



THE IRISH DONOR NETWORK



Alpha One Foundation (A1)

The Alpha One Foundation was founded in 2001 to raise awareness, increase diagnosis, promote research and improve the treatment of Antitrypsin Deficiency (Alpha-1)
www.alpha1.ie



Cystic Fibrosis Ireland (CFI)

CFI was founded in 1963 to support people and families living with Cystic Fibrosis (CF). Many people with CF will need a double lung transplant because of the damage caused to lungs by CF.
www.cfiireland.ie



Chronic Obstructive Pulmonary Disease Support Ireland (COPD)

Provides support for people with COPD in Ireland.
www.copd.ie



Cystinosis Ireland (CI)

Cystinosis is a rare, degenerative, inherited disease which frequently requires the need for kidney and sometimes other organ transplants.
www.cystinosis.ie



The Irish Heart and Lung Transplant Association (IHLTA)

The IHLTA is a voluntary organisation which includes heart, lung(s), heart and lung transplant recipients, family and supporters.
www.ihlta.com



The Irish Lung Fibrosis Association (ILFA)

The Irish Lung Fibrosis Association was set up in 2002 to support patients and families living with Idiopathic pulmonary fibrosis (IPF).
www.ilfa.ie



The Pulmonary Hypertension Association Ireland (PHAI)

Through the Pulmonary Hypertension Association we hope to reach patients, their families and friends. Our main aim is to create awareness through friendship.



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www.donornetwork.ie

**Saving
More Lives**
Bringing Ireland's
Organ Donor Consent
System into the
modern age



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The Irish Donor Network Support for 'Soft Opt Out' Organ Donation

The Irish Donor Network (IDN) is seeking your support for the introduction of the new form of organ donor consent that will be part of the forthcoming Human Tissue Bill, 2017. The IDN represents seven patient groups concerned with organ donation and transplantation in Ireland.

Summary of reasons for changing the organ donor consent system in Ireland to 'soft' opt out.

- 1. It will save more lives:** The number of people awaiting organ transplants in Ireland is more than double the operations carried out. 587 people are currently waiting for a potentially life changing organ transplant in Ireland in 2017. If more organs become available, more life-saving transplants can be undertaken.
- 2. It will bridge the gap between intention and the actual gift of organ donation:** The introduction of a 'soft' opt-out organ donor consent system in Ireland will bridge the gap between people's intentions and their behaviour. 85% of people in Ireland are willing to donate organs but only one third of us carry an organ donor card and many of us do not inform our next of kin of our intentions to donate or otherwise. This results in fewer organs than possible being donated.
- 3. It will improve organ donor rates in Ireland:** Ireland is in only 15th place out of the 28 European Union countries when it comes to organ donation, despite our very high support for organ donation.

International evidence has confirmed the positive impact of opt-out consent on deceased organ donor rates. Over a three year period, after making the change to an opt-out system, Belgium saw its rate of organ donation increase by 100%. The recent experience in Wales with soft opt out has also been very positive. The countries with the best rates of organ donation in Europe have some form of soft opt out system combined with sufficient infrastructure.
- 4. It will modernise our organ donor system:** Organ donor cards and similar ad hoc initiatives such as phone apps or use of the driver license have had their day. They were useful and worthy in the past, but how many of us have lost and not replaced our donor cards? How many of us have not informed our next of kin of our organ donation intentions? The introduction of an online register for opting out of organ donation will bring Ireland into the modern age.
- 5. Organ donation will continue to be a 'gift of life':** The new system will continue to embrace the concept of organ donation being a 'gift of life'. The only difference is that potentially more organs will be donated and as a result more families will benefit from the gift of life. Next of kin will continue to be consulted so no family will be forced to donate the organs of a loved one.
- 6. Ireland has sufficient resources to make soft opt out succeed:** We will always need more resources for our health system, but it should be noted that in the Government's annual budget of 2014 an additional €2.9m was granted for a significantly increased number of specialised organ donation and transplant staff.
- 7. 'Let us get on with it':** This proposed policy has been included in the last two programme for governments with no significant advances until the recent decision to implement the Human Tissue Bill. Meanwhile, people continue to die waiting for a life-saving organ transplant in Ireland. Sufficient resources are in place, though more could always be provided (for example the opening of additional pre and post-transplant rooms) but this is not a reason to further delay this vital legislation.

FAQ's

Q1 What is the Irish Donor Network (IDN)?

The seven individual patient groups that participate in the Irish Donor Network are listed below. Our website is www.donornetwork.ie

- A1FI Alpha One Foundation Ireland
- COPDSI COPD Support Ireland
- CFI Cystic Fibrosis Ireland
- CI Cystinosis Ireland
- IHLTA Irish Heart and Lung Transplant Association
- ILFA Irish Lung Fibrosis Association
- IPHA Irish Pulmonary Hypertension Association

The IDN has been involved in organ donor awareness for many years. We have made many submissions on soft opt out over the past 5 years. Further, we successfully supported the transposition of the EU Directive on organ donor safety and quality in 2013.

Q2: Will the change discourage donors?

All the international evidence points to the opposite. Introducing a soft opt out consent system will make more organs available for donation by creating more potential donors. Discussions with next of kin will become the norm in situations where organ donation is a possibility. This consent system will replace reliance on the worthy but ad-hoc organ donor card system of past years. The change is not complex but should be clearly set out by government through public information initiatives.

Q3: Is it the end of the 'gift of life'?

No- it is the opposite. Next of Kin will still be required to be consulted before donation takes place. With more organs donated it will mean that more people can and will

benefit from the 'gift of life'. There is hard evidence to support this from countries that have brought in an opt out system in Europe and globally (for example in Singapore).

Q4: Why not bring in a 'hard' opt out system?

This would mean next of kin would not be consulted about organ donation. Countries that went down this route such as Austria, dropped this system after a short time as it proved unworkable. The IDN agrees with a soft opt system whereby next of kin are always consulted in the event of forthcoming decision on organ donation and their wishes will be fully respected. This is fully in keeping with the present ethos of 'a gift of life'.

Q5: Some would say it is a resource issue, not a consent issue?

More resources are always welcome and will be needed for the development of an organ donor online registry and a public awareness programme to explain the forthcoming change in organ donor consent. However, there is sufficient overall infrastructure in place to support the change to 'soft opt out'.

Q6: Where are transplants carried out in Ireland?

The Mater Misericordiae University Hospital is the centre for heart and lung transplants; St Vincent's University Hospital is the centre for liver and pancreas transplants; Beaumont Hospital is the centre for deceased and living-donor kidney transplants. Temple St Children's Hospital also undertakes kidney transplants for children and young people. It should be noted that many patients are the recipient of more than one organ because of the complexity of their disease.