

Good Morning,

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Many of you know me from old, for the new comers I am the Chief Executive of the Irish Kidney Association, a 30 year old patient organisation which started by promoting kidney donations and now amongst many activities promotes all Organ Donation via public awareness campaigns in Ireland.

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The IKA is an active member of Ceapir - The European Kidney Patient's Federation.

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The Ceapir Federation has 22 European Country Kidney Patient organisations. Ceapir is a partner in an alliance in Brussels to lobby the European Union Commission on all renal issues. The IFKE, ERA and EDTNA along with Ceapir form this alliance called the "EKHA" The European Kidney Health Alliance.

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That's the introductions over with

I can only speak from a "European Christian Democracy" background and the comparisons I will make are broadly only from such jurisdictions and may also only be relevant to that type of political and religious countries only.

Presumed Consent versus Informed Consent in Organ Donation

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### **Presumed Consent**

It will be presumed that you consent for removal of your organs, for transplantation, if you die in the circumstances that favour organ donation. Unless, while you were alive, you mandated to exclude yourself from organ donation on a registry of objectors.

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## **Informed Consent**

If you die in the circumstances that favour organ donation your next of kin can be requested to consent to donate your organs for transplantation.

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If you look at 19 European Countries legal regulations this is the picture. You would believe presumed consent clearly wins the debate at 21.7 versus 13.2 pmp.

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The European and world leader, in organ procurement is clearly Spain. Most people here will have heard the phrase. The Spanish Model. They introduced a "Presumed Consent" Law 30 years ago in 1979 to combat the growing waiting pools or lists for organ transplantation which outweighed the available donors. Ten years of "Presumed Consent" Law, in Spain, had no significant effect on the organ donation rates. They discovered, as did so many other European countries, later on, that you simply cannot successfully go against the wishes of the next of kin and that "Presumed Consent" on the ground, is an unworkable law. The cooperation of the family, to describe and confirm the past life style and medical history of the potential donor, is essential. You cannot presume the grieving family will allow you to remove organs. You are more likely to aggravate the family and lose their essential cooperation if you attempt "Presumed Consent" hard or soft versions.

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I think "Presumed Consent" was thought as an easy simple way out for political leaders. It would cost nothing and it would improve Organ Donation rates. That simply does not and did not work.

20 years ago, in 1989, the Spanish created "ONT", their transplantation authority, which introduced the specialist in Donor Family Liaison. They perfected this role and, by about the turn of the century, they had introduced these trained

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specialists which we now call “Donor Coordinators” into every hospital in Spain with an intensive care unit.

This is what has made such a difference to Spain’s organ donation rates - not “Presumed Consent”. Many other countries followed the Spanish lead to “Presumed Consent” but they have learned like the Spanish did, that it is unworkable. The leader of the Spanish Transplant Authority, Dr. Raphael Matesanz will tell you - as he has told so many others - “do not bother changing your laws on donation, simply change clinical practices in your hospitals by introducing Donor Coordinators, specifically trained and employed by a transplantation authority.

What happens in practice? More countries actually practice Informed Consent and I see the 18.4 versus 19.5 pmp as been statistically insignificant.

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The intensive care staff’s duty by law should merely be to identify potential donors report them and maintain the potential donors. Then do what the Spanish perfected - employ and train Donor Coordinators and locate them throughout your countries hospitals. They will champion organ donation to be the normal practice of the hospital system while available to explain at lengths Organ Donation to potential donor families. They will be the liaison with the Organ Procurement Organisation and the Managers of an ongoing audit of the hospitals brain death potential donors.

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The Spanish have 9 year results which drives improvements and identifies weaknesses. In 2003 they replaced their team in La Rioja which has changed that area’s organ donation results significantly. This is a classic example of how the ongoing audit identified a problem area and how the right personnel can make a huge difference.

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Ideally, every country should have a National Transplant Authority” that would manage all Organ Donation and Transplantation - monitoring, reporting and driving organ donation, leading to maximum transplantation of all available organs in each country.

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Organisation is highly important I would like to show you a comparison between Ireland and Norway. Two countries with a similar size population and similar donation rates, but one with 40% greater transplantation rates. This is down to better organization of their transplantation system because of a transplant authority - not donor rates or laws.

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The Spanish claim that all the extra money poured into ONT, their transplant authority which employs all the Donor Coordinators and conducts all their public awareness campaigns, and funds their transplant centres have been recouped by the savings made in dialysis costs. In these economic arguments the danger is that organ donation takes on a financial value. The Spanish can show a 55 year patient life gain for a 6 organ multi donor, “that is the true gain”. Years of life saved and that is what you should concentrate on.

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One word of caution, the ‘euro transplant’ definition, of an organ donor, is someone where at least one organ has been removed and transplanted into another. The Council of Europe and Spanish definition of an organ donor, is “Every potential donor transferred to the operating theatre from whom at least one solid organ has been retrieved”. The Spanish organ donor count is overstated when you realise direct comparisons are not possible when many other EU countries use the more meaningful definition that euro transplant uses

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We all know that many people on transplant pools are lost – that could be saved with greater cooperation and advanced thinking across the Health Communities.

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Your public want this, the patients need it, and the public will cooperate - by donating organs - if they are asked, advised and informed by the right people in the right place with the right amount of time to give.

In summary: (I favour "Informed Consent" with mandatory reporting of potential donors with a well thought out Transplant Authority and System that utilises Donor Coordinators). Simply creating or changing laws on Organ Donation alone is a waste of valuable time.

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*Thanks*