



Cynulliad National  
Cenedlaethol Assembly for  
Cymru Wales

## **Y Pwyllgor Deisebau**

Adroddiad Cwblhad

Crynodeb o ystyriaeth y Pwyllgor Deisebau ar P-03-059 Aren Cymru i  
Gynyddu'r

**Hydref 2008**

## **Dyddiad cyflwyno'r ddeiseb**

10 Gorffennaf 2007

## **Dyfarnwyd yn dderbyniadwy**

18 Gorffennaf 2007

## **Ystyriaeth gychwynnol**

### **20 Medi 2007**

Ystyriodd y pwyllgor y ddeiseb am y tro cyntaf ar 20 Medi 2007 a chytunodd i wahodd y deisebwyr i roi tystiolaeth mewn cyfarfod yn y dyfodol.

(Gweler Atodiad 1 ar gyfer y darn perthnasol o'r trawsgrifiad o'r cyfarfod ar 20 Medi 2007)

## **Ystyriaeth bellach**

### **4 Hydref 2007**

Clywodd y pwyllgor dystiolaeth lafar gan y deisebwyr, a chytunodd:

- Y byddai'r Cadeirydd yn ysgrifennu at y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol ynghylch yr arian ychwanegol y gofynnodd y deisebwyr amdano.
- Y byddai'r Cadeirydd yn ysgrifennu at Gadeirydd y Pwyllgor lechyd, Lles a Llywodraeth Leol i ofyn iddynt ystyried y mater o ganiatâd tybiedig.
- Y byddai'r Cadeirydd yn ysgrifennu at Gadeirydd y Pwyllgor Busnes i ofyn am ddatl yn y Cyfarfod Llawn ar ganiatâd tybiedig.

(Gweler Atodiad 1 ar gyfer y darn perthnasol o'r trawsgrifiad o'r cyfarfod ar 4 Hydref 2007, Atodiad 2 ar gyfer y llythyr a anfonwyd at y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol, Atodiad 3 ar gyfer y llythyr a anfonwyd at Gadeirydd y Pwyllgor lechyd, Lles a Llywodraeth Leol ac Atodiad 4 ar gyfer y llythyr a anfonwyd at Gadeirydd y Pwyllgor Busnes).

Ysgrifennodd Cadeirydd y Pwyllgor lechyd, Lles a Llywodraeth Leol at Gadeirydd y Pwyllgor Deisebau gyda chanfyddiadau'r ymchwiliad ar ganiatâd tybiedig.

(Gweler Atodiad 3 ar gyfer ymateb Cadeirydd y Pwyllgor lechyd, Lles a Llywodraeth Leol)

### **2 Hydref 2008**

Ystyriodd y pwyllgor adroddiad ar ymchwiliad y Pwyllgor lechyd, Lles a Llywodraeth Leol i ganiatâd tybiedig, a chytunwyd i gau'r ddeiseb oherwydd ei fod yn teimlo na allai fynd â hi ymhellach.

Gellir gweld adroddiad y Pwyllgor lechyd, Lles a Llywodraeth Leol ar ei ymchwiliad i Ganiatâd Tybiedig ar gyfer Rhoi Organau drwy glicio ar y linc a ganlyn:

<http://assemblywales.org/cr-ld7192-e.pdf>

(Gweler Atodiad 1 ar gyfer y darn perthnasol o'r trawsgrifiad o'r cyfarfod ar 2 Hydref 2008)

**Clerc y Pwyllgor Deisebau**

**Hydref 2008**

## Atodiad 1

## Darn Perthansol o Drawsgriadau Cyfarfodydd y Pwyllgor Deisebau

**20 Medi 2007**

**Val Lloyd:** We now move to the first of the 10 petitions to which we are giving initial consideration today. The first is the petition by the Kidney Wales Foundation to increase the number of organ donors. Does anybody want to comment on that?

**Michael German:** This is one that I think would merit an evidence session, because it is such a major issue, and we must try to boil it down to the key things that the foundation wants. Yes, we need more kidney donors, and that is the objective, but I am unaware precisely how you achieve that, and it would be useful to have some evidence to give us a bit more direction as to where we send this petition afterwards.

**Val Lloyd:** The foundation asks for support from the Welsh Assembly Government, and I know that, in March, it supported UK Transplant's first-ever mailshot in south Wales, to 275,000 homes, though this was only in Cardiff, Newport and Swansea. I found that in an e-mail that someone sent me. I have always been interested in this particular subject. There has been a reasonably recent discussion in England about an opting-out scheme rather than an opting-in scheme, but that raises ethical issues. Personally, I would be in favour of it, but there are ethical issues.

**Michael German:** The reason that I asked for the foundation to give us its evidence is because although we could make a decision as to the best way forward, that is not quite what we are about. We should tell it that it should focus on the 'how' rather than the 'what', as regards the expedition of its petition. It might be helpful to do that in a question session next time.

**Val Lloyd:** Does everybody agree?

**Bethan Jenkins:** [Inaudible.] —what they entail.

**Val Lloyd:** Of course, the need is growing all the time, with the huge—

**Andrew R. T. Davies:** I have been impressed this morning.

**Val Lloyd:** Quite rightly.

**Michael German:** They must have known that this committee was—[Inaudible]

**Andrew R. T. Davies:** No. [Laughter.]

**Val Lloyd:** If we move on to the next one, which is the petition—

**Bethan Jenkins:** [Inaudible.]

**Val Lloyd:** Yes, I am sorry, Bethan—I am conscious of the time, that is all. We will invite the foundation to give us more evidence, I think. The foundation is the expert, of course.

#### **4 Hydref 2007**

**Val Lloyd:** We have four members of the foundation here to speak to us today. We took our first consideration of the petition at our last meeting, and we have requested them to attend today. I ask you to introduce yourselves, starting with Mr Aggarwal.

**Mr Thomas:** I was going to introduce the team, if that is still okay.

**Val Lloyd:** Certainly, Mr Thomas.

**Mr Thomas:** Diolch yn fawr. Prynawn da. On my right is Eirlys Hatcher, who is a trustee of the Kidney Wales Foundation. As a bit of background, she has worked with the BBC for 28 years on *Pobol y Cwm*. She has recently come on board because her daughter had a transplant some years ago. Allison John has had four transplants—lung, liver, kidney and heart. She is an ambassador for the Kidney Wales Foundation, and leads our campaign People Like Us, or *Pobl Fel Ni*. On my left, I have Raj Aggarwal, who will not need translating from Gujarati, I can assure you, although I received a housekeeping phone call to that effect. He is the chair of the trustees and he keeps us in order, and is a community pharmacist in Cardiff. I am Roy Thomas. I have been involved with the Kidney Wales Foundation for some years, in bringing the charity forward in terms of the campaign, which, as I mentioned, is led by Allison.

Thank you for having us, Cadeirydd, and for allowing us to petition your new committee. We believe very strongly in organ donation and that there is a need for increased awareness in Wales. That is why we petitioned you. Our petition is slightly different in that there are some action points in it. We pledge to match fund any public money given. We do not have a bottomless pit, very much like you here, but we are prepared to match fund to ensure that awareness raising is promoted. That is what we are trying to do. We also want to work with other charities, and we recently had a meeting with the British Heart Foundation, the Cystic Fibrosis Trust, the British Lung Foundation, the British Liver Trust, the Royal National Institute for the Blind Cymru, and Diabetes UK Cymru to touch on these issues.

Every year in the UK, 400 people die while waiting for a transplant. There is a great need and demand for organs. A total of 750,000 of the signatories to the organ donation register, which is run by UK Transplant, based in Bristol, are registered as living in Wales. That is 25 per cent of our population. That is about the average for the UK, according to Government figures. However, we believe that more than 400 people in Wales are waiting for a transplant at the moment. In Cardiff, in 2004-05, there were 83 transplants. In 2005-06, there were 78 transplants. In 2006-07, there were 89 transplants. Patients in north Wales receive transplants in Liverpool, and the figures there for those years were 16, 16 and 13, respectively. All transplants for children are currently carried out outside Wales: patients from south Wales go to Bristol, and those from north Wales go to Liverpool.

In July, Sir Liam Donaldson promoted the issue of presumed consent, and, on that day, he received 17,000 signatories to the ODR, which was astonishing. Awareness-raising does work, and we think that he has added around 22,000 signatures to the register in total. That call in England is increasing. I will now ask my colleague, Raj, to develop that further and to give you some more figures.

**Mr Aggarwal:** Chair and Assembly Members, in the UK as a whole, which has a population of 60 million, 3,000 transplants were carried out during 2006-07, compared with only 102 in Wales, which has a population of 3 million; 89 were carried out in Cardiff and 13 in Liverpool. In simple comparative terms, there are 50 fewer transplants on average in Wales than in the UK. What a difference 50 more per year in Wales would make.

UK Transplant spending figures are as follows: in 2004-05, it was £36,674, with £35,000 being core funding from UK Transplant and £1,674 carried forward from the previous year; in 2005-06, it was £42,000; in 2006-07, it was £95,000, with £35,000 being core funding from UK Transplant, plus an additional £20,000, which made it £55,000 from UK Transplant, with £40,000 being provided by the Assembly for a leaflet-drop in March.

As Roy stated earlier, it is all about increasing awareness. Surveys show that 70 per cent of people want to donate their organs after death, but only 22 per cent are signatories to the NHS organ donor register. We are petitioning the Assembly to increase the funding by a further £35,000 on the current levels for 2007-08. Kidney Wales Foundation pledges to match this £1 for £1, thus increasing the budget by £70,000—a massive 67 per cent increase. What a difference this would make to awareness. Thank you, Chair, and Assembly Members. I ask Alison to elaborate a little more.

**Ms John:** According to UK Transplant, it is actively campaigning. It employs a fine person in Wales, but it is based in Bristol. It is planning the following activities for 2007-08: a school education resource programme aimed at 14 to 16-year-olds in all secondary schools across Wales, a DVLA mailing in March, April and May next year, it is visiting freshers' fairs at universities in Cardiff and Swansea, and is mailing GPs and libraries nationwide, including those in Wales, and it will also use passport mailing.

The spring 2007 UK door-drop leaflet prompted a 0.71 per cent response rate, which is well within the industry's standard for unaddressed mail drops. Coupled with supporting paid-for advertising and publicity, the campaign managed to increase awareness about the NHS organ donor register by 6 per cent and also appeared to prompt a higher overall rate of registration in the door-drop areas by 63 per cent compared with 2006, and by 154 per cent compared with 2005. In total, there were 5,656 new registrations on the organ donor register from Cardiff, Newport and Swansea postcodes between 9 April and 25 May 2007.

Although the door-drop leaflet had a higher recall than the press and radio advertising, it would probably not be as effective in isolation. However, due to a lack of budget, UK Transplant did not look at television and media advertising. We in the Kidney Wales Foundation believe that the focused advertising and publicity activities heighten awareness around the time of the door-drop campaign and serve to

generate positive attitudes towards organ donation and help to reinforce the message. The relatively low response rate may have resulted from the fact that a high proportion of the Welsh population—25 per cent, as Roy said—is already registered on the organ donor register. However, we think that more work is needed and that this can be improved. We understand from UK Transplant that a future campaign would look at targeting postcodes with relatively low registration rates to increase the uptake in these areas. This should have been done before, but it is not easy in rural areas.

UK Transplant could not advise us of its budget for this financial year for activities in Wales. I would like to ask Eirlys to talk about this matter further.

**Ms Hatcher:** Thank you very much. If you do not mind, I will revert to my mother tongue and address you in Welsh.

Yn anffodus, dim ond unwaith y bu'n bosibl i UK Transplant gwrdd â swyddogion y Cynulliad yn ystod 2005-06 i gymharu â phum gwaith yn y flwyddyn cynt. Yn naturiol, yr oedd hynny yn peri gofid i ni fel elusen, ond deallwn fod y mater yn cael sylw ar hyn o bryd, ac mae hynny'n beth cysur i ni.

Unfortunately, it was possible for UK Transplant to meet Assembly officials only once during 2005-06 compared with five times the previous year. Naturally, that concerned us as a charity, but we understand that this matter is currently receiving attention, which is somewhat of a comfort to us.

Fel y bu inni glywed ynghynt, mae hybu ymwybyddiaeth am glefyd yr arennau a'r driniaeth sydd ar gael yn hollbwysig. Os yw'n effeithio ar eich teulu, mae hi'n bwysicach byth. Dengys ymchwil fod strategaeth sydd â chefnogaeth y cyfryngau yn fwy tebygol o gyrraedd y boblogaeth na'r dulliau mwy traddodiadol, sef llythyru a phamffledi. Felly, teimlwn y dylid ystyried ymgyrch sy'n defnyddio elfennau cryfaf y cyfryngau drwg annog a meithrin perthynas gyda chwmmnïau teledu a radio lleol yng Nghymru a hefyd rhedeg ymgyrch poster ledled Cymru. Byddai'r rhain yn cyrraedd y bobl mewn ardaloedd mwy gwledig lle nad yw'r dulliau mwy traddodiadol mor effeithiol.

As we heard earlier, promoting awareness about kidney disease and the treatment that is available is crucial. If it impacts upon your own family, then it is even more important. Research shows that strategies that are backed by the media are more likely to reach the population than the more traditional methods of communication, such as correspondence and pamphlets. Therefore, we believe that we should consider a campaign using the strongest media possible by encouraging and nurturing a relationship with local television and radio stations in Wales and also by running a poster campaign throughout Wales. These would reach more rural areas where the more traditional methods are not as effective.

Sylweddolwn fod yn rhaid i asiantaethau'r Llywodraeth fod yn ofalus wrth hysbysebu. Fodd bynnag, mae gweithio'n uniongyrchol gyda'r elusennau wedi profi'n effeithiol tu hwnt. Cafwyd enghreifftiau llwyddiannus o hyn gydag ymgyrch genedlaethol iechyd y galon, lle gwariwyd miliynau o bunnoedd

We realise that Government agencies have to be careful when advertising. However, working directly with the charities has proved extremely effective. There have been successful examples of this with the national heart health campaign, where millions of pounds were spent effectively by raising



yn effeithiol drwy godi ymwybyddiaeth am atal clefyd ac iechyd cyffredinol y galon.

awareness of heart disease prevention and general heart health.

Bu'r ymgyrch lawer yn fwy effeithiol gyda chefnogaeth y Llywodraeth gan ei fod yn gweithio yn uniongyrchol gyda'r elusen a'r sectorau gwirfoddol. Gwelwn enghraifft berffaith arall gyda'r NSPCC i hybu ymwybyddiaeth o greulondeb at blant. Ar hyn o bryd, nid yw UKT ym Mryste yn gwneud hyn ond yr ydym yn teimlo bod cyfle i ni yng Nghymru achub y blaen gan bod modd i ni fel elusen weithio'n annibynnol gyda'r cwmnïoedd teledu, a manteisio ar ein sefyllfa unigryw fel cenedl a rhanbarth i drafod telerau effeithiol ac felly sicrhau costau is o ran rhedeg yr ymgyrch. Yr ydym hefyd yn awyddus i weithio gyda sêr y cyfryngau mewn unrhyw ymgyrch deledu a radio neu phosteri, er mwyn codi proffil a hybu ymwybyddiaeth am glefyd yr arenau yn gyffredinol.

The campaign was much more effective with the Government's support because it worked directly with the charity and the voluntary sectors. Another perfect example is the NSPCC in promoting awareness of cruelty to children. Currently, UKT in Bristol does not do this but we feel that there is an opportunity for us in Wales to steal a march here because as a charity we could work independently with the television companies, and take advantage of our unique situation as a nation and region to negotiate efficient terms and therefore ensure lower running costs for the campaign. We are also keen to work with media celebrities in any television, radio or poster campaign to raise our profile and raise awareness of kidney disease in general.

**Mr Thomas:** So, Chair, to bring all this together, Kidney Wales Foundation has been doing this for several years—this is our fortieth year. We successfully lobbied the Prime Minister in the 1980s, Margaret Thatcher, on ensuring that donor cards were in driving licences with the DVLA being in Swansea. In 1986, we were one of the first charities to have an online donor registration and the late Princess Diana launched that in Cardiff. So, we have a track record for doing these things and we are trying to bring that to the fore.

I hope that the committee also understands that we want to work in partnership with other institutions and charities, and that that is the best way of doing it. Again, we have a track record of doing that. Our request is that we would like you to refer your proceedings and deliberations to the Minister for Health and Social Services so as to inform her and her budget, which we understand has not been settled, so that we are able to work with her department. I should add that we have had very good meetings with her to date on the People Like Us campaign, but budgets are another issue. I am sure that she would look at this differently but we would like her to look at these amounts—they are relatively small amounts, given her budget.

Secondly, we would like you to ask the appropriate Assembly committee—you will know best in this regard—to consider our evidence and for that committee to seek further evidence. We believe that the chair of the Health, Wellbeing and Local Government Committee, Jonathan Morgan, is prepared to consider what we are doing.

Thirdly, we would like the Assembly under our People Like Us campaign to consider the need for a more joined-up policy on the issue of organ donor register presumed consent.

**Val Lloyd:** Thank you to all the presenters. You have kept perfectly to time. I congratulate you. Perhaps it is due to long practice. [*Laughter.*] I would like to open the meeting now for 15 minutes or so to committee members if they would like to ask any questions of the four speakers we have before us.

**Andrew R.T. Davies:** Your points are pertinent and you are direct in what you are asking us to do, especially the three measures. It is a pleasure to have a petition such as this, because we can deal with exactly what you are asking us for. You highlighted an ongoing campaign but you also highlighted in the evidence that there has almost been a breakdown in dialogue, or a lack of opportunity to have a dialogue, with the Welsh Assembly Government over the last 12 months—I think you said that you had met once, while that you had met five times in the previous 12 months. Is there a reason for that? Had you almost exhausted the campaign, or is it a simple case of diaries clashing?

**Mr Thomas:** The position is that UK Transplant met only officials here, and not us, so we may have misrepresented that. Our point is that they met five times in the previous years and the then Minister for Health and Social Services perhaps had other priorities. After 40 years, we are saying that we want this issue pushed up the agenda. We think that we should be looking at UK Transplant and what it is doing in Wales. Our concern is that we have asked it what its budget is for Wales this year, so we can perhaps work with it, but it does not have that information. I have spoken to Chris Rudge, the chief executive, who is a fine person. He admits that perhaps there should be more dialogue.

**Val Lloyd:** Do you have any further questions, Andrew?

**Andrew R.T. Davies:** I was just a bit concerned about the breakdown in communication, but it obviously was not a breakdown.

**Val Lloyd:** Peter, do you want to ask a question?

**Peter Black:** I think that this is a worthwhile cause and you could spend as much money as you have on the whole thing. What sort of commitment are you looking for in terms of cash from the Welsh Assembly Government?

**Mr Thomas:** Raj, would you like to answer that? I think that we were looking at £35,000.

**Mr Aggarwal:** We are looking for an additional £35,000. We would match that £1 for £1. That is the promotion part of this. The Assembly gave us £40,000 last year for the leaflet drop. So this would be in addition to the £40,000 that was given last year. So, we are, effectively, asking for £75,000 from the Assembly to keep a similar budget. Just to emphasise this point: if we get the additional £35,000 from the Assembly, we would add another £35,000 to this to make it £70,000, which would bring about a tremendous amount of awareness.

**Peter Black:** In terms of presumed consent, what sort of financial implications are attached to that?

**Mr Thomas:** That depends on who is leading that campaign. If it were the Minister, then clearly it would be a different campaign, but we believe that other charities would chip in. As I mentioned, we are talking to them. One of the key issues here from my experience is how to buy into Welsh media—UK Transport is based in Bristol; ITV Wales has a different rate card from ITV in the south-west. It is being perhaps an acute buyer. If a charity comes in and starts negotiating with our friends in Culverhouse Cross, that would be a better way of dealing with it. The template for that is the British Heart Foundation. If you recall, it had some excellent campaigns on smoking, with the fat cigarettes. The British Heart Foundation did that, which is different from Government doing it. I suggest that a charity can be a bit more creative and surprising, or whatever, in their outlook so that the message hits home. The National Society for the Prevention of Cruelty to Children campaign, which Eirlys mentioned earlier, was pretty hard-hitting, but certainly got the message out. So, that is our example to put to you and to put to perhaps another committee and the Minister.

**Bethan Jenkins:** Just to clarify—you obviously want the Minister to deal with the budget side of things. So, would you like us to pass on the issue of the legislation to the committee? Would that be your wish, in terms of the presumed consent, for it to be passed to the Health, Wellbeing and Local Government Committee?

**Mr Thomas:** We would be very happy with that.

**Bethan Jenkins:** Could you expand on what you think is the joined-up thinking. Is that to come from us as an Assembly or within policy areas at the Assembly or generally nationally?

**Mr Thomas:** I think that the joined-up thinking here is a bit different. The Assembly has a great track record of joined-up thinking in other areas. Here we have UKT, which is a different body, which is accountable to the Assembly, but has never been in front of one of your committees and—although I cannot talk on his behalf—I would expect the chief executive to come over the bridge and be accountable to you in this or whichever committee. That is not happening at the moment because it is an England-and-Wales body.

**Bethan Jenkins:** So do you think that it would help if we communicated with that body, because communication between you and it is difficult? We could perhaps be the bridge in that respect.

**Mr Thomas:** You could be and we are liaising with it; I should add that we do not have a dispute with it. We would like to increase its budget, so the reason we are here today, oddly, I suppose, is to get it to spend more in Wales by getting the Assembly to provide more money and by getting us to put more money in, and to get it to take Wales—and this may be harsh on it—a little bit more seriously, although it has different parts of the UK to address. We have given you the figures on people waiting for transplants, and we think that it is a special case in Wales.

**Val Lloyd:** Picking up on Bethan's question on the joined-up approach, when you are working with UK Transplant, are you working on raising awareness or are you thinking more about the presumed consent?

**Mr Thomas:** I think that both flow into each other, but I would like Allison to address that point. We have been campaigning on these issues only since September, but we have been researching since the summer.

**Ms John:** We need to increase the number of people on the organ donor register and to think about presumed consent, because people are dying in Wales waiting for transplants, and we think that an opt-out system, which is the presumed consent, would be a better system in Wales. They already do that in Spain, where people have to opt out of giving their organs after death, rather than opting in, which is the system that we currently have. We introduced the smoking ban in Wales before England, so I think that we should follow that lead and do it for presumed consent. As well as having the law change as regards presumed consent, we need to keep people on the organ donor register. So, they need to work together.

**Mr Thomas:** I think that Allison is right and I think that, while we are waiting for legislation, we should not take our eye off the ball in terms of the register. So, if that failed, we would not want one or the other, because we should have both.

**Val Lloyd:** Do you think that the opt-in or presumed consent, whichever we call it, should be UK wide or should we be looking at it on a Wales-only basis? I know that we can look at it Wales wide only, but would you be seeking an approach that is UK wide?

**Mr Thomas:** It would be a good idea if it was UK wide. The Secretary of State for Health, Alan Johnson, has put it on the agenda—he did that, I think, on 19 or 20 September. We understand that our Minister for Health and Social Services in Wales is keen on it, and so are others in the Government. We have also talked, on an informal basis, to the deputy chief medical officer, not the chief medical officer. However, we think that that perhaps should be led by a public consultation, so that everyone is aware of, and understands, the issues, and so that it is not forced on the people of Wales. Radio 5 Live this morning had a phone-in on the issues, and this type of subject usually increases the ratings of these broadcasters. I think that there is a demand out there, particularly when case studies are shown, and we have a number of case studies that we have been using as a part of the campaign. Since the launch of the campaign, we have had people ringing up from Blaenau Ffestiniog, who are interested in what we are doing on the dialysis side, and from Welshpool and Cardiff.

The campaign has sought to be hard-hitting about the third-world conditions. For example, Glangwili hospital opened its unit in 1986, and it is in a portakabin now. The Minister is aware of these issues. Our children are also being taken to Bristol for transplants, which is quite a way for families to travel for, say, five or six weeks. We are concerned about that, and a part of our campaign is to have a dedicated transplant unit in Cardiff, as there was in the Cardiff Royal Infirmary. We are told that 89 transplants were undertaken last year, which is the same figure as 10 years ago. So, the situation should have developed by now in order to address the issues. We are also aware—and I have got onto my hobby horse here—that these matters have laid fallow for too long and patients are getting frustrated. So, this is a patient-driven issue, and we are fortunate that Allison is able to give her experience to the patients and understands what it is like to be on dialysis.

**Ms John:** I completely understand that presumed consent is a complex moral argument, but we need to have this public debate in Wales. Surveys have shown that 70 per cent to 80 per cent of people are in favour of presumed consent, but until we have a public debate, I do not think that we will know what the general consensus is. It is important to talk about these things. Not everyone knows what presumed consent is all about; it is alien to most people who are not involved with transplantation. So, airing these issues is really important.

**Val Lloyd:** Are there any further questions? As there are not, I thank you for your visit and for your cogent arguments. We will now discuss how we take them forward.

Are there any views from committee members?

**Andrew R.T. Davies:** The points were well made. They asked us for three things and I think that it is within our gift to sort all three out. Funding is clearly a Government issue that needs to be addressed by the Government. The renal unit and its development—I am sorry, the dedicated transplant unit—requires far more work and consideration, and I would suggest that that would be for the Health, Wellbeing and Local Government Committee because it is a complex issue. Given that presumed consent is such a moral issue, and as the committee has the right to do this, perhaps we should try to seek a debate on it in Plenary.

**Peter Black:** I concur that the health committee needs to look at these issues. A debate in Plenary would be interesting and it would be a useful forum. The health committee might also want to take evidence on presumed consent, if it was willing, because that sort of inquiry would help to inform the debate. The sum of £35,000 is not a lot of money, and maybe we should refer that particular aspect straight to the Minister.

**Bethan Jenkins:** Given that we are discussing budgets now, that is the most pressing issue, but the idea of having a debate is a good one. I am also concerned about the question that I asked about joined-up thinking, because what I think happens with a lot of UK-based charities is that they find not a conflict of interest, but problems with funding allocations from the centre. Perhaps we could communicate with them about that.

**Val Lloyd:** I am not quite certain what you are saying, Bethan.

**Bethan Jenkins:** They were raising the issue of not being able to secure funding through the central UK charity. Therefore, perhaps we could seek some information from the charity as to its allocation of funds for Wales so that we could have some clarity on this.

**Andrew R.T. Davies:** The only difficulty that we might find is that we were not charged with doing that. The petition asks for three things, and those do not refer to the funding stream from the UK into Wales. It asks for three specific things: one is for funding, and match funding, from the Welsh Assembly Government; and another is for a dedicated unit to increase the number of transplants. We heard that the transplant rate today—I think that 89 was the figure quoted—is the same as it was 10 years ago. There is a real question to be asked in that regard. In addition, there is the moral debate of whether presumed consent should be implemented as the first-

choice policy with an opt-out option.

**Val Lloyd:** That is how I saw it too. We should refer the request for additional money for promotion directly to the Minister. I informally know that the health committee is happy, or rather the Chair has indicated that he is willing, to consider further evidence. The only difficulty is that the health committee—I know this as a member—is fully committed this term, but that is for that committee as a whole to decide. We could also link in the third point about how to work with other agencies when we contact the Minister, or it could be that that should come under the committee's remit as well. Would a debate in Plenary be more fruitful after the health committee has looked at this issue or before?

**Peter Black:** If the health committee will not be able to look at it in this term—

**Val Lloyd:** I made that presumption.

**Peter Black:** You are most probably right. Most committees have set out their programme for the term. However, there would not be any harm in having the initial debate in Plenary on a motion to refer it to committee, or something like that. We could have an initial debate, then the committee could take it up from there.

**Val Lloyd:** Is that agreed? Okay. Just to clarify my understanding—the clerk will tell me whether we have got it right—we will refer the financial promotional side of match funding to the Minister, and the point has been rightly made that budgets are being set now, so it is an opportune time to do that. We then ask the Health, Wellbeing and Local Government Committee to consider the evidence, and to seek further evidence on a range of issues, and we initiate a debate in Plenary. Is that everyone's understanding? I see that it is. Thank you.

## **2 Hydref 2008**

**Val Lloyd:** I notice that our agenda says that we could have a break now. However, we have only just got under way. I think that that speaks volumes for our efficiency. We have a considerable number of petitions to get through, so I think we should continue.

The first are the two petitions that we received relating to similar, but not identical, subjects: one is from Kidney Foundation Wales and the other from the Kidney Patients Association. We have had these for some time. The Health, Wellbeing and Local Government Committee's report has now been published. The Minister has also commented on it and taken a different view to the majority view of the committee. That is the Minister's prerogative, of course.

**Michael German:** On this occasion, I think that she is right. Should we send her response to the report to the petitioners? We have sent them the committee's report. Do you think that we should also send them the Minister's response?

**Val Lloyd:** I am sure that we can. However, I am sure that they are very well aware of it. We will do that. We will also formally close both petitions today

## Atodiad 2

## Y Pwyllgor Deisebau

### Petitions Committee

Edwina Hart  
Minister for Health and Social Services  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: P-03-059

11 October 2007

Dear Edwina,

#### **PETITION – KIDNEY FOUNDATION WALES: DONOR CARDS**

As you will be aware, the Assembly now has a duty under Standing Order 28 to consider all admissible petitions it receives. The Petitions Committee has been established to consider these petitions. At its meeting on 4 October, the Committee considered a petition from Kidney Foundation Wales calling for the Welsh Assembly Government to provide £35,000 to fund an awareness campaign to increase the number of registered organ donors. Kidney Wales Foundation would match fund any money from the Government pound for pound.

The Committee discussed the petition and we agreed that the funding issue should be referred to you for consideration. A copy of the papers that the Petitions Committee considered is attached.

The Committee also agreed to refer the issue of presumed consent to the Health, Wellbeing and Local Government Committee to consider and that I should write to the Presiding Officer, as Chair of the Business Committee, asking that it consider whether a Plenary debate on presumed consent should be held.

The Petitions Committee will give further consideration to the petition in the light of the response.

A copy of this letter goes to Carwyn Jones for information.

Yours sincerely

**Val Lloyd**

**Chair, Petitions Committee**



## Atodiad 3

**Y Pwyllgor Deisebau**

**Petitions Committee**

Jonathan Morgan  
Chair, Health, Wellbeing and Local  
Government Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: P-03-059

8 October 2007

Dear Jonathan

**PETITION – KIDNEY FOUNDATION WALES: DONOR CARDS**

As you will be aware, the Assembly now has a duty under Standing Order 28 to consider all admissible petitions it receives. The Petitions Committee has been established to consider these petitions. At its meeting on 4 October, the Committee considered a petition calling for a campaign to increase the number of registered donors, and for a debate on presumed consent of organ donation.

The Committee discussed the petition and we agreed to ask the Health, Wellbeing and Local Government Committee to consider the issue of presumed consent and to provide us with further advice. A copy of the papers that the Petitions Committee considered is attached. The Committee also agreed that I should write to the Presiding Officer, as Chair of the Business Committee, requesting a Plenary debate on presumed consent.

I would be grateful if you could arrange for this matter to be considered by the Members of the HWLG Committee at an early stage and for its views, or any action that it takes on the petition, to be reported to us as soon as possible. The Petitions Committee will give further consideration to the petition in the light of the response.

Yours sincerely

**Val Lloyd**  
**Chair, Petitions Committee**

Y Pwyllgor Iechyd, Lles a  
Llywodraeth Leol

Health, Wellbeing and Local  
Government Committee



Cynulliad National  
Cenedlaethol Assembly for  
Cymru Wales

Val Lloyd AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: HWLG(3)07-07  
Your ref: P-03-059

12 November 2007

Dear Val

**Petition from Kidney Foundation Wales**

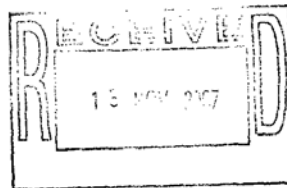
You will be aware that at its meeting on 7 November, the Health, Wellbeing and Local Government (HWLG) Committee considered the above petition, which was referred to them for consideration by the Petitions Committee.

Members discussed the petition, and agreed, given the importance of the issues raised by the petition, that they should undertake a short review into the proposal of presumed consent, with a view to possibly bringing forward a Legislative Competence Order (LCO). I shall begin the process by seeking legal advice as to whether this would be possible.

In light of the advice from lawyers, the Committee would then consider beginning a review of presumed consent in early 2008. I hope this is helpful.

Yours sincerely

Jonathan Morgan  
Chair



## Atodiad 4

**Y Pwyllgor Deisebau**

**Petitions Committee**

Lord Dafydd Elis Thomas PC  
Chair, Business Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: P-03-059

11 October 2007

Dear

**PETITION – KIDNEY FOUNDATION WALES: DONOR CARDS**

As you will be aware, the Assembly now has a duty under Standing Order 28 to consider all admissible petitions it receives. The Petitions Committee has been established to consider these petitions.

At it's meeting on 4 October, the Committee considered a petition from Kidney Foundation Wales calling for a campaign to increase the number of registered donors, and for a debate on presumed consent for organ donation. A copy of the papers that the Petitions Committee considered is enclosed as background.

The Committee agreed to refer the petition to the Assembly Government to consider funding issues and to the Health, Wellbeing and Local Government Committee to consider the issue of presumed consent.

The Committee also agreed that consideration should be given to holding a full plenary debate on presumed consent. The mechanisms for a Committee to request a plenary debate are not entirely clear, in circumstances where the Committee is not laying a formal report before the Assembly. However, the functions listed under Standing Order 11.7 suggest that the Business Committee may be best placed in the first instance to consider this request and I would be grateful if you could arrange for it to do so.

The Petitions Committee will give further consideration to the petition in the light of the Business Committee's response.

Yours sincerely

**Val Lloyd**  
**Chair, Petitions Committee**

