

## Petitions Committee

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Meeting Venue:

**Committee Room 1 – Senedd**

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Meeting date:

**15 July 2014**

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Meeting time:

**09.00**

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Cynulliad  
Cenedlaethol  
Cymru

National  
Assembly for  
Wales



For further information please contact:

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### Agenda – Supplementary Documents

#### Members' Brief

Please note the documents below are in addition to those published in the main Agenda and Reports pack for this Meeting

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**1 Introduction, apologies and substitutions** (Pages 1 – 20)

**P-04-571 Treating Pernicious Anaemia** (Pages 21 – 22)

**P-04-541 Support for the Mentrau Iaith (Language Initiatives)** (Pages 23 – 29)

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## BRIEFING

The Pernicious Anaemia Society is the only registered charity in the world that offers Information and Support to patients with Pernicious Anaemia and their families and friends. Pernicious Anaemia means the patient is unable to absorb Vitamin B<sub>12</sub> from food which means he or she is unable to produce healthy red blood cells and this leads to a wide range of symptoms including shortage of breath, extreme tiredness, memory loss, confusion and irrational behaviour.

The society has been successful in bringing to the attention of decision makers in the world of health and medicine that there are serious problems with the way in which Pernicious Anaemia is diagnosed. Misdiagnosis is rife:

21% of our members waited over two years for a correct diagnosis.

19% waited over five years.

14% waited over ten years to be told the reason for their symptoms.

Common misdiagnoses include: Chronic Fatigue Syndrome, Depression, Hypochondria, Multiple Sclerosis (left undiagnosed and untreated PA leads to severe and irreversible nerve damage), Psychosis.

Thankfully, following a series of meetings with officials from the Dept. of Health, new Guidelines on treating B<sub>12</sub> Deficiency and Folate were produced in May 2014. The new Guidelines highlight the problems with the current test used to diagnose B<sub>12</sub> Status in patients and whether that deficiency is caused by Pernicious Anaemia.

Now we want to highlight the problems with patients being treated for Pernicious Anaemia. Treatment involves replacement therapy injections of vitamin B<sub>12</sub> which is extremely cheap and extremely safe. This is what we know:

Injections were prescribed every month in the 1960's, this was changed to every two months in 1974 and then to every three months in 1984.

**By far the biggest cause of complaint by members is that they cannot get a treatment regimen based on their needs and often they have to suffer for two months before getting their injection.** When they experience a return of the symptoms patients suffer problems in the workplace and at home.

Patients who need more frequent injections than others are routinely refused these by their GP. Most doctors will believe that the patient is 'imagining' the return of the symptoms and will offer antidepressants. Often it is the patient's family and friend who will have noticed a return of the patient's symptoms long before their next injection is due.

Often the patient's blood will show 'adequate' levels of B<sub>12</sub> in their blood which endorses their opinion. But we now know that there are different types of B<sub>12</sub> (active and inactive) that the current test does not distinguish between.

Patients who need more frequent injections are then forced to explore a variety of solutions:

They can pay for injections in the private sector ('celebrities' do this) or turn to others who provide the injections including hairdressers and fitness instructors.

They buy forms of B<sub>12</sub> injections from the internet (totally advised against by the PA Society)

They buy nasal sprays, skin patches, sub-lingual drops and sprays from various sources including high street health shops (none of these alternative forms have been evaluated)

They travel to mainland Europe where the injections are available 'over the counter' at pharmacies in most countries – they then inject themselves without receiving any training and without using pre-injection wipes or lockable sharps bins

They undergo Intravenous Infusions where a bag full of B<sub>12</sub> is drip fed into a vein (a favourite of Simon Callow et al)

Or

They do nothing and suffer until their next injection is due.

#### WHAT DO WE WANT

We want someone who is professionally qualified to carry out a thorough Review of the way in which patients who have Pernicious Anaemia are treated and hopefully introduce a treatment regimen that is based on the individual needs of the patients.

Note – the PA Society is currently working with three teams of clinical researchers in four different universities to try to understand why some patients need more frequent injections than others.

The Pernicious Anaemia Society has offered a Membership Package for the past four years. We now have just a few short of 10,000 members from all parts of the world. We are based in Bridgend south Wales.

We are run entirely by volunteers.

B<sub>12</sub> Deficiency could be a problem for between 40-50% of the general population.

The symptoms of B<sub>12</sub> Deficiency are insidious and are often associated with advancing age.

The youngest member of the PA Society is 18 months', our oldest member has just celebrated her 100<sup>th</sup> Birthday.

ENDS

Further information from Martyn Hooper, Chairman, the Pernicious Anaemia Society,  
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**P-04-541 Support for the Mentrau Iaith – Correspondence – Petitioner to the Committee, 22.04.2014**

P-04-541 Support for the Mentrau Iaith

Dear Members of the Petitions Committee,

We are pleased to understand that you will be considering the Support for the Mentrau Iaith (*Language Initiatives*) petition at your next meeting on 29 April 2014. We sincerely hope that you will be able to proceed further with the petition following this meeting.

Mentrau Iaith are community-based organisations that operate for the benefit of the Welsh language in their local areas, and they provide a wide range of Welsh medium activities and projects for people of all ages and from all backgrounds within Welsh communities. A report by Cardiff University, commissioned by the Welsh Government, states that this work should continue and develop. The report also notes that the Mentrau Iaith do not receive adequate core funding to allow them to operate to their full potential. You can read the report here:

<http://wales.gov.uk/docs/dcells/publications/130130-adroddiad-y-mentrau-cy.pdf>

Dyfodol i'r Iaith (*A future for the language*) decided to submit the petition to support the Mentrau following the review of their work in order to call on the Assembly to ask the Welsh Government to increase its support for the Mentrau, and to respond in a prompt and positive manner following this survey.

I was therefore very pleased to hear the First Minister stating his support for the Mentrau Iaith in several statements recently, and within the Assembly, stating that he considers them to be “powerful and valuable tools”, and that he would like to “ensure that their work will continue in the future”. We now believe it is time for the First Minister and the Government to act to make a real difference to the future of the Mentrau and the Welsh language by investing in them.

I would be happy to discuss this further with you, and I would be more than willing to attend one of your meetings in the near future to discuss how you as a Committee can help us to support the Mentrau Iaith for the benefit of the Welsh language in Wales.

Best wishes,  
Heini Gruffudd

**P-04-541 Support for the Mentrau Iaith – Correspondence – Petitioner to the Committee, 09.07.2014**

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9 July 2014

**Letter to William Powell AM, Chairman of the Petitions Committee of the National Assembly for Wales**

**Dear Mr Powell**

This document is submitted by Mentrau Iaith Cymru, on behalf of the Mentrau Iaith, in response to the letter from Carwyn Jones AM to the Petitions Committee regarding the petition submitted by Dyfodol yr Iaith in April. We sincerely hope that it will be possible for the Committee to consider our views when considering the First Minister's letter during your meeting on 15 July 2014.

We welcome the first Minister's comments that the initiatives are "a powerful and valuable tool in promoting the Welsh language" and are extremely pleased that he, and the Welsh Government, recognize the importance of the Mentrau's work in their communities throughout Wales. We also note the Government's recent publication, '*Bwrw Ymlaen / Moving Forward*', which sets out the Welsh Government's strategic priorities for the Welsh language up until 2017. *Bwrw Ymlaen* was published following a long period of consultation and review – and we are pleased to see the development of the Welsh Government's work on promoting the Welsh language in our communities. It will also be important, of course, to ensure that the Government's language strategy (*Iaith Fyw: Iaith Byw | A Living Language: A Language for Living*) is achieved in full, as well as the issues mentioned in *Bwrw Ymlaen*.

As the Prime Minister acknowledges in his letter, the Mentrau Iaith are now an integral part of the communities they serve. With their help, an increasing number of communities are operating for the benefit of the Welsh language throughout Wales, by identifying opportunities, needs and local priorities.

The work of the Mentrau reaches all aspects of community life, dealing with a wide cross-section of people of all ages, backgrounds and linguistic ability. Between them, the Mentrau work with over 1,300 volunteers to organize 16,000 activities annually for 160,000 participants. It is important to note that the Mentrau laith are the only organizations which are involved in work and projects that relate to all priority areas in the Government's language strategy (i.e. Children and Young People, Families, the Community, Services, the Workplace and Infrastructure). To achieve this they undertake work and projects in a wide number of areas, ranging from recreation and play, training, festivals, support for learners, the arts, community development and economic development.

Despite the Mentrau's achievements, the review of their work published in January 2014 by Cardiff University notes that their work has the potential to develop and expand in the future. It identified a need to investment further in them, including offering training and developing their management and planning structures. Most importantly, however, it stated that each Menter requires a minimum level of core funding in order to function effectively. The review noted that there are inconsistencies in the achievement and the development of the Mentrau, and the lack of adequate funding and the inconsistencies between the various Mentrau in terms of their core funding is inevitably at the heart of many of the developmental needs identified in the review.

Following publication of the review by Cardiff University, the Mentrau prepared a broad assessment (within the short time available to them) of the core resources required to enable them to operate effectively, in order to serve their communities and further develop the use of the language. Mentrau Iaith Cymru published a response to the review (see annex) which proposed that the Mentrau needed £4.8m a year, over the next three years, in order to fulfill their potential. In addition, at about the same time, Dyfodol yr Iaith presented their petition 'Support for the Mentrau Iaith' to the Petitions Committee. It received over 1,800 individual signatories from across Wales, and calls on the Assembly to ask the Government to ensure that the funding given to the Mentrau fairly reflect the challenges they face, and to increase that funding significantly.

We were encouraged, therefore, to hear the First Minister announcing, in the Senedd on 17 June, further investment by the Welsh Government to develop the work of the Mentrau in 2014–15 and 2015–16, with a total of £ 750,000 to be earmarked for the work over two years. We welcome these additional resources, and agree with the First Minister that there is a need to develop and strengthen the work of the Mentrau through training – and sharing information, expertise and good practice. Discussions have already begun with Welsh Government officials about how to target additional resources to strengthen the Mentrau's structures and to invest in appropriate training. We intend to continue to work closely with them in the future.

We would like to take this opportunity, however, to stress that we welcome this investment as a *first step* only in the process of developing the work of the Mentrau for the benefit of the Welsh language in our communities. It is important to note, however, that more investment, and more resources, will be required to support the work of the Mentrau in order to increase the level of activity on the ground to a level that will have a positive impact on the use of the Welsh language. The Mentrau currently receive £1.77 m from the Welsh Government, and with the additional resources over the next 18 months announced by the First Minister, the funding will



increase to £2.52 m. As we explained in our response to the review of the Mentrau's work, £4.8m of core funding is required annually to enable them to operate effectively in their local areas, and they need sufficient resources to meet the challenges facing the Welsh language. This is £2.28m more than the sum currently provided.

We believe, therefore, that it would be timely to commission an assessment – to be conducted independently of the Government – in order to decide on the core resources needed by the Mentrau so that they can develop to their full potential. This has not been done before and, following the results of the census, it is more apparent than ever that there is a need to ensure adequate resources to support their work.

We want to help the Welsh Government to realize its vision of "seeing the Welsh language thrive", leading to an increase in the number and percentage of people who speak Welsh and use it as part of their everyday lives. In order to achieve this, additional funding is needed to ensure financial security for the organizations that operate for the benefit of the Welsh language. We fully recognize that we are experiencing a challenging economic period, but saving the Welsh language as a community language is something that cannot be set to one side, expecting better days. As we stated in our response to the Cardiff University review, if Welsh ceases to be the language of families, communities and young people, the challenge of restoring it to these circles of life will be very difficult, if not impossible.

We want the people of Wales to receive the same standard of service from the Mentrau Iaith, wherever they live. It is not possible to justify investment in the work of the Mentrau which varies from county to county.

We ask the Petitions Committee to agree with the wording of the petition submitted by the Dyfodol yr Iaith – and to also agree:

- a) the Mentrau Iaith are an important partner in relation to the Government's language strategy; they have a key role in increasing the use of the Welsh language, and that they should continue to be the Government's main partner in relation to promoting and facilitating the use of the language.
- b) the Mentrau Iaith require additional resources which should be adequate and fair so that they can offer the same quality of service in every part of Wales.
- c) a review should be conducted, independently of the Welsh Government, of the resources needed by the Mentrau to realize their potential.
- d) there is a need to increase the resources provided to the Mentrau and to develop an exciting vision for their work.
- e) there is a need for Welsh local authorities to support their work and contribute fairly to the resources they require.

We would be more than willing to discuss the above with the Committee.

Many thanks,

**M L Davies**

Meirion Llewelyn Davies  
Chair of Mentrau Iaith Cymru