

What We Want Every Provider to Know

Rainey Horwitz, MD

Caitlin Williams, PhD

Disclosures

- None

Objectives

1

Engage with personal stories of patients treated by sexual medicine specialists

2

Explain the importance of specialty training in sexual medicine

3

Provide patient perspectives on the expectations versus reality of sexual medicine and the role of provider-patient communication

4

Summarize common roles of a patient advocate in the field of sexual medicine

Caitlin's Story

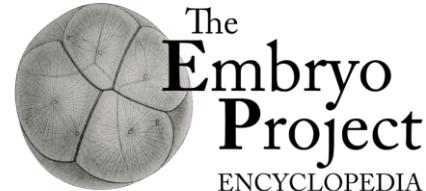
- Recognizing a problem: my pain is not normal
- Misdiagnosis & gaslighting
 - “It’s all in your head.” “Drink and you’ll be fine.”
 - Vaginismus
 - Repressed abuse
- Losing hope on a long road
- Correct diagnosis is life changing!
 - Congenital neuroproliferative vestibulodynia
 - Hypertonic pelvic floor dysfunction
- Proper treatment & slow success
 - Vestibulectomy, Bartholin’s gland duct repair
 - Pelvic PT, vaginal delivery
 - CBT
- Trying to make things better for others



PROSAYLA

Rainey's Story

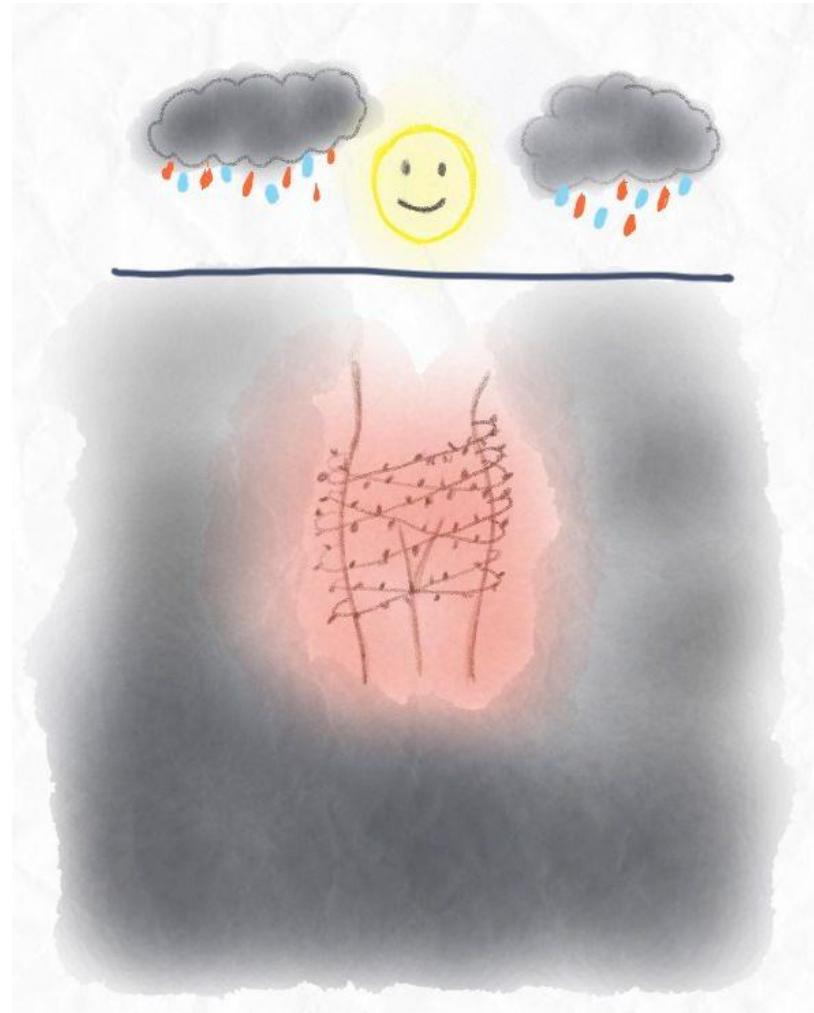
- Medical Education Journey
 - BS Biology, MS Biology and Society, Medical Doctorate, Urology Residency loading...
 - The Embryo Project
 - Sexplained Med
- When the young doctor becomes the patient
 - “It’s all in your head,” “if anyone knows what is wrong, it should be you, “you should know better”
 - Rampant sexual shame
 - Asking for help
- Correct diagnoses:
 - Recurrent Bartholin cyst
 - Clitorodynia/Clitoral adhesions
 - GAD/Neurodivergence
 - IBS



What should providers know
about the patient
experience?

This journey is difficult.

- Sexual dysfunction and chronic pain affects all aspects of life.
- Isolation
- Patients don't always look sick.
- FSD is more than infertility.
- Having a diagnosis is important.
- Rare vs. rarely diagnosed



Art by Michelle B.

How are providers trained about sex? Not well.

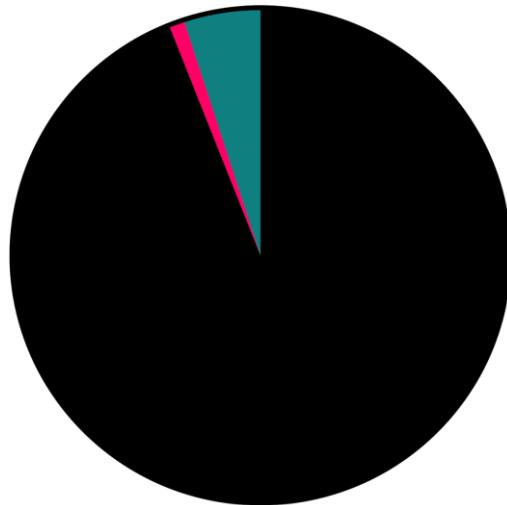
- Pre-medical sex education
- Medical school
 - History and physical
 - What's left out?
- Residency
 - Pelvic medicine and quality of life: OBGYN vs Urology
 - What about the others?

"You cannot diagnose what you do not (know how to) look for."

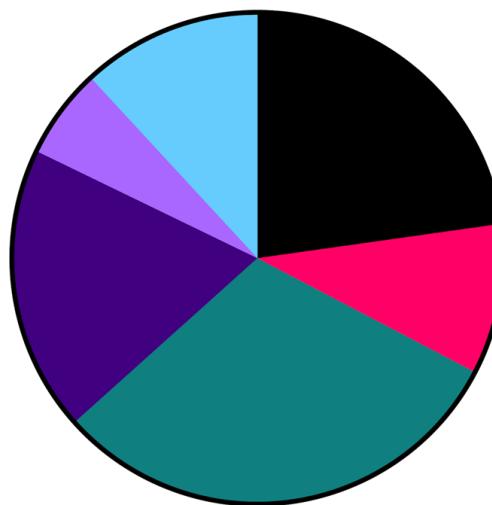
- Rachel Rubin, MD

Information for patients is hard to find online

**Patient Search Terms
(Poll Results)**



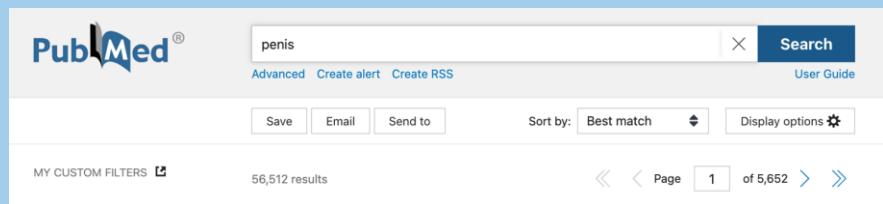
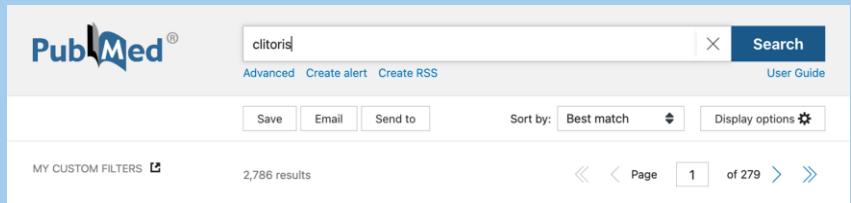
**Website Keywords
(Average)**



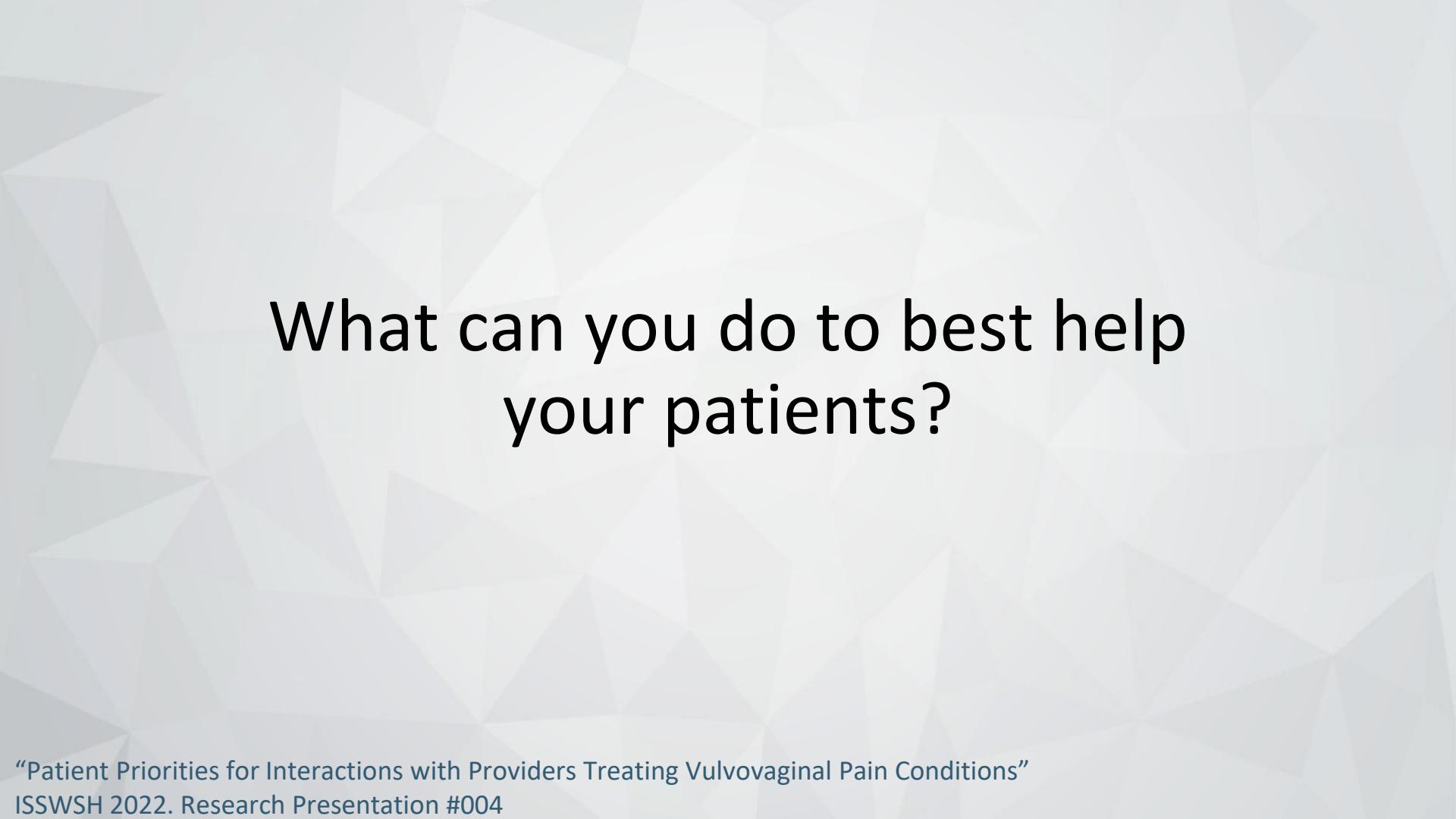
- Symptoms
- Non-medical Terms
- Medical Terms
- Anatomy
- Provider & Society Names
- Other

Research lags behind...

- Not enough high-quality data!
 - Limitations with research, IRB, etc.
 - Censorship
- Implications
 - Lack of widespread diagnostics
 - Lack of confidence in providers
 - Lack of insurance coverage



The image shows a journal article abstract from the journal *Sex Med.* The title is "Female sexual medicine: an assessment of medical school curricula in a major United States city". The authors listed are Nicolette Codispoti^{1,*}, Olivia Negri², Monica C Myers³, Anna Petersen⁴, Elsa Nico⁵, Jennifer P Romanello⁶, and Rachel S Rubin⁷. The article is dated September 14, 2023, and has a DOI of [10.1093/sexmed/qfad051](https://doi.org/10.1093/sexmed/qfad051). The journal logo, "SSM", is visible in the top right corner of the abstract box.



What can you do to best help your patients?

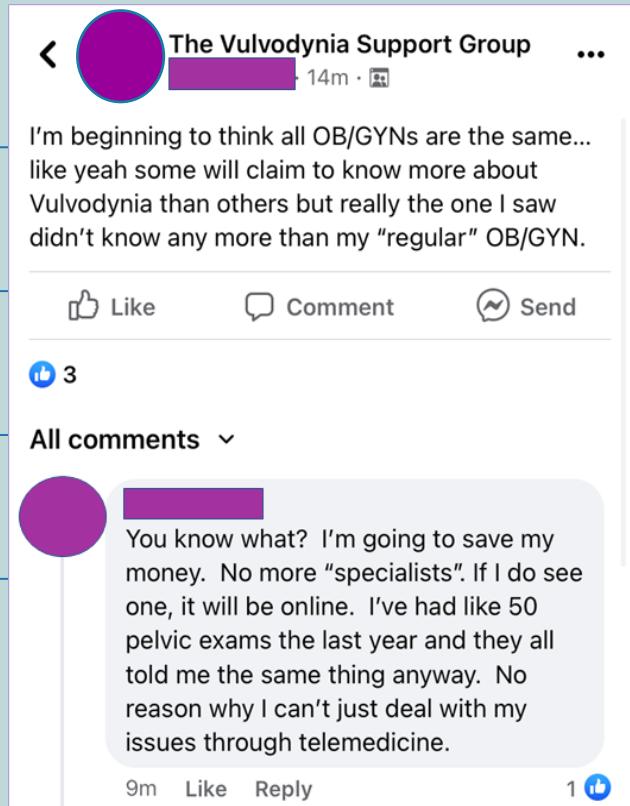
Be honest

Don't oversell

Say "we don't know" and/or "I don't know"

Share the data we do have

Discuss treatment options and ideas



The Vulvodynia Support Group · 14m ·  · ...

I'm beginning to think all OB/GYNs are the same... like yeah some will claim to know more about Vulvodynia than others but really the one I saw didn't know any more than my "regular" OB/GYN.

 Like  Comment  Send

 3

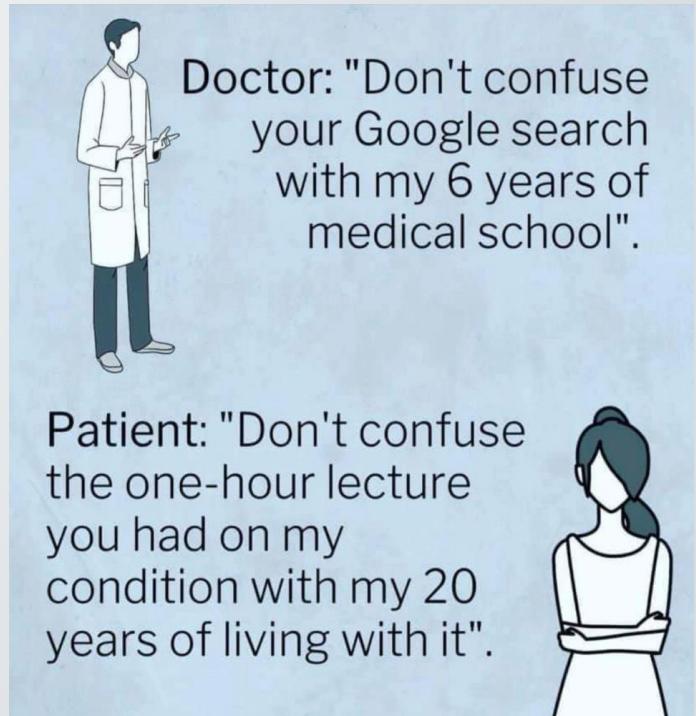
All comments ▾

 · You know what? I'm going to save my money. No more "specialists". If I do see one, it will be online. I've had like 50 pelvic exams the last year and they all told me the same thing anyway. No reason why I can't just deal with my issues through telemedicine.

9m Like Reply 

Be knowledgeable

- You are here - thank you!
- Diagnose accurately
 - Know what tests to perform
 - Know how to interpret results
 - Understand the strengths & weaknesses of test results and symptoms
- Know when to acknowledge and refer
- Seek training on unconscious bias



Be trustworthy



Recognize that most patients will not initially trust you



Have discussion with your patients while they are dressed



Ask for content



Follow through

Be a good listener



Listen!

Get a thorough history
Review records



Believe the patient



Learn & practice responses that don't
dismiss the abnormal

Be trauma conscious

Chronic pain is traumatic

Not being believed is traumatic

Medical care is traumatic

How can patient advocates help?

What do we do?

- Bridge the gap between the few of you and many who need your help
- Educate
 - Other patients
 - Providers & future providers
- How?
 - Research projects
 - Events
- Important topics: terminology, access to information



Who should you be following?

- SexMed Advocate
- DiscoverSexMed
- Tight Lipped
- Sexplained Med
- The Orgasm Lab
- Healthy Hooha (Aimee Cloutier)
- The Broken Brown Egg
- Unraveled Self (Kristen Loop)
- Vulval Pain Society
- Vulval Cancer UK Awareness
- NVA

Education/Data Resources

- **Prosayla by ISSWSH**
- Dr. Jill Krapf
- Dr. Rachel Rubin
- Dr. Ashley Winter
- Dr. Kelly Casperson
- AED Pregnancy Registry
- JustAsk Podcast



Prosayla.com

Tell your patients!

Be an author!



Your trusted source for women's
sexual health information

**There is hope for a better
experience for future patients**



What needs to change?



More access to trained providers

Invite your friends into ISSWSH
Financial barriers



Educate

Your patients
Everyone!

Connect with us!

Caitlin Williams, PhD

- @SexMedAdvocate
- SexMedAdvocate@gmail.com
- ISSWSH Public Outreach Committee

Rainey Horwitz, MD, MS (Urology)

- @Sexplained.Med
- rainey.sexplained@gmail.com