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THE EPF European Patients Forum
PATIENT PERSPECTIVE
MARCH 2023

EDITORIAL

Dear reader,

March arrived with the much-anticipated promise of the publication of revised pharmaceutical legislation. At the beginning of the month, we met with European Commission Vice-President Margaritis Schinas and Commissioner for and Food Safety Stella Kyriakides to discuss the pharmaceutical legislation, and reiterated our recommendations for better patient engagement in the early stages of policy development, particularly by allowing patients to report shortages to the authorities.

However, we have noted the delay of the proposal; we will continue to monitor the development of the revision of the EU pharmaceutical legislation, hoping to see it published as soon as possible and serving the ones who need it the most: patients.

Then - as you may have heard already: 2023 is the year we celebrate two decades of European-wide patient advocacy. We honour the EPF community this entire year, but especially in the month to come. The crowning event (on which more details will be revealed soon) will take place at the end of April, but throughout this entire year, you will find that we celebrate this momentous milestone in various ways.

For example, we kicked off with a new podcast series in which we speak to key figures from EPF history, looking back on where we came from and looking ahead on where we are going. Scroll down to find the link to the episode in which we talk to EPF's Nicola Bedlington. Expect more essential figures to look back on their personal EPF histories as the year progresses! Also, do keep checking in with us on social media, as more insights, news, and stories related to our anniversary will be shared on a regular basis.

Here is a quick preview of what we are sharing this month:

News from the Secretariat

- The monthly Policy Review
- Details about the high-level exchange on the pharmaceutical legislation with VP Schinas and Commissioner Kyriakides;

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- The official launch of the Master in International Patient Advocacy
- Open registrations for STYPA 2023
- Welcoming our new colleague - Bianca Pop
- The monthly roundup of speaking engagements
- Reflections from the EPF Youth Group

Project updates

- The kick-off of EUCAPA
- A new episode of the Periscope Talks Podcast series
- Launch of the Patient Engagement Resource Centre
- Data Saves Lives Bootcamp on AI

Member news

- Europa Donna reporting on the "Cancer and Family Planning" conference
- Mental Health Europe is setting the stage for the European Mental Health Week
- The European Haemophilia Consortium is preparing for World Haemophilia Week
- EFNA marked Brain Awareness Week 2023
- Three news publications and other valuable updates from Alzheimer Europe
- World Duchenne Organization has reached a milestone in the promotion of the Duchenne FAIR Data
- Parkinson's Europe is asking for our support in having World Parkinson's Day observed a global health day
- Gamian Europe has released two new publications

Until next month, get regular updates by following our social media channels!

[Facebook](#) | [Twitter](#) | [LinkedIn](#) | [Anchor](#)

Happy reading!

The EPF team

POLICY CORNER

March in Review

March started with a **high-level exchange of views** between the European Public Health Alliance, the European Patients' Forum (EPF), the European Commission Vice-President Margaritis Schinas and Commissioner for Health and Food Safety Stella Kyriakides on the forthcoming review of the pharmaceutical legislation, in particular on the

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by allowing patients to report shortages to the authorities.

In addition, we continued to monitor the development of the revision of the EU pharmaceutical legislation throughout the month and noted its delay. As the pharmaceutical legislation must meet the needs of patients, those who benefit from approved medicine, we hope to see the proposal published as soon as possible.

March also saw the formal approval of **the extension of the rules on medical devices**. We hope that this three-year delay and other changes will be accompanied by measures tackling bottlenecks of access and thus ensuring a high level of readiness for the implementation of the Medical Devices Regulation. Patient organisations will play a key role in this RESPECT, as they can ensure a direct flow of information between national authorities and their grassroots communities, and channel patient concerns when unexpected problems arise.

Finally, March was an intense month for digital health, as the European Health Data Space (EHDS) is currently being discussed by the two EU co-legislators, the European Parliament and the Council of the European Union. **EPF has joined other not-for-profit organisations** in calling for a society-centred digitalization of healthcare, where public needs are prioritised over profit. The NGOs, representing patients, healthcare professionals, hospital pharmacists, payers and healthcare institutions have four demands: 1) not to support the strengthening of provisions on intellectual property rights and trade secrets; 2) to include provisions on public return on data investment; 3) to incorporate a wider range of civil society representatives into EHDS governance; 4) to allow sufficient time to develop and implement the EHDS.

SECRETARIAT NEWS



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legislation

The **European Public Health Alliance** (EPHA) and the European Patients' Forum (EPF) were invited for an exchange of views with European Commission Vice-President Margaritis Schinas and Commissioner for Health and Food Safety Stella Kyriakides on the pharmaceutical legislation, with a focus on the issue of medicine shortages.

Marco Greco, EPF President: "We had a constructive meeting: we were reassured about the central role the patient community will play in the next steps and we are confident that our proposals will be integrated in the upcoming legislation."

Following the delay of the EU revision of the pharmaceutical legislation, EPF continues to monitor its development. As this legislative package must meet the needs of patients, as those who benefit most from approved medicine, we hope to see the proposal published as soon as possible.

You can read more about this high-level exchange of views in our [news item](#).



The image is a promotional graphic for a podcast episode. It features a blue background with a white and green curved design element. On the right side, there is a portrait of Nicola Bedlington, a woman with short blonde hair, smiling. In the top right corner, there is a logo for 'THE EU PATIENTS' PODCAST' which includes a green microphone icon. The main text on the left side reads '20 YEARS OF EPF' with the EPF logo (three stylized figures) and 'European Patients Forum' below it. Underneath, it says 'LOOKING BACK WITH KEY FIGURES'. A horizontal line separates this from the name 'NICOLA BEDLINGTON' in large, bold, white letters. At the bottom left, there is a green play button icon followed by the text 'EPISODE 2'.

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We are proud to announce a new episode of the EU Patients' Podcast!

With our anniversary happening this year, we will be looking back at 20 years of successful patient advocacy in Europe, but also looking forward to the challenges ahead.

In this podcast episode we have invited Nicola Bedlington, EPF Special Advisor, to join us for a heartfelt talk on how far EPF has come in the last two decades.

"EPF is a force to be reckoned with", Nicola says. And we couldn't agree more!

So this year, we will bring you a special series of podcast episodes in which we look back on two decades of patient advocacy in Europe.

Listen to the podcast [here](#).



15 March 2023: The Master in International Patient Advocacy Management was officially launched

We are pleased to announce that this month we have great news coming in from Italy!

EPF and Cattolica University have come together to launch the International Patient Advocacy Management master programme. EPF's President, Marco Greco, joined the opening meeting. During his intervention, he underlined the significance of this premiering master's degree: "With this degree, we are able to close an important gap in the academic recognition of patient advocacy".

This study programme is the result of the partnership established between EPF and Cattolica University (Patient Advocacy Lab, of the Graduate School of Economics and Management of Healthcare Organizations (ALTEMS), of the Graduate School of Psychology Agostino Gemelli (ASAG), of the Faculty of Economics and of the Faculty of Medicine "A. Gemelli", in collaboration with EngageMinds Hub - Consumer, Food & Health Engagement Research Center of Università Cattolica and the Foundation Policlinico universitario "Agostino Gemelli" IRCCS).



Registrations are now open for **STYPA 2023**

EPF's Skills Training for Young Patient Advocates (STYPA) is back in 2023!

STYPA is an exciting and unique opportunity offering a tailored, high-quality course for young patients or representatives of young patients, providing the space to dive deeper into the important topic of medicines shortages.

Some of the course topics include:

- ◆ Why do shortages happen in the first place?
- ◆ How can patients be part of the access and shortages scene?
- ◆ What are the regulatory aspects that patients must be aware of?

This year's edition of STYPA lasts from June to November, and includes a face-to-face meeting in Riga, Latvia, in July.

If you are interested in applying, follow [this link!](#)

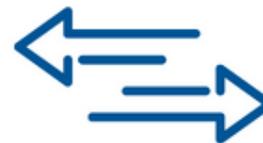
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MONTHLY ROUNDUP



Our agendas are usually very busy! We attend various policy and stakeholder events during which we voice the patient perspective.

Here's a highlight from our work on patient engagement:



As EPF joined DIA Europe 2023, EPF President Marco Greco and Director of Programmes **Valentina Strammiello** took part as speakers in various panels, covering topics that involve the European Health Data Space, data ethics, health literacy, and more.

Valentina, during the session on the EHDS: *"We need to keep in mind that without trust, the EHDS won't work. This trust may be built in through, i.e., a fit-for-purpose (opt-out) system that allows patients and citizens to decide if they do or do not want their data to be further processed and other protective mechanisms that ensure data will be used in the right ways and for the right purposes."*

On 29 March, at The Dental and Pharmaceutical Benefits Agency, TLV's NCAPR stakeholder event in Stockholm, EPF's Valentina Strammiello joined a session on the practical, financial, and ethical dimensions of orphan medicinal products (OMPs, i.e., medicines for rare diseases).

Valentina joined a panel session in which she talked about the need to bring a broader patient perspective across multiple diseases to the conversation on OMPs, unmet medical needs, and access to quality medicines. She discussed thorough and patient-centred evidence generation in OMP innovations, underlining that *"the quality of data and methods need to be reliable."*

Valentina focused also on the need to consider quality of life, to invest in methods that measure beyond the clinical status, and to make use of PROMs (patient-reported outcome measures) and PREMs (patient-reported experience measures).

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March, EPF's **Anca Toma** joined day two's panel discussion. This "Digital Deep Dive" session covered the topic of the European Health Data Space - Anca spoke alongside other panellists, emphasising the need for patient participation, transparency, an accessible opt-out system, and investing in digital literacy.

• A week before that, on the first day of the month, Anca Toma spoke as a panellist at MEP Sokol's event on the European Health Data Space, stating that: *"Ultimately, the European Health Data Space will need to facilitate an improvement of patients' lives and drive overall better health outcomes. Patients' needs and worries must be taken into consideration to ensure trust amongst the patient community and make the EHDS work for all. EPF stands for true and equitable stakeholder participation that includes and empowers patients and that gives them a seat at the table."*



• On 8 March, **Juan José Fernández Romero** spoke at the "Oath to Society" event, organised by The European Association of Hospital Pharmacists - EAHP together with European Society of Clinical Pharmacy (ESCP).

During the event, the Oath to Society initiative was discussed - Juan joined the stakeholder panel discussion, bringing the patient perspective to the topics of medicine shortages and unmet medical needs.



• On 15 March, **Julie Spony** spoke on EURACTIV's podcast with health journalists Marta Iraola and Gerardo Fortuna to dig into the implementation of the new framework for medical devices in Europe which entered into force in 2021 and has been subject to revisions and discussion over the past couple of years. More [here](#).

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Bianca-Alexandra Pop joined the team in March 2023 and she is currently working as Project Assistant at European Patients' Forum.

In her role, she contributes to all administrative tasks and provide active support to the tracking project progress.

A Romanian citizen residing in Belgium, Bianca holds a MA degree in European Law from Université Libre de Bruxelles (ULB), a Master's Degree in International Law and a Bachelor's Degree in Law from University of Strasbourg (France).

Previously, she has worked at the European Economic and Social Committee, Legal Service and before joining EPF, she has also worked as a consular officer for the Ministry of Foreign Affairs of Romania.

EU NEWS

JOINT STATEMENT ON THE EHDS

EPF  and co-signatories call for a society-centred digitalisation of healthcare

[READ MORE](#)

21 March 2023: EPF co-signed a joint statement calling for a society-centred EHDS

EPF, among a number of other not-for-profit organisations, has co-signed a joint statement to call for a society-centred digitalisation of healthcare.

In four points, the document calls for a coherent, fair, and society-centred approach to the European Health Data Space.

We ask:

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- Not to support strengthened provisions for IP rights and trade secrets.
- To include provisions on public return on data investment.
- To incorporate a wider range of civil society representatives into EHDS governance.
- To foresee sufficient time to develop and implement the EHDS.

Read the full statement [here](#).

UPDATE

ENTRY INTO FORCE OF THE EXTENSION OF THE RULES ON THE **MEDICAL DEVICES REGULATION**



is monitoring the situation closely

20 March 2023: EU granted extra time for the implementation of the Medical Devices Regulation

The European Parliament and the Council of the European Union formally approved the extension of the rules on medical devices.

Earlier this year, the Commission proposed the changes following reports of disruptions in the availability of many medical devices in the EU and repeated calls for action from stakeholders, including EPF.

The amendments introduce new deadlines for compliance with the Medical Devices Regulation (MDR) depending on the risk class of medical devices. Originally, devices on the market had to comply with the MDR by 26 May 2024. Under the proposed amendment, the deadline for high-risk devices to comply with the new rules would be extended to the end of 2027 instead of May 2024, while medium and low-risk devices would have to meet the requirements by the end of 2028.

Having originally argued for a one-year delay, EPF hopes that the three-year delay and other changes adopted this week will be accompanied by measures tackling bottlenecks of access and thus ensuring a high level of readiness for the implementation of the MDR.

Read more on this topic in [our position statement](#).



Progress of the Youth Group's Sexual Health and Well-being Project

By: Bianka Tomózer

As March being the endometriosis awareness month, I would like to share some news on a book that was released recently. The 'Together it's Easier for Women's Health Foundation', which is a Hungarian organisation, that I too am a part of, published a **book** about endometriosis called *Lost Days*. You can read professional information written by specialists, personal stories, and other useful details about this chronic condition. Also, due to the importance of the topic, **the book** contains the translated "Sexual Health and Well-being of Young People with Chronic Conditions" **article** written by Moira Tzitzika, PhD. This article was one of the main steps of the 'EPF Youth Group's' *Sexual Health and Well-being Project*.

We, on behalf of the EPF Youth Group, are

in an additional native language, therefore making it more accessible for young patients.

EndoMarch is about spreading awareness of endometriosis! If you experience painful menstruation, permanent, lasting, chronic pelvic and lower abdomen pain during menstruation or the cycle, painful urination and defecation (in severe cases, bloody urine and bloody excrement), painful sex or the difficulty of having a baby, you should visit an endometriosis specialist doctor.

We are looking forward to continuing to share our **Sexual Health and Well-being Project** on a wider range of platforms, and to further the discussion around the sexual health and well-being

PROJECTS PORTAL



EPF and partners launch EUCAPA, the European Capacity Building for Patients project, in Hall in Tirol

On March 17th, 2023, the EUCAPA kick-off meeting was held in Hall in Tirol, Austria. The meeting was attended by Flavia Topan and Ingrid Weindorfer from the [European Patients' Forum](#), along with partners from [EURORDIS](#) and [UMIT TIROL](#).

The focus of the meeting, hosted by UMIT TIROL, was to launch the European Capacity Building for Patients (EUCAPA) project. The project is designed to train patients and their representatives in Health Technology Assessment (HTA), which is the multidisciplinary and systematic process that evaluates the added value of a health technology in comparison to other existing or new ones.

Through EUCAPA, patients and their representatives will gain knowledge and skills to participate in HTA decision-making processes and advocate for equitable access to innovative treatments for rare diseases. This is an important step towards ensuring that patients have a say in the evaluation of health technologies and can advocate for their needs. EUCAPA will ensure that patients and patient organisations have the necessary knowledge of the HTA process to be meaningfully involved in HTA (both in scientific consultations and assessments), as foreseen by the new Regulation on HTA (EU) 2021/2282, which will start assessing health technologies in January 2025.

The EUCAPA project is a collaboration between EPF, EURORDIS, and UMIT TIROL, and is part of the EU4Health initiative implemented by the European Health and Digital Executive

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project will be to engage the patient community in the trainings offered by the project. Furthermore, EPF will be a key player in highlighting the importance of HTA to the patient community, while also sharing the outcomes and progress of the project with a diverse audience, that includes HTA bodies, academics, and the lay public.

At the kick-off meeting, participants discussed the project's goals, objectives, and timeline. They also shared their experiences and perspectives on patient advocacy in HTA. The meeting was a great opportunity for partners to come together and lay the foundation for a successful project that will benefit patients and their representatives across Europe.

periscope
MONTHLY TALKS

THE EU PATIENTS' PODCAST

15 March 2023

SEASON 2
EPISODE 3

about
COVID-ATLAS
Development and
Future Perspectives

with
Vladimir Urošević

belit

Periscope Monthly Talks | Season 2, Episode 2: COVID-ATLAS. Development and Future Perspectives

The new **PERISCOPE Project** Monthly Talks with **Vladimir Urošević** is live! The episode focuses on the COVID-19 ATLAS, a valuable tool that provides advanced visual analytics about aspects of the COVID-19 pandemic, with a focus on its impact on health, economy and society. Vladimir, Development Manager at Belit, will tell you all about it.

Listen to the [podcast here!](#)

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Patient Engagement
RESOURCE CENTRE

Patients as partners, not just participants.

patient-engagement.eu

EATRIS-Plus project has received funding from the European Union's Horizon 2020 Research & Innovation programme under grant agreement No 871096



Launch of the Patient Engagement Resource Centre

On 28 March 2023, **EATRIS** and **EPF**, together with affiliated partner **EATG** launched the Patient Engagement Resource Centre (PERC), a platform designed to help researchers better engage patients in their research. The PERC was developed as part of the Horizon 2020 project, **EATRIS-Plus**.

The PERC is an easy to navigate platform that offers publicly available guidance, training and practical tools to support researchers to begin engaging patients in their research. It is also a practical tool for patients to access and promote to the researchers they work with. The Centre features selected relevant public resources to help researchers understand the basics of patient engagement, and guide them through the different phases of patient engagement: from planning to conducting and evaluating, and will ultimately enable researchers to engage with patients in a meaningful way.

The PERC also features fundamentals section for researchers who are new to patient engagement as well as a stories section which includes testimonials from researchers, patients and carers who worked together.

The Patient Engagement Resource Centre is publicly available from 28 March 2023.

[Access the platform here.](#)



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Data Saves Lives Bootcamp on AI took place in Lisbon

The **Data Saves Lives** (DSL) team hosted the second **#DataSavesLives** Bootcamp boot camp in Lisbon earlier this week. DSL was joined by a delegation of 20 patient organisation ambassadors that wanting to take the first steps in embracing Artificial Intelligence for patient organisations.

The boot camp covered:

- > the potential benefits of AI in advancing healthcare and the potential risks of biases affecting data algorithms
- > the role of patient groups in influencing how AI is designed to improve the lives of their members
- > confidence to handle challenging questions concerning AI and health data from patient group members and wider stakeholders
- > an opportunity to workshop their own ideas surrounding the promotion of and education about the use of AI, with data and communications experts

Data Saves Lives was joined by expert trainers from **OneVision Health**, **EATRIS**, supporting agency **67Health**, as well as expert guest panellists and the core Data Saves Lives team to carry out the training.

Watch this space for the full boot camp report, which will be available soon!

Check out the updates, as they happened, on the **Data Saves Lives twitter**.

MEMBER FOCUS



EUROPA DONNA reporting on the "Cancer and Family Planning" event

The European Breast Cancer Coalition held a successful and well-attended policy event covering "Cancer and Family Planning" at the European Parliament in Brussels on 28th February hosted by MEP Frances Fitzgerald of the EPP Group. Stella Kyriakides, EU Commissioner for Health and Food Safety and a past president of Europa Donna, in her keynote address spoke of the recently updated EU screening recommendations and of the role Europe's Beating Cancer Plan is playing in making a difference for the lives of people suffering from cancer. The event hosted several other stakeholders, including Fedro Peccatori (Director, Fertility and Procreation Unit, Division of Gynecologic Oncology, European Institute of Oncology), Europa Donna's President Tanja Spanic and Katie Rizvi (co-founder, Youth Cancer Europe). They all underlined the human and social impact of breast cancer treatment on fertility and the important steps research has made in this field, access to which is a civil right of all European citizens.

Marzia Zambon, Europa Donna's Executive Director, summed up the speakers' position and the Coalition's asks, calling for legislation at the EU and national levels in favor of: the development of guidelines regarding availability of reproductive health procedures; requiring medical facilities to fully inform all cancer patients about the possibility of fertility preservation procedures prior to the start of active treatment; granting equal access to fertility preservation for all young oncological patients across the EU, regardless of age and financial means. She closed underlining that this can be achieved by setting up Onco-fertility Units within existing comprehensive cancer centers or cancer center networks, to address fertility concerns, family planning, contraception, and information on surrogacy and adoption.

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European Mental Health Week 2023 will take place between the 22nd and 28th of May

The awareness week is led by [Mental Health Europe](#) (MHE) and this year it will focus on mentally healthy communities.

This is the fourth edition of the pan-European awareness campaign and events will be held by organisations, public authorities, and individuals across Europe, both online and in-person. Mental Health Europe will be hosting a policy event at the European Parliament in Brussels on May 24th, in collaboration with the European Parliament Coalition for Mental Health and Wellbeing. The goal of this year's EMHW is to increase understanding and learning about mental health in our communities, schools, workplaces, and at home so that everyone can thrive and flourish at every stage of life.

Director of Mental Health Europe, Claudia Marinetti said 'The concept of European Mental Health Week builds on the long-standing global tradition of celebrating Mental Health Awareness month in May. The 2023 European Year of Skills focuses on vocational skills, education and digital skills. We have the opportunity this year to mainstream mental health across all of our communities and focus on the knowledge and skills that are needed to understand and take care of communities' mental health.'

European Mental Health Week is an awareness event to promote the mental wellbeing of millions of people in Europe, protect the rights of people with lived experience of mental health problems and raise awareness to end mental health stigma and discrimination.

If you are interested in hosting an event for European Mental Health Week, get in touch: info@mhe-sme.org



17 April 2023: World Haemophilia Day

Every year on April 17, the rare bleeding disorders community worldwide marks World Haemophilia Day. This commemoration is an opportunity to raise awareness about the needs of those affected by rare bleeding disorders. In 2023, the **European Haemophilia Consortium** (EHC) will focus 'On a Pathway Towards Healthy Ageing', a theme that is equally important for all groups of its community.

During the course of the week, different aspects of the topic will be addressed: needs assessment, multidisciplinary approach towards healthy ageing, and peer-to-peer support. The outcomes from the EHC needs assessment survey with the bleeding disorder patients aged 50+ will be published on April 17.

On April 19 join EHC's webinar on liver health to mark World Liver Day 2023. The discussion 'On a Pathway Towards Healthy Ageing: Liver Health' will feature Declan Noone (moderator), Brian O'Mahony (Ireland), Clive Smith (UK), and Prof Vincenzo La Mura (Italy). This event will have an interpretation in Russian. **Register here.**

On April 21 don't miss the presentation of the latest collaboration of the EHC with the documentary director Goran Kapetanovic – the trailer of the film 'On a Pathway Towards Healthy Ageing' accompanied by an invitation to the premiere of the film in the European Parliament on 16 June 2023.

For the full programme of the week, visit the **EHC website.**



EFNA marks Brain Awareness Week 2023

The European Federation of Neurological Associations (EFNA) announce their involvement in Global Partnerships' Brain Research panel on "Perspectives from the neurology community". Orla Galvin, Executive Director of EFNA, issued a call to action for all stakeholders, highlighting the key opportunities for action now – including the IGAP and EU NCD Initiative. She reaffirmed that mental health and neurology are so intertwined, especially for patients: *"Neurology and psychiatry are not necessarily two opposing, parallel universes; but, rather, housed within that context of brain health"*. [A full recording of the event can be watched here.](#)

This month EFNA also marked a busy Brain Awareness Week with an awareness campaign highlighting the troubling statistics relating to Female neurological conditions, rare neurology and the importance of Universal Health Coverage. [See a full overview of the campaign.](#)

Lastly, they have published their 2023 position paper on targets relating to national plans and awareness campaigns within the WHO Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP). Neurological disorders are a significant public health challenge and addressing them has become a global priority with the adoption of the IGAP in 2023. [Download the EFNA iGAP position paper from here.](#)



Updates from Alzheimer Europe

21 March 2023: Alzheimer Europe hosted a lunch debate focuses on dealing with behavioural and psychological symptoms (BPSD) in dementia care. The hybrid event was attended by MEPs and other representatives of the European Parliament, the European Commission, Health Ministries and other national policymakers, industry partners,

Three new publications: Alzheimer Europe recently launched three new publications: its **2022 Dementia in Europe Yearbook** dedicated to employment and related social protection for people with dementia and their carers; a **new set of guidelines** for the ethical and inclusive communication about/portrayal of dementia and people with dementia; and **a new guide** called "Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers".

Registrations are open for the **33rd Alzheimer Europe Conference**: the event will take place in Helsinki, Finland, from 16 to 18 October 2023, under the banner "New opportunities in dementia care, policy and research" and in collaboration with Muistiliitto, the Alzheimer Society of Finland.



World Duchenne Organization: Important milestone in promoting Duchenne FAIR DATA

World Duchenne Organization (WDO) shares an important milestone to share in their mission to promote Duchenne FAIR Data! Five rare disease registries for neuromuscular disorders have now become interoperable and provide joint answers to questions from researchers or patients.

This is a major step forward for the field of rare disease research and patient care. The collaboration was made possible under an EU-grant proposal for ERN EURO-NMD and coordinated by a FAIRification team at Radboudumc.

The registries that participated in the proof-of-concept with mock data are Duchenne Data Platform, CRAMP, DM-SCope, SMARTCARE, and the EURO-NMD registry.

It is now possible to conduct queries related to neuromuscular diseases in multiple, independent registries simultaneously without exposing sensitive patient details.

We congratulate WDO on their work in being part of this important milestone for rare disease research and patient care!

For more information, please read the [full press release](#).

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Show your support for [Parkinson's Europe!](#)

On World Parkinson's Day, Parkinson's Europe is asking people whether they would **like to see World Parkinson's Day officially recognised and observed as a global health day**. Many conditions such as Cancer are officially recognised in this way through a health day, but unfortunately Parkinson's is not.

If you would like to support the campaign to get WPD officially recognised and observed as a global health day please [click here to show your support](#).

Parkinson's Europe will be showcasing all the World Parkinson's Day events and activities taking place that we are aware of on their new [online map](#) to ensure that Parkinson's receives the attention it deserves.

If you are taking part in campaigns on World Parkinson's Day please share details on the webform on the [WPD2023 webpage](#) or email the details to info@parkinsonseurope.org.

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Updates from **GAMIAN-EUROPE**

For World Cancer Day 2023, GAMIAN-Europe, in collaboration with the European Cancer Patient Coalition (ECPC), released a comprehensive report and a testimonial video on the comorbidity of cancer and depression. Access the material [here](#).

How mental health patients can maintain good brain health? For this year's edition of Brain Awareness Week, GAMIAN-Europe launched a guide including top tips for supporting brain health. The guide was put together thanks to the support of patients and researchers. The guide is available [here](#).

GAMIAN-Europe participated in the 31st European Congress of Psychiatry that took place in Paris from 25 to 28 March. GAMIAN-Europe organised a joint symposium with EUFAMI on how to foster resilience with the involvement of mental health patients and relatives. GAMIAN also had a booth at the exhibition area where they displayed their educational material. Read more [here](#).

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