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Parliamentary Under Secretary of State for Mental Health and Women's Health Strategy  
Department of Health & Social Care  
cc: HPNR Consultation Email; [hpnrconsultation@dhsc.gov.uk](mailto:hpnrconsultation@dhsc.gov.uk)

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Dear Minister,

**Adding neonatal group B Strep disease to the list of notifiable diseases**

Group B Strep is the most common cause of life-threatening infection in newborn babies (including sepsis, pneumonia and meningitis) so we are writing as a group of charities who support affected families, asking that invasive group B Streptococcal infection be added to Schedule 1 of the Health Protection Regulations.

There is a strong case for this addition. The list of notifiable diseases is under review for the first time since 2010 as part of proposed amendments to The Health Protection (Notification) Regulations 2010 (HPNR). This gives the UK the opportunity to integrate GBS into the list and be a trailblazer in implementing systematic data gathering, which can protect the very youngest and most vulnerable in our society.

GBS causes serious infection in infants, and is a major cause of neonatal mortality and morbidity. As things stand, the lack of formal reporting limits prevention, early detection, and measurement of the effects of any interventions. We know from research that group B Strep infections in babies can lead to clusters in hospitals. This suggests a possible spread within the hospital, and it's important this is investigated promptly.<sup>123</sup>

Accurate reporting would be highly valuable both to the doctors treating these babies, as well as those who carry out research into GBS.

Adding GBS to the list of notifiable diseases would:

- **Improve accuracy on the burden of GBS disease.** Currently, data is voluntarily reported and likely significantly underestimates the rates of infection. This is evident in the differences between the numbers of infections reported to PHE/UKHSA compared to enhanced surveillance studies undertaken by the British Paediatric Surveillance Unit.
- **Establish baseline data to inform and evaluate a future vaccination programme.** No GBS vaccine is currently available, though multiple GBS vaccines are in development. Were a maternal GBS vaccination programme to be introduced, notification data could provide an early evaluation of the effectiveness of the programme.

Despite most cases being preventable, one baby a week dies from GBS infection in the UK, and one of the survivors has long-term disability as a result of their GBS infection. Adding

GBS to the list of notifiable diseases would be a vital step to preventing these unnecessary tragedies, for babies and their families.

We would welcome the opportunity to meet with you and discuss this in further detail at the Department.

Thank you for your consideration, and we look forward to hearing from you.

Yours sincerely,

Jane Plumb MBE, CEO, Group B Strep Support



Caroline Lee-Davey, CEO, Bliss



Vinny Smith, CEO, Meningitis Research Foundation and Confederation of Meningitis Organisations



Dr Ron Daniels BEM, CEO, UK Sepsis Trust



Tom Nutt, CEO, Meningitis Now



Jenny Ward, CEO, The Lullaby Trust



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<sup>1</sup> Jauneikaite E, Kapatai G, Davies F, et al. Serial Clustering of Late-Onset Group B Streptococcal Infections in the Neonatal Unit: A Genomic Re-evaluation of Causality. *Clin Infect Dis*. 2018;67(6):854-860. doi:10.1093/cid/ciy174

<sup>2</sup> Collin SM, Lamb P, Jauneikaite E, et al. Hospital clusters of invasive Group B Streptococcal disease: A systematic review. *J Infect*. 2019;79(6):521-527. doi:10.1016/j.jinf.2019.11.008

<sup>3</sup> Collin SM, Groves N, O'Sullivan C, et al. Uncovering Infant Group B Streptococcal (GBS) Disease Clusters in the United Kingdom and Ireland Through Genomic Analysis: A Population-based Epidemiological Study. *Clin Infect Dis*. 2021;72(9):e296-e302. doi:10.1093/cid/ciaa1087