June 8, 2021

Dr. Christopher M. Zahn, MD

Vice President, Practice Activities

American College of Obstetricians and Gynecologists

409 12th Street SW

PO Box 96920

Washington, D.C. 20024

Re: Request for an urgent review of clinical guidelines to prevent the formation of intrauterine adhesions following a dilation and curettage

We are writing to raise concerns about how many obstetrician-gynecologists in the United States, Canada, Europe, Australia and New Zealand are inadvertently causing infertility in their patients by using outdated surgical practices and techniques.

We believe, based on our own experience as well as medical research, that many women are still not receiving a good standard of care either during or after a dilation and curettage (D&C), and we want to urge you to use your voice as a leader in this field to change this long-standing problem.

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. [1] [2]

We are victims of Asherman's Syndrome, and many of us have connected with one another through various online support groups of women who have either been diagnosed with Asherman's or believe they have symptoms of the disorder and are seeking support and guidance.

Asherman's 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 following surgery.

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's Syndrome cannot conceive, and those of us who do often miscarry.

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 women, particularly when it comes on the heels of a miscarriage.

A recently published study found that doctors should automatically consider Asherman's Syndrome as a possible diagnosis "in any woman with a history of miscarriage or postpartum curettage who then fails to conceive again," [3] yet many women find it challenging to get properly diagnosed and treated in a timely manner.

About 90 percent of all Asherman's Syndrome cases stem from a pregnancy-related D&C, [4] though IUDs or other types of uterine surgeries such as a myomectomy can also cause the condition. [5]

We want to urge ACOG's gynecologic clinical review committee to promptly review its recommendations and update them so they are more aligned with the current research on how doctors can better prevent, detect, treat and manage Asherman's Syndrome.

While we appreciate that your November 2018 bulletin addresses the risks of developing intrauterine adhesions following pregnancy loss and cautions doctors to avoid using sharp curettage in a first trimester D&C surgery, your guidelines also incorrectly characterize Asherman's Syndrome as a rare disorder and fall far short of the best practices that our nation's top Asherman's experts are using and teaching to their surgical residents.

Contrary to claims by your organization, Asherman's Syndrome is not a rare disorder, and the risks of developing it after a pregnancy-related D&C have been well-established dating back many decades. [6] More diagnoses of Asherman's Syndrome are expected to increase as doctors perform better due diligence and conduct proper diagnostic followup testing with their patients after surgery to remove the products of conception or a retained placenta.

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,[7] while some studies have documented that up to nearly 31 percent of women who received a curettage after a missed miscarriage developed amenorrhea.[8]

Despite the devastating toll that Asherman's Syndrome has on a woman's fertility and prospects for future pregnancies, many OB-GYNs routinely fail to even mention the disorder to patients prior to undergoing uterine surgery, nor do they discuss other options that can minimize the risks of scarring, whether it be by avoiding surgery altogether with the use of Misoprostol, or alternative surgeries such as hysteroscopic resection to help prevent damage to the uterine lining.

After they perform a D&C, many OB-GYNs also rarely take any steps to check for scarring, and many women report that they have trouble convincing their doctors to check for Asherman's Syndrome after they develop symptoms such as missed periods, trouble conceiving and cyclical abdominal cramping.

The gold standard for diagnosing Asherman's Syndrome is the hysteroscopy, which provides for much better visualization into the uterine cavity. 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.[9] [10] [11] [12]

Yet despite this knowledge, the D&C remains the most common surgery available and is often still performed blindly without even the basic use of guided ultrasound. Further, doctors often fail to discuss the risks of developing Asherman's Syndrome ahead of any intrauterine surgery, when it should be a part of the informed consent conversation that doctors have with their patients.[13]

More than 10 years ago now, the practice committee of the American Association of Gynecologic Laparoscopists (AAGL) issued guidance that is much more aligned with the consensus among Asherman's Syndrome experts, saying it had determined "there is no evidence to support the use of blind dilation and curettage."[14] Yet to date, your own organization has not issued any similar guidance and does not directly address ways to prevent intrauterine scarring in any of its practice committee reports, even though most OB-GYNs across the United States look to you for leadership.

To help better illustrate the devastating toll that Asherman's Syndrome has had on us, we are sharing below with you a few examples of our own personal stories, and the pain we had to endure, from the time we developed this silent syndrome, to the process we went through to get it diagnosed and treated.

"I became pregnant for the first time in July 2020, and I was looking forward to being a mother. I was devastated when in September I discovered that my daughter's heart had stopped beating at 10 weeks. When my period never returned after my D&C, the OB-GYN who performed my surgery downplayed my symptoms of Asherman's and suggested stress was to blame. I later discovered she had done my D&C blindly. I had to fight, and do my own research to find a specialist who would listen to my concerns. It took more than 7 months to get diagnosed and treated before I could even try to conceive again. Since this experience, I have decided I cannot stand by and let this happen to other women. I need to fight for change so no one else must endure this pain." –S.N.L., Washington, D.C.

"My struggle with Asherman's Syndrome started when my obstetrician left a piece of placenta inside my uterus during a blind D&C after a missed miscarriage. Two and a half months later, I learned that more than 50% of my uterus was scarred and my reproductive endocrinologist told me I would potentially need a gestational carrier for any future pregnancies. I've been through a year of struggles with the sequelae of Asherman's Syndrome, and although my uterus is now clear of scarring, I have had difficulty attaining a lining suitable for an embryo transfer. Asherman's has wrecked me emotionally, physically, and financially, and it could have all been prevented, had the best practices been to utilize ultrasound during D&Cs to minimize the risk of retained tissue. It could have further been prevented by my obstetrician doing serial HCG draws to ensure my level dropped to zero, but this is also not considered a best practice. We MUST change this to save women from this devastating condition." – S.E.B., Austin, Texas.

"I was blessed to become a mother in 2017. What I was never prepared for was the aftermath: multiple hemorrhages due to retained products of conception. My OBGYN followed the standard of care for treatment - blind D&Cs - in my case, two within six weeks of giving birth. These procedures probably saved my life, but it wasn't until 14 months later, I learned that the D&Cs had also left me with severe Asherman's Syndrome. I have since gone through 7 hysteroscopies to restore my uterine cavity in the hopes of being able to carry another child to term, as well as two miscarriages. It shouldn't be this hard."- T.D., Washington, D.C.

"After my silent miscarriage in August 2019, I was advised a D&C was the best option. I wish I had known the devastation, grief, pain, and financial burden this procedure would cause me. There was no explanation that the D&C would be done blindly, without ultrasound

guidance. I was not given a choice. After almost a year of pain and amenorrhea my OBGYN still insisted I could not have Asherman's Syndrome. By the time I finally saw an Asherman's specialist, and was diagnosed, my uterus was 70% scarred shut. It took four surgeries over six months to clear. Almost two years later, I am still battling regrowth. My dream of becoming a mother is starting to feel impossible, all due to a blind D&C. Please stop this practice immediately and save another person from this horrible fate." – M.R., Oakley, Ca.

"I had an emergency D&C along with two postpartum hemorrhages, and no one ever mentioned potential complications - especially with continued breastfeeding. I complained of pain and the lack of a period years before I finally switched doctors and got someone to order a saline infusion sonohysterography for me. We shouldn't have to work this hard to get a diagnosis and there should be much better patient education all around." – K.B., New York, NY

"I was single and 38 and looking to start my family, so I tried to get pregnant with IUI. During an ultrasound after one of several attempts, my doctor noticed what appeared to be a fibroid. My OBGYN later removed it with a procedure called Myosure. Information online about this procedure does not mention any risk of scarring, and my doctor was unaware I actually had not one, but two "kissing" fibroids that were very close together. My doctor lacked the proper education, and did not take precautions to prevent the development of Asherman's Syndrome during my surgery. I was never checked for scarring afterwards, and I was cleared to try IUI again. I became pregnant with twins, but one vanished and I miscarried the other at 8 weeks. From then on, doctors claimed there was no problem with my uterus because I had still managed to get pregnant. They blamed my pregnancy losses on my age, even though every month I told them I

barely had a period. They let me proceed with four more failed IUI attempts and multiple failed IVF transfers. It was not until I found an Asherman's Syndrome expert that I finally learned my former doctor did not have the education or information necessary to remove kissing fibroids without causing scarring. Sadly, however, the new doctor was unable to remove my scarring. I am one of the 5% or so that cannot be fixed at all. I have since adopted the most amazing little boy, so I did get my family, but not the way I had originally planned." -D.K., Los Angeles, California

"After the birth of my daughter in 2018, I had some retained placenta with accreta, which I was told would require a D&C to properly remove. I was not informed by the obstetrician of the risks of adhesions or infertility, nor did my follow up care inquire as to the nature of how things healed; only that the bleeding should taper naturally, which it did. After trying to conceive for a year, I waited another 3 months to be referred and seen by an outstanding Reproductive Endocrinologist, who diagnosed my Asherman's syndrome after a very traumatic Hysterosalpingogram that lasted about an hour because we had so much difficulty trying to get fluid into the uterus. I endured three laparoscopic abdominal surgeries with amnion grafts and balloon stents to clear the over 90% scarred uterus and tubes in an attempt to have a healthy reproductive system. I am currently pregnant, but now my pregnancy is incredibly high risk and has been, in and of itself, extremely traumatic, as I've thought I was miscarrying at least 4 times due to the amount of bleeding that is more common among women with Ashermen's. My story is one of the few with a happier ending, and I still feel incredibly resentful about the poor standard of care surrounding my procedure and follow-up care from my D&C. I was told that a D&C was totally unavoidable with the placenta accreta, but if my follow-up care included the option of a diagnostic hysteroscopy, I could have caught my adhesions in their early stages and prevented further scarring or have been referred to a

Reproductive Endocrinologist sooner. I could have avoided the 2.5 years spent being depressed every month at a negative pregnancy test, enduring 5 saline intrauterine ultrasounds, a traumatic HSG, 3 major surgeries, weeks taken off of work, and a significantly higher quality of life." – J.T., Cleveland, OH

A much greater emphasis needs to be placed on how doctors can take basic steps to prevent the development of Asherman's Syndrome in the first place, and they should also be more proactive in checking for possible signs and symptoms of the disease following a miscarriage or complications after a birth.

Prevention is crucial because of the devastating impact that Asherman's 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]

More attention should 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]

In sum, we are respectfully asking for your organization to consider the following recommendations, as part of a broader effort to re-examine and update your guidelines on treatment for women following a miscarriage or to remove retained placenta:

- Work to improve the education of residents and doctors to prevent Asherman's Syndrome
- Provide recommendations for doctors and residents to recognize signs and symptoms of Asherman's Syndrome, and help them so they can make an expedient diagnosis

- Make the ultrasound-guided D&C the standard of care, in cases where a hysteroscopic resection or miscarriage management with medication is not available or appropriate
- We also ask that you recognize that Asherman's Syndrome is not a rare condition. 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's Syndrome.

The heartache of suffering from a miscarriage or stillbirth is hard enough for a woman to bear on its own. But when a woman develops a potentially preventable disease like Asherman's Syndrome that hinders her from trying to conceive again after a loss, the emotional trauma becomes even more acute.

Thank you for allowing us the opportunity to express our concerns. Should you have any further questions, please contact XXXXXX

Sincerely,

Signed by 128 women with Asherman's Syndrome from the United States, Canada, the United Kingdom and Australia

CC Dr. Diana W. Bianchi, Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development

CC Dr. Janine Austin Clayton, Director, NIH Office of Research on Women's Health

CC Dr. Jennifer Blake, CEO, Society of Obstetricians and Gynaecologists of Canada

CC Dr. Tim Draycott, Chairman of Clinical Quality at the Royal College of Obstetricians and Gynaecologists

CC Dr. Vijay Roach, President, and Dr. Benjamin Bopp, President-Elect, of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Research Citations:

---

[1] Long-term complications and reproductive outcome after the management of retained products of conception: a systematic review; Fertil Steril 2016 Jan;105(1):156-64.e1-2; Angelo B Hooker, Humeyra Aydin, Hans A M Brölmann, and Judith A F Huirne; https://pubmed.ncbi.nlm.nih.gov/26453977/

[2] Dilatation and curettage effect on the endometrial thickness; Iranian Red Crescent Medical Journal, 05 Apr 2013, 15(4):350-355; Davar R, Dehghani Firouzabadi R. and Kefayat Chaman Ara; https://europepmc.org/article/med/24083012

[3] Asherman syndrome: Audit of a single-operator cohort of 423 cases; ANZJOG Volume 60, Issue 4 26 May 2020 Pages 574-578; Thierry Vancaillie, Karen Chan, Jinzhu Liu, Rebecca Deans and Elizabeth Howard; https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/ajo.13182?fbclid=IwAR2WK6OetiZt7UVuIiKe8AgSBGqbuzrsqHAnA2BN6AcLErPUXtdKxOvJr98

[4] Schenker JG, Margalioth EJ. Intra-uterine adhesions: an updated appraisal. Fertility Sterility 1982; 37:593-610.

[5]"Effect of myomectomy on endometrial cavity: A prospective study of 51 cases"; J Hum Reprod Sci. 2016 Apr-Jun; 9(2): 107–111; Shilpa Bhandari, Ishita Ganguly, Pallavi Agarwal, Aparna Singh, and Nitika Gupta; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4915280/

[6] Up to Date Therapy of Asherman's Syndrome and Uterine Septum; December 22, 2015.; Dr. Charles March discusses treating Asherman's Syndrome and congenital uterine anomalies using hysteroscopy. See:

https://videolibrary.globalcastmd.com/up-to-date-therapy-of-ashermans-syndrome-and?fbclid=IwAR3CKM5JkTSKz_NMkmIkChBJWexNKuUSigXYHwiR0zbbV7rmIQTQMa6Y2W0

[7]"Prevalence of Asherman's syndrome after secondary removal of placental remnants or a repeat curettage for incomplete abortion. Human Reproduction. Vol. 13. No. 12 pp. 3347-3350. 1998. Iris C.D. Westendorp; Willem M.Ankum; Ben W.J. Mol; and Jan Vonk https://core.ac.uk/download/pdf/19186458.pdf

[8] "The incidence of intrauterine adhesions following spontaneous abortion"; Int J Fertil. 1982;27(2):117-8. Adoni A, Palti Z, Milwidsky A, Dolberg M

[9] "What today's ob/gyn needs to know about Asherman's syndrome"; June 17, 2019; James K. Robinson III, MD, MS and Nicholas D. Hazen, MD; https://www.contemporaryobgyn.net/view/what-todays-obgyn-needs-know-about-ashermans-syndrome

[10] "Systematic review and meta-analysis of intrauterine adhesions after miscarriage: prevalence, risk factors and long-term reproductive outcome." Hum Reprod Update. 2014;20(2):262; Hooker AB, Lemmers M, Thurkow AL, Heymans MW, Opmeer BC, Brölmann HA, Mol BW, Huirne JA; https://www.uptodate.com/contents/intrauterine-adhesions-clinical-manifestation-and-diagnosis/abstract/5

[11] "A comparison of reproductive outcomes following hysteroscopic management versus dilatation and curettage of retained products of conception;" International Journal of Gynecology and Obstetrics; 127 (2014) 86-89; Ido Ben-Ami, Yaakov Melcer, Noam Smorgick, David Schneider, Moty Pansky, and Reuvit Halperin; http://med-fom-obgyn.sites.olt.ubc.ca/files/2015/11/Ben-Ami-2014-A-comparison-of-reproductive-outcomes-following-hysteroscopy-versus-d-and-c.pdf?fbclid=IwAR2WQrVL_muV4JwKdP_IFjowoL0Lj6ZUBRbjs9uEmUzUAfL3DkRWGhJzbvk

[12] “Hysteroscopic Resection for Missed Abortion: Feasibility, Operative Technique and Potential Benefit Compared to Curettage” , 08 September 2020; Matthieu de Codt, Claire Balza, Pascale Jadoul, Patrice Forget, Jean-Luc Squifflet, Pierre Bernard and Mathieu Luyckx’; https://www.frontiersin.org/articles/10.3389/fsurg.2020.00064/full

[13] “Curettage and Asherman's syndrome-lessons to (re-) learn?”; J Obstet Gynaecol Can. 2014 Nov;36(11):997-1001; Ashley R Gilman Barber, Stephanie A Rhone, and Margo R Fluker; https://pubmed.ncbi.nlm.nih.gov/25574677/

[14] “AAGL Practice Report: Practice Guidelines for Management of Intrauterine Synechiae”; The Journal of Minimally Invasive Gynecology, Vol. 1, No. 1, January/February 2010 https://www.aagl.org/wp-content/uploads/2013/03/aagl-Practice-Guidelines-for-Management-of-Intrauterine-Synechiae.pdf

[15]“The incidence of placenta related disease after the hysteroscopic adhesiolysis in patients with intrauterine adhesions;” Taiwanese Journal of Obstetrics and Gynecology; Volume 59, Issue 4, July 2020, Pages 575-579; Lu-ping Zhang; Ming Wang; Xiang Shang, Qi Zhang, Bao-jun Yang, Yun Xu, Jing-hu Li, and Li-min Fenghttps://www.sciencedirect.com/science/article/pii/S1028455920301170

[16] “Efficacy of estrogen therapy in patients with intrauterine adhesions: systematic review;” J Minim Invasive Gynecology; Jan-Feb 2014;21(1):44-54. doi: 10.1016; Jolinda Johary, Min Xue, Xiaogang Zhu, Dabao Xu , and Prasad Palani Velu; https://pubmed.ncbi.nlm.nih.gov/23933351/

[17] “Meta-analysis of the use of hyaluronic acid gel to prevent intrauterine adhesions after miscarriage”; Eur J Obstet Gynecol Reprod Biol; 2020 Jan;244:1-4. doi: 10.1016/j.ejogrb.2019.10.018. Epub 2019 Oct 22. Zheng Fei, Xin Xin , He Fei, and Cui Yuechong; https://pubmed.ncbi.nlm.nih.gov/31731019/