

# **PE2080/C: Implement the recommended screening guidelines for people with Li Fraumeni Syndrome**

## **Scottish Hereditary Cancer Genetics Group written submission, 13 June 2024**

As the petitioner has rightly pointed out, UK consensus guidelines for cancer surveillance for individuals with Li Fraumeni syndrome were published by the UK Cancer Genetics Group in 2020. The guidance recommends annual whole-body MRI from birth which takes 90-120 minutes to complete the scan in adults. In addition, there is considerable radiologist time required in reporting each scan (takes approximately three times the length of time compared to conventional MRI and require to be double read effectively multiplying the radiologists' time for these scans by a factor of 6). Local health boards have therefore found this very difficult to implement without any additional resource.

NHS Grampian, NHS Tayside, NHS Lothian, and NHS Fife are all offering surveillance in patients with Li Fraumeni syndrome in line with these guidelines (despite the considerable strain on services) but given the larger numbers of affected patients in the West of Scotland, they have not yet been able to implement these guidelines. The Scottish Hereditary Cancer Genetics Group has raised this issue on several occasions, initially with a submission to Health Improvement Scotland (informed not within their remit) and subsequently with the Scottish Cancer and Genomic Policy Teams. This is just one of several issues that were recently presented to the above policy teams concerning management of patients at high risk of cancer which requires a national consensus and approach to service delivery with adequate funding. There is a clear gap in Scotland regarding a national process for managing these patients and this is becoming increasingly problematic with the advancements in precision cancer treatments and management guidelines around surveillance in people at increased risk. Although the need and potential benefits in this area were highlighted and recognised, there has been no move to address these issues which continues to rely on local efforts of individual clinicians and good luck!