

A4. BILLS FOR SECOND READING

**4.1. Human Tissue and Organ Donation Bill 2020 –
Second Reading approved**

Mr Perkins to move:

That the Human Tissue and Organ Donation Bill 2020 be read a second time.

The Speaker: We turn to Bills for Second Reading, and the first is the Human Tissue and Organ Donation Bill 2020. I call on Mr Perkins to move.

Mr Perkins: Thank you, Mr Speaker.

Hon. Members, I have been motivated to bring this Bill before this Hon. House as I am aware of a number of people on the Island who have had kidney, heart, cornea and other organ transplants and it has completely changed their lives. I am also very much aware of the relatives who have lost loved ones and have had to make the difficult decision to donate their organs at a time of family trauma.

Daniel Boyde was a young Manx lad who tragically lost his life following a car crash in 2007. His mum, Diane Taylor, bravely gave permission for his organs to be donated, which helped four other people. Since that time, Diane has worked tirelessly to keep the subject of organ donation in the public mind, raising enough money to fund a memorial garden in Noble's Hospital which commemorates all donors from the Island, including one of our own, a former colleague, Martyn Quayle. Consequently, with your agreement, I propose the unofficial title of the Bill should be Daniel's Law. (**A Member:** Hear, hear.)

The consultation received a total of just under 300 responses. The vast majority of these were very supportive. England changed to an opt-out system last May; Scotland and Wales have also adopted opt-out systems. A couple of years ago, Junior Tynwald voted unanimously for an opt-out system.

The main aims of the Bill are to modernise the law with regard to consent of organ donation, enable more organs to become available to save and improve lives, clarify the process and reduce the stress for donor families, and also facilitate the seamless transfer and use of organs retrieved on the Isle of Man to be used for transplantation in another place.

The legislation is known as a 'soft opt-out' option: everyone over the age of 18 will be considered opted in, unless they opt out of organ donation.

The UK NHS Organ Donor Database have kindly agreed that they will record Isle of Man residents' wishes, and, importantly, it will not cost the Isle of Man anything. Vitality, it is a quick and convenient one-stop shop for the medical team to ascertain your wishes. Hon. Members, time is of the essence when organ donation is taking place.

The easiest way of making your wishes known is to go on the UK NHS Organ Donor Database and register your decision. You can opt out with no stigma attached. You can opt in and choose which of your organs you wish to donate, by ticking the relevant boxes. Some people wish all their organs to be donated; other people do not want their eyes donated, so they just do not tick that box. You can also phone in, on the dedicated helpline, if you do not have access to a computer.

In any event, with this legislation, your family will always be involved before donation takes place. Currently, the question that is asked is 'Will you give permission for your loved one's organs to be donated?' If the legislation goes through, Hon. Members, the question will be different. It will be along the lines of 'Did you ever hear your loved one say they did not wish their organs to be donated?' as indeed the donor may have changed their mind the week before and told their relatives, in which case donation would not take place. This takes the stress out of

having to give permission at the time of trauma. Rather, it is a confirmation of a loved one's wishes.

It is important to register and discuss what you want to happen with your family, so your decision is clear and so that they and you know that your decision will be honoured. If you have not expressed your decision to opt out of donation and are not in an excluded group, it will be considered that you consent to donate your organs. So, even if you do not record that you want to be an organ donor, it is important to let your family know what you want.

This Bill does not facilitate the donation of what is sometimes termed 'exotic transplant', such as faces or whole limbs. That is for another time and another place.

As of yesterday, a total of 13,638 Island residents had already logged their decision on the UK NHS Organ Donor Database, and that is around 15% of the Island's population. A total of 133 people have completely opted out. Some people have said to me, 'I'm not going to let the Government snatch my organs!' Hon. Members, that is just not the case. This Bill will facilitate organs you no longer need going to a worthy recipient and will certainly be life changing or life giving.

The legislation places a requirement on the DHSC to provide Tynwald with an annual report, and also to publicise the benefits of organ donation on or around 15th March each year.

Coming on to the human tissue part of the Bill, following discussions with the Isle of Man Health Service professionals in organ donation and retrieval, it became clear that the Isle of Man human tissue legislation is currently sadly lacking. The Health managers, including the mortuary and path lab managers, were keen to update the legislation, highlighting the need for a legal framework in which they can work. So, the Bill, on the human tissue side, modernises all Isle of Man legislation regarding post mortems and tissue retained for other purposes.

The legislation is a 'Manxified' Scottish version of legislation. Having liaised with the UK Human Tissue Organisation, it was clear that England is moving to the Scottish model, as it is considered better.

The Bill recognises a child can give consent while alive. If not, a person with parental responsibility can give consent – that is for medical research, retention of organs and slides. If parents are not available, or are unwilling to deal with consent, a person who stood in a qualifying relationship with the child may give consent, and that is fully listed in section 5, in complete priority order.

It makes provision for people unable to give consent. If the activity includes research or transplantation purposes, the person is deemed to have consented unless there is evidence to the contrary. It also authorises a qualified person to retain a body while enquiries are made. At present, there is no legislation for this.

Surplus tissue may be disposed of as clinical waste. Urine and faeces contain human cells, and amputated limbs are also considered clinical waste. Hon. Members, we do not wish to go back to ask permission from the relatives to dispose of these things. Disposal of aborted fetuses is dealt with under the abortion legislation.

The Bill also permits the analysis of a person's DNA, if it is necessary for one of the excepted purposes, for example rape or domestic violence where the perpetrator has been killed and the victim wishes to find out more about the medical situation.

This Bill gives the Isle of Man regulatory independence and it enables facility and personnel licensing without UK cost or interference. It authorises 'the Department' as the Cabinet Office and Director of Public Health, which all through the Bill are referred to as 'the Department', not to be confused with the Department of Health and Social Care, similar to separation of powers between parliament and the judiciary.

Codes of practice will be modelled on the UK, through secondary legislation.

Importantly, the Bill deals with religious relics and museum exhibits and also gives powers of search and seizure.

Hon. Members, the Bill is a weighty piece of legislation. I would take this opportunity to thank the drafter and all the people who have given up many hours of their time, and members

of the public who have contributed to it. I consider the Bill to be one of the most important pieces of social legislation that this administration will be bringing forward.

Thank you, Mr Speaker.

The Speaker: I call on the Hon. Member for Ramsey, Mr Hooper.

Mr Hooper: Thank you, Mr Speaker.

I beg to second and reserve my remarks.

The Speaker: Hon. Member for Ramsey, Dr Allinson.

Dr Allinson: Thank you very much, Mr Speaker.

I would just like to thank the Hon. Member for bringing this Bill forward. He was quite clear in terms of its aims. One of those that he mentioned was the sometimes difficult conversations at the time of death of a loved one and having to broach the subject of organ donation with the family, and that is a difficult discussion to have, both from the family's point of view but also the clinician's point of view. Some of these people have died quite suddenly in a road traffic accident or similar occurrence, and, after trying to save that person's life, to then turn round and talk about organ donation can be extremely difficult.

What this Bill does is really champion those tenets of choice, autonomy and, above all, communication, to make sure that individuals have their choice respected, that their autonomy to either donate their organs or decide not to donate their organs is clearly stated and respected, but also that we have much clearer communication, not only between the medical profession and families but perhaps with each other, about what we would like to do if we were to die and what we would like to do to further other people's lives.

Organ donation is a life saver, and I have personally seen the benefits it can have for people on our Island who are struck particularly with liver disease, kidney disease, heart disease or lung disease, so I would just like to thank the Hon. Member for bringing this forward, but also for the compassionate way he has consulted on what can be quite a difficult subject to talk about.

Thank you.

Mr Thomas and another Member: Hear, hear.

The Speaker: I call on the mover to reply.

Mr Perkins: Thank you, Mr Speaker.

I thank the Hon. Member for Ramsey for pointing that out. It certainly is the intention of the Bill to make life easier for everybody. We are very lucky on the Island that we do have a special nurse for organ donation, who is very compassionate. I do thank him for his observations.

Hon. Members, I beg to move that the Human Tissue and Organ Donation Bill 2020 be moved.

The Speaker: The question is that the Human Tissue and Organ Donation Bill 2020 be read for a second time. All those in favour, say aye; against, no. The ayes have it. The ayes have it.