

EFNA ELECTION MANIFESTO:

Neurological conditions: the most frequent, disabling and costly of all non-communicable diseases: *time to prioritise neurology and brain health!*

Executive Summary

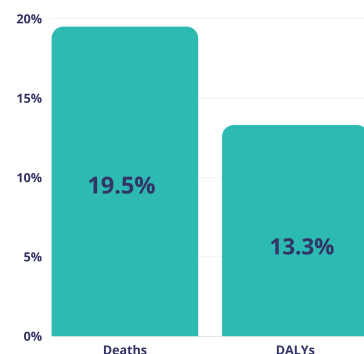
The EFNA Election Manifesto presents a comprehensive roadmap toward prioritising optimal quality of life for people with neurological conditions and their carers. Neurological conditions are the most frequent, disabling and costly of all non-communicable diseases in the EU. This manifesto outlines the urgent need for enhanced research, patient engagement and equitable access to treatments to support neurological patients. It emphasises the importance of collaborative efforts, including setting up an EU Joint Action on Neurological Conditions, launching a European plan to promote brain health, optimal living for neurology patients and combat neurologic and brain disorders, leveraging the upcoming Brain Health Partnership for the benefit of neurology patients and implementing the WHO neurological action plan, to improve outcomes for individuals with neurological conditions.

What are the neurological conditions?

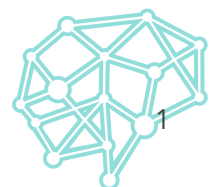
Neurological conditions affect the central and peripheral nervous systems– both connected to our body's most complex organ: the brain. They include neurodegenerative disorders like Alzheimer's and Parkinson's disease, cerebrovascular diseases including stroke, neuroinfectious/neuro-immunological disorders such as multiple sclerosis and myalgic encephalomyelitis (ME/CFS), neurodevelopmental disorders including ADHD and autism, and neuromuscular disorders like ALS and muscular dystrophy. They also encompass well-known diseases such as migraine and epilepsy, as well as many rare and neglected diseases.

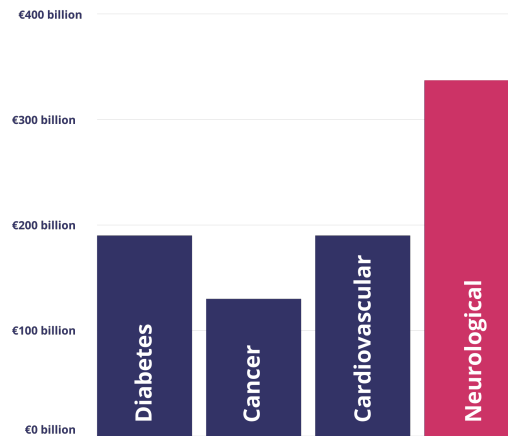
The human and economic toll of neurological conditions

Collectively, neurological conditions have the highest prevalence, lead to the most considerable disability and result in the highest costs among non-communicable diseases (NCDs). They are [the third leading cause of death](#) and the [third leading cause of Disability Adjusted Life Years \(DALYs\)](#) in the EU. Including stroke (now [classified as a neurological disorder](#)); these conditions account for 20% of all premature deaths – annually, 1.1 million Europeans die due to a neurological condition. Over the past 30 years, the number of deaths due to neurological disorders has [increased by almost 40%](#), and [projections suggest](#) a further 50% increase in DALYs due to



Percentage of deaths and DALYs from NCDs within the EU attributed to neurological conditions in 2017.





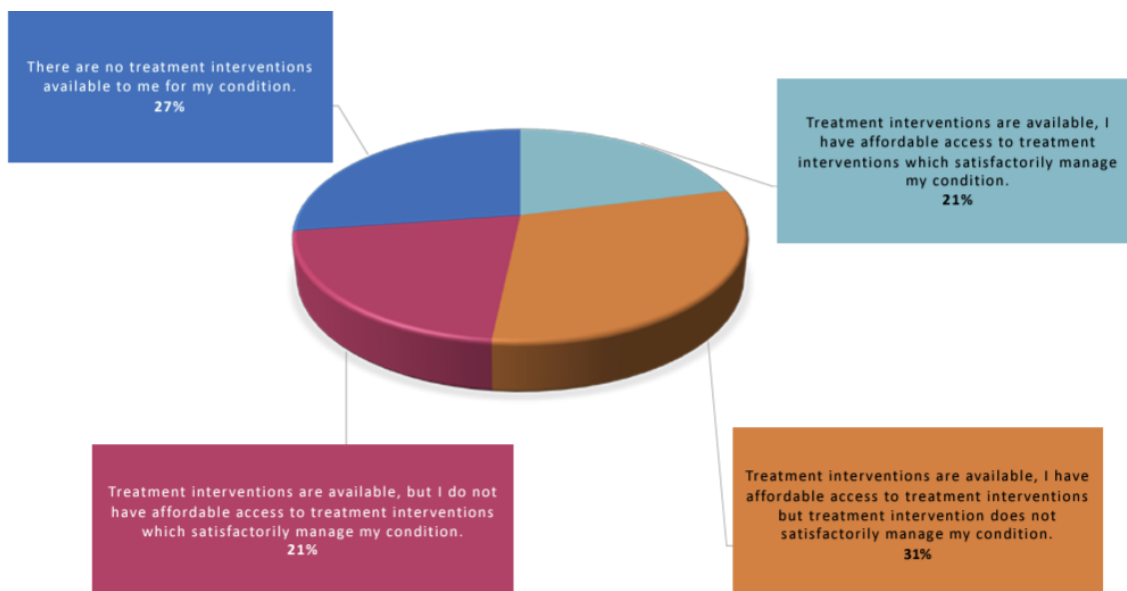
The cost of NCDs in Europe, 2011

neurological conditions by 2040. Neurological conditions are also extremely costly, with their [annual cost to the EU being €336 billion](#) - more than any other disease area.

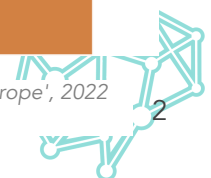
- **To counteract the immense and growing toll of neurological conditions, we call for a well-resourced EU Joint Action on Neurological Conditions and Brain Health to support member states in reducing the burden of these disorders.**

Advancements and research gaps in neurology

In recent decades, incredible advances and breakthroughs have been made in both understanding the human brain and developing new therapies to treat a growing range of neurological conditions. However, our limited understanding of the human brain and nervous system means we still have no cure for most neurological conditions. The complexity of the human nervous system presents formidable challenges to researchers, leading to high clinical trial failure rates in neuroscience. This trend often restricts investment in this field, creating a vast array of unmet needs in neurology. Despite strides in pharmaceutical research, the current landscape still reveals substantial gaps in adequately addressing the complexities of these high-burden diseases and meeting patients' needs.



Results from 'Assessing diagnosis and care pathways of people living with neurological disorders in Europe', 2022



For patients living with neurological conditions, the limited availability of effective treatments magnifies their struggle. The EFNA 2022 survey '*Assessing diagnosis and care pathways of people living with neurological disorders in Europe*' showed that only 1 in 5 of those living with a neurological condition have access to affordable therapeutic interventions that satisfactorily manage their condition. This underlines the urgency to stimulate research and development dedicated to creating innovative therapeutic solutions to tackle these under-prioritised conditions with significant unmet needs.

Encouragingly, in the realm of rare neurological conditions, the European Reference Networks (ERNs) play a pivotal role in expediting access to expertise. They facilitate diagnosis, training for professionals, data collection and sharing, registry building, and exemplify cross-border healthcare.

Due to the lack of affordable and accessible therapies, increased funding for research into neurological conditions is essential. It is crucial to conduct research that fully embraces sex- and gender-related differences in risk factors, disease progression, and treatment responses in neurology. Research sensitive to these issues is currently lagging behind, even though women are often disproportionately affected by neurological conditions.

- **We call for the revision of the European pharmaceutical legislation to foster an environment conducive to advancements in neurological treatments.**
- **We call for a further integration and better resourcing of the ERN's in national health care systems and higher priority of ERN participation from the national health authorities/hospital owners.**
- **We welcome the upcoming Brain Health Partnership starting in 2025 and call on all involved parties, including the EU Institutions and Member States, to allocate adequate resources to implement the Partnership objectives successfully.**
- **To better align with the Brain Health Partnership, we call for an EU-wide response by creating a European Plan to Promote Brain Health, Optimal Living for those with Neurologic Conditions and Combat Neurologic and Brain Disorders.**

Incorporating a neurological perspective in patient engagement and ensuring socio-economic support

Patient engagement is a pivotal factor in improving health research and delivery outcomes. As experts through lived experience, patients play a crucial role in healthcare. Their involvement can prevent harm, signal potential risks for themselves or others, and lead to meaningful improvements for the future. Research has shown that patient engagement creates a virtuous cycle, where improved patient safety and trust lead to more empowerment, continuously enhancing safety and trust. Healthcare should be directed towards people's health needs, outcomes, and experiences, with patients being the primary source to inform such decisions. The lived experiences of patients can contribute immensely to the relevance and quality of healthcare development and delivery.

Recognising patients as partners, not only in decision-making but also in research and development processes, is essential. By actively participating in scientific research, patients can provide invaluable insights that drive innovation in healthcare.



Additionally, greater adherence to the European Pillar of Social Rights is needed, particularly in supporting neurological patients who face financial hardships and workplace discrimination. This includes advocating for policies that ensure fair treatment, equal opportunities, and adequate support for those forced to leave their jobs due to their medical condition, aligning with principles such as equal treatment, work-life balance, and access to social protection and healthcare.

- **We call for patients to be active and equal partners in R&D activities, HTA and decision-making processes that impact their health, quality of life, and socio-economic well-being.**

Global and EU mandates to combat neurological conditions and improve brain health

The 2019–2024 term of the European Parliament has been marked by an urgent call to expand the EU's involvement in health policy. This period saw the EU4Health Programme, under a revitalised and more robust EU health mandate, recognise neurological conditions as critical non-communicable diseases for the first time. Consequently, mental and neurological conditions became a priority strand of the EU NCD Initiative 'Healthier Together', placing these conditions alongside major health challenges such as cancer, cardiovascular diseases, diabetes, and chronic respiratory diseases.

In 2022, a significant milestone was achieved when all EU countries adopted the World Health Organization Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 – 2031 (IGAP). The IGAP outlines a comprehensive, coordinated strategy to address the immense burden of neurological conditions, including in Europe. It aims to fill gaps in care and services, promote brain health, and set concrete targets for European nations, such as developing comprehensive national plans focused on neurological conditions and brain health.

This plan offers a unique opportunity for the EU to deliver a holistic, cross-sectoral response to neurological health challenges. Investment in this integrated approach promises both health and economic dividends by reducing the incidence and complications of neurological conditions, enhancing survival rates, lowering treatment costs, and ultimately improving the quality of life for affected individuals.

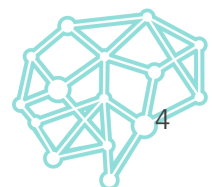
The IGAP, in conjunction with the European NCD Initiative, presents a pivotal opportunity for the EU to offer a comprehensive, cross-sectorial response to neurological health. Therefore

- **We call for the EU to align the NCD Initiative's neurological strand with the targets of the WHO's IGAP.**

Prioritised attention towards two essential WHO IGAP targets

Prioritised attention is needed towards two particular WHO IGAP targets essential for the expedited national delivery of the entire ten-year plan. These targets include IGAP's first strategic objective, to "raise policy prioritisation and strengthen governance," with the following country-level deliverables:

- **Adapting or updating existing national policies, strategies, plans or frameworks to include/prioritise neurological conditions.**
- **At least one functioning awareness campaign or advocacy programme for neurological conditions.**



National awareness campaigns and action plans focused on neurological or brain health plans are pivotal in implementing the WHO's IGAP. These plans should adopt a coordinated approach to address common challenges and solutions associated with neurological conditions. At the strategic level, neurological conditions should be addressed in a bundled fashion due to their common denominators, challenges, risks, and protective factors. For example, many neurological disorders share symptoms and complications like pain, fatigue, cognitive challenges, dizziness, seizures, and sleep disorders. Successful examples of such a bundled approach exist in other areas, such as cancer.

Regional coordination (EU) is needed to bridge the global (WHO IGAP) and national dimensions (country-specific targets) and achieve the best results in individual countries. As such, the EU can and should play a central role in facilitating the implementation of the WHO's IGAP across member states. 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+.

- **We call on the EC to provide an IGAP implementation platform to facilitate the development and implementation of national and EU-wide awareness campaigns and plans in a synergistic way.**

Building collaborative networks for neurological health: fostering national neurological alliances

Patient involvement in national awareness campaigns and plan development will be critical. The most effective approach involves national neurological alliances/coalitions that bring together various neurological disorders. In many countries, such alliances are yet to be formed. Often, there is a patchwork of national organisations dedicated to individual neurological conditions. Collaborating as one neurological platform in every country could yield a synergistic effect. National neurological alliances can become focal points for governments concerning the implementation of the WHO's IGAP, involving people living with neurological disorders. Building up the organisational capacity of neurology patient groups at a national level should be supported by the NCD Initiative, contributing significantly to implementing all the IGAP targets. EFNA can assist in creating or strengthening these national groups by leveraging our extensive membership covering all major disease areas in all the EU member states and other European countries.

- **We call for a dedicated EU project to build neurological patients' capacity at a national level, uniting and streamlining patient expertise to support the implementation of the IGAP.**

Capitalising on a critical window: advancing neurological health in the 2024–2029 EU term

Looking ahead, the 2024–2029 parliamentary term will be critical in ensuring that EU nations adhere to their commitments to combat neurological conditions and enhance overall brain health by implementing the WHO's IGAP goals. Putting the voice of people with lived experience and their needs at the centre of this work is essential. Together, we can foster an integrated, participatory, and tailored European and national IGAP response, yielding lasting health, economic, socio-political, and environmental benefits. This approach will improve the lives of individuals with neurological conditions, their carers and families, reduce the prevalence of neurological conditions in Europe, elevate brain health as a valued and protected asset, further contributing to optimal living for those with neurologic conditions, and benefiting society at large.



KEY RECOMMENDATIONS SUMMARY:

1. Implement a well-resourced EU Joint Action on Neurological Conditions and Brain Health.
2. Revise European pharmaceutical legislation to encourage advancements in neurological treatments.
3. Better resource and integrate the European Reference Networks in national healthcare systems.
4. Launch a patient-centred Brain Health Partnership with adequate resources from EU Institutions, Member States and for-profit actors.
5. Create the European Plan to Promote Brain Health, Optimal Living for those with Neurologic Conditions and Combat Neurologic and Brain Disorders.
6. Ensure active and equal patient participation in R&D activities, HTA and decision-making processes.
7. Adhere to the European Pillar of Social Rights, supporting neurological patients facing socio-economic challenges.
8. Align the EU NCD Initiative's neurological strand with the targets of the WHO IGAP.
9. Prioritise IGAP targets to raise policy prioritisation and strengthen governance.
10. Develop national and EU-wide awareness campaigns and plans for neurological conditions.
11. Strengthen neurological patients' capacity at a national level through a dedicated EU project.
12. Foster national neurological alliances to facilitate the implementation of the IGAP.

Together, these actions will lead to a more integrated, participatory, and tailored approach to neurological health in the EU, improving the lives of individuals with neurological conditions and their families.

