THE EPF European Patients Forum PATIENT PERSPECTIVE

MAY 2023

EDITORIAL

Dear reader,

Welcome to the May issue of the Patient Perspective!

As you know, during this year's Annual General Meeting, we welcomed two associate members, while the **National Association of Patients' Organizations** (NAPO), after joining last year as an associate member, has now become a full member, after meeting all the requirements and receiving a positive vote from the EPF membership. We now invite you to get to know our two new associate members: Sjögren Europe and the Latvian Network of Patient Organizations.

In news from the Secretariat, we welcomed the publication of the Commission's proposal for a Council Recommendation on stepping up EU actions to combat antimicrobial resistance (AMR) in a One Health approach. This month, as you could see on our social media channels, we joined the **European Public Health Association** in marking the European Public Health Week 2023, with a special focus on antimicrobial resistance.

The EPF Youth Group shares some reflections from their participation at the 20th Anniversary event and the AGM. *"Being able to feel included and part of the EPF community in this way was a very heartwarming experience and one that on behalf of the Youth Group we heavily value", says Anastasia Semaan, YG President. In turn, we would like to thank the young patient community for taking on the responsibility of carrying EPF's mission further in the years to come.*

It has been a busy month for our projects, with some important milestones being reached and with exciting upcoming events.

of the parliamentary parties.

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Happy reading!

The EPF team

WELCOME TO OUR NEW MEMBERS

A WARM WELCOME TO NEW MEMBERS

During our Annual General Meeting this April, we had the pleasure of welcoming two new associate members on board: **Sjögren Europe** and the **Latvian Network of Patient Organizations**, while one associate member - the **National Association of Patients' Organizations** - was voted in as a full member.

In this issue of the Patient Perspective, we invited Sjögren Europe and the Latvian Network of Patient Organizations to tell us more about their work.

Who is Sjögren Europe and what does your organisation do?
The main objectives of Sjögren Europe are to empower national organisations, to assist, promote and encourage the improvement of knowledge about Sjögren and raise awareness about the disease and all its aspects among national Sjögren and health-related organisations, patients, members of the health, welfare and medical professions, governmental bodies, pharmaceutical companies and the public, to work to achieve an optimal care system, medical treatment and follow-up, psychosocial support and quality of life for all the Sjögren patients in Europe. We want to be involved in decisions, programs, strategies etc. which affect patients with Sjögren in Europe and foster and/or undertake surveys and research projects related to the disease

Who is the Latvian Network of Patient Organizations (LPOT) and what does your organisation do?

Unlike other non-profit organizations in the field of health, patient organizations are civic society organizations that are run for the patients, by the patients, and about the patients. LPOT is created for all patient organizations in Latvia to have a common platform to cooperate and amplify their voices. The network does not substitute the work carried out by each patient group, but instead – supports and supplements each other, as well as creates new bonds with other stakeholders.
The goal of the Latvian Network of Patient Organizations is to improve the quality of life and access to health care services for all patients, regardless of different diagnoses and health conditions, to

What can your organisation bring to EPF?
Sjögren Europe can bring to EPF knowledge about Sjögren and the perspectives of Sjögren's patients. We can also be your ambassador to our members, by distributing information about EPF, and trying to engage our members and/or patient experts/PRPs or PAGs in EPF's various activities.

What does your organisation want out of its EPF membership?
We believe that working together and be a partner to all stakeholders of the sector, we shall build a better future for patients with Sjögren.

What is the biggest misconception about your disease?
The biggest misconception about Sjögren is the severity of this systemic disease. It can affect every single system of the body and differs from person to person.

Interview with Katy Antonopoulou from Sjögren Europe

information circulation and cooperation with each stakeholder and decision maker.

What can your organisation bring to EPF?
LPOT will help you distribute information about EPF, its members and initiatives in Latvia and engage patient experts from Latvia in various activities.

What does your organisation want out of its EPF membership?
LPOT wants to bring Latvian perspective to the work you do, be your partner, participate in various events and activities. As EPF members, we would seek your help and guidance for building capacity of patient experts in Latvia and raise awareness of important work and role that patients within patient organizations and in general have in modern society.

Interview with Baiba Ziemele from LPOT

SECRETARIAT NEWS

STEPPING UP THE INVOLVEMENT OF THE PATIENT COMMUNITY IN THE FIGHT AGAINST AMR

This month, we welcomed the publication of the Commission's proposal for a Council

We hope to see more meaningful involvement of the patient community in the proposed Recommendation, so we call on Member States to ensure that the patient perspective is considered in three key areas:

➡️ Improving health literacy
➡️ Raising awareness of AMR in collaboration with patient organisations
➡️ Including patients in incentives for innovation and access to antimicrobials

Read our entire position here

A Reflection on the Annual General Meeting 2023 and EPF's 20th Anniversary

By: Anastasia Semaan, Konstantina Boumaki and Marleen Sorensen

At the end of April, we on behalf of the European Patients' Forum Youth Group attended both the Annual General Meeting of EPF and their 20th Anniversary Event. Throughout both events, we as young patients held an active role, where we participated and had opportunities to represent the young patient perspective. The 20th Anniversary began with an Opening Introduction with Marco Greco welcoming everyone and highlighting the

Throughout being at the AGM and especially it being the first AGM in person since the Covid-19 Global Pandemic, there were many networking opportunities and conversations that took place, and as a group we are much looking forward to seeing where such networking continues in action in the future.

Here is what our Youth Group attendees have to say about these events:

Speech by our youth group (YG) member Marleen Sorensen.

She represented the young patient voice and recognised the values of embedding such on a daily basis. Throughout the 20th Anniversary within the plenary sessions and during the workshop sessions, as youth group members we not only attended such sessions, but also held an active role by presenting our young patient perspective and the role of our youth group within societal progress. Within these sessions there were strong, thought-provoking, and contradictory discussions that took place, but this only brought to the surface the importance of actively listening to each other's point of views.

During the Annual General Meeting (AGM), as the President of the Youth Group, I found it incredibly insightful to gain a further understanding of the accomplishments of EPF over the last year, as well as a deeper view on how EPF has been running financially etc. Furthermore, this AGM was incredibly special as new members were elected to join the EPF Board, and this included electing someone new to fulfill the role of the Youth Group Representative.

We are incredibly proud to announce that Konstantina Boumaki has been elected to become our Youth Group Board Representative and now holds a voting position on the EPF board. We wish her the best of luck and are very much looking forward to continuing to have the young patient voice prominent on such a level. During the AGM we also had the opportunity to reflect on our accomplishments from the last year, and additionally to present what our plans are for the next year to the EPF members who were in attendance.

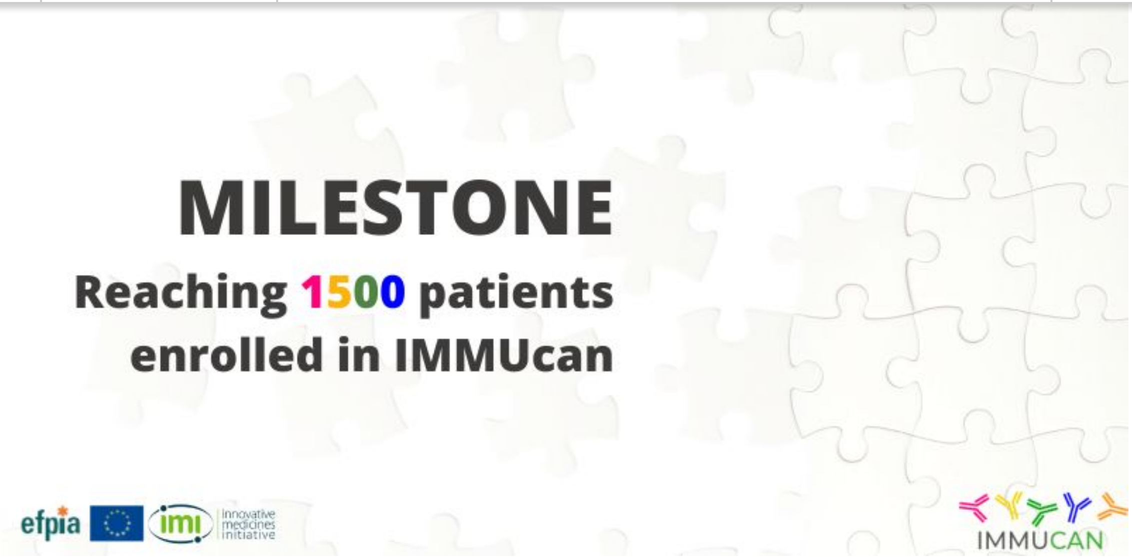
participate in the EPF's 20th anniversary event. I enjoyed learning about the history of EPF, and I am excited to see what they accomplish over the next 20 years." - Marleen Sorensen

"*It was an amazing experience participating in EPF's 20th anniversary event and we, as young patient advocates, feel so honored to be included and share our thoughts and values during the event. We've learned so much about the past of EPF and we can't wait to see what the future will bring and how the young patients can contribute in these next steps. I feel very distinguished to be elected as an EPF Board Member and very responsible for this commitment in this position to represent the young patients' voice!*" - Konstantina Boumaki

"*Being able to feel included and part of the EPF community in this way was a very heartwarming experience and one that on behalf of the Youth Group we heavily value. We look forward to continuing to celebrate all of EPF's achievements and highlights during the next year, and to continue to maintain our strong unity and collaboration. We hope to continue to spread our message that the young patient voice and perspective is not one to only be 'added on' or 'checked off', but wholeheartedly embedded, included, utilised and acknowledged.*" - Anastasia Semaan

Thank you and Congratulations to EPF for a Wonderful AGM and 20th Anniversary and Best of Luck to the team for upcoming years and events ahead!

PROJECTS PORTAL



IMMUCAN ANNOUNCES THE 1500 PATIENTS MILESTONE

The project consortium announces that they have reached 1500 patients enrolled in IMMUcan. The project thanks the SPECTA community of clinicians and patients for their contribution to this important milestone for cancer research.

This was made possible thanks to the prospective recruitment of patients in the SPECTA platform, combined with collaborations developed with external trials: EORTC-1559 Upstream, Bordet-Synergy, UZL-Dutrelasco.

High enrolment numbers are very important for us as we aim for a deeper understanding of how the immune system and cancer cells interact on the molecular level. The clinical data and samples analysed from patients with colorectal, lung, head and neck, breast, gastric, and renal cancers help us in building a detailed overview of the tumour microenvironment and the impact of treatments.

Interested to learn more about SPECTA and IMMUcan? Keep reading on **spectaplatform.org** and on the IMMUcan website.

Project Spotlight | **EU-PEARL: the project comes to an end**

EU-PEARL has actively worked together with patients and community representatives to co-design the platform trial framework, thus ensuring that the factors that matter most to patients are embedded within the design of the trial.

The project promotes a new paradigm of collaborative platform trials, where patients play a bigger part in trial designs and outcomes, whilst they increase their opportunities to gain speedier access to more effective and personalized techniques and treatments. Thus, the ensuing EU-PEARL framework aims to support better health and care for patients.

The epitome of this patient-centric approach is the Patient Engagement Platform, which allows you to see informational resources created and/or compiled by EU-PEARL to support patient-centric platform trials just by clicking on a stakeholder group.

Explore the platform **here.**

LABEL2ENABLE at HIMSS23Europe

Valentina Strammiello will speak at "Person-Enabled Care in Action: Engaging Patients in the Digital Experience" at HIMSS23Europe for Label2Enable.

When: June 8 13:45-14:35
Where: Lisboa Congress Centre (CCL), Auditorium 2

Find out more **information here.**
See the whole agenda on the **HIMSS website**.

MEMBER FOCUS

LUPUS EUROPE launched the **LUPUS100 website**

People with lupus often turn to the internet to find information about their disease. However, quality of information on the internet is often unreliable, which can lead to confusion, anxiety, and incorrect actions. Lupus Europe experience is that many people in Europe either do not speak English or do not speak English at the level required to understand complex medical concepts. Lupus patients need access to quality information about lupus. To address these issues, Lupus Europe has launched **lupus100.org** a multi-lingual website that provides access to reliable and accurate information about lupus in many European languages!

The multi-lingual Lupus100 website launched on World Lupus Day, with 11 languages currently available: English, Danish, German, Spanish, French, Italian, Dutch, Romanian, Finnish, Greek and Ukrainian. Many more languages will be added in the coming months with the aim of providing lupus100 in the native languages of more than 95% of the European population.

The Lupus100 website is a completely free resource that contains valid information about lupus and has been written in a patient-friendly language. Lupus patients can access Lupus100 in their native language, eliminating a significant barrier to accessing quality information about lupus.

Open Letter to the Leaders of the Parliamentary Parties

Athens, May 11, 2023

The **Greek Patients' Association** greets the democratic dialogue between the political parties and watched the debate of the political party leaders that took place on May 10th 2023.

Recognizing the difficult task of journalists, and while every question asked was important, we were surprised that in the context of the thematic section "Health, Education and the Social State", no questions were asked about your vision and commitments regarding the reconstruction of the National Health System, an issue of crucial importance for citizens and the economy in general.

The pandemic of COVID-19, the biggest health challenge of the last 100 years, highlighted

Health System, which, 40 years after its establishment, requires immediate reconstruction in order not to collapse.

If the Health System is a priority for your party, the Greek Patients' Association asks you what your commitment is regarding the following questions, either as the elected party or as an opposition party after the elections:

1. Given the deviation of Greece from the average public funding in Health and the programmatic announcements of most parties to converge or exceed the European average, you are asked the following:

a) What is your commitment regarding the increase in stated funding for Health for the year 2024 (plus the funding of the Recovery and Resilience Fund).

b) In case that the economy does not secure a budget surplus in 2023, where will you secure this increase from?

2. A decisive prerequisite for the reconstruction of the National Health System is a new Health Map with the necessary logistical infrastructure and decently compensated health and administrative staff. What are the intended reforms for the following:

a) the reordering of the existing health map regardless of "political costs", based on the health needs of the population and utilizing modern technologies to balance regional disparities

b) the development of merit-based management and accountability systems with modern reward models linked to productivity and quality of care

c) the measurement and evaluation of quality and effectiveness by recipients of health services?

Are you willing to discuss all health partners to achieve the necessary scientific, political and social consensus?

3. What is your strategy for transparency and the use of both digital tools and health data to achieve democracy in health, rationalize spending and access to innovation?

The Greek Patients' Association is committed to continue to submit documented, realistic and cost-effective proposals aimed at a sustainable Health System that ensures quality and access to health for all.

The Board of Directors of the Patients' Association of Greece

contact us **visit our website**

view this email in your browser

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