Written evidence from Lee Booth (MBV0009)

Thank you for taking the time to consider the above petition.

We are aware that the petitions committee would like to hear from families affected by the disease before scheduling a date for the debate. We have put together a document (Appendix 1) containing heartbreaking stories from families affected that are happy to be contacted. This information, we feel will be invaluable to your research.

We are fully aware that the initial response has been that we, as a country, simply cannot afford to vaccinate everyone and we are the first country to currently offer the vaccine to the most affected age group (0-1), which is a great achievement. The childhood immunisation programme is a huge cost to the NHS and we firmly agree that these funds have to be carefully considered and the overall impact of vaccine vs disease has to be fully evaluated. The next highest affected age group is 1-4 (Public Health England) and there are still too many children dying and being left with life altering effects from Meningitis B. The only way to prevent this is to make the vaccine available for older children.

The British National Formulary for Children, 2015-2016 state that Bexsero, the vaccine to protect against meningitis B, costs £75 per dose. The National Institute for Health and Care Excellence (NICE) has stated that for this vaccine to be effective and to be widely used on the NHS, it would have to be available to buy for £9 per vaccine. We can all agree that this a huge difference.

I have taken 2 case studies from the Meningitis Research Foundation (Appendix 2) to highlight the cost of a severe case of Meningitis B.

Case Study 1 - Emma - Age 3 - Cost to NHS £3,161,944
Case Study 2 - Peter - Age 1 - Cost to NHS £2,738,550

Just on 2 poorly children the NHS has spent an unimaginable £5,900,494. This would be enough to vaccine 78,673 children. These are both children that, depending on birth date, would have missed out on the vaccine.

It is not public knowledge as to how much the government buy this vaccine from the suppliers for, however, it is highly likely that it will be cheaper than the price stated above. For arguments sake, I have used the price of £75 (as previously mentioned) for these calculations.

The Meningitis Research Foundation state on its website that it is estimated that there are around 1,761 cases of Meningitis B in the UK each year, with an estimated figure of 450 children being severely disabled and 30 child deaths. Obviously not all cases will be as severe as the 2 case studies mentioned in appendix 1 but, how much more money could be saved and spent on vaccines if this was available to all children? A vaccine preventing these cases would in turn, reduce the cost and drain on the NHS resources and other government funds over time. For further informative information on the background of Meningitis B and the campaign, please see appendix 3 which includes information from fantastic sources.

Also, whilst it is really helpful to raise awareness for the symptoms of Meningitis B, it is also really difficult to catch this deadly illness in its early stages. As you can see from Appendix 1, the majority of families sought attention from a medical professional as soon as their child began to show signs of being unwell. Time and time again, it was initially misdiagnosed as something much less severe. It
wasn't until the illness was fairly advanced that Meningitis B was even considered to be the cause of the symptoms. In many cases, this was too late.

Although it must be really hard for any parent to be turned away, it's understandable that doctors find it hard to make a diagnosis in the early stages. The symptoms are exactly the same as a cough, cold or harmless virus. For the child to have a chance to beat the Meningitis B illness, time is absolutely of the essence. By the time the symptoms become serious enough, it's often too late and the child dies or is left with life changing effects.

If it was easier to spot this illness in the early stages, or if there was an effective cure, then you could absolutely argue that there was less reason for a vaccine. With this not being the case it seems that the only way to guarantee the safety of the child is to vaccinate and in turn this would save more money for the NHS.

We are aware that the JCVI have stated that the vaccine is currently not cost effective for older children and more research and evidence is needed in order for the vaccine to be routinely offered. How many more children can we allow to die and have life altering disabilities whilst this research is carried out?

The question that we really need to ask ourselves is at what price does a child's life become cost effective?

We look forward to joining the hearing on the 15th of March.

The following pages contain experiences of Meningitis B from families who have been affected. All these stories are in the parents own words and no attempt has been made to alter them. Each person was requested to provide their full authorisation to their story being used as formal evidence and has given their full agreement to this.

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