Bringing Epilepsy Out of the Shadows

Epilepsy remains the most common, serious neurological condition in the world. Despite it being so widespread, epilepsy continues to be misunderstood. The social impact for those who live with the condition can be serious, sometimes devastating.

Statistics
Epilepsy is the tendency to have recurring seizures. The condition is universal. It affects people whatever their age, gender, ethnic group or country. Fifty million people have epilepsy worldwide. One person in every 103 in the UK and 1 in 97 in Scotland – that’s 54,000 people - develops epilepsy in their lifetime.

Out of the Shadows Campaign
Raising awareness of epilepsy is a key priority of Epilepsy Scotland. We also work with the International Bureau for Epilepsy (IBE) and its World Health Organisation (WHO) partner, supporting their international campaign called ‘Out of the Shadows.’

This global campaign is the most ambitious attempt to raise awareness of epilepsy. It aims to overcome general ignorance, misinformation and stigma attached to this condition. We want to inform the public about the emotional and social consequences that can follow a diagnosis of epilepsy. The campaign also highlights the medical and social care needed by millions of neglected people across the world

Epilepsy Services
With early diagnosis and treatment, up to 70% of patients can have seizure freedom and lead normal lives. However, this does not happen uniformly because epilepsy services are fragmented, even in developed countries. Few governments or health departments have a national/ regional plan for epilepsy, far less implement them.

Misdiagnosis rates for epilepsy range from 20-30 per cent. There’s a UK shortage of neurologists, with under 60 in Scotland for a population of 5 million people. Epilepsy Scotland’s has campaigned for More Specialist Nurse, Better Epilepsy Care. The country only has half the specialist nurses needed (62.5) for the epilepsy population.

There are around 1,000 epilepsy-related deaths in the UK each year, and nearly 100 of these occur in Scotland. Until the 2002 national audit into epilepsy deaths, there was little recognition of the syndrome SUDEP - Sudden Unexpected Death in Epilepsy - which is between 3 times higher than the annual number of cot deaths.

Making epilepsy a priority
Epilepsy Scotland is determined to make epilepsy a priority of the health and social care agenda. We continue to press the Scottish Government, NHS Boards and various agencies to develop policies that improve services for people with epilepsy.

Media award
With ongoing media coverage, Epilepsy Scotland aims to raise public awareness. With your help, future generations will benefit from more enlightened attitudes.