

# Underground zine normalizes the taboo of vulvodynia

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Credit: George Hodan/public domain

Opening Up, a zine created by grassroots organization Tight Lipped, advocates for people with chronic vulvovaginal and pelvic pain. The 80-page zine, which was first published in 2020, is filled with art illustrations, Q&A interviews, handwritten letters and poems from people living with conditions including vulvodynia, vestibulodynia (a form of vulvodynia and a general term for pain in the vestibule), pelvic-

floor dysfunction (when the pelvic floor muscles function abnormally) and vulvar lichen sclerosus (a skin condition that primarily affects the genital skin).

Up to 28% of women deal with these physical conditions, which affect people's daily lives when it comes activities such as having sex, using tampons and wearing pants, according to a 2013 study published in the *American Journal of Obstetrics & Gynecology* that polled nearly 20,000 women. (This study doesn't appear to be inclusive of all gender identities.)

Because these medical issues aren't required study in most residency programs, including those for gynecologists, many patients are misdiagnosed or aren't given a diagnosis at all from their doctor. Also, for some people, the shame and embarrassment related to having one of these conditions keeps them from seeking treatment altogether.

Opening Up features entries from more than 50 contributors of various ages and backgrounds who come from L.A., San Francisco, Seattle, Chicago, Brooklyn and Indianapolis as well Australia, Canada, France, the U.K. and Germany.

In Opening Up, there's an entry from a 78-year-old woman, who wrote about how vulvodynia affected her marriage. Another entry tells the story of a woman who added her conditions—vulvodynia and pelvic-floor pain—to her dating app profiles to inform potential suitors. Some of the entries are anonymous, and content warnings appear on stories that discuss sensitive topics such as sexual assault.

In 2022, Tight Lipped launched a campaign for OB-GYN residency programs to include vulvovaginal and pelvic pain curriculum. The organization's first major win was at Yale School of Medicine, which will offer this area of study as an elective for residents, according to Dr.

Yonghee Cho, an assistant professor of obstetrics, gynecology and reproductive sciences at the school.

Fleischacker said Tight Lipped is hoping to work with Cedars-Sinai Medical Center and USC on future curriculum.

Tight Lipped also wants to make change on a federal level. When President Biden announced the first White House initiative on women's health in November, the organization sent a letter with signatures from more than 800 patients, medical students and health care experts to call for chronic vulvovaginal and [pelvic pain](#) to be included as a priority area of focus.

In the zine's foreword, the creators make it clear that Opening Up isn't just for people who are coping with these conditions. Rather they encourage people to share the publication with everyone they know including their romantic partners, doctors, high-school sex education teachers, family and friends.

"It's going to take more than just all the patients," Poree said. "I think that the more the general public knows about these conditions, the easier it is for people to talk about them and get directed to the help that they need."

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