EPF European Patients Forum

European Patients' Forum

20th Anniversary Event Report

2023

European Patients Forum

EPF TURNS 20

20 years after its founding, EPF, with its growing membership, occupies a unique position as the only cross-disease umbrella patient organisation at European level, linking patient communities across the Union and beyond and driving policy issues affecting all patients.

EPF's activity throughout its 20 years of existence has seen and, indeed, triggered, profound transformation in the role of patients and patient organisations in healthcare policy and practice. EPF has a successful track record of highly effective advocacy campaigns on policy and unique multi-stakeholder collaborations that brought the patient perspective to the design of health policies over the years.

The 20th Anniversary Policy Event looked back over these two decades, explored learnings, and built on these to inform and inspire a dialogue with participants about the future direction for the patients' voice and patients' advocacy in Europe. The event resulted in a vision for what the patient movement could achieve in 10 years.

This was the largest ever structured discussion to determine a roadmap and a manifesto for the overall patient movement in Europe in a multi-stakeholder format. It aimed to bring key past and current stakeholders that have helped to shape EPF into the impactful organisation it has become, and, crucially, the next generation of young patient leaders to help carve out the future.

HIGHLIGHTS

149
on-site participants

34
guest speakers

60%
patient organisations representatives

#EPF20
1.000.000
impressions
on social media

> *Let's stay united – when we work together, we achieve incredible things.*
> **Marco Greco**
> **EPF President**

PROGRAMME OVERVIEW

The event was structured in two main parts: the morning session explored the path of patient advocacy to date drawing lessons from EPF's first 20 years: "What worked well – and what didn't? What could be improved?", from the perspective of policy, capacity building, and the ability to shape the stakeholder and research environment.

In the afternoon session, participants were presented with a draft Patient Organisations' Manifesto, and asked to reflect on the future of patient advocacy from the same three general perspectives, with an aim to reach a shared vision for the future of patient advocacy and the role of patient organisations in policy, research, and practice.

OPENING SESSION

Marco Greco, EPF President, opened the event by briefly reflecting on the 20th Anniversary milestone and setting the frame for the event. He concluded that the shared journey of refusing to accept the status quo is what helps strengthen the patient community.

This observation was fully echoed by **Marleen Sorensen** (EPF Youth Group) who expressed the importance for young patient advocates, such as herself, to have their voices heard in issues and health policies that directly impact them and their communities.

For the keynote intervention we welcomed **Maya Matthews**, who brought a message from the European Commission. Maya Matthews underlined the role of patient organisations in shaping health policy and practice, with an emphasis on the current policy developments and files, recognising EPF's contribution to the ongoing relevant debates.

Looking at the road ahead, she laid the groundwork for a wider patient involvement acknowledging that "*where there is political will, a lot can happen*".

PLENARY ONE

Looking back: Did EPF deliver on its founding promise?

Brian West, EPF Vice-president, challenged the panelists to explore and to reflect on the path EPF took from its founding 20 years ago and until the present day. The discussion illustrated the challenges overcome, the opportunities seized, the successes and difficulties encountered by EPF along the way.

He was joined on stage for this first plenary session by **Anders Olauson**, honorary EPF President, **Maria Navarro**, former EPF board member, **Robert Madelin**, former Director General for Health in the European Commission, and **Nicola Bedlington**, former EPF Secretary General.

In retrospect of the last two decades, Anders Olauson highlighted that EPF encountered an initial challenge of forging the necessary synergies to deliver on its vision. However, today, EPF stands proudly as an organisation that has undeniably fulfilled its inaugural pledge.

Asked to reflect on how the creation of EPF was perceived by national patient organisations, Maria Navarro fondly remembered the formative years of EPF, describing it as elder sibling and an example to follow. EPF not only encouraged national patient organisations to broaden their horizons but also instilled in them an idealistic perspective within their national organisation.

Robert Madelin shared his perspective on EPF, considering it an integral component of the European health ecosystem right from its inception, all thanks to its visionary team. Reflecting on his experience, he emphasised that the key lesson for the next two decades of advocacy remains unchanged: to persist and not be deterred by initial obstacles, urging us all to "*not stop at the first no.*"

Nicola Bedlington identified key elements that fuelled the growth of EPF, encompassing a collaborative approach in co-creating strategies with members, establishing a clear transparent framework, and effectively addressing the initial distrust.

PARALLEL WORKSHOPS

Looking back: What can be learned from EPF's first 20 years? What worked well - and what didn't? What could be improved?

Parallel Workshop 1: Developing effective policy and advocacy campaigns

This session explored and reflected on the lessons drawn from EPF's first 20 years with a focus on its policy advocacy work. **Juan Garcia Burgos** (Head of Stakeholder Engagement at the European Medicines Agency) and **Michele Calabró** (Director of EUREGHA, the network of European Regional and Local Health Authorities) joined **Claudia Louati** (EPF Head of Policy) in a discussion on the challenges and best practices for patient engagement. **Susanne Melin** (Bosch Health Campus) took on the role of the rapporteur and later presented the key points back to the plenary.

Parallel Workshop 2: Building capacity in the patient community

Elena Balestra (EPF Head of Governance, Membership and Capacity Building) invited **Radu Ganescu** (COPAC) and **Anastasia Semaan** (EPF Youth Group) to reflect on the key learnings that the past two decades brought for EPF's membership growth, engagement, and capacity building programmes. Radu Gănescu shared his insights from the perspective of a national patient coalition member who participated in EPF capacity building programmes through the years, while Anastasia Semaan brought her perspective as a young advocate involved in the Youth Group for several years and having participated in the Skills Training for Young Patient Advocates (STYPA). **Veronica Rubio** (Association of European Coeliac Societies) reported the key takeaways back to the plenary.

Parallel Workshop 3: Shaping the stakeholder and research environment

Stakeholder engagement and patient involvement in research projects represented focus points in EPF's activity throughout the years. **Valentina Strammiello** (EPF Director or Programmes) challenged **Paul Robinson** (MSD) and **Nicholas Brooke** (PFMD/The Synergist) to comment on the evolution of patient engagement through the years and the factors that drove companies to build patient involvement and engage in multi-stakeholder projects. The insights of the session were reported to the plenary session by **Dimitrios Athanasiou** (EPF Board Member and World Duchenne Organisation representative).

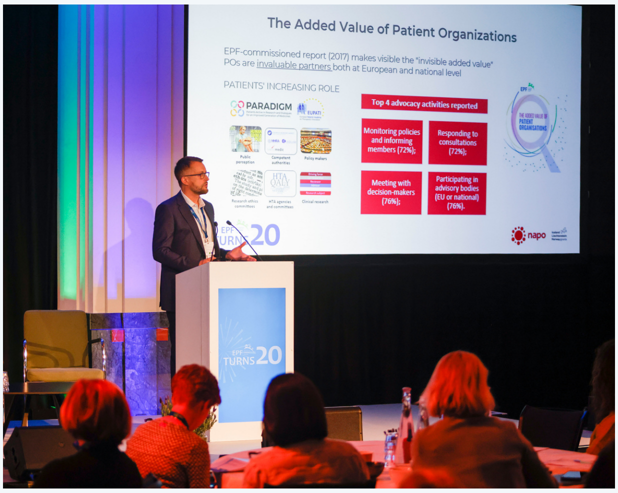
PLENARY 2

Looking back: What can be learned from EPF’s first 20 years? What worked well - and what didn’t? What could be improved?

The second plenary session of the day reunited the rapporteurs from the morning parallel sessions: **Susanne Melin** (Bosch Foundation), **Veronica Rubio** (Association of European Coeliac Societies), and **Dimitrios Athanasiou** (World Duchenne Organisation). Moderated by **Anca Toma** (EPF Executive Director), they collectively shared the key takeaways from their sessions and reflected on the impact EPF made in the past two decades in terms of advocacy work, capacity building, stakeholder engagement and patient involvement in research.

Reflecting on EPF's journey, it is essential to acknowledge the challenges and notable accomplishments it encountered along the way. Adapting, growing, and thriving within its environment, EPF has demonstrated resilience and dedication. The role of EPF's membership and partnerships was crucial in shaping its current standing. These alliances have played a pivotal role in pushing EPF forward and expanding its reach.

The morning parallel sessions showed that in the last two decades, civil society has steadily increased its impact and its reach. As we project into the future, it is crucial to recognise the patient community as an equally important stakeholder alongside others. Working together on a common goal fosters trust among participants, which extends beyond the immediate outcomes. A fundamental aspect of enhancing patient engagement is identifying the community involved. By understanding the specific needs that require attention, EPF has shown a track record of effectively addressing and fulfilling them.



PLENARY 3

The third plenary session welcomed **Robert Hejzák** (Czech National Association of Patient Organisations – NAPO) who spoke about the added value of patient organisations and the experience of patient organisations in other EU member states. Drawing from these learnings, he presented the call for action, drafted in cooperation with EPF.

The key principles emerging from the discussions for strengthening patient organisations' role and contribution to policy making are political will, consultation and partnership, operational involvement, funding and sustainability.

These principles aim to promote and enhance public participation in the design, implementation, and evaluation of national and regional health policies. They emphasise the importance of involving patient organisations and respecting key principles such as solidarity, trust, sustainability, empowerment, and accountability. The principles call for initiating a dialogue with patient organisations to identify appropriate channels for meaningful participation and implementing existing tools to support their involvement. Patient organisations should also be included in the development of all sector policies related to public health and quality of life. The principles advocate for formalising participatory processes and diversifying opportunities for participation to ensure truly participatory and democratic involvement of patient organisations.

PARALLEL WORKSHOPS

Looking forward: What ambition for the patient movement in the next 10 years? Where do we want to get to and how do we get there?

Parallel Workshop 4: Developing effective policy and advocacy campaigns

Nathalie Moll (EPFIA) and **Yannis Natsis** (European Social Insurance Platform) joined **Anca Toma** for the first parallel session of the afternoon, to contribute to a reflection on the future of patient advocacy. Drawing on EPFIA's history of engaging with patient organisations, Nathalie Moll saw patient involvement in all levels of decision making as key for solving the upcoming challenges for EU health policy making. Looking at the future challenges facing healthcare systems, Yannis Natsis commented that patient involvement will be crucial in making sure health systems can adapt to new societal realities. **Milka Sokolovic** (EPHA) took the role of the rapporteur, and presented the key points of the parallel session back to the plenary.

Parallel Workshop 5: Building capacity in the patient community

The session focused on the capacity building aspects and the skills that patient advocacy organisations will need to build to perform their representation role for the communities they represent. **Konstantina Boumaki** (EPF Youth Group) commented on how the young generation of patient leaders can be best trained and upskilled to further patient involvement at all levels of health policy and practice, drawing from her own experience as a young patient advocate. **Annabel Seebohm** (COCIR) was invited to reflect on how her sector interacts with the patient community, and what knowledge would be needed from patients in the future to continue interacting with, and impacting patient engagement in the digital medical devices industry. **Ilaria Leggeri** (EIT Health) moderated the session, while **Maria Dutarte** (EUPATI) reported the key takeaways.

Parallel Workshop 6: Shaping the stakeholder and research environment

Anke Peggy Holtorf (HTAi) moderated the third parallel workshop, focused on EPF's contribution on furthering patient advocacy in the coming decade and strengthening patient involvement in policy, research and practice. **Anne-Charlotte Fauvel** (EATRIS) noted the importance of activating management teams and funders, to facilitate meaningful patient involvement. **Laura Savini** (European Haemofilia Consortium) pointed out the need for the research and development mindset to shift, in order to ease the meaningful participation of patients in reporting real world evidence. **Neil Johnson** (Global Heart Hub) provided the support for reporting back to the plenary.

PLENARY 4

Reporting back from the parallel workshops, **Milka Sokolovic**, **Maria Dutarte**, and **Neil Johnson**, together with moderator **Anca Toma**, engaged the audience in a purposeful dialogue concerning the future path of patient advocacy.

During the workshops, participants identified several key learnings that can guide EPF's endeavors. To achieve a sustainable and significant impact on policy, research, and practice, EPF needs to further provide essential support and resources to patient advocacy organisations. This includes offering capacity-building initiatives, facilitating networking opportunities, and providing guidance on effective advocacy strategies.

The ambition for the next 10 years is not only inspirational, but also achievable. In Milka Sokolovic's words, being louder in our advocacy efforts is to demand what is rightfully ours. Looking ahead, EPF envisions a future where patient-centered health policy is the norm, ensuring that patients are active partners in decision-making processes.

CLOSING SESSION

Presentation of the Patient Organisations' Manifesto

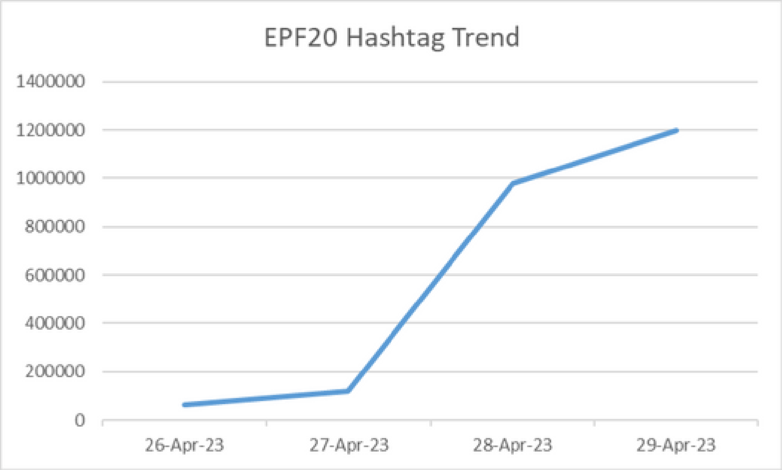
As we approached the end of the day, **Konstantina Boumaki,** representing a new generation of patient advocates, delivered the final form of the Patient Organisations' Manifesto – a collaborative effort that included the feedback received throughout the afternoon sessions.

The expectations put forth by patient organisations for national governments and EU institutions revolve around recognising the value and importance of involving them in policy, research, and practice.

By tapping into patients' unique expertise and lived experience, structured patient engagement can lead to better alignment with patient needs, improved information and adherence, increased awareness and trust, and reduced costs for both patients and healthcare systems.

Marco Greco, EPF President, closed the event with a inspirational address. By working together, he emphasised, patient organisations can reach ambitious goals: *"Let's stay united – when we work together, we achieve incredible things."*

#EPF20 CAMPAIGN



#EPF20

#20YearsStrong
#FutureofPatientAdvocacy

The #EPF20 social media campaign was focused on celebrating the 20th anniversary of EPF by highlighting accomplishments over the past two decades and by showcasing partnerships with our members and other stakeholders. The campaign was launched on April 21st and encouraged participants to share their stories and memories of EPF using the hashtags #EPF20, #20YearsStrong and #FutureofPatientAdvocacy.

The Communications team followed the #EPF20 using a tracking and reporting tool throughout the duration of the campaign. We observed the peak of the campaign on the 28th of April, during the event, as guests, attendees, and members shared messages across all social platforms using the EPF20 hashtag.

With over 250 posts, on EPF's own social media channels, but also on member organisations' and partners' channels, the #EPF20 surpassed the 1.000.000 impressions milestone, across all platforms.

@arellanomanu
17 hours ago

@EFA_Patients
18 hours ago

@milkasklvc
19 hours ago

ıca Toma • 1st
blic health advocacy

sAgo I was a poli-sci student working as an assi
iator with the EU. How incredibly lucky I was, aft
ortunity, to end up working in EU affairs, to buil

FH Europe - The European FH Patient Network
3K followers
1w •

#EPF20 first impressions from the anniversary meeting of the European Patients' Forum in Brussels.
...see more

interests of #PLHIV
represented on your board via
our member and EPF Vice...

@EATGx
2 hours ago

EPF European Patients Forum

THANK YOU, SPONSORS!

20

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