


**Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)104 - Eileen Rowlands**

Clerk to the Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF991 NA


January 22, 2013

Dear Sir,

Due to family commitments, I have only very recently been made aware that the National Assembly Committee opened a consultation on the Human Transplantation(Wales) Bill, which closed on 18th January, 2013.

Mark Drakefield AM, chair of the Health and Social Care Committee, states,
'The Welsh Government has already undertaken a significant consultation on this Bill before proposing it....'

I completely disagree with this statement. I have been involved with the issue of organ donation for twenty six years, and have attended all the public consultation meetings in the Swansea, Neath/ Port Talbot venues since January 2008. All of these meetings were poorly publicised and abysmally attended by the Welsh public.

January 2008 - Neath/Port Talbot - 5 attendees
November, 2011 Aberavon Beach Hotel- Approx. 15 attendees
January,2012 Brangwyn Hall Swansea-Approx. 20 attendees
July, 2012 Swansea University Approx 14 attendees

I have responded to the consultation documents and read all the responses. I would hope it is incumbent on all AMs and the First Minister to have read those responses too.

No AMs attended any of the public consultation meetings for the above areas and consequently could not gauge public feeling about the issue of legislation for a soft opt out organ procurement system. I have met with Edwina Hart, the former AM for Health and also Peter Black who seemed unaware of some facts relating to the procedures involved in organ donation.

Similarly, Dr. Chris Jones, Cardiologist, Medical Director of NHS Wales and presenter of two of the Consultation meetings, admitted at the Brangwyn Hall in January 2012, that he had only recently become familiar with the necessary procedures involved in organ retrieval. i.e. Potential organ donors are identified when admitted to ITUs with critical head injuries or traumas and subsequently diagnosed as brain stem dead NOT brain dead.

If representatives of the Welsh people in the Welsh Government are not adequately educated about all aspects of this issue, how can the public be given clear and transparent information on which to express true opinion and choice?

The consultation meetings I have attended have been biased by representatives of the Welsh Government in favour of legislation and were really only interested in gathering opinion and ideas on the implementation of the proposed legislation. No real public debate has been initiated by the Welsh Government where public opinion about all the issues surrounding legislation for a soft opt out system for organ RETRIEVAL has been welcomed and taken into account. Those opinions and concerns at these meetings were expressed despite organisers attempting to steer the dialogue to pre - arranged script ie. The consultation document with its pre-scribed ., specific questions.

The consultation meeting held at Swansea University in July, 2012, was again poorly attended. It seemed

strange to me at the time that I appeared to be the only independent member of the public present. As other people began to arrive I became aware that they were present in a medical / professional capacity. I later learned, via the media , that Lesley Griffiths had issued invitations to 'stakeholders' for these consultation meetings, but relied on poorly publicised and short noticed information for Joe Public. I was appalled at the term ' stakeholder ' which infers someone with a particular or vested interest in the success of this legislation. It was evident to me that ordinary members of the public, without an invitation, were not expected to attend .

During that meeting, I brought up the requirement for clarity and transparency with regard to informing families about brain stem death diagnosis and the context in which organ retrieval would proceed. I was challenged by another attendee who suggested that the public should trust the medical profession implicitly and that discussion of the complexities of brain stem death would not be appropriate. A heated exchange ensued where I found it necessary to declare my personal experience in such a situation. Following the meeting, I was informed that this individual was an intensive care consultant. This is a professional who should have a duty of care to the patient's family; a family, who , if not fully informed prior to a tragedy occurring, should have ALL information when a potential ' deemed to have opted out ' scenario occurs.

The Welsh Government has made numerous misleading statements regarding public attitudes to a soft opt out RETRIEVAL{ not donation} legislation. They have massaged statistics in their favour and have badly managed and organised public information and meetings. They have also given misleading information regarding the success of an opt out system in other European countries.

The Welsh public are being hoodwinked by this vain and arrogant Welsh Government whose political and economic aims are being disguised as altruistic values. They want to be seen as leading the way on this highly provocative legislation.....Metaphorically, exercising the Welsh Dragon's fire !

I am forwarding copies of my responses to the UK Parliament and the Welsh Governments consultation, together with letters and articles I have written to the press over a period of time.

Even though the period of response has ended, I hope that my letter and documents will be received and considered as a serious contribution to the National Assembly Committee's consultation.

I am not opposed to organ donation per se, providing it is based on a free and informed choice. Legislation should not replace goodwill.... It may even dispel goodwill and reduce organ donation rates. The Welsh Government is taking a huge risk and may rue the day this Bill was ever proposed.

There is no substitute for goodwill and no publicity more powerful than word of mouth.


Yours faithfully,

Eileen Rowlands (B. Ed. Hons.)

A handwritten signature in cursive script, reading "E. Rowlands".

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Organ Donation Bill Team
Medical Directorate
Cathays Park
Cardiff
CF10 3NQ

29 January 2012

Re: Consultation on the Proposals for Legislation on Organ and Tissue Donation

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The failure to opt out cannot possibly be interpreted, via legislation, as presumed consent or acquiescence. The probabilities that a person who has not "opted out" would have sought information about organ donation and discussed it with his/her family, would be very low or non-existent. A soft opt out system where such families are approached and consulted about their relative's intention would be acting on guess work; it would be taking advantage of a lack of pre-informed choice, ignorance and apathy. Such a system would acquire donor organs and tissue by default through pressured persuasion from dedicated health personnel intent on meeting targets.

I am a parent of an eighteen year old donor who has suffered as a result of the lack of transparency of information and who has researched this issue for over twenty years. I did not consider the diagnosis of brain stem death to be the biological death of my son when I offered his organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But despite asking to be present when the ventilator was switched off, I was not aware, nor made aware that my son would still be ventilated when his organs... his heart, his liver (which was not used because a transplant team was unavailable to perform the transplant operation), and his kidneys were removed from his body. Moreover, having discussed organ donation with him I know that he also was completely unaware of this information. When I discovered, incidentally, some months later, that my son's heart had been removed whilst it still beat, I was devastated.

Over the years, I have expressed my intrinsic belief that my son had not biologically expired at the point of brain stem death diagnosis. Often I was not taken seriously and sometimes perceived with derision and animosity by some professionals with a vested interest in organ transplantation. However, in the last few years, after a great deal of research, those beliefs have been validated. One research study of patients who had been diagnosed as brain stem dead but not considered as organ donors, were observed not to have biologically expired over various periods of time and that the brain stem continued to control certain

functions in the patient's body.

Then, at the time of my son's critical injuries, as now, the diagnosis of brain stem death through bedside tests, the futility of further treatment, and the lack of hope for recovery, does not mean complete biological death. Brain stem death is only a moment in the process of dying when viable organs may be retrieved for transplantation. In fact:

"There is no scientific basis for equating the state known as "brain stem death", as diagnosed by the UK Code, with the death of the person".

"A Code of Practice for the Diagnosis and Confirmation of Death"

Academy of Medical Royal Colleges (70 Wimpole St, London) October, 2008.

For some individuals that futility and lack of hope may be good enough reasons to allow their loved one to be used for organ and tissue retrieval. . For my family and many people I have spoken to they are not. To be compelled, by law, and not by choice, to opt out in order to uphold our belief , is a travesty.

With regard to the public Consultation meetings held in various venues in Wales, my husband and I have attended all those organised for the area between Carmarthen and Cardiff. The first, in January 2008, held at the Neath / Port Talbot civic buildings where only five members of the public attended. The second meeting held in November 2011 at the Aberavon Beach Hotel where only twelve members of the public attended, and recently, in January 2012, at the Brangwyn Hall , Swansea, where approximately twenty five members of the public attended. These numbers are hardly representative of the Welsh population in the South West region of Wales and indicate an enormous sense of disinterest, more important personal priorities, or even just plain apathy for the proposed legislation. (Especially when compared to some months earlier, when in May 2011, I stood outside the Brangwyn Hall amongst crowd of thousands celebrating the success of Swansea City Football Club.

Moreover, the inadequate prior notice and lack of publicity for these Consultation meetings, left a great deal to be desired from the Welsh Government and its intentions for healthy public debate. Additionally, the designated times for all these meetings were not conducive to the attendance of the working population in Swansea and outlying regions.

I am proud and privileged to live in Wales, but I am also a citizen of the United Kingdom. The evidence from the UK Parliament Task Force did not find it appropriate to introduce this legislation. Why does the Welsh Government arrogantly believe that it is appropriate for the Welsh nation to be the human salvage yard, via legislation, for the whole of the UK Transplant Service.

Should the Welsh Government surge ahead with its proposal for legislation, it may find that its misguided intentions will backfire , leading to many people opting out and a consequential drop in organ donor rates.

Eileen Rowlands (B.Ed. Hons.)

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(David Davies M.P.)

.....
David Davies MP.
The Grange,
16, Maryport St.,
Usk,
Monmouthshire,
NP15 1AB



7.3.2011

Dear Mr. Davies,

I am writing to you as a Welsh, United Kingdom citizen, in your capacity as Chair of the Welsh Affairs Select Committee in Parliament. I am extremely concerned about the Welsh Assembly's current proposal to introduce a law on organ donation, in favour of Presumed Consent.

I am aware that the matter has been referred to the Committee and Attorney General for further scrutiny and have listened to recent debates about the issue on BBC Wales television, in particular, Dragon's Eye, February 17. None of these debates have described how a person will possibly come to be considered as an organ donor or the procedures that will occur when retrieving organs. Very real issues which the general population should know when making vital decisions. In my experience, so few do!

I do not believe that the Assembly are competent enough to legislate on all matters that relate to Health and Health Services in Wales. I believe there is a conflict of interests in this area, especially since the Neurological Department at Morriston Hospital in Swansea has been transferred to Cardiff. Critically head_injured patients in Swansea and further west would have to be transported and treated there, and consequently might lose precious time in which injuries and their effects worsen.

I believe that the AM for Health has a responsibility to these patients, but by closing the critical neurological department at Morriston Hospital she has deprived them of the early intervention they require for optimum recovery.

Research stresses the importance of quick and professional treatment very soon after head injury. In many cases adequate treatment could minimize medical damage and lessen the mortality rate. The importance of getting a patient to a medical centre for appropriate treatment within the VERY FIRST HOUR from the moment of injury.....the 'Golden Hour' cannot be stressed enough.

Quicker link_up with senior medical personnel, use of advanced technologies of location, diagnosis, monitoring and treatment from the very first moment of injury, should be initiated in order to improve the chances of survival and lessen the chance of death.

Perversely, these will be the patients (not yet cadavers) who will be considered as 'presumed donors'! Energy and resources should be directed in this area, rather than towards changing a system which already works, and introducing a law which will do little to improve the chances of potential organ recipients.

Early intervention for critically, brain injured patients could alleviate swelling of the brain and pressure on the brain stem... the main cause of ' brain stem death'. Brain stem death became a very convenient criteria for diagnosis of death in the UK, when the technology and requirement for human transplantation became more successful and demanding.

However, I, as an individual, an intelligent, articulate mother, did not consider the diagnosis of brain stem death to be final expiration of my son, when in 1987, I offered my sons organs for transplant. I understood my son to be fatally injured, with no hope of recovery. But, despite asking to be present when the ventilator was switched off, I was not aware, nor made aware, that my son would still be ventilated when his organs...his heart, his liver, his kidneys, were removed from his body. Moreover, having discussed organ donation with him, I know that he also was completely unaware of this information.

The perception of death is a very personal one, but research has shown that even in someone who has been declared as brain stem dead, the brain still retains residual energy.

Most significantly, in their pursuance at any cost, of introducing legislation for Presumed Consent, AMs, Edwina Hart and Dai Lloyd must consider, that although clinical guidelines have been developed to define brain stem death, these have not been incorporated into legislation, which means the diagnosis is NOT A LEGAL DEFINITION OF DEATH.

I enclose several attachments for your perusal and consideration: A letter submitted to my local newspaper and printed as an article. Also enclosed is a copy of research I have discovered since writing this letter, with significant points highlighted for scrutiny.

I understand that Lord Dafydd Wigley plans to raise the issue in the UK Parliament's second chamber and this question is scheduled to be answered in the Lords on Wednesday, March 23

I trust you will read my letter and its contents and give them consideration in the scrutinization process. If the working parties for Parliament did not find it appropriate to introduce legislation for Presumed Consent for the rest of the UK, then it is not appropriate for Wales!

I look forward to your response.

Yours sincerely,

Mrs. Eileen Rowlands

January 25th 2011-01-24

Evening Post
Adelaide Street
Swansea

Dear Sir,

The Evening Post 'We Say' column, Friday, January 14, 2011, refers to the Welsh Assembly's proposed Legislation for 'Presumed Consent' regarding organ donation, as a 'small administrative change.'

I take issue with this statement since the proposal will devalue the positive altruistic process of giving willingly. The success of the legislation will depend to a great extent on the premise that many people will not take the deliberate and purposeful steps to 'opt out' of the donation process.

There are many areas of society where people, who may, through apathy, lack of knowledge on the issue, or more pertinently, have personal priorities such as homelessness, poverty, etc., which override or obscure their concerns for other people. Whatever the reasons, these should be respected.

Legislation will not increase the number of donors. This will only occur if there is a rise in the number of people who receive critical head injuries through road or other accidents and traumas such as stroke or brain haemorrhage which renders the patient deeply unconscious, able to be ventilated and not dead on arrival at hospital.

Spain is often cited as a successful example of how Presumed Consent works. However, Spain and other European countries which operate this system have a less successful road safety history than the U.K. Consequently, there are more critically injured patients received into trauma units. Moreover, in the U.K. the risk of stroke has been reduced by the successful diagnosing, monitoring and treatment of hypertension and high cholesterol levels.

Recently, the Secretary of State for Wales informed the Assembly that the proposed law for Presumed Consent would be placed before the Attorney General and the pre-legislative committee in Central Government. Concerns were expressed that it would not be appropriate for the Assembly to undertake this legislation as it may contravene aspects of the Human Rights Act.

Edwina Hart AM, Dai Lloyd AM and other members of the Assembly were surprised by this statement as it was delivered so close to the date for the Welsh referendum on its law making powers. Part of their response stated that Wales has been preparing for this change in the system to Presumed Consent for over two years. Part of this preparation was to place the debate in the public arena.

Two years ago, several public debates were held in a few areas of Wales, over a short period of time and with little notice or publicity. No meeting was organised for Swansea, the second city of Wales! The nearest meeting for the Swansea area and west towards Carmarthen was held in the Neath, Port Talbot Civic buildings on January 13 2009.

Five members of the public bothered to attend that meeting! My husband and I, parents of an eighteen year old son whose organs were donated for transplant; a female kidney recipient and an elderly couple with an altruistic interest in the issue. The three panel members, a consultant urologist, a consultant anaesthetist and a transplant coordinator all had a biased interest in promoting Presumed Consent. An administrative representative from the Assembly conducted the meeting. There was no AM present!

The lack of interest from the general public on this occasion could not have been more indicative of what will probably occur if an 'opting out' system is introduced.

The Evening Post opinion 'We Say', and others who support this legislation at any cost refer

to market research which allegedly indicates that 90% of people support organ donation. In my experience, over twenty years of speaking to many people, in all walks of life about their views, very few have sufficient information on which to make informed choices.

There are so many aspects of this issue to be taken into account before legislation should even be considered. Who will decide what organs a 'presumed donor' would be willing to donate? A heart, a liver.....a face! An arm. All body parts!

To quote the Evening Post, 'over the years donation has become more common', but that should not lessen the perception that it is a gift. A gift does not require legislation. 'Presumed Consent' will reduce the altruistic act of organ donation to one of acquisition by default and at worse requisition.

Yours faithfully,

Mrs. Eileen Rowlands

Organ donation should still be a gift - not a regulation

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By Eileen Rowlands, West Cross



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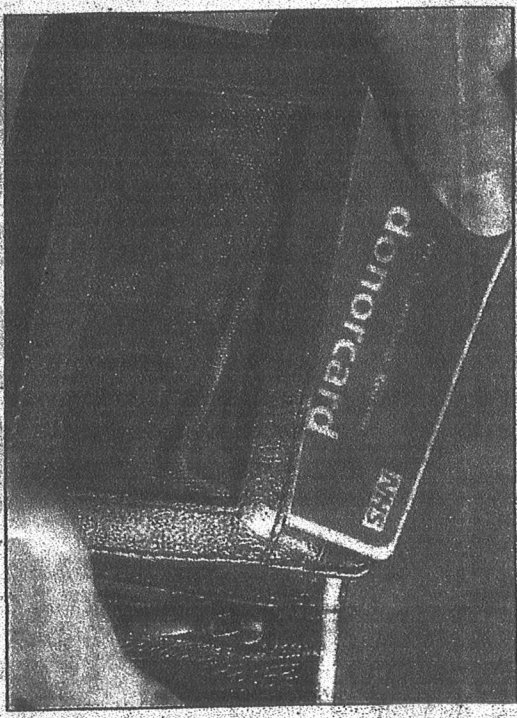
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SPECIAL GIFT The Assembly is proposing new legislation on organ donation.

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Duty Calls

SWANSEA Lord Mayor Richard Lewis will attend:

Tomorrow: No civic engagements

Monday: Sam Welcome assembly for International Inspiration Olympic 2012 Indonesian delegation, Gors Community School, Towrhill, Swansea. 10.30am, Welcome assembly for International Inspiration Olympic 2012 Indonesian delegation, Parnheol Primary School, Gorsellon.

2pm: Viewing of the Ugly Lively Town exhibition, Swansea Museum. 7pm: Valentine Evening in support of the Llewellyn charity, Mansion House, Swansea.

Neath Port Talbot Mayor Lelita James will attend:

Tomorrow: No civic engagements

Monday: No civic engagements

Carmarthenshire Chairwoman Tegwen Dewland will attend:


Tomorrow: No civic engagements

Monday: 10am Executive board meeting, County Hall, Carmarthen.

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Annibyniaeth 50+ Independence 50+

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Organ Donation Bill Team
Medical Directorate
Cathays Park
Cardiff
CF10 3NQ

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Eileen Rowlands (B.Ed. Hons.)

