

## Letter to the WH Initiative on Women's Health Research from Medical Providers and Researchers

To whom it may concern:

**We are writing to you as medical providers and researchers who specialize in the management, treatment, and scientific inquiry of chronic vulvovaginal and pelvic pain conditions.** We are thrilled to see the announcement about the White House Initiative on Women's Health Research and want to ensure that chronic vulvovaginal and pelvic pain is included as a priority area of focus. [Chronic vulvovaginal pain affects up to 28% of women in the United States](#), and chronic pelvic pain accounts for [10% of all gynecology office visits](#). Chronic vulvovaginal and pelvic pain refers to a variety of conditions that cause vulvar burning, itching, and sharp pain; pain with sex; UTI-like symptoms; urinary urgency, pain, and frequency; and pain with sitting and tight pants, among other symptoms.

These conditions [negatively impact women's ability to participate fully in daily activities](#), including their work and productivity, sexual and mental health, sleep, bowel health, reproductive health, and ability to maintain personal bodily autonomy in intimate relationships and healthcare settings. Women with these conditions often face difficulty holding down a steady job, staying in school, or managing their relationships. Many avoid routine and necessary medical appointments because of the pain they experience and their medical providers' lack of understanding. According to ACOG, [12-33% of female chronic pelvic pain patients develop major depression](#).

**Despite the fact that 1 in 4 women in the United States will develop chronic vulvovaginal pain in their lifetime, these conditions are under-studied, under-funded, and generally misunderstood and ignored by medical research institutions.** There is very little research on these conditions, leaving many patients struggling to find effective treatment for their pain. The NIH has allocated just 1-2 million dollars annually to vulvodynia, which is far lower than typical research dollars for similarly prevalent conditions. This amounts to roughly [only 33 cents for every patient affected](#).

In fact, ACOG does not list any Level A treatments in their [Practice Bulletin on Chronic Pelvic Pain](#). As Maya Dusenbery writes in her book on gaps in women's health research, [Doing Harm](#), "There have been very few randomized controlled clinical studies on treatments for the condition. One of the only ones that has been done, funded by the NIH in 2010, found that a tricyclic antidepressant, which has long been used to treat chronic pain and has been the first-line option for vulvodynia for over thirty years, was no better than a placebo." **Lack of effective treatment options combined with diagnostic delay takes a toll on our hospital systems when patients show up repeatedly with the same symptoms and their gynecologists aren't prepared to treat them.**

Chronic vulvovaginal and pelvic pain is [highly prevalent in all populations in the United States](#). Yet, racialized, marginalized patient populations, including Black, Indigenous, People of Color (BIPOC), sexual and gender minorities, low-income and/or low-resourced individuals, and other groups made vulnerable by stigma and discrimination are often unable to access diagnosis or treatment and bear the greatest burdens of healthcare inequities. **Funding research on chronic vulvovaginal and pelvic pain is essential to improving health outcomes and reducing persistent health disparities.**

**Given these concerns, we urge you to add “chronic vulvovaginal and pelvic pain” as a critical area deserving of research funding, recognition, and study.** We appreciate the mention of endometriosis as a key condition deserving of study, and want to ensure that other chronic pain conditions with similar prevalence receive attention and research as well. We also ask that your research committee includes representation from experts in the field of vulvovaginal and pelvic pain, including from the International Society for the Study of Women’s Sexual Health (ISSWSH), International Society for the Study of Vulvovaginal Disease (ISSVD), and the International Pelvic Pain Society (IPPS).

We’ve outlined below the particular conditions that are included in the category of vulvovaginal and pelvic pain:

**1. 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

**2. Generalized Vulvodynia**

- 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

**3. Localized Vulvodynia**

- a. Clitorodynia:
  - i. Clitoral Adhesions, Keratin Pearls, Periclitoral abscesses
  - ii. Tumors: Neuroma, Cancer
- b. Pudendal Neuralgia, Persistent Genital Arousal Disorder
- c. Vestibulodynia
  - i. Hormone-associated
  - ii. Inflammatory
  - iii. Acquired Neuroproliferative Vestibulodynia
  - iv. Congenital Neuroproliferative Vestibulodynia

**4. Vulvovaginal and Vulvar Dermatoses** (Chronic non-infectious vaginitis, desquamative inflammatory vaginitis, HSIL of the vulva and vagina, Lichen Simplex Chronicus, Lichen Sclerosus, Lichen Planus, Contact Dermatitis, Psoriasis)

Thank you for your consideration of this matter. We are grateful for the work you are doing to close the gaps in women's health research and ensure that patients receive the care and treatment they need and deserve.

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362. **Susan Fago**, LICSW
363. **Susan Kellogg Spadt**, PhD, CRNP

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383. **Yvette Fawzi**, MPT – *Pelvic Physical Therapist, Private Practice*
384. **Zoe Dillon**, *Physiotherapist*
385. **Zoë Pond-McPherson**, DPT – *Movement*

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## Medical Student Support

*We are medical students signing in support of this letter. As future medical providers, we know that far more research needs to be done so that we can effectively treat these chronic vulvovaginal and pelvic pain conditions. These are common conditions that we anticipate seeing at OB/GYNs, family medicine doctors, and providers and specialists in other fields.*

1. **Aileen Figueroa Sierra** – *Rush Medical College*
2. **Anisha Mittal** – *Penn State College of Medicine*
3. **Ariana Gopal** – *SUNY Downstate Health Sciences University*
4. **Aruba Asad** – *William Carey*
5. **Deeya Bhattacharya** – *Rush Medical College*
6. **Elizabeth Chun** – *Keck School of Medicine of USC*
7. **Eliza Burr** – *Michigan State University College of Human Medicine*
8. **Elver Ho** – *SUNY Downstate, New York Society of PM&R*
9. **Emily Markarian** – *Keck School of Medicine of USC*
10. **Emma Allen** – *Penn State College of Medicine*
11. **Guy Azriel** – *University of Rochester*
12. **Hannah McBride** – *Temple University*
13. **Ifeoma Ikedionwu** – *University of Chicago Pritzker School of Medicine*

14. **Janine Meurer** – *University at Buffalo Jacobs School of Medicine and Biomedical Sciences*
  15. **Jenna Bergmann** – *Yale Medical School*
  16. **Joanna Bhasker** – *Penn State College of Medicine*
  17. **Jocelyn Cheng** – *Keck School of Medicine of USC*
  18. **Julia Ding** – *Emory University*
  19. **Katelyn Maliszewski** – *Des Moines University*
  20. **Kelvin Alexis Alvarez** – *Keck School of Medicine of USC*
  21. **Krupa Modi** – *Keck School of Medicine of USC*
  22. **Madeline Petty**
  23. **Madeline Petty** – *Lewis Katz School of Medicine*
  24. **Mariah Milazzo** – *Tufts University School of Medicine*
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  26. **Morgan Finegan** – *Keck School of Medicine of USC*
  27. **Morgan Zugelder** – *Northwestern University Feinberg School of Medicine*
  28. **Muzna Ali** – *Penn State College of Medicine*
  29. **Nawrin Nishat** – *TouroCOM*
  30. **Olivia Negris** – *Rush Medical College*
  31. **Olivia Paulsen** – *Idaho College of Osteopathic Medicine*
  32. **Oscar Gomez** – *Keck School of Medicine of USC*
  33. **Pulkit Singla** – *LECOM*
  34. **Reni Forer** – *University of Michigan*
  35. **Sara Chitlik** – *Rush Medical College*
  36. **Sarah Herrman** – *Keck School of Medicine of USC*
  37. **Sarah Ponce** – *Keck School of Medicine of USC*
  38. **Sara Perelmutter** – *Weill-Cornell*
  39. **Savita Potarazu** – *George Washington University*
  40. **Shavana Singh** – *LECOM*
  41. **Stephanie Moss** – *Rush Medical College*
  42. **Swathi Mettela** – *Penn State College of Medicine*
  43. **Tori Valachovic** – *University of Rochester School of Medicine*
  44. **Victoria Fonzi** – *Emory*
  45. **Vivian To** – *SUNY Downstate Health Sciences University*
  46. **Whitney Black** – *University of Rochester*
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