

Mark Murphy, Chief Executive, Irish Kidney Association

Opening Statement

Madam Chairman and members of the committee; thank you for giving the Irish Kidney Association (IKA) the opportunity to address you all and share our observations and suggested amendments to the bill in question.

The IKA was formed 41 years ago to advocate for patients, and their families, affected by kidney failure. Our first mission was to introduce what was then the **Kidney Donor Card**, raise public awareness about how kidney donation works and how it can be the **Gift of Life**. As transplantation progressed to include more organs the kidney donor card became the **Organ Donor Card 20 years ago**.

The role of the organ donor card has always been to prompt the **organ donation conversation** within families as informed consent is key to the success of the process. Technology has allowed us to reach beyond the traditional card - we now also have a Digital Organ Donor Card app but the same principle applies – the app is there to prompt conversation and as a reminder of a decision made.

For over a decade we have been advocating for the introduction of an **Organ Donor Register**. This would offer a very clear ‘call to action’ for the public and can be very easily established in such a way that facilitates the **organ donation conversation**.

With a Register, ODTI would have, for the first time, have a central record of an individual’s decision to be an organ donor. This is consulted when a potential donor is identified and knowing that a loved one had proactively recorded their wish to be an organ donor makes the family decision to consent a much easier proposition.

In putting an emphasis on ‘Soft opt out with family consent’, this Bill is misleading the public as it implies a change of practice whereas the reality is that it actually stays the same. Currently, a potential organ donor is identified, the family is approached and consent for retrieval is given or not. Under the proposals in this bill, the public will have the opportunity to opt-out of organ donation. If they do not opt-out they will be considered potential donors but the family will still be approached for final consent – where’s the difference?

We want people to say YES to organ donation but just as importantly, we want their families to also say YES. How do we do this? We encourage conversation. The public will only look at the headlines

of this bill and see that if they do not opt-out then they will be considered potential donors – you removed the call to action, you remove the prompt for family conversation.

Don't just take my word for it, there are people a lot more learned than myself who will tell you that the introduction of an system of opt-out will not affect growth in deceased donors.

To quote a paper titled "Comparison of Organ Donation and Transplantation rates between opt-out and opt-in systems;"

'Our data demonstrates no significant difference in deceased donation or solid organ transplantation activity between opt-out versus opt-in countries.'

This suggests that other barriers to organ donation must be addressed even in settings where consent for donation is presumed. The author concluded that greater emphasis on education and informing the general population about the benefits of transplantation is the preferred way to achieve an increase in organ donation. These findings have important implications for transplant clinicians and health policy makers when considering the merits of organ donation strategies.

Another paper titled 'Opt out legislation, the Mysterious Viability of the False' was written by Rafael Matesanz and Beatriz Dominguez-Gil, the retired and current leader of the most successful organ donation organisation in the world; ONT in Spain.

In summary, the evidence does not support that shifting towards presumed consent will solve organ shortage. But still today, this measure is seen as a magic solution that departs from conviction that low deceased donation rates result only from a negative public attitude and poor contribution from society. It results from ignoring that the key to success lies within the healthcare system. We should never blame the population. If people donate less, it must be something we have done wrong.

Head 19:

The bill's focus on an Opt-out only register is a huge missed opportunity. Give the public an opportunity to Opt-in also! The register goes from being viewed negatively by wider society to being a useful call to action and decision aid for families when their consent is sought.

The UK has had a Register for 25 years. They also have detailed donor audit reports that show the evidence of the value of their Register and the role of Specialist Nurses for Organ Donation (SNODs).

Only 29.8% of families consent when no SNOD is involved in the formal organ donation conversation with the family. That increases to 57.5% consent when the SNOD is involved but the potential donor

had not signed the donor register. This increases again to 93.9% of families consenting to organ donation if a SNOD is involved AND the potential organ donor has signed up to the Register. It is hard to argue with such statistics...

In relation to developing a YES or opt-in Register we are actually already in a very strong position with 957 500 people who have the new format driving licence or driving permit have chosen to have the code 115 added to their licence to indicate their wish to be an organ donor. This data can easily be transferred to the department of health IF the desire is there to make it happen.

In conclusion, we have a number of edits for you to consider and plenty of supporting materials which we believe will help you make a truly informed decision on the future of organ donation in Ireland.

Thank you for not presuming our consent for this bill.

Mark Murphy

Chief Executive.