

"Headway – A new roadmap in Brain Health: Focus Epilepsy", realized by the Think Tank The European House – Ambrosetti in collaboration with Angelini Pharma, was conceived and launched in 2022 with the aim of creating a multidisciplinary platform for strategic reflection, analysis, dialogue, and comparison between various European experiences in the management of individuals with Epilepsy.

The initiative **keeps the trajectory** and **works in continuity and coherence** with programs, activities, and strategies of Governments and International Organizations (such as the WHO) and scientific societies/patient associations/advocacy groups (among others, ILAE, IBE, and Epilepsy Alliance Europe), as well as of European Institutions, to contribute to **reducing the burden of Epilepsy** in Europe. The specific goals include to:

- Increase knowledge and awareness of the critical issues/specificities related to Epilepsy, outlining the current scenario in Europe and elaborate reflections on the impacts of Epilepsy with a particular focus on the quality of life of individuals;
- Create benchmarks to compare policies and action plans developed and implemented across Europe;
- Stimulate debate among relevant stakeholders (including policymakers, institutions, patient and caregiver associations, clinicians, etc.);
- **Communicate and disseminate** the results of the initiative and its priorities areas of intervention.

Among neurological disorders, Epilepsy is the 4th most common in Europe, causing 1.3 million DALYs and 941,000 YLDs. The incidence of the disease is often underestimated given the complexity of symptom manifestation and underlying causes. Nonetheless, estimates report nearly 400,000 new cases in Europe each year, for a total of 6 million individuals living with Epilepsy (6-8% of the population).

Epilepsy and its seizures can develop in any person at any age, even though the latter are more common in children and the elderly. The risk of premature death in people with Epilepsy is up to 3 times higher than for the general population, while life expectancy is reduced by 2-10 years.

It is important to tackle Epilepsy and support individuals with Epilepsy due to its important **economic burden** equal to ~20 billion euro annually. Social exclusion and stigma largely contribute to the global burden of Epilepsy. Despite this, very few European countries have national plans for managing the disorder.

The **COVID-19 pandemic has exasperated** some of these issues: disruption of services, difficult access to medicines, interrupted immunization programs and increased mental health issues have added to the **burden of individuals with Epilepsy.**

In the past decade, global health policy has recognized Epilepsy as a **leading cause of disability**. In 2009, the WHO defined **Epilepsy as a social disease**, while in 2020 the 73rd World Health Assembly identified Epilepsy as one of the

most common neurological disorders, adopting a resolution aimed at developing the **Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) 2022-2031**. First discussed as a draft at the 150th session of the WHO Executive Board in January 2022, in May 2022 the document has been **unanimously approved**.

In the European context, the burden of Epilepsy is significant, yet access to quality care is often lacking, especially in some countries: even though approximately **70% of people with Epilepsy are likely to respond to treatment**, around **40% across Europe** - and **up to 90%** in some areas - are missing out (treatment gap), emphasizing the need for harmonization programs and European **guidelines outlining minimum standards of care**. Differences in access to treatment between European countries are not surprising, also given the great variability in terms of national income, life expectancy, and healthcare systems organization.

This preoccupying situation **highlights a serious underlying issue**, impacting also on the experience of people with Epilepsy and their families across all sectors:

- Within school settings, there is a complex interaction between learning ability and Epilepsy, which can result in a greater risk of children with Epilepsy being misunderstood and excluded: it has been estimated that between 25-50% of children with Epilepsy have some degree of educational difficulty.
- In workplaces, both under- and unemployment are more common in people with Epilepsy: studies have shown that people with Epilepsy have significant difficulties in obtaining jobs (in Europe, unemployment is 2-3 times higher among people with Epilepsy vs. general population). Nevertheless, when Epilepsy is well controlled, it has been proven that it has much less impact on employment rates and history.
- In general, people with Epilepsy often experience social withdrawal and isolation, which is frequently the result of anxiety about possible adverse reactions of others in case a seizure should occur in a public area.

SAVE THE DATE

We will talk about this and more at the **Digital Event** "HEADWAY – A NEW ROADMAP IN BRAIN HEALTH: FOCUS EPILEPSY", which will be held on July 21st, from 16.00 – 18.00 (CEST) to present the main findings of the report realized with the contribution of European Epilepsy experts.

For information and registration, please <u>click here</u>.



