

The [European Federation of Neurological Associations \(EFNA\)](#) is an umbrella group representing pan-European neurology patient groups.

In the EU, neurological disorders are the 3rd leading cause of [Disability Adjusted Life Years](#) (a DALY weights together mortality and morbidity). They are also the [3<sup>rd</sup> leading cause of death](#), making up for 11.5% of all deaths from NCDs in Europe. Importantly, this figure does not include stroke, which was reclassified in 2018 as a neurological disorder in the International Classification of Diseases 11 that came into force in 2022. Adding stroke, the actual percentage of deaths will rise to 20%. This means that every fifth NCD-related death in the EU is due to neurological disorders. The NCD Countdown 2030 states that the risk of dying from neurological conditions [increased for more than half of countries worldwide](#). This effectively makes them the fastest-growing cause of death among NCDs. It is projected that by 2040, neurological disorders will see a further [50% increase in DALYs](#).

This is why neurological disorders were included as one of the priority strands in the EU NCD Initiative.

In parallel, in May 2022 the World Health Assembly (WHA) is expected to adopt the Intersectoral global action plan on epilepsy and other neurological disorders (GAP) which was called for in a 2020 WHA resolution co-sponsored by all the EU countries.

A conjunction of the NCD Initiative and the GAP couldn't be timelier. The European community is now presented with a unique window of opportunity to provide an integrated and cross-sectorial response to neurological health. Investing in this holistic model can bring measurable health and economic gains to European countries. This includes decreasing the incidence of neurological disorders, improving survival rates, reducing complications and disability, lowering treatment costs and – ultimately – ensuring a better quality of life for all those affected.

In view of the above, we strongly believe that the NCD Initiative activities addressing neurological disorders should fully align with the targets of the GAP which provides a comprehensive framework for national action. This synergistic approach will be the most efficient use of resources that are limited and need to be spent wisely.

Based on this, EFNA and its members make the following recommendations:

### **RECOMMENDATION 1: National neurological/brain health plans**

While actions on the ground will inevitably address concrete neurological diseases, at the strategic level neurological disorders should be addressed in a bundled fashion. This is because they are all related to one discipline – neurology and share a lot of common denominators, challenges, risk and protective factors. For example, there are common symptoms and complications for many neurological disorders – such as pain, fatigue, cognitive challenges, dizziness, seizures and sleep disorders. Successful examples of such bundled approach exist in other areas such as cancer (there are more than a hundred distinct types of cancer, which can vary

substantially in their behaviour and response to treatment). This can be best achieved when individual countries develop dedicated neurological/brain health national plans, encompassing all major neurological disorders (or both neurological and mental health conditions), with a dedicated budget line. Such a bundled approach is the most effective way of addressing a disease area (e.g. cancer plans). This is particularly true in neurology: there are more than 400 neurological disorders and, given their huge collective burden, we need a strategy addressing common challenges and solutions. This is why the creation of national plans is the first target of the GAP, with a goal of 75% of countries worldwide developing those in the next ten years.

#### **RECOMMENDATION 2: European platform facilitating the implementation of the GAP nationally and creation of a European guide for quality national neurological/brain health plans**

The GAP will be implemented at the national level where member states will work toward meeting the Plan's targets. To achieve the best results in individual member states, between the global and national dimensions there needs to be regional coordination. The European Commission is well placed to provide a platform that can facilitate the development and implementation of national plans synergistically. Successful examples exist in other disease areas such as cancer and diabetes, e.g. CanCol JA, European Guide for Quality National Cancer Control Programmes or Guide for National Diabetes Plans in CHRODIS +.

#### **RECOMMENDATION 3: Awareness campaigns and advocacy programmes for neurological disorders**

The stigma surrounding neurological disorders is immense. 92% of those living with neurological disorders [report](#) feeling affected by stigma on account of the disorder they have. Lack of understanding is seen as the biggest cause of this, followed by myths and misconceptions about these disorders and their often invisible nature. The GAP second target sets out an ambition to have at least one functioning awareness campaign or advocacy programme for neurological disorders to improve understanding and reduce stigma and discrimination against people with neurological disorders. The objective of awareness and advocacy campaigns should be to foster an accurate understanding of neurological disorders, reduce stigmatization and discrimination associated with neurological disorders, educate people about the human rights of people with neurological disorders and the UN Convention on the Rights of Persons with Disabilities and enhance the general population's ability to recognize early symptoms and signs of neurological disorders.

#### **RECOMMENDATION 4: Inclusion of neurological disorders in the Universal Health Coverage benefits package**

The UHC priority benefits package is a set of evidence-informed, prioritized healthcare policies and interventions that respond to the most important needs of the population of a given country. They should be provided through appropriate service delivery and financing arrangements. The GAP includes a target on existence of a set of evidence-informed, prioritized, essential, quality health services and supports for neurological disorders within the UHC PBP package. Services and supports for neurological disorders include financial risk protection and promotive, preventive, treatment, rehabilitative, and palliative care across the life course. Implementing the UHC PBG have the following benefits: equity and access; financial protection; promoting quality; allocative efficiency; accountability; empowering the community.

#### **RECOMMENDATION 5: Routine collection and reporting on a core set of indicators for neurological disorders**

Reliable morbidity and mortality data on neurological disorders and their risk factors are the backbone of evidence-based healthcare planning, priority setting and resource allocation. However, these epidemiological studies are scarce for most neurological disorders, which limits the ability to compare and replicate findings. More high-quality studies of the burden of various neurological disorders are needed. For this to happen, capacity in information systems must be built up so that the health outcomes of implemented interventions can be adequately measured. This is why it is important that countries have functioning health data and information systems to routinely collect and report on a core set of indicators for neurological disorders, which is another target of the GAP. This can occur by means of a patient registry, aggregate data or medical records from various sources measured at a system level (national, subnational or local level).

## RECOMMENDATION 6: MEANINGFUL PATIENT INVOLVEMENT

Underlying those recommendations, patient involvement in the implementation of the GAP and the NCD Initiative will be critical. It can be best achieved when involving national neurological coalitions that bring together many different neurological disorders. However, in many countries such alliances don't exist yet; rather, there is a patchwork of national organizations dedicated to individual neurological disorders. Building up an organizational capacity of neurology patient groups at a national level should be supported by the NCD Initiative. Those groups can become focal points and critical enablers, greatly contributing to the implementation of the GAP targets and NCD Initiative projects. EFNA can assist in the creation or strengthening of those national groups by leveraging its extensive membership covering all major disease areas in all the EU member states and other European countries.

