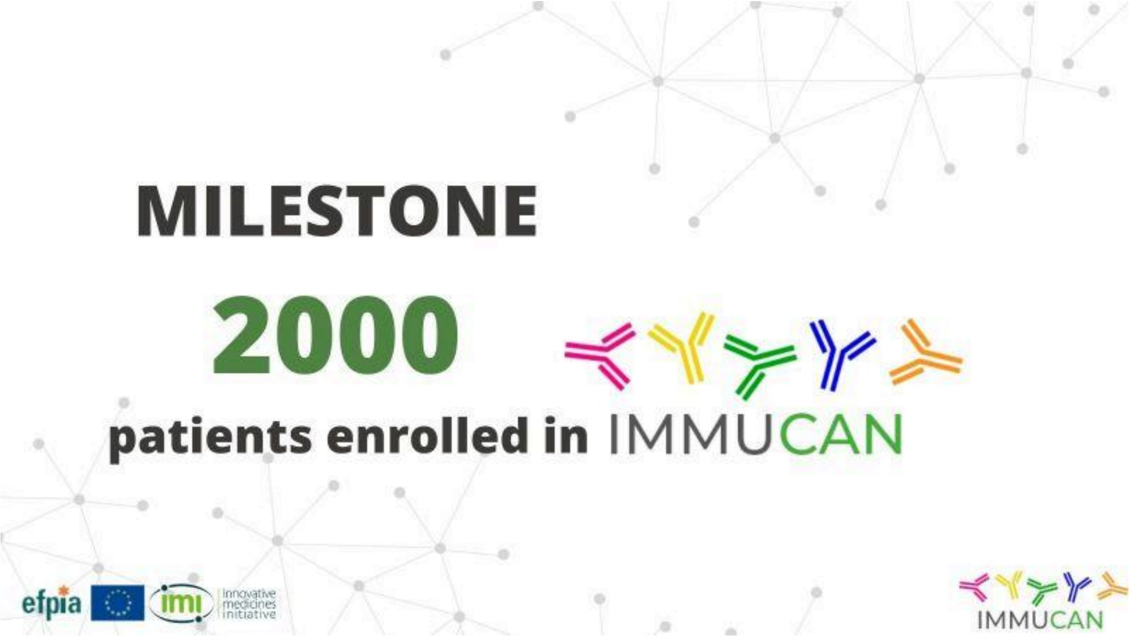
In the meantime, make sure to explore all the resources DSL has to offer. For instance, the Data Saves Lives Toolkit 2.0 aims to equip patient groups and health influencers with the download the materials here.

IDERHA
integrating health data

IDERHA | Shape the Future of Real-World Evidence Policies: Empowering Patient-Centric Healthcare

IDERHA recently published a global landscape analysis of current policies for using Real-World Data (RWD) and Real-World Evidence (RWE) in HTA and regulatory decision-making, in which they highlight the importance of responsible data sharing and patient-centric decision-making. In this report, the IDERHA team explores the challenges and opportunities associated with RWD and RWE in healthcare. It provides insights into the current landscape of RWE policies and identifies the policy gaps, emerging best practices, and priorities for action.

Read more here.



IMMUcan celebrates the 2000 patients milestone!

The IMMUcan team announces that the project has enrolled its 2000th patient!

This achievement not only advances IMMUcan's mission to revolutionise cancer treatment but also marks the largest immune-profiling effort in Europe to date. With each new

Make sure to stay tuned, as we will share more insights from their research.

To learn more, visit **the website**.

MEMBER FOCUS

European Federation of Neurological Associations | The Rare Neurology Charter

The majority of rare diseases have neurological manifestations, involving central, peripheral nerve and muscle. Most rare diseases are associated with high unmet needs due to the lack of available and effective diagnosis and treatment measures. There is a relative lack of research to develop such measures, at least partly due to the low number of medical experts available for each condition and limited financial resources.

From a lack of available specialists to be able to give a timely and accurate diagnosis, to fragmented care pathways, there are too many gaps in healthcare systems for people living with a rare neurological disease to fall through.

For these reasons, EFNA has led a multi-stakeholder group in developing the **Rare Neurology Charter**. The Charter outlines high-impact policy solutions with the potential to transform the lives of patients.

EURORDIS | LAUNCH OF THE RARE BAROMETER

How does your rare disease impact your life?

Join the Rare Barometer team on July 10 for a special webinar to discuss the upcoming launch of their survey on the impact of rare diseases on daily life, and how you can help maximise its impact! This is a unique opportunity to share your opinions, your daily experiences and contribute to shaping European policies. Your participation and your insights are invaluable and can help shape the understanding and support of rare disease communities.

📅 Date: July 10
🕒 Time: 2:30 PM CEST
🔗 **Register here**

EATG European AIDS Treatment Group

Updates from European AIDS Treatment Group

celebration. A protest against criminalisation as well as intersectional and systemic stigma and discrimination. A celebration for hard-earned visibility, the respect we deserve, and our constant fight against imposed shame. A celebration to honour the first few braves who marched for all our rights and in solidarity with all those who are still fighting for their rights.

EATG at AIDS 2024 conference

EATG will participate in the #AIDS2024, the 25th International AIDS Conference! AIDS 2024 takes place in Munich, Germany, and virtually from 22 to 26 July. EATG will be there at the Global Village with a booth and co-hosting two Networking Zones: The Silver Zone: Celebrating older people living with HIV and 555 Zone: We Won't Be Left Behind!

CORE Knowledge Hub Meeting #2

Gender Transformative Services: What's that all about? You can now stream the recording of the second online Knowledge Hub meeting.

Project

The European Commission has granted a 15-month extension to continue with the RBDCOV Project. So far, 240 volunteers have been recruited within all the centres set to join adolescents' clinical trial (named HH3) to test the efficacy, tolerability, and safety of the BIMERVAX® COVID-19 vaccine in adolescents aged 12 to 17. EATG is the leader of the Community Engagement work package.

PROMise: face-to-face Stakeholder Meeting

EATG's PROMise Stakeholder Meeting will take place face-to-face on Tuesday 2 July (10:00-16:00 CET) in Amsterdam, The Netherlands. The upcoming PROMise stakeholder meeting in Amsterdam will be a space for deep discussion and co-creation between several stakeholders, including community members, academics, and pharmaceutical, regulatory and HTA representatives.

Updates from Fertility Europe

Atlas presentation in the Austrian Parliament

On June 19, 2024, the second edition of the European Atlas of Fertility Treatment Policies, developed by Fertility Europe and the European Parliamentary Forum for Sexual and Reproductive Rights, was presented in the Austrian Parliament.

The regulations for fertility treatments in Europe vary significantly. The Atlas is a comprehensive comparative map that evaluates 49 countries and territories based on their access to equitable, safe, and efficient fertility treatments. The traffic lights colour-coded map presents the level of access to fertility treatments in each country with dark green indicating excellent access

European Commission's Conference on SoHO regulations in Brussels

On June 24, Klaudija Kordic, Chair of Fertility Europe, represented the organisation at the European Commission's Conference on the new regulations for SoHO (Substances of Human Origin) in Brussels where she delivered an impactful presentation. This significant event focused on the upcoming regulatory changes that will greatly influence patients, especially those whose treatments rely on donations.

Klaudija's presentation emphasised core parts of the Regulation aimed at enhancing the safety, transparency, and ethical standards in the donation and use of human substances, i.e. the importance of rigorous safety

Learn more about Atlas here.

make informed decisions and the necessity for all donations to be voluntary, free from any form of coercion or exploitation. She pointed out a significant omission: the new rules do not address the issue of anonymity in gamete donation. This oversight neglects the rights of donor-conceived individuals to access information about their genetical origins.

Programme for the 34th Alzheimer Europe Conference in Geneva is now online!

Alzheimer Europe, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève would like to thank everyone who submitted an abstract for the 34th Alzheimer Europe Conference (34AEC) that will take place in Geneva from 8 to 10 October 2024. They received a record number of abstracts for 34AEC, with a total of 578! All of them have been reviewed. If you have not received information about your abstract submission, please contact them via: **info@alzheimer-europe.org**

Following the abstract review, the organisers are pleased to announce a detailed **programme for the conference on the website**.

The conference registration portal is open. You can take advantage of the Early Bird registration fees until 15 July 2024. Register with these Early Bird rates and benefit from the reduced registration fees. A 25% discount is available for participants from low and middle income countries. Special rates are also available for people with dementia, students and member associations of Alzheimer Europe. **See here for more information**.

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