



To: Marco Greco (President of the European Patient Forum)
From: Manuel Arellano (Vice-President of the Spanish Platform for Patient Organizations)
Subject: COVID19 Pandemic

Dear friends,

From the Spanish Patient Platform for Patient Organizations, PPO (Plataforma de Organizaciones de Pacientes, POP), we wish you all are safe and sound amid the COVID19 pandemic.

The world in general, and Spain in particular, as one of the countries most devastated by this crisis, are witnessing the vulnerabilities in our social, economic, and political systems. As such, besides the deep wound in health, we are experiencing a detrimental impact on social protection, employment, as well as the adverse effects on the psychological and emotional realm, among others.

We want to share with you our work to minimize the impact of Coronavirus on patients with a disease, in case it might be helpful.

First, we have strengthened our free legal clinic service, in operation since 2016, to provide legal advice to patients and organizations, especially given the increased number of requests and consultations received as a result of the pandemic. At the same time, the legal team keeps us fully informed and advised to defend the rights of patients effectively.

Second, we continue to strive to offer reliable and accurate information to our partner members and patients, which is especially challenging due to the overload of data, the fast speed of publications, and the general collapse in institutions, organizations, and media. As far as this point is concerned, we have strengthened our communication actions both internally (with our member organizations), and externally. We try to avoid one-way communication to encourage debate, and confrontation of ideas, since our goal is to make proposals with a holistic approach to ensure the full coverage of the patient's needs.

Some of the concerns collected and transferred to the regional and national policymakers were focused on the following:

- The protection of individuals with a risk illness in the working environment.
- The home delivery of treatments provided in hospital pharmacies. Thanks to our collaboration with some hospitals, and through volunteer initiatives, we could make such delivery.
- The need to keep COVID19 free spaces in hospitals so that we can continue to provide health care to risk patients who require their treatments.

- The elimination of the necessary visas requested for some medications and food products, to avoid risks for our patients due to administrative delays.
- Specific social protection measures for individuals at risk of exclusion, such as patients with chronic diseases, regardless of their age.

Third, as a further step, we are currently working on a document that will be reinforced with the inputs from our advisory committee (made up of agents from the health and social sector), to raise the patients' needs, as well as proposals accordingly upon the completion of confinement. These measures are fundamentally focused on healthcare, social care, and labor protection.

Fourth, we are working with our partners to launch a new project to measure the impact this crisis is having on patients. We hope this initiative will help in the design of a public health strategy that guarantees the patients' safety, and meets their needs.

To conclude, we would like to thank the European Patient Forum for the work that your institution has been doing so far, and offer our support for the actions and initiatives being developed to protect European patients in this problematic situation. We are fully aware that our people need us more than ever before, and it is at these times that it is key to share information, and to work in the most cooperative and united way possible, putting in the most courage and heart.

We will be happy to provide you with further information on the issues of your interest.

Remain healthy and take care.

Best wishes,

Manuel Arellano

Vice-President of the Spanish Platform for Patients Organizations

List of National member organizations of the PPO:

- Asociación Ayuda Afasia (Help Aphasia Association).
- ASPAYM, Asociación de personas con lesión medular y otras discapacidades físicas (Association of people with spinal cord damages and other physical disabilities).
- UNIMID, Asociación de personas con enfermedades crónicas inflamatorias inmunomediadas (Association of people with chronic inflammatory immune-mediated diseases).
- Asociación de Personas con Epilepsia (Association of People with Epilepsy).
- AECC, Asociación Española Contra el Cáncer (Spanish Association Against Cancer).
- AEMICE, Asociación Española de Migraña y Cefalea (Spanish Association of Migraine and Headache).
- Asociación Nacional Hipertensión Pulmonar (National Pulmonary Hypertension Association).
- Cardioalianza (Cardio-alliance)
- CEFAA, Confederación Española de Asociaciones de Familiares de Personas con Alzheimer y otras demencias (Spanish Confederation of Associations of Relatives of People with Alzheimer's and other Dementias).
- CESIDA Coordinadora estatal de VIH/Sida (State HIV/AIDS Coordinator).
- ACCU ESPAÑA, Confederación de Asociaciones de Enfermos de Crohn y Colitis Ulcerosa de España (Confederation of Associations of Crohn's Disease and Ulcerative Colitis of Spain).
- CONFESQ, Coalición Nacional de Fibromialgia, Electrohipersensibilidad Magnética, Síndrome de Fatiga Crónica, Encefalomielitis Miálgica, Sensibilidad Química Múltiple (National Coalition of Fibromyalgia, Magnetic Electrohypersensitivity, Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, Multiple Chemical Sensitivity).
- DEBRA España, Asociación Piel de Mariposa (Spanish Butterfly Skin Association).
- EME ESPAÑA Federación Española para la lucha contra la Esclerosis Múltiple (Spanish Federation for the Fight against Multiple Sclerosis).
- FEASAN Federación Española de Asociaciones de Anticoagulados (Spanish Federation of Anticoagulate Associations).
- FECMA Federación Española de Cáncer de Mama (Spanish Breast Cancer Federation).
- FEDER, Federación Española de Enfermedades Raras (Spanish Federation of Rare Diseases).
- Federación Española de Fibrosis Quística (Spanish Federation of Cystic Fibrosis).
- FEDEHEMO, Federación Española de Hemofilia (Spanish Federation of Hemophilia).
- Federación Española de Ictus (Spanish Stroke Federation).
- Federación Española de Trasplantados de Corazón (Spanish Federation of Heart Transplant Patients).



PLATAFORMA DE ORGANIZACIONES
DE PACIENTES

- Federación Nacional de Asociaciones de prematuros (National Federation of Associations of Premature Babies).
- ALCER, Federación Nacional de Asociaciones de enfermos renales (Spanish kidney patients Federation).
- FNETH, Federación Nacional de Enfermos y Trasplantados Hepáticos (National Federation of Liver Disease Patients and Hepatic Transplant Recipients).
- FEDACE, Federación Española de Daño Cerebral (Spanish Federation of Cerebral Damage).
- Federació d'Entitats Catalanes contra el Càncer (Federation of Catalan Entities against Cancer).
- LIRE, Liga Reumatológica Española (Spanish Rheumatology League).

