



ALL PARTY PARLIAMENTARY GROUP ON MENINGITIS

Notes for the inaugural meeting - 25th October 2015

Tuesday 25th October, 12.00 – 13.30

Room R, Portcullis House

Liz Brown:

Group Purpose:

To provide a forum for MPs and Peers to work on behalf of people affected by meningitis, raising issues of concern with Government and other policy makers and keeping meningitis high on the political agenda.

Objectives and Aims of Briefing

In March 2016, we presented a 10 point action plan to the joint Health and Petitions committee as part of an evidence session following the e-petition to extend use of the Men B vaccine. The plan contained a series of measures to help and enable policy makers to meet the three core concerns the charities had:

1. The unfairness of the cost effectiveness framework
2. Completing the Men B adolescent carriage study
3. Protecting the most vulnerable with an effective vaccine

Based on information available at that time, the plan detailed a series of actions and time frames that would, if adopted, help achieve the 10 point action plan. During the subsequent debate more details and information on timeframes emerged; the core argument and call for action, however, remained unchanged.

Today, we would like to revisit and update you on these key issues and in doing so seek the support of APPG members in asking the Health Committee to hold ministers to account for the commitments they have made. We will also update you on the uptake of the Men ACWY vaccine amongst teenagers.

Claire Wright:

1. **Men B Cost effectiveness** - The consultation and publication of the Cost-Effectiveness Methodology for Immunisation Programmes and Procurements (**CEMIPP**) Working Group report. We know that:

- a. The final report was given to the Department of Health on 20th July 2016.
- b. The Secretary of State for Health, Jeremy Hunt MP and the Under Secretary of State for Health, Lord Prior, have both said that public consultation would be considered.
- c. Previous Health Minister Jane Ellison MP confirmed that she would publish the report and provide the Petitions and Health Committees with a written briefing summarising the report and the Government's proposed next steps in the summer.
- d. In our action plan we asked for ministerial level commitment to funding research into how peace of mind health benefits can be included in the cost effectiveness framework.

Despite these assurances, a decision as to whether this much-awaited report will be put out for consultation or a publication date has not been forthcoming. We would ask APPG members to raise this with Health Select Committee and for them to DH/PHE:

- **Why consultation was not sought?**
- **What is causing the delay in publishing the report?**
- **When will the report be published?**

We would remind APPG members, many of whom spoke passionately during the parliamentary debate in support of extending the Men B vaccine, that the hope and aspirations of the 823,000 people who signed the parliamentary e-petition are, in-part, pinned on outcomes of this report and for the Department of Health to continue to delay a decision on consultation and publication is simply unacceptable.

- 2. Men B teenage carriage study** - Seek assurances and commitment from the government to deliver on its plans to undertake this important and urgent study to determine whether vaccinating teenagers against Men B could prevent them from carrying and transmitting the infection to others. In order for this larger study to go ahead as promised, we are asking members to seek confirmation that effective planning is or is about to take place and that:

- a. **The required budgetary commitment has been secured? – We understand that Department of Health R&D budget cannot pay for vaccines.**
- b. **That a timetable to aid planning has been agreed and can we see this?**
- c. **Enough Men B vaccine is being procured to enable the study to commence as announced by Jane Ellison in December 2017. We know that GSK require approximately 12 months to produce and supply the significant volumes that will be required. If this is not the case then why not?**
- d. **That the reported delays in completing preliminary investigations that would inform the larger study, will not impact on the commencement of the full study.**

Liz Brown:

- 3. Men B awareness programme** – As part of her response to the Parliamentary debate Jane Ellison said: *'I have asked PHE to develop a national awareness campaign that will focus on the dangerous infections parents most worry about – meningitis, septicaemia and sepsis - and the symptoms they need to look out for.'*

In response, the three charities have been working collaboratively in partnership with PHE to achieve a meaningful response to this campaign challenge. Research carried out by PHE in April

2016 targeting parents with young children indicate high levels of disease awareness amongst this group, so awareness, as a standalone response was considered not to be the only need. With the additional pressure of trying to deliver a stand-alone campaign for this winter season, the charities and PHE have agreed to:

- a. Undertake a research study to establish how to move parents from awareness to action be it knowing signs and symptom, taking urgent action and/or challenging clinical response if the parent remains concerned. This research reflects PHE best practice in planned journey change methodology. This research is underway and will report after Christmas.
- b. During discussions with PHE it was agreed that the timeframe for the delivery of the awareness programme would be a challenge and it was agreed in principle that PHE consider direct investment into the charities behind a joint safety netting proposal and independent awareness campaigns that leverage their proven ability to successfully run such programmes. Both meningitis charities have independently made campaign submissions to PHE for review, as have the Sepsis Trust.

4. **Extending the Men B vaccine** – As part of the debate process, it was stated that the JCVI had been asked by the Minister to carry out a cost-effective review of giving Men B to children aged 2. In July the JCVI announced its findings saying *‘that while the lifesaving Men B vaccine could prove cost effective for children aged between 13 and 24 months, there is insufficient supply of the vaccine to offer it to children in this age group without jeopardising stocks of the vaccine set aside for the existing NHS immunisation programme. For this reason they (JCVI) were unable to recommend extending implementation of the vaccine to all children under age 2’*.

This news was poorly received by the people who had signed the petition to extend the vaccine and highlights the critical need for high level discussions and planning between the DH and industry when forecasting vaccine supply, manufacturing capacity and issues that affect these.

Given the issues over supply and effective planning, we would ask APPG members to:

- **Call on DH to instruct JCVI to carry out an immediate cost effectiveness study for children aged between 36 and 48 months and 48 to 60 months – these being the remaining cohorts who are considered to be most at risk?**
- **Should DH find reason not to instruct such a study, we would ask that DH is held to account and asked to provide a formal statement detailing the reasons for such a decision, so that we can help provide answers to those who signed the petition.**

5. **Men ACWY** – Vaccine level uptake amongst young adults aged 17 and 18 year olds in England remains stubbornly low with only 17% of this year’s cohort in England having taken up the vaccine offer.

The data^{*1} published by PHE on 19 September also shows large regional variations from at best 28% in parts of the West Country to at worst 9.9% in parts of London.

The position in Scotland is the polar opposite with the Scottish Government not offering the vaccine to students studying in Scotland. Scotland completed the catch-up programme for the ACWY vaccine during 2015/16. This was completed using both schools and GPs to deliver the vaccine and has achieved an uptake rate of between 70-80%.

^{*1} *Health Protection Report* Vol. 10 No. 32 – 23 September 2016