



9 September 2020

Dear Minister Donnelly,

We trust this finds you well. Further to our correspondence with you on the 8th July, we are writing to you again in relation the drug sodium valproate and a number of concerns that affect families who have been impacted by the drug and the wider epilepsy community.

While we received an acknowledgement, we are disappointed to have not received a substantive reply as of today, September 9th.

We enclose below a copy of our previous correspondence for your convenience. As noted in our initial letter, we are seeking a meeting with you to discuss:

- 1) The establishment of an independent inquiry
- 2) The establishment of a Ministerial-appointed valproate stakeholder group
- 3) The need to activate measures proposed by HSE in 2019 to support families affected by foetal valproate syndrome.

The 2018 recommendations of the Oireachtas Committee on Health, coupled with recent responses from Governments in the UK & France – and indeed, your own previous commitment to the issue – have given families hope that their questions will be answered by this Government under your stewardship.

While we appreciate the ongoing challenges that face you and the various arms of the health services in responding to the urgent COVID-19 situation, we are equally cognisant of the fact that there are families caring for children in Ireland whose disabilities were entirely avoidable. These families' lives have been defined and dictated by sodium valproate. They have already waited too long for answers. They cannot be asked to wait any longer.

We urge you to give this issue your earliest attention and we look forward to discussing these matters with you shortly.

Yours sincerely,

Peter Murphy CEO, Epilepsy Ireland Karen Keely Chair, OACS Ireland