

Board Meeting in Public Tuesday, 24 September 2024

Title of Paper	Patient Story- Dáithí's Law. Waiting for a heart transplant and successfully campaigning for the introduction of a soft opt out system in Northern Ireland.	Agenda No.	2.1
Nature of Paper	<input checked="" type="checkbox"/> Official <input type="checkbox"/> Official Sensitive		
Author(s)	Máirtín McGabhann, Dáithí's father		
Lead Executive	Dee Thiruchelvam, Chief Nursing Officer		
Non-Executive Director Sponsor			
Presented for (tick all that applies)	<input type="checkbox"/> Approval <input checked="" type="checkbox"/> Information* <input type="checkbox"/> Assurance <input type="checkbox"/> Update * See Note i		
Executive Summary (max 300 word count)			
<p>This patient story tells the story of Dáithí Mac Gabhann and his family.</p> <p>Dáithí was born with Hypoplastic Left Heart Syndrome and, after two major heart surgeries in his first 6 months of life, he was placed on the heart transplant waiting list when he was 18 months old.</p> <p>Dáithí's family launched the Donate4Dáithí campaign and began working to educate people on organ donation and lobbying for a change in the law.</p> <p>This resulted the passing of Dáithí's Law which introduced a soft opt out system for organ donation in Northern Ireland. This took effect from the spring of 2023.</p>			
Previously Considered by			
N/A			
Recommendation	The Board is asked to note the contents of this paper		
Risk(s) identified (Link to Board Assurance Framework Risks)			
P-01 – Donor and Patient Safety, P-04 – Donor numbers and Diversity, P-06 – Clinical outcomes and Health Inequalities			
Strategic Objective(s) this paper relates to: [Click on all that apply]			
<input checked="" type="checkbox"/> Collaborate with partners <input type="checkbox"/> Invest in people and culture <input checked="" type="checkbox"/> Drive innovation <input type="checkbox"/> Modernise our operations <input checked="" type="checkbox"/> Grow and diversify our donor base			
Appendices:	None		

Dáithí's Story: Waiting for a heart transplant and changing the law on organ donation in Northern Ireland.

Dáithí Mac Gabhann was born in October 2016, bringing an unimaginable journey of hope, courage, and resilience to our family. Diagnosed with Hypoplastic Left Heart Syndrome (HLHS)¹, a condition where the left side of the heart is critically underdeveloped, Dáithí came into this world facing incredible challenges.

At two days old, the family travelled to the Evelina London and four days after his birth, Dáithí underwent his first open-heart surgery, the Norwood procedure. Though the initial surgery seemed successful, Dáithí soon faced life-threatening complications. He was placed on an Extracorporeal membrane oxygenation (ECMO) machine, a lifesaving bypass, for six days—days filled with anxiety, fear, and little hope. At just 10 days old, Dáithí underwent a second surgery to reconstruct the Norwood procedure. The odds were overwhelmingly against him, and Dáithí was given less than 10% chance of survival. Against all the odds, Dáithí made it home to Clark Clinic in Belfast in time for his first Christmas.

In February 2017, Dáithí underwent his second major surgery, the Glenn procedure. This time, the surgery was more straightforward, and by March, Dáithí was discharged from the hospital, ready to experience life outside of medical walls. For most of 2017, he managed to stay hospital-free, a rare and cherished period of stability for a child with HLHS.

However, Dáithí's journey took another turn on St. Stephen's Day 2017, when he was readmitted to the hospital with the flu. As he recovered, the medical team began to express concerns about the regurgitation in his tricuspid valve and its impact on his ability to undergo the final Fontan procedure. By January 2018, it became clear that Dáithí's only hope for survival was a heart transplant. The news was devastating, but it also ignited a spark of determination in our family.

The beginning of the Organ Donation journey

In June 2018, Dáithí was placed on the heart transplant waiting list after specialists at The Freeman in Newcastle confirmed that further surgery was not an option. Since then, Dáithí has been waiting for the gift of a new heart, a gift that could save his life and give him a future full of possibilities. This wait, now over six years long, has been filled with uncertainty and anxiety, but also with hope.

While Dáithí waits, our family decided to launch the Donate4Dáithí campaign², and have become powerful advocates, educating the public about organ donation, and even lobbying for a change in the law. Our efforts culminated in the passing of Dáithí's Law in February 2023³, which introduced a soft opt-out system for organ donation in Northern Ireland. Knowing that lives are being saved in our son's name is a source of immense pride for the family—a legacy that will endure far beyond Dáithí's wait. We recently celebrated the first anniversary of Dáithí's Law, we also marked six years of Dáithí being on the transplant waiting list. It was a bittersweet milestone, a reminder of the fragility of life, but also the strength and resilience of Dáithí.

¹ <https://www.bhf.org.uk/-/media/files/information-and-support/publications/children-and-young-people/c81117understandingyourchildshearthypoplastic-left-heart-syndromeweb.pdf?rev=aa723079093f4cc1b90ce0a57a19ca17>

² <https://donate4daithi.com/>

³ <https://lordslibrary.parliament.uk/research-briefings/lln-2023-0014/>

The Donate4Dáithí campaign is a call to action for all of us—to make the courageous, but informed, decision to join the NHS Organ Donor Register⁴ and to share that decision with loved ones.

Dáithí's Law

Dáithí's Law, which introduced a soft opt-out organ donation system in Northern Ireland in 2023, is named in honour of Dáithí, and it represents the culmination of years of hard work, determination, and the belief in the power of community action.

Since its introduction, Dáithí's Law has already begun to save lives. Although the full impact will take years to measure, the early results are promising. In 2023/24, Northern Ireland recorded its highest number of organ donors to date, with 64 donors compared to 59 the previous year. These donors helped save the lives of 158 people in need of transplants—a direct testament to the importance of the law and the awareness it has raised.

Celebrating the first anniversary of Dáithí's Law at Belfast City Hall was a moment of profound pride for our family. We are delighted to know that lives are being saved in Dáithí's name, and we hope that organ donation will continue to be normalised in society.

The road to achieve the passage of Dáithí's Law was incredibly rocky. Our family said that we had moved mountains in February of 2022, when the final stages of the law passed in Stormont. The NI government collapsed shortly afterwards, which left the planned introduction of Dáithí's Law for spring 2023, in doubt. Our team refused to accept this delay and brought the campaign to the Secretary of State for Northern Ireland. The campaign garnered huge media attention. Although we were told that it would be impossible to achieve in the period, the British Government made an “extraordinary intervention,” which allowed Dáithí's Law to pass. Dáithí was later presented with a Points of Light Award from the then Prime Minister Rishi Sunak, and the Freedom of Belfast City was bestowed upon him as well for his efforts – which brought further awareness to organ donation.

In addition to achieving this law change, Máirtín is a teacher in an Irish Medium school and he and his family have launched Irish language organ donation school resources. These resources aim to introduce organ donation education at an early age and provide Key stage 1 and 2 pupils with the information they need to find out more about the topic and to discuss with family and friends. Máirtín was awarded an MBE in June 2024

⁴ <https://www.organdonation.nhs.uk/register-your-decision/>