

## Executive Overview

Encephalitis is a thief. In the same way that we have watched other neurological conditions and diseases rob people of their lives and loved ones, encephalitis has quietly been at work for hundreds, if not thousands, of years, robbing families of their loved ones, and even in those families where the person survives, it often robs them of the person they once knew. Encephalitis steals their capacity to remember as well as their personalities and the types of abilities we all generally take for granted: concentration, attention, thinking, judgement, inhibition. For many there are additional outcomes such as epilepsy and levels of fatigue so great that returning to work or education are mere pipe dreams. This is of course where the person survives, but many do not.

For many years understanding of the condition has been a poor relation to that of many other neurological conditions or diseases. Encephalitis was often relegated to the silo of 'rare disease'. Yet despite many suggestions that incidence is underestimated, encephalitis has a higher incidence than motor neuron disease/ALS, bacterial meningitis, and multiple sclerosis in many countries. With new and emerging infections, our increasing understanding of the causes of the condition, improvements in treatments, and activities of global change-maker organisations, now is the time to elevate encephalitis onto a platform shared by many other conditions that receive much greater public and policy attention.

Encephalitis International is knocking on the door to 30 years old and over that time has developed a rounded expertise on the condition and its impact on patients and families, including those left bereaved, that does not exist anywhere else in the world. Improvements in its governance and infrastructure along with the development of a passionate and dedicated team of paid and voluntary team members means that the organisation found itself well placed to secure funding for, and commission, this report. It has been a collaborative effort including the charity's Chief Executive and its Scientific Advisory Panel, supported by its Board of Trustees.



In this report we not only identify the issues, but we also propose a range of solutions to the impact of encephalitis around the world, ranging from epidemiology, incidence, and economic impacts through to prevention, diagnosis and treatment, and the needs of patients and families. Encephalitis International has the infrastructure to align and lead a collaborative initiative based on this report that will result in both quick and longer-term wins. We will bring together leading global health organisations, public health bodies, and policy makers who are best placed to steer the findings of this report and help us build a global response that will result in preventing and reducing the impact of encephalitis around the world. Now is the time to come together and advance the fight against encephalitis and its many causes resulting in greater access and equity across healthcare in relation to encephalitis. Only then will our global communities see a reduction in its devastation and thrive in ways we can currently only dream of. This report is the first step in a global commitment to reducing the incidence of, and morbidity and mortality from encephalitis.

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