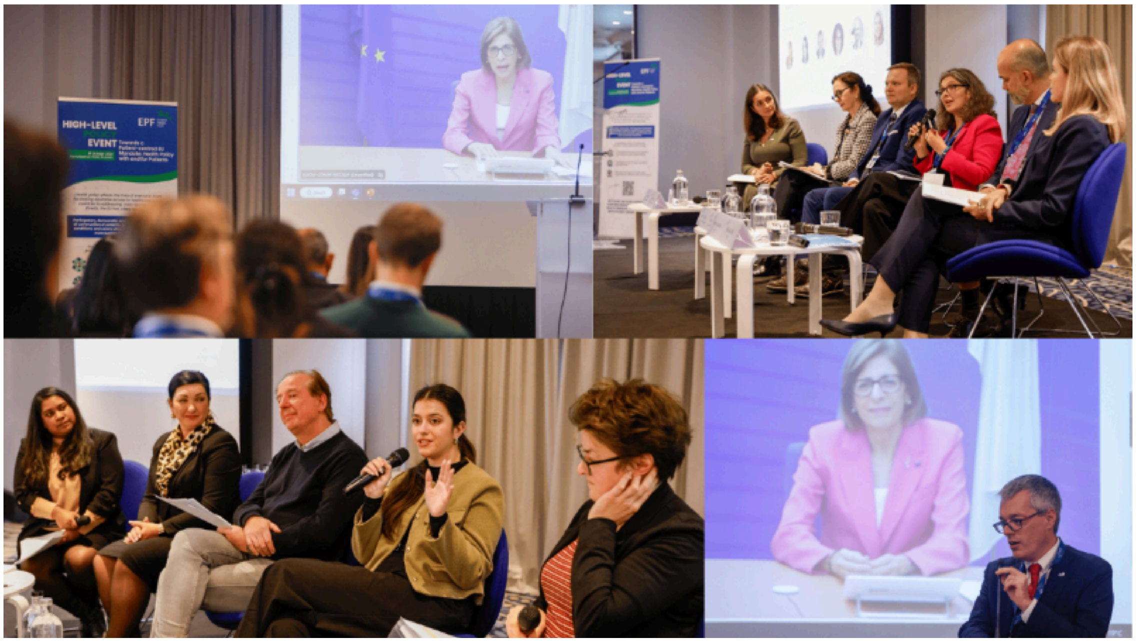
THE EPF European Patients Forum
PATIENT PERSPECTIVE
OCTOBER 2024

EDITORIAL



Towards a patient-centred EU mandate: Health policy with and for patients

The High-Level Policy Event organised by the European Patients' Forum took place on October 16th, 2024, in Brussels, Belgium. The event marked a step toward enhancing patient representation in healthcare policymaking, reaffirming the commitment to prioritise the voices of patients in every aspect of health policy development.

Opening remarks from key figures like Stella Kyriakides (European Commissioner for Health) and Dr. Hans Kluge (WHO Europe) stressed the need to include patients' lived experiences in shaping healthcare systems.

meaningful. Experts across the healthcare continuum, from research to regulation, pointed out that patient involvement needs to evolve - from merely including patients to empowering them to shape decisions. It became clear that this is moral imperative if healthcare systems are to truly serve those at their heart.

The fireside chats with Members of the European Parliament made the issue even more tangible. As different MEPs shared their perspectives, it became evident that patients' rights on paper often don't match their real-world experiences.

The final reflections of the event invited attendees to think about the future. What does it look like to truly co-create health systems with patients at the center? Dr. Natasha Azzopardi Muscat from WHO urged stakeholders to embrace this collaborative approach, while Anca Toma closed the #Vote4Patients campaign by outlining the EPF’s future vision, including a barometer to measure patient involvement across Europe.

All in all, the High-Level Policy Event was a call to rethink, redefine, and genuinely act on the principle that healthcare should be shaped by the very people it serves: patients.

SECRETARIAT NEWS

EPF WARNS AGAINST RUSHED REVISION OF THE EU MEDICAL DEVICES REGULATIONS

A rushed revision would not serve the interests of European patients, who rely on a fit-for-purpose regulatory framework for medical devices and a thorough, evidence-based policy-making process. **Read our full statement**.

EPF LAUNCHES ADVOCACY TOOLKIT ON THE REVISION OF EU PHARMACEUTICAL LEGISLATION

The toolkit collects essential resources for organisations and advocates seeking to promote a more patient-centred approach to healthcare, ensuring that the revised legislation improves access to safe, effective medicines and encourages innovation that addresses unmet medical needs. **Access the toolkit and its resources here.**

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5 years Data Saves Lives

DATA SAVES LIVES 5-YEAR ANNIVERSARY EVENT

The Data Saves Lives (DSL) 5-year Anniversary Event will take place on 26th-27th November 2024 in Brussels, Belgium.

patient community, and will facilitate discussions on multistakeholder collaboration on European Health Data Space, AI, HTA and other key health data literacy areas. **Read more details here.**

European Public Health Conference 2024

On 12 November, HaDEA will organise a workshop on '**Best practices in EU-wide projects contributing to achieving the objectives of EU Health policies**'. To attend, **register to the pre-conference**. HaDEA will also be present with a stand in the exhibition area, with information about funding opportunities managed by the Agency.

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europeanpatients'forum
Youth Group

The Mixture Emotions of Sadness and Inspiration at the Youth Group Fall Meeting 2024 in Brussels

By: Blaž Urbanč

From October 4th to 6th, we from the EPF Youth Group convened in Brussels for our annual Fall Meeting. This gathering provided an invaluable opportunity for us to align our expectations, reflect on our progress made, and set clear goals for our collective time together. Even though we meet in person twice a year on a standard basis, this time there was a difference. We can say there was a mixture of diverse emotions ranging from the feelings of sadness to feeling inspired to achieve our future goals.

We opened the meeting by discussing our shared objectives and the outcomes we aimed to achieve over the two days. This initial session was instrumental in ensuring that all of us were unified in our purpose and roles within the Fall Meeting. Our key objective within this meeting was focused on working towards the finalisation of the ongoing *Youth Involvement in Patient Organisations* project. We engaged in detailed discussions, addressed outstanding issues, and refined various aspects of our initiatives. This collaborative effort enabled us to make significant progress and ensure that each member was clear on their responsibilities moving forward. We are very much looking forward to seeing this project come together and move towards the finalisation and the launching

The most emotional moment of the meeting was especially because one of our esteemed members and former Vice President Cornelia, upon aging-out, transitioned out of the Youth Group. We took this opportunity, whilst being together in Brussels to celebrate her contributions and reflect on the meaningful time we spent together. Her departure underscored the deep connections that we have formed and highlighted the significant impact each member has on our Youth Group. We had the chance to conduct an interview with Cornelia about her time spent in the Youth Group, memories that she will cherish, and her advice to other young patient advocates.

Cornelia became a member of the Youth Group in Spring 2021, following her participation in STYPA. She added that being part of the Youth Group has provided her with several opportunities that she may not have otherwise encountered, such as involvement in events, projects, and patient advisory groups. Additionally, this experience has facilitated personal and professional growth in ways that she had not previously anticipated.

Cornelia reflected on a few memories that she will remember for a long time to come. She highlighted that the *"projects that we worked on were of course very important, but what I will remember the most will be the people and the way I felt being part of that group. Usually, it takes me a while to become comfortable in a new group but with these people everything was so natural and honest that I was relaxed around them from the very beginning. Time is our greatest asset, and so I will be forever grateful that we got the chance to spend some time together."*

When asked to provide some advice to other YG members and young patient advocates, Cornelia exposed that: *"My hope is that young people get more confident to speak their truth while also practising self-care. Advocacy work can become overwhelming because it often means to focus on what does not work well, how to communicate the issue, and how to potentially change it. And so, what I would advise to young patient advocates is to find their passion or purpose, invest time in understanding it, but in between allow time, patience, and care to disconnect and find the beauty in life. I truly believe that with batteries fully charged people tend to have clearer perspectives."*

Cornelia will be greatly missed from the EPF Youth Group and all of her countless efforts, positive spirit and energy, powerful critical thinking abilities, and her drive as a young patient advocate will never be forgotten. We are wishing her the best of luck in all that she chooses to undertake in the future!

This structured approach will help us maintain momentum and continue our work effectively. To find out more about what we are working on and collaborating in as a team, continue to follow us on our social media channels on **LinkedIn**, **Facebook**, **X** and **Instagram**.

Stay tuned to find out about all that we have been working on!

PROJECTS PORTAL

IMMUCAN

Patient Recruitment Has Been Completed

At the end of August 2024, **IMMUcan** marked the successful completion of patient recruitment, marking a significant milestone in its ongoing research initiatives. This achievement reflects years of dedicated planning, collaboration, and perseverance by the team.

Having completed this crucial step, the operational focus now shifts to finalising the collection of samples. The aim is to have all samples dispatched to the labs for analysis by this year's end. The data to be analysed include samples from 1,450 to 1,500 patients enrolled in the SPECTA study, which will significantly advance IMMUcan's research endeavors.

In addition to these samples, the project includes data from 1,100 patients from external collaborations. This will result in the development of comprehensive molecular and cellular datasets from over 2,600 cancer patients, contributing valuable insights to cancer research.

EDiHTA

EDIHTA | First Sustainability Roundtable

The First Sustainability Roundtable will take place on Monday, 4th November 2024 at 16:00 - 18:00 CET, with the participation of HTA professionals across the EU.

The roundtable will be online, in collaboration with **ASSESS-DHT**, and will focus on the progress and developments of both projects. The outcomes of this discussion will be shared with all consortium members in due course.

The link to connect is available **here**.

H2O | Patient Engagement Workshop

EPF and the **H2O** national observatory in Germany, in collaboration with **Data Saves Lives**, will be organising a Patient Engagement Workshop for patient representative organisations from Germany.

Date & Time: Monday, 4th November 2024 | 9:00 - 16:00 CET
Venue: Adina Hotel Mitte Berlin, Platz vor dem Neuen Tor 6, 10115 Berlin, Germany

The workshop will be held in German, for more information please contact EPF's Project Officer Bianca Pop, bianca.pop@eu-patient.eu.

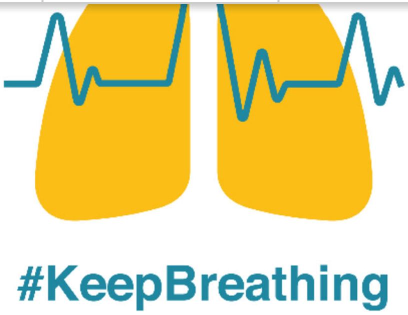
MEMBER FOCUS

“One Million Minds”: EMSP’s European Elections 2024 Campaign

The manifesto is a response to address the unmet needs faced by over 1.2 million people living with multiple sclerosis (MS) across Europe. MS manifests uniquely in each person, with unpredictable symptoms such as pain, fatigue, reduced mobility, and cognitive issues. An MS diagnosis can have a profound impact on a person’s life, disrupting their education, careers, families and life path.

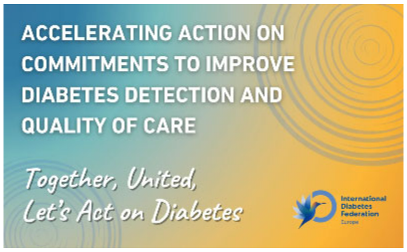
Championing the Rare: Building the Engine of an Inclusive European Health Union

EURORDIS – Rare Diseases Europe and its over 1,000 rare disease patient organisations are calling for rare diseases to be a priority of the candidates to the European Parliament, the future European Commission, and all other relevant policymakers.



Health Group's Campaign

Tackling lung health relies on early diagnosis and timely intervention, as well as ensuring access to the right treatments. It requires a multidisciplinary approach to lung health which focuses not only on symptom management but holistic care; one that also places a strong emphasis on preventative measures – including increasing health literacy, strengthening overall, lifelong health to prevent infection and promote research into the most pressing challenges.



#UnitedForDiabetes: A Campaign by IDF Europe

The campaign aims to showcase what people living with diabetes would like to see improved in the prevention, management, and care of diabetes in their respective countries.

Earlier this month, EPF joined Fertility Europe and several other organisations in the launch of the **Coalition Fertility**. This coalition unites those affected by involuntary childlessness, medical professionals, and advocates for women's rights, mental health, and reproductive rights. Its shared mission is to ensure access to fertility treatments, comprehensive sex education, and family planning support for all.

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Co-funded by the European Union