

WEBINAR INVITATION

Covid-19: Shaping the Future of Neurology Advocacy

MAY 21st - 15 – 17h CET - ZOOM WEBINAR

What's this webinar about?

EFNA is regularly receiving reports from our members who are concerned that their communities are being forgotten as the efforts to contain and stop the Covid-19 pandemic are in full flow across Europe.

We have heard reports of patients and their families who are reluctant to attend their GPs or visit the hospital, creating a high risk to those who are experiencing untreated symptoms, complications or exacerbations in their disease. We have heard from patients who can no longer access their outpatient clinics for rehabilitation or pain management, for example. Appointments are cancelled, clinics rescheduled. Patients are struggling to see the members of their multi-disciplinary care team who provide crucial ongoing monitoring and support services but who have now been redeployed into new roles to fight the pandemic. We are also told stories of those with underlying chronic conditions who feel that the stigma, isolation and discrimination felt previously has been increased. This includes elderly patients or those with underlying health conditions being triaged out of system. And, of course, patient organisations who have seen their revenue streams run dry: fundraising activities curtailed, sponsorships cancelled or reduced, and so on.

But now, more than ever, we need active patient organisations and empowered representatives to advocate for the needs of patients with chronic conditions in the current and post-pandemic recovery phase. Our already over-burdened health systems will completely collapse if those with chronic conditions see their health worsen in the coming months. More positively, though, the pandemic has shown that innovation is possible and we need to consider how we can optimise the lessons learned to serve our communities in the coming months and years – telemedicine, flexible regulatory environments, remote clinical trials, new digital technologies, collaborative research efforts...

Through this webinar we want to collect the concerns and recommendations of our members and partners to influence our future advocacy actions in line with our three themes of:

- Fighting stigma, isolation and discrimination
- Ensuring equitable access to treatment, services and support
- Promoting patient empowerment for more meaningful involvement and engagement

So please, join us for a Zoom Webinar and share your experiences and expertise as we discuss how we shape our future neurology advocacy to best support our community during and after the Covid-19 pandemic.

The agenda is over-leaf and registration is mandatory using the link below.

REGISTER NOW AT THIS LINK TO RECEIVE THE MEETING INVITE, LINK AND PASSWORD: <https://forms.gle/yQvqw6gRSFbRisDu9>



AGENDA

Moderators: Neil Betteridge and Brian Kennedy, European/Global Alliance for Patient Access [EAFPA/GAFPA]

Welcome Joke Jaarsma, President, European Federation of Neurological Associations

Objectives Donna Walsh, Executive Director, European Federation of Neurological Associations

#Neuro-Covid: WHAT DO WE KNOW?

Prof. Elena Moro
Treasurer, European Academy of Neurology

Prof. Matilde Leonardi
Besta Neurological Institute, Milan, Italy

Prof. Monica di Luca
President, European Brain Council

Ms. Mags Rogers:
Executive Director, Neurological Alliance of Ireland

#PatientPerspective: CHALLENGES AND OPPORTUNITIES

- Georgina Carr, The Neurological Alliance, England
- Arlene Wilkie, Stoke Alliance for Europe
- Astri Arnesen, European Huntington Association
- Elisabeth Kasilingam, European Multiple Sclerosis Platform

*... with contributions from EFNA members and partners,
followed by audience Q&A ...*

Conclusions and Recommendations

Neil Betteridge and Brian Kennedy, EAFPA/GAFPA

Next Steps and Close

Joke Jaarsma, President, European Federation of Neurological Associations

