## Petitioner submission of 16 June 2022

## PE1865/HHHH: Suspend all surgical mesh and fixation devices

This is my submission based on the meeting held on Wednesday the 8th of June. Myself and Lauren weren't notified or given a chance to prepare anything ahead of this meeting. This was extremely disappointing for us.

Having watched the meeting back we want to thank the petition committee as they clearly have a good grasp of the mesh issues we all face and in the absence of instruction from us they nailed the points that are very important.

There are a few points we would like to make regarding the meeting.

The mention of Alison Britton doing case reviews we would like to try and meet with Alison as we do feel a lot of the reporting she will be doing will benefit us also.

We agree whole heartedly with the BRAN style of care that the government speak of. This is what should always have been in place and, in our view, it still currently isn't filtered right through yet. I know I'm a patient still going through the systems. I don't see it yet. We need to be given the best trained surgeons. We agree that no surgery is risk free but we should have the choice no matter what the surgeons opinion is. No 2 surgeons will have the same views just like politicians. We need that choice.

I also worked with <u>NHS Education for Scotland</u> to make the changes in the NHS regarding when things go wrong in the NHS. I attach a <u>link to</u> <u>the study</u> carried out by Jean McQueen and would draw the Committee's attention to the recommendations in Table 3 of this report. There is talk there are not enough hernia surgeries in a year to create a centre for routine or complicated situations. The Scottish Government have based the current mesh centres on 600-800 woman with TVT/TVT mesh. Based on the figures just given to Paul Sweeney MSP by The Health Secretary (<u>S6W-08789</u>), from 2012 to 2021 the number of hernia mesh surgeries alone were 72,683. That's 7268 a year in Scotland. If the figures are correct, and 1 in every 10 people are affected by chronic pain as a result of their mesh surgery, that's 726 people a year. More than the numbers the Scottish Government set up the specialist mesh centre for gynaecological mesh. Why are the numbers of us affected not enough? The Scottish Government suggest we are a small minority. Not that small when it's severely affecting our lives. Also I am a hernia mesh patient who may lose my bowel due to mesh so I believe there is a cross over here for the mesh centre if it's going to include rectopexy meshies. This would give us a better chance to all specialists who deal with mesh complications if we could have the mesh centre utilised for all mesh. We have the foundation why not use it? There are no current pathways for any other meshies at the minute. I know I've battled for 8 years to find help.

Again there is not enough data collected even Dr Terry O'Kelly stated that Scottish Government/NHS Scotland don't know the full risks of these surgeries as they don't have 10 years of data. Short term they are happy to use it but long term when damage is done it's too hard to remove the device. This isn't acceptable.

The MHRA I have tried to work with, and sadly they aren't listening to us. They are failing us. They don't personally test devices they have a trust relationship with manufacturers trusting the devices that are being put through are as safe as they say they are. Very much like the FDA do. Through the 510K process if you can prove your device is like a device already on the market it is automatically passed, but wait aren't the devices before already failed and been removed from the market??? There is the issue. So I am all for Scotland regulating these devices and testing them. Then we know whole heartedly these would be safe to use and not based on trust from manufacturers. What about the trust between surgeon and patient? When a patient is saying they are suffering. We're dismissed as the surgeons believe in the process that is failing us. Too many failures.

Complications from mesh implants are not rare. It's the same material no matter where it is placed in the body. Its causing chronic, debilitating pain and autoimmune conditions. All the same. Use the data in front of you. We are your data. We are the evidence. What more do you need to see the damage? The Scottish Government/NHS Scotland say they use mesh as it's robust holds up. That's all well and good but what about the quality of life for us implanted with it? Again as Dr Spencer Netto from Shouldice said " we can fix reoccurance but pain we can't". No truer statement said. In my view, the quality of life should be factored in here instead of the science of a material. The Scottish Government can't deny that mesh is causing complications. They are putting us into minority groups. Mesh is mesh whether it is TVT/TVTO, hernia, rectopexy, hysterectomy, gallbladder, breast reconstruction or any new upcoming surgery. We are all mesh affected.

We ask for an independent review in Scotland of all mesh. Get the data. Put people first. Make it natural tissue repair first before mesh. We know mesh has to be used in life or death situations. Emergency situations. But give us natural tissue first. If someone is so against mesh then they will do all the can, i.e. weight etc to have this surgery. Give us the power back. I'd rather face 10 natural tissue repairs than 1 mesh repair. I live with mesh I know how damaging it is.

We ask you to listen to us. You talk about being listened to and supported? Our own government aren't listening. They are dismissing us. The government are keeping these issues going by not listening, by not making the changes. Please we ask allow us an independent review of all mesh.