**Subject Line: Sodium Valproate (Epilim)**

Dear Deputy/Senator,

I hope you are keeping well. I am contacting you as my local representative regarding the ongoing campaign of OACS Ireland & Epilepsy Ireland regarding the medication Sodium Valproate – also known as Epilim.

Sodium Valproate is a very common epilepsy medication which can have devastating impacts if prescribed to a woman in pregnancy.

I am contacting you to seek that you support this campaign and put forward questions on several matters surrounding Sodium Valproate on the behalf of families who have been impacted by this medication. These are as follows:

1. **Inquiry on historical licensing and prescribing of Sodium Valproate.**

In November 2020, Minister for Health Stephen Donnelly announced that an inquiry into the historical licensing and prescribing of Sodium Valproate. This is because for decades, many women were prescribed the drug during pregnancy and were not made aware of the impacts it could have on their child. Children exposed to Sodium Valproate have a 30-40% chance of having a neurodevelopmental delay while 10% will have a congenital malformation. Families want to know why and how this was allowed to happen – as evidence that the drug could have severe impact on a child was emerging since the 1960s; yet no risk reduction measures were put in place until 2014. Unfortunately, there has been no further details on the prospective inquiry since the Minister’s announcement in Nov 2020.

***The key question is when will the inquiry be established?***

1. **Strengthening of risk reduction measures.**

Due to the risks associated with Sodium Valproate, several measures were introduced around the prescribing and dispensing of the drug in 2014 which were strengthened once again in 2018. Perhaps the most important measure put in place was the “Pregnancy Prevention Programme”. This programme was put in place to ensure that all women on the drug would be made fully aware of the risks associated with the medication; be educated about the potential impacts of the drug; and that that they would be seen yearly by a specialist to sign an annual risk acknowledgement where a woman would acknowledge she was fully aware of the risks associated. There are approximately 1,600 women on Sodium Valproate in Ireland and to help cater for the extra demand this protocol would place on services, it was agreed in 2018 that 6 epilepsy nurse specialists would be recruited to help ensure women were fully informed. To date, only two of these nurses have been put in place.

In addition to the lack of recruitment of these crucial posts, an Epilepsy Ireland survey in 2020 also found that women on the medication are still dangerously unaware of the risks of Sodium Valproate and of the protocols around the prescribing and dispensing of the drug. For this reason, Epilepsy Ireland and OACS Ireland called for the establishment of a stakeholder group consisting of representatives of those involved in the treatment of a women with epilepsy (HSE, Department of Health, HPRA, Clinicians, GP reps, pharmaceutical reps, Patient Groups etc). The aim of such a group would be to review and strengthen the measures which are currently in place to ensure that no family is affected by Sodium Valproate in the future. The Minister has agreed to establish this stakeholder group but again, there has been no further detail on this.

***The key questions are – when will the nurses be recruited and when will the stakeholder group be established?***

1. **Services for families impacted by Sodium Valproate**

Families whose children were exposed to Sodium Valproate in pregnancy are now caring for children with a range of lifelong disabilities. Their needs are varying, wide-ranging and complex. It was agreed in 2018 that a range of services would be put in place for families who were caring for children impacted by exposure to Sodium Valproate. This is known as the Community Operations Programme and would allow a streamlined pathway to access services for families in dire need of support. This programme included a designated support officer in CHO’s, a package of community supports and a pathway of care for children/adults affected by sodium valproate. This programme only exists on paper as to date, no family who has been impacted by Sodium Valproate has been able to access the supports under the plan.

**The key question here is when will the supports be fully operational for families impacted?**

As you can see, there are several outstanding issues on this most important matter. The above is a brief insight on this issue and as a local constituent, I would appreciate if you could raise these matters at your earliest convenience. If you need any further information, I would appreciate if you could reach out to OACS Ireland and Epilepsy Ireland via Epilepsy Ireland Advocacy & Communications Manager, Paddy McGeoghegan to discuss these matters further. Paddy can be reached on pmcgeoghegan@epilepsy.ie.

Thank you for your attention to this matter and I look forward to hearing from you on same.

Yours sincerely,

***Full Name***

***Full Address***

***Contact Details***

***(We recommend that you give these details as it will highlight to your local representatives that this is an issue presenting in their constituency.)***