

COVID-19 Task Force

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Task Force Aims/Goals

When the COVID19 pandemic took hold in 2020, the ILAE recognised the need to be responsive with information for the epilepsy community, and set up the COVID19 Task Force in March 2020. This task force had representation from all regions, as well as the YES group, the IBE, and the ILAE administrative staff. The primary aim was to provide up to date information to the professional epilepsy community and to be responsive to their needs at this time.

Taks Force Key Activities and Accomplishment

In the first instance a section of the website was dedicated to information on the Sars-Cov2 virus , for patients, clinicians and researchers (<https://www.ilae.org/patient-care/covid-19-and-epilepsy>) . This included answers to frequently asked questions for patients (available in 12 languages) and clinicians (available in 8 languages). Guidance on what to ask during a teleconsultation, as well as EEG, video EEG and neuropsychology evaluation was made available along with useful links to further information and references. Web statistics showed frequent traffic to the site in the early phases of the first wave of the pandemic; little change was seen as cases surged globally later in the year. However with the advent of vaccinations, further information was uploaded on the

vaccination for people with epilepsy, available in 9 languages and this area has been visited frequently (<https://www.ilae.org/patient-care/covid-19-and-epilepsy/covid-19-vaccines-and-people-with-epilepsy>).

COVID-19 Research Award

Aware that many individuals around the world were trying to determine the effect of the pandemic on clinical practice and patients, the Task Force offered a competition for the best reported project in each region, with a deadline of December 2020. A total of 13 applications were received; after full evaluation four prizes were awarded. Winners are each in receipt of a certificate, and \$500.

- Nirmeen Adel Kishk – Eastern Mediterranean
- Ali A. Asadi-Pooya – Europe
- Lu Lu – Asia Oceania
- Christian Ramos – Latin America

A further competition will be run in the New year when we hope there will be applications from all regions

Epilepsy Research during the pandemic

During the first wave it was clear that many centres had restricted research. The Task Force sought to garner opinions from around the world to determine the possible effect on epilepsy research moving forward. Several themes emerged including a move to virtual working, project delays with laboratory work halted and clinical work reduced, funding concerns, a worry about false data regarding COVID research and concern about research time lost. However, a number of positive outcomes were highlighted, not least the efficiency of online working and other adaptations that could be sustained in the future. Findings were formulated into a paper, accepted for publication in *Epilepsia Open*¹

Patient wellbeing and clinical practice during the pandemic

With little information about the disease in people with epilepsy, we enabled a portal through which clinicians could report cases of seizures, new onset or exacerbation, in association with infection with the virus. By January 2021, 20 cases had been reported, 17 with new onset (13) or exacerbation (4) of seizures. The overall descriptions indicated that most cases had acute symptomatic seizures, although some cases suggest that COVID-19 lowered the threshold for seizure occurrence in individuals with a recognised or unrecognised risk for epilepsy

Cognisant as to the fact that individuals with epilepsy may be finding difficulties in the pandemic, we made available a questionnaire focusing on access to care as well as a measure of psychological stress (k score) available for patients. A total of 590 respondents completed the questionnaire; 539 (91%) provided an answer on whether seizure frequency had changed during the COVID-19 period: 22.8% (88/386) PWE and 27.5% (42/153) CG reported an increase in seizure frequency. Difficulty obtaining medications during the study period were reported by 19.8% (80/405) of PWE and 26.2% (43/164) of CG. 57.1% (173/303) of PWE and 21.5% (23/107) of CG had a K-6 score of >13, which is a marker of severe psychological distress. The proportion of people with a K-6 score of >13 was significantly greater among PWEs than among CG ($p < 0.01$).

The Task Force also worked with the ILAE Task Force for Telemedicine to formulate a questionnaire on experience with telehealth circulated amongst health care professionals. A total of 267 healthcare providers completed the questionnaire with representation from 53 countries across all six ILAE regions. Prior to the COVID-19 pandemic a large proportion of healthcare providers did not use teleneurology ($n=166$; 62.2%). Since the pandemic, this proportion had increased to 87.3% ($n=233$), with an estimated mean of 40% (IQR 17.5-70) of consultations completed via this method. Most healthcare providers considered teleneurology a useful tool for clinicians ($n=246$; 92.1%) and for patients ($n=244$; 91.4%). Furthermore, 74.9% ($n=200$) of healthcare providers thought that

teleneurology was impacting the current care of their patients mostly positively, but barriers to care were also identified.

A paper summarising the findings of the case reports, patient experience and telemedicine questionnaire has been submitted for publication²

Recommendations for future work

As we move through the second wave at different time points around the world, we need to review the information provided, and ensure accuracy. We also need to address the changing needs of the epilepsy community. Risk to the patients appears to be a recurring theme, as well as concern about resilience and mental health. As we move forward we look to collaborate with others to ensure robust support. The Task Force will continue through 2021.

1. Volkens N, Wiebe S, Akbar Asadi-Pooya A, Balagura G, Gómez-Iglesias P, Guekht A, Hall J, Ikeda A, Jetté N, Kishk NA, Murphy P, Perucca E, Pérez-Poveda JC, Sanya EO, Trinkka E, Zhou D, Cross JH. The initial impact of the SARS-COV2 pandemic on epilepsy research *Epilepsia Open in press*
2. Cross JH, Kwon CS, Asadi-Pooya AA, Balagura G, Gómez-Iglesias P, Guekht A, Hall J, Ikeda A, Kishk NA, Murphy P, Kissani N, Najji Y, Perucca E, Pérez-Poveda JC, Sanya EO, Trinkka E, Zhou D, Wiebe S and Jette N on behalf of the ILAE Task Forces on COVID-19 and Telemedicine *Epilepsy care during the COVID-19 pandemic Submitted*

Submitted by Helen Cross