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To Dr. Mazure and The White House Initiative on Women's Research:

The International Society for the Study of Women's Sexual Health (ISSWSH) is the leading international academic and scientific organization supporting communication among scholars, researchers, and practitioners regarding evidence-based knowledge of female sexual function. Of critical importance, we provide the public with accurate information about women's sexuality and sexual health, which often cannot be found elsewhere. As such, we believe our organization to be a key participant in The White House Initiative for Women's Health Research.

It is time to prioritize and allocate substantial funding towards research in women's sexual health, sexual dysfunction, and sexual pain, particularly recognizing the historical imbalance in support when compared to men's sexual health. It is common knowledge that there are many FDA approved drugs and devices for treating male sexual problems, but few FDA approved products for sexual problems in women. A large reason for this imbalance is the **lack of investment dollars going into basic and clinical research in women's health as a whole**¹, let alone sexual health. Yet, female sexual problems are highly prevalent with survey data consistently showing that over **40% of women report having problems with either desire, sexual arousal, orgasm, or pain with sexual activity**²; this percentage increases significantly for women with concomitant chronic conditions (e.g., breast or gynecologic cancer) and women whose intersectional identities (racial/ethnic minority, sexual and gender minority, physical/cognitive/developmental disability) increase their likelihood of poor health outcomes across the life course. Despite this clear patient need, women have not been adequately informed that sexual health is a basic human right and a legitimate healthcare concern that deserves treatment. Women are desperate for help with their sexual concerns and 85% seek solutions from their PCP or gynecologist. However, clinicians are not sufficiently, if at all, educated to assess or treat female sexual problems, which even extends to gynecologists. **In one large multidisciplinary survey study, up to 86% of clinicians were found to be poorly trained**³ and 94% were unlikely to discuss sexual issues with their patients.

Critical breakthroughs in women's sexual health have been initiated or championed by ISSWSH and its members. Yet, there remains a struggle to reach widespread adoption among providers and patients due to a critical lack of funding and support in these vital areas, hindering the dissemination of knowledge and awareness necessary for meaningful impact. Classification of these conditions under mental health diagnostic codes, rather than acknowledging their anatomic and physiologic roots, has done patients a great disservice. Patients often refer to this as "medical gaslighting," which leads to feelings of powerlessness, isolation, prolonged trauma, and ultimately, treatment discontinuation, failure, or reticence

¹ <https://www.nature.com/immersive/d41586-023-01475-2/index.html>

² <https://www.sciencedirect.com/science/article/pii/S0025619619300643>

³ <https://doi.org/10.1080/0963828021000031188>



to seek treatment. **This misclassification contributes to exacerbated health disparities, particularly affecting vulnerable individuals who lack the financial means to access specialized care that we already see in reproductive health care access⁴.** Ignoring sexual health concerns has resulted in extraordinary psychosocial consequences including trauma, depression and anxiety.

If we consider only the impact of pelvic pain conditions on sexual health, **chronic vulvovaginal pain affects up to 28% of women⁵** in the United States with **chronic pelvic pain accounting for 10% of all gynecology office visits⁶.** **Data show that over 40% of women will develop chronic vulvovaginal pain in their lifetime⁷.** In fact, it is virtually inevitable, that every woman will develop pain, discomfort, or concerns that affect this part of their body during their lifetime, even if only transiently, such as during puberty, pregnancy, the post-partum period, or menopause. These disorders are associated with reduced quality of life, interference with everyday activities, missed days from school and work, lost revenue, relationship issues, and can even culminate in suicide. The dearth of research in women's sexual health has imposed a significant burden on our healthcare system. **This manifests as repetitive visits to offices and emergency rooms, with some estimates showing an annual national burden ranging from \$31 to \$72 billion in the US⁸.** Patients typically encounter healthcare providers that are ill-equipped to diagnose and treat these conditions due to the systemic lack of research, leading to a crucial deficiency in the education needed to effectively care for these individuals.

One of the gravest implications of sexual health disorders and pelvic pain is their profound effect on mental health: **12-33% of female chronic pelvic pain patients develop major depression⁹.** **The chronic nature of these conditions frequently results in emotional distress, anxiety, and depression, imposing a substantial burden on individuals' mental well-being¹⁰.** The lack of attention given to these issues exacerbates the suffering of those afflicted and contributes to the growing mental health crisis in our nation.

The biggest setback in advancing women's sexual health research has undeniably been the lack of sufficient funding. A dedicated and comprehensive initiative from the White House can play a transformative role by directing substantial resources to address existing gaps. Such an initiative would not only promote gender equality in healthcare research but also lead to improved diagnostics, treatments, and preventative measures specifically tailored to women's unique sexual health needs.

ISSWSH urges your intentional, sustained and multidisciplinary focus on women's sexual health as it can greatly influence overall patient health and plays a crucial role in **cardiovascular health¹¹**, the leading cause of mortality and morbidity in women. **We are just beginning to understand how hormones, which change during puberty, pregnancy, and menopause affect overall wellbeing and the aging process in women¹².** We know that early entry into menopause is accompanied by increased risk of bone fracture, dementia, cognitive decline, dyslipidaemia, excessive weight gain, and cardiac failure. However,

⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7813444/>

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3885163/>

⁶ <https://pubmed.ncbi.nlm.nih.gov/34128995/>

⁷ https://journals.lww.com/greenjournal/abstract/2008/11000/sexual_problems_and_distress_in_united_states.3.aspx

⁸ <https://login.microsoftonline.com/d689239e-c492-40c6-b391-2c5951d31d14/saml2>

⁹ <https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2020/03/chronic-pelvic-pain>

¹⁰ https://journals.lww.com/menopausejournal/abstract/2020/02000/prevalence_of_depression_and_anxiety_in_women.4.aspx

¹¹ <https://doi.org/10.1016/j.beem.2023.101781>

¹² <https://www.nia.nih.gov/news/research-explores-impact-menopause-womens-health-and-aging>



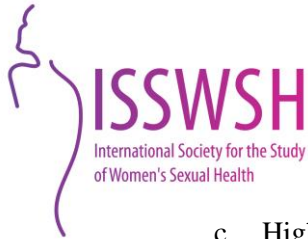
this area is poorly researched and incompletely understood. Hormone therapy can reverse these potentially life-threatening effects of menopause, yet concerns of increased breast cancer risk, which arose from the **Women's Health Initiative**¹³, have prompted a more cautious approach in their application. As a result, there is a burgeoning online market for non-hormonal products to ease menopause symptoms, yet the vast majority are not clinically approved and may, in fact, do more harm than good. These women deserve safe, FDA-approved, and affordable options for menopause management. Investment in women's sexual health research is the solution.

By acknowledging and rectifying the historical underinvestment in women's sexual health and pain research, the White House can propel us toward a future where women's health is thoroughly understood, researched, and prioritized. This initiative is not just a matter of equity and health justice; it is a crucial step in ensuring comprehensive and personalized healthcare for all, fostering a society where women's well-being is given the attention and resources it rightfully deserves.

As the preeminent agency in female sexual health and pain disorders, ISSWSH deserves a prominent role in discussions to offer its expertise to identify research gaps, delineate projects that merit attention and focus on the subjects most deserving of study. We implore you to include the following conditions in future research funding.

1. Menopause and perimenopause
 - a. Focus on connection to system-wide health issues and aging
 - b. Genitourinary Syndrome of Menopause (GSM)
2. Female Orgasmic Dysfunction
3. Hypoactive Sexual Desire Disorder
4. Female Arousal Disorders
5. Chronic Pelvic Pain
 - a. Hypertonic and Hypotonic Pelvic Floor Muscle Dysfunction
 - b. Painful Bladder Syndrome (“Interstitial Cystitis”)
 - c. Recurrent pelvic infections and Pelvic Inflammatory Disease
 - d. Pelvic adhesions
6. Generalized and Localized Vulvodynia (otherwise unexplained chronic vulvar pain)
 - a. Nerve-related: Pudendal neuralgia, Persistent Genital Arousal Disorder, Genito-Pelvic Dysesthesia
 - b. Infectious: Cutaneous and vaginal yeast, Shingles, Post-herpetic Neuralgia
 - c. Musculoskeletal: Hypertonic Pelvic Floor Muscle Dysfunction
 - d. Clitorodynia:
 - i. Clitoral Adhesions, Keratin Pearls, Peri-clitoral abscesses
 - ii. Tumors: Neuroma, Cancer
 - e. Pudendal Neuralgia
 - f. Vestibulodynia
 - i. Hormonally-mediated
 - ii. Inflammatory
 - iii. Neuroproliferative
7. Vulvovaginal and Vulvar Dermatoses and Cancer
 - a. Chronic non-infectious vaginitis
 - b. Desquamative Inflammatory Vaginitis

¹³ <https://www.whi.org/>



- c. High-grade squamous intraepithelial lesion of the vulva and vagina
- d. Lichen Simplex Chronicus
- e. Lichen Sclerosus
- f. Lichen Planus
- g. Contact Dermatitis
- h. Psoriasis

Our patients are suffering in silence - invisible to researchers, healthcare practitioners and, bluntly, to our society. We appreciate that a list of conditions does not convey the struggles our patients go through. Listen in their own words to what they must endure due to a lack of research and medical education.

“From the moment I knew that something was wrong, it took approximately 16 years for me to reach a diagnosis of congenital neuroproliferative vestibulodynia. By this time, I had seen at least 9 gynecologists and 6 physical therapists to reach a proper diagnosis - those are the ones that I can remember; I am sure that there were more. I always knew that the pain I felt - the excruciating, burning, mind-numbing pain that prevented me from ever experiencing vaginal sex - wasn't “just in my head,” like so many providers suggested. I knew that the pain wouldn't magically go away when I “found the right partner,” like so many providers also suggested. I knew the pain wouldn't go away if I “drank a glass of wine and relaxed,” like one physical therapist suggested. The pain was due to a birth defect that caused excess nerve endings, and was in fact not imaginary pain, or pain that would just go away spontaneously. It was pain that could be quantified. While I take great solace in knowing there is a name for what I have experienced my whole life, and a solution to my pain, my heart aches for all of the women who go their entire lives never receiving a correct diagnosis, moving through life with feelings of isolation, pain, and sadness.”

We urge your administration to prioritize sexual health and pelvic pain in ongoing and future research initiatives. By dedicating resources to understanding and addressing these issues, we can enhance the quality of life for millions of Americans, alleviate the burden on our healthcare system, and contribute to a healthier, more resilient society. It is about time women get the respect and attention their health and well-being rightfully deserve.

We appreciate your attention to this matter and believe that your leadership can make a profound impact on the lives of those affected by sexual health disorders and pelvic pain.

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