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Wendy Chamberlain MP  
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Dear Wendy,

I am writing in response to the concerns you have raised about children affected by PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections). This issue was recently brought to my attention during a meeting with Alex Cole-Hamilton MSP on Wednesday, 6 November 2024, and I understand it has also been a topic you highlighted in the House of Commons in relation to a young constituent.

In light of these discussions, I wanted to provide an update on how the Scottish Government is supporting families affected by these conditions.

I recognise that parents who notice the sudden onset of symptoms such as those associated with PANS and PANDAS want to seek a diagnosis and effective care for their child as quickly as possible. My sympathies are very much with children who are living with these conditions and the upset this causes to all aspects of their lives.

I would like to assure you and your constituents that the Scottish Government is committed to improving the lives of people in Scotland living with rare conditions such as PANS and PANDAS. I know that a great deal of the battle can be to have unfamiliar symptoms taken seriously, and the highest of our priorities in work for rare conditions is to raise awareness of them among healthcare professionals; to encourage 'thinking rare'. As set out in this year's Progress Report on Scotland's Action Plan for Rare Diseases, the first step towards this goal has been to develop animated video resources in formats aimed both at healthcare professionals and people and families living with a rare condition. Development of these resources will continue, in collaboration with NHS Education for Scotland, into the new year. This includes embedding rare condition awareness in medical training curricula and continuous professional development, ensuring clinicians can better identify and support these conditions.

We are also aware of the significant challenges that parents and children face due to the lack of a universally accepted diagnostic criterion for PANS and PANDAS, as well as the

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ongoing medical debate surrounding these conditions. It is essential that decisions regarding clinical guidelines and treatment protocols are informed by the latest evidence, which is why organisations such as SIGN (Scottish Intercollegiate Guidelines Network) and NICE (National Institute for Health and Care Excellence), rather than the Scottish Government, are responsible for the development and updating of guidelines.

In the meantime, NHS Boards across Scotland are responsible for planning and delivering services to meet the needs of their local populations. Multidisciplinary services for PANS and PANDAS are currently available in Glasgow and Edinburgh, and we will continue to monitor the recommendations from the PANS/PANDAS Working Group to explore how best practice can be expanded across other health boards.

We recognise the opportunity early intervention offers in reducing the strain on child and adolescent mental health services (CAMHS). By improving awareness and understanding of conditions such as PANS and PANDAS among clinicians, we can better connect early neuropsychiatric symptoms to possible underlying infections, leading to more timely and effective care. This aligns with our broader priorities for improving mental health services for children and young people in Scotland.

Additionally, we continue to monitor developments across the UK, particularly regarding service models and guidance updates. This ensures that our approach remains informed by the latest advancements and practices, providing equitable care for families in Scotland. The Scottish Government remains committed to improving access to specialist care for all individuals with rare conditions. Through Scotland's Action Plan for Rare Diseases, we aim to enhance early diagnosis and provide targeted support, ensuring that no child or family faces these challenges alone.

Thank you again for raising this important issue. I hope the information provided is helpful.

Yours Sincerely,



**NEIL GRAY**

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