



THE **EPF**  
PATIENT PERSPECTIVE  
MAY 2024

## EDITORIAL



EPF PRESIDENT  
**MARCO GRECO**



### Vote4Patients: A Call to Action for the European Elections

With the European elections less than a week away, we are stepping up our efforts to promote health as a key EU priority for the next mandate. Despite an unprecedented focus on health during the COVID-19 pandemic, the subject seems to be attracting less and less attention from the European institutions, as exemplified by the **€1 billion cut to the EU4Health programme**. The inclusion of a sizeable health budget as part of the next multi-annual financial framework (2028-2034) – which accounts for over 60% of the EU budget – will be a decisive factor for the achievement – or not – of the European Health Union.

In this context, the European Patients' Forum (EPF) and its members have been actively involved in the **#Vote4Patients campaign**. Since February 2024, EPF has engaged with current Members of the European Parliament to record **podcasts**, **video interviews**, and thought-provoking **quotes** to stimulate the debate on patient-centered healthcare – reaching over 1.2 million impressions on social media. Nearly a dozen MEPs support the **Patient Organisations' Manifesto**. EPF also engaged with MEP candidates and coordinated with national coalitions to identify potential new health champions. Our members have played an invaluable role in rolling out the campaign among their communities. They are engaging with candidates and health stakeholders at national level, organising events and webinars to raise awareness of our call to action, and helping gather signatures for the **petition**.

As the cornerstone of our campaign, the Manifesto was adopted at our 20<sup>th</sup> Anniversary and puts forward 10 principles for greater involvement of patient organisations in healthcare systems. For example, it calls for patient organisations to be involved at all stages of policy development (participation in parliamentary committees, health policy working groups), and to be meaningfully involved in health technology assessment (HTA). Most importantly, it urges decision-makers to provide unrestricted, sustainable, and long-term operating funding to support patient groups' daily activities and allow them to fulfil their public health mission.

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in previous elections. This is a challenge but also a potential opportunity for patient organisations to reopen the debate. There are also uncertainties because the new composition of the European Parliament could redefine the balance of power between the political groups and result in a change of tone regarding the EU's role in health. Finally, with negotiations already underway or finalised for the [EU-Pharmaceutical legislation](#) and the [European Health Data Space](#), the Parliament's focus may evolve towards more non-legislative work, making stakeholder engagement and advocacy even more crucial.

As we make our way to the polls next week, let's remember that we all play a role in building the Europe we envision. Together, we can ensure a bright future for the patient movement across Europe. In the meantime, join our campaign!

Marco Greco, EPF President

## SECRETARIAT NEWS

**WEBINAR SERIES**

# Amplifying patient advocacy on Antimicrobial Resistance (AMR)

[Register](#)

1

Webinar 1: Patient Advocacy on AMR in the EU: where do we begin?



Date & Time: 20 June 2024, 3 - 4pm CEST



Platform: Zoom



Language: English

EPF and [The AMR Narrative](#) are organising a webinar series to create an exchange space for diverse groups of patients, carers, survivors and civil society organisations impacted by AMR who want to advance advocacy efforts.

[Click here for more information about the series](#)

[Register here](#)

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## EPF RECEIVED THE INTERNATIONAL DONABEDIAN AWARD

The distinction was given to EPF by the **Instituto Avedis Donabedian** and the gala took place in Barcelona, on the 8th of May. [Read more ->>>](#)

## CONGRATULATIONS TO THE INAUGURAL GRADUATES OF THE INTERNATIONAL PATIENT ADVOCACY MANAGEMENT MASTER PROGRAMME!

Earlier this month, the first graduates of the International Patient Advocacy Master Programme had their graduation ceremony. The study programme was established by Università Cattolica del Sacro Cuore, in partnership with EPF. Registrations are now open for the 2024-2025 academic year. [More information here ->>](#)

# UPDATES FROM THE EMA

## EPF represented at the 10 year anniversary of the EU Network Training Centre (EU NTC)

On 30 May, EPF President, Marco Greco, attended the 10 year anniversary of the EU Network Training Centre (EU NTC). The EU NTC is a joint initiative by the Heads of Medicines Agencies and the EMA to spread good regulatory practices among the EU network and provide high quality training shared through a central platform. While the NTC primarily targets the staff members of the national agencies, a wider audience will now receive access to the training catalogue, including members of the Patient and Consumer Working Party (PCWP).

In his intervention, Marco Greco highlighted the role of the NTC in building a strong and highly qualified regulatory network to ensure patients' access to safe and effective medicinal products. He also emphasised the importance of adequate resources and training for patients involved in regulatory processes to ensure that they can meaningfully contribute. Patient organisations have extensive experience in providing training to patients, which can be leveraged as the NTC's access and curriculum are extended to broader audiences.

## Joint EMA, ECDC, ECHA, EEA, and EFSA initiative: One Health

EMA announced a **partnership** with the European Centre for Disease Prevention and Control (ECDC), the European Chemicals Agency (ECHA), the European Environment Agency (EEA), and the European Food Safety Authority (EFSA) to strengthen cooperation to support the implementation of the One Health agenda in the European Union. **One Health** recognises the complex interplay between human, animal and plant health, food safety, the climate crisis and environmental sustainability. Strengthened cooperation among the various agencies will ensure better consistency and coherence between policy and regulatory activities. It will support a comprehensive approach to current public health and environmental challenges and improve the EU's ability to prevent and address health threats.

## A new look and feel for the Human Medicines Highlights newsletter

Make sure to **re-subscribe** to the revamped Human Medicines Highlights newsletter to continue to receive the newsletter as current subscriptions have not been automatically renewed. The

# YOUTH GROUP UPDATES

## **Empowering Action Against Diabetes in Humanitarian Crises: A Youth Advocate's Perspective**

By Konstantina Boumaki

On May 9th and 10th, I attended an international symposium focused on diabetes in humanitarian crises organised by International Alliance for Diabetes Action, where we explored the urgent needs and solutions for diabetes management in crisis settings.

The symposium brought together experts dedicated to addressing diabetes care during emergencies. Sessions highlighted the significant challenges faced by individuals with diabetes in crises and showcased innovative solutions.

One impactful session discussed efforts during a recent natural disaster, demonstrating a commitment to delivering insulin and supplies to those in need amidst chaos. This adaptive approach to locating and aiding people with diabetes in camps underscored the importance of resilience in crisis response.

Another session addressed the struggles refugees face in accessing insulin, emphasizing the urgent need for affordable access. This call for action resonated throughout the event, highlighting the critical need for systemic changes to ensure insulin accessibility during crises.

Challenges such as language barriers and healthcare complexities were also discussed, with a focus on enhancing psychological support and community aid. Comprehensive care extends beyond medical supplies to include mental health and community integration. The power of peer support and community engagement was highlighted, with various initiatives demonstrating how community networks can play a pivotal role in crisis response.

A key insight from the symposium was that diabetes is a global humanitarian crisis, not just a problem needing humanitarian help. This perspective calls for collaboration among healthcare providers, policymakers, and community organizations to create sustainable solutions.

It was a very impactful and interesting symposium with important conversations, and we look forward to seeing what's next.



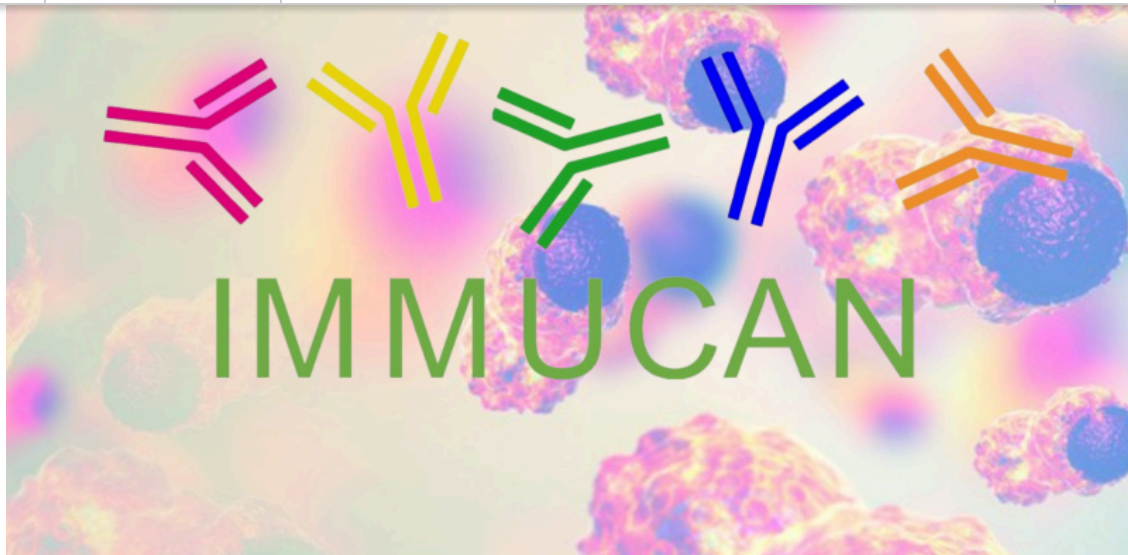
KONSTANTINA BOUMAKI

# PROJECTS PORTAL

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### IMMUCan in the spotlight

So far, this year has been busy for the IMMUCan team. With more than 1,800 patients analysed, IMMUCan arguably represents Europe's largest tumor-immunoprofiling effort to date.

And the results are coming in! Here is a brief chronological overview of some of the highlights of 2024:

March: A study conducted by Amelie Franken and her colleagues, was featured on the cover of one of the leading scientific journals in the field of immunology: Immunity by Cell Press. The research conducted by our colleagues, using IMMUCan resources, advances our understanding of immune cell dynamics in head and neck squamous cell carcinoma (HNSCC) patients. [Read the full article here ->>>.](#)

April: Novigenix joins forces with the IMMUCan consortium. Their contribution to the project consists in the integration of the AI driven LIToseek platform to the project's work. By using AI and next-generation RNA sequencing, the platform will enhance the immune profiling capabilities of IMMUCan. [Click here for more information. >>>](#)

May: Partners gathered in Paris, for the General Assembly. Over the two-day meeting (16-17 May), we went through updates from all work packages and we exchanged on the project's ambitious ongoing analysis.

## MEMBER FOCUS



European  
AIDS Treatment  
Group

### Updates from European AIDS Treatment Group

#### EATG Annual Report 2023 was launched

This month EATG published the European AIDS Treatment Group Annual Report for

#### EVENT

**CORE Knowledge Hub Meeting # 1** | The HIV, Viral Hepatitis and STIs Testing and

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figures for finances and membership, updates on communication, and governance at a glance.

## ENDORSEMENT

**Coalition PLUS: 56 organisations call on MEPs to end the war on drugs**

**EATG General Assembly 2024: steering EATG to the future of HIV activism in Europe and Central Asia**

On 10-12 May, **EATG's annual General Assembly (GA)**, was held in Frankfurt, Germany. EATG members and staff gathered again, in the first face-to-face General Assembly since 2022. This GA elected a new Board of Directors and renewed representation in other bodies of governance. The composition of the **Board of Directors (term 2024-2025)** is:

- Nyambe Mukelabai (Chair)
- Daniela Rojas Castro (Vice Chair)
- Tamás Bereczky (Secretary)
- Koen Block (Treasurer)
- Rosaline M'Bayo (Director)

## BLOGS

**RECAP with the RBDCOV Community Advisory Panel | Why not HIV? A comparison between mRNA vaccine research for COVID and HIV**

ReCAP is a series of interviews with the members of the RBDCOV Community Advisory Panel that will explore the world of community engagement in EU projects and the importance of including people living with immunocompromising conditions in clinical trials. Our guests for this second interview are Beatriz Mothe Pujadas, Infectious Diseases Physician and Research Scientist at IrsiCaixa acting as Principal Investigator of the HH-4 clinical trial in people with immunosuppressive conditions and Deniz Uyanik, EATG member and member of the Community Advisory Panel for the RBDCOV project.

**RBDCOV How do we engage communities to vaccine clinical trials?**

Discover how EATG leads community engagement within the **RBDCOV\_EU** consortium. From reviewing study designs to ensuring participant-friendly contents, our efforts are centered around involving communities every step of the way... Because "Nothing about us without us!". Read RBDCOV's latest specialised article by Apostolos Kalogiannis, EATG Communications Manager and member of the RBDCOV Community Advisory Panel.



## EUFAMI Congress 2024

The Congress promises an enriching programme featuring insightful keynote speeches, engaging workshops, and valuable networking opportunities, where participants can share experiences, and strengthen community bonds in the field of mental health support.

♦ **Date:** 21-22 June 2024

♦ **Venue:** Radisson Blu Hotel Lietuva, Konstitucijos pr. 20, 09308 Vilnius, Litauen (If you would like to stay directly at the venue, please book your accommodation [here](#)).

♦ **Theme:** Conflict and Recovery in Mental Health

♦ **Register here**

**All details on the EUFAMI Congress agenda, venue, location, travel and accommodation can be found in the [EUFAMI Congress Information Pack](#).**

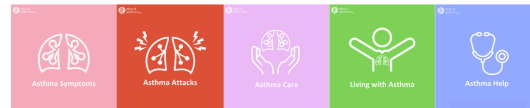
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## EFA contributes to European Commission study on indoor technologies for pathogens such as respiratory virus

EFA brought the perspective of allergy and asthma patients to a new study published by the European Commission Joint Research Centre (JRC) and DG HERA. This research brings a new policy dimension to the need to improve Indoor Air Quality and to protect vulnerable populations, such as patients from harmful exposures indoors. [Read more on EFA website.](#)



aboutasthma.org



## World Asthma Day 2024: EFA introduces AboutAsthma.org to empower asthma patients and caregivers with science-based information

With more than 30 million people in Europe living with asthma, the need for improved asthma control and information is critical. On World Asthma Day 2024, themed 'Asthma Education Empowers', EFA launched an innovative resource to support asthma patients and carers – [AboutAsthma.org](#). Now available in three new languages: French, Italian and Spanish. Visit the new [AboutAsthma.org](#) and read more [on EFA Website.](#)

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