



Councillor Jane Hanna  
Chair of the Oxfordshire County Council Joint Health Overview and Scrutiny Committee  
By email

12<sup>th</sup> January 2024

Dear Cllr Hanna,

I was very interested to hear that the Joint Health Overview & Scrutiny Committee of the Oxfordshire County Council has included an agenda item for your 16<sup>th</sup> January meeting to support a request from SUDEP Action and Epilepsy Action concerning the MHRA's latest regulatory measures for Valproate prescribing.

SUDEP Action is a member of the third sector stakeholder group of the MBRRACE-UK Collaboration led by the National Perinatal Epidemiology Unit at the University of Oxford, which conducts investigations into maternal and perinatal deaths in the UK. As the maternal lead for MBRRACE-UK, I would have requested to speak to the committee directly regarding this agenda item, but I am already committed to speak to the Joint Committee on Vaccination and Immunisation (JCVI) on that date. I would therefore hope that this letter could be brought to attention of the committee at the meeting as I am unable to attend.

The 2023 *Saving Lives, Improving Mothers' Care* report produced by MBRRACE-UK included a Confidential Enquiry into the care of women with epilepsy who died during pregnancy or up to one year after the end of pregnancy. The findings from this enquiry show that that rate of SUDEP has almost doubled between 2013-15 and 2019-21, which represents the period when initial changes to the guidance on prescribing Valproate to women and girls occurred, necessitating an alteration in medication among women of reproductive age. None of the women who died between 2019 and 2021 were taking valproate but most had poorly-controlled epilepsy both before and during pregnancy. Few had received pre-pregnancy advice, or counselling regarding SUDEP and additional risk factors, including the need for reassessment of risk, which may change during pregnancy. It is critically important to recognise the significant risk uncontrolled seizures pose to pregnant women and their unborn and existing children.

The report emphasised the need to promote adherence to anti-seizure medications and recommended standard care for women with epilepsy to include informed discussions on medication safety and early, consistent review of medications with neurology/epilepsy specialists. Many of these recommendations were reiterated from a similar report published in 2020 indicating widespread variation in care and that there is still a need for national implementation.

It is imperative that the needs of both women and their children are considered in the management of epilepsy. I have significant concerns that without appropriate services in place to provide appropriate and informed counselling and epilepsy management, pregnant women will be put at greater risk of SUDEP.

Therefore, I would like to offer my support for the letter written by SUDEP Action and Epilepsy Action as well as the proposed action of the committee to write to the Parliamentary Health Select Committee and to request the integrated care board to seek a delay in implementing the MHRA guidance until appropriate safety measures for women are in place.

Yours sincerely,

A handwritten signature in black ink that reads 'Marian Knight'.

**Professor Marian Knight MA MBChB MPH DPhil FFPH FRCPE FRCOG FMedSci**  
**Professor of Maternal and Child Population Health**