

Mr M Hedges
Chair
National Assembly for Wales
Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF99 1NA

Dear Mr Hedges,

Petition P-05-693 – Give every child in Wales the Meningitis B vaccine for free

Thank you for your letter of 2 November seeking the views of Meningitis Now and Meningitis Research Foundation on the petition raised by Rhian Cecil. Meningitis is the disease that parents fear the most. It is a disease that is notably complex and difficult to diagnose. Onset is rapid and if it's not effectively diagnosed and treated, those affected may die or be left with long-term and severe after-effects.

We know from Public Health England (PHE) data, that children aged up to five years represent the biggest meningococcal B (Men B) at-risk group with 57% of disease cases occurring in this age group. Very young children cannot explain their symptoms and, as many stories serve to illustrate, parents frequently lack the confidence to ask for a second medical opinion.

The impact on families and, indeed, the community is far-reaching. Today, 500,000 people in the UK have been affected by meningitis. We know that 1 in 10 children who get Men B will die and 1 in 3 of those who survive will suffer from long-term effects such as limb loss, scarring, brain acquired injury and emotional/mental health issues.

The petition before the Welsh Assembly offers legislators a unique opportunity to independently respond to the wishes of its people and to protect children in Wales who make up this at-risk group. We know there are barriers to extending the vaccine programme, including unfair frameworks for assessing how cost effective the vaccine is measured and issues around current vaccine supply. We are working to reduce these barriers and your support on these issues will save lives.

As you are aware, a similar petition in March this year drew down over 823,000 signatures; including many thousands from Wales. At that time both Meningitis Research Foundation and Meningitis Now worked together in providing evidence to a joint Petitions and Health Committee. During one of these sessions we presented a 10 point action plan detailing our main concerns. This document included a recommended course of action that could, if adopted, provide a route to completing the science required to undertake a Men B carriage study amongst adolescents, give clarity to the issues around vaccine cost effectiveness and a way to extend the Men B vaccine to children up to the age of five. A copy of this document is attached for your reference.

With regards to the substantive issue raised by the petition and the subsequent debate in England, this being the call to extend the use of Men B vaccine, this was rejected by the Health Minister, citing cost effectiveness as the reason for this decision.

During the debate, the Minister confirmed that she had asked the Joint Committee on Vaccinations and Immunisation (JCVI) to undertake a cost effectiveness assessment for children up to two years of age. In August this year, the JCVI announced that it had found this assessment to be cost effective, but wouldn't recommend vaccination of two year olds due to vaccine procurement issues. We also know that the JCVI has conducted a further study to assess vaccine cost effectiveness against children aged three to five. Using the current assessment framework this study did not find in favour of vaccination.

We think it would be fair to say that both the initial rejection by the Health Minister and the JCVI's subsequent rejections were not well received by those who signed the petition!

To ensure that you are fully aware of the issues that the combined charities are pursuing with PHE, we have also attached a copy of a submission made to the newly inaugurated APPG for Meningitis. This document outlines and updates a number of key meningitis issues included in the 10 point action plan and they are therefore relevant to your discussions around Men B.

In order to more fully understand the impact of meningitis we would urge you to talk with families in Wales who have suffered the consequences of the disease and consider the peace of mind benefits that undertaking such a vaccine programme could deliver. Should you seek assistance with this, please do not hesitate to contact us.

We are grateful for the opportunity to comment on the petition raised by Rhian Cecil.

Yours sincerely,

Mark Hunt – Director of Communications Meningitis Now

Rob Dawson – Head of Communications, Advocacy and Support

Att:

Meningitis Now and Meningitis Research Foundation joint submissions:

1. 10 Point Action Plan to the joint Health and Petitions Committee
2. Briefing paper to the All Party Parliamentary Group on Meningitis