Dr Vijay Roach
President, RANZCOG
and
Dr Benjamin Bopp
President-Elect, RANZCOG

Sent via email: ranzcog@ranzcog.edu.au

10 September 2021

Dear Dr Roach and Dr Bopp,

Re: Prevention, diagnosis and management of Asherman Syndrome

We gratefully acknowledge the efforts of Sarah Lynch, an American advocate for women with Asherman Syndrome, who on our behalf, cc'd you into a copy of an international letter titled '*Request for an urgent review of clinical guidelines to prevent the formation of intrauterine adhesions following a dilation and curettage'*, in June 2021.

We, as an alliance of Australian and New Zealander women with Asherman Syndrome, are sending you this follow-up letter expressing our keen desire to work alongside RANZCOG to raise greater awareness and promote improved treatment of Asherman Syndrome. We have integrated our collective experiences with current medical research – and do so with full acknowledgement that we are not medical professionals. We hope you can read this letter from a place of understanding that our primary aim is to prevent other women from experiencing the levels of pain and distress that we have.

Asherman Syndrome is the formation of scars known as "adhesions" inside the uterus and/or cervix. Most known cases are caused by a surgical trauma to the uterus.

Symptoms can include light or missed menstrual periods, and cyclical menstrual pain, though not all women with the disorder experience these symptoms. Many women with Asherman Syndrome cannot conceive, and those of us who do are much more prone to miscarriage than we were prior to acquiring Asherman Syndrome. The emotional toll of developing this disorder, and the often long and fraught journey to get it diagnosed and treated, is physically and emotionally devastating for many women.

Our concerns about dilation and curettages (D&Cs)

We believe, based on our own experiences as well as medical research, that there is much room for improvement in the standard of care many women receive either before, during or after a D&C.

About 90 percent of all Asherman Syndrome cases stem from a pregnancy-related D&C, [1] though IUDs or other types of uterine surgeries such as a myomectomy can also cause the condition. [2]

The D&C remains to this day the most common surgery women undergo following a missed miscarriage or to remove retained placenta after a birth, even though multiple prior studies have shown the surgery can cause harmful scarring and/or damage to the endometrial lining. [3] [4]

The risks of developing Asherman Syndrome after a pregnancy-related D&C have been well-established dating back many decades. [5] Research suggests that women who have a curettage performed after delivery to remove a retained placenta, or who have had repeat curettages due to a missed miscarriage can face up to a 40 percent risk of developing intrauterine adhesions,[6] while some studies have documented that up to nearly 31 percent of women who received a curettage after a missed miscarriage developed amenorrhea.[7]

With great technological advancements, it is now growing increasingly clear that the use of hysteroscopic resection is a preferred method to dilation and curettage in many cases where surgery is necessary and medical management is ineffective.[8] [9] [10] [11]

Yet despite this knowledge, the D&C remains the most common surgery available and is often still performed blindly, without even the use of guided ultrasound. Many women we have spoken to have had their D&C performed with a sharp curette – please see the attached Q&A with Asherman Syndrome specialist Dr Thierry Vancaillie who specifically advises against the use of sharp curette and instead advocates the use of suction curette, in cases where a D&C must be performed.

The importance of informed consent and consideration of options

Despite the devastating toll that Asherman Syndrome has on a woman's fertility and prospects for future pregnancies, doctors often fail to discuss the risks of developing Asherman Syndrome and associated fertility issues, ahead of any intrauterine surgery, when it should be a part of the informed consent conversation that doctors have with their patients [12] in cases where treatment is not a medical emergency. From our discussions with Australian and New Zealander women, it appears obstetricians/gynaecologists also routinely fail to discuss other options that can minimise the risks of scarring, whether it be by avoiding surgery altogether with the use of Misoprostol or oral antibiotics if these are appropriate alternative options (dependent on the woman's medical condition), or alternative surgeries if appropriate, such as hysteroscopic resection to help prevent damage to the uterine lining.

It is worth noting that in recent years in Australia, Asherman Syndrome has emerged as an area of medical negligence litigation. There is at least one recent publicly documented legal settlement in Australia, in relation to Asherman Syndrome [13]. It is expected that more women will pursue claims in the coming years as community expectations around 'informed consent' for medical care shift, placing greater responsibility on doctors to adequately inform patients of significant risks.

Timely diagnosis

After undergoing a D&C, many women report that their obstetrician/gynaecologist did not take steps to check for scarring, and many women report that they have trouble convincing their doctors to check for Asherman Syndrome after they develop symptoms such as missed periods, trouble conceiving and cyclical abdominal cramping. More frequent diagnoses of Asherman Syndrome are expected as doctors become increasingly aware of the importance of conducting proper diagnostic follow-up testing with their patients after surgery to remove the products of conception or a retained placenta. The gold standard for diagnosing Asherman Syndrome is the hysteroscopy, which provides for much better visualization into the uterine cavity.

A recently published study found that doctors should automatically consider Asherman Syndrome as a possible diagnosis "in any woman with a history of miscarriage or postpartum curettage who then fails to conceive again," [14] yet many women find it challenging to get properly diagnosed and treated in a timely manner.

The role of General Practitioners (GP's) in recognising the signs of Asherman Syndrome is also crucial. Many women report having a difficult time convincing their GP to make referrals for appropriate testing due to the common perception that Asherman Syndrome is ‘rare’. The majority of women report a lengthy process to get the correct diagnosis, often involving multiple specialists and out-of-pocket costs. This raises equity issues for women who cannot afford this level of care, and also for those who are living in country/regional areas away from specialists and diagnostic facilities.

Given the amount of effort that most women go to in order to obtain a diagnosis, we urge reconsideration of Asherman Syndrome as a ‘rare’ disorder, and think that ‘rarely diagnosed’ may be a more apt term.

Prevention

We advocate for a much greater emphasis to be placed on how doctors can take basic steps to prevent the development of Asherman Syndrome in the first place. Prevention is crucial because of the devastating impact that Asherman Syndrome can have, even after scarring is cleared. Those who have been diagnosed and later go on to become pregnant can face increased risks for miscarriage, placenta previa, placenta accreta, vasa previa and cervical incompetence. [15] We have already outlined our concerns about D&Cs and outlined some evidence around best practice e.g., use of suction instead of sharp curette; or avoidance of D&C when other valid options exist. More attention could also be paid to secondary methods to prevent the formation of scarred tissue. While more research is needed to understand the efficacy of estrogen following a surgery, there is still some evidence [16] to suggest it could be beneficial in conjunction with other treatments such as repeat hysteroscopies and/or the application of hyaluronic acid gel.[17]

Best standard of treatment

Australia and New Zealand have a lack of specialists in the field of Asherman Syndrome. A large number of women are unable to get successful treatment in their home towns/cities and so fly to Sydney to be treated by an Asherman Syndrome specialist. Obviously, this is unaffordable for many women who as a result go without adequate treatment, and are potentially unable to conceive again, or conceive on a scarred uterus, leading to increased risks in pregnancy. Some women who have sought treatment from specialists in their home towns/cities have had surgeries that have in fact worsened their Asherman Syndrome to the point that they have become untreatable, and without any prospect of ever carrying a child of their own. For this reason, it is crucial that RANZCOG reviews clinical guidelines for management of Asherman Syndrome to ensure that women are receiving the best possible advice and care.

Our recommendations

Based upon the available medical literature as well as our personal experiences, we urge you to consider the following recommendations – or to collaborate with us to form what you believe to be more appropriate recommendations.

Prevention	➢ Work to improve the education of obstetricians/gynaecologists to prevent Asherman Syndrome. This may be through reform of clinical guidelines e.g., for management of miscarriage/retained products of conception.

	➢ Make the ultrasound-guided D&C using suction the standard of care, in cases where a hysteroscopic resection or administration of appropriate medications is not available or appropriate
Improve consent protocols	➢ Work to improve consenting procedures for women undergoing a D&C so that they are aware of their relative risk of acquiring Asherman syndrome and associated fertility issues, and can make an informed choice, or at least be aware of the need to be assessed for Asherman Syndrome after a D&C. Women should also be informed of the process they should follow if they believe they have symptoms of Asherman Syndrome and want this to be investigated.
Increase identification and diagnosis	➢ Increase training for General Practitioners into signs of Asherman Syndrome which may enable faster referral for appropriate investigation and intervention. ➢ Recognise that Asherman Syndrome is not a rare condition, but instead, a 'rarely diagnosed' condition. There is a big difference, and the perception of it being 'rare' has hindered many women's diagnosis. We acknowledge more published research on this may be required in order to change this conventional wisdom, and we urge you to help foster this research by promoting the need for more attention to be paid to the epidemiology of Asherman Syndrome.
Improve treatment standards	➢ Review guidelines into treatment and management of Asherman Syndrome. Many women report that seeking treatment has in effect made their condition worse, as the surgical techniques used to treat their condition were inappropriate. This is why so many Australian women end up seeking treatment in Sydney from an Asherman Syndrome specialist.
Support and validation	➢ Increase recognition from doctors of the need for mental health support for many women diagnosed with Asherman syndrome. ➢ Improve responses from doctors and hospitals when women report acquiring Asherman Syndrome as a result of their care. ➢ In cases where Asherman Syndrome has been caused and where more conservative treatment alternatives have not been offered to patients (where appropriate), hospitals and doctors should consider their responsibility in financially supporting patients for their diagnostic and treatment costs in relation to Asherman Syndrome.

To further demonstrate the difficulties caused by Asherman Syndrome, we are attaching testimonies from ten Australian and New Zealander women who have been affected by this condition. Our website also contains information aimed at health professionals around Australia and New Zealand.

Thank you for allowing us the opportunity to express our concerns and work together on this important issue. Please let us know if you are open to meeting with any women either face-to-face (some of our women are based in Victoria) or virtually. We would like to do whatever we can to help address this issue.

Sincerely,

(surnames redacted on publicly available version of this letter)

Naomi, Rebecca and Kimberley (Western Australia);

Meaghan (Victoria); and

Libby (New South Wales),

on behalf of Australian and New Zealander women with Asherman Syndrome.

Contact: ashermans.australia@gmail.com

With thanks to Sarah Lynch for kindly sharing her research with us to assist in preparation of this letter.

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