PE1823/D
Petitioner submission of 5 October 2020

I would like to respond to the submission from Genetic Alliance UK about petition PE 01823. Firstly, thank you to Genetic Alliance UK for their support of the aim of this petition to improve the early detection of rare conditions and to improve opportunities for treatment. As I mentioned in my previous submission, I fully agree that scanning of newborns carries “an element of risk“, as stated by the Scottish Government. However, this can sometimes be the only way of detecting certain rare and hidden conditions such as AVM. Also, as I wrote earlier, the earlier such conditions are diagnosed and treated, the higher the potential for a successful outcome. This is also highlighted in the response from Genetic Alliance UK. That’s why such scans should be made optional if the parents want to accept them. Medical science is advancing all the time and it may be possible that in the future, a better screening method for AVM might be developed. But in the meantime, if this is the best way to detect such a condition, then surely it should be available if requested? All procedures carry an element of risk, but we still carry out other invasive methods of screening. We can operate on babies who are days old, so why can’t we offer a body scan that could potentially save a life? Just because conditions such as AVM are rare and often difficult to treat doesn’t mean that we shouldn’t try to detect and treat them. I have met people who have been treated for brain and other AVMs. Although some cases have sadly been fatal, others are living relatively normal lives. Was my son’s life worth nothing?

I fully agree with the views of Genetic Alliance UK that the newborn screening programme in Scotland should be reviewed and expanded. This would in turn improve our understanding of rare conditions and help to develop future tests and treatments. Hopefully by doing this, we will be able to find a better and less risky method for the detection of AVM, and also develop methods of potentially successfully treating this fatal condition.

In summary, I thank Genetic Alliance UK for supporting the aim of this petition and fully agree with their view that the newborn screening programme in Scotland should be reviewed and expanded. However, at present, the only way of detecting certain rare and hidden conditions such as AVM is through a brain or body scan. While I appreciate the risks, surely if the parent wishes, then such scans should be carried out to give parents peace of mind and to potentially successfully treat such a condition should it be detected? As I mentioned in my previous submission, medical science is advancing all the time and that one scan could potentially improve or save a child’s life. Surely then the risk would be worth it? Without wishing to keep going on about this, had my son been given such a scan, then he might still be with us now. Our children are our future and we have to give them the right to live.