

PE1823/B

Petitioner submission of 25 September 2020

I would like to provide this reply in response to the Scottish Government's written submission of dated 4th September.

I understand that newborns in Scotland are offered certain screening tests and that tests for other conditions are also being introduced. I also appreciate that not all conditions can be detected, and furthermore, I fully understand that all scans and tests carry an element of risk that needs to be counterbalanced against the positives. But we still carry out such tests that detect other conditions, so why not scan babies for AVM? Although AVM is a rare condition, it can be a fatal one as we sadly found out when we lost our son very suddenly. We had no idea that he had this condition. It is a rare and often "hidden" condition. He had no signs or symptoms and was a healthy, active boy. That just made his loss all the more devastating.

If body scans are offered as an option to parents, they can hopefully help to save lives by detecting rare and hidden conditions such as AVM. Again, I appreciate it could be costly and I am well aware of the dangers of scanning neonates. But if these measures can help to save lives then surely they should be offered to parents? Life is precious and we need to do everything we can to save our children's lives. Is cost more important than a child's life? Did my son's life mean nothing? That one loss may be a statistic for some, but for another, it is their child, their sibling or another relative whom it is very difficult to live without.

Research indicates that if a condition such as AVM can be detected and treated within the first six weeks of a child's life, then the chances of a successful outcome are higher than if such a condition is detected and treatment is attempted later on in life. Conditions such as AVM are often fatal within the first few years of life if they are not detected and treated early. Body scans for neonates should be offered to all parents if they want to accept them. I understand many parents will not agree with this, but that one scan - had it been offered to me seventeen years ago - could potentially have saved my child's life. I will forever have to live with the fear that my other children could potentially have this life threatening condition too, but because they have not been offered any kind of body scan, I will never know if they have this condition or not. Should parents in my position have to just sit and wait for their children to die when a body scan at birth could potentially detect hidden and rare conditions such as AVM that could then hopefully be treated and children's lives saved? All children have a right to live and if carrying out body scans at birth can help some children to potentially have longer, healthier and improved quality lives, then that is what we should be doing.

There are a number of parents of children who have rare and hidden conditions who will agree with my comments. Had their children been given a body scan at birth, then their lives could be somewhat different now, in a more positive way. These days, babies can be given life saving surgery when they are just a few hours old. So why are we reluctant to give neonates potentially life saving body scans? Yes, both types of procedure carry an element of risk, but why do we favour one over the

other? Both are equally important. Body scans can also help to save lives and should routinely be offered to parents of neonates. Then leave the choice up to the parents.

In summary, I believe that full body scans should be routinely offered to all neonates in the hope of detecting and potentially treating rare and hidden conditions such as AVM. I appreciate these scans can be risky for neonates, but all medical procedures carry some element of risk. If we can test for other conditions at birth, then why not offer to carry out body scans too? Children can have lifesaving surgery a few hours after birth, so why not a lifesaving scan? Offer the scan to parents and let them decide whether they want their child to have it or not. Cost should not be given importance over a child's life. That one body scan could potentially have saved my child. Please don't let other children die when that one scan could save them.