



The Patient Perspective

February 2020 edition

With the new decade now in full swing, we figured it was time to give our monthly newsletter a bit of a refresh. Following an action-packed month of events, programmes, policy briefings, we are happy to present our upgraded newsletter, *The Patient Perspective*.

This month, we take a look back at some interesting member-led events and initiatives and focus on the need for the involvement of patient organisations in continuing education and the Commission's Digital Health Plan in our Policy & Advocacy Corner. We're extremely happy to have a Guest Feature from Ann Marie Borg of the European Public Health Alliance (EPHA) as well.

We have a few announcements regarding internal arrivals and departures plus we have added a list of upcoming events for March so feel free to update your calendars. We kindly encourage you to take the time to participate in some of our EU and member-led surveys at the end.

Happy Reading and enjoy your weekend!

News from the Secretariat

updates from the inside

EPF Announces Departure of Usman Khan as Executive Director

We would like to inform you of the departure of our Executive Director, Dr. Usman Khan. Having worked under an annual service agreement through his consultancy company Modus Europe, the EPF Board and Dr. Khan

thank Dr. Khan for his valuable contribution to the organisation and wish him the best of success as he continues his consultancy and academic work.

[Full Statement](#)



ImmUniverse

EPF & Project ImmUniverse: Transforming Diagnosis and Therapy of Immune-Mediated Diseases

ImmUniverse has been formed as a European trans-disciplinary consortium to tackle unmet needs and pave the way towards a truly personalised disease understanding of two different IMIDs: **Ulcerative Colitis and Atopic Dermatitis**.

[Read Full Press Release](#)

Policy & Advocacy Corner

discussing the most relevant patient-centred policy and advocacy issues

Exploring Patient Involvement in Continuing Professional Education

Patient involvement in the education of healthcare professionals – including medical doctors – was identified in 2014 as a priority to ensure that the future European health workforce have the skills, knowledge and attitudes to practice truly person-centred care. Last year, EPF was invited to join the BioMed Alliance permanent committee on Continuing Medical Education (CME) and Continuing Professional Development (CPD) to contribute a patient perspective.

On the Commission's Digital Health Plan

On February 19, the European Commission announced its plans to shape Europe's digital future, including digital health. Digitalisation is often cited as a solution towards sustainability of healthcare, in a context of growing healthcare demand due to demographic change, and shortages of healthcare professionals. While digitalisation holds many promises for EU patients and healthcare systems, EPF calls on the EU institutions and Member States to foster patient-centred development of digital health, with equity of access, patient safety, and quality of care as key pillars.

[Read Full Article](#)

Member Focus

highlights from our member organisations



Lung Cancer Europe (LuCE)

To mark World Cancer Day, LuCE released its latest **position paper** which identifies disparities and challenges in access to lung cancer diagnostics and treatment across Europe.

[Learn More](#)

MARCH

Calendar of Events

February 29

[Rare Disease Day](#)

March 1

Zero Discrimination Day

March 3

World Hearing Day

[The Patient Safety](#)

[Policy summit](#)

European Kidney Forum

March 4

[WHO's 'The Future of Digital Health Systems 2.0'](#)

[EFPIA Webinar on the](#)

[Coronavirus call](#)

[Digestive Cancers](#)

[Europe: Beautiful Lives](#)

March 8

International Women's Day



EURORDIS Rare Disease Day

29 February 2020 will be the 13th **International Rare Disease Day** coordinated by EURORDIS. On and around this day hundreds of patient organisations from countries and regions all over the world will hold awareness-raising activities

Get Involved



GAMIAN & Mental Health Europe's 'Shaping a Future EU Mental Health Strategy'

GAMIAN and MHE-SME held a joint meeting in the European Parliament, addressing the urgent need to put in place a comprehensive and proactive **EU Mental Health Strategy**.

Read their Statement

Deadline for EPF Youth Group Registration

March 16-22
Brain Awareness Week 2020

March 21
World Tuberculosis Day

March 24
European Parliament Informal Carers' Interest Group

March 28-29
EPF's Empowering Leadership & Positive Organisational Governance Module

March 30
World Bipolar Day



EPF would like to welcome two new members to its Secretariat.



Dante Di Iulio is EPF's new Communications Manager. He has an extensive



Our Youth Group member Jana Popova is the winner of the EURORDIS Young Patient Advocate Award.

EURORDIS Black Pearl Awards 2020

The event was organised to celebrate the work of decision makers, scientists, patients advocates and volunteers. This was a unique opportunity to exchange experiences and establish cooperation with important figures in the field of rare diseases. Congratulations to all of the winners!

[Watch the 2020 Ceremony](#)

campaigns for public and private sector organisations across various sectors in North America, Africa and Asia.



Isabelle Manneh joins our Policy Team as Vaccination Initiatives Coordinator.

Isabelle is a registered Pharmacist (RPh), and a certified Public Health Professional (CPH,) with a passion for community immobilization specializing in EU Health Policy & Project Management. She is a EUPATI Alumni and has worked very closely with the EPF Nutrition Working Group, the EPF Project Team in Patient Involvement in Research, and the EF Policy Team on Cross Border Healthcare, HTA & Data protection.

Guest Feature

by Ann Marie Borg, European Public Health Alliance (EPHA)



MEP Interest Group on Antimicrobial Resistance Official Launch

At the high-level launch of the MEP interest group on AMR which took place on 19 February 2020 at the European Parliament, a packed room of key actors committed to tackling **Antimicrobial Resistance (AMR)** from a One Health approach, agreed that everyone must do their part in fighting AMR. The new MEP Interest Group, composed of fifteen MEPs from across the political spectrum, is the only AMR-dedicated group in the European Parliament. Driven by a comprehensive strategic work programme guiding its activities for the parliamentary term 2019-2024, the MEPs fight AMR Group will use its leverage to ensure that AMR stays high on the European policy and political agenda and effective actions are taken at European, national and local level to combat this global health threat.

[Read Full Article](#)

Get Involved

initiatives, stories and events to join and share in EU healthcare



Become Part of the Young Patient Community!

The aim of our Youth Group is to become the reference group of the young patient community and its role is to communicate the needs and expectations of young patients to EPF and its members. If you know anyone who may be interested, please encourage them to apply. **Deadline to apply is March 15.**

Apply Now!

The image features the HIVACAR logo in red, with a stylized DNA double helix integrated into the 'H'. The background is a close-up of a blue, textured surface, possibly a virus particle, with a red sphere in the center. The text is overlaid on this background.

HIVACAR

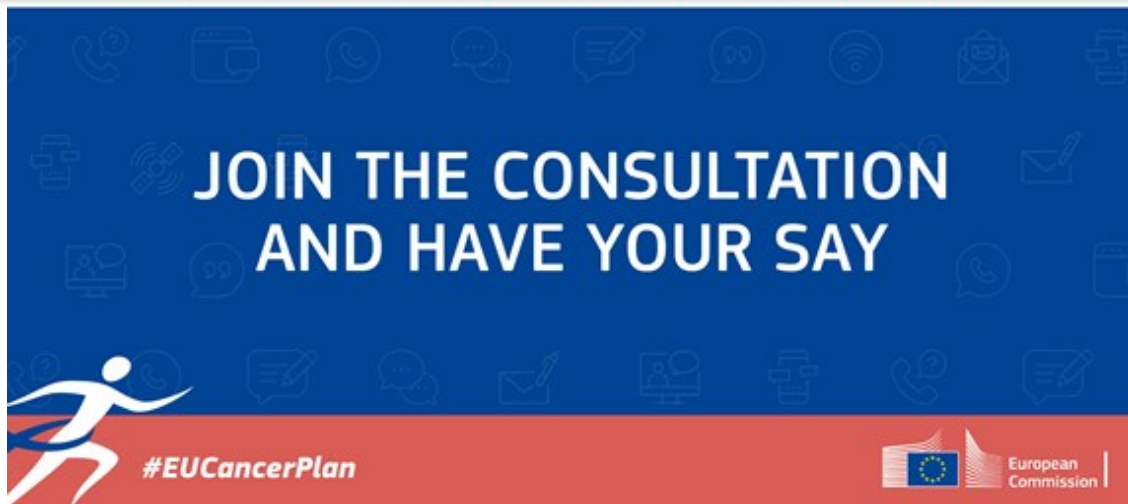
A COMMUNITY-LED PSYCHOSOCIAL SURVEY ABOUT HIV REMISSION

European AIDS Treatment Group (EATG) Survey

One of the objectives of the HIVACAR project is conducting a survey seeking to assess, **from the participants' perspective**, the impact of achieving a remission from the HIV infection on people's own well-being and on the society at large.

If you are part of or familiar with the HIV community and live in Belgium, Denmark, France or Spain, help our member the European AIDS Treatment Group (EATG) gain better understanding about HIV remission by filling out the survey!

[Take the Survey](#)



Public consultation on the Commission's Europe's Beating Cancer Plan

The European Commission wants to place European citizens at the centre of its [Europe's Beating Cancer Plan](#). Therefore, they have developed a public consultation (via online survey) to hear your views.

As a European-level umbrella organisation whose membership not only includes several specific cancer organisations but also national coalitions that comprise cancer, EPF wholeheartedly agrees that cancer patients' views and knowledge should be at the heart of the EU's new plan.

EPF will be consulting its membership shortly on a coordinated response. Meanwhile we encourage our members to also respond individually via the online survey. **Please share your experience and show why the patients' voice should play a strong role in driving better health in Europe.**

The online survey is out until **7 May, 2020**

[Take the Survey](#)

The Last Word

"When 'I' is replaced by 'WE', even illness becomes wellness"

- Malcolm X



Copyright © 2020 European Patients Forum, All rights reserved.

You are receiving this email because you opted in at our website www.eu-patient.eu

Our mailing address is:
European Patients' Forum
Chaussée d'Etterbeek, 180
Brussels 1000
Belgium

[Add us to your address book](#)

Want to change how you receive these emails?
You can [update your preferences](#) or [unsubscribe from this list](#).

This email was sent to <<Email Address>>
[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)
European Patients' Forum · Chaussée d'Etterbeek, 180 · Brussels 1040 · Belgium