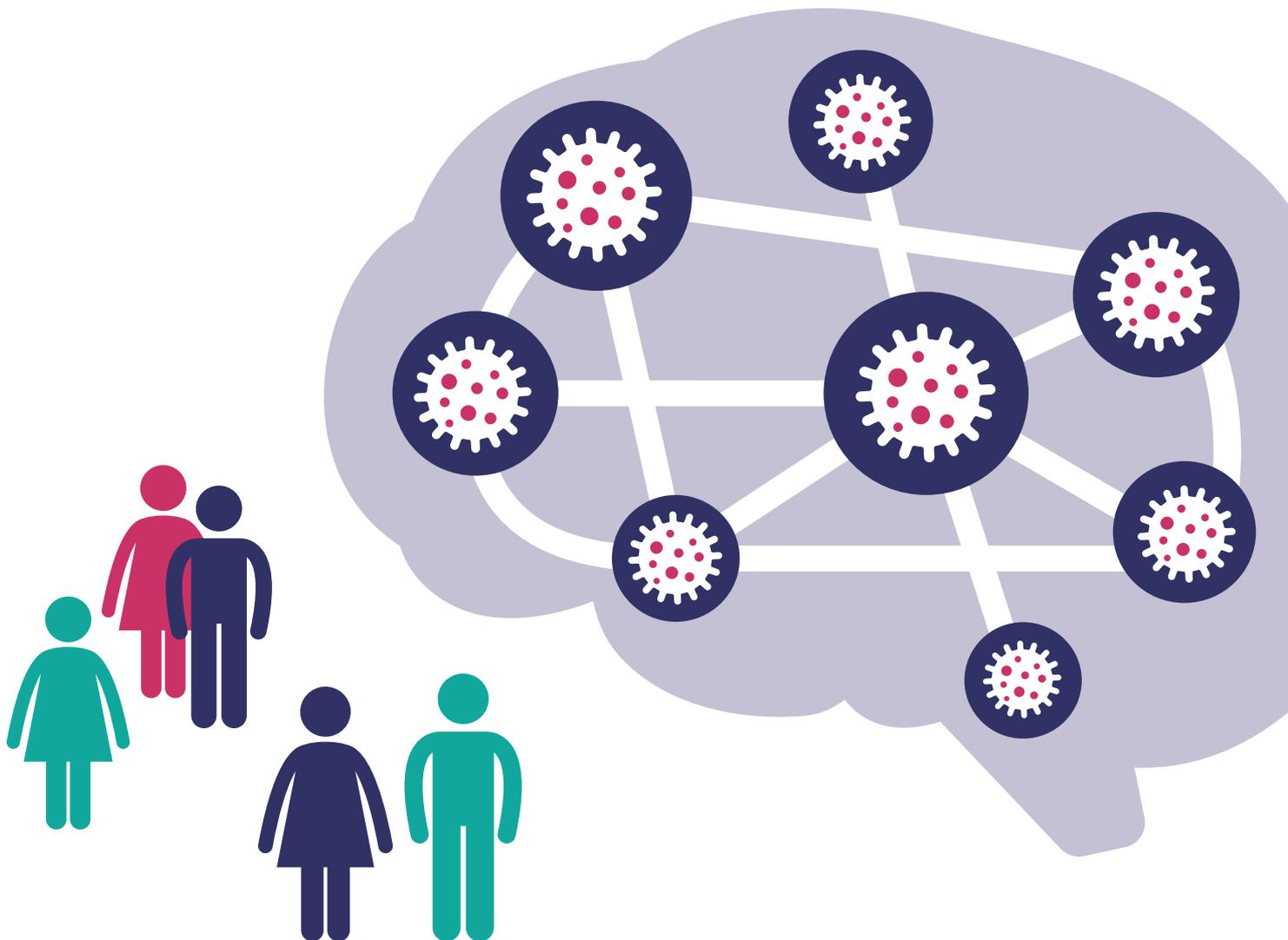




**EFNA**

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

# Addressing the impact of COVID-19 on the lives of people living with neurological disorders



June 2021

Across the world, hundreds of millions of people of all ages struggle with neurological disorders in their day to day lives. These conditions can include Alzheimer's and Parkinson's disease, strokes, multiple sclerosis, epilepsy, migraines, brain injuries, brain tumours and neuro-infections. These are in addition to a wide range of rare and neglected neurological disorders. In Europe alone, the death and disease burden due to neurological disorders is staggering, and ranks number three among all disease groups, according to recent studies.<sup>1</sup> Globally, neurological disorders represent the largest cause of Disability-Adjusted Life Years (DALYs) and the second largest cause of deaths.<sup>2</sup>

The COVID-19 pandemic has had a profound impact on people living with neurological disorders and has posed various challenges for healthcare services across Europe, with neurology services being no exception.

Essential services, including those of patient organisations, were interrupted, and chronic illnesses were deprioritised in face of the COVID-19 emergency. Patients, caregivers and healthcare professionals have all had to experience disruptions and changes in treatment and care, impacting the daily lives of millions of people. Moreover, the pandemic response saw a real lack of patient engagement and involvement. The neurology patient voice needs to be systematically embedded on every level – from healthcare delivery to policy and decision-making as we move out of this crisis.

As global, EU and national policy priorities turn towards post-COVID-19 recovery planning, to future pandemic preparedness and efforts to make healthcare systems more resilient, the impact that the pandemic has had, and continues to have, on those living with neurological disorders needs to be accounted for. Europe needs to apply the lessons learned and address the challenges people living with neurological disorders had to endure. The patients' perspective must not be forgotten.

This report summarises evidence gathered from organisations across the European neurology community about the impact of COVID-19 on people living with neurological disorders in Europe. It shows how care pathways for the neurology patient community were reconfigured during the early waves of the pandemic and makes key recommendations that policymakers and decision-makers should follow in order to ensure that any future changes to service delivery are made in the interests of patients and those affected by neurological disorders – rather than, solely, in the interests of the healthcare system.

**“ COVID-19 has impacted healthcare service delivery in ways we could never have imagined. But this has given us the opportunity to think about how we can reimagine healthcare. As the most frequent, disabling, and costly of all NCDs, neurological disorders must be prioritised if we are to get healthcare service delivery back on track during and after the pandemic. ”**

*Joke Jaarsma, President,  
European Federation of Neurological Associations*

## The interplay of COVID-19 and neurology<sup>3</sup>



The COVID-19 pandemic has challenged and, in many cases, exceeded the capacity of hospitals and intensive care units worldwide. However, the consequences of the pandemic had a disproportionate impact on already vulnerable communities, including people with chronic diseases – including neurological disorders.

From a neurological viewpoint, the resource allocation for patients with COVID-19 disrupted the routine care of individuals with acute and chronic neurological disorders. This detrimental development of reduced options in medical care was accompanied by patients' fear of contracting COVID-19 during hospital care. Even in medical emergencies, people were jeopardizing their health for this reason.

Increased social isolation and psychological stress resulted in a worsening of chronic neurological conditions. Efforts to reduce the spread of COVID-19 via stay-at-home orders, quarantine and social distancing recommendations exacerbated mental disorders and led to more inadequate sleep and unhealthy eating habits.

COVID-19 patients requiring intensive care are older and have various comorbidities. To this end, chronic neurological disorders and neurological sequelae were identified as comorbidities associated with more severe COVID-19 and unfavorable outcomes.

On the one hand, neurological manifestations are an important component of the disease spectrum of COVID-19 during both the acute and post-acute phases of infection. However, the neurological elements of COVID-19 require more research. It appears that dysfunction and damage to the nervous system is caused by the inflammatory reaction of the body against this coronavirus – *see table*. But, inconsistent study designs, inadequate controls, poorly validated tests, and differing settings, interventions and cultural norms confound the generalizability of these findings. So more research is needed.

Long COVID-19, also known as post-acute sequelae of SARS-CoV-2 infection, is characterized by symptoms persisting after the typical convalescence period of COVID-19. Long COVID-19 can affect nearly every organ system. Neurological and psychiatric manifestations may include loss of taste and smell, fatigue and disordered memory, sleep disturbances, and cognitive impairment – *see table*. The further spectrum could comprise pain, headache, symptoms of dysautonomia, depression and anxiety, and potentially new-onset dementia. However, there is a lack of long-term follow-up data to characterize the neurologic and psychiatric aspects of Long-COVID in more detail.

Only the investigation and follow-up of well-defined cases with coverage of the entire spectrum of disease, including mild, moderate, and severe courses, can provide an estimate of the actual burden of disorders associated with COVID-19. Prospective standardized and multi-national data collection on Neuro-COVID-19, such as in the ENERGY registry,<sup>4</sup> which is maintained by the European Academy of Neurology (EAN) are required to improve the understanding of acute and chronic neurological complications of COVID-19 and to move towards both prevention and treatment. See [www.ean.org](http://www.ean.org) for more details.

**Table 1: Spectrum of neurological symptoms, signs and diseases in COVID-19** adapted from Beghi E et al *Ann Neurol* 2021

Symptom/Disease	Range of reported frequencies
Headache	3.5-66%
Anosmia (Loss of smell)	5-86%
Ageusia (Loss of taste)	6-88%
Myalgia (Muscle pain)	2-61%
Altered mentation	2-21%
Stroke	0.5-77%
Seizures/epilepsy	1-9%

## The impact of COVID-19 on people living with neurological disorders

### Disruption of treatment and care

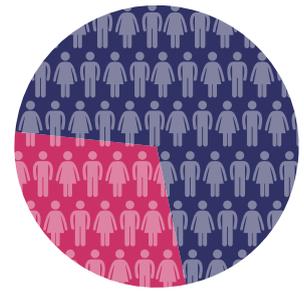


Through the disruption of health and social care services, the pandemic has significantly impacted non-COVID-19 patients' access to care and treatment and, subsequently, their quality of life. Closure of healthcare services in both primary and secondary care due to increased focus on COVID-19 (e.g. redeployment of staff or a lack of hospital beds) has led to neurological treatments being halted, limited or delayed.

This includes routine procedures such as screening and monitoring and has resulted in a huge backlog.<sup>5</sup> Some patients have not received their treatment/medications, or have experienced difficulties in switching to new treatments.

Concerns around delayed diagnosis and its impact are also prevalent. This has left those more vulnerable feeling left behind, isolated, and excluded from society. Gaps already existed in the neurological workforce prior to COVID-19, so it remains important to address these shortcomings, and to ensure the appropriate levels of treatment and care across the field – now and in the future.<sup>6</sup>

In addition to facing a reduction in services, patients have not been able to receive adequate treatment from carers – due to a fear of contracting COVID-19, restrictions on home visits and/or the inability of carers to provide adequate care due to illness. As a result, a greater burden and responsibility have been put on families and informal carers, which in turn resulted in self-reported symptoms of depression or anxiety. Furthermore, the reduction of home care support has led to increased challenges in the patient’s daily life.



**35%**  
of neurology patients experienced delays or a complete stop to access to care during the first wave of the pandemic<sup>12</sup>

**“ I have had my neurological appointments cancelled until next year, and in the meantime my neurological condition is worsening. I have experienced much mental distress. I experience intense neuropathic pain – it’s like someone pouring hot water onto my foot, and it prevents me from sleeping. I have tried everything to help manage the unbearable pain, but it is incredibly difficult to treat. I have been going to a pain clinic for nearly 20 years, but this shut down when COVID-19 hit. I have also been shielding, which means the risk of me travelling to hospital on public transport was too great. I have not been offered any remote appointments. My walking clinic has been cancelled too – this has to be done face to face anyway so they can assess how you are walking properly [...]”**

*Patient living with Complex Regional Pain Syndrome, Reflex Sympathetic Dystrophy (RSD) and Causalgia*

### Going digital: new approaches to care



The COVID-19 pandemic has accelerated digital health solutions for people living with neurological disorders, such as the introduction of telemedicine and remote monitoring. Healthcare systems have adapted to be more patient-centred, flexible and accessible.<sup>7</sup> The acceleration of the digital transformation has shown to be beneficial to some patients. For example, telephone and video consultations have lowered the barriers in terms of time and travel, resulting in a reduction of stress for some patients.

**“ Having my appointment online is so much less stressful than traveling to the hospital and waiting in a busy waiting room. ”**

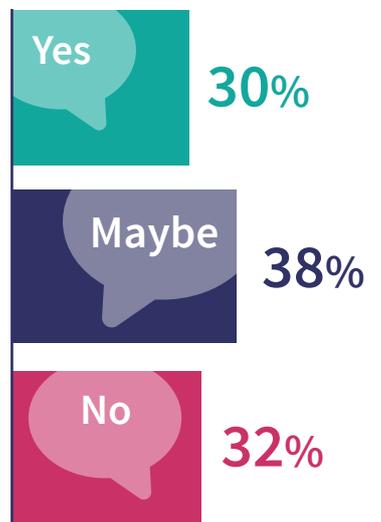
*Neurology patient Ireland*

In the case of multiple sclerosis, for instance, patients have been given more responsibility to track their own health by observing their symptoms and following up on their developments via online applications and other innovative tools.<sup>8</sup> Consequently, this has provided patients with more knowledge and confidence, increasing their sense of empowerment. It has also made remote consultations more efficient.

However, the increased use of digital tools has not been taken up equally by all patients. Access to telemedicine can be problematic for some patients as they are not able to interact online due to a number of factors. This can include health condition, low socioeconomic status, poor digital health literacy, inequitable access to equipment, connectivity issues, regulatory/legislative barriers or various challenging life circumstances. This means that fully going digital could mean leaving some patients behind. Therefore, more attention needs to be put on these vulnerable populations to ensure optimal treatment and care, regardless of their personal situation.

Overall, and despite the increase in the use of modern technology, most patients would still prefer personal contact (e.g. face-to-face consultations) with their healthcare professionals or, at least, wish to find a balance between telemedicine and face-to-face consultations. It remains crucial for patients to be in contact with healthcare professionals, to be provided with the necessary assistance and information, but also to receive appropriate and quality assessments. It is important to upscale online services for continued use after the pandemic, but also as a back-up solution to be used when physical consultations are not possible.

**Would you like to see the new approach to care continued in the future?<sup>12</sup>**



### PATIENT ORGANISATIONS GOING VIRTUAL

Patient organisations are seeing an increased demand for their services and had to adapt to the virtual environment. By going digital, organisations were able to reach more people than with face-to-face meetings. People unable to travel due to other commitments, financial considerations or severe symptoms have now been able to take part in online events, and virtual peer-to-peer or community support. Hence, tools for online communication have improved and been used more effectively.

Although patient organisations have seen an increase in demand for activity, they have also had to face a decrease in their resources and income. Fundraising opportunities have been restricted and organisations had to let go staff members (sometimes temporarily), which has led to a decline in visibility for both patients and their organisations.

**“Being able to digitally interact helps and I’ve found connecting online with the Parkinson’s community has been extremely comforting for me. For those who can, I recommend finding others that you can talk to, bounce ideas off and have a laugh with.”**

*Patient with Parkinson’s disease*



### Mental health and wellbeing

The pandemic has created mental health and wellbeing issues that will be felt long after the pandemic is over. Not only has there been considerable psychiatric and neurological damage in patients diagnosed with COVID-19, but people with neurological disorders have also been directly affected. Many have had to shield for nearly a year – leading, in some cases, to isolation and loneliness.

This isolation due to the pandemic has exacerbated already-higher rates of stress and anxiety, sometimes leading to depression. This coincides with the loss of appropriate and timely support services, restrictions due to lockdowns, and impact on employment and income leading to pressure on both family members and caregivers.

**“During the time of confinement, I came to think of suicide. I was alone at home, unable to go out or see anyone and night after night without sleeping ...”**

*Patient with restless legs syndrome*

People with neurological disorders are perhaps not so much at risk of the COVID-19 infection as they are bearing emotional, psychological, and physical risks due to the indirect consequences. Fear, insecurity and uncertainty have affected their lives and wellbeing. Hence, there has been a huge mental, emotional, and cognitive impact for many of them.

On the other hand, some patients have experienced lower levels of social pressure due to reduced social interaction. Some have even reported a reduction in their stress levels – for example, in the area of epilepsy, there was acknowledgement of the lower risk of experiencing a seizure in a public place.

**“Life is not just a disease, and we are not just patients or caregivers – we are human beings with very specific and particular needs.”**

*European Huntington Association*

## Disruption and Mitigation of Neurological Services during COVID-19: a global perspective<sup>10</sup>



As part of its COVID-19 strategic preparedness and response plan, the World Health Organization (WHO), released operational guidance on maintaining essential services during COVID-19. This contained recommendations for mental, neurological and substance use disorders. It focussed on maintaining emergency/acute care, treatment and care in outpatient settings, residential care, and cross-sectoral service delivery.

Additionally, neurological patient associations and scientific societies have collected evidence, published guidelines and advocated actively to address the impact of COVID-19 from the early stages of the pandemic.

The community increasingly recognises the effects of COVID-19 on neurological care, for those already living with a neurological disorder, as well as for those who have developed neurological consequences of COVID-19 – the second leading cause of complications in affected patients.

However, despite all these efforts, a WHO Commissioned review<sup>9</sup> of the literature and a Global Survey carried out by the WHO essential services working group of the WHO Neuro Covid Forum, including EFNA,<sup>11</sup> showed that in all regions of the world, essential neurological health care services have been disrupted.

The results of the global survey confirm multiple reasons for the disruptions of neurological services including:

1. Historic lack of targeted neurological policies, systems and services
2. Effects of governmental policies and ranking of national priorities
3. Movement restrictions and of transportation limitations
4. Lack of health workforce for neurological patients worldwide
5. Lack of involvement in policy decisions/political planning of the neurological community including scientific and patients' organisations

The respondents to the global survey, representing associations and scientific societies from 43 countries from all WHO Regions, reported that governmental intervention in ensuring the continuity of neurology care was not at the required level. In several countries, it was the healthcare professionals and patients' associations who managed to ensure the maintenance of care.

The review and the global survey highlight the need for most countries to invest in the development of neurological health care at policy, system and service levels in primary, secondary and tertiary care. This includes investment in the neurological health workforce, in education and in research. This also includes support for the development of infrastructures to implement the use of telemedicine, which was shown to enable neurologists to reach most patients, even in remote areas.

A global action plan on mitigation strategies for disruption of neurological services during pandemic situations should be established and neurological scientific and patients' associations must be involved in such decision making.

## Patient involvement and engagement

The pandemic also had consequences for patient engagement and involvement – mainly since real patient engagement was missing throughout the crisis response. Most patients claim to have suffered a lot during the pandemic due to a lack of personalised medical attention and information, and neurology patients were often omitted from those groups deemed 'priority' during the pandemic. Most patients were not consulted when their treatment changed and are not being consulted about care delivery in the future, despite their concerns.

Real patient engagement must become more systematically embedded in healthcare delivery, policy, and decision-making – during and after the pandemic.

Looking into the future, services for people with neurological disorders face both challenges and opportunities. For this reason, it will be paramount to integrate the neurology patient perspective comprehensively into the process of post-pandemic recovery planning.



**Less than 50% of patients were consulted before their treatment and care plan was changed during the pandemic<sup>12</sup>**

**“Neurology could be a flagship in creatively building new care pathways, paving the way for the future of healthcare in the overall area of NCDs – whether that is in the acceleration of digital health, reconfiguring service delivery to ensure progress towards universal health coverage, developing personalised healthcare solutions or pushing the boundaries with breakthroughs in R&D. But, for this to happen, we need political will to position neurology as a public health priority in Europe.”**

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

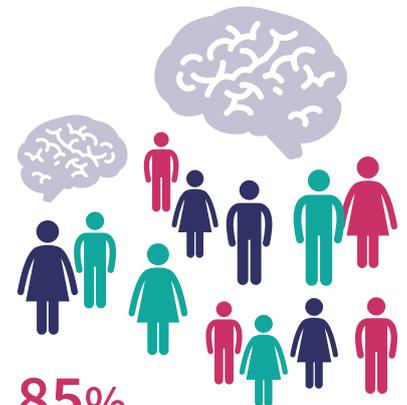


**The great majority (83%) were not consulted about how care will be organised in the future<sup>12</sup>**

## Future proofing: our asks to policymakers

The COVID-19 pandemic has had a dramatic impact on the agenda of the European institutions and the wider health community, leading to a reprioritisation of programmes and activities. However, it has also triggered a response from the European institutions with a stronger focus on health policy. Such policy action at European level could deliver significant improvements for people with neurological disorders.

Neurology has to be an integral part of COVID-19 recovery planning across Europe. As we reimagine healthcare, we have the chance to create a resilient and futureproofed infrastructure which places our patients and carers at its core. A unique opportunity exists for the EU to put those living with neurological disorders at the centre of new and ongoing EU health policy initiatives. Both European Union and national authorities have an important role to play in such a patient-centred health policy agenda.



**85% of patients are worried of how future waves of the COVID-19 pandemic might impact care of their neurological disease<sup>12</sup>**

## Acknowledging neurology as a priority area of non-communicable diseases

The full burden of neurological disorders should be acknowledged, and more EU action should be taken to fully integrate neurological health as one of the priority areas in the field of non-communicable diseases. Any future legislative or non-legislative action proposed by the European Commission, including COVID-19 recovery planning, must include neurology.

The increased budget for health within the European Commission’s EU4Health Programme 2021-2027 provides an important foundation to support health and wellbeing for all European citizens across all policies, including neurology. Moreover, through the new Pharmaceutical Strategy for Europe more policy attention needs to be devoted to ensuring that future needs for neurological disorders are met and to address the lack of treatment in this field. This is already cited in the text and must be implemented.

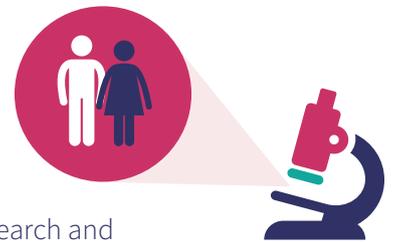




## Putting brain health at the forefront in health emergency preparedness and resilience planning

Brain health must be at the forefront of post-COVID-19 recovery planning and any efforts to build resilience in healthcare systems across the EU. Long-term consequences of the pandemic should be kept in mind as the pandemic has caused severe mental and neurological consequences.

The new European Health Emergency Preparedness and Response Authority (HERA) will increase Europe's preparedness in responding to crucial and urgent health issues beyond the area of infectious diseases. Brain health should be an integral part of the HERA's work. Moreover, as part of the COVID-19 recovery planning, dedicated funding should be set aside for health and wellbeing resources to deal with the back log of delays to access screening, counselling, treatments, and rehabilitation services – especially given the disruption on care for people living with neurological disorders.



## Driving research and innovation in neuroscience

We need to ensure that neuroscience and brain health has a prominent role in research and innovation to develop better treatments across the spectrum of brain-related diseases to reduce the overall burden of neurological disorders. Horizon Europe should be used to fund research into neurological manifestations of COVID-19 and long COVID-19 as the long-term impact is still unknown. Sharing portals should be created to generate research data on the long-term outcomes of care solutions during the pandemic. Risk assessment for extensive samples of neurological disorders do not (yet) exist at EU level and should be addressed through the European Health Data Space. Similarly, cross-border analyses of health data and interoperable systems are crucial for improved quality and safety of care for those living with neurological disorders.

Neurological health could be a flagship in creatively building new care pathways, paving the way for the future of healthcare in non-communicable diseases overall – whether that is in the acceleration of digital health, reconfiguring service delivery to ensure progress towards universal health coverage, developing personalised healthcare solutions, or pushing the boundaries with breakthroughs in research and development.



## Building digital and health literacy

The pandemic has accelerated digital innovation in the health space as well as increased our dependence on digital solutions. It has also revealed important differences in terms of digital literacy and access to digital solutions, thereby increasing health inequalities in some areas.

The allocation of Next Generation EU Recovery Funds, European Regional Development Funds and other structural funds should be used to boost equal access to neurology care and treatments so that patients can be treated regardless of their age, gender, socioeconomic background or geographical location. Moreover, European Structural and Investment Funds should be used to invest in digital solutions to offset delays and disruptions in care and improve health and digital health literacy overall.

## Ensuring patient involvement across all areas



The COVID-19 pandemic has highlighted the impact of neurological disorders on those living with them as well as their carers. Clearly, their experiences and perspectives, need to be included in any conversation around post-COVID-19 healthcare setting. Whilst there is a strong commitment to health, neurological disorders and those living with them should not be forgotten and should be considered amongst vulnerable and priority groups. Improving efforts for people living with neurological disorders will take better policies, funding and cooperation amongst all stakeholders to ensure a better quality of life for patients. Patients need to be at the centre of this discussion.

Patient organisations must also be resourced to ensure that they can continue to provide essential services to those living with neurological and other disorders across Europe, as well as being equipped to participate in EU level policy making.

### We therefore urge EU and national policymakers to take action:

- ✓ Acknowledge neurology as a public health priority, and consider people living with neurological disorders amongst priority groups in any ongoing and upcoming EU health policy initiatives.
- ✓ Position brain health at the forefront of post-COVID-19 recovery planning and in efforts to build resilience in healthcare systems across the EU.
- ✓ Integrate neurological disorders in any work in the area of non-communicable diseases.
- ✓ Prioritise neuroscience in future EU research and innovation funding frameworks, including a focus on the neurological implications of long-Covid.
- ✓ Devote more policy attention to ensuring the needs of people living with neurological disorders are met; addressing past, current and future shortcomings in treatment and care, and optimising the digital transformation of healthcare.
- ✓ Establish sharing portals to generate and share research data on the long-term outcomes of care solutions during the pandemic and beyond to improve quality and safety of care of patients.
- ✓ Ensure better, more targeted information and advice for neurology patients and improve health and digital health literacy for Europe's citizens.
- ✓ Support and resource EU patient organisations, and systematically embed patient involvement in all EU policy and decision-making processes.

## About EFNA

The European Federation of Neurological Associations (EFNA) is an umbrella group representing pan-European neurology patient groups. Our slogan 'Empowering Patient Neurology Groups' encapsulates our goals as an Association. We strive to add capacity to our members – allowing them to be the most effective advocates possible in their own disease specific areas. EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders from different fields, including policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

## Methodology

This report summarises evidence from organisations across the neurology community on the impact of COVID-19 on people living with neurological disorders in Europe. It is based on several surveys and reports run by EFNA member organisations (listed below), who have captured the impact of the COVID-19 pandemic on patients' access to treatment and care. This includes a recent survey run by EFNA in partnership with the European Academy of Neurology (EAN), among its membership to better understand how care pathways for the neurology patient community were reconfigured during the first wave of the pandemic.

We would like to express our sincere gratitude to the organisations who provided their valuable input and recommendations during the process of drafting this report:

- Asociación Española de Síndrome de Piernas Inquietas (AESPI)
- Dystonia Europe
- European Brain Council (EBC)
- European Academy of Neurology (EAN)
- European Huntington Association
- European Myalgic Encephalomyelitis Alliance (EMEA)
- European Myasthenia Gravis Association (EuMGA)
- European Parkinson's Disease Association (EPDA)
- International Bureau for Epilepsy (IBE)
- Myeloma Euronet Romania
- NeuroCovid Global Forum
- Neurological Alliance (UK)
- Neurological Alliance of Ireland
- Pain Alliance Europe
- Retina International
- Stroke Alliance for Europe (SAFE)

**“ [...] So many of the things I enjoy, like visiting art galleries, have closed – it means I don't have a break. I try to keep active, and go on walks, but my life has been turned upside down. I am confident that if Government knew what life has been like for so many people with neurological conditions during COVID-19, they would be taking it more seriously. ”**

*Patient living with Complex Regional Pain Syndrome, Reflex Sympathetic Dystrophy (RSD) and Causalgia*

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