

Dear Practice Manager,

Re: Request of support for a new SUDEP and Seizure Safety Check List and the Epilepsy risk self-monitoring mobile App (EpsMon) – launching 14th July 2015

I am writing to alert the Practice to the launch of the **SUDEP and Seizure Safety Check List** an easy reference, practical, evidence based tool that is quickly completed in clinic by doctors and patients with epilepsy to assess their current level of risk. This tool helps to support the prioritisation of clinical activity, gives a baseline to compare changing risk factors and encourages meaningful communication about risk between doctor and patient. The Check List has been developed following a Research project in Cornwall called the Epilepsy Life Project. It is based on evidence of risk factors for Sudden Unexpected Death in Epilepsy, and includes the major risk factors known to be associated with fatality in epilepsy. This Check List will shortly be available for Health Professionals to download from www.sudep.org/checklist and **I would be grateful if you could discuss the use of this within your General Practice and across your CCG team.**

The **NICE guidelines** recommend that people are told of risk, including the risk of SUDEP on or soon after diagnosis, but there is evidence that this does not always happen. A recent editorial in the British Medical Journal highlights premature mortality in epilepsy. It also highlights the lack of screening methods in place to assess and 'flag up' the risks for people with epilepsy, unlike those available for conditions such as Stroke and Cancer; even though epilepsy mortality is second only to stroke amongst Neurological conditions and higher than the deaths caused by Cervical cancer.¹ The SUDEP and Seizure Safety Check List has been used in Cornwall to support improved engagement between Health Professionals and their patients and with this in mind, we hope that you will ensure that patients with epilepsy in your care have on-going access to information regarding their risk and risk management by implementing the Check List into your general practice. By doing so you are also helping to lower the public health burden of Epilepsy on the NHS by empowering your patients to work with you to monitor and manage their condition within a primary care setting.

Also available is **EpsMon**, a digitalised version of the SUDEP and Seizure Safety Check List which has been adapted for people with epilepsy to download to help them monitor their condition and level of risk. Experts in the field of epilepsy have collaborated to develop this new epilepsy risk monitoring app which is the first of its kind in this information rich world. It supports the user to assess their risk every three months, alerting the user when they report a new risk factor or the worsening of an existing risk factor and prompts them to seek advice from their GP as to how they can manage their risks. Further information about the App can be found at www.epsmon.com.

I have included a poster and a leaflet about EpsMon, and **I would be most grateful if you could display the poster and leaflet in your reception area.** Once the App is launched in July we anticipate that GPs may come across patients who are using the App – in preparation for this, if you have any specific questions on EpsMon and its expected impact on patient well-being and clinical practice please email epsmon@sudep.org.

¹ Risdale, L, 'Avoiding premature death in epilepsy General practice is the place to start, and much can be done', BMJ 2015;350:h718
https://www.sudep.org/files/sudepaction/2015_bmj_avoiding_epilepsy_deaths.pdf

SUDEP Action is able to provide more EpSMon leaflets should your practice wish to make these available to your patients during consultations. Similarly if you require any of their other information leaflets (available to view and download at www.sudep.org), please contact the office via info@sudep.org and they will be happy to send them to you.

Finally, should your practice experience a sudden death in epilepsy, services are available from SUDEP Action to support the bereaved family and the practice including the opportunity for families to support research through the Epilepsy Deaths Register. 400 families have now reported to this register and have said they have found this a positive experience following a tragic unexpected death. If you could make anyone bereaved by epilepsy aware of our services that would be appreciated.

Thank you in advance for your support,