

# The Patient Perspective (March 2020)

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The Patient Perspective - March 2020



## The Patient Perspective

March 2020 edition

It has been a whirlwind month! Taking into account the current emergency situation regarding COVID-19 which has been defined as 'pandemic' by the World Health Organisation, EPF has reorganised its operations with its entire Secretariat working from home.

We call for Member States to put in place effective strategies for protecting those who are most vulnerable. In particular, countries should give all possible support to their hospitals and healthcare staff. The situation shows that patients' lives are endangered when hospitals are overwhelmed. In addition to COVID-19, some patients with chronic conditions, for example cancer and other life-threatening diseases, as well as acute patients, will still need urgent medical care.

**Now is the time for solidarity.** We call on the European Commission to take rapid action in concert and in solidarity to ensure the continuing supply of vital medicines,

protective gear and equipment such as respiratory machines where they are needed.

**We need your input more than ever!** In order to convey your concerns and issues related to COVID-19, it is essential that you (our members) share information with us regarding your current situations during this period. You will find several testimonies below from patients during this tumultuous period.

EPF stands in unison with all those affected by the crisis, in Europe and globally. We need to continue to remind others to practice social distancing and adopt more stringent hygiene measures. **Please stay home, stay safe and stay protected.**

As the Director General of WHO, Dr. Tedros Adhanom Ghebreyesus stated:

***"We're all in this together. And we can only succeed together."***

## News from the Secretariat

*updates from the inside*



### **EPF's Annual General Meeting (AGM) going Virtual!**

Due to the increasing concerns and lockdown precautions regarding the COVID-19 spread in Europe, EPF has decided to **virtually host its Annual General Meeting (AGM) on April 25** and cancel the Leadership Meeting on April 26.

We shall provide you with an **updated agenda** along with all of the necessary information on how to join the AGM online. Despite the difficulty, we sincerely look forward to

welcoming you virtually at the AGM on April 25. We appreciate your understanding and thank you for your continued support of EPF's mission.



### **Working Remotely During COVID-19**

Following the decree from the World Health Organisation (WHO) that the COVID-19 outbreak has officially reached pandemic status, companies and organisations from around the globe have made remote work mandatory. While several of our members and patient organisations may be used to working from home as well, we wanted to provide some tips and tricks to assist in ensuring that your organisation's operations can run seamlessly. Even if you are already used to remote working, perhaps this could provide you with some new ideas or tools to use. [Read Our Tips & Tricks When Working From Home>>>](#)



Keep your  
**corona**  
**in**sanity

**5 Ways to Protect Your Mental Health during COVID 19**

Coronavirus has plunged the world into uncertainty and the constant news about the pandemic can feel relentless. Isolation and remote working can take a huge toll on people's mental health, particularly those already living with chronic conditions. So how can we protect our mental health during this tumultuous period?

[Read EPF's Tips to Protect Your Mental Health>>>](#)

## Testimonies in the Time of Corona

*perspectives from the patient community during the COVID-19 outbreak*



**From our unique position at the centre of the European Patient Community, we asked how patients with chronic conditions are affected by the COVID-19 outbreak.**

**Here are some of the responses:**

**Bettina Ryll, Melanoma Patient Advocate (Sweden)**

"COVID-19 is ravaging through our societies. We already see how it affects cancer patients. In the last weeks, we have seen in our Melanoma community that our follow-up appointments and control scans are postponed while patients have been switched to treatments that are less effective but have fewer side effects, can be taken orally instead of IV or are completely taken off treatment. Clinical trials are closed, leaving patients whom all other therapies have failed out of options while Stage 4 cancer patients are not being given permission to self-isolate at home 'because they had no COVID19 symptoms' Some

given permission to self isolate at home because they had no COVID19 symptoms. Some patients on forums do not recognise the need to self-isolate and feel that 'cancer was already enough to worry about' and we all possess a high level of anxiety and uncertainty especially when facing rampant levels of incorrect or unhelpful information. We have no reason to believe that this would be different for other cancer communities." [Read full testimony>>>](#)

#### **Young woman with Hydrocephalus (UK)**

"I have not checked if my local doctors are greatly affected but am due to order a repeat dose of anti-epileptics soon. My pharmacy is located in a supermarket a 5 minute walk away and I do not know further measures from the government will impact my ability to obtain medication for my epilepsy and any other unrelated conditions. I have never been in a situation where I have been out of medication for more than a day or two which has not been a problem. I do not know how long it would take for tonic clonic seizures to occur if I did not have my medication to hand."

#### **Mother of a young woman with spina bifida and hydrocephalus (Sweden)**

"I don't think we will be out of medical supplies that are necessary for people with SBH as those supplies are sent by transport companies so you don't have to go out to get them. The medical supplies that our country is lacking are masks within hospitals so the staff could be safe (and also other equipment they might need to be safe from the virus)."

#### **Marcus, Spina Bifida patient (Ireland)**

"As someone who has had a disability since birth, I am no stranger to hospitals and my healthcare system. I have had several operations and many more hospital stays due to spina bifida related issues. I have always received a very high standard of care in the Irish health service HSE, despite it's limited resources.

I would like to thank the doctors and nurses in Ireland who are doing everything they can to make sure that we can limit the spread of coronavirus as much as possible. They are working very long hours in an extremely stressful atmosphere against a deadly virus, potentially putting their own lives at risk in the process. They really are our true heroes in our time of need."

#### **Declan Groeger, MS Patient (Ireland)**

"I've been communicating with my neurologist via email and it's working just fine."

#### **Joan Jordan, MS Patient (Ireland)**

"Calling my pharmacist in advance so medication is ready for pickup. Not visiting my GP in person to stay safe."

**Carine Besselink Berendsen, Kidney Transplant Patient (Netherlands)**

"As a transplant patient (happy owner of a new kidney), I care a great deal for good hygiene, especially the proper method of hand-washing, as I used to work as a nurse. To keep my distance from other people seems like a small price to pay to avoid the dangerous spread of the COVID-19 virus. The real challenge is to keep the faith on issues like: are there enough medications available on the long run, can I rely on the continuation of doctor appointments in the hospital? A regular check up nowadays is a bit of a necessity because I happen to be pregnant! So a bit of hope in this time is needed to lighten up every step of the way, as miracles do happen even when time seems a bit desperate."

**Cassandra Alexis, Lupus Patient (France)**

"One of the discussed medicines for the treatment of COVID-19 is chloroquine and my basic treatment is based on chloroquine. I use hydroxychloroquine in my daily life to treat myself and stabilize the activity of my disease. Without it, much more alarming symptoms might touch vital organs. People who are not sick and or contaminated have gone to drugstores to buy those medicines without any prescription to self-treat themselves without medical advice and stock for emergency measures. I know several lupus patients and others with chronic conditions cannot find Plaquenil in any pharmacy in France. We must stay confined to be safe, but we also must venture outside to ensure we have enough medicine to follow our treatment and stay healthy. As a result of this constant fear, I am plagued by stress, anxiety, insomnia and fatigue, and I hope these will not lead to more aggressive symptoms. This is how the COVID-19 pandemic is affecting my daily life and I hope that other chronic condition patients are not facing a similar scenario."

**Borislava Ananieva, Kidney Transplant Patient (Bulgaria)**

"As an immunosuppressed patient, with two kidney transplantations, I feel very worried but also relieved, seeing the changes that society is making to keep all of us safe. The current restrictions we are facing are something that many young patients are actually used to doing, during flu seasons, after an immunosuppressing treatment or daily, according to their condition.

I think that the young patient community is very much used to hearing something in the lines of 'You need to do this and this, in order to remain healthy and for your condition to be stable,' and we immediately act on it, because we know what it's like to be endangered. That's why I wouldn't say that the current restrictions are that hard to follow through and I absolutely understand why they are necessary.

As I mentioned, working from home, social distancing, constant hygiene maintenance and trying to keep physically and mentally healthy, while not leaving the house are nothing new



or extreme for a young patient with a lifelong chronic condition. I hope that people without chronic conditions take a second to think about how they're feeling right now and approach people with chronic conditions with a bit more understanding next time."

**SHARE YOUR PATIENT PERSPECTIVE WITH US AT**  
[communications@eu-patient.eu](mailto:communications@eu-patient.eu)

## Policy & Advocacy Corner

*discussing the most relevant patient-centred policy and advocacy issues*



### **The EU needs to Guarantee the Delivery and Supply of Cross-Border Medical products during the COVID-19 Outbreak**

The COVID-19 (coronavirus) pandemic has highlighted the challenge of protecting the health of the population whilst avoiding disruptions to the free movement of persons, and the delivery of goods and essential services across Europe.

EPF supports the Commission's guidance that the transport of medicines and medical products – via 'green lanes' - should have priority and that current control measures should not undermine the operation of supply chains, in particular of vital medical and protective equipment and supplies. [Read EPF's Full Reflection>>>](#)



### **ECH Alliance on the Impacts of COVID-19 on European Health R&I Activities**

Several European organisations, including EPF, have expressed their concern about the potential impact of the COVID-19 pandemic on the health research and innovation ongoing projects and current calls for proposals.

ECH Alliance stresses the need for a careful assessment of such impact and the postponement of the April deadlines for the H2020 Societal Challenge 1 at least until the end of May 2020. [Read Full Position Paper>>>](#)

## **Projects Portal**

*briefings on EPF's ongoing projects*



### **PERMIT Project Kick-Off Meeting**

On 24 January in Paris, EPF joined 11 other partners for the kick off meeting of the PERsonalised Medicine Trials (PERMIT) project, a Horizon 2020 initiative within the Framework Programme for Research and Innovation. The aim of the meeting was to:



1. Present the project in detail to all participants and associated partners,
2. Discuss Work Package 2 activities (namely: a review of personalised medicine methodologies, and a gap analysis of missing recommendations)
3. Review the financial and reporting procedures.
4. Present the PERMIT [project website](#)

PERMIT will be based on a series of workshops held with experts on the topics of methodology, design, data management, analysis and interpretation in **personalised medicine research programmes**. The project's objective is to establish recommendations that ensure the scientific excellence, validity, robustness and reproducibility of results generated by these programmes. **PERMIT project will last for 24 months, until December 2021.** [Read More About EPF's Role in the PERMIT Project>>>](#)

## Member Focus

*highlights from our member organisations*



### EURORDIS Statement on COVID-19

Our member EURORDIS is conscious of the stress the pandemic is causing on people living with a rare disease, their families and our organisations. Protective measures and containment may make it more difficult for those affected to go to hospital appointments or get medicines at the pharmacy, may disrupt the organisation of the specialised healthcare services or generate medicine shortages, may hinder some clinical trials or result in more difficulties that we cannot yet anticipate.

**Full Statement on COVID-19**

## APRIL

Calendar of Events

### April 2

World Autism Awareness Day

### April 3

National Walking Day

### April 7

World Health Day

### April 11

World Parkinson's Day

### April 17

World Haemophilia Day

### April 22

World Earth Day

World Primary Immunodeficiencies Week

### April 24

European Haemophilia Consortium's 'World Haemophilia Day' Event

### April 25

EPF Virtual AGM

World Malaria Day



### **Mental Health Europe (MEH) is Hiring!**

Our members at MEH are hiring a [Policy Manager](#) and a [Policy and Research Officer](#) to join their growing team. The application deadlines are 02 April and 08 April respectively.

[Apply Now](#)



### **What does COVID-19 mean for people living with MS?**

Our members at European Multiple Sclerosis Platform (EMSP) have together a blog piece based on global recommendations for people with MS to inform our communities about the relationship of the virus and Multiple Sclerosis. As this strain of the coronavirus is new, the knowledge on how this will affect people with MS is still limited. This information will be reviewed and updated by MSIF as new evidence about COVID-19 becomes available.

[Read their Statement](#)

## **WELCOME ABOARD**

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



### **Estefania Cordero is EPF's new Projects Communications Officer.**

She will be communicating project developments and results, and managing content coordination across web platforms.

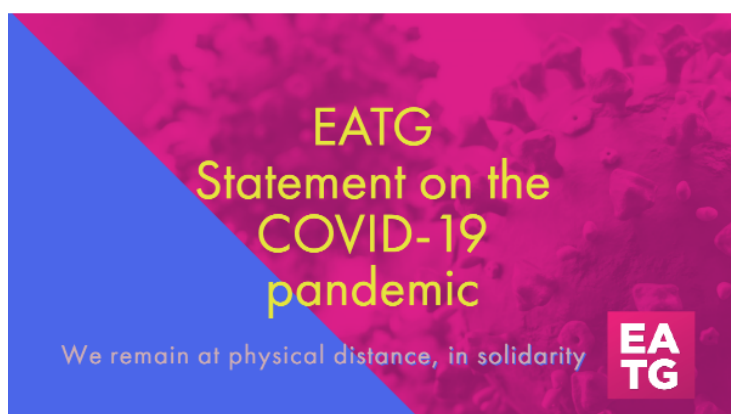
Previously she has worked at the European Commission's DG Research & Innovation in activities to promote social sciences integration and behavioural change in the Horizon research programmes.



### **15 Things We Know So Far about COVID-19 for People affected by Duchenne or Becker**

The World Duchenne Organization hosted a webinar to facilitate the questions to clinicians on the current novel Coronavirus or COVID-19 outbreak and how this affects the Duchenne and Becker muscular dystrophy community. They have collected the frequently asked questions and have clustered them.

#### **Read their Report**



### **European AIDS Treatment Group's statement on the evolving COVID-19 pandemic**

While people living with HIV who have achieved viral suppression of HIV through antiretroviral treatment seem to have similar vulnerability to SARS-CoV-2 as the general public, there are many who have intermittent or no access to treatment and their immune system remains compromised. More than half of people living with HIV in Europe are older than 50 years and have increased comorbidities such as cardiovascular disease, diabetes, chronic respiratory disease and hypertension, which current clinical data suggest are risk factors for COVID-19 vulnerability and implications



### **Maria Dutarte is EPF's new coordinator of the European Patients' Academy, EUPATI.**

Previously, she worked as a Project Manager at the European AIDS Treatment Group (EATG) coordinating community involvement in a number of training initiatives and scientific projects. Maria has worked in project management & communications for different organisations in the fields of international health & research

[Read their Full Statement](#)



PLATFORM FOR INTERNATIONAL COOPERATION ON  
UNDOCUMENTED MIGRANTS

### **PICUM's Statement on the COVID-19 pandemic**

Being undocumented in Europe today means being among those most exposed to COVID-19, and among the least protected. To limit the spread of the virus, measures urgently need to be put in place to ensure that every corner of the population has access to the services and support they need to avoid infection or further transmission. It will also be necessary to reform existing policies that create vulnerability to infection for people with precarious residence status

[Read their Full Statement](#)

## **Youth Group**

*initiatives, stories and events from our most budding members*





## **“A Rare Exhibit” Photo Exhibition Experience in Geneva**

by Anastasia Sofia Semaan, an EPF Youth Group Member

On 25 October 2020, I had the honour, as the Youth Ambassador of Unique Smiles, to give a speech at the Inauguration of a Photo Exhibition titled “A Rare Exhibit.” It was hosted at the United Nations Headquarters in Geneva, Switzerland on the margins of the 43rd Session of the Human Rights Council. The purpose of this event was to **raise awareness about the Rare Disease Community and their human rights**. This exhibition was honouring all individuals with Rare Diseases and more importantly celebrating all that they have done and can do.

This experience was truly life changing for me as I got to have my voice heard and more importantly spread the importance of establishing accessible human rights for patients with Rare Diseases. This exhibition was possible due to the collaboration of the Permanent Mission of Cyprus and the Permanent Mission of Brazil. The exhibition was fulfilled through the photography of Petros Petrides from Cyprus with Unique Smiles in their project titled *Unlimited Possibilities*, and Aldo Soligno from UNIAMO-Rare Diseases Italy, the Italian Federation of Rare Disease patient association, and his project titled *Rare Lives*.

I had the honour of listening to the Minister of Foreign Affairs of Cyprus, Mr. Nikos Christodoulides, the Minister of Women, Family and Human Rights of Brazil, Mrs. Damares Alves, and a Member of the Council of Rare Diseases International, Mrs. Rachel Yang, speak in support for all people with rare diseases, as well as the President of Unique Smiles, Mrs. Katia Kyriacou. This inauguration was so much more than presenting photos of the faces that make up patients with rare diseases. It was about steps being taken at the physical location where human rights were established in order to modify what needs to be changed; so that all patients, particularly those with Rare Diseases can live in more inclusive world that highlights every part of who they are



## Full Event Recap

### Inside the Bubble

*updates, stories and events around EU healthcare*

#### **The EU's Health Security Committee Working Group on the clinical management of COVID-19 cases**

In view of the ongoing COVID-19 outbreak, the EU's Health Security Committee have set up a Working Group on the clinical management of COVID-19 patients, including participation in clinical trials to coordinate activities and exchange information and best clinical practices. Enrolling patients in clinical trials and conducting them in a more coordinated way would support gaining information on effectiveness of these investigational treatments and allow information to be conveyed across the EU more quickly and efficiently. Members include experts from member states, as well as representatives of ECDC and EMA.

#### **European Commission confirms it will propose MDR deadline delay due to COVID-19**

The Commission will propose a one-year delay for the Medical Device Regulation (MDR) transition deadline. The Commission is still working on the proposal, but it aims to have it go to the Council and the Parliament at the beginning of April. The delay was decided to relieve pressure on industry and allow them to focus fully on urgent priorities related to the coronavirus crisis.

The MDR transition deadline is May 26, 2020. The [medtech industry](#) said this week it's struggling to meet these new rules while also getting protective gear to help health care systems during the coronavirus outbreak. Citing those pressures, the medtech industry has asked for the deadline to be delayed six months after the coronavirus pandemic is declared over.

#### **Joint Statement of the Members of the European Council**

The COVID-19 pandemic constitutes an unprecedented challenge for Europe and the whole world. It requires urgent, decisive, and comprehensive action at the EU, national, regional and local levels. The European Council has stated it will do everything that is necessary to protect its citizens and overcome the crisis, while preserving the European values and way of life. [Read their full Joint Statement>>>](#)

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## The Last Word

*"Healthy citizens are the greatest asset any country can have."*  
**Winston Churchill**



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