Supplementary Submission No 944a

# INQUIRY INTO BIRTH TRAUMA

Name: Mrs Lyn Leger

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## **Additional Information**

#### Introduction

Thank you for the opportunity to provide additional information following my appearance at the hearing for the NSW Parliamentary Inquiry into birth trauma on 9<sup>th</sup> October 2023.

During the hearing (and previously in my submission) I have provided information regarding my physical birth injury (levator ani avulsion), flow on impacts, the prevalence of the injury and my recommendations. In this Additional Information I have collated all the recommendations I provided previously, as well as some new recommendations.

Implementation of my recommendations will:

- Ensure that funding can be allocated to research on and management of levator ani avulsion, commensurate to the economic burden of avulsion.
- Address gender bias in the health system, providing funding for research into women-focused medical issues that affect our quality of life from giving birth, and for the remainder of our lives.
- Improve the lives of women with this injury by ensuring access, early diagnosis, affordability of medical and allied health services, and long term treatment and management options.
- Provide a positive impact on the economy and society as women with avulsion will more likely be able to participate fully in society again.

## **Summary of recommendations**

### A) Research

- Immediately undertake a study into the economic burden of levator ani avulsion. Considering the
  prevalence of avulsion, and the various types of impacts as I have shown in my mind map (attached),
  the economic burden of avulsion must be HUGE!!
  - On another women-focused issue, endometriosis, the total economic burden has been estimated to be between AUD 7.4 and 9.7 billion. Endometriosis affects 1 in 9 Australian women, and has a similar range of impacts. Approximately 1 in 5, and possibly up to 1 in 3 women have avulsion, which is almost double or 3 times that of endometriosis.
- 2. Develop better and more accurate methods of diagnosing avulsion in the early post partum period that are accessible to all. This is important so people can identify and manage their injury and hopefully delay or prevent subsequent prolapse. Relying on women's health physios only is not an ideal scenario (see below, recommendation B)2).
- 3. Urgently invest in research and development for women with avulsion on 3 key areas:
  - i. Research to develop permanent surgical fixes for avulsion. Additionally, where experimental surgeries are occurring outside Australia and showing reasonable results, provide funding for our Australian surgeons to learn these techniques, improve on them, and make them available to women in Australia.
  - ii. Research to improve outcomes and longevity of prolapse surgery for those of us with avulsion. A 70-80% failure rate in prolapse surgery for those with underlying avulsion is not acceptable.
  - iii. Research to develop new and better pessaries that work for all women with avulsion, potentially using imaging and 3D printing, or other innovative techniques. We need this while we wait for improvements in prolapse surgery and development of permanent fixes.

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<sup>&</sup>lt;sup>1</sup> <u>https://www.aihw.gov.au/reports/chronic-disease/endometriosis-in-australia/contents/impact/economic-burden</u>, accessed 13 November 2023.

## B) Access, care and outcomes

- 1. **Training of physiotherapists to diagnose levator ani avulsion.** In my personal experience, less than 20% of women's health physios are able to diagnose levator ani avulsion from a physical examination. This demonstrates the need for better and targeted training of women's health physios. This needs immediate attention as women seeking treatment for symptoms may not be properly diagnosed and therefore inappropriate treatments may be recommended.
- 2. Training of ALL practitioners who deal with birth injuries on the nature of the injury and extent of the impacts. In my own experience I have had to explain to countless practitioners (including GPs) the nature of the injury and what that means for me in terms of the far-reaching impacts (refer to mind map attached). This is re-traumatising and means that practitioners may be misunderstanding the inability of a woman to cope in this situation, what practical assistance is required, and impacts to mental health which may need to be treated to prevent the very real risk of depression, self-harm or even suicide.
- 3. Ease the ongoing financial burden on individuals, one of the key impacts of avulsion, by putting in place Medicare-funded care plans focused on birth injury and trauma. These would likely be similar in nature to Eating Disorder treatment and management plans which provide for comprehensive treatment from both psychological services and allied health professionals. With such a wide range of potential impacts from avulsion, these care plans need to be personalised and be targeted at the care required.
- 4. **Include pilates pelvic floor classes under Medicare or other funding mechanism.** Specialist women's health physios are limited in number. In regional areas, women's health physio programs appropriate to the level of ongoing treatment required are not available. Other alternatives such as pilates MUST be funded.
- 5. **Include birth injuries such as levator anit avulsion as an invisible disability.** Normal able-bodied activities are difficult and difficulties may be more pronounced in certain life stages (e.g. when children are young and require carrying, post menopause after hormonal changes and worsening of condition). Assistance should be provided as per other physical disabilities e.g. at a minimum, access to parking permits, but also with help in the home with cleaning, yard maintenance etc.

## C) Implementation of recommendations

- 1. Coordinate and implement the above recommendations on behalf of the women of NSW. Where these recommendations require coordination with the Australian Government, lead the way in establishing the appropriate committees or bodies to implement the changes required. Coordination with the Australian Government Department of Health and Ageing will also ensure that a long term view is taken.<sup>2</sup>
- 2. Ensure funding is allocated immediately and on an ongoing basis to birth trauma focused organisations. Organisations such as the Australasian Birth Trauma Association can assist with the implementation of the above recommendations, but need to be appropriately funded as currently they are run on a volunteer-basis by mums who also juggle jobs and kids.

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<sup>&</sup>lt;sup>2</sup> Note that the The Hon Ged Kearney MP, Assistant Minister for Health and Aged Care recently called for Australian women to share their experiences in the health system to better inform policy development and improve health outcomes for women and girls. This includes and opportunity to address gender bias in the health system across priority areas including research, and access, care and outcomes (<a href="https://www.health.gov.au/ministers/the-hon-ged-kearney-mp/media/call-for-women-to-share-their-stories">https://www.health.gov.au/ministers/the-hon-ged-kearney-mp/media/call-for-women-to-share-their-stories</a>, accessed 13 November 2023).

