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# **Tight Lipped**

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# **Annual Report**

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# **2020**

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# Numbers

In 2020, Tight Lipped grew, expanded, and developed our storytelling podcast and community organizing initiatives.

875

Our email newsletter grew to 875 subscriptions.

2  
7,400

The Tight Lipped podcast had over 7,400 downloads this year.

64  
3

We have listeners and participants from all over the world, including 64 countries.

21,581

Our website reached 21,581 people with 15,934 hits in 2020.

2,800+

We have over 2,000 followers on Instagram, 550 on Facebook, and 250 on Twitter.

# 65

Tight Lipped hosts six different virtual book clubs with a total of 65 members, led by trained facilitators.

# 425

We distributed 425 copies of our zine, *Opening Up*.

# \$48,000

We grew our annual budget from \$0 in September 2019 to \$48,000 in December 2020.

# 14

We brought in 14 new volunteers, including 4 interns.

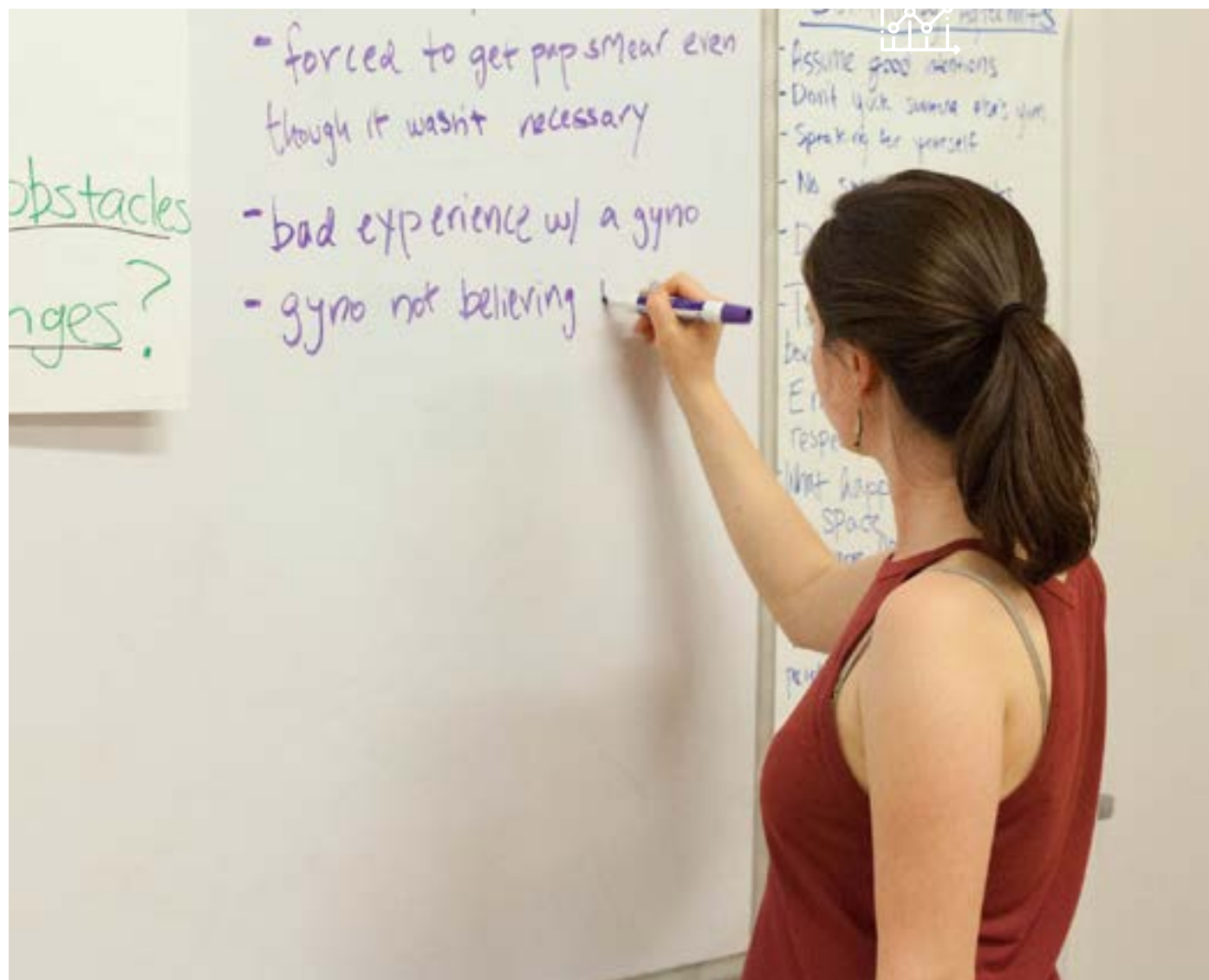
# \$13,000

Our first fundraising effort raised over \$13,000 from small-dollar donors.

# 170+

We have received an outpouring of support for our work, including over 170 written testimonies by people with these conditions and medical providers.

**Working Mission Statement:** *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 core values

**1. Creating a Public Conversation:** We see value in speaking openly, honestly, and publicly about vulvovaginal pain. We tell our personal stories and commit to listening and sharing these stories in public forums because we know how isolating these conditions can feel.

**2. Systemic Change:** We see underlying systemic problems in how the healthcare system views, understands, and treats chronic vulvovaginal and pelvic pain. Our work is directed at the root causes of diagnostic delay, ineffective treatment, and negative social attitudes towards these conditions. We want to see concrete and tangible change from private and public institutions that will improve people's daily lives.

**3. Destigmatization:** We actively break the silence and secrecy that have accompanied these conditions for centuries. We believe that no one should live in shame because they have vulvovaginal pain. We are committed to shifting the narrative to make clear that vulvovaginal pain is worthy of care. We underscore the high prevalence of these conditions (1 in 4) as a way to destigmatize and build collective power.

**4. Scientific and Medical Knowledge:** Our work is driven by and rooted in scientific and medical research. We are committed to educating ourselves about the latest research, clinical trials, and medical findings. We work in collaboration with researchers and medical

professionals.

**5. Embodied Knowledge:** We are experts in our own bodies and our own lived experiences. We honor the personal stories and experiences of people with chronic vulvovaginal and pelvic pain conditions. We know that patients are often more educated, knowledgeable, and well-versed in the issues contributing to misdiagnoses, ineffective treatment, and prolonged pain.

**6. Racial and Economic Equity/Justice Analysis:** We are committed to an anti-racist framework for every aspect of our campaigns and programs. We see how racism and classism impacts access to healthcare, insurance, and medical specialists. We believe healthcare is a human right.

**7. Disability Justice:** We take care of ourselves and each other. We understand these conditions as disabilities that profoundly impact our lives. We understand disability as social, political, and economic, and fight for accommodations for those who require it. We are dedicated to creating campaigns and programs that people living with chronic pain and chronic illness can actively participate in.

**8. Collective Responsibility and Collective Action:** We build relationships and bring people together into our work in a way that is sustainable, life-giving, and has urgency. Our leadership is made up of those most impacted by these conditions.

# Our story

8

Tight Lipped began with the Tight Lipped podcast, which launched in May 2019. In June 2019, we organized our first weekend-long workshop where individuals living with vulvovaginal pain conditions came together in one physical space. We sat in a circle, hidden away in the waiting room of a doctor's office loaned to us for the weekend. It felt symbolic: we'd all spent years waiting for this kind of community. As each person told stories about their pain, we saw how our deeply personal, intensely isolating experiences overlapped. By the end of the weekend we knew: we needed to build an organization that addresses the ways the healthcare system has failed vulvovaginal and pelvic pain sufferers. From there, we expanded from a podcast and informal group to begin the process of founding an advocacy organization that would change the ways that the healthcare system

treats people with chronic vulvovaginal and pelvic pain.

**OUR VISION IS SIMPLE: WE WANT A WORLD WHERE VULVOVAGINAL AND PELVIC PAIN IS BELIEVED.**

Our vision is simple: we want a world where this pain is believed. Where everyone receives accurate diagnosis and free, effective treatment. Where research institutions fund and prioritize these conditions, and where conversations about vulvovaginal and pelvic pain find their rightful place at the table. Where we decenter penetrative sex and 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 sex, pain, ability, and chronic illness.

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





# Core team



**NOA FLEISCHACKER, EXECUTIVE DIRECTOR**

Noa was raised in Evanston, Illinois and earned a B.A. in Anthropology, Education Studies, and Dance from Oberlin College. As the Executive Director, Noa manages the core staff, interns, and programs of TL. She leads all financial aspects of the organization, which include donor cultivation, grant writing and research, communicating with our fiscal sponsors, and overseeing the budget and accounting. Within the organizing branch, she builds relationships with volunteers, women's health and chronic illness advocacy organizations, medical professionals, community organizers, and nonprofit consultants. She also works on developing core team strategy, planning and executing core team retreats, and facilitating organizing retreats. Within the podcast branch, she hosts the podcast, writes the scripts and narratives, conducts medical and scientific research on podcast topics, and works with editors and marketing consultants.



**HANNAH BARG, PRODUCER & STORY EDITOR**

Hannah is a St. Louis, Missouri native with a passion for education, radio, and storytelling. Hannah graduated from Mount Holyoke College in 2014 with a B.A. in Anthropology. Hannah is currently based in Chicago where she works at a nonprofit and as a freelance audio producer. As audio producer and story editor of the Tight Lipped Podcast, she conducts interviews and pre-interviews with podcast guests, writes, edits, and scores podcast episodes, and builds relationships with podcast producers and editors from related shows. She is the sound engineer for the podcast and also designs our website and develops social media content.

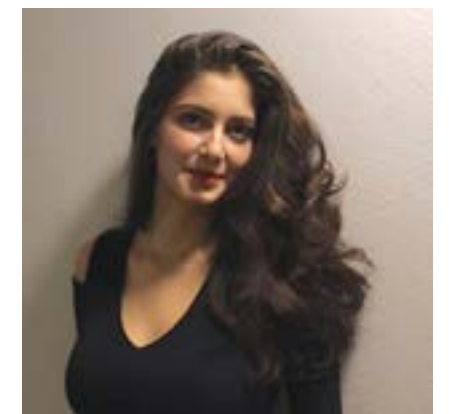


**SARAH MINION, ORGANIZER OF PUBLIC ATTITUDES**

Sarah grew up in New Jersey and lives in Brooklyn, NY. She graduated from Oberlin College where she studied American Studies, Politics, and Gender, Sexuality and Feminist Studies. As an organizer for ten years, she brings her experience to the role of organizer of Public Attitudes Projects. Sarah worked with a team of volunteers to create, publish, and distribute the zine, organize online events, conduct community outreach, and develop marketing materials. She works with the core team to develop long-term strategy and campaigns.

**HANNAH SRAJER, ORGANIZER OF MEDICAL ADVOCACY**

Hannah is a PhD student in the history department at Yale University, where she studies incarceration, healthcare, and social movements. As an organizer of Scientific and Medical Advocacy Projects, she conducts research and authors publications about these conditions, builds relationships with scientific and medical professionals, and carries out recruiting conversations with people who have these conditions. As a core team member, she leads the private small-dollar donation fundraising effort, writes and edits grant proposals, develops language about the organization, and advances long-term strategy and campaigns.



# Interns and fellows



**VALERIA DONOSO**  
**RESEARCH & SOCIAL**  
**MEDIA FELLOW**

Valeria was born and raised in Miami, Florida. She is a Posse and Bonner Scholar and a junior Biology Major on the Pre-Medical Track at Davidson College in North Carolina. At Davidson College, Valeria is the Vice-President of the Rape Awareness Committee, a Mathematics Tutor, and a member of Latinas Promoviendo Comunidad, Lambda Pi Chi Sorority, Inc. Valeria focuses on particular research questions that relate to medical training and education, vulvovaginal and pelvic pain symptomatology, diagnosis and treatments, and access to care. She creates graphics and content for our social media accounts and takes part in meetings with relevant medical professionals and experts.



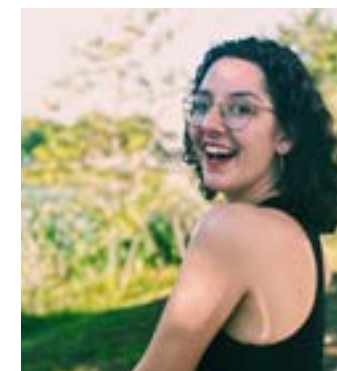
**SARAROSA DAVIES**  
**STORYTELLING &**  
**PRODUCTION FELLOW**

Sararosa is a Minnesota native and recent graduate of the University of Oregon's School of Journalism and Communication. Sararosa was a production assistant at opbmusic from Oregon Public Broadcasting; she currently works as audio editor for Spooning with Spoonies, a podcast on chronic illness and romantic relationships. She assists in pre and post production work for upcoming podcast episodes by conducting interviews and organizing transcripts and interview materials. She works with the podcast production team to draft and edit scripts and score music in the episodes, and creates content for our social media accounts related to our podcast's topics and themes.



**REBECCA MAGNAN**  
**SUMMER INTERN**

Rebecca was raised in Hollywood, Florida and currently attends Pomona College. She is studying public health and working towards a B.A. in Public Policy Analysis and Art, hoping to one day become an Osteopathic Physician. Rebecca researched questions related to episode topics such as the history of racism in endometriosis diagnosis and racial differences in hysterectomy rates. She also created graphics and content for our social media accounts and grew our instagram presence and followership. She continues to volunteer with us and works on graphic design and content creation.



**ABBY CALI**  
**VISUAL STORYTELLING**  
**FELLOW**

Abby is an artist, writer, and educator based in Baltimore, MD and is a current MFA candidate at MICA's Illustration Practice Program. She is the co-editor of Rise, a collaborative book of poetry, prose, and visual art by survivors of sexualized violence. At Tight Lipped, she designed graphics, gifs, and contributed art to our zine, *Opening Up*.

# Our organization



Tight Lipped has evolved from a conversation between friends to an established organization with fiscal sponsorship, a growing budget, a paid staff member, and an army of volunteers. TL has three part-time (20 hours/week) core team volunteer members, Sarah Minion, Hannah Srajer, and Hannah Barg; Noa Fleischacker (50 hours/week) became a paid employee in August of 2020. In April of 2020, we became a fiscally sponsored project of the Social Good Fund. In the past fourteen months, we have grown our budget from \$0 in September 2019 to \$48,000 in December 2020. Our funders include The Vagina Collective, the National Vulvodynia Association, the Dorot Fellowship, and private donors.

As we've expanded, the Tight Lipped team has worked to define our mission. TL held two week-long Strategic Core Team Retreats in September 2020, where we set goals and timelines for our first campaign launch, defined and refined our mission statement, solidified our team roles and responsibilities, and developed relationships with providers and stakeholders. During this retreat, we were trained by the Midwest Academy, the Sunrise Movement, and Yotam Maron.

Tight Lipped has also been working with leaders in the nonprofit sector to strengthen and grow our organization. This year, we brought in two nonprofit consultants to help guide our fundraising development and three podcast consultants to guide our production and

marketing development. We also began the trademark process for our logo and name in September 2020, and have been working with an intellectual property lawyer to insure that we protect our organization from legal liability.

Throughout this year, we've expanded our volunteer-led team. Through the Posse Foundation, which "is rooted in the belief that a small, diverse group of talented students—a Posse—carefully selected and trained, can serve as a catalyst for individual and community development," we hired two summer interns, Valeria Donoso and Rebecca Magnan. They helped us craft and execute our community engagement strategy, and Valeria continues to volunteer with us part-time as a Research and Social Media Fellow. We also brought on Abby Cali as a Visual Storytelling Fellow and Sararosa Davies as a Storytelling and Production Fellow for the podcast.

We brought in 10 volunteers who helped create, design, and edit the zine. We've been recruiting additional volunteers who are involved in distributing the zine to ensure our work reaches chronic pelvic pain patients wherever they are in their journey. We've put together a distribution plan and strategy to reach pelvic floor physical therapists, medical professionals, medical students, college students, therapists, and others. Our team of volunteers has also expanded our social media presence and designed content to reach new listeners and participants.



# Community reach



The Tight Lipped Organizing Project has a global audience, reaching people with chronic vulvovaginal pain conditions all over the world. Our website has reached 21,581 people, with 15,934 hits in 2020. We have over 2,000 followers on Instagram, 550 on Facebook, and 250 on Twitter.

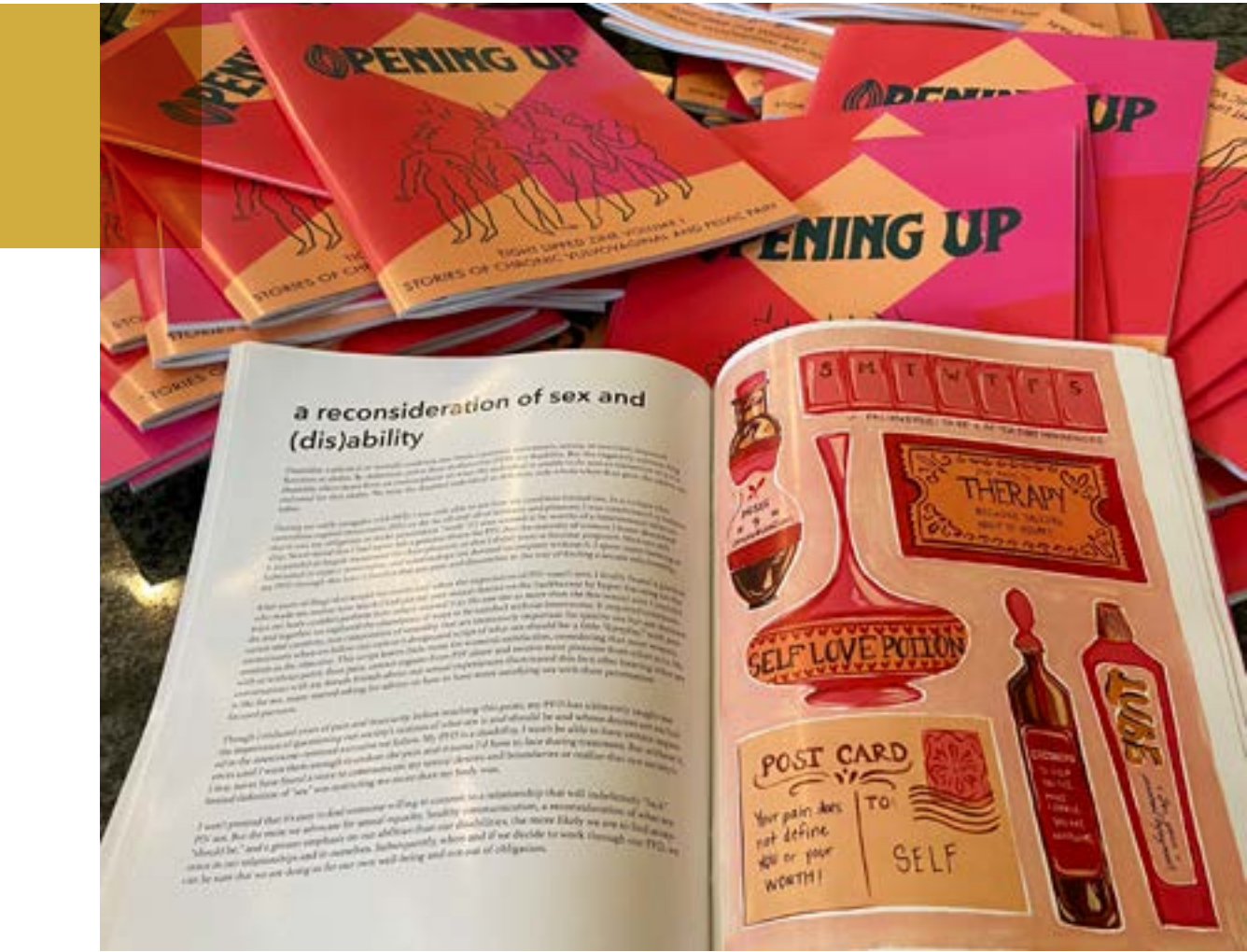
In addition to our larger initiatives, we've also hosted and facilitated three virtual events with 100 participants from all over the world, including a virtual film screening and conversation with the filmmaker with 45 attendees. At the beginning of the pandemic, we launched a virtual book club for 65 people with chronic vulvovaginal and pelvic pain, which has grown into six different groups across the country, each with their own trained facilitator.

This year we have also developed our personal and professional relationships. We have worked with and consulted epidemiologists, including Dr. Gregg Gonsalves, ACT UP AIDS activist and Professor of Epidemiology at Yale and Dr. Bernard Harlow, Professor of Epidemiology at Boston University who studies the prevalence of vulvodynia and pelvic floor disorders. Medical doctors and doctors of physical therapy number among our

champions: Dr. Georgine Lamvu, chair of the board of the International Pelvic Pain Society (IPPS), Dr. Alice Rothschild, OBGYN and a founding member of the feminist health collective and publication, *Our Bodies Ourselves*, Dr. Tanaka Dune, Urogynecologist, and DPTs Rhonda and Elizabeth Katorinos.

We have built lasting relationships with writers and scholars in the field of medicine, women's health, and health advocacy, including Professor Naomi Rogers, Maya Dusenbery, Paula Kamen, Christine Labuski, Mary Lou Ballweg, and Lara Parker. We have also connected with chronic disease and women's health activists, such as Christin Veasley, co-founder and director of the Chronic Pain Research Alliance, Cindy Pearson, Director of National Women's Health Network, and the staff of MEAction, an innovative organization leading the way in changing medical and public attitudes about Chronic Fatigue Syndrome. Tight Lipped has also built relationships with artists who address pelvic pain, including filmmaker Shelby Hadden (creator of *Tightly Wound*), filmmaker Savannah Magruder (creator of *Debbe Does Dilators*) and comedian Molly Brenner.

# Tight Lipped zine



To launch our community-building and community organizing work, we dedicated much of this year to creating and distributing the Tight Lipped Zine: *Opening Up*. The printed zine (DIY magazine) includes art, poetry, and prose compiled from more than fifty contributors who submitted their stories about living with chronic vulvovaginal and pelvic pain conditions. We received submissions from all over the world and the authors come from all different backgrounds and ages. The zine is 80 pages long and divided into four sections: secrets, desire, treatment, and healing. It includes pieces about navigating sex and intimacy, medical gaslighting, disability, and how these conditions profoundly influence our relationships to our bodies, identities, and sexualities.

We released *Opening Up* in October as part of our 2020 fundraising campaign and we’ve distributed 425 copies and raised \$13,000 from individual and small-dollar donors. We’ve heard from hundreds of readers that reading the zine was a deeply moving, emotional, and powerful experience for them and we’ve created a new “testimonials” page on our website to showcase the incredible messages and testimonies we’ve received from people who have ordered copies and donated. As part of our zine launch, we hosted a private virtual

event for the authors whose work is featured in the zine. We had over 25 attendees at the event and it was an opportunity for them to read and share their pieces, tell their stories, and open up to each other about their experiences.



*The Tight Lipped Zine was our first campaign within our Changing Public Attitudes Project.*



# Tight Lipped podcast



EMBODIED  
KNOWLEDGE

Like the Tight Lipped Organizing project, our podcast reaches listeners from around the world. We produced and released three podcast episodes and reached over 7,400 downloads this year from 64 countries. Each episode is 25-30 minutes long, utilizing a combination of written narration, interviews with relevant professionals, and stories of personal experiences. In addition to the three episodes we released this year, we also produced three episodes that we will release in early 2021. As two of our upcoming episodes explore how race and class impact patient experiences with diagnosis and treatment, we plan to release these episodes during Black History month in February.

This year, we worked with multiple marketing consultants to develop a strategic plan for building our listenership. We have multiple ads on different shows that will all be released at the same time as our three remaining episodes in early 2021, in order to draw new listeners into our show. We worked with related podcasts to cross-promote each other's episodes and feature each other's work on social media. We also had a consultation with Juleyka Williams, a well-known journalist, producer, and owner of her own podcast production company. Juleyka will continue to consult with us as we begin developing the second season of our podcast and building our marketing and publicity plan for 2021. We joined the Health Podcast Network, which will open up new possibilities for cross-promotion, audience growth, and developing our listenership.

The first episode from 2020, "A Broken Optimism," explored the message that many

of us grew up with, that "sex hurts the first time." We looked at how many people who have pain with sex spend years putting up with their pain without seeking medical advice or attention. The episode featured personal stories, as well as insight from sociologists and therapists, and looked at how popular culture and medical professionals often "normalize" vulvovaginal pain. The second episode we produced this year, "Did I dream?," discusses how a doctor's dismissal can lead you to question your own sanity. The episode looks into what patient advocates call "medical gaslighting," and details well-known activist and author Lara Parker's personal story. After years of dismissal from doctors, Lara started to wonder: Am I imagining it?

Our most recent episode, "Embodied Knowledge," looks at the history of the women's health movement of the 1960s and 70s. We tell the story of the founding of *Our Bodies, Ourselves* and explore how one group of women came together to build community, educate themselves, and change how we talk about and treat women's bodies. This fall, we collaborated with other like-minded podcasts to release a series called "Tight Lipped Presents." This was an opportunity for us to showcase other podcasts that cover similar topics, build relationships with producers and storytellers who share our mission, and reach a broader audience of listeners. Through Tight Lipped Presents, we were able to reach out to Allison Behringer, who is the founder and host of the successful *Bodies* podcast, the co-hosts of the *NATAL* podcast, Gabrielle Horton and Martina Ilunga, and the popular *Call Your Girlfriend* hosts Ann Friedman and Aminatou Sow.

# Tight Lipped testimonials

*We've heard from hundreds of people who tell us that Tight Lipped makes them feel less alone and wish that Tight Lipped had existed when they were younger.*



*"I'm 52 and never met anyone else with this problem so it was incredible for me to hear other people explaining exactly how I feel!!!"*

*"It's really hard for me to talk to my friends or my mom about it. It does feel like you're the only person in the world that is broken...I want to thank the hosts from the bottom of my heart for making and producing this....Hearing others talk about their similar issues helps me feel less alone. It validates my pain. Thank you."*

*"I've struggled with vulvovaginal pain for most of my life...I am exhausted and have felt so isolated around this issue. It means the world to connect with other people who share similar experiences."*

*"I have experienced pelvic pain with penetration for years. I am so grateful to Tight Lipped for making this condition more visible for everyone who experiences it and everyone who doesn't but should be aware of something that affects so many people with vaginas. For many years I felt alone and confused about why I couldn't use tampons until I went to a physical therapist and started using dilators."*

*"As someone who's suffered from pelvic pain for a decade I wish something like this existed when I was in the beginning of trying to figure out what was wrong. This podcast is so open, honest, accurate, and raw. It's amazing!"*

*"Because it is wonderful to experience education stories and support around pelvic pain through podcasts, book clubs and other offerings. I wish I had something like this 10 years ago."*

*"Because I WISH these sorts of resources were available when I was going through vaginismus. I want awareness of sexual health challenges to spread far and wide."*

*"If this zine had existed in 2006 when I was an inconsolable 22 year old newly diagnosed with vulvodynia it would have brought me so much joy."*

*"Because I wish you'd existed when I was 15 and scared and alone with my vestibulodynia."*



## People say Tight Lipped has changed their relationship with their bodies and their pain.

“This podcast is changing the way I think about myself. Anxieties that for the most part have been so well buried that I rarely think about them were brought to the surface and validated by the storytellers’ vulnerability, bravery, and compassion.”

“Tight Lipped helped me understand and realize my own experiences and lead me to schedule my first pelvic floor PT appointment.”

“I’M SO EXCITED ABOUT YOUR PODCAST. I just made a post on my page sharing my vaginismus diagnosis publicly for the first time.”

“I literally paused the podcast half way through to call my mom and finally tell her that I have vaginismus and penetration anxiety, after wanting to for years and actually telling my therapist earlier today that I wasn’t ready.”

“[The podcast] changed my life and allowed me to start my journey towards healing, loving myself, my body and confidently being my own advocate.”

“The Tight Lipped community changed my life. I went from dealing with my pain privately with my partner and doctors to attending the Chicago workshop in 2019 and making new friends who understood what I was going through. I am gradually beginning to feel more empowered to speak up and advocate for myself and others with pelvic pain.”

“I can’t express how much your podcast has helped me adapt work through my experience with chronic vulvar pain. Thank you for everything.”

## Medical providers believe our work is critical.

“As an emerging mental health professional and advocate for all women this resource is precious: we are lucky to have Tight Lipped.”

“Bless you for all you are doing for humans....Count me in to help you in any way I can....We got a long way to go in medicine as you know.”

“As a nurse-midwife I want to support my patients who struggle with vulvovaginal and pelvic pain by learning more about their stories. Activism around this issue is long overdue both in and out of the exam room.”

“I am a pelvic floor PT and after reading the zine realized how valuable it would be to have copies to share with patients.”

“As a Pelvic Floor therapist, the cause is close to my heart. So often, those with pelvic pain feel isolated. It is so important for healing to know that you are not alone.”

“I have been involved in vulvovaginal work for >40 years. I want to support discussion about this area, all too often [an] area of hidden taboo and misinformation.”

“As a pelvic health physical therapy practice, we are thrilled that this exists so people feel less alone. Awareness and advocacy is so important!”

“You guys are doing really good and very much needed work. I am honoured to have been of any service to you.”

# Media coverage & awards

This summer, two of our team members published an op-ed in Jewish Currents, “Unorthodox Bodies,” about the representation of vulvovaginal pain in the Netflix series, Unorthodox. As of December 2020, Tight Lipped has been featured in Glamour Magazine, Wit & Wire, Do You Even Podcast?, Chronicles of a Broken Body, and the Erika Lust Weekly Round-Up. At the moment, we are editing the Our Bodies Ourselves web page on chronic vulvo-vaginal pain. Tight Lipped received the \$5,000 Dorot Alumni Leadership Award and the Health Podcast Network named us as a Top Health Podcast.

## Publications

“[Unorthodox Bodies](#)” in Jewish Currents, July 14, 2020.

“[You’re Not the Only One Having Painful Sex](#)” in Glamour, December 14, 2020.

“[The Lust Weekly Roundup](#)” by Erika Lust, December 14, 2020.

“[Review of Tight Lipped Zine: Opening Up](#)” in Chronicles of a Broken Body, December 6, 2020.

“[Guest Pod Post: Noa Fleischacker from the TIGHT LIPPED Podcast](#)” in Do You Even Podcast? December 1, 2020.

“[Storytelling & How to Create a Narrative Podcast with Tight Lipped Podcast](#)” in Wit & Wire, July 29, 2020.

# CONTACT

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