

Written Evidence from Donate4Dáithí on the Organ and Tissue Donation (Deemed Consent) Bill

Donate4Dáithí

Donate4Dáithí is a family and community run campaign to raise awareness of organ donation and to help normalise organ donation in our society. Our campaign has also lobbied politicians on this issue of the Organ and Tissue Donation (Deemed Consent) Bill. Donate4Dáithí is very proud of the role played in this bill getting this far and hopes that it will become law before this end of this legislative mandate.

The campaign is organised by us Dáithí's parents (Máirtín and Seph), and Dáithí. Dáithí Mac Gabhann was born in October 2016 with a condition called Hypoplastic Left Heart Syndrome, which basically means that Dáithí was born with half a working heart with the left side not forming correctly in the womb. Dáithí has now been waiting for the gift of a new heart for 3 over years.

Normally for children with HLHS, they will have three open heart procedures. The first (**Norwood**) shortly after birth, the second (**Glenn**) after a few months of birth, and the third (**Fontan**) a few years after birth. Dáithí had the Norwood procedure at just 4 days old, and after initially working, Dáithí needed to be placed on a lifesaving bypass machine called ECMO for 6 days to save his life. Dáithí's Norwood procedure would need to be reconstructed, and at just 10 days old and all the odds were against him, Dáithí managed to pull through and make it home to Clark Clinic for Christmas 2016.

Dáithí then went for the Glenn procedure in February 2017, which was much more straightforward, and he was discharged from hospital for the first time in March 2017. Like many children with HLHS, Dáithí's journey has been quite rough, although he did manage to stay hospital free for most of 2017 after being discharged.

Dáithí was readmitted on St. Stephen's Day 2017 with the flu, and this would start his transplant journey. While recovering from the flu, the team at Evelina and RVH were worried about regurgitation in Dáithí's tricuspid valve and how that would affect the Fontan procedure. In January 2018, the team at Evelina London felt that the regurgitation in the tricuspid valve was too severe, therefore ruling Dáithí out of the Fontan procedure. This is when Dáithí and his parents were told for the first time that, a heart transplant would be Dáithí's only hope.

Dáithí was then sent to The Freeman in Newcastle for transplant assessment and a second opinion on the tricuspid valve. On 1 June 2018, Dáithí was placed on the routine waiting list for a heart transplant, with the Freeman team agreeing that the regurgitation of the tricuspid valve was indeed too severe for further surgery.

Dáithí has now been on the waiting list for a heart transplant for more than 3 years, and his family and community have continued this Donate4Dáithí campaign to raise awareness of organ donation, while he waits.

Information

Organ transplantation is the only effective treatment available for many patients with organ failure. Around 14 people die each year while on the waiting list in Northern Ireland.

- As of 30 June 2021, there were 125 people waiting for an organ transplant in Northern Ireland, 16 of them waiting on a new heart.¹
- Over 90% of the population in Northern Ireland supports organ donation but only 50% have recorded this decision on the NHS Organ Donor Register.²
- A recent poll commissioned by BHF showed that 74% of people here support the introduction of a soft opt-out system for organ donation.³
- Evidence from Wales, which introduced a soft opt-out system in 2015, has shown an increase in both consent rate and donation rate as well as support from health service staff for the change in organ donation system.
- In England, a new opt-out system came into effect from 20 May 2020. Scotland's opt-out system came into effect on 26 March 2021. In the last year, the organs of 296 people have been donated under the new law which accounts for 29% of all donors (1,021) since 20 May 2020 and resulted in a total of 714 organs being transplanted.⁴

Recommendations for action by the government departments and/or others that Donat4Dáithí would like the committee to consider for inclusion in its report

To maximise the potential of a soft opt-out system, legislation must be accompanied by:

- a comprehensive communications strategy pre and post the introduction of a soft opt-out system;
- investment in health structures including workforce to maximise the potential of a soft opt-out system;
- organ donation becoming a key part of the everyday routine within hospital practice.
- children under the age of 18 are excluded from this bill, and although Donat4Dáithí understands the sensitivities around organ donation and children, we would encourage further awareness around children and organ donation. The Department of Health's public consultation showed that 37% of responses thought that children should be included in this bill. Although, we are not suggesting that children should be included we

¹ <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/>

² <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/24209/nhsbt-northern-ireland-summary-report-jun-21.pdf>

³ Poll conducted by YouGov on behalf of British Heart Foundation Northern Ireland. Total sample size was 500 adults. Fieldwork was undertaken between 24th - 29th June 2021. The survey was carried out online. The figures have been weighted and are representative of all NI adults (aged 18+).

⁴ [Family and public support helping save lives one year on from the introduction of Max and Keira's Law - NHS Organ Donation](#)

do believe that this high number suggests that our society are more willing to have those conversations around children and organ donation and to do more to make parents and guardians that children can indeed join the NHS Organ Donor Register. We do believe that it is currently unclear for parents and guardians. 47% answered that children should be excluded from this bill.

Donate4Dáithí would welcome the opportunity to give oral evidence to the Committee for Health on the Organ and Tissue Donation (Deemed Consent) Bill.

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