



Dearadh agus Nuálaíocht Chliniciúil; Oifig an Príohifigeach Cliniciúil  
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29<sup>th</sup> March, 2022

Deputy Neasa Hourigan, TD  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

**RE: PQ 14951/22**

**To ask the Minister for Health if he plans to conduct a national awareness campaign in relation to osteogenesis imperfecta to help raise awareness among the general public of the condition; and if he will make a statement on the matter.**

Dear Deputy Hourigan,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Children on your question and have been informed that the following outlines the position.

Wishbone Day falls on 6<sup>th</sup> May every year and is an International Day of Awareness of Osteogenesis Imperfecta (OI) and related conditions of bone fragility. The day is celebrated by the staff of the Centre for Rare Paediatric Bone Disorders (#OurTribe) in conjunction with the Brittle Bone Society, which is based in Scotland but reaches out to families across the UK and Ireland to raise support and awareness for this condition. In January 2022, Our Tribe was welcomed as a member of the European Reference Network for Rare Bone Disease (BOND) which works with patient advocates across Europe to advance care and awareness of this condition.

Children and Adolescents with OI are cared for by many teams across the country, encompassing general paediatrics, endocrinology and orthopaedics. Since 2019, Our Tribe has set up dedicated OI clinics in CHI at Temple Street Hospital with the support of funding from the Temple Street Foundation (now Children's Health Foundation). One of the aims of the service is to increase knowledge and advice for local care provision for children through the outreach model from CHI. It would include information meetings for local allied health professionals (AHPs) and schools/social outlets at important stages in a young person's development.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

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**Anne Horgan**  
General Manager