Bringing Epilepsy Out of the Shadows

Epilepsy is still the most common, serious neurological condition in the world. However, even though it is so widespread, epilepsy continues to be misunderstood. This often results in devastating social penalties for those living with the condition.

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 or 1 in 97 in Scotland – that’s 54,000 people in Scotland - 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 the World Health Organisation (WHO). We support their international campaign called ‘Out of the Shadows.’

The global campaign is the most ambitious attempt to raise awareness of epilepsy. It aims to overcome misunderstandings 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, between 50% and 70% of patients will have seizure freedom and can lead normal lives. However, this often does not happen because epilepsy services are fragmented even in developed countries. Very few governments or health departments have any national or regional plans for epilepsy.

Misdiagnosis rates for epilepsy range from 20-30 per cent. There is a UK shortage of neurologists; Scotland has around 57 for a population of 5 million people. Epilepsy Scotland’s has campaigned for More Specialist Nurse, Better Epilepsy Care. Scotland has 31 specialist nurses yet needs 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 3-4 times higher than the annual number of cot deaths.

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

Journalist of the Year award
With ongoing media coverage, Epilepsy Scotland, aims to raise public awareness. Through our combined efforts, epilepsy will finally come out from the shadows.