

**TIGHT
LIPPED
ANNUAL
REPORT
2021**

Our Story

Tight Lipped launched in May 2019 as a curated storytelling podcast providing a platform for public conversation about chronic vulvovaginal and pelvic pain conditions. 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 for the first time they felt empowered to speak openly about their symptoms and seek care for their conditions.



Our New York workshop in November 2019



Spring 2021 team meeting

A small team of volunteers, each with a personal history of pain and medical gaslighting, came together to facilitate community workshops, create and distribute our zine, and bring patients together to fight for change. This year, we reached over 500 participants through 14 virtual events, including educational workshops for college students, presentations on the patient experience for medical students, and community-building programs for our broad network. We expanded

our staff and volunteer team and reached thousands of new community members around the world. We began visioning and planning for our expansion as the first and only grassroots movement working to change how healthcare systems treat people with these conditions. Even in a difficult year when we were not able to meet or work together in person, Tight Lipped's team, community, and podcast listenership has grown immensely. We're excited to share with you our work from 2021.



Backyard Bash October 2021

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.

2021 in Numbers



18,168 podcast downloads



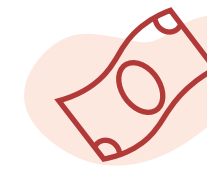
Listeners in 78 countries



1,404 newsletter subscribers



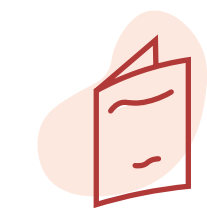
21,000 website views



\$150,000 raised



4,150 followers on social media



700 copies of our zine, *Opening Up*



This year we hosted our biggest-ever event with 115 attendees.

Community Reach

This year we hosted, organized, and facilitated more events and programs than ever before. These programs brought people together to create community, share stories, and identify how our deeply personal, intensely isolated experiences overlap. Many people with chronic vulvovaginal and pelvic pain don't know that they have a legitimate medical condition and, if they do, feel uneasy speaking up. Tight Lipped's programs have helped people understand their personal experiences in the context of broader systemic issues in the healthcare system. Our volunteers and leaders demonstrate how speaking out can be powerful and liberating rather than shameful and alienating. This kind of transformation not only destigmatizes people's pain, but also empowers patients to advocate for themselves in the doctor's office and beyond.



Opening Up: We hosted a virtual community building event centered around the zine for 115 people from around the world. Many participants were surprised by how much in common we all had with one another.

Zine Distribution: We held "zine action calls" for community members to form volunteer teams and get the word out about the Tight Lipped zine to friends, family, college students, and medical providers. 30 community members joined and helped distribute copies of the zine around the country.

Student Workshops: We organized and facilitated educational events for college students for the first time. Tight Lipped leaders spoke and presented their personal stories and common patient experiences at Washington University in St. Louis and Bryn Mawr College.

Film Fest: Our team member Hannah Srajer spoke about vaginismus at the Skin A Cat movie premier at Femme Folks Fest.

Press Conference: We hosted a press conference to launch the digital zine and showcase the stories of those who have navigated serious barriers to care. The event focused on racial and gender disparities in how the healthcare system treats people with vulvovaginal pain conditions. Speakers included: Dr. Tayyaba Ahmed, Ankita Patel, Jazzmine Brooks, Stephanie Leonard, and Hannah Srajer.

Book Clubs: Our book clubs welcomed new members this year and took different forms each time they met. In October, Tight Lipped leader Rachel



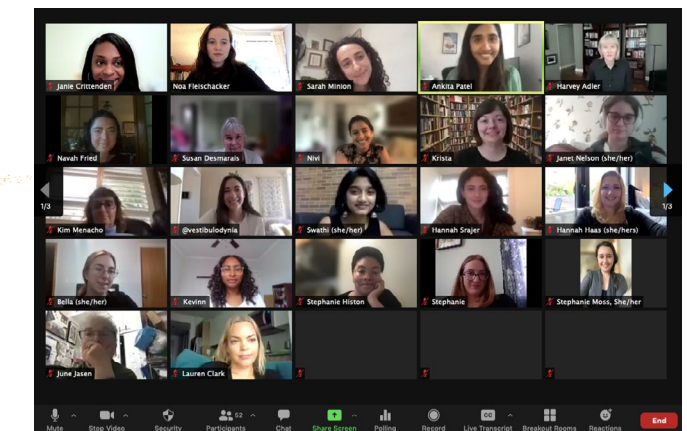
Hoh organized a book club for anyone who identifies as queer to talk about navigating doctors, pain, and partners. In November, Tight Lipped leaders Rebecca Ostroff and Krista McKinney organized "To Disclose or Not to Disclose" a book club to discuss navigating painful sex and dating.

Backyard Bash: We hosted our first-ever in-person fundraiser in Brooklyn. We loved getting a chance to meet community members in person, play Tight Lipped-themed trivia, and swap stories over our signature cocktails.

Community Writing Conference: Tight Lipped leaders Sarah Snider and Noa Fleischacker presented "Perilous Narratives: Writing Activism and Pedagogies of Change," looking at the Tight Lipped zine as an example of community-based creative writing and a tool for teaching in the classroom.

Roadmap to Healing: We gathered for a community event with sessions on navigating cultural impact on care, advocating for yourself with a medical provider and reclaiming your body. This event was organized and facilitated by Tight Lipped leaders Janie Crittenden, Stephanie Histon, Swathi Mettela, Ankita Patel, and Kevinn Poree.

It Hurts Down There: We collaborated with DES Action, an organization for individuals exposed to DES (a synthetic estrogen prescribed to millions of pregnant women from the 1940s-1970s) to host a private discussion for people with vulvovaginal and pelvic pain.



No More Silence: This was our first program and community conversation specifically for post-menopausal people with vulvovaginal and pelvic pain, organized by Tight Lipped leaders Geri Hutchings and Susan Desmarais.

Our Zine

In the Fall of 2020, we launched and distributed *Opening Up*, an 80-page printed zine that includes art, poetry, and prose compiled from more than 50 contributors who submitted their stories about living with vulvovaginal and pelvic pain. Volunteers created, wrote, designed, edited. We distributed over 700 copies to medical providers' offices, college campuses, and individuals with these conditions. In the Spring of 2021 we released the digital version of the zine, which has reached over 1,800 readers and includes audio recordings from zine authors or other members of our community.

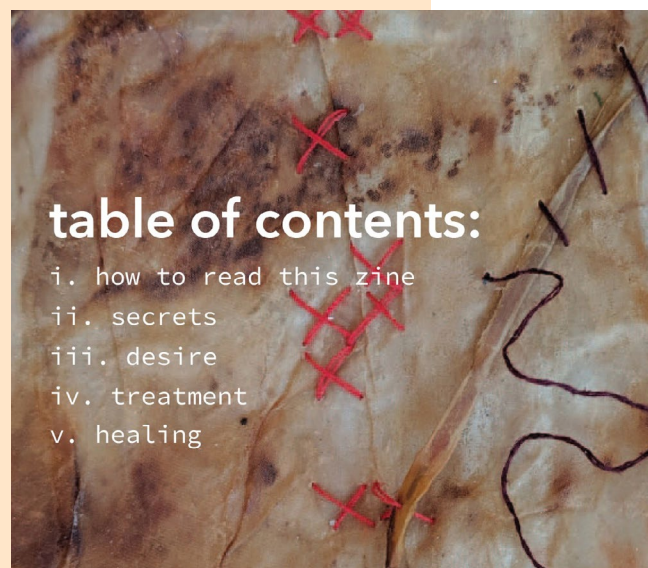


table of contents:

- i. how to read this zine
- ii. secrets
- iii. desire
- iv. treatment
- v. healing

Medical Education

This year, the Tight Lipped team worked closely with medical providers and medical students to raise awareness about vulvovaginal and pelvic pain. Our team reached out to providers around the country to share our experiences and build relationships.

Chronic Pelvic Pain and Pain with Sex Event: In April, Tight Lipped leaders planned and facilitated an educational event for 30 medical students at Pennsylvania State College of Medicine to learn about common patient experiences and barriers and obstacles to care.

Medical Student Forum on Female Sexual Medicine Symposium: Noa Fleischacker was an invited guest speaker at the symposium, the cutting edge of medical student education on these conditions.

International Society for the Study of Women's Sexual Health (ISSWSH) Conference: Our team members Hannah Srajer and Noa Fleischacker attended the ISSWSH conference for the first time to build relationships with providers and learn more about the current state of sexual medicine.

"As a pelvic health physical therapy practice we are extremely passionate about helping people with vulvovaginal pain and other pelvic pain conditions. Thrilled that this exists so people feel less alone! Awareness and advocacy is so important!"

- Jessica Reale, PT

"Thank you so much to the creators and members of the Tight Lipped team for speaking to our disability advocacy and awareness group at the Penn State College of Medicine. It was truly an eye opening experience for everyone involved and we could not be more grateful."

- Lauren Mazur

"I aspire to be a pelvic floor therapist and I believe hearing personal stories is just as important as taking classes to further my education. [The zine] will further my understanding."

- Marianne Meneses

Chronic vulvovaginal and pelvic pain refers to a variety of conditions that cause: **vulvar burning, rawness, itching, and pain; pain with penetration, UTI-like symptoms, pain with urination, sitting, and tight pants.** These conditions can impact women, non-binary, and transgender people’s reproductive choices, sexual and mental health, ability to work and participate in daily activities, and ability to maintain personal bodily autonomy in intimate relationships and health-care settings.

While these conditions are shrouded in stigma, shame, and silence, they are remarkably common. Epidemiologist Dr. Bernard Harlow, at Boston University, **describes the prevalence of chronic vulvovaginal pain as a public health crisis. These conditions are under-researched, under-funded, and generally misunderstood by the medical community and broader society.**

10–28%
of women will experience chronic vulvar pain in their lifetime

As of December 2021, PubMed has almost **4 times** as many clinical trials studying erectile dysfunction as it has on vulvovaginal pain:



Nearly **40%** of women with vulvodynia never seek medical treatment

60% of women with vulvodynia who seek treatment see **3** or more doctors, many of whom could not provide a diagnosis

35% of people with vestibulodynia attended more than **15** appointments before receiving a diagnosis

More than **50%** of people who sought care received no diagnosis

The NIH allocates just **33 cents** for every patient which is far lower than typical research dollars for similarly prevalent conditions.

Vulvovaginal pain is common in people of all racial and ethnic backgrounds, yet limited access to healthcare resources makes it difficult for people to find care, leading many low-income patients and patients of color to live in pain and silence without diagnosis or treatment. Those who have the financial means and geographic access to seek medical treatment often encounter medical providers who minimize the seriousness of their pain, discount their symptoms as “all in their head,” and lack the training to properly diagnose and treat their condition. **The medical system mirrors a wider problem: we, as a society, don’t see vulvovaginal pain as real or deserving of research, care, and attention.**

Sources

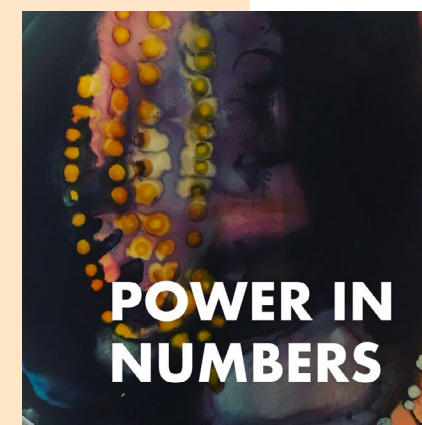
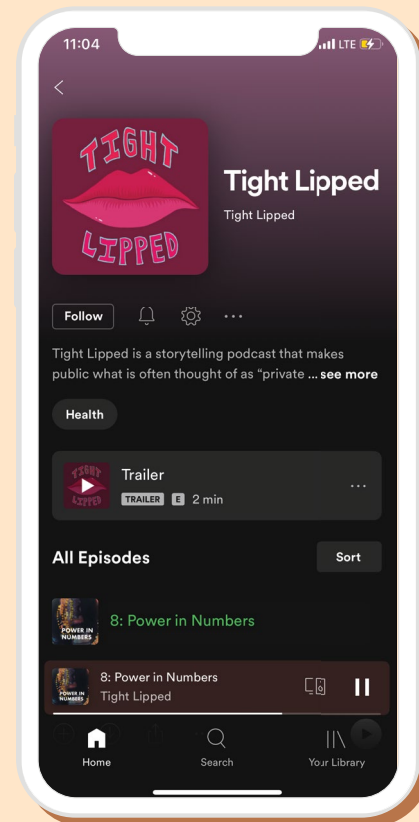
- [Prevalence of symptoms consistent with a diagnosis of vulvodynia: population-based estimates from 2 geographic regions](#)
- [The diagnosis of provoked vestibulodynia: Steps and roadblocks in a long journey](#)
- [A population-based assessment of chronic unexplained vulvar pain : have we underestimated the prevalence of vulvodynia?](#)
- [Estimates of Funding for Various Research, Condition, and Disease Categories \(RCDC\)](#)
- [The female price of male pleasure](#)

These conditions impact non-binary, transgender, and people of all genders. The studies cited here looked at cisgender women with vulvovaginal pain.

Podcast

In Spring 2021, Tight Lipped wrapped up **Season One of our podcast, which has reached over 18,168 downloads.** The first season of the Tight Lipped podcast examines how the history of hysteria, politics of medical research funding, social pressure and norms, and public sexual discourse have kept people silent about vulvovaginal and pelvic pain for so long. Each episode features personal stories of those living with these conditions alongside insight and analysis from medical professionals, academics, journalists, and experts who study vulvovaginal healthcare through a medical, scientific, social, and cultural lens.

In our last episode of the season, we showed **what's possible when patients, researchers, and policy-makers come together to fight for a healthier, more hopeful future.** We concluded the episode with voices from our community who told us how much **Tight Lipped's work has inspired and empowered them to seek treatment, advocate for themselves in the doctor's office, strip away their shame around their vulvovaginal pain, and foster a more positive relationship to their conditions and their bodies.**



Season Two

The Tight Lipped Podcast Team is storyboarding, scripting, and developing the second season of the podcast. The second season will provide political education for Tight Lipped listeners and community members in order to support future organizing campaigns. This season will focus on sharing stories that resonate with people's personal experiences, enabling listeners to see their own stories in a broader context, and motivating them to get involved in our community.

Our second season will explore topics such as:

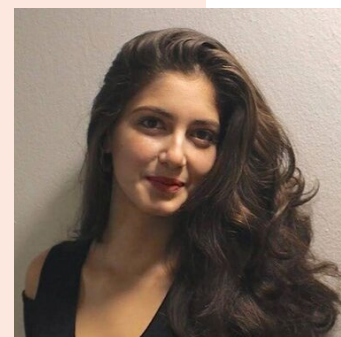
- Medical education and training
- How racial, ethnic and cultural background can impact someone's relationship to their vulvovaginal pain
- Insurance coverage and access to treatment and care
- How individuals navigate relationships and sexual intimacy when sex hurts
- The history of the "sexual dysfunction" category of the DSM and the psychologization of vulvovaginal pain

Our Team

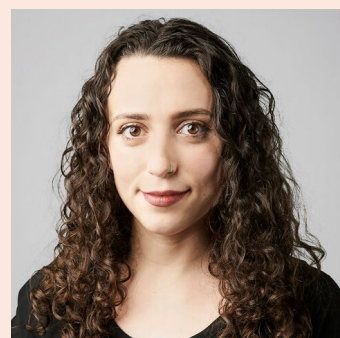
Tight Lipped's work this year would not have been possible without our team and our many volunteers and leaders who have bravely spoken up and taken on responsibility for changing how vulvovaginal pain is treated and understood. We are incredibly grateful to have so many passionate and dedicated community members and volunteers who planned events, facilitated book clubs, publicized and distributed our zine, and brought new folks into our community this year.



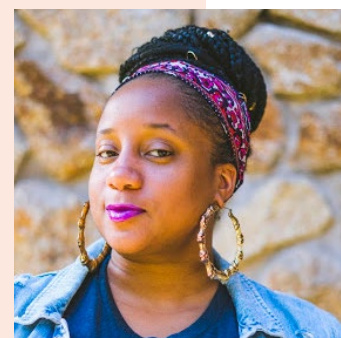
Noa Fleischacker
Executive Director



Hannah Srajer
Community Organizer



Sarah Minion
Community Organizer

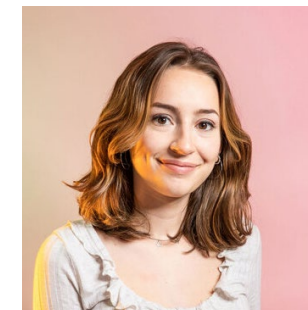


Brandi Collins-Calhoun
Development Associate

Interns and Fellows



Grace Anderson
Intern, Spring 2021



Eve Bishop
Intern, Spring 2021



Mira Hartshorn
Intern, Spring 2021



Valeria Donoso
Social Media and Research Fellow, 2020-2021



Sophia Lo
Intern, Spring 2021

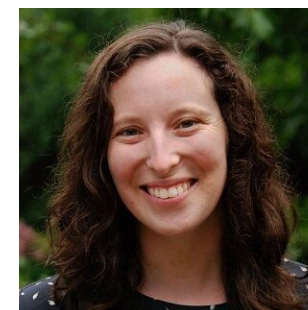


Rebecca Magnan
Intern, 2020-2021



Tiffany Yuen
Intern, Spring 2021

Podcast Team



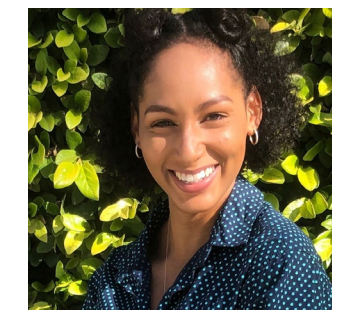
Hannah Barg
Executive Producer



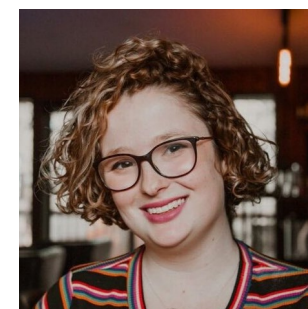
Ava Ahmadbeigi
Story Editor



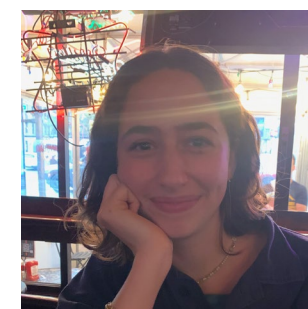
Olivia Good
Story Writer



Kalaisha Totty
Production and Research Assistant



Sararosa Davies
Production Fellow, Spring 2021



Delilah Righter
Production Intern

Press & Awards

- [I Have Vulvodynia. This Is How I Have Sex](#) by Mark Hay
- [Vaginismus Is Not All in Your Head](#) from Breath Physical Therapy
- [Women Are Given the Wrong Treatment for UTIs Nearly Half the Time. Here's Why](#) by Anne Branigin
- [Hidden Pain: Vulvodynia](#) by Devon Fegen-Herdman
- [Women's History Month: Pelvic Health Edition Feature](#) from Chronicle's of a Broken Body
- [Painful Sex Shouldn't Be a Mystery Condition](#) by S. Nicole Lane
- [Building Community & Advocacy for People with Vulvovaginal Pain Conditions](#) by Jessica Reale
- [The Sexual Fantasies Episode](#) from Joy of Text
- [Podcast Spotlight: Tight Lipped](#) from EarBuds Podcast Collective
- [When Private Pain Becomes Public: One Organization's Quest to End the Stigma around Vaginal and Vulvar Pain](#) by Madhu Kandasamy and Sophie Tucker
- American Jewish Press Association Award for Arts Reporting, Second Place, Hannah Srajer and Mari Cohen, [Unorthodox Bodies](#) in Jewish Currents

“My journey with pelvic pain has been long and deeply traumatizing. It is thanks to people who vocalize the taboo that I’ve found the courage to advocate for myself and to tell the people around me that they’re not alone either. Thank you.”

- Cassie Gherardini

“I'm so glad you all are doing the work to break the silence around this. I loved the community building event and want to support however I can!”

- Alice Wilder

“I binged the entire podcast in one day (and cried, and laughed, and all of the things). I felt validated and seen in ways I hadn't before.”

- Severine Stier

Connect with us:

www.tightlipped.org



Instagram: @tightlippedorg



Facebook: facebook.com/tightlippedorg



Twitter: twitter.com/TightLippedOrg