

**TIGHT
LIPPED
ANNUAL
REPORT
2022**

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Our Year

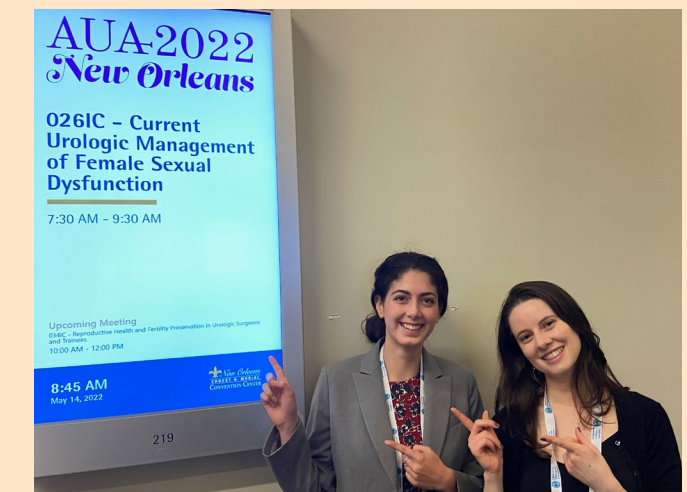
2022 was a pivotal year for Tight Lipped. We launched our first grassroots campaign, which advocates for every OB/GYN residency program in the United States to provide training on common chronic vulvovaginal and pelvic pain conditions.

We started the campaign by launching our “Core Team,” a dedicated group of patient organizers committed to developing our community organizing strategy. **The Core Team facilitated conversations with patients across the country to better understand the key obstacles and systemic issues that patients confront when seeking care.** The team conducted research on healthcare policy, models of other successful patient-led campaigns, and existing initiatives to change vulvovaginal pain education and treatment.

Through listening to patients who have spent years searching for an accurate diagnosis and treatment plan, holding meetings with dozens of medical providers and experts in the field, and participating in our first medical conferences, it became clear that our advocacy campaign needed to focus on OB/GYN education and training.

We asked our community if they would be interested in getting involved in this campaign, and the response was an overwhelming “yes.” Our team recruited hundreds of new community members and facilitated programs for volunteers who were interested in tackling this issue. We held our first-ever community meet-ups and virtual meetings in **New Orleans; Washington, DC; Boston; New Haven; New York City; and Los Angeles.** This Fall, we established our Medical Advisory Board and officially launched our campaign to make sure that every single OB/GYN receives comprehensive training on the diagnosis and management of chronic vulvovaginal and pelvic pain.

Thank you for your support in 2022. Because of you, we are able to fight for every patient in pain to receive the care they need and deserve. We are incredibly proud to share this annual report with you.



Our Story

Tight Lipped launched in May 2019 as a curated storytelling podcast that provided a platform for a public conversation about chronic vulvovaginal and pelvic pain. **Within weeks of releasing the pilot episode, it became clear that Tight Lipped was more than an audio project.** Messages from listeners poured in, sharing that they felt empowered to speak openly about their symptoms and seek care for their conditions for the first time.

A small team of volunteers, each with a personal history of pain, came together to facilitate community workshops, create and distribute our zine, and **bring patients into our fight for change.** We organized presentations on the patient experience for medical students and community-building programs for our broad patient network. **Tight Lipped expanded to become the first and only grassroots movement working to change how healthcare systems treat women and people with chronic vulvovaginal and pelvic pain.**



Mission and Vision

Our Mission

Tight Lipped is a grassroots movement by and for people with chronic vulvovaginal and pelvic pain. We fight for a world where those with these conditions are diagnosed correctly, treated effectively, and given compassionate care.

Our Vision

We want to see a world where pain is believed, where everyone receives accurate diagnosis and free, effective treatment, where research institutions fund and prioritize these conditions, where conversations about vulvovaginal and pelvic pain find their rightful place at the table, and where we transform how we imagine and understand what constitutes sex, pleasure, and intimacy.

Together, we believe our work has the power to shift the narrative around pain, sex, ability, and chronic illness.

The Issue

Chronic vulvovaginal pain impacts up to 1 in 4 women and people with vaginas, so every gynecologist should be prepared to diagnose and treat these conditions, right?

Yet across the country, OB/GYN residents are not learning the basics of vulvar anatomy, vulvar disorders, and chronic vulvovaginal pain conditions.

Chronic vulvovaginal and pelvic pain refers to a variety of conditions that cause vulvar burning, itching, and sharp pain; pain with insertion; UTI-like symptoms; urinary urgency, pain, and frequency; and pain with sitting and tight pants, among other symptoms. These conditions can impact women, non-binary, and transgender people's ability to participate fully in daily activities, reproductive choices, sexual and mental health, and personal bodily autonomy in intimate relationships and healthcare settings.

Medical providers are not receiving the training they need to diagnose and treat these conditions:

“There is no standard medical curriculum devoted to the vulva exam or to female sexual health complaints. So if you're at a medical school that has someone who's teaching it...then you are lucky.”

- Dr. Rachel Rubin, Urologist and Sexual Medicine Specialist, Education Chair for the International Society for the Study of Women's Sexual Health (ISSWSH)

“‘Must be able to diagnose vulvodynia’... these words are not even mentioned in the [residency training] requirements... Yet we have very specific requirements for obstetrics, urogynecology, genetic counseling.”

- Dr. Sara McKinney, OB/GYN, Director of the Vulvovaginal Clinic at Beth Israel Deaconess Medical Center

Our community members have shared some of the responses they've received from their gynecologists when they've disclosed their painful symptoms:

It is normal for sex to hurt, you'll get better with practice.



We can't find anything so it's probably a mental block.

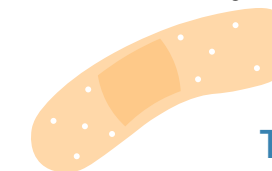


Try using a cucumber to stretch it out.

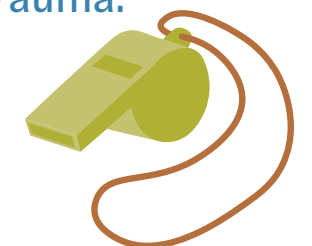
You need to get over it since you'll need to make your future husband happy.



Sometimes it'll just hurt and us women have to be okay with that.



There is no reason that this exam should be painful. The only possible explanation is that you have repressed sexual trauma.

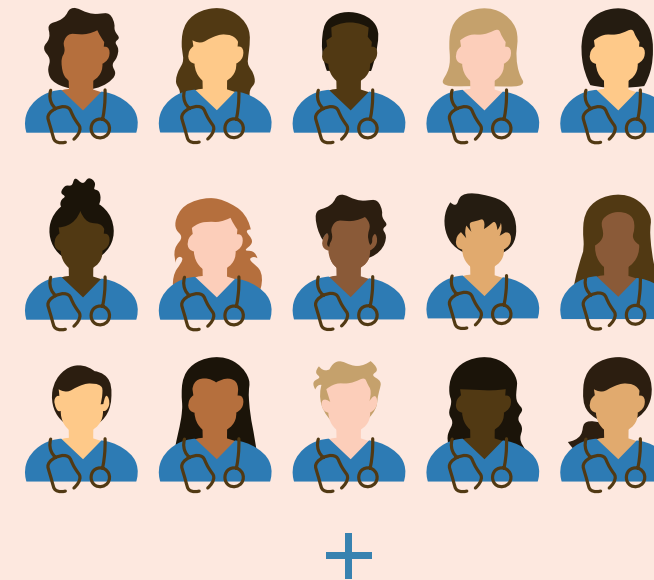


OB/GYN Residency Education

Our first patient-led grassroots campaign aims to address the current gaps in OB/GYN resident education. We're advocating for Obstetrics and Gynecology (OB/GYN) residency programs to provide training on the diagnosis and management of common chronic vulvovaginal and pelvic pain conditions. OB/GYNs must be able to evaluate patients for chronic vulvovaginal conditions and treat patients respectfully. If all OB/GYNs were equipped to effectively manage these conditions, it would dramatically increase access to care for patients and decrease incidents of medical trauma.

more than **50%** of people who sought care for chronic vulvar pain received no diagnosis.

35% of people with provoked vestibulodynia went to more than **15 appointments** before receiving a diagnosis.



37% reported more than **36 months** between first symptoms and receiving a diagnosis.

64% of current Minimally Invasive Gynecologic Surgery (MIGS) fellows stated that their OB/GYN residency did not prepare them at all (or only slightly) to care for patients with chronic pelvic pain. **42%** of fellows reported receiving no formal training in residency related to chronic pelvic pain.

60% of women who sought care saw **3** or more doctors, many of whom could not provide a diagnosis.

10-28% of women in the United States will develop chronic vulvar pain at some point in their lifetime.

Chronic pelvic pain accounts for **10%** of all gynecology office visits.

The economic costs of chronic pelvic pain were conservatively estimated in 1996 at **\$2.8 billion** annually (equivalent to **\$5.8 billion** in 2020) in the United States alone.

Sources

[Chronic Pelvic Pain Educational Experience Among Minimally Invasive Gynecologic Surgery Fellows and Recent Graduates: A Needs Assessment](#)

[Prevalence of Symptoms Consistent with a Diagnosis of Vulvodynia: Population-based estimates from two geographical regions](#)

[Chronic Pelvic Pain in Women: A Review](#)

[The diagnosis of provoked vestibulodynia: Steps and roadblocks in a long journey](#)

Community Organizing

Tight Lipped is using a community organizing framework for building and running our first campaign. **Building a constituency and a team of volunteers marks the first stage of any grassroots campaign.** This year we've had hundreds of one-on-one conversations with community members, zoom calls for volunteers to meet each other and learn from medical providers, and in-person programs to learn about the gaps in OB/GYN residency education. Each time we met with community members, we shared our collective vision and strategy for addressing this issue.

Expanding our Core Team

In February, we established our six-person Core Team to guide our strategic planning for 2022. This team has been responsible for setting Tight Lipped's goals, strategy, and vision for our community organizing work. Individual Core Team members have represented Tight Lipped at conferences and events and given presentations about our work to local and national audiences.



Noa Fleischacker, Hannah Srajer, Stephanie Histon, Sarah Minion, Kevinn Poree, and Swathi Mettela.

Special thanks to our 2022 interns, Grace Culqui and Tiffany Yuen, who worked with our team to grow and expand our community organizing efforts.



February



April



May



October

Leadership and Strategic Planning Retreats

We organized and hosted four strategic planning retreats this year to lay the groundwork for our campaign. These retreats included training in base-building, storytelling, and campaign development with Midwest Academy, a community organizing training institute. The retreats allowed us the time and space to conduct research and speak to stakeholders to gain a better understanding of the medical education landscape.

Growing our Movement

The community we're building is always at the center of our work. This year, we hosted community and campaign events across the country. We facilitated one-on-one and group virtual meetings and recruited new volunteers from eight different cities: New York City, Philadelphia, Chicago, Boston, Washington, DC, New Orleans, Los Angeles, and New Haven.

New Orleans: In May, we hosted our first-ever community event in the South. Planned by Core Team member Kevinn Poree, the Tight Lipped Bayou Bash in New Orleans brought together community members from across the region and was an inspiring night of deep conversation about the state of care for vul-



Tight Lipped 2022

vovaginal pain in Louisiana, Mississippi, and Alabama and barriers that community members have encountered.

New York City: In September, we hosted a "New York City Meet-Up" where patients came together to talk about diagnostic delay and difficulty accessing care. Core Team members Swathi Mettela and Sarah Minion facilitated a training session where participants learned about the key issues of our first campaign and divided into committees to work on research, storytelling, and building relationships with medical providers.

New Haven: Core Team member Hannah Srajer has been building out our membership base in New Haven. The Connecticut city will be one of the first to run our full campaign focused on OB/GYN residency education. Srajer and a team of graduate students, medical students, and community members hosted events in November and December, flyer-ed around the city, and began building relationships with relevant stakeholders in the university hospital system. Starting as a team of two, there are now 28 active members in New Haven who are dedicated to fighting to win the campaign together!

Los Angeles: In November, Tight Lipped volunteer Arielle Friedtanzer hosted our first-ever community event on the West Coast for people with chronic vulvovaginal pain in Los Angeles and San Diego to meet each other. The event was facilitated by Tight Lipped community members Becky Feldman, Sarah Ponce, Arielle Friedtanzer, and Noa Fleischacker and included comedic performances, creating vulva-themed art, swapping stories, and learning how we can take collective action together.



Virtual Events: We've continued to host virtual events to build community and share resources. Early in 2022, our volunteers organized "No More Silence: Talking about Vulvovaginal Pain," a conversation for community members ages 60 and up. The first event was focused on finding hope and positivity in our experiences and sharing how we practice resilience and cope with chronic pain. During the second event we shared tools and discussed how to advocate for ourselves in a medical context and common challenges we face navigating healthcare. In January 2022, Tight Lipped community member Sara Edwards facilitated a session about communicating about painful sex. In February, community member Rachel Hoh organized a Tight Lipped Queer Book Club for community members to meet each other and share their stories.

Tight Lipped in the Media:

The Washington Post:
[Sex in your 20s is supposed to be easy. For some women, it's painful.](#)
by Netana Markovitz

Giddy:
[The Patchy History of Vaginal Pain Treatments](#)
by María Cristina Lalonde

"Women can go decades before getting a diagnosis, resulting in years of pain [and] emotional suffering."

- Dr. Sara McKinney

Our Medical Advisory Board

As patients, we know how critical it is to have medical experts and allies in our corner. There are dedicated medical professionals across the country working towards better care for people with chronic vulvovaginal pain, and we're honored and grateful to welcome many of them onto our Medical Advisory Board.

Tight Lipped's Medical Advisory Board is responsible for providing medical and scientific guidance in support of our patient advocacy and community organizing work. The board will ensure that the patient community and medical experts are aligned on the standards for clinical care and medical training and education.

“Tight Lipped is a wonderful advocacy organization that was started by patient advocates who have vulvovaginal pelvic pain and who are pissed to high heaven about why their doctors don't know anything and why'd it take so long to get a good diagnosis and to see people who know what they're doing. And they have banded together and they are changing the world. They are going to change medical education, they are going to change everything because that's what it takes. It takes an army of pissed off people.”

- Dr. Rachel Rubin, Chair of Tight Lipped's Medical Advisory Board 2022-2023



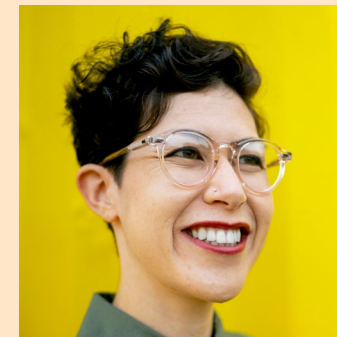
Rachel Rubin, MD
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Janeane Anderson, PhD, MPH
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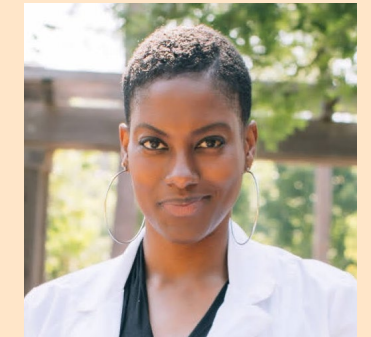
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Juan Michelle Martin, PT, DPT
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Obstetrician and Gynecologist
Brookline, MA



Kiran Sigmon, MD
Obstetrician and Gynecologist, Lifestyle Medicine Clinician
Asheville, NC



Alyssa Yee, MD
Sexual Medicine Physician and Reconstructive Urologist
San Diego, CA

Presenting Patient Perspectives

American Urological Association's Annual Meeting

In May, we attended and presented at our first in-person medical conference, the American Urological Association's (AUA) annual meeting in New Orleans. Our team members Hannah Srajer, Noa Fleischacker, and Kevinn Poree had the opportunity to brainstorm, strategize, and share ideas with many urologists and sexual medicine specialists who are changing the landscape of pelvic health.

Hannah Srajer gave a presentation titled, "The Voice of the Patient: Pelvic Pain Patient Advocacy and Perspectives in Urological Disease Management." She spoke on the need for urologists to recognize and address overlapping urinary and pelvic pain symptoms as part of the AUA's new Patient Perspectives Program. The AUA received a



high level of interest in this initiative, and our abstract was one of only a handful accepted for presentation.

Let's Talk About It: Undoing the Stigma Around Vulvar and Vaginal Health

Medical Herstory, an international youth-led non-profit on a mission to eliminate sexism, shame, and stigma from health experiences hosted an event focused on pelvic pain. Tight Lipped's Noa Fleischacker presented about her personal healthcare journey and spoke about the need for pelvic pain patients to take collective action to change how we're represented in mainstream media and medical research.

"Ten years after my UTI-like symptoms began and derailed my life, I once again met with urologist after urologist. Only this time I was not looking for a diagnosis, and I was not alone. Instead, I was meeting with providers to talk about Tight Lipped and all the ways physicians can take action to support their patients and change how vulvovaginal and pelvic pain is treated."

- Hannah Srajer

"I remember almost a decade ago when I received my first diagnosis. I felt such intense shame and confusion that I wasn't willing to tell anyone what I was going through. I never would have imagined that I would get on a plane and fly to another state to tell my story."

- Kevinn Poree

Obstacles to Care: The Patient Experience

We presented at the Chicago Medical Student Forum's events on improving and overcoming obstacles to care in female sexual medicine. These events consisted of two panels with patient advocates sharing their stories, research, and advocacy work to medical students who are interested in improving the field of female sexual medicine.

Building Relationships with Medical Providers

Tight Lipped organized virtual community meetings with medical experts and providers across the country. We spoke to OB/GYNs, epidemiologists, pelvic floor physical therapists, urologists, sexual medicine specialists, and researchers to bridge the gap between patients and providers. Our community members joined these conversations and asked questions about the landscape of OB/GYN residency education and how we can work together to change vulvovaginal pain care.



SisterSong Reproductive Justice Conference

Tight Lipped Core Team member Kevinn Poree presented at the 2022 Let's Talk About Sex (LTAS) conference, hosted by SisterSong in Dallas, Texas. The presentation was titled "Tight Lipped: Navigating Life with Vulvovaginal Pain" and many of the participants identified as having chronic vulvovaginal and pelvic pain. One attendee said that it was the first time she had found a space to talk about her pelvic pain experience in a reproductive health conference setting. Kevinn spoke about the need to address vulvovaginal pain in a reproductive justice context and how we can collaborate to address overlapping issues, such as medical gaslighting and difficulty accessing care.

"This community helped me find the care I needed and has the potential to help so many people with their advocacy and by organizing those affected by these conditions to demand better care."

- Suzanne Greene

Looking Ahead

Award and Publication

The Organization of American Historians awarded Tight Lipped core team member and Yale University PhD candidate Hannah Srajer the 2022 Louis Pelzer Memorial Award for her paper on vulvovaginal pain. Hannah's work, "Imperfect Intercourse: Sexual Disability, Sexual Deviance, and the History of Vaginal Pain in the Twentieth Century United States," examines the legal and medical history of vaginal pain.

Hannah's work expands the field of disability history to include vaginismus. She charts the development of "psychosomatic gynecology" and Freudian approaches to vaginal pain from the 1930s to the 1960s. Hannah reveals how the US medical community has often conflated sexual disability, particularly genital disability that prevents vaginal penetration, with gender and sexual queerness. The committee members wrote that Hannah's work was an "extraordinary shift in the way we think about law and marriage. This changes the framework." One committee member added, "I was blown away."

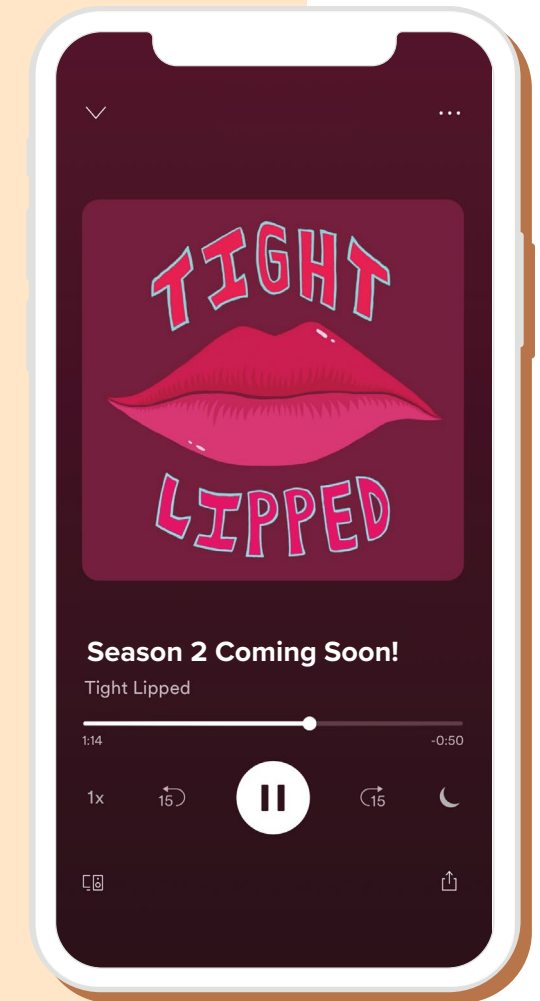
Hannah's paper will be published in the March 2023 issue of the Journal of American History, one of the most prestigious US history publications.

Our Second Podcast Season

In 2022, we hired a team of experienced and talented podcast production team members and spent months researching, interviewing, and producing five episodes for our second season, including one in Spanish. The season will be released in early 2023 and the episodes will explore topics such as navigating relationships and intimacy with vulvovaginal pain; the "sexual dysfunction" category of the DSM; and stories from medical students and providers about medical education on these conditions.

We will be sharing narratives and histories that are closely tied to our grassroots campaign, such as the paucity of adequate medical education on vulvovaginal pain and the historic and contemporary psychologization of these conditions.

Ava Ahmadbeigi *Story Editor*
Hannah Barg *Executive Producer*
Sararosa Davies *Production Assistant*
Noa Fleischacker *Editor and Host*
Olivia Good *Writer*
Angela Johnston *Writer*
Delilah Righter *Associate Producer*
Kalaisha Totty *Production Assistant*



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...and 30+ anonymous donors

“Tight Lipped is the reason I sought treatment for my pelvic floor pain, and the reason I was able to advocate for myself with my doctors. Thank you Tight Lipped!”

“So proud of this organization and fully support this campaign! As a family medicine resident, I hope this will improve education to get patients the care they need.”

“Thanks for this important work. If it helps even one woman avoid years of misdiagnosis and being told the pain is psychological, it will be worth it!”

“Love being part of Tight Lipped! Tight Lipped has brought community, friendship, clarity, and new avenues of empathy to my life.”

“The work you do is so important and amazing. The podcast blew me away. I'm so impressed by the depth of the research on the history of women's health, patient rights advocacy and racial bias in health care. Should be shared with everyone who seeks healthcare or provides healthcare.”

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