

Y Pwyllgor Deisebau
Petitions Committee

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



Mark Drakeford AM
Chair, Health and Social Services
Committee
National Assembly for Wales

Bae Caerdydd / Cardiff Bay
Caerdydd / Cardiff
CF99 1NA
P-03-295
21 May 2012

Dear *Mark*

P-03-295: Kyle Beere – Paediatric Neuro Rehabilitation

Thank you for your letter of 29 February in which you conveyed the Health and Social Care Committee's decision to await the outcome of the Petitions Committee's round table discussion on neuro rehabilitation before taking further action. I am pleased to report that the round table discussion took place on 1 May and the evidence received was considered at the following meeting on 15 May.

The Committee heard evidence from the petitioner, Katherine Simmons and her supporter, Emma Wools along with representatives of WHSSC, Headway and the Minister for Health and Social Services' Officials. A transcript of the session is enclosed, as is the other evidence the Committee has received on this petition.

Following its consideration of this petition, the Committee feels that there is a need for further work to be carried out on neuro-rehabilitation services in Wales. I hope that your Committee will agree to take this issue forward. If so, the Petitions Committee would close the petition and look forward to the outcomes of your deliberations.

Yours sincerely

William

William Powell AC / AM
Cadeirydd / Chair

Enc: Transcript 1 May 2012 & Written evidence relating to the petition

Bae Caerdydd / Cardiff Bay
Caerdydd / Cardiff
CF99 1NA

Ffôn / Tel: 029 2089 8393
E-bost / Email: William.powell@wales.gov.uk

P-03-295 Kyle Beere Gwasanaethau Niwroadsefydlu Paediatrig: Trafodaeth
P-03-295 Kyle Beere Paediatric Neuro-rehabilitation: Round Table Discussion

[143] **William Powell:** Welcome, everyone, and thank you for braving the elements to join us this morning for this important session considering the petition on paediatric neuro-rehabilitation services. Rather than asking for some opening remarks, we will go straight to questions, I think, to make the best use of the time available. I ask Russell George to open things up. Over to you, Russell.

[144] **Russell George:** Good morning to you all. What are the main features that you would like to see in a rehabilitation service based at the children's hospital in Cardiff?

[145] **Ms Woolls:** It might be handy to talk through the business case that has already been presented to the Cardiff and Vale University Local Health Board, first about its components and then about the broader functions and services that we would like to see added to that, to put it into context. Would that be useful?

[146] **Russell George:** I asked the question. You go ahead and answer that as you would like.

[147] **Ms Woolls:** Okay. From our perspective, ideally, we would like a service that looks at children and young people from birth to 18 years who have an acquired brain injury, but who also have other conditions that could benefit from therapy interventions or a programme within that service. We would like the service to be available to all children and young people in Wales, but also, potentially, to be accessed by children from the south-west of England, given that there is clearly a lack of services.

[148] On the service design, ideally, it would include a rehabilitation facility or centre staffed by a multidisciplinary team, and a person-centred approach would be adopted with an individualised package of care. Our experience has shown that the services that are currently available seem to be more resource-led than needs-led, and that we need a service that is bespoke and flexible to the whole spectrum of conditions, ranging from mild brain injury to the severe, as Kyle has presented with.

[149] As I said, we would like to see the service cater for a spectrum of needs, and so we would like it to look at initial intensive in-patient intervention, so providing a residential service as well as ongoing out-patient services.

[150] The most important aspect to highlight is the delivery of core therapy provision, such as neuropsychology, so that we can get assessment right at the start, to identify the presentation of conditions and residual issues resulting from any condition or traumatic brain injury. Other therapy provision would include neurophysiotherapy, speech and language therapy, occupational therapy, education input, and then other proven therapy interventions that are known to work and help to develop a child's engagement with the core therapy interventions.

[151] We would like the centre to be a central point of contact and co-ordination for services from hospital to home and ongoing, and also for there to be some type of outreach service provision, as we have seen delivered in the Children's Trust in Tadworth, Surrey. That would help to provide consultancy or advisory services to mainstream service provision such as education, social services and care support, namely other service areas that children and families would need to access over a lifetime or during a short period of intervention.

[152] Talking of family services, there definitely needs to be more holistic provision, including respite services, counselling and education. Speaking from my personal experience and my sister's, Kyle's injury came as a shock for which there was no preparation, and it was life-changing overnight. We found that the services available to us lacked expertise of what Kyle had suffered, and were therefore not able to guide or educate us on how to manage him to reintegrate. That was aside from dealing with the grief that comes with the sense of loss that you have, even

though the child is still alive, fortunately. My sister would advocate more of a network of family support, but one that is very much led by specialist guidance, because, at times, we felt very much alone in our situation and as though we were floundering.

[153] We would also like the service to look at transition management. That is paramount. Kyle is now 15 years of age and will soon be reaching the stage of accessing adult services. Coming from a public sector background, I know that the transition from youth to adult services is not always managed right. If we are to set up such a service, the transition aspect needs to be included at the design and planning stage, so that it is integrated with existing adult service provision and organisations such as Headway, to guide how that looks.

[154] I am sorry, but I am rambling on now. Please feel free to ask questions and interject.
10.30 a.m.

[155] Funding is a key issue. Whatever service is looked at needs to be based on tripartite funding from the key service areas that are generally involved in this, namely social services, education and health. We have experienced a huge number of obstacles and challenges because of siloed budgets and because people or departments do not necessarily understand where their commitments, requirements or responsibilities start and end. This has led to delay or sometimes to the absence of services in their entirety. They are the main components of a service to which we would like commissioners to give consideration. Obviously, this needs to be based more on increased comprehensive evidence. We are here today, really, to ask the committee and others to consider commissioning a comprehensive research study about the actual picture and the population who could benefit from such a service.

[156] **William Powell:** Thank you, Emma, for setting that out in such a full context and so comprehensively for us. Russell, are there questions that have not been answered in the area that you wanted to pursue?

[157] **Russell George:** I have just one further question. Emma, you are not rambling at all. Thank you for your full answer: answer as you want; we are here to listen to your views. The questions are there to facilitate the discussion, so thank you for your contribution. I wanted to ask what rehabilitation services and support are currently offered at the hospital to children with acquired brain injury.

[158] **Dr Rogers:** I will hand over to Dan.

[159] **Russell George:** I was not quite sure who to look to for an answer.

[160] **Mr Phillips:** The Welsh Health Specialised Services Committee is accountable to the seven health boards. We are responsible for planning and funding specialised paediatric neurology services. The health boards are directly responsible for the local multidisciplinary teams, community services and the continuing healthcare packages, and together they have delegated responsibility to WHSSC for the specialist paediatric neurologists, the multidisciplinary team that surrounds them at the Children's Hospital for Wales, Alder Hey and Bristol, and for the very small number of children who are also referred to Tadworth. On the services that are provided locally, there are paediatric neurologists who specialise in paediatric neurology in Cardiff, but there is not anybody who has a full-time interest in paediatric neuro-rehabilitation, as there is in Tadworth. There is a multidisciplinary team containing many of the therapists to whom Emma referred, but they are spread over many services, and we recognise that the services in Cardiff need to be strengthened. We are in dialogue with the Cardiff and Vale local health board about the best way to do that. The plans for phase 2 of the children's hospital include a hydrotherapy pool and increased multidisciplinary therapy rooms—so, by 2015, those will be in place. We recognise that, as it stands now, those facilities are not available. That is a known fact and that is why we need phase 2 of the children's hospital. Is that sufficient or do you want me to paint a broader picture?

[161] **Russell George:** No, that is fine, although some of my colleagues may pick up on what you said.

[162] **Dr Rogers:** We recognise all the elements that Emma has just described as being appropriate for a paediatric neuro-rehabilitation service. We would also agree that it ought to be needs led, in terms of what individuals receive. In that sense, there is not a discrepancy between us in terms of where we would like to be going and what we think should be available. We have the same sort of approach, and the holistic element that you mentioned is important. As you said, it is a spectrum of needs and, although the whole health budget is the responsibility of the LHBs, WHSSC plans and secures the most specialist end of it. We need to work across the whole spectrum and put that together, to ensure that people have that needs-led service. It would be very difficult if there were a boundary. I do not think that there is a boundary in terms of the funding; we have the mechanisms to address it across the spectrum.

[163] **William Powell:** Dr Payne and Dr Jones, do you have any comments on further plans for the enhancement of the service? We have already heard some information from Mr Phillips and Dr Rogers. Are there any additional items that you would like to bring to the table at this point?

[164] **Dr Jones:** We wish to add a word of strong support for the petition. We are keen to see the issue being resolved, and we accept the position that things could be better. We will continue to use the Tadworth centre for the very small number of children who have very specialised needs. I think that we have sent only eight children there over the last 10 years, and I believe that that number is similar to the number of children sent from similar populations in England. It is a national English centre and we would not be able to replicate it in Wales. However, we recognise that we need to improve specialist neuro-rehabilitation for a number of other children who do not need to go to Tadworth, and for children when they come out of Tadworth.

[165] **Dr Payne:** A report on the national service framework for children shows that we have identified that transitional planning is an area in which improvement is needed, and it is incorporated in the new guidance that we are about to issue on the planning and delivery of continuing care. We deal specifically with the fact that care packages for children and young people should not be delayed by any arguments about funding. We have put in lines that address those specific issues that cause a lot of difficulty for people.

[166] **William Powell:** I am eager to broaden things out to look at the arguments for and against the continued use of Tadworth in those particular cases. Frances, do you want to make a contribution or challenge something that has been said?

[167] **Dr Gibbon:** We have not sent a lot of children to Tadworth, because it is a long way to travel for a lot of Welsh people and the children do not like being away from home. There is a huge financial commitment as well as a social commitment to having a child as an in-patient at Tadworth, which Kyle's family certainly found hard to deal with. There is an unmet need as well for the children who cannot go to Tadworth—I want to make that point.

[168] On the other point that Heather raised about the NSF for children, you may be aware that Edwina Hart commissioned the children and young people's specialised services project a while ago. That project outlined a service for children requiring neuro-rehabilitation. On what a service should look like and what shape it should take, information on that has already been published—in addition to the things that Emma has brought up—but it has not yet been implemented. So, that is already recognised and published. Personally, I have been trying to improve this service since 2004. I have been trying to get this project going for many years.

[169] **William Powell:** It has been a long-term commitment.

[170] **Dr Gibbon:** It is not a new thing, and I commend Katherine and Emma for being able to raise awareness of this issue at such a level, because these children are disadvantaged and do not have a voice.

[171] **Joyce Watson:** On the theme of equality of access, which is what you are asking for, do you think that children in Wales with and acquired brain injury and their families receive the same standard of service wherever they live in Wales? If not, what are the issues that prevent that from happening?

[172] **Ms Wools:** Correct me if I am wrong, but, anecdotally, it is our understanding from talking to parents and families who have gone through this that different local health boards, and perhaps professionals within those boards, would not necessarily be as aware of Tadworth as a facility as others. We are not sure about how much encouragement there is to make referrals. From a personal point of view, Kyle was in intensive care with two other children who were both at the severe end of the spectrum and would have benefitted from accessing Tadworth. Only two out of the three of those children were referred; one of them was not. Again, I could not comment on the reasons why that referral did not go ahead because I do not know what they might be, but it does seem that there is not any consistency. Whatever the referral criteria might be, it is certainly not the case that all children who present with conditions as a result of an acquired brain injury are referred to that service. Tadworth does not deal only with the severe end of the spectrum; it deals with the whole spectrum. So, there are many children with all sorts of conditions who would benefit from the service and I do not feel that those referrals are coming through.

[173] That said, Tadworth is a limited facility with 49 bed spaces and a waiting list of up to six months. Therefore, with regard to the timeliness of provision, even when a child has the benefit of being referred there, there can be a long wait. In Kyle's case, he had to wait five months in hospital to be placed. There is a great deal of literature on the timeliness of intervention when recovering from a brain injury. Did we miss an optimum window within those five months? Could there have been more guidance? He remained locally and received interventions from a great many committed staff within the hospital and the trust, I have to say, but perhaps they did not have the expertise required to deal with his condition.

[174] That has since been evident on Kyle's return to the community in respect of the staff and professionals who are now delivering community provision and support. Having asked staff in the special school he is now placed at how many of them have received training on children with acquired brain injuries, not one of them has said that they have. This is moving slightly away from your original question but, again, I feel that the lack of specialist provision in Wales means that the learning and education does not span out to other professionals in other quarters. It makes sense because we have to draft in that expertise from elsewhere, and when you are reliant on out-of-area services it means that you do not have that quality of experience and learning.

[175] **Bethan Jenkins:** Thank you for coming to give evidence. My only declaration of interest is that I helped to set up Headway in Neath Port Talbot and that, having spoken to many of the adults there, it is clear that there are many unseen issues that do not present themselves directly to the health service, so I believe that it would be of superior benefit to involve patients when scoping services. These are not issues that people can see straight away.

[176] My question relates to Headway's letter about the problems of children with ABI going undiagnosed or whose difficulties are not recognised. This is a question to any of you really: which agencies should take the lead on raising awareness of ABI and its effects so that children and families get the right support when they need it?

[177] **Ms Smith:** I think it needs to start with statutory services and improvement in the rehabilitation services we have already outlined. I would like to support everything Emma has said about the priority being to support family and carers with information and education because it is very much a hidden disability at the moderate-to-mild end where children are presenting at hospital, at accident and emergency or to their GP. The long-term effects of these injuries are often unrecognised and the family only become aware of the difficulties as time progresses

following an injury, when they try to return to normality. That is a huge area of concern for us. We talked about tri-partite working, but in fact I think it should be quad-partite working, including the voluntary sector. We are able to get very close to the people in need, but we need that support, in financial and resource terms, from the statutory bodies and the professional input.

10.45 a.m.

[178] What happens as well is that, if people are misdiagnosed or unrecognised, they are categorised incorrectly as having learning disabilities, so when we are commissioning services we are basing that on figures that are inaccurate and, therefore, are underestimating the occurrence of brain injury. Those instances are probably on the mild to moderate end of the spectrum rather than severe, but there are long-term, lifelong effects for these people. After a brain injury, people have a normal life expectancy, so they are living with these difficulties for 70 or 80 years. There is unsubstantiated evidence and statistics to show that something like 50% of the prison population has a mild to moderate brain injury, and if you understand brain injury you can immediately see how that would happen.

[179] **Ms Wools:** I would just add some figures to substantiate or put into context the degree of hidden harm caused by head injuries. The National Institute for Health and Clinical Excellence produced a report in 2007 that outlined that over 300,000 children under 16 presented with head injuries in accident and emergency departments in England, and, of those, up to 20,000 had mild, moderate, or severe traumatic brain injury, with additional children presenting with brain injury as a result of non-traumatic conditions, such as the experience we have had with Kyle. Again, there is no reason why Wales should not be comparable to that. Why would fewer children suffer head injuries here? These figures are not directly comparable, but they definitely present a case to look into this further, and perhaps not to focus on specialised and severe injuries, but to look along the spectrum of services, because the demand is clearly far higher.

[180] **Bethan Jenkins:** Do those from the health service have anything to add?

[181] **Dr Jones:** I would like to emphasise the central point that clinicians should lead these services with support from management colleagues within the health boards and the Welsh Health Specialised Services Committee. Clinicians will learn during their training, but also during their contact with families and other partner organisations. They will understand the evidence base from NICE and other bodies, and they generally have to advise us which services should realistically be in place. With all these funding decisions, it is a question of placing the money where there is best value and, generally speaking, if there is NICE guidance to recommend a certain type of treatment, we would want NHS Wales to provide it. There is likely to be other, low-value work out there that we could do less of, but that case has to be made by clinical colleagues generally, because they know most about these subjects, and they need to work alongside colleagues in management to support them.

[182] **Bethan Jenkins:** Are they making the case now? You say that they need to.

[183] **Dr Jones:** Absolutely, and I think that clinicians sometimes become frustrated because these things do take time and are not all that straightforward. When WHSSC allocates money, clearly it is redistributed money from elsewhere. This investment has to be high value, and the clinician is best placed to understand the value and work with colleagues in WHSSC. That process is ongoing and active; this is not an area that has been neglected entirely, but it is taking time to work through these processes. Of course, WHSSC cannot just receive a business case and then fund it; it has to understand where moneys that are currently invested in services are being spent, how they are being used on what is already there, and what the gap is realistically.

[184] **Dr Rogers:** We are actively pursuing the business case at the moment, but what we have heard so far is that this is about the full spectrum. In particular, Julie was just saying that Headway wants to see that full spectrum addressed. We can look at the specialised end of it, and

there is definitely a need to do that, but we also need to be looking at these other issues that you have raised. That is probably harder to achieve, because there are a lot more people involved and it is about being clear about what we are addressing at any one time. Certainly the message that I have taken away from this is that, whatever service is funded and developed, we need to be very clear about the needs that it can meet and will be attempting to meet, and what will not be met by it, so that people can at least see where potential gaps are.

[185] It is quite easy to get confused in this bigger picture about where services are, and when you start to talk about the other services that need to come in other than health services, it gets even more complex. So, clarity and a common understanding of the whole pathway of the spectrum and the burden of the disease out there is really important. We have talked about acquired brain injury, but, obviously, there are many different forms of it, and some of these services would be helpful for people with other disorders who have similar needs. So, it is quite complex. It is being looked at, but we have quite a way to go, and we probably will have to continue developing this over some considerable period of time. I do not think that there are any quick fixes, but we can do better with regard to what we are looking at now.

[186] **Bethan Jenkins:** I am a little confused. The first timeline is the second phase of the children's hospital. I know that a broader discussion is needed other than saying that this must be done by this point, but are there any goals currently in place that you can make us aware of—or send us a document afterwards, because we are pressed for time—so that we can understand where you are in the timeline of development?

[187] **Dr Rogers:** Yes, we can do that with regard to the specialised services.

[188] **Mr Phillips:** It is also important to say that we have had discussions with Alder Hey and Bristol hospitals about their services. There is a lot of work going on at a UK level, looking at paediatric neurosciences, paediatric neurosurgery and neuro-rehabilitation. So, we are not alone in looking at this. We are talking with Alder Hey and Bristol, which are both bigger children hospitals, and they also recognise that they need to strengthen their services. We are not alone in moving forward in this area.

[189] Later this year, we are expecting some UK-level standards about some of these services, which will inform our thinking. In 2015, we will have better physical facilities. We are now working with Cardiff and Vale health board and are planning to take a paper to our June joint committee with proposals about what the next step should be. We have had a business case from Cardiff and Vale, which was referred to earlier, and we have responded to it. There is an active dialogue, as Chris said, about what will be the real benefits from this. It is a very difficult area, because it is not as simple as one turning a knob to get an outcome; these are patients with very complex needs, and we recognise that. It is about what benefits will come from what staff, what is the most value we can get, and what the changes are. We invest about £1.6 million in specialised paediatric neurology services in Cardiff. It is about how much more we have to spend to get how much more. We will have a proposal to the joint committee.

[190] **Bethan Jenkins:** Some £1.6 million does not seem to me to be much really. I am not here to judge, but it does not seem to be a lot of money.

[191] **Mr Phillips:** That is just on the specialised element. There are local packages of care and individual patients' ongoing continuing healthcare.

[192] **Bethan Jenkins:** Could Frances come in quickly as well, because I know that she wants to say something from the clinicians' point of view?

[193] **Dr Gibbon:** It is very difficult to decide who you should have. There are no standards, as Dan said. There are no nationally accepted standards for what neuro-rehabilitation should contain. The next standards to come out are the paediatric neurosurgery standards in England, which are due to come out next year. They will contain a section on what neuro-rehabilitation

should look like in a hospital. If you can provide a specialist service in a hospital that can then advise and do some outreach work in schools where children like Kyle are, we see that as being part of the service, not just for the children in hospital. Although the bricks and mortar will improve the new children's hospital for some of our in-patients, it does not include service. So, the service is not part of that process.

[194] I also wanted to raise another service that we do not have enough of in Wales, which is neuropsychology or psychology, first, to support people who are grieving and who are in a difficult place and, secondly, to support people who have had a brain injury to see what their problems are and how we should address them. For example, if you come to Frenchay Hospital as a child with a brain injury, you will get seen by a neuropsychologist as soon as you can communicate. We do not have that service at all in Wales; we have to buy it in from Bristol. People who have a mild brain injury will end up not having anything at all, and many end up in the criminal justice system. So, as Dan was saying, there is not a quick fix; there is a lack of foundation for looking at this problem in the wider sense for adults as well. As has been said, if we have a business case to do something in hospitals, it does not fix everything for these people. However, it is a start.

[195] **Ms Simmons:** To comment on that, I feel, as a parent, that there has been no emotional support from the services either for me or for Kyle, which has been a real struggle for us. From my point of view, it is only through the assistance of my family and friends that I have been able to get on with things and to support Kyle. I am well aware that there are other parents who do not have that. So, it is obviously a very emotional subject for me, but I believe that the psychology element is very important.

[196] **William Powell:** I am sure that I am not alone in finding this one of the most useful and rewarding evidence sessions that the committee has had recently, because we have heard so many different views—from the petitioners, whose views were articulated so clearly and were formed by direct experience, and the specialists in the field, who are seeking to improve provision in Wales. The clock is against us now and I am conscious that colleagues need to be moving to group meetings very soon. Thank you very much indeed for what you have brought to the table this morning. It is something that we shall seek to take forward at our next meeting on 15 May, because we do not have the opportunity to consider the evidence immediately. However, we will have a full transcript of the evidence and we also have the opportunity to draw on anything else that you can submit in the light of one or two of the questions that we have had. So, thank you very much indeed. I also thank colleagues for their full contribution. Diolch yn fawr iawn.

10th January 2012

William Powell AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA



Headway Cardiff

Dear William Powell,

Headway Cardiff is a registered charity that provides support and services to adults affected by acquired brain injury (ABI), their families and carers throughout south east Wales.

The survivors we assist are adults, but many sustained their injury during childhood and have experienced paediatric neuro-services first hand.

Firstly it is important to acknowledge the lack of accurate statistics relating to ABI due to a combination of shortfalls in the coding system and in the case of minor brain injury, non-identification or mis-diagnosis.

It is also important to not wholly focus on those who are classified as having a severe brain injury. Those with a moderate or even a mild classification have complex, life-long difficulties, that impact on their ability to live an independent life.

Beyond the acute setting, it is vital that children receive a period of specialist neurological intervention. Appropriate, timely specialist intervention can greatly improve the level to which individuals recover and the speed in which this happens.

As the input of the family is crucial at this stage and throughout recovery, this service needs to be as accessible to the family as possible and offer as flexible and as personalised a programme as possible.

Following this intensive period of rehabilitation, a long term community based specialist multi-disciplinary team should be available until the child reaches adulthood and then in theory, there is a seamless transition to specialist adult services.

Headway Cardiff

Rookwood Hospital, Llandaff, Cardiff CF5 2YN
Tel: 029 2057 7707 E.mail address: info@headwaycardiff.org

A Company Limited by Guarantee Registered in Wales No. 3331865 Registered Charity No. 1063221
Registered address: 5th Floor, Hodge House, 114 - 116 St Mary Street, Cardiff, CF10 1DY
Patron: Mr Jonathan Davies M.B.E.
Affiliated to Headway - the brain injury association. A Registered Charity



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It is in the area of community services that the biggest gap appears in adult specialist neuro- services and it is vital that this area is considered in the development of any paediatric service.

Community services in Wales have not kept pace with acute services and the piecemeal nature of services has left many survivors feeling isolated and unsupported leading to crisis and family breakdown. Many of the gains they make in the immediate aftermath are lost due to the lack of ongoing therapy and support.

For those children whose impairments are severe enough to warrant a placement in a specialist educational establishment, ongoing treatment such as Occupational Therapy, Speech and Language Therapy and Physiotherapy is available.

What then happens to those with moderate and mild difficulties, who frequently go undiagnosed, unrecognized or whose difficulties are attributed to behavioral problems?

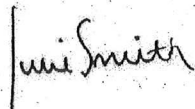
Who then supports them as the child reaches each new stage of development?

Who then provides the individual with ongoing rehabilitation and strategies?

Who supports the family in ensuring the child's educational needs are recognized and they are stated correctly?

Headway Cardiff wholeheartedly endorses the Petition to the Welsh Government to recognize the need for and to deliver specialist services for the rehabilitation of brain injured children within Wales.

Yours sincerely


Julie Smith
General Manager



GIG
CYMRU
NHS
WALES

Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

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Tel/ffôn: 01443 443443
Fax/ffacs: 02920 869534
Email/ebost: debra.davies5@wales.nhs.uk

William Powell AM
Chair, Petitions Committee
National Assembly for Wales
Petitions Committee
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Powell

**RE : P -03-295 Kyle Beere – Paediatric Neuro
Rehabilitation Services**

Thank you for your letter dated 23rd November 2011, requesting the number of children requiring admission to Tadworth over the last 10 years.

I can confirm that since the 1st of February 2002 to date, 8 children have required admission to The Children's Trust, Tadworth.

I hope this answers your request. If I can be of further assistance, please do not hesitate to contact me.

Yours sincerely

Dr Cerilan Rogers
Director of Specialised & Tertiary Services

Welsh Health Specialised Services Committee
Unit 3a
Caerphilly Business Park
Caerphilly
CF83 3ED

Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru
Uned 3a
Parc Busnes Caerffili
Caerffili
CF83 3ED

Chair/Cadeirydd: *Professor Mike Harmer*

Director of Specialised and Tertiary Services/Cyfarwyddwr Gwasanaethau Arbenigol a

Thrydyddol: *Dr Cerilan Rogers*