

Item	Title	Page
1	Response from Minister for Children, Education, Lifelong Learning and Skills regarding Abolishing the name 'Ysgol Gyfun Rhydfelen'	3
2	Response from the Deputy First Minister regarding Multi-user path at Talybont-on-Usk	5
3	Response from the petitioner regarding Hypothyroidism in Wales	6
4	Response from NICE regarding Hypothyroidism in Wales	11
5	Response from the petitioner regarding Mencap Cymru petition	22
6	Response from the Deputy First Minister regarding Restore the Swansea-Cork Ferry (#1)	27
7	Response from the Deputy First Minister regarding Restore the Swansea-Cork Ferry (#2)	28
8	Response from the petitioner regarding Pernicious Anaemia	29
9	Response from the Trafnidiaeth Canolbarth Cymru regarding Improved Rail Services in Aberystwyth	52
10	Response from the Deputy First Minister regarding Improved Rail Services in Aberystwyth	54
11	Response from the Minister for Health and Social Services regarding Special Care Baby Unit	56
12	Response from the Minister for Environment, Sustainability and Housing regarding Save the Vulcan	57
13	Response from the Welsh Local Government Association regarding Save the Vulcan	59
14	Response from the Minister for Environment, Sustainability and Housing regarding the Glamorganshire Canal	61
15	Response from the Minister for Heritage regarding Free swimming all-year round for children and young people	62
16	Response from the Minister for Health and Social Services regarding Free swimming all-year round for children and young people	63
17	Response from the Chair of the Audit Committee regarding Free swimming all-year round for children and young people	64
18	Response from Job Centre Plus regarding Support for the unemployed in Monmouth	65
19	Response from the Deputy Minister for Skills regarding Support for the unemployed in Monmouth	66
20	Response from the Minister for Children, Education, Lifelong Learning and Skills regarding Abolish top-up fees in Wales	67
21	Response from the Deputy First Minister regarding Traffic relief for St Asaph	69
22	Response from the Minister for Rural Affairs regarding Abandon the Badger Cull	70
23	Response from the Minister for Heritage regarding National Library of Wales – Saturday Opening	72
24	Response from the National Library of Wales regarding National Library of Wales – Saturday Opening	74
25	Response from the Deputy First Minister regarding Reducing the speed limit on the A40 near Abergavenny	75
26	Response from the Minister for Health and Social Services regarding Improved NHS Chiropody Treatment	77
27	Response from Cwm Taf NHS Trust regarding Improved NHS Chiropody Treatment	79
28	Cynon 50 Plus Older People's Forum Report on Improved NHS Chiropody Treatment	81

29	Response from the Deputy Minister for Regeneration regarding Stepping Stones Nursery	83
30	Response from the Deputy Minister for Skills regarding Stepping Stones Nursery	84
31	Response from the Minister for Health and Social Services regarding Sands – the stillbirth and neonatal death charity	86
32	Response from the Minister for Environment, Sustainability and Housing regarding Proximity of wind turbines to residential dwellings	88
33	Response from the Auditor General for Wales regarding Ffynnone and Cilgwyn Woods	90
34	Response from Calon yn Tyfu Cyf. Regarding Ffynnone and Cilgwyn Woods	91
35	Response from Forestry Commission Wales regarding Ffynnone and Cilgwyn Woods	94
36	Response from the Minister for Rural Affairs regarding Ffynnone and Cilgwyn Woods	97

Jane Hutt AC/AM

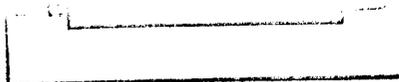
Y Gweinidog dros Blant, Addysg, Dysgu Gydol Oes a Sgiliau
Minister for Children, Education, Lifelong Learning and Skills



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-098
Ein cyf/Our ref JH/00831/09

Val Lloyd AM
National Assembly For Wales
Cardiff Bay
Cardiff
CF99 1NA



22nd June 2009

Dear Val,

Thank you for your letter dated 5 June enclosing a copy of a letter you have received as chair of the Petitions Committee from Gareth Jones, AM, chair of the Assembly Government's Enterprise and Learning Committee about the situation at Rhydfelen School.

You have specifically sought my views on two issues that Gareth Jones has raised, namely that appropriate democratic channels of consultation (concerning the change of school name) are being disregarded; and this is undermining the fundamental relationship between pupils and teachers as well as between governors and the LEA.

I have previously received correspondence from both you and Gareth Jones on various issues raised over the naming of Ysgol Gyfun Gartholwg and have responded by giving detailed explanations to clarify the situation. I have been advised that appropriate democratic channels of consultation (concerning the change of school name) were not being disregarded. The change of school name took place about two years ago. At that time the LEA consulted on their proposals to change the name of the school and gave the governing body a sufficient opportunity, as is required by the 2005 school government regulations, to consider the name change. The LEA and governing body could not agree on the school's name. In these circumstances the LEA has the power under current law to make the final decision. The decision on naming the school has therefore been lawfully made and there is no need for the LEA to continue to consult anyone on the matter.

On the issue of the relationship between pupils, teachers, governors and the LEA being undermined, there is a risk that bad feeling will hold the school back. I have been advised that since this matter first arose, a new headteacher has been appointed who is content with the name of the school and who is working hard to move the school forward and focus on the real task of raising standards and delivering a quality education for the pupils. However, if people refuse to let the matter rest, and are seeking to keep the issue alive by continually raising objections to the school's name, this is likely to have an adverse effect on the effectiveness of the school and the governing body.

In situations like these it is the role of the LEA to support schools and intervene if they consider it necessary. I know that LEA officers are fully aware of what is happening and are closely monitoring the situation and supporting the headteacher and governing body.

I understand the disappointment some feel about this situation. I know that they have great pride in their school and its achievements which is why they continue to seek to retain the Ysgol Gyfun Rhydfelen name. My hope is that all staff, governors, pupils and parents will accept the situation and work together for the benefits of everyone in the school community.

Best wishes,

Jane

Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-099
Ein cyf/Our ref DFM/05299/09
Sandy Mewies AM
Temporary Chair of the Petitions Committee
National Assembly For Wales
Cardiff Bay
Cardiff
CF99 1NA

28 July 2009

Dear Sandy

I am responding to your further letter dated 13th July regarding PET-03-099, the petition for a multi-user pathway along the A40 at Talybont-on-Usk.

The report is still in draft form and being considered by the Mid Wales Trunk Road Agency, it is hoped that my transport officials will receive a copy by the end of the summer for consideration by the end of the year to allow for the potential inclusion of any works into next year's budget.

Ieuan

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidiaeth
Minister for the Economy and Transport

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8198
PS.DeputyFirstMinister@wales.gsi.gov.uk

To: Val Lloyd AM – Chair, Petitions Committee, National Assembly for Wales
Andrew R T Davies AM, Petitions Committee, National Assembly for Wales
Michael German AM, Petitions Committee, National Assembly for Wales
Bethan Jenkins AM, Petitions Committee, National Assembly for Wales
Edwina Hart AM MBE, Minister for Health and Social Services, Welsh
Assembly Government
Gwenda Thomas AM [Neath], National Assembly for Wales,

4th July 2009

Dear Ms Lloyd, Mr Davies, Mr German, Ms Jenkins, Ms Hart and Ms Thomas,

Reference: PET – 03 –137 [HYPOTHYROIDISM IN WALES]

Thank you for copying to me, the response from Professor Ian Gilmore, President of the Royal College of Physicians dated the 10/6/09, which was sent to Val Lloyd in response to her letter of the 18/5/09.

It is notable that this response from the Royal College of Physicians and the other organisations named in the letter [RCP et al] has not provided views with regard to the petition as requested by Val Lloyd, Chair of the Petition's Committee. Rather, Professor Gilmore has chosen instead to comment on the joint statement [which he has now copied to Val Lloyd], which he says, is based on best evidence.

Such a response is similar to those received by numerous others [including myself] who have raised questions with regard to the joint statement. Therefore, to my knowledge and to date, the RCP et al have steadfastly refused to answer any questions put to them relative to this issue [including that from the Petition's Committee of the National Assembly for Wales]. Furthermore, it would appear that the RCP et al have chosen to disregard or even comment on, the enormous amount of research and/or academic referencing sent to them about hypothyroidism and its treatment. This has been an ongoing problem for hypothyroid patients and their supporters. No matter what scientific information is provided to support the view that all is not well regarding this issue, it has been seemingly impossible to persuade the 'medical profession' to enter into dialogue, discussion or debate so that together we can begin to resolve the problems being encountered by hypothyroid patients.

As the 'medical profession' have continually failed to respond satisfactorily, to questions raised with them or have simply side stepped such questions, what are we to do? Well, we have appealed to our political representatives to act on our behalf as this is a very serious issue and unless addressed, is not going to go away and so we would like to see the National Assembly for Wales and the Welsh Assembly Government take the lead on this issue, as they have with so many other important health initiatives.

As I have been at pains to emphasise all along, this petition was put forward on behalf of hypothyroid patients, by such patients, their families and supporters for the potential benefit of hypothyroid patients because serious concerns exist with regard to the non-diagnosis, misdiagnosis and mismanagement of hypothyroidism in Wales and beyond. [But note there are some scientists, doctors and researchers who support our views – as the research papers and other information submitted to the NAFW and the RCP et al would indicate].

These concerns have not been alleviated as a result of the joint statement rather these concerns have been exacerbated and there is now genuine worry that hypothyroid patients will come to harm as a result of this joint statement, which contains some contradictory points, some examples of which are covered in Annex 1 of this letter.

In fact, there are also many frightened patients who are concerned that their medication [particularly Armour Thyroid – which contains T3] will be stopped as a result of the RCP et al joint statement. Two such patients, recently wrote to the Minister, Edwina Hart in order to voice their concerns. They were invited to meet with Dr. Sarah Watkins, the Senior Medical Advisor for Chronic Conditions and so the Welsh

Assembly Government has now been alerted to this potential worry and risk to hypothyroid patients, which is a direct result of the RCP et al joint statement. Hypothyroidism is of course one of several chronic health conditions. It is life threatening if left untreated or is inadequately treated and as a result of this, merited free prescriptions even before prescriptions became universally free to all in Wales – as a result of a policy decision by the Welsh Assembly Government.

However, the concerns raised in the petition are historical and existed prior to the issue of the joint statement. Such concerns have led to the formation of several national and localised hypothyroid patient support groups, some of whom have written to the Petition's Committee in support of this petition. Together, such groups represent the interests of many thousands of hypothyroid patients and each group has, in its own way been campaigning for better treatment for hypothyroid patients, including [and backed up by] research into this profoundly debilitating condition.

Some individuals, such as Diana Holmes [you were all provided with a copy of her book] have not only become lay researchers but have over the last 15 years been active in increasing awareness within the medical profession and with other interested parties with regard to hypothyroidism. This has included appearing on TV and radio and presenting information on this issue. Back in 2005, Diana also developed a 'Thyroid Petition,' which she personally presented to the General Medical Council [see Annex 2 of this letter for the wording of that petition]. This petition, which was signed by approximately 3000 people, was also copied to a number of organisations, including, The Royal College of General Practitioners, the Society of Endocrinology, the British Thyroid Association and the British Thyroid Foundation. Thus, the medical profession has been aware of the many concerns and the issues raised by hypothyroid patients for several years now.

So as can be seen from the above, no effort has been spared in bringing concerns to the attention of the medical profession, yet still there is a refusal to listen to our viewpoint even though we are able to substantiate our claims with a vast array of appropriate and specific evidence and research.

You will have already been sent a copy of the critique [entitled 'REBUTTAL'], that my daughters and I sent to Professor Gilmore and also to all the nominal heads of all the organisations who were involved with the production of joint statement, [an extract of which is given at Annex 1 at the end of this letter]. So I can confirm that the RCP et al have not responded to one single question originally raised with them or to any supplementary questions asked of them and following the review of all material sent to them, they have recently said that, "We cannot enter into any further correspondence on this issue."

Thus the RCP et al have not:

[1] Responded to any questions raised either before or after the review

[2] Have not responded to any of the comments raised before or after the review

[3] Have not acknowledged or acted upon the hundreds of medical references sent to them which do not comply with the assertions made within the joint statement and which support our views.

[4] Have not acknowledged the plight of patients who are intolerant of thyroxine and have to date not amended their press release, which states that, 'thyroxine is the only treatment for primary hypothyroidism.' In a letter to me dated 22nd of May they have said, "It should be noted that it [ie the joint statement] is about the treatment of primary hypothyroidism and does not preclude other treatments for exceptional cases by specialist endocrinologists who can make clear to patients any associated risks." Thus they have acknowledged in writing to me that 'exceptions' do exist – yet still refuse to amend the wording of the statement or press release, or when asked have refused to say what these 'exceptions' are.

[5] Have not provided any explanation for their widening of the reference interval for TSH blood tests in direct contrast to what is happening globally, including the USA, where the reference interval has been truncated and lowered in order to identify and treat hypothyroid patients not previously diagnosed.

[6] Have not provided satisfactory evidence of medical research, which would fully substantiate their stance - rather they have stated, in an e-mail sent to me dated the 4th of June that, "It represents the consensus of medical opinion of the College and the other bodies that were involved in its preparation."

[7] Have not disclosed who the authors of the statement are or who the reviewers of the statement are or whether both authors and reviewers are the same people.

[8] In addition the RCP et al have refused to discuss now and it would seem in the future, this issue with all those patients, their families and supporters who had and still have deep concerns regarding the joint statement [which in a recent letter to me] from the RCP has now been designated 'the position statement or guidance (not a guideline).' **The above list of 'have nots' by the RCP et al is not exhaustive.**

Therefore, to summarise, the petitioners have requested an investigation into this issue. This request still stands and is now regarded as more urgent than ever given the RCP et al joint statement and their stance on this issue. Whilst the RCP et al agreed to review the information sent to them, they did so behind closed doors, refused to reveal who would be conducting the review [ie either names or designations] or whether or not the authors of the joint statement and the reviewers were the same people. Furthermore, they ignored a request to involve patient support groups, other than those affiliated to them and to date it would seem that they have refused to answer any of the questions raised with them. There is already sufficient academic evidence and scholarship in existence, already provided to the RCP et al [and examples of which have also been provided to the NAFW], to support the opinion that there is something seriously remiss with regard to the diagnosis and management of hypothyroidism for many thousands of patients. But it would seem from the outcome of this review [ie no change], that despite the dearth of information sent to them that **every single item of this has been disregarded**. In addition, the assertion within the statement, 'that the vast majority of patients with suspected thyroid disease are supported very well in primary care by their General Practitioners and their condition, hypothyroidism or otherwise' is appropriately diagnosed and well managed,' is disputed.

If hypothyroid patients were satisfied with the treatment they receive, why have we initiated this petition? Why did so many people sign the 2005 petition? Why have there been so many campaigns by hypothyroid patients, support groups and forums regarding this issue? Why have so many people spent so much time trying to raise awareness of this issue in an attempt to resolve the problems experienced by patients due to the non-diagnosis, misdiagnosis and/or mismanagement of hypothyroidism? Therefore, I can only re-iterate our request for an investigation into this issue as a matter of urgency and the National Assembly for Wales is called upon to listen to what [hypothyroid patients and their supporters] have to say and so a formal request to meet with you at the earliest opportunity in order to discuss this issue is now being made. Many thanks.

Yours sincerely

Julie Ann Cameron MBA [Petition Co-ordinator]

PS: As a matter of interest, see below a quote by Professor Ian Gilmore, President of the Royal College of Physicians as given on the RCP website.

"Physicians are privileged to have the daily opportunity to make a difference to people's lives, usually when illness strikes and individuals are most vulnerable. But **we cannot take for granted the trust patients afford to physicians nor assume that we know best the care they want.**"

ANNEX 1 – AN EXTRACT OF THE CRITIQUE SENT TO THE ROYAL COLLEGE OF PHYSICIANS ET AL – [CONCERN NUMBER 6 OF 11]

CONCERN 6

The 'joint statement' includes the following; *"We do not recommend the prescribing of additional Tri-iodothyronine (T3) in any presently available formulation including Armour thyroid, as it is inconsistent with normal physiology, has not been scientifically proven to be of any benefit to patients, and may be harmful" and "The College does not support the use of thyroid extracts or thyroxine and T3 combinations without further validated research published in peer-reviewed journals. Therefore, the inclusion of T3 in the treatment of hypothyroidism should be reserved for use by accredited endocrinologists in individual patients"* [1].

If the argument that Armour Thyroid USP is inconsistent with normal physiology is used against Armour Thyroid USP, since this preparation contains a higher proportion of T3, then the same argument could be used against thyroxine [T4 only treatment], since it contains no T3 at all, nor T1 or T2. Thus, by the same logic, thyroxine [T4 only] would be even more inconsistent with normal physiology.

Further, if the argument that thyroid treatments containing T3 and/or Armour Thyroid USP, have not been scientifically proven to be of benefit to patients and may be harmful to such patients is being used by the Royal College of Physicians and others – then this can be contradicted by scientific evidence that indicates that treatments containing T3 and/or Armour Thyroid USP, have been of benefit to certain categories of hypothyroid patients.

The use of T3 and T4 combination treatment has been shown to be of benefit to patients, by Bunevicius et al. (1999)[8], Bunevicius and Prange (2000) [9] and by Bunevicius et al. (2002) [10]. Other researchers demonstrated that only combined treatment with thyroxine and tri-iodothyronine prevented hypothyroidism in all of the tissues of the thyroidectomized rat, implying that in humans combined treatment with thyroxine and tri-iodothyronine would be necessary to achieve euthyroidism [11].

In 2007, Gautam Das gave Armour Thyroid to three patients who were intolerant to L-thyroxine with a successful outcome and recommend that, ***"a trial of Armour could be considered in patients who have not responded to this conventional treatment..."*** [12]. More recently, in 2008, Lewis et al concluded that, ***"in appropriately selected hypothyroid patients, Armour appears to improve the quality of life in patients who have either had an inadequate clinical response to conventional T4/T3 therapy or are unable to tolerate such therapy"*** [13].

Despite the caveat within the 'joint statement' saying, ***"the inclusion of T3 in the treatment of hypothyroidism should be reserved for use by accredited endocrinologists in individual patients,"*** there is concern that, the net effect of the 'joint statement' could be to effectively prevent the prescribing of any treatment for hypothyroidism other than synthetic thyroxine (T4) irrespective of the individual clinical needs of the patients concerned, because of the emphasis elsewhere in the 'joint statement' and the RCP press release that, ***'Thyroxine is the only treatment for primary hypothyroidism'***.

- **Therefore what redress is available for patients suffering from untreated or under treated hypothyroidism as a result of doctors following this 'joint statement' and not providing or discontinuing the treatment of their hypothyroidism with any treatment other than synthetic thyroxine [T4] only?**
- **Does this introduce yet another two-tier system, whereby patients currently being prescribed treatments other than synthetic thyroxine only would have their treatment continued but new patients would no longer be treated with alternatives to synthetic thyroxine – which might be better suited to their individual needs?**

NB: The full critique, under the title of 'REBUTTAL' has already been sent to you but to re-iterate neither the above nor any other points raised with the RCP by myself, my daughters and others or any additional questions raised have been commented upon or clarified or answered by the RCP et al to date.

ANNEX 2 – THE WORDING OF DIANA HOLMES' PETITION TO THE GMC [2005]

THYROID PETITION

We the undersigned [thyroid patients, families/friends] wish to lodge this petition with the General Medical Council as a formal complaint against the clinical practice of the majority of the medical profession with regard to the diagnosis and management of hypothyroidism on four counts: -

1. Over reliance on thyroid blood test results and a total lack of reliance on signs, symptoms, history of the patient and a clinical appraisal.
2. The emotional abuse and blatant disregard by the majority of general practitioners and endocrinologists over the suffering experienced by untreated/incorrectly treated thyroid patients and their lack of compassion over the fate of these patients.
3. Stubbornness by the majority of general practitioners and endocrinologists to treat patients suffering with hypothyroidism with a level of medication that returns the patient to optimum health. In addition, the unwillingness to prescribe alternative thyroid treatment for patients on individual clinical grounds. For example a combination of T4/T3, T3 alone or a natural thyroid treatment such as Armour Thyroid.
4. The ongoing reluctance to encourage debate or further research on hypothyroidism.

In addition we formally request an independent investigation into patients who are hypothyroid, which includes examination of clinical results of patients treated by private doctors (whose work is outside NHS directives), and comparative examination of clinical results of patients treated by NHS practitioners who diagnose and manage hypothyroidism.

Failure to address these issues will result in a vote of no confidence in the General Medical Council



National Institute for Health and Clinical Excellence

Valerie Lloyd
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

MidCity Place
71 High Holborn
London
WC1V 6NA

Tel: 0845 003 7780
Fax: 0845 003 7784
Email: nice@nice.org.uk
www.nice.org.uk

Dear Ms Lloyd,

Thank you for your letter of 18 May 2009 about a petition calling for a review of the treatment and diagnosis of hypothyroidism.

NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health, in three areas:

- Health technologies – guidance on the use of new and existing medicines, treatments and procedures, including interventional procedures used in the NHS.
- Clinical practice – guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS
- Public health – guidance on the promotion of good health and prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector

The Department of Health commission us to develop clinical guidelines, guidance on public health and technology appraisals. The topics that we consider come from a number of sources such as clinical and public health professions, the Department of Health's national clinical directors and policy teams or the National Horizon Scanning Centre which suggest new and emerging health technologies that might need to be assessed. Topics can also be suggested directly to the institute for consideration.

NICE has responsibility for managing the administration of the early stages of the topic selection process on behalf of the Department of Health. Ministers at the Department of Health have responsibility for the final decision about which topics are referred to NICE.

When considering topics, NICE reviews each of the suggestions received to ensure they are appropriate and to check whether they are already included in its work.

The topics that we develop guidance on are chosen according to the Department of Health's topic selection criteria – the selection criteria takes into account:

- Burden of disease (population affected, morbidity, mortality)
- Resource impact (i.e. the cost impact on the NHS or the public sector)
- Policy importance (i.e. whether the topic falls within a government priority area)
- Whether there is inappropriate variation in practice across the country
- Factors affecting the timeliness or urgency for guidance to be produced

The suggestions are then reviewed by consideration panels composed of experts in the topic area, generalists with a good knowledge of the health service, public health and the public sector, and patient and carer representatives. The panels' recommendations go to the Department of Health and a health Minister makes the final decision on which topics are referred to NICE for guidance to be produced.

Our topic selection consideration panel meeting on Long Term Conditions (LTC) met on Friday 16th March 2007 to consider developing a guideline on 'the diagnosis and management of hypothyroidism (1794) and 'the diagnosis and management of thyrotoxicosis (968).' These topics were considered together. It was felt that there was insufficient robust evidence available to facilitate the production of a guideline on hypothyroidism (i.e. thyrotoxicosis).

The panel consisted of a number of clinical professionals – including a primary care representative. The primary care representative felt confident in dealing with straightforward cases of hypothyroidism in the absence of guidance, perhaps because the Quality and Outcomes Framework states that this condition should be monitored within the community. GPs are also able to recognise the more difficult cases which require referral to an endocrinologist.

As a consequence, this topic scored 2 out of a potential score of 5 – deeming it a low priority with the final decision not to develop guidance on this topic. Currently, we do not have any specific guidance on the diagnosis and management of hypothyroidism nor, have we been commissioned by the Department of Health to issue guidance on this topic.

I hope that this information is of help.

Yours sincerely



Tony Beaman
Communications Executive (Public Affairs)

**Topic selection consideration panel meeting:
Long Term Conditions (LTC)**

Minutes: Confirmed

Date and time: Friday 16 March 2007 12.00-4.00pm

Venue: The Royal College of Paediatrics and
Child Health
50 Hallam Street
London
W1W 6DE

Attendees

Vice Chair

- Dr Orest Mulka, General Practitioner, Council Member RCGP (Vice Chair)

Voting members

- Professor Max Bachmann, Professor of Health Care Interfaces
- Mr Graham Brack, Pharmaceutical Adviser
- Ms Elizabeth Brain, Lay Vice Chair of Patient Participation Group of the Royal College of General Practitioners
- Professor David Chadwick, Consultant Neurologist
- Professor Usha Chakravarthy, Consultant Ophthalmologist
- Professor Peter Crome, Professor of Geriatric Medicine, Keele University; Consultant Geriatrician, North Staffordshire Combined Healthcare NHS Trust
- Professor Brendan Delaney, Professor of Primary Care
- Dr Stuart Dollow, Vice President and UK Medical Director, GSK, representing ABPI
- Dr Kevin Gormley, Assistant Director of Education, School of Nursing and Midwifery, Queens University, Belfast
- Dr Carol Hawley, Principal Research Fellow
- Ms Amanda Hutchinson, Head of Long Term Conditions and Older People Strategy, Healthcare Commission
- Ms Robin Mackenzie, Director of Medical Law and Ethics
- Ms Elaine Oliver, Head of Health Economics, Medtronic Ltd, representing ABHI
- Ms Lynda Price, Non Exec Chair, East Devon PCT
- Dr Michael Rudolf, Consultant Physician
- Dr Peter Selby, Consultant Physician

Non-voting members

- Dr Bob Coates, Director of Public Health/Visiting Fellow, NCCHTA
- Ms Sarah Evans, Research Associate, NHSC
- Ms Luan Linden, Research Associate, NHSC
- Dr Norma O’Flynn, Clinical Director, National Collaborating Centre for Primary Care
- Dr Cathryn Thomas, Senior Lecturer representing Appraisals Committee

Specialist advisors

- Professor Janusz Jankowski, Consultant in Gastroenterology for topic 823, the diagnosis and management of coeliac disease
- Dr John Lee, Consultant in Pain Medicine, National Hospital for Neurology and Neurosurgery for topic 227, the use of drugs for neuropathic pain

Also in attendance

- Ms Laura Boughen, Implementation Coordinator, NICE
- Ms Caroline Miller, Information Specialist, NICE
- Ms Janet Robertson, Technical Advisor, NICE / Observer
- Ms Nuzhat Sen, Topic Selection Administrator, NICE
- Dr Nicholas Summerton, Consultant Clinical and Public Health Advisor, NICE
- Ms Andrea Sutcliffe, Deputy Chief Executive, NICE
- Ms Lindsey Wilby, Topic Selection Project Manager, NICE

Apologies

- Dr David Colin-Thomé, National Clinical Director for Primary Care (Chair)
- Dr Noemi Eiser, Chest Physician
- Dr Mercia Page, Clinical Practice Centre Director, NICE
- Mr Mark Salmon, Topic Selection Associate Director, NICE

1. Welcome and introductions

The Vice Chair, Dr Orest Mulka, introduced himself and welcomed members – particularly those joining the panel for the first time – to the second meeting of the Long Term Conditions Topic Selection Consideration Panel.

The members of the panel introduced themselves.

2. Apologies for absence

Apologies were received from Dr David Colin-Thomé, Dr Noemi Eiser, Dr Mercia Page, and Mr Mark Salmon.

3. Appointment of a Vice Chair

In the absence of the Chair, Andrea Sutcliffe proposed the appointment of Dr Mulka as Vice Chair for an initial period of one year, after which the post will be opened up to nominations from the panel. Ms Sutcliffe thanked Dr Mulka

for agreeing to chair this meeting at short notice. The panel agreed to the proposal.

4. Evaluation of the first round of panel meetings

It was highlighted that, in response to comments made by panel members following the first meeting in November 2006, NICE had made various adjustments to the meeting arrangements and the documentation presented to the panels.

As it had originally been envisaged that some of the panel meetings would be held in Manchester, the panel was asked to confirm whether they would be able to attend if one of the 2008 meetings was held there. The majority of the panel confirmed that this would be acceptable to them.

Action: Topic Selection Secretariat to arrange one of the 2008 panel meetings in Manchester.

5. Minutes of the previous meeting

Other than a typographical error at section 2.1, the minutes were agreed to be a true and accurate record of the meeting of December 5th 2006.

6. Matters arising not covered elsewhere on the agenda

There were no matters arising.

7. Progress of topics discussed at the first panel meeting

The progress report provided by the secretariat at item 3 in the briefing pack was reviewed, and Andrea Sutcliffe gave an update on the functioning and outcome of the first meetings of both the Consistency Checking Group (CCG) and the Referral Oversight Group (ROG). Andrea Sutcliffe explained that they need to devise a method of ensuring that topics which are valuable, but not immediately successful at progressing through the process, are not "lost", but are available for future referral.

NICE asked the panel for their comments. Panel members expressed a variety of views. In the discussion it was felt to be useful for panels to emphasise and differentiate between their priorities to the ROG where possible.

8. Declarations of interest

In relation to section 9.1, drugs for neuropathic pain (227), the following declaration of interest were made. Ms Oliver declared that her employer, Medtronic, manufactures some of the devices mentioned in the briefing note for this topic. However, as the focus of the briefing note is on the use of drugs,

it was not felt that this interest should prevent her from taking part in the discussion or voting on this topic.

Professor Chadwick declared that a lot of the drugs mentioned in the briefing note are primarily used in the treatment of epilepsy, which is his area of expertise. However, he has no particular experience of using these drugs for the indication highlighted in the briefing note. Dr Dollow declared that his employer, GSK, manufactures an epilepsy drug which is not licensed for use in the management of neuropathic pain, and there are no plans to seek a licence or promote the product. Professor Crome declared that he has a small shareholding in GSK. As product manufactured by GSK is not licensed for the indication under consideration, these were felt to be non-specific interests, and should not preclude either Professor Chadwick, Dr Dollow or Professor Crome from taking part in the discussion or voting on the topic.

Dr Lee declared that he had received hospitality from numerous drugs companies in relation to drugs for neuropathic pain. However, as he was present in order to advise the panel on this topic, and would therefore not be voting on the topic, this was not felt to be problematic.

In relation to section 9.4, coeliac disease (823), Mr Brack declared that he is a professional member of Coeliac UK, and is therefore aware of their views. As he does not suffer from the condition himself and does not receive payment from the charity, it was not felt that this interest should prevent him from taking part in the discussion or voting on the topic.

In relation to section 9.6, zoledronic acid (2062), Dr Dollow declared that his employer manufactures a direct competitor to this product. It was therefore agreed that he would leave for the duration of the discussion about, and the voting on, this topic. Dr Selby declared that he has received speaker fees from Novartis in relation to this drug. It was agreed that he could stay to answer questions from the panel on this product, but would then absent himself for the remainder of the discussion and the voting on this topic.

In relation to sections 9.7 and 9.8, maraviroc (1742) and raltegravir (2061), Dr Dollow declared that his employer manufactures direct competitors to these products. It was agreed that he would absent himself for the duration of the discussion about, and the voting on, these topics.

9. Topics for discussion – A list

Following a brief introduction of each topic by Dr Nick Summerton, the eight A list topics on the agenda were discussed by the Panel in turn.

9.1 The use of drugs for neuropathic pain (227)

Dr Lee was present to advise the panel on this topic. He made several points:

- Guidance on this topic could alleviate a huge burden of disease. Neuropathic pain and back pain between them account for 70-80% of chronic pain, and NICE is already preparing a guideline on back pain.
- With appropriate guidance, effective treatment could be initiated by GPs and pharmacists. This would greatly reduce the volume of referrals to neurologist and pain clinics. There is evidence that effective early treatment can prevent people from developing a chronic pain condition.
- Patients are often prescribed the correct drugs by non-specialist clinicians, but in sub-therapeutic doses.
- Some patients are being prescribed pregabalin, which is very expensive, when amitriptyline, which is not, might be equally effective.
- Although the briefing note is focused on drugs, it would be wrong to exclude consideration of cognitive behavioural therapy (CBT), as there is a huge evidence base for the effectiveness of this treatment.

The panel was strongly in support of this topic, and felt that the remit should be extended to include consideration of CBT and non-drug treatments such as nerve stimulating devices. The ABHI representative highlighted that “spinal cord stimulation for chronic pain” has recently been referred to NICE within the 13th wave, to be appraised via the MTA process. The outcome of this appraisal could be referred to within a broader guideline.

The panel was of the view that the guideline should be focussed at non-specialists, to enable effective early treatment, be that in general practice or a pharmacy setting.

The Vice Chair summarised the features of this topic in relation to the DH selection criteria, as follows:

- This topic is relevant to both the practice-based commissioning agenda and the 18-week referral target.
- There is a large burden of disease, both recognised and unrecognised.
- There is wide variation in practice: GPs lack the knowledge and confidence to prescribe drugs in sufficiently high doses and/or outside of their licensed indication.
- Guidance on this topic would be timely as, to the best of our knowledge, it does not appear that guidance is being planned or prepared by any other body.

Remit: To prepare a clinical guideline on the identification and management (both drug and non-drug) of neuropathic pain in non-specialist care, including indications for onward referral.

Provisional score: 4.5

9.2 The diagnosis and management of thyrotoxicosis (968)

9.3 The diagnosis and management of hypothyroidism (1794)

These topics were considered together. There was little enthusiasm from the panel for either of them. It was felt that there was insufficient robust evidence available to facilitate the production of a guideline on hyperthyroidism (i.e. thyrotoxicosis).

Remit: To prepare a clinical guideline on the diagnosis and management of thyrotoxicosis.

Provisional score: 1.5

The primary care representative amongst the panel felt confident in dealing with straightforward cases of hypothyroidism in the absence of guidance, perhaps because the Quality and Outcomes Framework states that this condition should be monitored within the community. GPs are also able to recognise the more difficult cases which require referral to an endocrinologist.

Remit: To prepare a clinical guideline on the diagnosis and management of hypothyroidism.

Provisional score: 1.5

9.4 The diagnosis and management of coeliac disease (823)

Professor Jankowski was present to advise the panel on this topic. He expressed his views to the panel as follows:

- The appropriate management of coeliac disease relies on shared care between the GP and gastroenterologist, but 95% of the work could be done by GPs (if they had appropriate guidance). For example, the long term monitoring of the condition may include a gastroenterologist seeing a patient once a year to ask “how they are” – this could clearly be done elsewhere.
- 60% of cases go undiagnosed in the early stages. Late diagnosis is associated with additional morbidity (e.g. osteoporosis and, rarely, untreatable cancer in younger individuals), at great cost to the NHS.
- Some ethnic populations in the UK (e.g. South Asian and Irish) are particularly predisposed to coeliac disease. Differing cultural practices for dealing with symptoms can lead to very late diagnosis when the patient presents with a devastating osteoporotic vertebral collapse.
- The production of guidance would be timely. Given that gastroenterologists are now assisted by endoscopists and numerous new technologies, they would be in a position to take a step back to determine where their services can best be employed, and provide advice to colleagues in primary care.

The panel were strongly in favour of this topic, given that coeliac disease is so hugely under-diagnosed. One panel member had carried out a vignette study in which 80% of GPs tested did not even consider coeliac disease as a potential option, in a scenario where the symptoms described would have supported it as a differential diagnosis.

The panel was particularly concerned about the disproportionate prevalence of the condition within certain ethnic sub-groups. The panel felt that this topic was a particular priority in the absence of a National Service Framework for gastrointestinal disorders.

The panel asked Professor Jankowski about the scale of the problem in children. He explained that 30% of cases occur in children, but these are picked up easily because they are usually more severe, and the condition is well managed in paediatric practice. He was more concerned about elderly patients who have gone undiagnosed for 30-40 years, then present with osteoporotic fractures.

The panel was concerned to emphasise that any guideline should not be restricted to primary care, as coeliac disease is frequently missed by clinicians across a number of specialties. The panel also explored the issue of screening: simple blood tests could prevent the need for endoscopic biopsies. It might even make sense for GPs to screen all of their anaemic patients for coeliac disease.

Remit: To prepare a clinical guideline on the diagnosis and management of coeliac disease in adults and elderly people.

- In both primary and secondary care
- To include an assessment of the appropriate role of diagnostic blood testing

Provisional score: 5

9.5 Ethyl-EPA for Huntington's disease (2063)

[Confidential discussion]

Remit: To prepare a technology appraisal on the clinical and cost effectiveness of Ethyl-EPA for Huntington's disease.

Provisional score: 2.5 (8 votes for deferring)

9.6 Zoledronic Acid – once-yearly treatment for post-menopausal osteoporosis (2062)

[Confidential discussion]

Remit: To appraise the clinical and cost effectiveness of zoledronic acid for the treatment of post-menopausal osteoporosis.

Provisional score: 0

Action: NICE to liaise with osteoporosis GDG as necessary to ensure that this topic is included within the guideline.

9.7 Maraviroc for resistant HIV (1742)

9.8 Raltegravir (MK-0518) for infection with HIV (2061)

[Confidential discussion]

Remit: To produce a technology appraisal on the clinical and cost effectiveness of maraviroc for resistant HIV.

Provisional score: 0

[Confidential discussion]

Remit: To produce a technology appraisal on the clinical and cost effectiveness of MK-0518 for infection with HIV.

Provisional score: 4

10. Prioritising topics for recommendation to Referral Oversight Group: confirmation or amendment of provisional scores

After a comprehensive discussion bringing in the views of all members of the Panel, a decision was taken by the Vice Chair on the priority of each A list topic. This decision reflected the panel consensus on the importance of the topic.

Each topic suggestion was assigned a numerical score between 0 and 5, where 0 indicates that the topic suggestion should not be referred to NICE, and where 5 indicates that the topic suggestion is very high priority for referral to NICE. The scores were as follows:

- The use of drugs for neuropathic pain: 5 (amended from 4.5)
- The diagnosis and management of thyrotoxicosis: 1 (amended from 1.5)
- The diagnosis and management of hypothyroidism: 2 (amended from 1.5)
- The diagnosis and management of coeliac disease: **5***
- Ethyl-EPA (Miraxion) for Huntington's disease: defer
- Zoledronic Acid – once-yearly treatment for post-menopausal osteoporosis: 0
- Maraviroc for resistant HIV: 0
- Raltegravir (MK-0518) for infection with HIV: 4

*Both neuropathic pain and coeliac disease scored 5, but the panel voted to decide which topic was a more urgent priority: 11 voted for coeliac disease, 5 for neuropathic pain. The panel was keen to communicate to ROG that they viewed both topics as being equally important, but coeliac disease as being slightly more urgent, if capacity was not available to commence work on both topics immediately.

11. Topics for discussion – B list and C list

The panel had no comments on these topics.

12. Comments on A list topics assigned to other panels

The panel had no comments on these topics.

13. Any other business

There was no other business.

14. Evaluation and expenses

The Vice Chair drew the attention of the panel to these items within their briefing pack, and asked the panel to give some verbal feedback. Their responses were as follows:

- “We learn more each time we meet, especially about technology appraisals”.
- “As a lay person it's quite difficult to know how to participate, but it should become easier with time”.
- “We need more data to fully consider technology appraisal topics”.
- “We've learnt a lot about NICE”.
- “We need to be careful how we use terms like primary and secondary care, as they are used differently across the UK”.
- “There was greater consensus as to scores today”.
- “A mixture of clinical guideline and technology appraisal topics makes the meeting more interesting”.
- “It will be interesting to see the outcome of ROG next time”

15. Date of next meeting

The next meeting of the panel will be on Friday, 20th July at 12.00pm, at the NICE offices, MidCity Place, 71 High Holborn, London WC1V 6NA.

Lindsey Wilby, Topic Selection Secretariat, 27th March 2007

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

7th September 2009

Dear Ms Lloyd,

Mencap Cymru is pleased to be able to continue our work with the Petitions Committee and the National Assembly for Wales as part of our campaign for better employment opportunities for people with a learning disability.

This letter is written in response to the letter received by the committee from the Minister for Children, Education, Lifelong Learning and Skills, Jane Hutt AM, dated 19th June 2009. We appreciate the Minister taking time to look at the concerns raised in our campaign about Welsh Assembly Government policies designed to support people into employment or to take advantage of employment opportunities. We do unfortunately feel that her response does not answer our concerns and still have some real issues of contention with the Minister's response and would like to address these in this letter.

Skills that Work for Wales

While we recognise that Skills that Work for Wales (STFW) is a pro-active strategy that makes some excellent strides to support people to gain employment, Jane Hutt's statement that it "cuts across all client groups" looking to access employment opportunities is true in theory. The experience of people with a learning disability and their families that we speak to, suggests that in practice this is not happening.

Skills that Work for Wales outlines a personal approach to supporting people to gain relevant skills and help them find and keep paid employment. This approach should be ideal for people with a learning disability. Unfortunately the key commitments: to basic skills, to apprenticeships linked to qualifications and to high level skills are not relevant to many people with a learning disability.

Again in our experience, and in line with the academic research, the most effective way of supporting people with a learning disability into work is through work based learning whereby the ability to carry out the job should determine the success or otherwise of the learning. Literacy, numeracy and qualification based outcomes whilst desirable for people with a learning disability for whom this is an effective and meaningful intervention, are not relevant for the majority of people with a learning disability in Wales.

Reasonable adjustment of qualification based learning programmes is required to prevent discriminating against people with a learning disability. This principle was discussed several years ago with the then Minister Jane Davidson who was supportive of this approach but we have not seen this explicitly stated in policy nor widely implemented in practice within WAG funded programmes. Skills that Work

for Wales does not work for people with a learning disability and will continue to fail them until this specific issue is addressed. (The focus on qualification based approaches is widespread and likely to increase in the future and we can see the logic of this for the majority of the Welsh population. This makes the need for a new approach around learning disability more critical.)

A review of policies and practice is required to agree what the approach to qualification based programmes, especially work based learning programmes, will be and to ensure it is embedded within future policies and implementations.

We welcome the introduction of learning coaches and learning plans that are mentioned in the strategy. We would however question how numerous these have been in their uptake amongst people with a learning disability. Through our contacts within Mencap's supported employment services and other Supported Employment Agencies (SEAs) with whom we work, we have yet to come across a school or pupil with a learning disability who has benefited from this type of support. This is not to say that the strategy is necessarily poor, rather that the implementation is flawed. A review is required to understand why these initiatives are not reaching people with a learning disability and how this could be better provided.

In her response the Minister also highlights "Career Ladders" as a holistic approach to mapping an individual's journey to working life through various channels. Again, we have yet to come across an example of a person with a learning disability accessing *Careers Ladders*, this would lead us to suggest a review of how this scheme is marketed, and whether this process is fully inclusive and far-reaching so as to attract all of its intended targets, is much needed.

There has been a focus on people who are "NEET" in recent policy guidance. In Skills that Work for Wales, the definition of whether someone is NEET is given as "a young person aged 16 – 19 who is not in employment, education or training". The majority of people with a learning disability wanting to work are not in this age range. It is also questionable whether a significant number of people with a learning disability (of all ages) would be considered as "not in employment, education or training". It is unclear whether this definition encompasses people who are being provided with support through day services. Many adults with a learning disability will be attending day services and therefore we believe are excluded from targeted work aimed at those who are not in employment, education or training. Furthermore, others will be attending college courses for many years, often repeating the same courses several times and not gaining places on the courses they actually want to do. Again, this would exclude people from the NEET definition, but they are not actually gaining skills that will increase their employability and increase the chances of attaining their goal of paid work.

WAG Placements

The placements that the Minister draws attention to within the Assembly Government are very encouraging and set a good example of how employers can demonstrate that employment opportunities are open to people who could otherwise be excluded. The majority, but not all participants, on this programme have a learning disability. The types of permanent paid positions also vary in the hours offered with some working full time hours and some as little as six per week.

This provides valuable flexibility. We wholeheartedly support the Wales wide nature of the scheme and the ability of candidates to apply for internal vacancies.

The scheme is relatively new and as we have supported individuals working through the process we are finding that there is some confusion about what happens at the end of the year. In particular the transfer of funding responsibilities for the roles needs to be more transparent and should a role not continue support needs to be provided to individuals to apply for and learn any new role.

Valuing Employment Now

Mencap, both at a UK and Wales-wide level, welcome the initiative behind the Cross Governmental Department scheme *Valuing Employment Now* in its objective of increasing the number of people with a learning disability in paid employment by statutory bodies (including the DWP itself). This demonstrates the public sector taking the lead in promoting equality in the workplace for people with a learning disability.

At a recent LDIAG meeting, a representative from DWP presented on the strategy, and it was clear the commitment to employing people with a learning disability in the DWP itself is applicable only to England at present. We believe a Wales specific strategy is required. The principles and approach of Valuing Employment Now are very welcome and mirror the work we have done in Wales with all members of the Association of Supported Employment Agencies in Wales, (previously presented to the committee as the Employment Model). We would welcome the opportunity to work with the Welsh Government in both the formulation and implementation of such a strategy.

Statement on Policy and Practice

Mencap Cymru agrees with the vision of the Statement on Policy and Practice for Adults with a Learning Disability that authorities seek to “maximise an individual’s potential to be gainfully employed.” We would like to see this being implemented effectively. The current trend appears to be less support available to people with a learning disability.

We are aware of several local authorities who have withdrawn funding from employment services for people with a learning disability either cutting completely their support of employment initiatives or cutting learning disability specific services and combining them into a generic service. Consequently we have seen a reduction in the support provided to people with a learning disability to find employment contrary to the Policy and Practice Statement direction.

LDIAG is currently working on developing guidance on employment services and we understand that this guidance will focus on standards for employment services in Wales. This is very different from a comprehensive strategy. For example, it is likely to look only at adult provision. In our employment model sent to you when we presented in May, we demonstrated the case for interventions from the age of 11 (this is outside the LDIAG remit) and an integrated approach across public sector workforce planning, education services for 11 – 25 year olds, benefits advice as well as good quality supported employment. Only the latter will be covered by the LDIAG work.

Data Collection

From Mencap Cymru's research into current employment levels of people with a learning disability with local authorities, the majority responded that they do not monitor specific disabilities of employees. While all employees certainly have a right to privacy and equality in the workplace, we believe that without this information it will be difficult to ascertain if people with a learning disability are being given an opportunity to contribute to civil society in Wales through finding and keeping paid employment. A simple adjustment that allowed for the number of employees with a learning disability to be recorded would allow local authorities and the Welsh Assembly Government to be able to monitor success in this area.

Whilst it is difficult to determine how many people with a learning disability are in work, due to this lack of data, we are not seeing any change in the actual experience or opportunities of our members. Most say they want to work but do not have the chance to find paid work; day services or voluntary work substituting for this important aspect of life experience. This in itself demonstrates that Government policies and initiatives are not changing the experiences of people with a learning disability and employment.

Related policies with an impact on employment

You may be aware that over the summer holidays a group of people with a learning disability toured Wales on public transport to raise awareness of our employment campaign. It was interesting to discover that a Wales wide problem arose with the use of supporters on disabled bus passes which prevented people with a learning disability from using their bus passes for travel training. This is one small example of how other Welsh Assembly Government policies can create a barrier to people with a learning disability finding and keeping paid work.

Summary

We hope that our response shows that there are still significant gaps in the DCELLS initiatives highlighted in the response given to the Committee and additional policy barriers to supporting people with a learning disability to find and sustain paid work. We believe we have demonstrated there is a need for a comprehensive review of the policies that should be providing support to people with a learning disability to gain and keep employment. We want to see such a review take place urgently.

We believe that any review should include the development of key principles for a comprehensive strategy on how to increase the proportion of people with a learning disability in work in Wales, including how this will be monitored, targets for the public sector and agreed approaches to reasonable adaptation for qualification based approaches.

We know that you will agree with us that it is vital to ensure that the policies intended to support for people with a learning disability find work, are effective, unfortunately our discussions with professionals who work in the field of supported employment, have found very few people who have heard of or accessed the services set out in the policies/strategies referred to in Jane Hutt's response. We

believe that reviewing both the content of the policies/strategies and the way the services they offer are marketed, would truly show how many people who could experience significant benefit, actually are.

A Wales specific strategy that mirrors the initiative taken by *Valuing Employment Now*, is essential if people with a learning disability are to be supported to make a contribution to the Welsh economy. Mencap Cymru would also welcome the opportunity to be involved in any further work needed on developing such a strategy, to highlight some of the solutions as well as support understanding of the barriers and current shortfalls in existing policy.

Again we like you want policies that are not merely aspirational, but actually see more people with a learning disability find and keep paid employment. We therefore ask that you consider referring our petition to the Enterprise and Learning Committee and request that they undertake a full scale review of all policies created by the Welsh Assembly Government to help people with a learning disability find work. We believe that it is time to undertake such a critical review and would support the review of services for disabled young people carried out by the Equality of Opportunities Committee in 2006 and the recent review of further education provision for disabled students carried out by the ELC.

We would be happy to meet with you again to discuss our concerns.

With very best wishes

Liz Neal
Director, Mencap Cymru

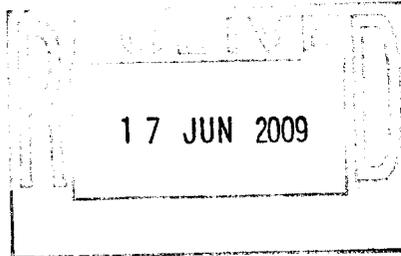
Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-172
Ein cyf/Our ref DFM/00941/09

Val Lloyd AM
National Assembly For Wales
Cardiff Bay
Cardiff
CF99 1NA



16 June 2009

Dear Val

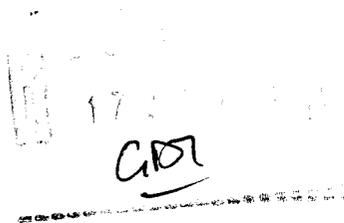
Thank you for your letter dated 20 May in respect of the evidence provided to the Petitions Committee on 5 May about the re-establishment of the Swansea to Cork ferry.

I am grateful for a copy of the transcript and I note the evidence provided by the lead petitioner, Mr John Hosford.

My officials are in regular dialogue with the British-Irish Lines Ltd and we have received an updated business plan, which we are currently considering.

Ieuan

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidiaeth
Minister for the Economy and Transport



Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref your ref. – PET-03-0172
Ein cyf/Our ref our ref. – DFM/05063/09

Sandy Mewies AM
Temporary Chair of the Petitions Committee
Cardiff Bay
Cardiff
CF99 1NA

08 July 2009

Dear Sandy

Thank you for your letter dated 22 June regarding the Petitions Committee's enquiry into re-establishment of the Swansea – Cork ferry service.

My officials are in dialogue with British-Irish Lines Ltd and a copy of the most recent business plan has been received. The plan is currently being appraised and I will write to you again when this has been completed.

I am copying this letter to Val Lloyd AM for information.

Ieuan

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidiaeth
Minister for the Economy and Transport



Q07



Sandy Mewies AM
Chair of the Petitions Committee
Welsh Assembly Government
Cardiff Bay
CARDIFF
CF99 1NA

17th August, 2009.

Dear Ms. Mewies,

Ref. PET-03-181

Thank you for your letter of the 13th July asking for my response to the Minister for Health and Social Service's letter regarding the treatment of Pernicious Anaemia. I have the pleasure to note the following.

The Pernicious Anaemia Society is the only organisation in the world that provides information, advice and support for sufferers of Pernicious Anaemia and their families and friends. It has been in existence for five years and was entered onto the U.K.s Charity Commission register three years ago. We are based in Wales but with a global membership.

Until the middle 1950's the treatment of Pernicious Anaemia was based around the patient consuming large amounts of, preferably, raw liver in order to carry on living. When Vitamin B12 was isolated and cloned the treatment improved and the slow death could be avoided.

There has been no improvement in the treatment of Pernicious Anaemia for the last fifty years. The single most common cause of concern, and complaint, by members of the society is that the intramuscular injection of Hydroxocobalamin (B₁₂) every three months is inadequate. When patients ask for more frequent injections they are often offered anti-depressants as a matter of routine. The British National Formulary stated that an injection should be given every month (1964), this was changed to every two months (1974) and changed again to every three months in 1984. Patients whose GPs refuse to depart from the BNF Guidelines are then either forced to suffer for two months out of every three or resort to buying Cyanocobalamin (another source of B₁₂) from internet pharmacies or over the counter at pharmacies in mainland Europe – the injection is available only via prescription in the U.K. The patient then either learns to self-inject or gets a family member or friend to inject – some with the consent of their GP but, more often, without either the knowledge or consent of their doctor. Most members receive no appropriate medical training on how to self-administer their injection and it is evident that most inject sub-cutaneous (just under the skin) and not into the muscle – which can be very painful.

The petition called on the Welsh Assembly Government to provide treatment for patients of Pernicious Anaemia based on the needs of the patient. Such treatment is available in the Private Sector using a purer form of B₁₂ – Methylcobalamin. This form is usually infused straight into the vein and the patient is provided with smaller amounts that are injected sub-cut (which is painless) according to the need of the patient. The injections are given using the same size needle and syringe

as used by diabetic patients. This leads to the patient controlling his or her medication, reduces the time taken up by nurses to administer the injection (estimated at £10) and allows the patient to lead an economically productive life. Baroness Thatcher used this form of supplement during her political career as did JFK. Celebrities such as Madonna and Tracy Emin also use B12 injections. It is not used by the NHS and consequently denied to patients of Pernicious Anaemia and B₁₂ Deficiency.

Following on from the enthusiastic response from the Minister for Health last year, I contacted Abertawe-Bro Morgannwg Trust and arranged a meeting between the Chief Pharmacist and the Head of Community Nursing. The purpose of the meeting was to explore the possibility of running a pilot scheme whereby patients would be taught to self-inject themselves with Hydroxocobalamin, but instead of injecting into a muscle (which is difficult) they could be taught to inject sub-cut. The meeting didn't last long because the pharmacist advised right at the outset that the injection wasn't licensed for sub-cut use.

I then met with the Welsh Assembly Government's Chief Pharmaceutical Adviser earlier on this year and made her aware of the problems with the treatment of Pernicious Anaemia and she kindly agreed to investigate the possibility of getting the Hydroxocobalamin licensed for sub-cut use by the pharmaceutical industry. I have heard nothing since.

There are major problems associated with the Symptoms, Diagnosis and Treatment of Pernicious Anaemia (actually there is no definitive diagnostic tool for the condition any more) which are highlighted in the Review that the society published in March. The cost to the NHS in administering the three monthly injections has been calculated at over £20 million per year. This is the cost of the actual injection (around 35p) and a rather convenient £9.65 in nurse time to administer the injection. This figure, though large, is tiny in comparison with the time taken up with repeat visits to GPs by the patient asking for more frequent injections, and more visits because the patient is either still symptomatic or has relapsed a month after the injection. This society's postbag and online forum is littered with stories of repeat visits to the GP – often for many years. Then there is the enormous loss of productivity with patients unable to operate at 100% capacity because they are still symptomatic – especially in the afternoon. There will be members of the secretariat of the WAG who 'hide' in the afternoons, or just stare blankly at their computer screens. I know, because we have members in the secretariat who tell me this.

The total number of people in Wales (and the U.K.) who have Pernicious Anaemia is not known. Non-diagnosis (based solely on serum B₁₂ levels), and mis-diagnosis (MS, ME, Depression) are, unfortunately, common. And because there is no definitive reliable test for PA many are just labelled as B₁₂ Deficient.

The answer would be to develop a treatment regime that is based on the needs of the individual that could be modelled on the treatment available in the private sector. There are a number of stages that such a regime would need to go through. Firstly the Methylcobalamin needs to be licensed, then, on diagnosis, the patient can be taught to self inject according to his or her needs. This will produce enormous savings in nurse and doctor time, and in the economic productivity of the patient – a clear win/win situation.

Whilst this society is based in Wales, we have an international perspective and an international membership. It has already raised the profile of Wales internationally and it would be wonderful if the society, with the backing of the Welsh Assembly Government could bring about this sea change in the treatment of Pernicious Anaemia that would reverberate around the world. The treatment is fifty years old and badly needs modernising.

Finally, the society has worked with a leading Haematologist to develop a research proposal that would explain why some patients (usually non symptomatic) manage perfectly well on three-monthly injections and why some need much more frequent injections. So far we have been unsuccessful in obtaining funding to undertake this research. We also have a research proposal into the symptoms and diagnosis of PA being considered by the National Institute of Health Research's Health Technology Assessment Programme's Diagnostic Technologies and Screening Panel.

Following a successful petition on the No. 10 website we have been assured that the Department of Health firmly believes that treatment should be provided on the basis of the individual patient's needs. As per the Minister's suggestion I have met with the Chair of Abertawe Bro-Morgannwg University NHS Trust to explore any other ways this can be taken forward and further discussions with interested parties will hopefully emerge from this that will lead to a more efficient and less costly treatment regime becoming available to NHS patients as it is the case in the private sector.

I apologise for the length of this response, but there are so many inter-related issues it was, despite some ruthless editing, never going to be a short one.

Finally I would like to thank the Minister for Health for providing advice and guidance to me and the society. I would also like to thank the Assembly Members who have also taken an interest in this issue. I will, along with the society, continue to try to change things in the NHS; having the support of the WAG and the National Assembly for Wales would be most helpful in this uphill struggle.

Yours sincerely

Martyn Hooper

Martyn Hooper
Executive Chairman

**Pernicious
Anaemia
Society**



www.pernicious-anaemia-society.org

Reg. Charity No. 1115195

REVIEW

**OF THE PRINCIPAL ISSUES
RELATING TO THE SYMPTOMS, DIAGNOSIS AND TREATMENT OF
PERNICIOUS ANAEMIA/Vitamin B12 Deficiency.**



Martyn Hooper
Executive Chairman
February 2009

©The Pernicious Anaemia Society - 2009

INTRODUCTION

1. The past two years has seen rapid and radical changes to the society. These changes include:
 - a. The establishment of a Management Council.
 - b. The writing and adoption of a Strategic Plan.
 - c. The investigation of a number of issues relating to the Symptoms, Diagnosis and Treatment of Pernicious Anaemia.
2. The amount of information that has been relating to the above has been revelatory, relevant and eclectic.
3. In order to disseminate all of the information relating to these revelations to all parties concerned with these issues, it has been requested that the main issues relating to the above be gathered into one single document in order that members of the Management Council, et. al, can assimilate, contribute to and comment on the findings of the research relating to Pernicious Anaemia.
4. The purpose of the above is to *use*, to good effect, the information that has been collected. To good effect means for the benefit of the members of the society, their family and friends. The ultimate goal will be to change the present way in which Pernicious Anaemia is not only treated but also regarded by medical professionals,
5. This *Review* will form the basis for a discussion that will lead to the formulation of an agreed written plan that will map the immediate and short-term goals of the society in order to facilitate progress in changing the way in which Pernicious Anaemia is treated and regarded by medical professionals.
6. It is envisaged that a series of goals will be formulated by the Management Council Meeting that discusses this *Review* and that the progress towards meeting those goals will be reviewed during the late summer, 2009.

The Patients

There are four distinct '**types**' of patients who have Pernicious Anaemia.

1. Pre-Symptomatic Members – Type A:

These members typically:

- a. Access the site for personal reasons or are diagnosed from low blood Serum B₁₂, are pre-symptomatic or with very early stage symptoms.
- b. Join the society to access and download information but don't leave a case history.
- c. Are inactive on the forum.
- d. Appear to manage on the typically prescribed treatment regime of a monthly IM Injection of Cyanocobalamin or three-monthly Hydroxocobalamin.¹
- e. Have Serum B₁₂ levels below the UK and other countries lower limit.
- f. Have no other auto-immune or other associated conditions.

2. Symptomatic Members with Classic Symptoms but with no evident Neurological Damage – Type B:

These members tick all or most of the 'classic' symptoms of Pernicious Anaemia/B₁₂ Deficiency but are unaware of any neurological problems even though 'the Fogs' are probably due to neuropathy.

Typically these members:

- a. Receive three monthly injections of B₁₂² and struggle to lead a normal life – especially from week four after receiving the injection.
- b. Turn to the Online Forum to receive peer support and information.
- c. Become very frustrated with the medical community for not recognising that the three monthly Hydroxocobalamin (or monthly treatment of Cyanocobalamin) is insufficient.
- d. Resort to buying Hydroxocobalamin or Cyanocobalamin injections either OTC in Europe or North America, or obtain supplies from the internet. He or she will then resort to either injecting themselves or getting a friend or family member to inject them with the vitamin. Some members:
 - i. Do so without receiving any training or instruction by a medical professional.
 - ii Do so without the consent of even knowledge of their G.P.
 - iii Do so in defiance of instructions from their G.P.
 - iv Do so with the consent and encouragement of their G.P.
 - v. Have tried other forms of replacement therapies including:
 - Sub-Lingual B₁₂ Lozenges
 - Behind-the-ear Patches

¹ Hydroxocobalamin in the treatment usually prescribed every three months in the U.K. and every two-three months in Australia. Most other countries prescribe monthly injections of Cyanocobalamin.

² This is monthly in countries that use Cyanocobalamin Injections.

Nasal Sprays

- e. Have disturbed sleep patterns – needing more than the normal amount of sleep or suffering from Insomnia.

3. Symptomatic Patients with Temporary Neurological Damage – Type C:

These members might only have cognitive problems (the fogs) but may have some peripheral nerve damage (numbness/pins and needles) and some balance problems and typically:

- a. Are diagnosed early with low Serum B₁₂ levels and the neurological damage was associated with the low Serum B₁₂.
- b. Receive adequate 'loading doses' of B₁₂ injections.
- c. Receive more frequent injections of B₁₂ until no further neurological improvements are felt (as per the BNF Guidelines).
- d. Have Serum B₁₂ levels above the normal range due to the increased frequency of the replacement therapy if they are able to access the medication via their doctor.
- e. May have reversed some or even all of their initial symptoms.

4. Symptomatic Patients with Permanent Neurological Damage – Type D.

These patients typically:

- a. Have been misdiagnosed or undiagnosed for a period of time after first displaying the symptoms.
- b. Need more frequent replacement therapy than the normally prescribed regime but are not prescribed it.
- c. Have Serum B₁₂ levels above the normal range due to the increased frequency of the replacement therapy if they are able to access the medication.
- d. Experience some or all of the original symptoms to a varying degrees.
- e. Did not receive loading doses when eventually receiving a diagnosis.
- f. Have resorted to buying Hydroxocobalamin or Cyanocobalamin either over the counter in mainland Europe or North America, or have purchased the vitamin injections from the internet as a last resort to receive more frequent injections. He or she will then self-inject, sometimes with the consent and encouragement of their doctor and only after receiving professional instruction as to how to self-inject correctly, or, worryingly, will self-inject without the consent, knowledge and even against the express will of their doctor and without receiving any professional instruction on how to do so safely. He or she will have to buy the injections and the syringes and needles.
- f. Struggle to lead a normal life.
- g. Have motor problems, cognitive issues and balance problems.
- h. Need more sleep than a 'normal' person, even if this is not possible due to insomnia – “at least ten hours, usually twelve and sometimes more” or “It’s The Archers – then bed”
- i. Play a more active role in the society and especially the on-line forum asking, receiving and giving advice and peer support.
- j. Be registered Disabled.
- k. Receive long-term social security benefits.

5. There is another group of patients who deserve special attention here who will neatly fit into one of the above categories and is one of the most worrying discoveries by the society. **Infantile and Juvenile** members of the society are a special group that have special problems that will be discussed under 'Symptoms'.

The Symptoms

There are numerous issues relating to the symptoms of Pernicious Anaemia that need to be addressed and resolved by medical professionals. These include:

1. There is a disparity between the symptoms described by members and those listed in often out-of-date textbooks that are used by medical professionals. These are illustrated below where the textbook symptoms that are recognised and used by medical professionals are shown on the left while on the right are the society's more accurate description of the patient experience.³

SYMPTOMS OF PERNICIOUS ANAEMIA/B12 DEFICIENCY WITHOUT NEUROLOGICAL DAMAGE

Old Perceived Symptom/Text book Symptom	New Symptom based on Patient Experience
Tiredness, Lethargy, Exhaustion.	The 'Strange Tiredness' .
Lack of concentration	The Fogs/A fog
Breathlessness	The Sighs/The Gulps
Brittle nails	Brittle nails, cut quick, dry skin on digits
Pins and needles	Pins and needles in hands or feet or both
Swollen 'Beefy' Tongue	Few members experience this.

SYMPTOMS OF PERNICIOUS ANAEMIA/B12 DEFICIENCY WITH NEUROLOGICAL DAMAGE

Old Perceived symptom/Text book Symptom	New Symptom based on Members Experience
Unusual Gait	Unusual walk
Pins and Needles (paraesthesia)	Pins and Needles

2. The importance of making patients and medical professionals aware of the unique nature of the symptoms above cannot be overestimated as the 'old' or unrefined symptoms are generic to a great many other conditions including M.E., M.S., C.F.S., and Depression among adults and, worryingly, Behavioural Problems and associated psychological or psychiatric disorders among juveniles. This means that the patient often suffers unnecessarily and a young person can be wrongly labelled and regarded with suspicion for years, and, ironically, can suffer additional psychological problems because of this.
3. There are symptoms that are experienced by most of our members⁴ that are not widely or normally accepted as being symptoms associated with Pernicious Anaemia or B12

³ These are based on the online focus groups that took place in 2008 and on the postings on the society' online forum where a number of polls have been set up.

⁴ This information is based on online polls and postings on the online forum.

Deficiency. A list of these follows:

COMMON SYMPTOMS NOT RECOGNISED BY MOST MEDICAL PROFESSIONALS

Irritability: Frustration: Mood Swings: Impatience	This can lead to a breakdown in relationships. ⁵
Desire for Isolation, Quiet and Peace	Often seen as Behavioural Problems in young members.
Inability to cope with Information	Makes reading possible but the member forgets what he or she has recently read. Can cause problems in the workplace.
Memory Loss	Repeatedly asking the same question.
Aversion to Bright Lights and Crowded Spaces	Could be linked with the above.
'Tear Jags'	The feeling of wanting to cry or weep for no reason. Heightened emotions.
Dry Skin	Can occur anywhere on the body.
Unaccountable and Sudden Diarrhoea	Often reported following a spell of constipation.
Insomnia	Even though the member is exhausted, he or she is still unable to sleep.
Hair Loss	This can range from moderate to severe
Premature Greying of hair	
Waking up still tired	Even after many hours sleep
Feeling Bloating or Full	Sometimes accompanied by physical swelling in the stomach.

These are further complemented by symptoms with **neurological damage**

Balance problems and the need for visual reference.	Known as 'The Shoulder Bumps' as the member frequently bumps into walls or falls against them.
General Unsteadiness	Especially when showering and dressing.
Inability to stand up with eyes closed or in the dark	Problems when showering
Vertigo	Linked to the need for a visual reference as compensation for damage to the brain's balance mechanism.
Burning Legs and Feet	Brierson-Goplan Syndrome
Sudden pain in one or more areas on only one side of the body.	Neuropathic Pain
Vertigo	Inability to cope with heights.

⁵ A great many callers to the society state that their partner is able to tell when the member's injection is due because of a change in personality.

4. Because the textbook symptoms are shared with other diseases and medical conditions misdiagnosis takes place. This is especially the case where:

- a. No test for Serum B₁₂ levels is conducted. This occurs when the patient's symptoms lead the physician to suspect a disease which is untreatable (M.S., C.F.S., M.E.) or involve the use of toxic medications (Depression, A.D.D., and other psychiatric/psychological/behavioural problems among both juveniles and adults).
- b. The test for Serum B₁₂ levels shows the patient is within the reference range which erroneously leads the physician to rule out Pernicious Anaemia or B₁₂ Deficiency. This is wrong because Serum B₁₂ levels can be high but the patient can still have Pernicious Anaemia or B₁₂ Deficiency.⁶
- c. The Serum B₁₂ level is either just under the lower reference range or, just as worrying, the Serum B₁₂ level is just over the lower reference range – both of which lead physician to rule out P.A. or B₁₂ Deficiency.
- d. Members have also reported (with supporting documentary evidence) that once the serum B₁₂ level is within the reference range after receiving loading doses then the replacement therapy is stopped. The patient is then diagnosed as having Chronic Fatigue Syndrome as the high Serum B₁₂ levels cannot explain why the patient is still symptomatic.

5. Most of our members (especially those who are symptomatic) also present other medical conditions which are mostly, but not all, other auto-immune diseases. The most common, based on postings on the online forum, are as follows – starting with the most common:

Tinnitus - (ringing, rumbling or screeches in the ear) – perhaps caused by nerve damage in the brain.
Hypo or Hyper-Thyroidism – almost exclusively among female members.
Psoriasis/Eczema/Acne – all skin conditions.
Rosacea – a reddening of the skin around the nose and cheeks.
Arrhythmia – irregular, fast or slow heartbeat.
Fibromyalgia – sensitivity to pain – especially in one specific spot or only on one side.
Rheumatoid Arthritis
Coeeliac's Disease – sensitivity to wheat and or wheat products.
Myasthenia Gravis – weak muscles leading to problems swallowing, chewing and opening eye(s).
Vitiligo – white patches that develop on the skin.
Psoriatic Arthritis

6. There are medical professionals who recognise the inadequacy of the textbook symptoms and have produced a more robust diagnostic tool that doesn't rely solely on Serum B₁₂ levels. Documentary evidence proves that taking this more holistic approach has proved that raising

⁶ V. Devalia, 'Diagnosing Vitamin B₁₂ Deficiency on the basis of Serum B₁₂ Assay' – BMJ Volume 333, 19th August 2006

and maintaining high levels of Serum B₁₂ based on the need of the patient can reverse the damage or damages caused by low Serum B₁₂/Pernicious Anaemia.⁷ Dr Chandy, from the Shinwell Medical Practice in Co. Durham in the U.K., has developed a checklist that is based on over thirty years experience of documenting B₁₂ deficiency as a G.P. The checklist allows physicians to help to identify those symptoms which indicate early-stage B₁₂ deficiency, and when further diagnostic tests should be carried out to ensure that another condition is not missed in making the B₁₂ deficiency diagnosis. This is available through the patient support group website⁸. Another medical professional who believes that the reference levels for Serum B₁₂ are far too low is Dr. J. Dommissee.⁹

- 7.** There is need to bring these new, more accurate symptoms to the attention of medical professionals in order that patients can:
- a.** Be understood when they present themselves before a physician and explain or describe their symptoms and the physician will be able to respond appropriately to the symptoms. This will, or should, lead to a more accurate and quicker diagnosis.
 - b.** Provide the physician with a set of *prompts* that he or she can use to extract accurate symptoms from the patient.

Possible ways in which these new symptoms can be recognised by both patients and medical professionals include:

- a.** Publishing case-studies and articles in appropriate medical journals including Blood, BMJ and Nerve.
 - b.** Producing a patient fact-sheet that states the revised symptoms with advice on what to tell the physician about the symptoms.
 - c.** ‘Sensationalising’ using magazines, tabloids and television documentaries.
 - d.** Having a physical presence at conferences and congregations of medical professionals with dedicated banners and exhibition stands and handouts.
 - e.** Publishing a paper or article in the education press.
 - e.** Attending education conferences to highlight the issue.
- 8.** The council needs to identify and choose a strategy to facilitate the dissemination of these new, more accurate symptoms and the current U.K. and W.H.O Guidelines for treatment for the benefit of patients. This might necessitate changing official guidelines, references and attitudes. We need to emphasise the importance of:
- i. Loading Doses before Maintenance Doses
 - ii. Therapeutic Trial where there is the suspicion or possibility of B₁₂ Deficiency. A response would be indicative of a deficiency.

- 9.** Juvenile and Infantile Pernicious Anaemia/B₁₂ Deficiency brings with it all kinds of problems for the sufferer.
- i. The society has become aware that young people who present the symptoms above (especially the behavioural symptoms of The Fogs, wanting

⁷ See ‘Could it be B₁₂? An epidemic of Misdiagnosis. Sally M. Pacholok & Jeffrey J. Stuart, Quill Driver Books. ISBN 1-884956-46-7

⁸ www.b12d.org

⁹ See J. Dommissee – What You Don’t Know About Vitamin B₁₂ CAN Hurt You. The MoneyChanger, November 2005. http://the-moneychanger.com/articles_files/health/vitamin_B12.phtml

and needing isolation, mood swings, irritability and lack of concentration) are routinely diagnosed as being behavioural problems. This stems from the basic misunderstanding among medical professionals that replacement B₁₂ therapy means the patient becomes non-symptomatic whereas this occurs in only a fraction of our members. And whereas adults can make adjustments to their everyday lives, this option is not available to children or young adults in school or college where the lack of concentration and the need for isolation is often taken to be a refusal to co-operate. This leads to the involvement of Educational Psychologists and Special Needs Teachers. The Society played the role of advocate for three cases involving young people and, where adjustments were made to the school day, timetable and teaching methods the young person has been able to cope in the classroom. Unfortunately there are many other young people who are being labelled as having behavioural problems rather than having special educational needs in other areas.

- ii. Infants who are either born with, or develop Pernicious Anaemia or B₁₂ deficiency, are treated solely using Serum B₁₂ levels. Injections are given only when the Serum B₁₂ drops below the minimum threshold used by the laboratory. This means that the babies or young children are continually having blood samples taken and analysed, and then receiving B₁₂ replacement by IM injection. The whole treatment regime rests entirely on Serum B₁₂ levels using the same reference ranges as used for adults.¹⁰

¹⁰ The society's youngest member is 18 months old.

The Diagnosis

Even if the patient's symptoms lead the physician to suspect Pernicious Anaemia/B₁₂ Deficiency is the cause of the patient's demur, there are still numerous problems associated with arriving at an accurate, unambiguous and robust early stage diagnosis of Pernicious Anaemia/B₁₂ deficiency. The major obstacles to arriving at an accurate diagnosis early enough can lead, far too frequently, to a misdiagnosis or late diagnosis which in turn leads to the wrong treatment being given and can lead to permanent nerve damage.

These issues are as follows:

1. There are issues surrounding the use of Serum B₁₂ levels to diagnose early stage (reversible) B₁₂ deficiency and Pernicious Anaemia. These issues centre around the following:
 - a. The level at which a patient is considered to be Serum B₁₂ deficient appears not to be defined at any point officially. In the U.K. most clinicians use Serum B₁₂ levels between 180-200_{ng/L} whereas the World Health Organisation has recently defined the calibration level and by implication the mid point of 'normal' as 480_{ng/L}. In Japan a generally accepted threshold level is 500_{ng/L} (people would receive supplements if below this level). This is further complicated as form of B₁₂ that show up on the assay¹¹ may not be useable by the individual.
 - b. Then there is the confusion caused by using different methods of measuring the amount of B₁₂ in the blood. The table below gives the different relative values using the different methods used for the measuring of Serum B₁₂ levels.

ng/l	pg/ml	pM (picoMol./L)
180ng/L	180pg/ml	130pM
200ng/L	200pg/ml	150pM
480ng/L	480pg/ml	350pM
1300ng/L	1300pg/ml	960pM

Comparing Units. Ng/l from Nano (10^{-9}) are the same as pg/ml (pico 10^{-12} and mili 10^{-3}).¹²

- c. People are individuals and just as there are a wide range of normal cholesterol levels, and some have unsafe levels for themselves personally even though the levels are considered within the normal range for the population, some people are asymptomatic (exhibit no symptoms) with serum B₁₂ levels below the threshold

¹¹ An Assay is a procedure for measuring the property or concentration of an *analyte* – in this case Blood is the analyte.

¹² Moles are Molecular gram weight and the conversion factor is 1355.5 (the molecular weight of B₁₂ molecule) so ng become pM.

whereas others may still exhibit symptoms with levels in the normal or high-normal range (480ng/l – 1300ng/l).¹³

The reference ranges are not realistic. A recent article on Brain Shrinkage by Dr. David Smith used a cut off point of 308 pmol/L as the point where the brain began to shrink in healthy 60 year old patients.¹⁴

Another study from Japan states that the normal reference levels are 500 – 1,300pg/ml.¹⁵

A further study from the United States observed that in a single case study of a dementia patient with normal B₁₂ values, the dementia was reversed with I.M. B₁₂ injections that boosted the patient's B₁₂ levels.¹⁶

- d. Many patients need much higher levels of Serum B₁₂ than is currently recognised as high levels by physicians to lead a more or less normal life. Just why this is so is not known. Some scientists believe that the key lies in the way in which Vitamin B₁₂ (Cobalamin) is absorbed at cell level. There is a great deal of activity that has to take place before the B₁₂ which is present in blood actually enters the cell. The main issue here lies with Transcobalamin II Receptors at cell level. It remains a mystery how the cobalamin enters the cell – no definitive research has been conducted on this which would explain why some members need more frequent injections than others.
 - e. B₁₂ deficiency problems occur in a number of different points in the pathway, right from lack of B₁₂ in the diet, through the ability of the stomach to digest and the ileum to absorb, through the liver's ability to activate the B₁₂ and the cell's ability to use certain forms of B₁₂. Different people may require different levels to function
 - f. Research conducted and published in 1967 in the U.K.¹⁷ provided evidence that, due to the existence of long and short receivers, some patients need more frequent injections of B₁₂, and this may address the issue of why some symptomatic patients require higher levels of Serum B₁₂ than others.
- 2.** Members are often diagnosed with other diseases and conditions before being correctly diagnosed as having Pernicious Anaemia/B₁₂ Deficiency.¹⁸ It is worth noting that if many people were wrongly diagnosed in the past there are probably a great many people who are currently diagnosed as having a disease or condition other than Pernicious Anaemia and are not receiving replacement therapy B₁₂. This makes the symptoms worse and the patient will run the risk of serious and permanent nerve damage. Below is a list of wrong diagnosis encountered by our members, the most

¹³ See Devalia.

¹⁴ Vitamin B₁₂ status and rate of brain volume loss in community-dwelling elderly: *Neurology* Vol. 71, Sept. 2008

¹⁵ Mitsuyama Y, Kogoh H. *Serum and cerebrospinal fluid vitamin B₁₂ levels in demented patients with CH3 -B₁₂ treatment: Preliminary study.* Jpn J Psychiatry Neurol 1988;42:65-71.

¹⁶ *Journal of the American Geriatrics Society* – Volume 44, Issue 10 – October 1996.

¹⁷ G.R. Tudhope, H.T. Swan and G.H. Spray – *Patient Variation in Pernicious Anaemia, as shown in a Clinical Trial of Cyanocobalamin, Hydroxocobalamin and Cyanocobalamin-Zinc Tanate.* *British Journal of Haematology*, 1967, Vol13, p.216 University of Sheffield and Oxford.

¹⁸ This is based on anecdotal evidence gathered from the online forum and letters to the society.

common misdiagnosis first:

- i. Depression¹⁹
- ii. Multiple Sclerosis²⁰
- iii. Myalgic Encephalopathy (M.E.)
- iv. Chronic Fatigue Syndrome (C.F.S.)

Depression is by far the most common misdiagnosis, especially if Serum B₁₂ levels are just above the lower reference range. Many of our members were prescribed anti-depressants for years before being diagnosed with PA or B₁₂ deficiency and, once replacement therapy commenced, were able to live without the anti-depressant medication. M.E. and C.F.S. is sought to be an explanation of the patient's symptoms that cannot be explained by low Serum B₁₂ levels.

3. There is no gold standard test for Pernicious Anaemia, especially as macrocytosis (megaloblastic condition where the red blood cell becomes enlarged) is virtually unheard of since the U.K., along with many other developed countries, adds Folate cereals to ensure that pregnant women are not short of this vital vitamin (folate=folic acid=B₉ – another B vitamin).
4. Research is currently being carried out into a more reliable test for B₁₂ using Urinary Methylmalonic Acid (uMMA) which could be a replacement for the vague Serum B₁₂ test which proves that the medical community realises that there are problems associated with Serum B₁₂ levels.
5. Different laboratories use different low reference ranges for Serum B₁₂.
6. There is no official government low B₁₂ threshold in any country. Low, medium and high thresholds are based on medical publications.
7. There is no gold standard test for Vitamin B₁₂ deficiency: failure to diagnose B₁₂ deficiency can make progression to Pernicious Anaemia with irreversible symptoms becomes inevitable if it is not diagnosed early.
8. The tests used to confirm the traditional PA symptoms are expensive (Schillings test), difficult and time consuming, and only identify problems at specific points on the pathway rather than diagnosing the condition. For example Intrinsic Factor Antibody (tests for autoimmune disease which can indicate problems with absorption of B₁₂) are only around 60% accurate.²¹
9. The tests used to identify Intrinsic Factor Antibodies are only 60% reliable which means

¹⁹ Ironically, many doctors identify psychiatric disorders including depression with B₁₂ deficiency. See Berry, Sagar and Tripathi – Catatonia and other psychiatric symptoms with vitamin B₁₂ deficiency. <http://www.ncbi.nlm.nih.gov/pubmed/12823174>

²⁰ Very few of our members were diagnosed with this but many were suspected of having it. Often doctors spent years trying to prove that is what the patient was suffering from. Eventually, sometimes after many years, the correct diagnosis of Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia was made.

²¹ Source – The Australian Society of Clinical Immunology and Allergy states this to be 60%.

that at least three tests should be carried out to accurately determine the existence of IFA. (to eliminate false positive readings).

10. Very few patients are referred to Haematologists or Neurologists when a diagnosis has been made.
11. Most diagnoses are made by the Primary Care Provider.
12. Monitoring of the patient after diagnosis is almost unheard of and consists of monitoring of Serum B₁₂ in all but the very rarest of cases. It is assumed, erroneously, by doctors monitoring the patient that if the Serum B₁₂ is within the 'normal' range then the patient must be experiencing psychosomatic reactions,²² whereas B₁₂ is instrumental in removing homocysteine (which is a mood altering chemical causing depression and irritability but is a precursor to an important biological chemical) and in creating SAME (a mood altering chemical causing good feelings)
13. Some doctors are aware that it might be the case that those still displaying symptoms of Pernicious Anaemia even after replacement therapy has been started and Serum B₁₂ is within the normal reference ranges or higher might be suffering from another, yet to be identified, disease that is separate from Pernicious Anaemia and which shares the same symptoms as P.A.
14. Best practice in the diagnosis of Pernicious Anaemia would be to treat the Serum B₁₂ levels as an **indicator** of the amount of B₁₂ in the blood. The evidence from the 1967 Paper in the BMJ by Tudhope, Swan and Spray demonstrates that the minimum dose given to patients of P.A. should be at least every two months. The study found that **variation between patients** makes it impossible to anticipate the duration of effect of a single injection of Cyanocobalamin-Zinc Tanate, Hydroxocobalamin or Cyanocobalamin in any patient.²³ Furthermore it is not fully understood how the B₁₂ that shows in the serum B₁₂ level is available for the cells to use and how great the variation in the uptake is. What is clear here is that in best practice the physician making the diagnosis should take a holistic approach that would concentrate on the symptoms of the patient as well as the Serum B₁₂ level.²⁴
15. The society has collected evidence from members that clearly demonstrate that the vast majority of medical professionals do not understand or are unaware that patients can remain symptomatic after replacement therapy has begun. This ignorance can be attributed to the following:
 - a) Until the advent of the society there was no forum where patients

²² There is an American Psychosomatic Society - <http://www.psychosomatic.org/>

There is also a U.K. society website - but it doesn't seem to be linked with a particular society. <http://www.psychosomatic.org.uk> There is also a U.K. and International website relating to psychosomatic issues and Obstetrics and Gynaecology <http://www.bspoga.org> No published information has been found relating to PA and psychosomatic issues.

²³ Our emphasis.

²⁴ There are physicians who already take this approach and who realise that Serum B₁₂ is only an indicator of what might be occurring at cell level and place as much, or more emphasis on the patient's symptoms as on the result of any blood tests.

diagnosed with Pernicious Anaemia could exchange information and relate experiences. From the patients' point of view the society can be seen as a vectoring point for all issues relating to Pernicious Anaemia and the issue that affects the most of the members is the issue of still being symptomatic after treatment and the need for more frequent injections than the usually prescribed regime.

- b) Doctors' reliance on Serum B₁₂ levels to monitor patients' well-being is not an accurate measure of the wellness of the patient. Yet it is Serum B₁₂ levels that is almost universally used whilst the patient's continuing symptoms are often ignored or, more worryingly, attributed to psychological factors. The scientific laboratory-based evidence take precedence over the experiences felt by the patient that cannot, yet, be scientifically proven.

- 16.** There is plenty of evidence²⁵ to demonstrate that Doctors do not understand that Pernicious Anaemia can be as debilitating as it can be. There is a general lack of gravitas afforded the condition and this is borne out by the lack of monitoring of patients future need, the propensity for anti-depressants to be prescribed to 'treat' ongoing symptoms and the general casual air with which treatment is prescribed. The number of misdiagnoses which do not respond to medication (eg a misdiagnosis of MS would mean the patient would not respond to MS drugs as this is not the actual problem – the difference is straightforward as MS is a condition of the Central Nervous System; many PA and B₁₂ deficient patients exhibit single limb paralysis and other conditions which point to peripheral nerve damage or spinal cord deterioration) can result in a laissez faire attitude to treatment.
- 17.** Another test is used to determine the amount of B₁₂ not in the blood but in the tissue. The Holotranscobalamin Test (Holo T) is used in Australia and New Zealand and centres on *active* B₁₂ in tissue which is where it is needed to prevent neurological damage from developing or prevent further damage.²⁶ It may be that in the future the Holo T test is used instead of Serum B₁₂ to determine accurate B₁₂ levels in patients.

²⁵ This is based on the experiences of patient members on the online forum, and from calls to the society's helpline.

²⁶ **D. M. Bobilewicz**, M. Iwanowska, B. Serafinska, M. Omid, M. Bozentowicz. *Medical University, Warsaw, Poland*, 'Active B₁₂ (holotranscobalamin) in different serum B₁₂ ranges.' See appendix 2 See also: <http://www.ncbi.nlm.nih.gov/pubmed/14656030?dopt=Abstract> and <http://www.ajcn.org/cgi/reprint/85/4/1057.pdf>

TREATMENT

There is a short ***window of opportunity*** between confirmed diagnosis, (where the nerve damage is reversible), and the point where the nerves have degenerated to the point that the damage is irreversible. It is important that adequate and appropriate treatment should be started as soon as possible in order that that window of opportunity is not lost.

Even when the treatment is started the way in which the replacement B12 is administered differs.

Treatment is the area that is the most controversial in relation to both patients and medical professionals and the issue that causes the most requests for information and support. The way in which the replacement therapy for Pernicious Anaemia is administered is dependent upon individual countries. The following table illustrates this:

Replacement Therapy by individual country:

Country	Prescription or OTC	Therapy	Frequency
Australia	Prescription and OTC	Hydroxocobalamin	Two -Three Monthly Two Monthly with Neurological Involvement
Canada	Prescription and OTC	Cyanocobalamin	Monthly
Finland	Prescription Prescription Prescription and OTC	Hydroxocobalamin Cyanocobalamin Cyanocobalamin Tablets	Two-Three Monthly Two-Four Monthly 1-4mg/day
France	Prescription and OTC	Cyanocobalamin	Monthly
Germany	Prescription and OTC	Hydroxocobalamin	
Ireland	Prescription	Hydroxocobalamin	Three Monthly
Japan		Methycobalamin	
Netherlands	Prescription only	Hydroxocobalamin	Three Monthly
New Zealand			
Spain	Prescription and OTC	Cyanocobalamin	Monthly
United States	Prescription and OTC	Cyanocobalamin Hydroxocobalamin ²⁷	Monthly
United Kingdom	Prescription Only	Hydroxocobalamin Cyanocobalamin Lozenges	Three Monthly ²⁸

²⁷ Cyanocobalamin is almost exclusively used in the U.S. with most doctors unaware that Hydroxocobalamin is available. There has been a decline in the number of doctors prepared to treat patients using IM injections and many of our members have to self-inject. We have no evidence of this other than it is regularly reported by members.

²⁸ This table is still being compiled.

1. The most common complaint among members is centred around the fact that the usually prescribed treatment regime of one 1,000 μ ²⁹ IM injection of Hydroxocobalamin every 12 weeks is not enough (U.K., Australia) or that the 1,000 μ IM Injection of Cyanocobalamin every month is not enough (U.S.A., Canada and Continental Europe) and the patient needs a more frequent injection regime.

2. In the U.K. the 1963 Edition of the British National Formulary stated that the Hydroxocobalamin³⁰ injection should be prescribed every month. By 1974 that had changed to “once every two months” and by 1984 this had changed to once every three months.³¹ This means that either the IM injection had been improved, for which there is no evidence, or that there had been physiological change in humans over the twenty year period. B₁₂ is a water-soluble vitamin like Vitamin C: it is well known that Vitamin C flushes out of the body within days and needs to be topped up regularly (preferably every day) yet medical professionals continue to believe that the body stores the injected B₁₂ for years.

c. The 2007 edition of the BNF states:

*Hydroxocobalamin has completely replaced Cyanocobalamin as the form of vitamin B12 of choice for therapy; it is **retained in the body longer than Cyanocobalamin**³² and thus for maintenance therapy may be given at intervals of **up to 3 months**³³. Treatment is generally initiated with frequent administration of intramuscular injections to replenish the depleted body stores. Thereafter, maintenance treatment, which is **usually for life**³⁴, can be instituted.*

3. The refusal of Primary Care providers to sanction more frequent injections than the B.N.P. guidelines state results in the following:

a. Unnecessary suffering for patients who are refused more frequent injections. The society has ample evidence, including written evidence that some patients operate just one month out of every three.³⁵

b. In the U.S. and Canada the same problem occurs with Cyanocobalamin with patients feeling the need for weekly injections. Cyanocobalamin is an artificial form which appears to be less available or more easily flushed through than Hydroxocobalamin.

c. In Sweden treatment is mostly by oral replacement therapy (either Methylcobalamin or Cyanocobalamin) the efficacy of which has not been subject to robust

²⁹ μ = microgram

³⁰ The BNF is quite particular here stating that **only Hydroxocobalamin** was to be used – not Cyanocobalamin and that oral preparations were useless.

³¹ See the chart of BNF changes in appendix 1.

³² Our emphasis – we can find no research which confirms this claim that Hydroxocobalamin is retained longer than Cyanocobalamin.

³³ Note that the formulary states ‘up to three months’ which allows for weekly, two-weekly or monthly injections.

³⁴ The term ‘usually for life’ was introduced between 1978 and 1981. Previous editions stated ‘for life’

³⁵ This includes over thirty letters from non- internet members who have written the following or similar sentiments – “I have lived one month out of every three for the past forty years”.

testing.

d. Many of our members are told that their perceived need for more injections is invented and imaginary and all too frequently they are asked if they would like anti-depressant medication.

4. U.K. Members whose doctor refuses to depart from the BNF and sanction more frequent injections become frustrated and often resort to buying Cyanocobalamin OTC in mainland Europe or Hydroxocobalamin via internet stores. The weeks leading up to this less than satisfactory conclusion are that the frustration of the patient and the experience and opinion of the doctor based on clinically based knowledge of the doctor results in a stalemate situation and a breakdown in the patient/doctor relationship. From the patient's point of view the doctor is being unreasonable and from the doctor's point of view the patient is no longer in need of treatment because the serum B₁₂ levels are normal. Only by looking at the whole range of symptoms still being experienced by the patient and taking these into account will the medical professional realise that Serum B₁₂ is not the sole indicator of the patient's health. The Serum reference ranges need serious revision and, at present levels, may only indicate one aspect of the B₁₂ deficiency.

5. The society has been contacted on three occasions by family members who are concerned that an elderly patient has had his medication stopped because as he is elderly he will no longer need any B₁₂ injections.³⁶

6. Patients are forced to seek private consultations in order to receive more frequent injections of B₁₂.

7. Celebrities inject or receive injections frequently believing the injections gives them energy, heightened awareness and greater clarity of thought. Lady Thatcher received injections every two weeks (and probably still does), while Madonna, Lindsay Lohan, Gerri Halliwell, and Robbie Williams are all keen recipients of B₁₂ injections. Tracey Emin recently complained that it was a pity they only lasted two weeks.³⁷

8. The Window of Opportunity for reversing symptoms is short. Failure to provide treatment early, and to sustain that treatment until the damage has been reversed, results in irreversible Pernicious Anaemia with all the troubles that entails including head aches, phantom pains and numbness in hands and feet, dizziness, double incontinence, and all of the symptoms previously described. In the worst cases the window of opportunity is lost and severe irreversible neurological damage results.

³⁶ All three cases featured a male octogenarian.

³⁷ See The Sunday Times, June 24th 2007. 'Help! Get me a shot'. Also Marie Clair, Wednesday 5th December, 2007 - The Truth about Vitamin Shots.

OTHER ISSUES

There are other issues that relate to Pernicious Anaemia/B₁₂ Deficiency that the society has discovered. These include the following:

1. Hereditary Factors

There seems to be a strong hereditary disposition for patients to develop the disease.³⁸

2. Male Female Membership Ratio

80% of our members are female.

3. Eye Colour of members:

- 50% Blue eyes
- 25% Green
- 12% Brown
- 12% Hazel
- 0% Black.

4. Age on Diagnosis of members:

- ▶ 0-15 2%
- ▶ 15-25 13%
- ▶ 25-35 31%
- ▶ 35-45 35%
- ▶ 45-55 14%
- ▶ 55-80 5%

5. Frequency of Treatment:

- ▶ Hydroxocobalamin every 12 weeks 41%
- ▶ Hydroxocobalamin every 8 weeks 11%
- ▶ Hydroxocobalamin every 4 weeks 11%
- ▶ Hydroxocobalamin when needed 5%

- ▶ Cyanocobalamin every 4 weeks 11%
- ▶ Cyanocobalamin every week 13%
- ▶ Cyanocobalamin when needed 4%

³⁸ The Society is playing an active part in the research into the Genetics of Pernicious Anaemia being conducted by Dr. Siddharth Banka et al at Manchester University.

SUMMARY

1. There are serious issues relating to the symptoms, diagnosis and treatment of Pernicious Anaemia and B12 deficiency that is causing unnecessary suffering, often among the most vulnerable in society.
2. This suffering has been occurring for many decades.
3. Pernicious Anaemia/B12 deficiency is not treated as a serious medical condition.
4. Medical professionals are generally and genuinely unaware that patients can still suffer from the symptoms of Pernicious Anaemia to varying degrees even after Replacement Therapy has been administered.
5. Patients who seek private consultations are able to receive treatment dependent on their needs.
6. Points one to five above are an international phenomena.

CONCLUSION

1. There is an urgent need to re-assess the Symptoms, Diagnosis and Treatment of Pernicious Anaemia/B12 Deficiency in order to alleviate unnecessary suffering that is taking place on a global scale. This reassessment should be the responsibility of the medical community.
2. The society should become pro-active in pushing this issue onto the political agenda.
3. The society's intended integrated promotional campaign to be held in the autumn should be used to highlight the issues that surround the symptoms, diagnosis and treatment of Pernicious Anaemia/B12 Deficiency.

Ends

Appendix 1 - History of the British National Formulary 1955 - 2007: Treatment of Pernicious Anaemia © I. Mclean 2009

	1955	1957	1963	1978	1981	1982	1983	1985	1997	1998	1999	2001	2007
Loading Dose without neurological involvement	Cyano 50 - 100 mcg weekly	Cyano 100 - 250 mcg every other day for several days. Then weekly until blood picture is normal	Cyano 1000 mcg and again in 3 days. Then 250 mcg weekly until blood count normal	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	Hydroxo 1000 mcg repeated 5 times at intervals of 2 - 3 days	250 - 1000 mcg every other day for 1 - 2 wks then 250 mcg weekly until blood count within normal range	250 - 1000 mcg every other day for 1 - 2 wks then 250 mcg weekly until blood count within normal range	Hydroxo 1000 mcg 3 times a wk for 2 wks	Hydroxo 1000 mcg 3 times a wk for 2 wks
Loading Dose with neurological involvement	No special dose	No special dose	No special dose	No special dose	No special dose	No special dose	No special dose	No special dose	No special dose	Hydroxo 1000 mcg every other day until no further improvement	Hydroxo 1000 mcg every other day until no further improvement	Hydroxo 1000 mcg every other day until no further improvement	Hydroxo 1000 mcg every other day until no further improvement
Maintenance Dose with no neurological involvement	Cyano 50 - 100 mcg every 2 - 3 wks.	Cyano 100 - 250 mcg every 2 - 3 wks	Cyano 250 mcg every 3 wks	Hydroxo 1000 mcg every two months	Hydroxo 1000 mcg every two months	Hydroxo 1000 mcg every 2 months/ Cyano 250 mcg every 4 wks	Hydroxo 1000 mcg every 2 - 3 months/ Cyano 1 mg every month	Hydroxo 1000 mcg every 3 months/ Cyano 1 mg per month	Hydroxo 1000 mcg every 3 months	Hydroxo 1000 mcg every 2 - 3 months	Hydroxo 1000 mcg every 2 - 3 months	Hydroxo 1000 mcg every 3 months	Hydroxo 1000 mcg every 3 months
Maintenance Dose with neurological involvement	No special dose	No special dose	With SCD up to 500 mcg every 3 wks (Cyano)	No special dose	No special dose	No special dose	No special dose	No special dose	No special dose	1000 mcg every 2 months	1000 mcg every 2 months	1000 mcg every 2 months	1000 mcg every 2 months
Lifelong Treatment Required?	No mention	Yes	Yes	Yes	Usually	Usually	Usually	Usually	Usually	Usually	Usually	Usually	Usually
Will more B-12 help if neurological involvement?	No mention	No mention	With SCD up to 500 mcg every 3 wks (Cyano)	No mention	No mention	There is no evidence that larger doses provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that larger doses provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that larger doses provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that larger doses provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that doses larger than those recommended provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that doses larger than those recommended provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that doses larger than those recommended provide any additional benefit in vitamin B-12 neuropathy	There is no evidence that doses larger than those recommended provide any additional benefit in vitamin B-12 neuropathy
Guidance regarding oral treatment	No mention	No mention	No. Advises against.	No - absorption unsatisfactory	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for B-12 orally or vitamin B-12 intrinsic factor	Little place for low dose B-12 orally and none for intrinsic factor complexes given by mouth. Large oral doses of 1- 2 mg daily (unlicensed) may be effective	Little place for low dose B-12 orally and none for intrinsic factor complexes given by mouth. Large oral doses of 1- 2 mg daily (unlicensed) may be effective
Hydroxo versus Cyano	No mention of hydroxo	No mention of hydroxo	Place for hydroxo has not been established	Equally effective/ but hydroxo less freq. inj. thus now the preparation of choice	Hydroxo now the form of vitamin B-12 of choice/Cyano has been largely replaced	Hydroxo now the form of vitamin B-12 of choice/Cyano has been largely replaced	Hydroxo has largely replaced cyano	Hydroxo has completely replaced cyano	Hydroxo has completely replaced cyano	Hydroxo has completely replaced cyano	Hydroxo has completely replaced cyano	Hydroxo has completely replaced cyano	Hydroxo has completely replaced cyano

Note: Prepared by Ian McLean, American Delegate, Pernicious Anemia Society, using the copies of the British National Formulary available at the University of California at San Francisco Medical Center library. Rev. 2/19/09.

Appendix 2

Active B12 (holotranscobalamin) in different serum B12 ranges.

Topic: Hematology/Coagulation

D. M. Bobilewicz, M. Iwanowska, B. Serafinska, M. Omid, M. Bozentowicz. Medical University, Warsaw, Poland

Presentation Number: C-89

Keyword: holotranscobalamin, serum B12, B12 deficiency

Macrocytic anemia and neurological disorders are known to be results of B₁₂ deficiency. Until now serum B₁₂ has been the most common laboratory test nevertheless its values did not correlate well with clinical symptoms. New test holotranscobalamin (holoTC) - "active B₁₂" measures transcobalamin-B₁₂ only complex recognised by cell membranes receptors. Aim of the study was to evaluate serum holoTC in 3 groups of patients according to their serum B₁₂ (in pmol/L). Group 1. (n=28) 151-250, group 2. (13) <150, group 3. (34) >251. They were not receiving B₁₂ treatment. The separate group (n=84) consisted of patients on long term parenteral nutrition (TPN) for whom the only source of B₁₂ was 6ug daily given I.V. Results : The high values for both B₁₂ (295) and holo TC (73pmol/L) as well as correlation (r=0.63) was observed in TPN group with constant and well controlled vit B₁₂ supply. Lowest serum values and high correlation was found in B₁₂ deficient group 2. Weakest correlation (r=0.39) and the widest range of serum holoTC was in group 3 (15-158pmol/L) in which 5 out of 34 persons had serum holoTC values below 30 (mean 19,9) with normal MCV and Hb.

Conclusion: In spite of good statistically significant correlation between serum B₁₂ and holo TC there are several discrepancies what may be in favour of suggestion that serum holoTC can give earlier information about active B₁₂ status than serum B₁₂

Results

B ₁₂ range pmol/L	Hb g/dl (mean, min-max)	MCV fl (mean, min-max)	B ₁₂ pmol/L (mean, min-max)	holoTC pmol/L (mean, min-max)
150-250	13,0 (9-16)	93 (92-94)	189 (155-232)	35 (12-64)
<150	12,1 (9-15)	96 (92-110)	103 (44-149)	15,5 (1,5-35)
>250	12,7 (9,5-16,8)	93 (92-94)	430 (253-856)	58 (15-158)

Cardiff Bay, Queen's Quay, Cardiff
 Cardiff, Tracc Office, 11 Heol, Bwthynau Street
 Aberystwyth, Ceredigion, SY23 3DB

Sandy Mewies AM
 Temporary Chair of Petitions Committee
 National Assembly for Wales
 Cardiff Bay
 Cardiff
 CF99 1NA

COPY

Ffôn / Your ref: PET-03-183
 Ffôn / Our ref:

Ffôn / Phone: 01970 633431 / 07781447363
 Ffacs / Fax: 01970 633 430

Dyddiad / Date: 21st July 2009

e-bost / e-mail: enquiries@tracc.gov.uk

Dear Ms Mewies

Re: Petition- Improving Rail Services

Thank you for your letter dated 14th July 2009 regarding a petition for received from students at Coleg Ceredigion, Aberystwyth for improvements to the local rail service.

I can confirm that I will arrange to meet the students at the earliest opportunity to discuss their experiences and concerns as outlined to your Committee. I would be grateful therefore if you could supply contact details for me to engage with the petitioners.

You will of course be aware that under the Railways Act 2005 and Transport Wales Act 2006, the Welsh Assembly Government is now responsible for service/ operational matters (such as management of the Wales and Borders Franchise operated by Arriva Trains Wales) and for infrastructure planning through the Rail Forward Programme/ National Transport Plan (NTP). Indeed it is with great pleasure that Tracc has noted the commitment within the consultation draft of the NTP to introduce an hourly service on the Cambrian Main Line between Aberystwyth and Shrewsbury by 2011. The emerging Tracc Regional Transport Plan will focus on bidding for funding to carry out improvements to accessing rail services (e.g. station enhancements) and identifying future service and infrastructure enhancements for delivery by the Assembly Government.

I look forward to hearing back from you at your earliest opportunity.

Yours sincerely

Chris Wilson
 Tracc Co-ordinator
 On behalf of the Tracc Chairman
 CC. Val Lloyd AM

Handwritten notes and signatures, including a signature that appears to be 'C.P.' and a stamp with the Tracc logo.



Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-183
Ein cyf/Our ref DFM/05300/09
Sandy Mewies AM
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

28 July 2009

Dea Sandy

Thank you for your letter of 14 July 2009, on behalf of the Petitions Committee, regarding an hourly train service on the Cambrian Line.

I launched the consultation of my National Transport Plan (NTP) during Plenary on 15 July. I am pleased to confirm that the consultation document states that hourly services between Aberystwyth and Shrewsbury will be introduced by 2011.

Ieuan

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidiaeth
Minister for the Economy and Transport

Edwina Hart AM MBE

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/05143/09

Your ref: PET-03-188

Sandy Mewies AM
Temporary Chair of the Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Cardiff Bay
Cardiff CF99 1NA
English Enquiry Line: 0845 010 3300
Fax: 029 2089 8131
E-Mail: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

Bae Caerdydd
Caerdydd CF99 1NA
Llinell Ymholiadau Cymraeg: 0845 010 4400
Ffacs: 029 2089 8131
E-Bost: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

30 June 2009

Dear Sam -

Edwina Hart

It is recognised that there are some difficulties in recruiting junior and middle grade doctors in some specialties and localities in Wales. The reasons for under recruitment can be attributed to a number of reasons including an overall drop in applications across the UK and the recent changes to immigration rules.

A 2nd round of recruitment for specialist trainees has been undertaken which has resulted in some of the vacant posts been filled. Trusts will be looking to fill unfilled training posts with locums or fixed term appointments.

NHS Wales has in the past employed a significant number of overseas doctors as staff grade doctors. The complexity and lack of clarity over how non EU doctors can enter the UK for employment or training has led to a significant decrease in applications from this group of doctors this year. Discussions are being held with the Borders agency to seek clarity and to make representation about the effect of the changes. I have written to the Home Office Minister in the UK Government expressing my concerns and asking for an early review.

Officials are gathering and analysing vacancy data and the effects such vacancies are having or may have on service delivery and intend to work with the service managers and medical directors to develop an action plan which will minimise the effect vacancies have on the service and also improve recruitment.

The BMA and post graduate deanery have already produced a promotional DVD which portrays Wales and NHS Wales as a good place to work and live. This is available on the deanery website and given to all graduating medical students in Wales and also to all who express an interest in post graduate training in Wales.

Edwina Hart

Jane Davidson AC/AM

Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-197
Ein cyf/Our ref JD/05081/09

Sandy Mewies
65 Chester Street
Flint
Flintshire
CH6 5DH

5 July 2009

Dear Sandy,

Thank you for your letter of 23 June 2009 regarding the petition that your Committee is considering about the Vulcan pub and the questions your committee has over the Welsh Assembly Government's policy position and determination criteria for Article 4 Directions.

The Town and Country Planning (General Permitted Development) Order 1995 provides the right to carry out a range of developments without the need to go to the local planning authority for planning permission. These are usually referred to as 'permitted development rights' and may be carried out subject to any conditions or limitations imposed by the 1995 Order.

Local planning authorities may withdraw these permitted development rights through the making of a Direction under Article 4 of the 1995 Order. Such a Direction does not "ban" the development to which it relates but merely provides the mechanism by which a specific application for planning permission would need to be made to the local planning authority for that development. Any application for planning permission made necessary because of an Article 4 Direction must be considered on its own merits. Refusal of planning permission following the making of a Direction, or the grant of planning permission subject to conditions other than those imposed by the 1995 Order, may give rise to a claim (under Section 108 of the Town and Country Planning Act 1990) for compensation for abortive expenditure, or other loss, directly attributable to the withdrawal of permitted development rights.

There are four types of Article 4 Direction:

- a. the first type, under the provisions of Article 4(2) of the 1995 Order, is made by the local planning authority in respect of land within a Conservation Area. It does not require approval by anyone other than that authority, but it can only relate to permitted development prescribed in Article 4(5);
- b. the second is made by the local planning authority under Article 4(1) of the GDPO in respect of development permitted by Parts 1 - 4 and 31 of Schedule 2 to the GPDO. This Direction does not need the approval of the Welsh Ministers to take effect, but it will expire within six months if not approved by the Welsh Ministers within that period;

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8129
PS.minister.for.ESH@wales.gsi.gov.uk

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

Printed on 100% recycled paper

- c. the third is made under Article 4(1) of the GPDO in respect of development permitted by Parts other than Parts 1 - 4 and 31. This type will not take effect unless approved by the Welsh Ministers;
- d. the fourth type is one made by the Welsh Ministers – none have been made by the Welsh Ministers and only two were made by previous Secretaries of State for Wales.

Guidance in Welsh Office Circular 29/95 (Appendix D) says that permitted development rights should be withdrawn “only in exceptional circumstances” and that withdrawal will rarely be justified unless there is a “real and specific threat”. Local planning authority’s and the Welsh Ministers are bound to adhere to this guidance when considering Directions and, consequently, the Welsh ministers would expect to see a well-founded and reasoned case for each Direction incorporating, among other things, why the particular building(s), or area, are considered worthy of protection and an explanation as to what leads the local planning authority to consider that there is a real and specific threat (in this respect the issue is the probability rather than possibility of the development being carried out).

It is acknowledged that there is little guidance on the criterion of “real and specific threat”, but each Direction must be considered on its own merits and it is considered that further guidance in that respect could become prescriptive and reduced in its usefulness. The desire to protect a property, or an area, is not, in itself, sufficient to justify the approval of a Direction and the Welsh Ministers would expect to see reasonable evidence to support the local planning authority’s concerns about the impending permitted development e.g. the area could be detrimentally affected by the carrying out of uncontrolled permitted development.

The boundaries of land subject to an Article 4 Direction should be drawn as tightly as possible having regard to the circumstances of the case. Directions covering wide areas of land will not normally be approved. The Welsh Ministers would also expect the permitted development rights to be withdrawn to be the minimum necessary to bring within the normal planning régime those aspects of permitted development it is considered could damage an interest of acknowledged importance. The Welsh Ministers would also expect the wording of the Direction to reflect the wording in the relevant Part(s) of Schedule 2 to the 1995 Order to which the Direction relates.

We have no plans at present to modify or amend the existing regulations or guidance to Article 4 Directions.

Yows,



Jane Davidson AM

Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing

Our Ref/Ein Cyf: ST/CM/SJ
Your Ref/Eich Cyf:
Date/Dyddiad: 27 July 2009
Please ask for/Gofynnwch am: Craig Mitchell
Direct line/Llinell uniongyrchol: 029 2046 8625
Email/Ebost: craig.mitchell@wlga.gov.uk



WLGA • CLILC

Sandy Mewies AM
Temporary Chair of the Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

Dear Sandy

Petition – Save the Vulcan

I should declare an interest here as someone who has frequented the Vulcan over the years obviously to stop for a coffee! I agree that the issue of the preservation of buildings of local importance is indeed an issue of concern to Local Planning Authorities across Wales.

There is often unease about the deterioration (in some cases wilful neglect) of locally important buildings in our areas. Whilst demolition in Conservation Areas requires consent, the problem we face in some of our conservation areas is the neglect of buildings and their subsequent demolition by virtue of them being unsafe. However there is also the issue your petition highlights which is the lack of protection afforded to a locally listed building outside a conservation area.

One solution may be to bring under planning control 'demolition' as a form of development. This may well assist in this issue, but there are problems that for demolition to constitute demolition it has to be total demolition. The legislation and the current case law do not help on this matter.

The public clearly think it is somewhat strange that as planners Local Authorities can involve ourselves in porches and alterations to houses in the street, but we cannot prevent gaps appearing in those streets through demolition and clearance-which often have a far more detrimental impact.

This case shows how little actual weight is given to 'locally listed' buildings; it shows that often a strong case cannot be made for protecting isolated buildings outside of Conservation Areas using Article 4 Directions.

The only remaining tool is a planning policy within the Local Development Plan which seeks to protect locally important buildings and which would be a material consideration in any future planning applications application.

Steve Thomas
Chief Executive
Prif Weithredwr

Welsh Local Government
Association
Local Government House
Drake Walk
CARDIFF CF10 4LG
Tel: 029 2046 8600
Fax: 029 2046 8601

Cymdeithas Llywodraeth
Leol Cymru
Tŷ Llywodraeth Leol
Rhodfa Drake
CAERDYDD CF10 4LG
Ffôn: 029 2046 8600
Ffacs: 029 2046 8601

www.wlga.gov.uk

An example has been developed by Pembrokeshire National Park which seeks to highlight the majority of historic buildings within their protected landscape as worthy of careful treatment. In this example they have 14 Conservation Areas and have benefited from a number of spot-listings in recent years where hitherto undiscovered buildings have been afforded statutory protection. However this leaves a vast amount of 'ordinary' buildings which give the Park its essential flavour, the majority of which are locally special.

Therefore they have developed Policy 50 in their Deposit LDP, which is criteria rather than list-based and application-led. Thus if the building is intact or is of quality or is of landscape/townscape value, then it is of local importance and the policy is of material consideration. Hence it is afforded some potential protection via the planning system. The WLGA will raise this approach with the 25 Heads of Planning at the next Planning Officers Society meeting.

However this circuitous route may not be the most effective method and the WLGA would welcome a fuller debate on how to deal with this issue in a proportionate, administratively appropriate manner which protects our local heritage in partnership with local communities.

The WLGA representative on the Minister's Heritage Environment Group; Nic Wheeler recently raised this issue; both in its own right, and in terms of the wider agenda of issues in the planning and heritage area that need addressing in the light of the continued absence of the new Heritage Bill. We understand that the Minister will address some of these in a statement to plenary shortly.

The WLGA will continue raise this issue; both in terms of the likely discussions if the Heritage Bill proceeds at any point, and in our response to the ongoing WAG consultation on the 'Conservation principles, policies and guidance for the sustainable management of the historic environment in Wales'.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Steve Thomas', written in a cursive style.

Steve Thomas
Chief Executive / Prif Weithredwr

c.c. Val Lloyd AM

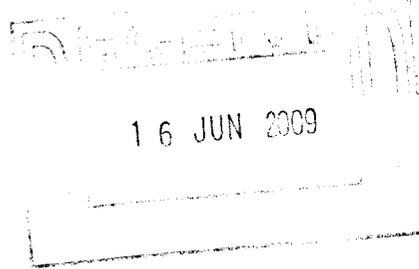
Jane Davidson AC/AM
Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-200
Ein cyf/Our ref JD/00709/09

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



15 June 2009

De Val,

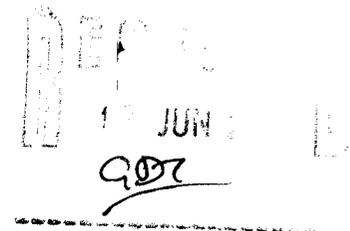
Thank you for your letter of 22nd May 2009 about the petition calling for the creation of a Glamorganshire Canal historic trail from Merthyr Tydfil to Cardiff Bay.

I think this is an interesting suggestion. However, there will I imagine be some problems in terms of formally designating a trail as a public right of way, if this is the intention. This is because I believe that much of the route of the former canal between Aberfan and Cardiff is now covered by development. I understand though that part of old canal route forms part of the Taff Trail so progress there may be more straightforward.

Longer term maintenance of any route and how that would be secured and funded would be another issue that would need to be considered as part of any designation proposals.

Yours,

Jane Davidson AM
Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing



Alun Ffred Jones AC/AM
Y Gweinidog dros Dreftadaeth
Minister for Heritage



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-206
Ein cyf/Our ref AJ/00399/09

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

24 June 2009

Dear Val,

Thank you for your letter dated 5 June regarding Petition PET-03-206, Free Swimming for Children and Young People throughout the year.

As you are aware, the Welsh Assembly Government is already supporting physical activity for young people through a number of initiatives which already offer free access. These include the Free Swimming Initiative, Dragon Sport and the 5x60 scheme.

There are also commitments to support extending provision through these programmes to weekends all year round, and our delivery partners are introducing ways of providing more opportunities for young people to access activities on either a free or subsidised basis.

However, as I am sure you will understand, it is ultimately a matter for local authorities to decide the exact programmes to be offered via their recreation services in order to respond to particular local needs.

I hope you and the Committee find these comments useful.

Yours sincerely,
Alun Ffred

Alun Ffred Jones AC/AM
Y Gweinidog dros Dreftadaeth/Minister for Heritage

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)
paper

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8015
correspondence.alun.ffred.jones@wales.gsi.gov.uk
Printed on 100% recycled

Edwina Hart AM MBE

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/05088/09

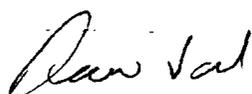
Your ref: PET-03-206

Val Lloyd AM
Constituency Office
2 Sway Road
Morrison
Swansea
SA6 6HT

RECEIVED

Cardiff Bay
Cardiff CF99 1NA
English Enquiry Line: 0845 010 3300
Fax: 029 2089 8131
E-Mail: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

Bae Caerdydd
Caerdydd CF99 1NA
Linell Ymholiadau Cymraeg: 0845 010 4400
Ffacs: 029 2089 8131
E-Bost: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

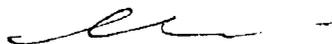


3 July 2009

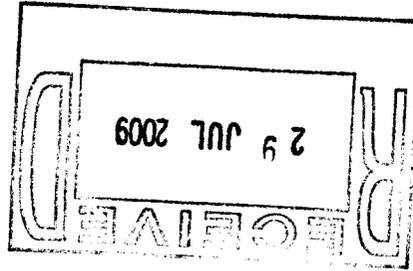
Thank you for your letter to the Chief Medical Officer dated 5 June regarding a Petition on Free Swimming for Children and Young People and its merits related to health promotion. Responsibility for health improvement policy sits within my portfolio.

Physical activity is beneficial to both physical and mental health and we have a range of policies and programmes in place to encourage people to build physical activity into their everyday lives. A number of initiatives targeting children and young people have been put in place through the implementation of the Food and Fitness 5 Year Plan, June 2006, to encourage children and young people to be more physically active. The Welsh Network of Healthy School Schemes supports physical activity programmes in schools across Wales, such as the introduction of playground markings and bicycle racks. The Class Moves programme helps primary school children and teachers to discover the pleasures and benefits of movement. The 'MEND' programme, launched in January 2009, will target around 2,000 children at risk of obesity enabling them to access, free of charge, bespoke activity sessions in leisure and community centres.

I understand that the Minister for Heritage has also written to you on this subject, and with regards to the extension of free access to leisure facilities and specifically Free Swimming I refer you to his response as this sits within his portfolio. You may also like to suggest to the Youth club of Ammanford Junior Gateway that they could respond to the consultation on Creating an Active Wales which closes on 31 July.
<http://wales.gov.uk/topics/childrenyoungpeople/havingfun/climbing/?lang=en>



**Y Pwyllgor Archwilio
Audit Committee**



Cynulliad National
Cenedlaethol Assembly for
Cymru Wales

National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

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

Your ref: PET-03-206

29 July 2009

Dear Val,

I wrote to you on 17 June in response to your letter dated 5 June regarding the Audit Committee's consideration of the Assembly Government's free swimming initiative. In my letter, I committed to responding more fully to your letter following the Audit Committee's consideration of the Assembly Government update on the issues contained within the Committee's report 'increasing physical activity'.

On 2 July, the Committee considered the update and felt that as progress was satisfactory in this area, the Committee would not undertake any further work on this at the present time. The update in full is attached as an annex to this letter recommendation v may be of especial interest to you.

Yours sincerely,

**Jonathan Morgan,
Chair, Audit Committee**

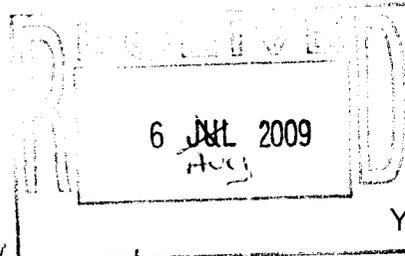
South East Wales District Office
Block 4 Government Buildings
St Agnes Road
Gabalfa
Cardiff
CF14 4US

Tel (029) 20423620
Fax (029) 20423629
Text Phone (029) 20423603
www.jobcentreplus.gov.uk

Swyddfa Dosbarth De Ddwyrain Cymru
Bloc 4, Adeiladau'r Llywodraeth
Ffordd St Agnes
Gabalfa
Caerdydd
CF14 4US

Ffôn (029) 20423620
Ffacs (029) 20423629
Ffôn Testun (029) 20423603
www.canolfabydgwaith.gov.uk

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



Your Ref: PRT-03-207

Dear Val Lloyd,

4 August 2009

Thank you for your letter of 24 July to Sue Matheson regarding Jobcentre Plus services in Monmouth and enclosing a letter from the Monmouth Town council. I am replying as the issues you have raised fall within my responsibilities as District Manager for Jobcentre Plus in South East Wales.

When making the decision to close Monmouth Jobcentre, Jobcentre Plus considered a range of options, including leaving some part time service in the town. Our priority was and is to provide the full range of services in a proper environment for our customers and staff.

We need to consider the range of staff skills needed, IT requirements, health and safety and cost. We concluded that Abergavenny Jobcentre or the other Jobcentres that are easily accessible to Monmouth residents, like Coleford and Ross, are the best places to deliver the service. We have written to all our customers to make them aware of the options available to them

Many of our services are available on line or on the telephone and we still have the arrangement for telephone access using a free customer access phone in the One Stop Shop in Monmouth.

For those reasons we do not think it appropriate to open up part time services in Monmouth.

I hope this clarifies our position, however, if you wish to discuss the matter further, I can be contacted by writing to the above address or by telephone on (029) 2042 3620.

*Yours sincerely
Ian Williams*

Ian H Williams
District Manager

cidz

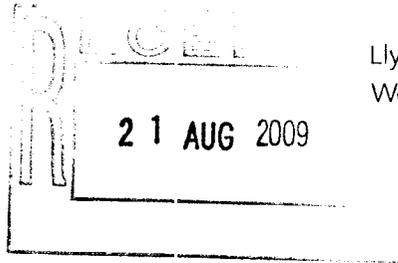


John Griffiths AC/AM
Y Dirprwy Weinidog dros Sgiliau
Deputy Minister for Skills



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-207
Ein cyf/Our ref JG/05255/09



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

19 August 2009

Dear Val,

Thank you for your letter of 26th July, addressed to the Minister for Children, Education and Lifelong Learning, Jane Hutt AM, regarding JobCentre Plus availability in Monmouth. I am replying to you as the issues you raise fall within my area of responsibility.

My officials have contacted JobCentre Plus on this issue who have advised that during the decision making process for the closure of the Monmouth JobCentre, JobCentre Plus considered all available options to them before reaching their final decision. The Welsh Assembly Government were informed of the situation during the 3 month consultation period, resulting in the closure. However, it should be noted that this is not a devolved matter and therefore decisions such as these are reserved for JobCentre Plus and the Department for Work and Pensions.

I understand that JobCentre Plus has written to you separately outlining their reasons for the closure of Monmouth JobCentre Plus and the alternative options available to their customers.

Best wishes

John



Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8522
correspondence.john.griffiths@wales.gsi.gov.uk

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

Printed on 100% recycled paper



Eich cyf/Your ref PET-03-209
Ein cyf/Our ref JH/05029/09

Sandy Mewies AM
Chair of the Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

5
July 2009

Thank you for your letter of 15th June from the Petitions Committee asking me for the Welsh Assembly Government's position on the abolition of the proposed introduction of student top-up fees in Wales through continuing to provide the tuition fee grant to Welsh-domiciled students.

It became evident through numerous queries received concerning student support for Welsh students that there was a need to review current policies, including the issue of Welsh domiciled students studying outside of Wales. In June 2008, I asked Professor Merfyn Jones, Vice-Chancellor of Bangor University, to lead a Task and Finish Group in reviewing our Higher Education policy. In its first stage, the Group was asked to consider student finance arrangements in Wales.

Following their recommendations, I announced on 18 March 2009 that I would be refocusing higher education student finance. The changes will apply to student finance for full-time undergraduate students normally living in Wales. They will be phased in, beginning, as intended, for new students entering higher education in the academic year 2010/11.

The Welsh Assembly Government is determined to ensure that financial barriers should not deter those students from less privileged backgrounds from entering higher education. For this reason, grant support is being targeted at those students from lower income households.

The key changes are as follows.

For new students entering higher education from academic year 2010/11:

- The level of a full Assembly Learning Grant will be £5,000;
- The household income threshold to qualify for partial Assembly Learning Grants will rise by about £10,000 to £50,020;

- There will be no Tuition Fee Grant;
- There will be an increased Tuition Fee Loan facility to ensure no full-time undergraduate students have to pay up front fees;
- All new Welsh domiciled students who take out a maintenance loan from academic year 2010/11 will receive up to £1,500 debt relief when they enter repayment.

Continuing students will be entitled to the same student finance arrangements as they were in previous years (including tuition fee grant if studying in Wales), and continuing students taking out new maintenance loans from academic year 2010/11 may also be eligible for debt relief.

It is anticipated that legislation governing the 2010/11 Academic Year, including the above policy changes, will come-in-force in October- November 2009 – although I am unable to provide a specific date at the present time.

I enclose a copy of my statement on future HE Student Finance arrangements which will provide a more equitable basis for Welsh students whether they study in Wales or England.

[Handwritten signature]

[Handwritten signature]

Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref your ref
Ein cyf/Our ref DFM/05273/09

Sandy Mewies AM
Cardiff Bay
Cardiff
CF99 1NA

28 July 2009

Dee Sandy

Thank you for your letter of 9 July 2009 sent on behalf of the Petitions Committee requesting my assistance in developing proposals to improve traffic flow through St Asaph.

As explained in my previous letter of 9 June 2009, responsibility for the highway network in Wales is divided between the Welsh Assembly Government who manage and maintain the trunk roads and motorways and the local authorities who manage and maintain the local road network. Denbighshire County Council would be responsible for leading and promoting any scheme to improve traffic flow, and my officials in Transport would be pleased to assist and make appropriate contribution to any proposal, which interfaces with the A55 trunk road.

A copy of this correspondence has been sent to Denbighshire County Council for information.

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidiaeth
Minister for the Economy and Transport

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8198
PS.DeputyFirstMinister@wales.gsi.gov.uk

Elin Jones AM/AC
Y Gweinidog dros Faterion Gwledig
Minister for Rural Affairs



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-213
Ein cyf/Our ref EJ/05120/09

Sandy Mewies
Ty Hywel
Cardiff
CF991NA



28 July 2009

Dear *Sandy*

Thank you for your letter of 9 July 2009 regarding the petition against the badger cull that the Petitions Committee considered at its meeting on 23 June 2009 and for informing me of a further petition from the RSPCA.

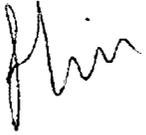
I am of the opinion that a cull of badgers in TB endemic areas alongside even more stringent cattle measures is required to eradicate bovine TB from Wales and this would be taken forward in an Intensive Action Pilot Area (IAPA) located in north Pembrokeshire. I identified this area for the IAPA given its high incidence of bovine TB. In fact, in 2008, 68% of the total number of cattle slaughtered in Wales were located in the old county of Dyfed so this area has a serious problem with bovine TB.

As you are aware, a consultation is currently underway on the necessary powers to allow Government to deliver the culling and vaccination of badgers in Wales. A decision, therefore, on the timescales for the IAPA has not yet been made.

We know, however, from the work on the Randomised Badger Culling Trial (RBCT) in England, that any cull of badgers needs to be co-ordinated, effective and sustained over several years in order to impact on bovine TB incidence in cattle. The IAPA would, therefore, take place for at least 4 years with a minimum of 1 cull per year. In relation to the timings of each cull, there would be a closed season in spring when culling would not take place.

It is important to note that the IAPA will be investigating and dealing with all sources of bovine TB infection. The measures aimed at cattle in the IAPA are currently being considered and preparatory farm visits will begin this year. We will also be working with goat and camelid owners in the area in order to assess the potential risks posed by these animals.

I understand that the Petitions Committee will be considering these petitions again following the completion and evaluation of the IAPA. As I have explained, I am not in a position to make a decision on the timescales involved in the implementation or evaluation of the IAPA. I will, however, continue to keep the National Assembly for Wales informed of progress with the TB Eradication Programme, which will include timescales where appropriate, and I will ensure that evaluation of the IAPA is made publicly available.



Elin Jones AC/AM
Y Gweinidog dros Faterion Gwledig
Minister for Rural Affairs

Alun Ffred Jones AC/AM
Y Gweinidog dros Dreftadaeth
Minister for Heritage



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-217
Ein cyf/Our ref AFJ-05022-09

Sandy Mewies
Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

July 2009

Dear Sandy,

Thank you for your letter of 15 June 2009 regarding the petition for the National Library of Wales to reverse its decision to close on Saturdays from 1 April 2009.

In my Remit Letter to the President of the National Library of 24 March 2009, I stated that:

"I was disappointed to hear about the Board of Trustees' decision to close the Library on Saturdays from 1 April 2009. I consider it to be extremely important that the Library reopens on Saturdays as soon as possible in order to continue providing an accessible service for the people of Wales."

For 2009-10 the Welsh Assembly Government increased the funding allocated to the Library to £12.032 million. This increase in funding came against the backdrop of the extremely difficult financial climate that currently exists. In addition, I was pleased to announce on 15 April 2009 an additional £2 million capital funding (£1 million in 2009-10 and £1 million in 2010-11) for the Library from the Strategic Capital Investment Fund (SCIF). This funding is for the Library's project *'Welsh newspapers and magazines online'* and brings the Library's total grant in aid to £13.032 million in 2009-10, compared to £11.915 million in 2008-09.

The decision to close the Library on Saturdays from April 2009 was taken at a meeting of the Library's Board of Trustees on 14 November 2008 as part of a range of financial savings recommendations. The Library has estimated that closing the Library on Saturdays will provide an annual saving of £80,000.

I discussed the importance of the National Library remaining open on Saturdays during my six-monthly meetings with the President and the Librarian of the National Library of Wales, held on 9 December 2008 and 11 June 2009. At both meetings the National Library stated that it was their wish to open on Saturdays and that it was currently looking at ways of reducing the cost of opening on Saturdays in order to achieve this aim. This included looking at different service and staffing models.

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs * Fax 029 2089 8015
Correspondence.alun.ffred.jones@Wales.gsi.gov.uk
Printed on 100% recycled paper

I also met with trade union representatives in the Library on 19 February 2009 and discussed the impact of Saturday closures on staff and users.

Best wishes,

Alun Ffred

Alun Ffred Jones AC/AM

Y Gweinidog dros Dreftadaeth/Minister for Heritage



Llyfrgell Genedlaethol Cymru
The National Library of Wales

Llyfrgell Genedlaethol Cymru
The National Library of Wales
Aberystwyth SY23 3BU

un o lyfrgelloedd mawr y byd
one of the great libraries of the world

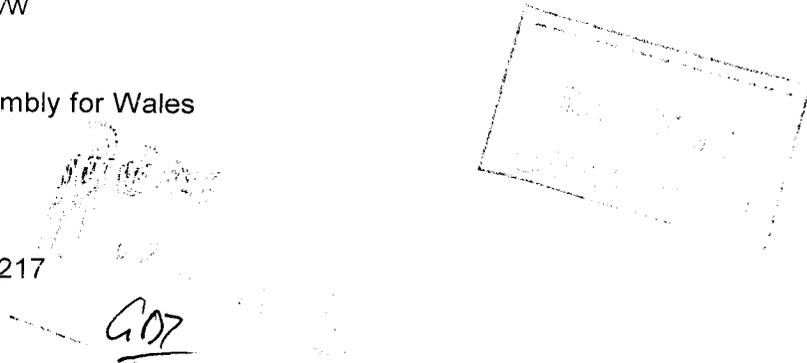
Ffôn/Tel: +44 (0) 1970 632800
Ffacs/Fax: +44 (0) 1970 615709
Eboest/Email: holi@llgc.org.uk
www.llgc.org.uk

2009/LLGDD/LL/SM-1/RVW

Sandy Mewies AM
The National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Your ref.: PET-03-217

Dear Ms Mewies



Petition on Saturday opening at the National Library of Wales

Thank you for your letter of 15 June about the current Petition before the National Assembly for Wales about reversing the National Library's decision to close its building on Saturdays.

The Petitions Committee asks us two questions: we give our responses below.

- 1 *Has the National Library of Wales any plans to review its decision to close on Saturdays?*

The Board of the National Library decided in November 2008 to close on Saturdays from 1 April 2009 in response to the Library's serious financial position. The latter arose from a series of below-inflation grant settlements from the Welsh Assembly Government in recent years, increased costs impossible to avoid, and the Government's failure to inject more money into the Library's staff pension scheme to maintain its viability. (For a number of years the Library has sought to improve efficiency and minimise the impact on services, but this is becoming increasingly difficult.) News about the grant settlement for 2009-10 arrived late in the year. It was necessary for the Board to reduce costs substantially and almost immediately to avoid a deficit in the forthcoming year. Staff costs are by far the largest element of the Library's running costs and there is little flexibility in the methods of achieving staff savings in the short term. The Library is run in a financially responsible manner and balancing the budget is essential. Closing on Saturdays resulted in an immediate and assured saving.

The Board took its decision to close on Saturdays with a heavy heart. Reducing opportunities to use the Library's facilities runs against our philosophy and current strategy. We were aware of the damage that would be done to our users' interests.

We have therefore been keeping the decision under review ever since 1 April. We should like to be reopened as soon as we can, and indeed we have devised a way of being able to do so, at a reduced cost, with reduced services and different forms of



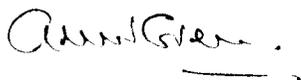
staff working. However we are reluctant to commit to reopening before we hear what our budget settlement is likely to be in 2010-11. It would make no sense to reopen only to close again in the light of a very poor settlement, or to have to make even more severe cuts than may be necessary otherwise. We are of course aware of the future threats to our budgets and therefore to our services as a result of cuts in public spending.

2 *What are the total savings from the decision to close on Saturdays?*

Closing on Saturdays saves £80,000 a year, and contributes to an overall saving in 2009-10 of about £250,000. The other savings are derived from reductions in non-staff budgets and reductions in staffing costs resulting from the failure to fill vacant posts (these measures too have serious, but less immediately noticeable, effects on our users).

I hope this answers your questions satisfactorily, but I should be pleased to give more details if needed.

Yours sincerely,



Andrew M W Green
Librarian

Direct Line: 01970 632 805
Fax: 01970 632 886
Email: ang@llgc.org.uk

copies Officers
 SMT
 Huw LI. Evans (CyMAL)

Ieuan Wyn Jones AC/AM
Dirprwy Brif Weinidog /Deputy First Minister



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-220
Ein cyf/Our ref DFM/05302/09
Sandy Mewies AM
Temporary Chair of the Petitions Committee
Cardiff Bay
CARDIFF
CF99 1NA



30 July 2009

Dear Sandy

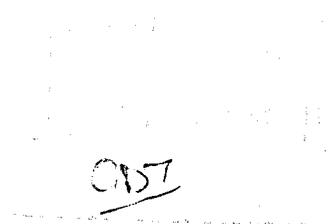
I am responding to your letter of 14th July 2009 sent on behalf of the Petitions Committee requesting a copy of the guidelines for "Setting Local Speed Limits in Wales".

I am pleased to be able to inform you that I have recently approved the proposed guidelines "Setting Local Speed Limits in Wales". We plan to publish these guidelines towards the end of the summer. I will arrange for my officials to forward a copy of the guidelines to the Committee when they are published. The guidelines will also be made available on the Assembly web-site.

Speed limits on trunk roads are kept under general review across the network. Issues such as higher than average accident statistics would draw attention to the possible need for a more detailed review. A study of types of accidents, their severity, causes and frequency, together with a survey of traffic speeds, should indicate whether an existing speed limit is appropriate for the type of road and mix of use by different groups of road users, or whether it needs to be changed. Local speed limits would not be set in isolation, but as part of a package with other measures to manage vehicle speeds.

*Yours
Ieuan*

Ieuan Wyn Jones
Gweinidog dros yr Economi a Thrafnidlaeth
Minister for the Economy and Transport



Edwina Hart AM MBE

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/05056/09

Your ref: PET-03-221

RECEIVED
1 - JUL 2009

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Sandy Mewies AM
Temporary Chair of the Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Cardiff Bay
Cardiff CF99 1NA
English Enquiry Line: 0845 010 3300
Fax: 029 2089 8131
E-Mail: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

Bae Caerdydd
Caerdydd CF99 1NA
Llinell Ymholiadau Cymraeg: 0845 010 4400
Ffacs: 029 2089 8131
E-Bost: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

RECEIVED
2009

ADJ

Deu Senn

30 June 2009

Thank you for your letter of 15 June on behalf of the Petitions Committee about the petition submitted by the Cynon Valley 50 Plus Older People's Forum regarding Chiropody treatment in Wales. You asked for details of foot-care provision throughout Wales and details of the actions the Welsh Assembly Government has taken to ensure consistency of footcare services across Wales particularly in the Rhondda Cynon area.

It is the role of Local Health Boards (LHB) to assess the health needs of the local population and to plan and prioritise services accordingly. I recognise that services currently provided across Wales do vary, primarily as a legacy of eligibility and access criteria determined by the individual commissioners. I want to ensure that patients are treated as close to home as possible. The abolition of the internal market and the establishment of the new LHBs will help facilitate greater standardisation of service provision across Wales over time.

I have asked officials to produce briefing papers on the current position of each of the therapy services, including podiatry. This will build on the Therapy Strategy published in 2006 and is being taken forward under the title 'Mapping Therapy Services'. The mapping exercise will provide a clearer picture of NHS therapy provision and highlight areas of innovative practice which are relevant and can be applied across other parts of Wales. The podiatry paper, together with those from the other therapy services, will be used to help inform future planning processes in the newly evolving LHBs. They will be of particular interest to the new Directors of Therapies and Health Science in the LHBs. I have also asked the Welsh Therapies Advisory Committee to develop a set of national recommendations in response to this mapping work.

In addition, I have commissioned a scoping exercise on the level and nature of provision of social footcare in Wales. This work is nearing completion and I feel confident that taken together these elements of work will help ensure that future provision of services will meet local needs more consistently.

A handwritten signature in black ink, consisting of a series of fluid, connected strokes that are difficult to decipher as specific letters.

Cwm Taf
Ymddiriedolaeth GIG / NHS Trust



NHS
GIG
26 AUG 2009

Your ref/eich cyf:

Our ref/ ein cyf: GB/DJ/LT

Date / dyddiad: 18/08/2009

Tel: 01685 728110

Fax/ facs: 01685 724449/4452

email/ ebost: Gillian.Bowtell@wales.nhs.uk

Dept / adran:

Therapy Directorate/Podiatric
and Orthotic services

DEPARTMENT OF THERAPIES

Sandy Mewies
Temporary Chair of the Petitions Committee
National Assembly for Wales
Cardiff Bay
CARDIFF
CF99 1NA

Dear Ms Mewies,

Re: Petition: Improved NHS Chiropody Treatment

Thank you for your recent communication regarding the issues raised by the Cynon Valley 50 Plus Older People's Forum calling for 'Improved Chiropody Service (foot care) to be available on the NHS especially for Older People who are housebound in the RCT area'.

In their foot care survey (2008), Age Concern Cymru found that there had been a "clear decline in the provision of foot care services in Wales" and that there was "no provision for lower level foot care services". Recognising the value for social foot care and in response to the concerns raised by Age Concern Cymru, Mrs Edwina Hart commissioned a scoping exercise to explore the issue and develop options to improve services for the future. The scoping exercise being lead by Mrs J Smith, Therapy Advisor for Wales, began late December last year and its finding and options are awaited.

Cont'd.....

Return Address:

Therapies Department, Block 6, Prince Charles Hospital

The service in Cwm Taf provides lower level podiatric foot care where there is a podiatric pathology or a primary medical condition which has had or may have a direct effect on Foot Health. The department is unable to provide social foot care for people who have no appropriate underlying medical condition affecting foot health. As the service offers an assessment for each referral accepted, education and empowerment is offered at this occasion to enable self / family care to be successfully achieved.

The Trust appreciates the demand for social foot care in the communities and awaits the recommendations from the Welsh Assembly Government on how organisations will best move forward to meet the need.

Whilst the Head of Podiatry and Orthotics, Mrs Denise Jenkins, was unaware of this petition, she would be more than happy to discuss the local issues with you.

Yours sincerely,



GILL BOWTELL
Clinical Director of Therapies Services

c.c. Val Lloyd (AM)



REPORT ON FOOTCARE IN CYNON VALLEY AREA:

This report is written on behalf of the Cynon Valley Fifty Plus Older People's Forum.

Good Foot care is essential for the dignity, quality of life and well being of older. Many older people struggle to care for their feet due to health problems, such as sight impairment and arthritis, or they simply find it impossible to reach their feet to cut their toenails. Increasingly nail cutting and other foot care services are being withdrawn or restricted by the NHS' Although nail cutting may sound trivial, lack of even the most basic foot care frequently leads to complications than can result in dangerous falls, severe restrictions on mobility and social isolation.

Older people are increasingly being forced to pay for private foot care. The alternative – which disproportionately affects the poorest and most vulnerable older people – is to take desperate measures or to lose independence and suffer deterioration of their physical and mental health.(Little steps can make a Big Difference – ACCymru Oct.2008).

David Davies one of our members highlighted the issue of Foot Care specifically Toe Nail Cutting at the end of 2008, when he realised the NHS were referring to Toe Nail cutting: as a social need and not a medical one. This has brought the issue to the attention of the forum, as many currently pay for such a service in their own homes as it isn't readily available on the NHS.

After considerable research we find that some GP Surgery's offer Chiropody/Podiatry service in some part of Wales and even some parts of RCT. However, we feel once again this is a post code lottery, service for some and not for others.

We have met with Age Concern Cymru who have printed a document on this subject 'Little steps can make a Big Difference' and are carrying out some research to consider this issue.

Falls Prevention – the new strategy takes into consideration that falls can happen if that person has long toe nails/hard skin/in-growing toe nails which are untreated. Routine foot care services are a simple and inexpensive way of preventing problems and avoiding the necessity of more expensive hospital based interventions.

David Davies highlighted that in Burry Port where his daughter lives, they have an organisation named 'Wellbeing Regeneration' organisation which is a Social Enterprise offering an affordable service to older people. You receive your first examination which includes consultation. Once they agree for regular toe nails cutting, you then visit your local Day Centre where you have your toe nails cut and provided with a kit all for £16.00. Future toe nail cutting is provided for the cost of £6.00 per visit.

The 'Wellbeing Regeneration' – an innovative Ageing Well project in Llanelli, is an excellent example of joint-working: the NHS Podiatry Department train staff to undertake toenail cutting, the Local Authority provides free venues and the centre receives referrals from lots of different avenues.

Additionally the clinic provides information about different services and activities available to older people and carer and will signpost people to specialist agencies dependent on their needs. People enjoy the friendly environment, the social aspect and the opportunity to learn more about what is on offer elsewhere (ACCymru).

Recently a Falls Prevention Event was organised for the Older People's Forums in RCT in partnership with the teaching Local Health Board. There were 96 members present from the five forums: the workshops were facilitated around developing a Falls Prevention Strategy. One of the causes of a fall with older people is toe nail cutting and/or the lack of sufficient chiropody services.

We have carried out a survey in the Cynon Valley Forum on how people felt about the lack of service provision, whether they currently pay for foot care now and whether in the future they would participate in an organisation like the 'Wellbeing Regeneration' that provides a service in Burryport. Many of the participants needing foot care services would be happy to join a scheme similar to the 'Wellbeing Regeneration' project.

Age Concern Ceredigion is currently providing a nail cutting service with trained volunteers. At present the service is only available once a week in South Ceredigion at a Day Centre. This year 3 new volunteers have been trained by the Podiatry Department at Cardigan Hospital providing a total of five volunteers delivering the service on a rota basis. There is a charge for this service to cover costs of equipment. The scheme supports basic toe nail cutting for older people with mobility difficulties who find cutting their toe nails difficult. The service can improve quality of life substantially. The cost is £21.00 for registration and examination (includes £15.00 for foot care kit) then each visit afterwards cost £6.00. (Information via Director ACCeredigion). (From Little Steps can make a big difference – Report ACCymru).

However, some people could argue that why should volunteers provide a service that the NHS should be providing?

Others feel they would rather a service organised by volunteers than no service at all.

The expectation from some NHS Trusts, specify training family members and Carers.

This is abhorrent to some family members and carers, and it could prove extremely dangerous if they had an accident while cutting the nails, if they didn't notice something wrong with the toe/feet, and or if they badly cut the area. The carers of older people feel they have enough pressure from their role as a carer without introducing another task they would have to undertake.

We the Older People's Forum in Cynon Valley, have presented a petition to the Welsh Assembly Government copied to Age Concern Cymru who are organising a similar campaign.

The Cynon Valley Forum members want to put an end to this post code lottery, and have a standardised service for all.

It has been proven over time, that prevention is better than cure, so can you help and prevent future accidents/diseases/conditions by endeavouring to look at the issue; is it Medical or Social Care for Chiropody/Podiatry services in Wales?

Report provided on behalf of Cynon Valley Forum Members by Sian Jones and David Davies.
August 2009.

Leighton Andrews AC/AM
Y Dirprwy Weinidog dros Adfywio
Deputy Minister for Regeneration



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-224
Ein cyf/Our ref LA/05003/09

Sandy Mewies AM
Temporary Chair of Petitions Committee
National Assembly For Wales
Cardiff Bay
CF99 1NA

8 July 2009

Dear Sandy,

Thank you for your correspondence regarding the Stepping Stones Nursery on the Ebbw Vale campus of Coleg Gwent.

I am obviously disappointed to hear that the nursery is due to close.

I have asked my officials to liaise with the Department for Children, Education, Lifelong Learning and Skills. I am afraid that there are very limited revenue budgets in the regeneration portfolio.

I wish the organisation all the best in their endeavours to find the support they need.

*Yours ever
Leighton Andrews*

Leighton Andrews AM
Deputy Minister for Regeneration

John Griffiths AC/AM
Y Dirprwy Weinidog dros Sgiliau
Deputy Minister for Skills



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-224
Ein cyf/Our ref JH/05028/09

Sandy Mewies AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

RECEIVED
13 JUL 2009

Handwritten notes and signatures, including the initials "GPT".

8 July 2009

Dear Sandy,

Thank you for your letter dated 15th June 2009 detailing the petition received calling on the National Assembly for Wales to 'intervene to halt the closure of the Stepping Stones Nursery on the Ebbw Vale Campus of Coleg Gwent'. I appreciate the concerns of the learners affected by the possible closure of this nursery. Officials have contacted Blaenau Gwent in connection with the difficulties faced at Stepping Stones Nursery and are informed the authority is working with the students to find alternative forms of childcare. I hope alternative provision can be sought for these learners.

When looking at childcare provision it is essential to look at the needs of parents within a community and to respond to these needs. The Childcare Act 2006 requires that Local Authorities undertake a full childcare sufficiency assessment within a year of commencement date of legislation (1 April 2008) and then at least every three years following that, keeping their assessment under review in between the main assessment. Childcare Sufficiency Assessments should identify gaps in childcare provision and address any shortfalls or gaps that are discovered.

Cymorth – the Children and Youth Support Fund aims to provide a network of targeted support for children and young people within a framework of universal provision, in order to improve the life chances of children and young people from disadvantaged families. Cymorth is administered through Children and Young People's Partnerships in each local authority areas and funding is distributed to meet local needs and priorities. Blaenau Gwent's funding for childcare under the RSG for 2009/10 is £215,392.

In addition, the Financial Contingency Fund (FCF) allows further education institutions (FEIs) to provide discretionary financial help to learners whose access to, or completion of, education might be inhibited by financial considerations or who, for whatever reason, including physical or other disabilities, face financial difficulties.

Of the 25 FEIs accessing FCFs (excluding Welsh for Adults Centres), 21 used the fund in 2007/08 to help students with the cost of childcare. The budget for the year was £6.5m

which was a slight reduction on the money available the previous year. In 2009/10 it will be restored to the same level as in 2007/08 i.e. £7m.

FElS are very aware of the importance that availability of high quality childcare facilities plays when parents are making decisions about further education opportunities. Naturally, whether a nursery is provided at any particular campus is a matter for college themselves to make taking into account all the local circumstances. When making decisions many competing priorities have to be taken into account and are often very difficult.

It is of real concern that there is a range of quality childcare provision in order to support progression into training and employment. I understand that childcare is a hugely important issue and we will be reviewing the provision of childcare across Wales as part of our review of the Childcare Sufficiency Audits. This review will form the basis of the next Childcare Strategy for Wales and will set out the types and patterns of childcare that we will need to consider in the future, to provide the best outcomes for children and for parents.

Best wishes,

A handwritten signature in black ink, appearing to read "John". The signature is written in a cursive style with a long, sweeping horizontal line above the name.

Edwina Hart AM OStJ MBE

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/05398/09

Your ref: PET-03-226

Sandy Mewies AM
Acting Chair Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Cardiff Bay
Cardiff CF99 1NA
English Enquiry Line: 0845 010 3300
Fax: 029 2089 8131
E-Mail: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

Bae Caerdydd
Caerdydd CF99 1NA
Llinell Ymholiadau Cymraeg: 0845 010 4400
Ffacs: 029 2089 8131
E-Bost: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

3 August 2009

Dear Sand

Thank you for your letter of 10 July regarding the Petition on Sands - Stillbirth and Neonatal Death Charity.

On 15 June I met with Mr Neal Long, Chief Executive of Sands, and his colleagues to discuss stillbirth and neonatal death issues in Wales and their recent report *Saving Babies Lives*, 2009. As a result, I will be taking forward a number of the issues they raised. Their report identified the need for action at a strategic level on antenatal and neonatal care. While considerable work is already underway to improve maternity and neonatal services across Wales, I recognise there is more work to do.

Plans have been developed and are being implemented to improve neonatal care for sick and premature babies in Wales. The services that will be developed will be provided through clinical networks. The networks will comprise linked groups of health professionals from primary and secondary care and where necessary specialist services. I remain committed to improving these services as evidenced by the additional £4million I announced last year to be used over the next two years to support improvements. I also launched the All Wales Neonatal Standards on 8 December 2008 which will be used to underpin the development of the managed clinical networks and the planning, design and delivery of services which ensure equity of access across Wales. Work is also currently underway to produce an implementation plan to map the future of neonatal transport services in Wales.

In addition there is work in progress to improve maternity services in Wales. We are increasing the number of midwifery training places and we are also increasing training for maternity support workers to allow them to take on more non-midwifery

training for maternity support workers to allow them to take on more non-midwifery duties, currently undertaken by the midwives, to allow midwives to spend more time caring for mothers and babies.

The report also referred to a need for better data for monitoring and research. Work is currently being undertaken to standardise the data recorded across maternity services in Wales. This data will monitor services available to women during antenatal, birth and postnatal periods. It is expected that 'secondary information' recorded from the dataset will inform all responsible, both at local and national levels, and will assist NHS trusts in planning, managing and performance management and will help them to continually improve maternity services to meet local needs.

We already have good information about deaths of babies in the perinatal period from the All Wales Perinatal Survey, but the proposed new system should provide more detailed information, particularly about maternal factors, and about preterm babies.

Following the useful meeting I held with the organisation in June, I have instructed my officials to continue to work with Sands to establish what further can be done to ensure that services for mothers and babies are further improved.

As a further outcome of this meeting I will be considering proposals on the possibility of extending the RADIS 11 project, currently being rolled out in Wales, to include the recording of growth scans to establish whether links can be made between reduced foetal growth and still birth; rationalise and increase the quality of the data collected on still births and neonatal deaths and to establish links with existing Working Groups already in place within the Welsh Assembly Government to consider what further research work can be done on still births and neonatal deaths in Wales and to consider best practice guidance.

On the 17 June at the Welsh Liberal Democrat Debate on Neonatal Services, a number of issues raised by the report and petition were debated, resulting in an amended motion being agreed which included a call on the Welsh Assembly Government to raise awareness of stillbirth and neonatal death as a key public health issue. My officials are working to take this forward.

A handwritten signature in black ink, appearing to be 'ew' followed by a flourish.

Jane Davidson AC/AM

Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-231
Ein cyf/Our ref JD/05298/09

Sandy Mewies AM
Transport House
64 Chester Street
Flint
Flintshire
CH6 5DH

Handwritten notes and a signature 'AM' in the center of the page.

7 August 2009

Dear Sandy,

Thank you for your letter of 10 July 2009 requesting my view on increasing the minimum distance for the location of wind turbines from 500m from residential dwellings to 2KM.

Guidance on proximity of wind turbines to residential dwellings, as set out in paragraph 3.4, Annex D (page 59) of Technical Advice Note (TAN) 8: Planning for Renewable Energy, states that "500m is currently considered a typical separation distance between a wind turbine and residential property to avoid unacceptable wind impacts." The research 'Facilitating Planning for Renewable Energy in Wales: Meeting the Target - Final Report' carried out by Arup in 2004, commissioned by Welsh Assembly Government in 2002, concluded that wind industry professionals generally accept 500m as a suitable separation distance between a wind turbine and residential property/community to avoid unacceptable noise impacts. However, the Arup report also indicates that the buffer should be applied flexibly and that separation distances can be judged locally as part of the refinement work by local planning authorities on a case-by-case basis, taking into account issues such as topography and orientation when taking decisions on planning applications for wind turbines. This is reflected in TAN 8, paragraph 3.4, Annex D (page 59), which explains that the buffer "when applied in a rigid manner... can lead to conservative results and so some flexibility is... advised". The issue is less to do with distance than the need to limit noise from wind farms to 5dBA above background noise for both day and night-time. Noise generation can be influenced by landscape, orientation, turbine size, and wind speed but it is not always directly related to distance. All of these factors need to be considered when applications are being determined.

TAN 8 provides technical advice to supplement national planning policy set out in Planning Policy Wales and the Ministerial Interim Planning Policy Statement (MIPP) 01/2005 Planning for Renewable Energy. TAN 8 provides guidance only.

In terms of Scottish policy, Scotland has the responsibility for designing and implementing its own policies on renewable energy, and as a result I cannot offer comments on their policies.

Regarding problems associated with wind turbines, wind turbines operating in the UK are designed, installed and maintained as part of mandatory health and safety legislation in addition to rigorous technical standards including BS EN 50308 (Wind Turbines – Protective measures – Requirements for design, operation and maintenance) and BS EN 61400-1 (Wind turbines - Design requirements).

Furthermore, where a wind power development involves more than two turbines or the hub height of any turbine (or height of any other structure) exceeds 15 metres, an Environmental Impact Assessment (EIA) will be required if the development is likely to have significant effects on the environment by virtue of factors such as its nature, size or location.

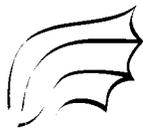
An EIA is a means of drawing together, in a systematic way, an assessment of a project's likely significant environmental effects. This helps to ensure that the importance of the predicted effects, and the scope for reducing them, are properly understood by the public and the relevant competent authority before it makes its decision. In addition, each wind farm development is subject to a detailed health and safety appraisal and risk assessment that takes into account specific installation, location and turbine specific issues. This helps to determine the separation distance required for individual wind power schemes.

Yours,

A handwritten signature in black ink, appearing to read 'Jane Davidson', written in a cursive style.

Jane Davidson AM

Y Gweinidog dros yr Amgylchedd, Cynaliadwyedd a Thai
Minister for Environment, Sustainability and Housing



WALES AUDIT OFFICE

Wales Audit Office / Swyddfa Archwilio Cymru

SWYDDFA ARCHWILIO CYMRU

Date: **18th August 2009**
Our ref: **JC/0902/fgb**
Your ref:
Pages: **1 of 1**

24 Cathedral Road / Heol y Gadeirlan
Cardiff / Caerdydd
CF11 9LJ
Tel / Ffôn: 029 20 320510
Fax / Ffacs: 029 20 320555
www.wao.gov.uk

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

19 AUG 2009
Email / Ebost: jeremy.colman@wao.gov.uk
PA / CP Fiona Bashford, fiona.bashford@wao.gov.uk

Dear Ms Lloyd

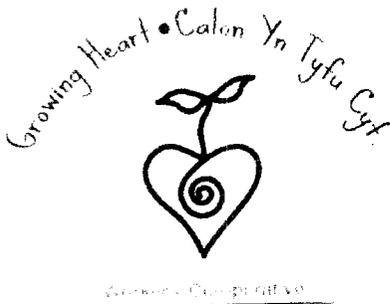
PETITION: FFYNNONE AND CILGWYN WOODLAND

Thank you for your letter of 24 July to the Auditor General for Wales.

The Forestry Commission Wales had already been in touch with us about this matter and is co-operating in our investigation. That work is likely to take a few weeks and we will be in touch again as soon as it is concluded.

Yours sincerely

FIONA BASHFORD
PA TO JEREMY COLMAN
AUDITOR GENERAL FOR WALES



Henparcau Farm
Boncath
Pembrokeshire
SA37 0JY

01239 841675

growingheart@cooptel.net
www.growingheart.co.uk



4th August 2009

Dear Petitions Committee

Thank you for your invitation to respond to a request for a public enquiry into our Cyd coed grant application, and our management approach.

As far as we are concerned a public enquiry is unnecessary and would be a waste of tax payers money for the following reasons:

We applied for a Cyd coed grant that was advertised publicly, it was deemed we were an eligible group, so we then followed the procedures given to us, made a bid, based solely on our actual intentions, and were subsequently successful in our application. We were then asked to sign the same standard contract as all the other successful applicants under the same scheme. Since then we have been fulfilling our contract commitments as laid down in our bid. We therefore feel our application was as transparent and open as all other grants under the same scheme.

We believe our management of the project is open and inclusive, and our management of the actual woodlands is restorative in nature and is following guidelines and practices in line with current forestry best practice. Apart from some initial clear felling, to both generate income to fund operations and create age and species diversity, the remainder of the woodland is to be managed on a continuous cover basis. We have worked closely with all relevant agencies to ensure environmental protections are in place, including The EA, CCW, PCC, as well as FCW, we have also undertaken surveys for various European Protected Species including, badgers, otters and bats, and we work closely with the relevant experts when working near various habitats and have gained all relevant licensing when required. We also employ a fully qualified forester to advise us on all forestry operations and all members, employees and contractors are qualified and competent for the task they are performing.

We feel both the felling and subsequent conversion to broad leaf cover, as well as continuous cover forestry are in line with the Welsh Assemblies current policy. We feel the Forestry Commission fully support our management approach and feel it was a factor in the award of the grant, as sound forest management was also a criteria.

The installation of new forest roads has many benefits, including less ground damage by forest vehicles and operations, improved access for the general public, who are free to use these tracks, for walking, cycling and horse riding. They also act as fire breaks between the forest blocks they dissect, as well as creating wildlife edges of diversity. We have created disabled access and off road car parking making the woods accessible now to a much wider cross section of society.



CYDCOED
WOODLANDS FOR YOU



Calon yn Tyfu Cyt, registered at Companies House Cardiff. Reg. #3176209
Henparcau Farm, Boncath, Pembrokeshire, SA37 0JY

We have been engaging with the wider community throughout this process. We have listened to and amended our plans and actions in accordance with various concerns, as well as attracting new workers and supporters who are now involved in developing this process as we move forward. These include forest workers as well as those involved in social development, including schools and excluded groups. We have formed ties with the local scouts and guides and have made a woodland area available to them to develop over time.

The site has also been used by youth groups, including Ceredigion young carers, for overnight respite stays and training in survival skills.

We have worked with various training providers, but principally PTP quality training who offer a range of LANTRA based courses.

All of this whilst still at the initial stage of infrastructure development, we believe the breadth and depth of inclusion will develop over time, once the infrastructure work is complete.

However we feel also it is impossible to respond to your request about funding and management without mentioning the wider context of opposition we are working with, this includes 3 neighbours who have pursued adverse claims through the land registry against land registered to the woodland. These people are the driving force behind the opposition although we accept that other people also have concerns, we feel that without the vehemence of their campaign the other issues would have been resolved more readily. For an insight into the nature of their campaign try reading their blog site which regularly makes personal attacks and misleading statements about us and this project <http://brokenheartcoop.wordpress.com/>

Having looked at the supporting document on line proposing a petition we are concerned about the misleading nature of many of the statements, we feel this is indicative of the malicious campaign against this project, and we would like to respond to them point by point.

We feel it is untrue to say there is no transparency as all documentation is available on line and as well as the public meetings where we have explained and discussed our plans before starting work, the process of the Better Woodland for Wales process ensured a public consultation process that was well used by some neighbours, a separate independent consultation at the height of the forestry operations in sept 08 also sought to find out public opinion.

We believe statements made in the bid document are all true and accurate Calon yn Tyfu Cyf. was “chosen” to receive this grant as it was the structure which both had the vision to link this idea with this grant, and made the application. If any other group had done so, we believe they would have been assessed on the merits of their proposal like we were.

We know people have brought up the number of members in our group as a reason of unsuitability, this was never an issue when applying for the grant, or previously or now within our group, as the number of members is not the whole story. We have a number of prospective members, currently 5 as well as several workers who are happy at that status, as well as casual workers, seasonal workers, volunteers and supporters, all of which is based on our 13 year record at employing people and involving them in our various works, which include, tree planting (2 million so far) tree seed collection, (which we also operate in England and Scotland), organic fruit and vegetable production and delivery, cider making, firewood production, kindling supply and quality sawn timber production, Christmas tree growing, and now a range of timber products. The successful delivery of all these projects from self generated funds by a grass roots network of people involved in sustainable activities, is evidence of our ability to deliver this project also.



CYD COED



Calon yn Tyfu Cyf registered at Companies House Cardiff Reg #3176209
Henparcau Farm, Boncath, Pembrokeshire SA37 0JY

As we pay our workers a living wage, much of our development of inclusion is based on the natural development of our work.

We believe it is untrue to state that FCW has little or no control over the way the woodlands are used, or disposed of. All operations in the woodland are covered by our bid document and contract, as well as ongoing commitments under BWW. Whilst we have no plans to ever sell the land, like all land purchases in this Cyd coed scheme the grant rules state we are unable to sell or give away the land for 20 years. Our disillusionment clause also prevents the cooperative members profiting from any assets of the cooperative. This clause from our recollection was why no legal charge was taken over the land.

There has been no claim by the FCW that we are failing in our duties, or working in an unsatisfactory manner, we believe our operating procedure and close cooperation with FCW will ensure successful delivery of this project and any perceived oversight by FCW will not affect this projects performance.

Claims that our woodland management is disproportionate or inappropriate and damaging, we believe are made by unqualified parties, and in our communications with FCW and CCW we have always been informed that they fully support the complete scope of improvements being made, These sites are protected by both SSSI and SAC designation, we believe any damage such as that alleged would already have been highlighted by the monitoring process.

Claims that the local community have been deliberately excluded are untrue, and evidence to the contrary are manifest. From the initial meeting with neighbours, which we announced as soon as we bought the land, through to the second meeting in May 2008 which we ran with Small Woods Association, which was specifically designed to attract new participants. We believe these are the two meetings referred to by the forestry officer, and in the supporting document. One had happened already and the other was already well advertised. More recently an apple pressing day where more than 30 people made over 250 bottles of apple juice to share, and just last month, an open day and tour through the woods, attended by almost 100 people, and in conjunction with the local green dragon public transport vehicle, the atmosphere was positive, and most people expressed support, including several older residents who had previously been unable to access the woodlands. We are still yet to have our official launch which will be when the infrastructure is finished.

As long term residents and members of the wider local community we individually also have wide circles of inter connected friends and relations, which ground us fully into the community.

Claims of corruption of a Cyd coed officer are both libellous and untrue, his role was to support grant applicants through the grant application process, however he, as far as we are aware had no authority to make any decisions as to who was successful, as this was made by senior FCW staff with whom there had been no previous contact let alone implied relationship. From our perception we worked with him in a professional manner and always found him helpful and friendly, apparently he had helped us previously when we applied to the WDA for £4,000 to help establish a firewood processing venture although our principle contact then was someone else.

Since getting the grant several new people have started the process of joining the cooperative as full members, their current status is prospective members We do have a long joining procedure as we cooperate closely and wish to ensure compatibility amongst members, our joining procedure was given to Cyd coed as part of our grant application process and we feel as such this was clear before the grant was awarded.



CYD COED



Calon yn Tyfu Cyf. registered at Companies House Cardiff. Reg #3176209
Henparcau Farm, Boncath, Pembrokeshire SA37 0JY

Claims that the standing value of timber is valued at £700,000 is also untrue and can be seen to be so by the fact the previous owners sold the woodlands for £485,000, which obviously includes some residual land value. A forester valuation could also substantiate this.

It is true that more felling is planned, one area is still to be clear felled, this is an area of Western Hemlock (an invasive species) planted on an ancient woodland site, it is considered best practice to remove it and restore native species. The rest of the proposed felling is because the plantation species have now grown and need thinning, to allow remaining trees to continue growing, and let natural regeneration by increasing light levels on the ground

Planning procedures have been followed and in our application for a GPDO we described our proposals as forest roads, PCC then advertised it as footpaths, this was their decision not ours, the scenic footpath described, is in fact a forest road put in 12 years ago by the previous owners, showing that these roads settle and become scenic in a very short period of time. It was our decision to alter the route and not that of any council official.

If any doubt still remains that we are being clear, honest and open, then we would like it known that we asked FCW in March to help facilitate mediated meetings between ourselves and the wider community, our intention is to dispel the current wave of 'rumours' being spread about us, as well as identify and clarify real concerns, and work towards a suitable solution of inclusion to move forward.

We feel it is sad that some members of the local community have not been more supportive, but we feel we have also received support from a large percentage of local people, and once the initial infrastructure work is complete, and the social aspects start to be developed more, and in conjunction with mediated meetings to address concerns we are confident that this project will deliver the wide social benefits promised in our bid.

We have always worked from a bottom up approach, making real one to one connections building a real and lasting group network of people, connected through a common, sustainable, approach to living and working.

Thank you for taking the time to read, what we know is a long response, we look forward to your decision with interest.

Yours sincerely

Handwritten signature

Willow

Handwritten signature

K MOORE

for and on behalf of Calon yn Tyfu Cyf. / Growing Heart workers cooperative



CYDCOED
WYDDIANSY CYF. LTD.



Calon yn Tyfu Cyf. registered at Companies House Cardiff Reg #3176209
Henparcau Farm. Boncath Pembrokeshire. SA37 0JY

26 AUG 2009



Comisiwn | Forestry
Coedwigaeth | Commission
Cymru | Wales

Swyddfa Office

Rhodfa Fuddug Victoria Terrace
Aberystwyth
Ceredigion
SY23 2DQ

fc.nat.off.wales@forestry.gsi.gov.uk
Ffôn/Tel: 0845 604 0845
Ffacs/Fax: 01970 625282

Cyfarwyddwr Cymru
Director Wales
Trefor Owen

25th August 2009

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

Your ref: PET-03-232

C.T.O.J.

Dear Ms Lloyd

PETITION – FFYNONE AND CILGWYN WOODLAND

Thank you for your letter dated 24th July 2009 in respect of a call for a independent inquiry from Cyngor Cymuned Manordeifi Community Council in respect of the purchase of the Ffynone and Cilgwyn Woods by Calon yn Tyfu Cyf under the Cydcoed grant scheme.

Cydcoed was an EU Objective 1 programme managed by Forestry Commission Wales (FCW). This innovative programme supported the use and creation of woodlands for community development. Funded over two phases (2001-2004; 2003-2008), it provided 100% funding to 163 community groups across the Objective 1 (West Wales and the Valleys) region. Cydcoed has now closed. In order to encourage a wide range of groups to apply for grants, no restrictive definitions of a community group were applied.

Calon yn Tyfu Cyf purchased Ffynone and Cilgwyn woodland using a Cydcoed grant. The funding was primarily for the purchase of the land and associated legal costs. The woodland was previously in private ownership with minimal woodland management, and with large areas of non-native species. Calon yn Tyfu Cyf has subsequently undertaken a range of woodland management and infrastructure works, with the long-term goal of reinstating the woodland with native species and providing appropriate woodland management. The long-term aim for the woodlands is to focus on converting the woodlands to native broadleaves, with an emphasis on sustainability, diversity, education and improving access for the public. Calon yn Tyfu Cyf are now the legal owners of the woodland.

Calon yn Tyfu Cyf has a good track record as a well-established co-operative of 13 years standing and, we have every faith in its pledges to deliver a wide range of community benefits. Its bid, which was accompanied by several letters of support, was considered



strong in terms of social benefit, woodland management and economic regeneration. The contract states that FCW will monitor the site and project development until 2026.

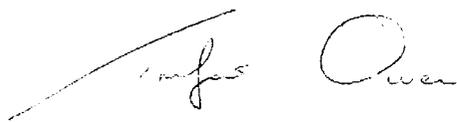
The application process for grants awarded through Cydcoed is fully transparent, and all the relevant details are available to all who wish to view them. Calon yn Tyfu Cyf followed the same application process as every other group seeking funds from Cydcoed.

Mr Paul Davies AM Conservative Member for Preseli Pembrokeshire has also exchanged correspondence and met with the Minister for Rural Affairs and myself on the 5th May 2009 to discuss the funding of Calon yn Tyfu Cyf. The Minister was not convinced that there was any need for an inquiry as nothing further could be gained by this action. I together with my officers have attended two public meetings called by Mr Davies (16th March 2009 at Boncath and 9th July 2009 at Bwlchygroes) to which all interested community members were invited to attend. All of the issues that were raised both prior to and during the meetings were addressed and FCW have also agreed to make all the information appertaining to the project available to interested parties via their website <http://www.forestry.gov.uk/forestry/INFD-7ULEK4>.

There have been previous calls for a public inquiry into the funding of this project by some members of the local community. If the project or grant scheme was part of a statutory process for example, in planning and harbours legislation, the relevant statute provides how and when a public inquiry must take place. There is no corresponding statute (which includes provision for a public enquiry) for the awarding of grants through the Cydcoed or forestry grant schemes. As there is no requirement within the terms of a grant scheme to hold a public inquiry, then there is no statutory obligation upon the Forestry Commission Wales to hold one.

However, I recognise the continued public interest in this case. In response I have discussed this further with the Wales Audit Office (WAO). In light of these discussions and other correspondence received the WAO has agreed to review Forestry Commission Wales' handling of this case, and provide me, as Accounting Officer, with a report.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Trefor Owen', written in a cursive style.

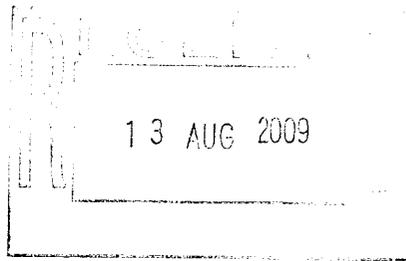
Trefor Owen
Director, Forestry Commission Wales

Elin Jones AM/AC
Y Gweinidog dros Faterion Gwledig
Minister for Rural Affairs



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Eich cyf/Your ref PET-03-232
Ein cyf/Our ref EJ/05183/09



Val Lloyd
Bae Caerdydd
Cardiff
CF991NA

10 August 2009

Dear *Val,*

Thank you for your letter dated 24 July 2009 regarding a call for an independent inquiry from Cyngor Cymuned Manordeifi Community Council in respect of the purchase of the Ffynone and Cilgwyn Woods by Calon yn Tyfu Cyf under the Cydcoed grant scheme.

Calon yn Tyfu Cyf purchased the Ffynone and Cilgwyn woodland using Cydcoed grant aid. Cydcoed was an EU Objective 1 programme managed by my department with responsibility for forestry in Wales, the Forestry Commission (FCW) and it provided 100% grants to a total of 163 community groups across the Objective 1 areas in Wales. The main objectives of Cydcoed funding were to maximise the use of community forestry in order to encourage social inclusion and to support high capacity community groups who would be able to undertake and sustain the development of the long term social, economic and environmental benefits that woodlands can provide, to as wide a user group as possible but with particular focus on the immediate communities. In order to encourage all types of groups to apply for grants, no restrictive definitions of a community group were applied.

The funding provided to Calon yn Tyfu Cyf through Cydcoed was primarily for the purchase of the land known as Ffynone and Cilgwyn and the legal costs associated with its purchase. The woodland was previously in private ownership with minimal woodland management and with large areas of non-native species. Calon yn Tyfu Cyf has subsequently undertaken a range of woodland management and infrastructure works, with the long-term goal of reinstating the woodland with native species and providing appropriate woodland management. The long-term aim for the woodlands is to focus on converting the woodlands to native broadleaves, with an emphasis on sustainability, diversity, education and improving access for the public. Calon yn Tyfu Cyf are now the legal owners of the woodland.

Calon yn Tyfu Cyf has a good track record as a well-established co-operative of 13 years standing and their bid, which was accompanied by several letters of support, was considered strong in terms of social benefit, woodland management and economic

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

English Enquiry Line 0845 010 3300
Llinell Ymholiadau Cymraeg 0845 010 4400
Ffacs • Fax 029 2089 8522
Correspondence.Elin.Jones@Wales.gsi.gov.uk
Printed on 100% recycled paper

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

regeneration. Their contract states that FCW will monitor the site and project development until 2026.

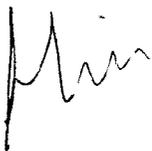
The application process for grants awarded through Cydcoed was a fully transparent and officially audited one and all of the relevant details are available to anyone who wishes to view them. Calon yn Tyfu Cyf followed the same application process and were treated in the same way as every other group seeking funds from Cydcoed.

I met with the Conservative Assembly Member for Preseli Pembrokeshire, Mr Paul Davies on 5th May 2009 (together with the Director of FCW) in order to discuss the concerns of his constituents and I am not convinced that there is any need for an independent inquiry because I see nothing further could be gained by such action. The Director of FCW, Mr Trefor Owen attended two public meetings called by Mr Davies (16th March 2009 at Boncath and 9th July 2009 at Bwlchygroes) to which all interested community members were invited to attend. All of the issues that were raised both prior to and during the meetings have been addressed and FCW have also agreed to make all the information appertaining to the project available to interested parties via their website (www.forestry.gov.uk/wales).

There have been previous calls for a public inquiry into the funding of this project by some members of the community but it should be noted that a public inquiry is not applicable to this project. If the project or grant scheme was part of a statutory process for example, in planning and harbours legislation, the relevant statute provides how and when a public inquiry must take place. There is no corresponding statute (which includes provision for a public enquiry) for the awarding of grants through the Cydcoed or forestry grant schemes. As there is no requirement within the terms of a grant scheme to hold a public inquiry, then there is no statutory obligation upon the Welsh Assembly Government/Forestry Commission Wales to hold one.

I conclude therefore, that an independent inquiry would not provide any additional information beyond that which is already available to the Community Council or any other member of the public. The scheme is closed and an inquiry would not add any value to the process of managing Cydcoed or the ongoing delivery of the aspirations of Calon yn Tyfu Cyf in Ffynone and Cilgwyn Woodlands.

Yours sincerely,



Elin Jones AC/AM
Y Gweinidog dros Faterion Gwledig
Minister for Rural Affairs