

# Dear Member of Parliament,

I am writing to you as one of your constituents to highlight the insufficient treatment options available for patients suffering from what many believe to be debilitating symptomatic pineal cysts.

This situation seems to stem from ongoing debates within the medical community regarding the symptomatic nature of pineal cysts. While the prevailing view is that these cysts are typically asymptomatic, a growing body of research suggests otherwise, indicating that pineal cysts may indeed cause a wide range of distressing and debilitating symptoms.

In my search for answers, I found myself exploring online resources and eventually came across a Facebook group named ‘Pineal Cyst U.K.’ This discovery reassured me that I am not alone in my struggles, as hundreds of individuals throughout the U.K. share similar experiences. This realization brought me a sense of unexpected relief and comfort.

However, my initial sense of relief was short-lived as I delved deeper into the discussions within the group.

Many individuals affected by pineal cysts report experiencing strikingly similar debilitating symptoms, which have significantly impacted their ability to lead normal lives. In some cases, these symptoms have forced individuals to leave their careers, making it challenging to maintain employment. This situation can inadvertently lead to financial difficulties for families who are affected.

Given the absence of other identifiable causes for these symptoms, some argue that it is unwise to dismiss the potential impact of pineal cysts. A more thorough investigation into treatment options and the management of symptoms associated with pineal cysts is warranted in order to support those who are suffering.

Due to the current limited treatment options for pineal cysts in the UK, many patients are compelled to seek care abroad, often incurring significant expenses. Access to treatment within the UK would provide greater convenience for patients and potentially reduce financial burdens associated with overseas medical care. Exploring options to enhance the availability of treatment for pineal cysts domestically would be beneficial for those affected.

**We at The Sara’s Hope Trust, propose the following:**

1. That the Department for Health, in collaboration with Public Health England and other relevant organizations, conduct an urgent and comprehensive review of all existing research regarding the potential relationship between



pineal cysts and debilitating symptoms. Additionally, we recommend an examination of the extent to which surgical intervention may alleviate the symptoms experienced by individuals with pineal cysts.

We believe that such a review could provide valuable insights and inform future treatment options, ultimately benefiting those affected by this condition.

We propose the establishment of an independent panel composed of leading experts in the field to conduct this urgent review of the scientific literature related to pineal cysts and their management. This review would aim to consolidate existing knowledge, assess treatment options, and provide recommendations based on the latest evidence. By undertaking this comprehensive evaluation, the panel could contribute to a better understanding of pineal cysts and inform future clinical practices.

1. We propose the establishment of an All-Party Parliamentary Group (APPG), for Arachnoid cysts, which includes pineal cysts as a subcategory, that would serve as a liaison between medical professionals and patients. This group could facilitate communication and ensure that patients are kept informed of the latest developments regarding pineal cysts and related treatment options. By fostering dialogue between stakeholders, this initiative could help to bridge the gap between clinical research and patient experiences.

I appreciate your consideration of the challenges faced by individuals in the UK with pineal cysts. Your support for this issue would be valuable in raising awareness and potentially improving access to treatment options for those affected.

# Kind regards,