

PE1517/LLLL

Petitioners' submission of 30 August 2020

Since lodging our petition, there has been huge cross-party support for all we have campaigned for, but not enough change from the government.

Scotland led the world when, in June 2014, former Scottish Health Secretary Alex Neil brought in the first suspension on the use of mesh implants, however, the lack of action by subsequent Health Secretaries has left Scotland trailing behind. Worse of all, due to almost 18 months of prevarication by government, and despite the personal guarantee by the First Minister and Health Secretary that they would "listen" and "do everything in their power to help us", we have lost the golden opportunity to have our mesh injured women treated by the world's most renowned and respected mesh removal expert Dr Dionysious Veronikis, who had kindly offered to come here to treat women and train surgeons in his unique technique.

Losing out on this opportunity was not only shameful, it left Scotland's mesh injured women devastated, terrified, and unwilling to use the service of the very surgeons who had not only implanted them with the mesh which destroyed their lives, but had also campaigned to continue using the implants long after evidence showed devastating lifelong injuries were being inflicted on upwards of 30 per cent of patients, and while mesh manufacturers were paying out money to victims.

During many meetings, letters and pleas to Government Ministers mesh injured women made clear that they did not want to be treated by the surgeons who had implanted them, and that they had lost "all trust" in the service being offered to them. Instead of availing themselves of the services of the world's most respected mesh removal surgeon, the Scottish Health Secretary announced the establishment of a national mesh removal service, to be staffed by those very same surgeons injured women do not wish to see.

The service evaluation document published in parliament last year confirmed that all women who underwent partial mesh removal surgery continue to suffer the same chronic pain and injuries which devastated their lives.

The very reason Scottish mesh injured women were so desperate to be treated by Dr Veronikis was because he has a proven track record of mesh removal without causing further devastating damage.

None of the surgeons on the national mesh removal service has a proven track record of successful, full mesh removals, and indeed on many occasions they discharged desperate women from their care telling them "nothing more could be done for them". In their own report in a medical journal, these surgeons admitted that they could not fully and safely remove mesh. These same surgeons are now, however, telling women they *can* remove mesh implants, apparently without any evidence of new training.

These surgeons have repeatedly refused to use ultrasound to trace implants inside mesh injured patients, publicly declaring that they do not believe it to be of use, despite scientific evidence to the contrary. They have refused to allow mesh injured patients to attend multi-disciplinary meetings to discuss their own cases and treatment, and

have even refused to adopt the patient information leaflet and patient decision aid which won plaudits by the recent Cumberlege Review, which was so critical of the way mesh injured women have been treated, ignored and disparaged by the medical teams who were supposed to help them and keep them safe.

We understand that the annual budget for the service amounts to around £1.3million for 35 patients, which is just over £37,000 per woman. Although the Scottish Government has advised women they can get surgical help elsewhere if the service cannot be offered in Scotland, we are the evidence that it cannot.

We would therefore ask that the budget set aside for mesh removal should be made available to attend the surgeon of her choice, including Dr Veronikis. Patient choice is supposed to be at the heart of the NHS. After everything mesh victims have suffered, we believe, at the very least, they should have the ability to attend a surgeon with a proven track record of safe full removal.

A small number of women, told that the NHS in Scotland could do nothing more for them, requested their health board consider out of country treatment for them. Receiving only an acknowledgement in a year, and in excruciating pain because of their implant, they felt their only choice was to use their life savings to travel to the US to attend Dr Veronikis.

These women have already suffered the loss of the lives they once enjoyed, their jobs, mobility, and marital lives. They have been left on benefits and dependent on others because they trusted their implanting NHS surgeons when told they were receiving 'gold standard treatment'. We do not believe they should have to suffer the loss of their life savings too. As this number of women is very small, we would ask that the Committee support our call to have their surgery costs refunded.

Throughout this debacle, nobody has taken responsibility. The NHS and surgeons denied for years that there was anything wrong with implants, telling affected women they were "unique", even advising them that they needed psychiatric help rather than admit there was a physically devastating issue with mesh implants. It is time to now right those wrongs, for the Scottish government to take responsibility, and that can begin with at least replacing the life savings which were used by women seeking safe treatment which was unavailable here.

In the meantime, until we have a mesh removal service women trust, one staffed by surgeons with a proven track record of safe full removal and adequate training, we call for the immediate cessation of services for all but emergency treatment.

The development of mesh removal services in Scotland should have injured women at their very heart. But they have not even been consulted on what they wish, never mind been asked to get involved. Until safety and patients are put at the very heart of Scotland's mesh removal service we believe it cannot be operational and we urge your backing to ensure the mistakes of the past are not repeated, that mesh injured women get access to the safe and full removal services of surgeons of their choice, and they are able to access the continence and other services they need that are 'fit for purpose' for their complex clinical needs to allow them to regain as much of the lives and dignity they once had.