To: Senate Community Affairs References Committee

[redacted]

The number of women in Australia who have had transvaginal mesh implants and related matters.

My name is [redacted]. In December of 2010 I was implanted with a Tension-free Vaginal Tape – Obturator (TVT-O) system of transvaginal mesh to treat Stress Urinary Incontinence (SUI) following the vaginal delivery of my four children. I was told at the time that this was the “Gold Standard” in treating SUI, was a day procedure, very safe, and came with only minor risks, those being the standard risks associated with all surgeries (reaction to anesthetics, blood loss, small risk of infection or rejection). Roughly two years post-implantation, I started experiencing vaginal pains and a pulling sensation in my groin. At first the pulling sensation presented as a dull ache but became more severe over time. By early 2016 the pain was so severe that I could barely sit, I was finding it difficult to sleep, and I was having trouble being active enough to carry out normal everyday tasks. In April 2016, upon seeking relief from the pain, I found a surgeon who had informed me that it was her belief that my mesh had “shrunk” causing the pulling sensation and the pain. She offered me a revision to release the mesh and also informing me that my SUI would most probably return. I agreed to the revision and things got much worse. Almost immediately I began experiencing severe pain in my vagina. After four months a raw, burning pain was now my norm. Some days it felt like a hot knife in my vagina and the pain also started to migrate to my bottom and my legs. This was attributed to the mesh eroding through the vaginal wall. I have since had full removal of the mesh, in March 2017, by [redacted] in Melbourne. While feeling better that the mesh has been removed I am left with pudendal nerve damage, fibromyalgia, inability to sit or stand for any length of time, inability to be intimate or have sexual relations with my husband, inability to pursue an active lifestyle, and the inability to attend regular family functions (sport practices/events, movies, dinners, parent/teacher conferences, etc.) due to the pain in my vaginal and gluteal areas.

I offer the following submission to the points referenced.

2. Information provided to women prior to surgery about possible complications and side effects.

My surgeon informed me that the only complications would be those associated with the surgery itself as "no surgery is free from risk." I was told I could experience reactions to the anesthetics used and nothing further. I was not told about the ability of the mesh to ruin my life. I was not told of the possibility of the mesh shrinking and possibly eroding through the vaginal wall. I was not told that the procedure or the device would leave me in constant, permanent pain due to nerve damage. My surgeon did not warn me against the risk of painful sex, the ability of the mesh to cause damage to my husband during sex, or that I could possibly never have sex again. I was not told that most GPs, or even gynecologists, were not well versed in the issues, pains, or symptoms caused by mesh, nor was I told that I'd be led to believe that my pain and disabilities were all in my head. My surgeon was correct in saying that the procedure would change my life although I thought he meant it would be changed for the better.

5. The types and incidence of health problems experienced by women with transvaginal mesh implants and the impact these health problems have had on women's lives.

I was a fairly active wife and mother. Bringing up four children of my own (plus my husbands two boys; total of 6) required me to always be on the go. Throw a couple of dogs into the mix and relaxation time was of a premium. I now spend most of my days lying on one side or the other as to avoid direct pressure on my vagina and my bottom. I have pains running down my legs to my feet, which are also sore causing an inability to stand for long periods. I can no longer work. I can no longer lead the active life to which I was accustomed. The pain in my vagina, even after removal, which is caused by vulvodynia (a chronic vulvar pain), lichen planus (an autoimmune disorder), and permanent nerve damage, to include the pundendal nerve, keeps me from sleeping. I sleep with two to four pillows every night trying to find relief from the pain and achieve a comfortable position.

7. Options available to women to have transvaginal mesh removed.

Firstly, I was lead to believe that the mesh was permanent – a risk I was willing to take given the promised results and that there were apparently only a few small risks. However, I wasn't told of the major complications I am now experiencing. The implantation of such a device, knowing the possible negative outcomes, without a plan for removal is tragic. How can the medical community continue to use these devices armed with no knowledge and no documentation on how to resolve post-implantation complications? Upon seeking help from several GPs and gynecologists I was met with misunderstanding, lack of knowledge, and very few options. The only options were to treat the pain (and not identify/rectify the cause), or undergo a revision. I was not aware of removal options until much later and even they were limited to one or two surgeons in the USA. I underwent revision surgery not knowing that full removal was possible and unaware that there was indeed a surgeon in Australia that could perform this removal. In the end an Australian surgeon in Melbourne performed a 100% removal of my mesh. This surgeon is sadly only able to remove a very small percentage of the mesh systems currently available on the market today. As awareness of this issue continues to grow we are finding that there are still many women out there who are living in pain, misery, and silence…not knowing how or where to find help.