

<u>Leinster House Goes Red for World FASD Awareness Day 2024</u> (https://www.activelink.ie/node/110824)

CEANN Comhairle, Deputy Seán Ó Fearghaill and Cathaoirleach of Seanad Éireann, Senator Jerry Buttimer illuminated the Kildare Street façade of Leinster House on Monday, 9 September to mark World FASD Awareness Day 2024. Foetal Alcohol Spectrum Disorder (FASD) is a lifelong neurodevelopmental disability that occurs as a result of prenatal alcohol exposure.

CEO of FASD Ireland, Tristan Casson-Rennie commended the move, saying; "FASD is Ireland's most prevalent neurodevelopmental disorder, and it is long beyond time that the State starts to recognise the significant epidemiology of FASD in Irish society. We have learned from replies by the HSE to recent Parliamentary Questions that they estimate one in every ten babies born in Ireland today will live with FASD, with a tenth of those born with the most severe form of FASD, requiring lifelong support and care. We must start a national conversation about FASD in Ireland and the harms of prenatal alcohol exposure. Every year that ticks by where we as a State are failing to discuss FASD openly and honestly is another year that approximately 380,000 people who live with FASD in Ireland and their families continue to go without support. It is vital that everybody who works in health and social care, and education settings in particular get trained up on FASD, how it effects the people who live with it, and what management strategies and accommodations can be put in place to make schools, hospitals and everywhere in between more FASD inclusive. We all have a part to play when it comes to FASD, for our part, FASD Ireland provides free education to all teachers, SNAs and SENCOs who are working within our education system, and we offer a myriad of training to the HSE, CAMHS, TUSLA, the NCSE, An Garda Síochána and other agencies of the State as well as the private sector. We support the families of people living with FASD through our non-judgemental peer support telephone line and through in-person and online follow-up sessions. FASD Ireland provides advice and support to those families where no State agency can or will, and a listening ear after many doors have been repeatedly shut in their faces. To that end, we then fiercely advocate for those families with legislators and key decision makers, speaking truth to power in the halls of Leinster House."

He continued; "Ireland currently has no statutory diagnostic criteria, no diagnostic pathway, and no recognition of FASD as a disability. It is Ireland's silent epidemic."

Commenting further on the move to mark the occasion, Mike Taylor, Director of Policy & Public Affairs at FASD Ireland said; "this represents the first time that the Houses of the Oireachtas have recognised World FASD Awareness Day, which is very fitting given that this is the first year a national organisation with an FASD remit has been State funded.

FASD Ireland received funding of €200,000 this year from the Minister of State for Disability, Anne Rabbitte TD. We are seeking to increase that funding to €1.2 Million next year, which we have included in our Pre-Budget Submission, which was launched recently. Our Pre-Budget Submission also calls for investment into indigenous research into FASD in Ireland by the Centre for Autism & Neurodevelopmental Research (ICAN) at the University of Galway and for a national FASD awareness programme to be piloted to all Transition Year cohorts at every secondary school, with a view to rolling out training across the school system over the coming years. We're aware that all of these things cost money to do. The total cost of our Pre-Budget Submission would come to just under €1.4 Million, however we propose to make this cost neutral by calling on the Government to establish a ringfenced Alcohol Related Harm Fund, funded through a levy imposed of 1% ontrade and 2% off-trade on the existing VAT paid on alcohol by the consumer.

Taylor went on to explain; "The levy as we have proposed it would ringfence around €80,000,000 a year from the existing alcohol tax-take by the exchequer. It would fully fund several alcohol related harm services like FASD Ireland, cancer services, addiction support, and various medical services. This alcohol levy is a cost recovery mechanism. The high expense of issues linked to alcohol makes it very important to identify areas for initiatives in harm reduction and support. The introduction of the levy can mobilise the concept of harm as a lever to involve the alcohol industry in efforts to reduce the harm from the use of its product. When a product such as alcohol causes harm that impacts large swathes of the population (estimated 2.8% -7.4% of Ireland living with FASD) its critical to consider accountability of the industry for adverse health outcomes. According to the Alcohol Market Review from the Health Research Board in 2022, the societal cost of alcohol use estimates range from €2.4bn to €3.7bn per year."

The Pre-Budget Submission can be viewed at www.fasdireland.ie/prebudget-submission-2025 (http://www.fasdireland.ie/prebudget-submission-2025)

(http://www.fasdireland.ie/workshops)

Region

Nationwide

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