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THE ASTHMA UK AND
BRITISH LUNG FOUNDATION
PARTNERSHIP

The Health Committee Clerk,
Room 419,
Parliament Buildings,
Ballymiscaw,
Stormont,
Belfast,
BT4 3XX

23 September 2021

Dear Health Committee Clerk,

RE: Organ and Tissue Donation (Deemed Consent) Bill

I am writing to you in response to the Committee's call for evidence during the Committee Stage of 'Organ and Tissue Donation (Deemed Consent) Bill' on behalf of Asthma UK and British Lung Foundation Northern Ireland. AUK-BLF Northern Ireland is a charity which seeks to promote understanding of lung health, to campaign for prevention and better treatments, to provide support for patients and their families, as well as undertaking critical research into lung health.

AUK-BLF Northern Ireland welcomes the Bill brought to the Assembly by The Minister of Health in July 2021. Chronic lung diseases cause significant lasting damage to the lungs. Whilst there are some treatments available these are often short-term solutions to the feeling of breathlessness and significant reduction on quality and length of life. The presentation of this Bill to the Assembly, bringing deemed consent of organ donation to Northern Ireland, presents a significant opportunity and hope to those living with lung disease.

Those who have received a lung transplant note a significant transformation in their lives. On average life expectancy increases by 5 years after receiving a lung transplant with many more living beyond that mark. With this extra time comes renewal of many hopes and opportunities abandoned beforehand because of the limitations of living with lung disease. No longer is there a need to be tethered to an oxygen concentrator 24 hours a day. Most importantly for recipients there is more time to spend on the most important aspects of life for them including sharing more time together with friends and family at the most special times of year.

For the lung diseases for which transplant is a viable treatment option, such as idiopathic pulmonary fibrosis (IPF), the average survival time from diagnosis is 3 years. Every month spent on a waiting list means more people desperately waiting for the call that could save their life. Sadly, we know that a quarter of people on the waiting list for a lung transplant waiting list will die, or be unfit to undergo surgery, before donated lungs become available.

This legislation will not deliver solutions for everyone who requires treatment for their lung condition, and there especially remains a need for significant strategic planning and investment in respiratory care in Northern Ireland. However, the switch to deemed consent will enable a conversation around organ donation in Northern Ireland to take place.

An opt-out system of organ donation will have the most dramatic impact on family refusal, which is one of the biggest barriers to transplant. Clause 7 of the Bill, amending Health (Miscellaneous Provisions) Act (Northern Ireland) 2016 strikes the right balance by ensuring that those who do not want to donate have their wishes respected, whilst at the same time encouraging more people to give the gift of life to others. By requiring the Department to engage annually with adults in Northern Ireland concerning their donation choice the Bill works to establish an environment of confidence for individuals concerning if and how they donate organs in the event of their death. For families this clause will allow for peace of mind at the most difficult of times, knowing that a decision has been made at an earlier stage.

Our hope at AUK-BLF is that the tabled legislation and the prospect of a greater number of lung transplants for those waiting in Northern Ireland will bring a ray of hope to those living with lung disease.

Yours sincerely,



Joseph Carter
Head of Devolved Nations
Asthma UK and British Lung Foundation Northern Ireland

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