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To The Chair and Members of the Committee for Health, Social Services and Public Safety Room B32, Parliament Buildings, Ballymiscaw, Stormont, Belfast, BT4 3XX

Dear Ms McLaughlin

Re: Human Transplantation (Northern Ireland) Bill

I welcome the desire of the Committee, expressed by you, and recorded in the Official Report of Assembly business on 16 November 2015, "to hear from those clinicians who will be making judgments and decisions on the ground."[1] Those of us who have been championing organ donation and transplantation for many years, and who are actually working in the intensive care units (ICUs) where potential donors are identified and cared for, consider that it is vital that our insights inform the decisions to be taken on this Bill. I am one of these clinicians, and have for many years been conducting Brain Stem Death Tests and dealing first hand with the families of potential donors in sensitive discussions at a time of great distress. I have also been part of the process auditing donor numbers and refusal rates in Northern Ireland, and hosting educational meetings aimed at maximising organ donation. I was one of the two Clinical Leads in Northern Ireland during the UK Transplant Donor Liaison scheme, and subsequently have been a member of the Northern Ireland Organ Donation Taskforce Implementation Group. I am also on the Organ Donor Register myself. I remain passionate that we optimise donation rates primarily because of the life-saving, and life-transforming benefits of transplantation, but also because of the financial efficiencies which accrue to the health service following successful transplantation. In order to deal adequately with the issues, this letter is necessarily lengthy and so, for your convenience, I have taken the liberty of highlighting key elements in bold font. Nevertheless, I caution against reading only the bold text, and encourage serious consideration of the entire content.

It is self-evident that donation and transplantation are intimately related. They should be considered to be two sides of the one process. I confess that I have found it disturbing at times that those wishing to introduce changes to the process around *donation* and donors

often have sought advice predominantly from our colleagues in nephrology and from those involved in the *transplantation* side of the process, the vast majority of whom do not work in intensive care and are not engaged in dealing with the donors or their families during the very difficult part of the process which this Bill attempts to modify. Indeed the terminology and title of this Bill repeats this tendency. It is also disturbing that relatively uninformed opinions from public surveys seem to have been given value over/ahead of directly seeking input from Intensive Care Consultants. I commend Mrs Cameron for highlighting this in the Assembly.[1] Hence it is most welcome that the views of Intensive Care clinicians are being sought by the Committee. I am responding as an individual Consultant, as I have not had the opportunity to consult widely during the short time frame permitted for response. If the Committee wishes to determine whether the opinions I express below are representative of Intensive Care Consultants across Northern Ireland, Members may wish to consider a further specific consultation after the deadline of 4 December, 2015. However, alongside informed opinion, I will be presenting factual information. One of those facts is that my overall view on presumed consent is completely in line with views expressed by Intensive Care specialists nationally in the UK.

In the Committee's discussions and thinking on this matter, I would counsel Committee Members to be scrupulous in ensuring that those who are "pro deemed consent" are not (whether consciously or unconsciously) permitted to be characterised as being more "pro increasing transplantation" than those opposed to deemed consent. **As the Parliamentary Office of Science and Technology noted[2] "the evidence surrounding opt out [deemed/presumed consent] is not clear cut." That is, it is not clear whether presumed/deemed consent will improve, worsen, or make no difference to the number of organs available for transplantation**. **Pending definitive proof, it is my passion to see more organs donated and transplanted (alongside my experience in the specialty of Intensive Care Medicine) which is a key reason that I view introduction of deemed consent to be a mistake.** It would be wrong to tolerate any suggestion in Committee that opposition to deemed consent is a mark of less enthusiasm to achieve sufficient donation and transplantation, or that being pro-deemed consent is a badge of greater commitment to transplantation than the converse. **In the absence of definitive data, support for deemed consent must not be conflated with commitment to increasing donation rates.**

In a similar vein, many emotive accounts may be presented on one side or other of the debate which highlight the need for increasing donation. However, it should be remembered that these moving, and sometimes harrowing, accounts do not have a bearing on whether or not introduction of deemed consent is the appropriate response to the current shortfall in consent for organ donation. The shortfall in consent is predominantly a consequence of (i) many people not registering their wishes on the organ donor register or discussing them with their family, and (ii) in the absence of potential donors being on the register, relatives not assenting to donation despite being approached sensitively by highly trained staff.

As has been requested, I will address issues with the Bill under the broad headings of several of its clauses but, rather than present them in numerical order, I will prioritise the main ones early in the sequence.

CLAUSE 4. DEEMED CONSENT.

"If an adult has died and hasn't made his or her views on transplantation known, then the person is deemed to have consented to transplantation."

Critically ill ICU patients as a whole are a vulnerable group. We owe a duty of care both to these patients and also, should they die despite optimal treatment, to patients who may benefit from receiving their organs. ICU patients are usually much too ill to participate in treatment decisions themselves, and family members routinely play an important role in helping determine what are the likely wishes of their relative. This determination then helps guide provision or discontinuation of life support. An important part of intensive care is support not just of the patient, but of their family too. Crucial to this is good, sensitive communication, and the creation and maintenance of trust - trust that the key priority of those providing care is delivering high quality care that is in the best interests of their critically ill relative.

A subset of critically ill patients who die despite treatment can be *identified before* death as potential organ *donors after* death. It is important that all patients who are potential organ donors are identified and all their wishes respected, including wishes related to donating or not donating organs. Some of these potential organ donors will be found to be Brain Stem dead, and some will suffer cardiac death. I have conducted many sets of Brain Stem Death Tests in order to facilitate the retrieval and donation of organs from patients who are legally deceased, but whose hearts still beat as they remain on life support technology. During intensive care treatment of all of these patients, it has been important to be very clear about the difference between
(a) treatment aimed at achieving medical benefit (recovery) of the critically ill patient and
(b) [only when (a) has been shown to be futile] treatment whose sole goal is preservation of organs in order to deliver the likely wishes of the patient after death, and benefit another series[3] of individuals.
Historically this clear separation has been considered essential in maintaining families' trust that there are no mixed motives involved in decisions to stop life supportive treatment when it is judged to be futile. It is important to avoid any conflict of interest between (a) and (b), and I believe we have done so to date. However, this Bill threatens that separation.

In contrast to the potential recipients of transplanted organs, ICU patients and their relatives have, for obvious reasons, had little or no "voice" in considerations around, as vulnerable individuals, their consent potentially being presumed/deemed for organ donation. Therefore it is important to be careful that they are appropriately respected and have an advocate.

It is also important in society at large to avoid any perception that vulnerable critically ill patients could be being subjected to a cold utilitarian approach, in which the main/only interest of society (and of disciplines outside the ICU) in ICU patients is in retrieving organs from the dead ones. Introduction of legislation to secure presumed/deemed consent could contribute to such a perception, particularly since provision of adequate ICU beds to meet the needs of the wide range of ICU patients is not secured by specific legislation.

Loss of trust as a result of neglecting *any* of the above issues is likely to undermine the confidence of the public and of relatives in the organ donation process, to the harm of those needing organ transplants.

In addition to the potential adverse effects on organ donation rates, another reason I have concerns about presumed/deemed consent is that we ICU Consultants cherish and indeed require the trust of relatives of *all* patients when making difficult decisions about providing, continuing, or discontinuing life support. As I'm sure Committee Members appreciate, because of the nature of critical illness, a sizeable fraction (often around one fifth) of ICU patients do not survive to leave hospital despite optimal care. The vast majority of deaths in the ICU setting occur following decisions to limit or withdraw life support technology. By comparison, sudden, unexpected deaths are unusual in the ICU.

As a result of our efforts, an increasing number of patients now donate organs following cardiac death. In these cases cardiac death occurs after implementation of a decision to withdraw ventilator or cardiovascular support (on the grounds of perceived best interests of the patient), but *without* Brain Stem Death being present before withdrawal of such support. **In the setting of Donation after Cardiac Death there is therefore a particularly increased risk of families or society inferring that the decisions to withdraw supportive treatment might be influenced by a desire to harvest organs**. Neither transplant surgeons nor nephrologists, nor indeed doctors of any other specialty, have to face this potential conflict of interest. We work hard as a team to prevent such an inference being made by families, and do not discuss donation in this context until after family members have agreed that ongoing supportive treatment is not in their relative's best interests. However, **high profile introduction of legislation which results in presumption of patients' consent to donate could undermine our efforts, and undermine trust generally of relatives of the wider group of ICU patients, who are *not* suitable donors, in whom we judge ongoing or escalating supportive treatments to be against their best interests - particularly since we do not discuss donation until agreement has already been reached that withdrawal of supportive treatments is the best course. So such legislation has the potential to harm not only those in need of a transplant, but a wider group of patients and relatives in the ICU setting than those who could become organ donors. This could have adverse effects on our efforts to ensure deaths are not inappropriately prolonged in those who will not be donating, and adverse effects on our efforts to ensure they are granted dignity and appropriate emphasis on comfort rather than on inappropriate heroic or invasive treatments in their terminal phase.**

Let us now look at three premises upon which presumed/deemed consent is being promoted and whether or not they are valid.

(a) **Comparisons with other countries having presumed consent.**[1] Donation rates vary between nations, and the reasons are likely to be multiple and complex. There has been an unfortunate tendency to assume that differences in donation rates between countries are because of differences of process rather than different societal views, and that by altering the process of gathering consent we will improve donation rates. That approach does not have a strong track record. Because higher donation rates were noted in Spain, embedded donor co-ordinators were introduced in the UK at some expense to change the way consent was sought. However, the results of the ACRE study[4] showed that collaborative requesting between donor co-ordinators and clinicians did not significantly reduce relative refusals. What the study did confirm, however, was a previous observation that refusal in black and ethnic minorities (despite their need for transplants being higher) was much more frequent than when the patient's relatives were 'white' - suggesting a strong societal/community/ethnic

influence.

Another factor in higher donation rates in Spain is that the Spanish transplant organs from older donors than has been the case in the UK, which increases number of patients considered to be suitable donors. There may also be differences in practice relating to withdrawal of mechanical ventilation in patients in the UK with poor chances of meaningful recovery. Yet another factor has been the difference in the scale of ICU provision (27 beds per million population in the UK vs 87 per million population in Spain), which in the UK encourages exclusion of patients with a poor prognosis to target the expensive resource at those most likely to benefit.

Spain passed legislation for presumed consent in 1979, and some have thought that it contributed to the increase in donation rates there. What is often missed is that (i) 10 years later the donation rate was still similar to the UK's (ii) the improvements in donation rate followed changes to organ donation infrastructure in 1989. Indeed the founder and Director of the Organizacion Nacional de Trasplantes (Spain's governing transplant organization), who was the guest speaker at an educational meeting I hosted in Northern Ireland some years ago, has repeatedly stated that Spain's high donation level should be attributed to Spain's model of practice and organization *rather than* to its legislation.[5] He goes further and writes regarding the UK: "The government should also be conscious of its obligation to maintain an ethical framework in society. The idea that the absence of an objection represents informed consent is plainly nonsense and consent that is not informed is valueless. Inevitably, the socially disadvantaged and poorly literate will be less aware of their rights, less likely to care about them in advance and less likely to have confident advocates in the face of medical authority at the time of their deaths."[5] This article is co-authored by John W Fabre, Professor at the Department of Hepatology and Transplantation at King's College London School of Medicine.

Figures showed that Wales had already approached Spanish levels of donation, before they legislated for presumed/deemed consent,[6] and that Welsh donation rates already exceeded Belgian rates, despite Belgium having presumed consent. The Organ Donation Taskforce, in a separate dedicated report on presumed consent/opt out systems[7], pointed out that **Sweden switched to presumed consent in 1996 but continues to have one of the lowest rates of organ donation in Europe**. **The Organ Donation Taskforce report also stated that there was evidence that introduction of presumed consent could result in a fall in donation rates, and cited Brazil as an example. Brazil passed presumed consent legislation in 1997, and it "had to be repealed in 1998, principally because of mistrust of government and accusations of body snatching."**

Belgium's model is not one which I consider to be worthy of following. It is reported that physicians in Belgium are under no obligation to ask the prospective donor's family for permission to recover organs, or even inform them of their intention to do so (although if a family member explicitly opposes organ recovery, it cannot proceed).[8]

(b) The discrepancy between (i) results of surveys of members of the public on donation/transplantation of organs and (ii) relatives refusing donation. This

discrepancy has been interpreted and presented by proponents of presumed/deemed consent as evidence of relatives getting in the way of the patient's likely views being carried out. However, this is presumptuous, and certainly not the only possible interpretation. After all, relatives are also part of the society from which that survey data are drawn. **It is quite possible that views sought during a survey change when one actually finds oneself in the situation. It is possible that patients have not made their wishes known regarding donation of organs for transplantation because they are uneasy about it personally, whilst supportive of the principle generally.** There is a difference between 96% of the population thinking that "donating organs is the right thing to do"[1] and actually doing it. I am confident most people would not wish to be perceived as lacking altruism or concern for others, and they may feel that an overt expression of their unease would be judged as selfish. I contend that (a) relatives may perceive this to be a factor in why patients do not discuss the issue in advance, and also that (b) relatives are in a better position to reach conclusions of their loved ones' likely wishes than are others (who do not know the patient) on the basis of generic survey data collected at a time when the issue is a hypothetical one.

Proponents of presumed/deemed consent *claim* that the discrepancy between (i) societal views in favour of donation in surveys and (ii) relative refusal rates is because (a) many people procrastinate in registering their wishes to donate on the Organ Donor Register, and then (b) when these patients do not explicitly discuss their wishes in advance, relatives do not make their judgments based on reliable perception of their loved one's likely wishes, but rather that they regularly make a default decision which is the *opposite* of their loved one's likely wishes. However claim (b) may be ill-founded and, with regard to claim (a), lack of registration could also affect an opt out system. The opportunity to register a wish *not* to donate (as is allowed for under the Bill), along with encouragement to register such a wish, cannot imply that *absence* of such registration indicates a wish *to donate* (which is presumed under the Bill) any more than, as proponents of deemed consent argue, the *absence* of registration *to donate* under the present opt in system, despite encouragement to register wishes, can be certain to indicate a clear wish *not* to donate. **The Organ Donation Taskforce concluded that the results of opinion surveys are not a sufficient basis on which to conclude (under an opt out system) that all those who fail to opt out intend to donate.**[7]

Signalling a move away from relying on the previous strategy to persuade the public to consent in larger numbers to donation, **this Bill adopts a strategy which as far as possible reduces the expression of patient views as perceived by their family. The implication of passing this Bill would be that (on the basis of surveys conducted in a hypothetical situation) Government considers it *routinely* knows better than family members what the view of their dying relative was likely to be when that relative had not initiated an explicit conversation on the subject.** Perhaps the situation is analogous to conducting a survey on whether or not folk like the idea of doing a parachute jump and then deciding that, when those on board the aircraft are standing at the open door looking down and decide they don't want to jump, it is deemed by those operating the flight that they should jump because the vast majority of those who did the survey on the ground (most of whom are still on the ground) have said it's a great idea. So someone is tasked with pushing them out the door. I for one do not want to be that someone, and I imagine I am not alone. Yet my specialty is

the one which would be asked to implement and deliver such an arrangement. We have a duty not to add further distress to relatives who are already grieving the loss, or imminent loss, of a loved one. Great distress could be caused if families consider the patient would have *withheld* consent, but patient consent is presumed/deemed by legislation to be present and the family do not meet the requirements of the Bill to allow them to withhold affirmation (e.g. they may be classed as having insufficient evidence because the patient had never vocalised their views in explicit terms).

(c) **Public Health Agency Surveys on Soft Opt Out System.**[1] The same issues apply to these local surveys as to the surveys mentioned above. Furthermore, the local surveys have been conducted in a societal context where the appearance has been created that to be against so-called soft opt out is to be against increasing transplantation rates i.e. the conflation I counselled against above (page 2 paragraph 2). I would be concerned that **such consultations present questions to the public about clinical contexts which are far removed from most people's experience, and which are not explained in detail.** Hence, as in the paragraph immediately above, when faced with the consequences of implementation of this Bill in an ICU setting with a loved one, I believe, many individuals could find themselves extremely distressed and unhappy with being given such a limited role as this Bill seeks to impose on relatives of patients who have not explicitly expressed a view regarding donation. Also, the survey statistic quoted by Mrs Dobson that "79% of the public agreed with the statement 'The soft opt-out system will result in more lives being saved'" serves to demonstrate that the survey response is not adequately informed since, as noted by the Parliamentary Office of Science and Technology,[2] there is no evidence to support such a view.

It would be remiss of me not to acknowledge that the British Medical Association (BMA) has taken a stance in support of opt out/presumed consent. Despite being a BMA member, and despite being in the specialty directly concerned, I was not asked my opinion before this stance was adopted. I am concerned regarding how the BMA has reached this position. I fear that academic ethicists and/or large numbers of doctors who take no part in the consent process for organ donation may have had undue influence. Such folk have little insight into the clinical context, no hands-on experience of having the difficult discussion with relatives at such a distressing time, have never conducted Brain Stem Death Tests, and have never had to judge when and when not to withdraw life support technology in those who are very ill but not Brain Stem Dead.

Besides the uncertain effect that presumed consent would have on donation rates, there are other concerns. In my clinical practice I have, prompted by the Transplant community, often discussed donation with families as a "Gift" of Life, in accordance with the promotional campaign slogan. I value greatly (as do organ recipients) the decisions which many relatives have made over the years to consider and assent to organ donation at a most distressing time. I'm inclined to agree with those who have argued that introduction of presumed/deemed consent shifts the emphasis toward duty rather than remaining a considered gift. **I appreciate that, for those waiting for an organ to become available, their need may seem to trump preservation of the distinction between duty and gift in organ donation. However, I'm not at all convinced that allowing a utilitarian ethic to distort usual consent practice is a good direction for society to go.**

I can think of no other area in medicine or surgery where consent is routinely "deemed"

to be present when the patient has not expressed a view previously and cannot express a view at the time. I commend Mr Ross for highlighting this issue in the Assembly.[1] When patients do not have capacity to consent for even life-saving surgery, the view of the family, where available, is sought in determining what the patient would likely have wished, and in helping to determine what is in the best interests of the patient. Similarly when patients are critically ill and too sick to participate in decision-making, and have potential to benefit from intensive care, family members have an important role in guiding our decisions on admission and commencement or non-commencement of life support, on the basis of the patient's likely wishes. In this context, life support is actually support of vital organs, but in an attempt to secure the survival of the patient being admitted. In neither of these situations is the role of the family restricted to "affirming deemed consent," much less having to provide evidence that a patient would not consent. Yet this Bill requires that relatives provide evidence in order for consent not to be deemed.

It seems somewhat ironic that, only a couple of decades ago, consent was presumed to retain organs from those who died, or had no more need of the organs, for the benefit of other (future) patients - through the less direct route of education in pathology departments of doctors in training, or as part of research. It was perhaps thought gruesome to enter into the explicit discussions necessary for formal consent in years gone by. Furthermore, there were potential issues around legality of consent, in terms of who 'owned' the body, or body parts, of a dead person. It was also neither normal nor expected practice to enter into discussions with patients or family regarding the fate of organs or tissue removed during surgery. Following enormous public outcry, such organ or tissue retention practice is now considered unacceptable, and many clinicians and institutions were held accountable for it in the face of rapidly changing public expectations. **It is now usually necessary to seek explicit consent, rather than presume it, to retain even tiny samples of tissue following surgery or death; and when patients have organs or tissue removed for treatment, clinical staff must seek and document their wishes regarding how the excised tissue is to be dealt with e.g. incinerated or buried. Yet it is being argued that, in this one area, consent should be presumed to retain organs after death (for the purpose of transplantation), and a Bill introduced to impose that presumption. We should not distort 'consent' law in this one area in a way we are not prepared to see it distorted in others.**

It is perhaps for some or all of these reasons that the following groups have registered their views as *opposed* to introduction of presumed/deemed consent:

- **The government-appointed Organ Donation Taskforce** (see text above)
- **The Intensive Care Society (UK),** the main specialty society for those working in the discipline, held a pro-con debate on the subject, the outcome of which was unanimous rejection of presumed consent.
- **The Patients Association**, which has campaigned on behalf of patients for 50 years has stated "Presumed consent is no consent" and that any failure in the current take up of donor options is no reason to do away with a patient's fundamental right to decide what happens to their own body.[9]

I note also that it is reported that **Transplant Surgeons in Northern Ireland** have recently written as a group to the Health Minister expressing concern about introduction of an opt out system at this stage. Objection from Transplant Surgeons is not just a local phenomenon.[10]

It is also of some concern that Clause 4 makes no mention of consent to donation.

Consent to Donation is being presumed along with consent to Transplantation being presumed. It seems to me that this is a further example of the focus being diverted away from the very element this Bill seeks to alter – the process of consent to *donate* organs. Once consent for donation has been achieved in the past, there has not been a barrier to consent to transplant the donated organs. Patients consent to donate organs for the specific purpose of transplantation, so the terminology of this, and indeed the name of the Bill itself, seems misleading. The aim of introducing the Bill is to circumvent a specific obstacle to transplantation – relative refusal of *donation* of organs. It is therefore remarkable that the Bill has been titled and phrased as it has. One has to ask why. Is it because it is felt that (although transplantation cannot occur without donation) there is a possibility that organ Donation/harvesting is not as palatable a concept to society as Transplantation? If so, and this Bill were to proceed as it is, the implication would be that government does not have confidence in the very survey data which proponents of presumed consent present to support the introduction of presumed consent. As explained above, there may be a good reason for not being confident in the validity of such survey data when faced with difficult real-life decisions in the moment. **I would invite those presenting the Bill to justify why the focus of terminology is on Transplantation when relative refusal of Donation is the obstacle it seeks to circumvent.**

Finally, I am curious also why the term 'deemed' has been substituted for 'presumed' (as it was in the recent Welsh Bill). I am aware of the term deemed consent being used in a legal context outside medical practice but not previously within medical or surgical practice. I can see no real difference between the two terms regarding the nature of the consent (it must be presumed to be deemed) and I suggest that the term deemed has been chosen in this hitherto unprecedented way because it may be seen as either more nebulous or more palatable than making clear that consent is being presumed. **Presumed consent is a clearer term.**

CLAUSE 8. DEEMED CONSENT: ACTIVITIES INVOLVING MATERIAL FROM LIVING ADULTS WHO LACK CAPACITY TO CONSENT

This clause allows for the Department to make regulations setting out the circumstances in which consent may be deemed for living donation. The clause lacks important information. No explanation is given of the scenarios in which the Department might decide to make regulations such that living adults who lack capacity might have consent presumed/deemed to donate tissue while alive. **This is potentially a very disturbing proposition involving presuming consent to take tissue from vulnerable adults while alive, for the purposes of donation. It could be seen as a blank cheque. It is not possible to assess it or comment further in the absence of any detail.**

CLAUSE 14: ANNUAL REPORT ON TRANSPLANTATION

Again, the focus of the annual and 5 yearly report is on transplantation rather than donation, when the purpose of the Bill is to achieve increased donation. Furthermore **there appears to be no attempt to look for and capture the potential adverse consequences in ICUs** (described previously) which might affect potential donors and their families, and also potential adverse effects in undermining trust between clinicians and relatives when other patients may benefit from treatment limitation or withdrawal. **It would be irresponsible to**

introduce changes in the ICU setting and only look for effects outside that setting.

CLAUSE 1. DUTY TO PROMOTE TRANSPLANTATION.

Arguably no new legislation is required for the Department of Health and Social Services to have a duty to promote transplantation. However Clause 1 includes a new "specific duty to inform the public about … the role of friends and family in affirming deemed consent." In addition to the problems already highlighted above of the terminology of deemed/presumed consent being applied to healthcare, the phraseology regarding the role of friends and family in this clause is not neutral. This choice of phraseology suggests that the role of family is *not* to clarify the patient's wishes but rather to affirm deemed consent. I suggest that, even if deemed/presumed consent is to be introduced, it would be disingenuous to limit the role of the relatives to affirming deemed consent. Even if Department were to inform the public in these terms, inevitably members of the public will not take this on board until they find themselves in the situation. When they do find themselves in such a clinical situation, **it will fall to healthcare professionals working in intensive care to inform relatives, at the time of (or hard on the heels of) difficult decision-making on withdrawal of life support technology from their loved one, that their role (by legislation) is not to make the patient's likely wishes known but rather to affirm consent which is being presumed. Such scenarios would undoubtedly add to the distress of some families, and potentially undermine trust that there have been no mixed motives in the decision to withdraw life support from their loved one.**

Closing Comment.

I hope that Committee members take all these concerns seriously, and reject this Bill. It certainly seems to be foolhardy to rush to pass it without seeing the consequences of the Welsh experiment. If it is felt that new legislation may be useful to increase donation rates, I would find introduction of "mandated choice" a much superior alternative ethically to presumed/deemed consent. This was suggested by some in Wales, but not pursued. I would hope that Northern Ireland would think more creatively. The anticipated cost (£2million to £5million over 10 years) to implement this Bill could be spent in a better way. As noted by Westminster, the percentage of the population signing up to the Organ Donor Register is higher is Scotland than in the rest of the UK, and this is attributed to hard-hitting advertising campaigns and education about organ donation in schools.[2]

Yours sincerely

John Trinder

[1] Official Report of Assembly/Private Member's Business: Monday 16 November 2015. http://aims.niassembly.gov.uk/officialreport/report.aspx?&eveDate=2015/11/16&docID=249232#1682350 [Accessed 3 December 2015]

[2]Parliamentary Office of Science and Technology, Postnote 441, September 2013. http://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-441/#fullreport [Accessed 3 December 2015]

[3] organs from one patient can benefit several recipients, each of whom requires a different organ.

[4] Effect of "collaborative requesting" on consent rate for organ donation: randomised controlled trial (ACRE trial). The ACRE Trial Collaborators. BMJ 2009;339:b3911 doi:10.1136/bmj.b3911 http://www.odt.nhs.uk/pdf/acre_study.pdf [Accessed 2 December 2015]

[5] Matesanz R, Fabre JW. Too many presumptions. The Guardian. http://www.guardian.co.uk/commentisfree/2008/nov/17/organ-donation-health [Accessed 3 December 2015]

[6] BBC News http://www.bbc.co.uk/news/uk-wales-politics-16797510 [Accessed 2 December 2015]

[7]The potential impact of an opt out system for organ donation in the UK. An independent report from the Organ Donation Taskforce http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_090303.pdf [Accessed 2 December 2015]

[8] Presumed versus Expressed Consent in the US and Internationally. Sheldon Zink, Rachel Zeehandelaar and Stacey Wertlieb. AMA Journal of Ethics. http://journalofethics.ama-assn.org/2005/09/pfor2-0509.html [Accessed 3 December 2015]

[9]UK Parliament. Welsh Affairs Committee Records. http://www.publications.parliament.uk/pa/cm201011/cmselect/cmwelaf/896/896vw08.htm [Accessed 2 December 2015]

[10] Presumed consent for organ donation: a case against. Simon Bramhall, Consultant Liver Transplant Surgeon, Queen Elizabeth Hospital, Birmingham. Annals of the Royal College of Surgeons England, 2011. 93(4):270-272. doi: 10.1308/147870811X571136b http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3363073/ [Accessed 3 December 2015].