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The Patient Perspective

November 2022



Reflections

Welcome to our November Patient Perspective newsletter!

November is almost over, so it's time to look back at EPF's activities over this month.

Our Policy team shared their updates and reflections on current and relevant advocacy issues: the European Health Data Space, the revision of the pharmaceutical legislation, the European Antibiotic Awareness Day, and the EU4Health Work Programme. The Secretariat has been busy this month with attending policy and stakeholder events: scroll down and check out the monthly roundup of speaking engagements where we talked about patient involvement.

Another highlight comes from the COMPAR-EU project. We hosted the COMPAR-EU final advocacy conference, to mark the end of the project. The two day event was held in Brussels, on the 15 & 16 November and welcomed guests from various stakeholder groups.

The "Understanding AI" series continued this month with the fourth virtual event, focused on AI in Medicines Innovation. To mark the European Antibiotic Awareness Day we spoke to the European Centre for Disease Prevention and Control and discussed the need for prudent use of antibiotics. Moreover, we published a statement on the expected 2023 Council Recommendation on antimicrobial resistance, as we believe the patient community plays an essential role in the fight against antimicrobial resistance.

We're proud to announce the official launch of the Advocacy 101 training course - an online training tailored for your patients, aged between 18 and 35, aimed to provide young patients with baseline knowledge of patient advocacy

We thank the EPF Youth Group for their monthly contribution and we are looking forward to meet them in Brussels this weekend, as they join forces for the Autumn meeting.

The Projects team is happy to share the launch of Data Saves Lives Germany. The initiative will provide regional patient organisations a dedicated hub to access the resources they need to have a positive dialogue about health data. The Patient Engagement Open Forum hosted its final event of 2022, focusing on the upcoming 2023

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Our members have been extremely busy this month. Some of them still have events coming up this month:

- EFNA: Gender Bias in the Prevention and Treatment of Neurological Conditions (29 November)
- Digestive Cancers Europe: CRC Screening Summit (30 November)
- World Duchenne Organization: The Duchenne Patient Academy 2022 (1-3 December)

Others are reflecting on their finalised projects:

- Lung Cancer Europe: Lung Cancer Awareness Month (November)
- The Greek Patients' Association: The 11th Panhellenic Patients Conference (15-16 November)
- Fertility Europe: European Fertility Week (7-13 November)
- Alzheimer Europe: Anti-Stigma Award (19 October)
- Gamian-EUROPE: Resilient Mental Health in the EU (14 November)

The EATG and EURORDIS are also sharing their updates and work, so make you read to the end and discover their wonderful initiatives.

We'll see you next month with a recap of EPF's 2022 activities!

Meanwhile, keep an eye out for the newest EPF updates on our social media channels!

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The EPF Team



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

November in review

We started November with a series of events in which our policy team participated. We brought the patient perspective to the 15th **European Public Health Conference** in Berlin and discussed the **European Health Data Space (EHDS)** and **financial protection**. Both topics are crucial when it comes to patient care. User fees and co-payments lead to financial hardship and even to patients foregoing needed care. Whereas the EHDS is an opportunity for patients to access their own health data in a common and understandable format.

We also spoke at a joint event of the Cyprus Association of Pharmaceutical R&D Companies (**KEFEA**) and the European Federation of Pharmaceutical Industries and Associations (**EFPIA**) on the forthcoming **revision of pharmaceutical legislation**, which must put patients at the centre. During the event, we argued that the new system of incentives put in place for developing new medicines needs to 1) foster access across all

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transparency of R&D costs), and 3) put forward a comprehensive definition of "unmet medical needs". A detailed EPF position on these topics is upcoming.

18 November marked the **European Antibiotic Awareness Day**, in which the EPF participates every year, and this year was no exception. We published our **five key recommendations** on the forthcoming Commission's proposal for a Council Recommendation on antimicrobial resistance (AMR), and participated in the European Centre for Disease Prevention and Control (ECDC) event on "Preventing Antimicrobial Resistance Together". This was an opportunity to recall the key role of the patient community in the fight against AMR. Patients with chronic conditions are particularly vulnerable to healthcare-associated infections and resistant bacteria, as they spend more time in healthcare facilities, sometimes requiring routine care procedures using antibiotics. AMR is complex, and no one can tackle all aspects – everyone must do their part. Patient organisations play an essential role in promoting prudent antibiotic use and advocating for patient empowerment, as research shows that shared decision-making reduces antibiotic prescribing.

The European Commission adopts the EU4Health Work Programme for 2023

On 22 November, the European Commission announced the **total budget for the EU4Health 2023 work programme**. It amounts to €735.8 million. The areas it will cover are: 1) health emergencies due to Russia's unjustified and unprovoked war against Ukraine, 2) cross-border health threats, 3) digital health developments, 4) pharmaceutical strategy for Europe, 5) the European cancer plan, 6) global health and 7) mental health. Of these, thematic areas 2, 3 and 4 are the most relevant to EPF's work. Of the total budget above, €428 million will be grants – €176 million will be procurement (both directly managed) and €131 million will be indirectly managed. In addition, **€9 million will be for operating grants, which patient organisations may consider applying for**.

Furthermore, €493 million of the total will be dedicated to major actions supporting DG SANTE's key priorities:

- EU resilience to cross-border health threats, including strengthening national surveillance systems and EU reference laboratories – €105,1 million.
- European Health Data Space for the primary and secondary use of data – €26 million.
- Pharmaceutical Strategy for Europe and implementation of health legislations, such as medical devices and health technology assessment legislation – 21,3 million.

Here are some key documents for more information on the work programme:

- Summary of the EU4Health 2023 Work Programme – available [here](#)
- Factsheet - European Health Union: EU4Health Work Programme 2023 – available [here](#)
- Commission Implementing Decision – available [here](#)
- Annex to the Commission Implementing Decision – available [here](#)



News From the Secretariat
updates from the inside

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MONTHLY ROUNDUP

Our agendas are usually very busy, as we attend various policy and stakeholder events during which we voice out the patient perspective. From this month on, we will start sharing with you some highlights from our work on patient engagement.



📍 10 November: **Anca Toma** was a speaker at a **#EURegionsWeek** side event, organised by **COCIR**, where she discussed resilient health systems in Europe and the role of medical and digital health technologies.

📍 15 November: Anca Toma spoke at the Brussels-held EU Health Summit, voicing the patients' perspective on collective efforts to integrate health at both the national and the EU level, stating that "we need to build a system from the needs up, not from the resources down. Needs and values must come first."



📍 9-12 November: **Kaisa Immonen** spoke at the European Public Health Conference in Berlin. She joined important conversations during **#EPH2022** on, i.e., financial protection policies and the European Health Data Space. As heard from her during the conference: "No one should need a dictionary or a glossary to understand their health data." She also called for patient participation in the governance of the EHDS.

📍 15-16 November: **World Health Organization (WHO)** European Centre for Primary Health Care organised a two-day hybrid event to launch the manual "BRIEF: Integrated Brief Interventions for Non-communicable Disease Risk Factors in Primary Care". Kaisa Immonen joined and spoke about self-management, patient empowerment, and shared decision-making. She made recommendations, e.g., to involve patient organisations in designing projects and healthcare professionals trainings and to include **patient** reported outcomes where possible.

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EU Patient-centric clinical trial platforms Stakeholder Event 2022 to discuss EPF's experience with early patient and community engagement for protocol design in platform trials, a session chaired by **Nicola Bedlington**.



📍 11 November: **Juan José Fernández Romero** was a speaker at "A New Era for Healthcare in Cyprus", highlighting the patients' expectations of being at the centre of the soon-to-be new pharma legislation. Juan: "A new system of incentives put in place for developing new medicines needs to foster access across all member states and ensure that new pharmaceutical products are affordable."



📍 17 November: **Julie SPONY** joined **European Centre for Disease Prevention and Control (ECDC)**'s **#EAAD** event on the complex topic of AMR. Julie: "The fight against AMR is of paramount importance for patients with chronic conditions. Patient organisations play a key role in promoting the prudent use of antibiotics and in advocating for patient empowerment."



📍 17 November: **Valentina Strammiello** attended a patient advocacy summit involving patient organisations from all over Europe and across different diseases. She discussed the contribution to legislative processes and a shared EPF experience on EU-wide legislation and meaningful patient involvement in HTA.



COMPAR-EU's Final Advocacy Conference was a success!

The European Patients' Forum hosted the COMPAR-EU Final Conference Advocacy Event, to mark the end of the project.

This advocacy conference marked the culmination of **5 years of interdisciplinary work** to identify, compare, and rank the most effective and cost-effective self-management interventions for adults in Europe living with high-priority chronic conditions. The conference took place on 15 & 16 November, 2022, in Brussels, Belgium.

It gathered approximately 70 stakeholders who exchanged experiences and expertise on self-management (SM) best practices, shared lessons learned from implementation of SM policies, and discussed how to best integrate and incorporate the project's findings across various settings. Other topics, like the **Self-Management Europe Initiative**, project lay-language materials, and self-management policy implementation practices were also feature in the programme.

Lyudmil Ninov joined a session on the Self-Management Europe initiative and patient involvement, while **Kaisa Immonen** led an important session on health literacy and the social determinants of healthcare. **Valentina Strammiello** opened and closed the event, and guided discussions.

An important conclusion? Having self-management plans and procedures in place should be strongly encouraged in order for these to become an integral part of healthcare systems across Europe.



EPF European Patients Forum presents

Understanding AI | Webinar series

WEBINAR 4:

AI in Medicines Innovation

18 NOVEMBER 2022 at 14:30, WITH:



LUIS PINHEIRO
European Medicines Agency



LIESBET GERIS
KU Leuven
University of Liège

Understanding AI Series: Webinar #4: AI in Medicines Innovation

The fourth webinar of the "Understanding AI" series covered topics linked to AI in medicines innovation, such as pre-clinical research, clinical trials, regulatory approval, and medicines safety monitoring. Our guests, together with the audience, reflected on how the use of AI could improve or accelerate medicines development, and what the implications may be for patients. The webinar recording is available [here](#).

Thank you to our speakers:

- Luis Pinheiro, senior epidemiology expert and doctor in Pharmacy at EMA
- Liesbet Geris, research professor at KU Leuven and University of Liège and director at VPH Institute

The fifth and final webinar from the "Understanding AI" series will take place on the 2 December at 14:30 CET and will examine the topic of "Patients, Healthcare Professionals, and AI". Register for the upcoming webinar [here](#).

The "Understanding AI" webinar series aims to present complex technical content in an understandable and engaging way to equip the European patient community with the necessary know how to shape and present the patient perspective on the new and increasingly important AI policy topics that are becoming an important field of policy discussions both at European and national level.

This project has been supported by the European AI Fund, a collaborative initiative of the Network of European Foundations (NEF). The sole responsibility for the project lies with the organiser(s) and the content may not necessarily reflect the positions of European AI Fund, NEF or European AI Fund's Partner Foundations.

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▶ EPISODE 8

European Antibiotic Awareness Day
with ECDC

Special Guest:
Vivian Leung, ECDC
Antimicrobial Consumption Expert

EPF European Patients Forum

ecdc EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL

PATIENTS' PODCAST

The EU Patients' Podcast Episode 8: European Antibiotic Awareness Day

"Antibiotic resistance has been around for a long time, but in recent decades it has been a growing concern because of increased opportunities for spread, increased antibiotic use, and slowed antibiotic discovery. The European Antibiotic Awareness Day (EAAD) helps bring awareness to these issues and promotes action to help antibiotics work." Vivian Leung, antimicrobial consumption expert, ECDC.

European Antibiotic Awareness Day (EAAD) is a European health initiative coordinated by the **European Centre for Disease Prevention and Control**. It provides a platform and support for national campaigns on the prudent use of antibiotics in the EU/EEA and takes place each year across Europe on 18 November.

EAAD is held in partnership with the World Antimicrobial Awareness Week, organised annually by the World Health Organization from 18 to 24 November.

To mark the European Antibiotic Awareness Day, we spoke to the **European Centre for Disease Prevention and Control**'s Vivian Leung, who discussed the growing public health issue of AMR and the need for a prudent use of antibiotics.

[Listen to the full episode here >>>](#)

COUNCIL RECOMMENDATION ON AMR

LEARN ABOUT EPF'S FIVE KEY POINTS

**EPF's statement on the expected 2023 Council Recommendation on AMR**

In 2023, the European Commission is expected to adopt a proposal for a Council Recommendation on antimicrobial resistance (AMR), including recommendations to the Member States for an effective response, with a focus on human health and a global dimension.

We believe the patient community is an essential stakeholder in the fight against antimicrobial resistance.

To mark the European Antibiotics Awareness Day, EPF published a statement with five key points on the Commission's expected adoption of a proposal for a Council Recommendation on antimicrobial resistance.

What does this entail? EPF calls for:

- ◆ Person-centred dialogue between prescribers and patients in shared decision-making
- ◆ Development of national guidelines by Member States for antibiotic treatment, in collaboration with patient organisations
- ◆ Patient organisations' involvement as active partners and multipliers in public awareness and information campaigns
- ◆ Substantial investment to develop faster and more accurate diagnostics
- ◆ Collection of accurate data on antibiotic use in different settings

Read the entire statement by following [this link >>>](#).



Launch of the 🗨️ **ADVOCACY 101** 🗨️ training course

Young patients have an important place in the EPF work. We aim to empower them, to strengthen their confidence and express their voices, so they can play their rightful role in the healthcare space. We promote better cooperation between younger and adult patients, and greater partnership between young patients, their families and carers, and the wider community. In this way, we encourage young patients to take an active role in developing policies and programmes at national and the European level.

We aim to allow more young patients to have a baseline knowledge in patient advocacy and acknowledges the need for a flexible tailored training on the topic, which participants can take at their own pace. In order to reach more young patients and provide them with easily accessible information and resources, which can remain present for their use, we believe the online programme will accommodate the needs of the young patient community.

The Advocacy 101 training course is available to participants aged between 18 and 35 and it aims to provide young patients and representatives with baseline knowledge of patient advocacy.

The training takes into account that participants are familiar with some of the foundations of patient advocacy, but is very much open to the entire young patient community!

Join the training by registering [here](#) >>>

Should you have any questions, please feel free to reach out to youthgroup@eu-patient.eu.



Updates from EPF's Youth Group

By Bhagirathi Shah

Last week, our Youth Group member Konstantina Boumaki had the opportunity to attend the **COMPAR-EU** Final Advocacy Conference in Brussels, Belgium.

Her experience, as she shared with us was:

"The **COMPAR-EU** is a Horizon2020 project ending this year, focusing on self-management interventions in four high-priority chronic conditions: heart failure, COPD, type 2 diabetes and obesity. This gives a whole new perspective and meaning to self-management, not only for the patients themselves, but for the healthcare system, too. The aim for this project is to contribute to bridging the gap between current knowledge and practice of self-management interventions.

In this conference we had the chance to see the results of many studies that took place for this project and to speak about specific topics via amazing panels that analyzed the theme and answered all the questions of the audience.

Three of the panels that I really enjoyed and made me very interested in them were:

- Social Determinants of Healthcare & Health Literacy
- Self-Management in the Digital Health Era
- Self-Management Europe Initiative & Patient Involvement

My key takeaways from this advocacy conference are:

1. The importance of patients' representation, especially young patients, in these conferences and panels, which have important discussions about guidelines development and decision-making tools.
2. The best way for a successful self-management is a combined work of the patients themselves, the healthcare professionals and up-to-date guidelines.
3. It takes a lot of time and work from different professionals and researchers to create an organized project like this, that can benefit so many patients in different ways and the importance of projects like this are significant for patients' lives

The Youth Group is very thankful to EPF for giving us, the young patients, the opportunity to attend these important events and giving us the chance to participate in these discussions."

The EPF Youth Group will be coming back together at the end of November for their Autumn meeting and to say goodbye to Bhagirathi, who joined the EPF Youth Group as its article manager in early 2022.

Here are some of Bhagirathi's thoughts on her time with the group:

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Welcoming is the first word that I would use - from the first face-to-face meeting in Brussels, being a part of the EPF Youth Group felt like being a part of a family. Meeting a group of people from different countries and different backgrounds and feeling, somehow, like we had known each other forever isn't a feeling you come across often. I feel really grateful to leave the youth group having been able to connect with such an inspiring, intelligent and kind group of people.

The next word I would use is changemakers. I've learnt a lot from how the EPF Youth Group leads with empathy and kindness but works with passion and determination to advocate for young patients and de-stigmatise key issues about living with chronic conditions - and the world has a lot to learn from them too!

If you are reading this as someone from a patient organization, I would urge you to follow EPF Youth Group's work, learn from their experience and expertise of living with chronic conditions as young adults and support and elevate their voices and work so the rest of the world can too. If you are reading this as a young person living with a health condition and want to learn about advocacy and make a change for your community, I would encourage you to join the force! And finally, if you are a fellow EPF Youth Group member, thank you for inviting me into the group with open arms and allowing me to be a part of it; I hope this is not the end!"





briefings on EPF's ongoing projects

It's official, Data Saves Lives Germany #DSLDE has finally landed!

We're delighted to announce that **Data Saves Lives Germany** #DSLDE has just launched, providing patient organisations, within the region, with a dedicated hub to access the information and materials they need to have a positive dialogue about health data with their communities.

The mission of Data Saves Lives is to build awareness and understanding of health data and how it can be used to improve the health and well-being of people in Europe. Launching in 2018, the campaign has gone from strength to strength - exploring societal questions about the uses of health data and supporting stakeholder dialogue. Data Saves Lives has grown to become an established and trusted voice among patient communities across Europe.

DSL Germany is the first offshoot of this campaign and it's fantastic to see the guiding principles being adapted to provide tailored support to patient groups across Germany. Our hope is that this is the first of many regional initiatives that go on to carry the DSL torch and bring the benefits of health data to more people.

Please show your support by following and sharing their [Twitter page](#) and [Instagram page](#) with your network.



Final Patient Engagement Open Forum event of 2022

The final virtual event of the Patient Engagement Open Forum (PEOF) took place on 22 and 23 November.

This edition featured a multi-stakeholder discussions on shared decision-making in precision medicine, patient engagement in Japan, and also featured a session on shaping PEOF's 2023 programme.

PEOF is an initiative co-led by [PFMD](#), [EUPATI](#), and the [European Patients' Forum](#). PEOF is a patient-centred environment for co-creation of solutions with and by all involved stakeholders to practice and advance patient engagement.

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November 22, 2022
11:00 to 12:30 (GMT+02:00)

JPPaC (日本
Japan) 第2回 患者
参画セミナー /
PEOF 2022 &
JPPaC PE Session

November 22, 2022
14:00 to 15:30 (GMT+02:00)

Shared clinical
decision making in
Precision Medicine

November 23, 2022
16:30 to 17:00 (GMT+02:00)

PEOF Closing
Session - celebrating
our 2022
achievements and
setting up our
ambitions for 2023



Member Focus

highlights from our member organisations

UPCOMING EVENTS FROM OUR MEMBERS



GENDER BIAS IN THE PREVENTION AND TREATMENT OF NEUROLOGICAL CONDITIONS

Under the patronage of the European Parliament and the Czech Presidency of the Council of the EU, the MEP Interest Group, coordinated by the **European Federation of Neurological Associations** (EFNA), is organising an event on **"Addressing Gender related issues and bias in the Prevention and Treatment of Neurological Conditions"** that will be hosted in the European Parliament by MEP Sirpa Pietikäinen (EPP, FI).

The event will take place on **Tuesday, 29 November from 13.00-15.00hrs** and will bring together relevant stakeholders to exchange views on key EU policy initiatives that promote health and gender equity and address the unmet needs of women with neurological conditions, with a particular focus on access to timely diagnosis and treatment.

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The banner features a light blue background with a map of Europe. Overlaid on the map are several circular icons: a person with glasses, a person with a beard, a person with a mustache, and a person with a ponytail. A central icon shows a stylized human figure with a brain. The text on the banner reads: 'SCREENING SUMMIT', 'Future Challenges & Opportunities for CRC Screening in Europe', '30 November 2022 + 9:00 - 12:30 CEST', 'A virtual event', and the 'DIGESTIVE CANCERS EUROPE' logo.

Digestive Cancers Europe: Future Challenges and Opportunities for CRC Screening in Europe

For the third year, Digestive Cancers Europe (DiCE) is hosting the CRC Screening Summit. An event to share best practices and facilitate the exchange of experiences and learnings. This year the discussion will focus on the future possibility and challenges awaiting CRC screening programs across Europe.

The upcoming online event will take place from **9H-12:30H CET** on **30 November 2022**. For more details, please contact marianna@digestivecancers.eu

[Agenda and registration link are available here >>>](#)

World Duchenne Organization: Duchenne Patient Academy 2022

Happening next week:

World Duchenne Organization partners with Duchenne Data Foundation to enhance patient advocacy and education and help drive the international advocacy agenda for people living with dystrophinopathies.

Duchenne and/or Becker MD patient advocates are invited to join WDO on December 1 – 3 at **Duchenne Patient Academy** and receive training and updates to set a strong basis for current and future global advocacy. The online training will take place online, between 15:00 – 19:00 Central European Time.

As the dystrophinopathy field seeks to empower patient representatives to advocate for better quality and quantity of life, collaborating to educate the global community is essential.

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Connecting DMD/BMD patient advocates
of the future

December 1 – 3, 2022
duchennepatientacademy.org



WORLD
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 ORGANIZATION
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DUCHENNE
 DATA FOUNDATION

MONTHLY ACTIVITIES RECAP FROM OUR MEMBERS

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Lung Cancer
Europe

Did you know?
November is
lung cancer awareness month.



Follow us!
Help us create
awareness by
re-sharing
our posts.

Calendar icons created by Smashicons - Flaticon

November: Lung Cancer Awareness Month

Lung cancer has the highest death rate of all cancers in Europe, because many people are not aware of the symptoms and risk factors associated with lung cancer.

As November marks Lung Cancer Awareness month, **Lung Cancer Europe** has launched its *Get Diagnosed 2022* campaign. The goal of this campaign is to encourage people to get checked for lung cancer, if they have any symptoms or risk factors of the disease.

The getchecked.eu website is a high-value resource available to Europeans in 17 languages—Croatian, Danish, Dutch, English, Finnish, French, German, Greek, Hungarian, Italian, Norwegian, Polish, Portuguese, Romanian, Spanish, Swedish, and Ukrainian.

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World Diabetes Day: 14th of November

Did you know that by 2030 1 in 9 people will have diabetes? Healthcare professionals are under pressure to provide the best care and protect tomorrow. How up-to-date is your knowledge?

To mark World Diabetes Day, you can access the [free diabetes training](#) to find out more about the condition.

World Diabetes Day is a global occasion on which people with diabetes, health professionals, diabetes advocates, media, the general public and government organisations unite to raise awareness of diabetes.

The **theme** for World Diabetes Day 2021-23 was **Access to Diabetes Care** and the focus of the 2022 campaign was access to diabetes education, with the slogan **"Education to protect tomorrow."**



The 11th Panhellenic Patients Conference of [Greek Patients' Association](#)

The 11th Panhellenic Patients Conference of Greek Patients' Association was held on Tuesday 15 and Wednesday 16 November 2022.

For the past eleven years, the Panhellenic Patients Conference gathers members from more than 90 Patient Associations from all over Greece, representatives of the State and the academic and scientific sector, in an effort to holistically map the main challenges in the health sector.

During the two days, the Greek Patients' Association presented for the first time two health

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Greek population, under the title "European Health Literacy". In the third section, the Greek Patients' Association presented a study on the evaluation of the role of patient representatives in health policy decision-making in Greece, with an emphasis on the health technology assessment (HTA) process. Finally, during the final section, a short documentary was screened for the first time, highlighting the true stories of chronic patients and caregivers, initiating a productive dialogue between the citizens and the State.



Rounding up European Fertility Week 2022 | Rewatch [Fertility Europe's](#) event

This year, [Fertility Europe](#) marked European Fertility Week 2022. It took place 7-13 November with the theme "25 million Journeys. One (in)fertility Challenge".

There is an estimate of 25 million people across Europe facing infertility – 25 million people... and 25 million different journeys. For each patient, this journey is different but it's a one big challenge that they all have to face and overcome. The main focus of the campaign this year [was] on raising awareness about how different people's (in)fertility journey can be depending on the country and background they come from, and demonstrating to policymakers the gaps and barriers that need to be addressed to tackle these healthcare inequalities.

To support the event, Anca Toma voiced out EPF's support to the cause: *"Equitable access to high-quality healthcare for all patients represents one of our core values at the European Patients' Forum. We believe everyone has the right to make their own fertility choices. For those who do choose to have children and require medical assistance with their fertility journey, they have the right to access fertility treatment and services efficiently and safely. Echoing this year's theme for the European Fertility Week, we would like to stress the importance of ensuring access and support to safe, equal, and efficient treatment options, for all patients throughout their chosen fertility journey, regardless of their country or background."*

Find the link to rewatch the event below and [follow](#) Fertility Europe for regular updates!
[Rewatch the event here >>>](#)



Dutch "Adoptionproject" wins Alzheimer Europe's Anti-Stigma Award at Annual Conference in Bucharest

On 19 October 2022, at the closing ceremony of the 32nd Alzheimer Europe Conference (#32AEC), the "Adoptieproject: Jong adopteert Oud" (Adoption project, young adopts old) of the Alzheimer Centrum Limburg (Maastricht, Netherlands) was announced as the winner of Alzheimer Europe's new Anti-Stigma-Award. The award, together with a cash prize of EUR 5,000 was presented by Iva Holmerová, the Treasurer of the Alzheimer Europe Foundation.

The second place award, with a cash prize of EUR 3,000, was presented to the campaign "Non ti scordare di volermi bene" (Don't forget to love me), by Federazione Alzheimer Italia, while the third place, with a cash prize of EUR 1,500, went to "Changing perceptions of dementia in the Punjabi community", by Alzheimer's Society, UK.

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Biogen, Lilly and Roche had launched a call for applications in June 2022, with the aim of recognising an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. Applications were open to individuals and organisations established in a member country of Alzheimer Europe, for projects, campaigns, films, videos, publications or books developed and/or implemented in the past three years (2019-2022).

52 applications were received and reviewed by the Jury. Promising and innovative campaigns were included on a special page on the [Alzheimer Europe website](#).

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe anti-stigma award: Alzheimer Europe Foundation, Biogen, Lilly and Roche.

The Anti-Stigma Award Jury was comprised of the following representatives:

- Alzheimer Europe: Iva Holmerová and Marco Blom
- European Working Group of People with Dementia: Chris Roberts and Bernd Heise
- Alzheimer Europe Foundation: Heike von Lützu-Hohlbein (Chairperson) and Maria do Rosário Zincke dos Reis
- Biogen: Katja Buller

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Updates from EATG

Joint Statement on the Revision of the Pharmaceutical Legislation: EATG joined its voice with EPHA and other organisations to call on the European Commission to include their considerations in the revision of the general pharmaceutical legislation.

Older people living with HIV cannot be ignored and must NOT be left behind: Overlooked in global plans to end AIDS by 2030, a growing, International Coalition of Older People with HIV (iCOPE HIV) and allies have issued a wake-up call about serious gaps in the world's HIV response.

STEP-UP: The Best Expert Course for Practical Advocacy Work in the HIV Field Available Online Soon

The production of video lessons for the online training platform STEP-UP MOOC is underway with great anticipation. The programme was developed by the European AIDS Treatment Group (EATG) in partnership with the Alliance for Public Health (APH)

EHVA Halts Clinical Trial to Test a Candidate **Therapeutic HIV Vaccine and Immunotherapy Drug**



Updates from GAMIAN-Europe

On 14th November, GAMIAN-Europe (GE) participated in the Czech EU Presidency conference entitled 'Resilient Mental Health in the EU'. GE's President Peter Keri welcomed the current momentum in relation to EU mental health action. Read the full note [here](#).

As part of the pan-European Mental Health Coalition, GAMIAN-Europe's president Peter Keri is travelling to Ankara to represent mental health patients during the second meeting in Ankara. Challenges, goals, and actions to improve mental health in Europe will be discussed. Stay tuned.



Updates from EURORDIS

2023 EURORDIS Photo Award

Don't miss out on the opportunity to win the **2023 EURORDIS Photo Award!** Hundreds of people from around the world take part in our Photo Award each year, and the next winners will be announced at our EURORDIS Black Pearl Awards in February 2023. For creative inspiration, check out our Flickr album of the many heartening entries from last year's competition, and send us your photo by 22 January 2023!

Open Academy courses on EU decision-making

To bolster your advocacy on behalf of those living with a rare condition, learn more from **EURORDIS Open Academy's latest two online courses.**

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institutions, and the second course introduces learners to the Ordinary Legislative Procedure – the general process for how legislation is adopted at the EU-level. [Learn more!](#)



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