

Dear Prime Minister,

We are petitioning to urge your new government to recognise the distress of families suddenly bereaved through epilepsy and honour the ministerial and official commitments made to SUDEP Action and Olly Glover MP on 7 July and following cross-party Parliamentary debate on epilepsy deaths.

With more than 21 epilepsy-related deaths each week in the UK, many involving young people and most with treatable epilepsies, families are deeply concerned that a proposed ministerial roundtable with SUDEP Action and supporting MPs did not take place on 20 October and no new date has been set. This was one of several official commitments made to the charity and bereaved families this year. In August, officials apologised for long-standing delays in working with the charity and families.

Three national reports on epilepsy deaths this summer show poor quality of care, service and barriers to access the right medication. A consistent finding across these reports and many recent prevention of death and independent reports is the need for practical action to improve SUDEP awareness, training and communication. Indeed, existing safety tools developed by SUDEP Action with families, partners and government working with SUDEP Action on training, form part of the government's response to coroners this year. Bereaved families often spend years seeking answers through official investigations, making it especially distressing when commitments to engage and work together on practical solutions are stalled.

Over two decades ago government pledged action to tackle the SUDEP gap noting lack of epilepsy risk awareness and complacency in local systems and unfulfilled government reports. Yet deaths have risen, with the same failures repeatedly identified.

Too many lives are being lost. Prime Minister, please ensure the commitments made to SUDEP Action and bereaved families are honoured, help drive the action needed to prevent sudden young deaths and restore hope to families.

Contact/Return Address:

Jane Hanna OBE
18 Newbury Street
Wantage
Oxfordshire
OX12 8DA
Jane.hanna@sudep.org

Signed by the following petitioners