

# What We Want Every Provider to Know

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# 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

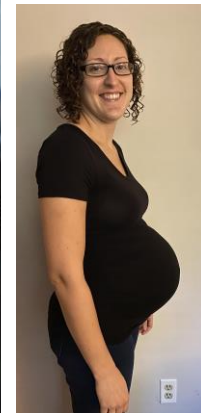
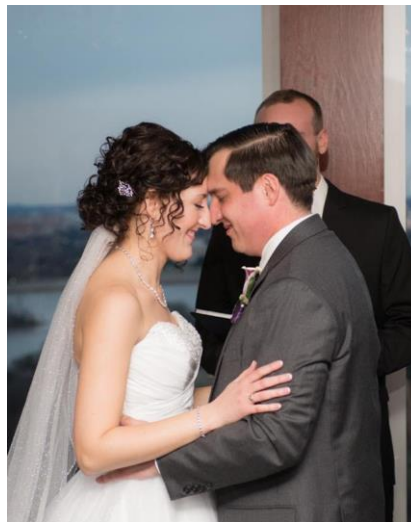
Provide patient perspectives on the expectations versus reality of sexual medicine and the role of provider-patient communication

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

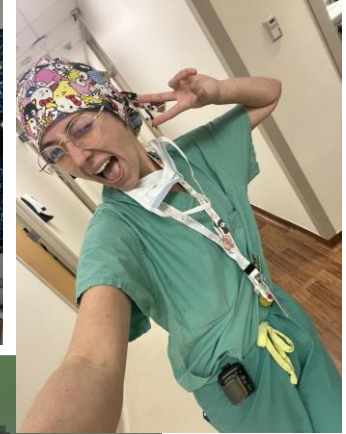
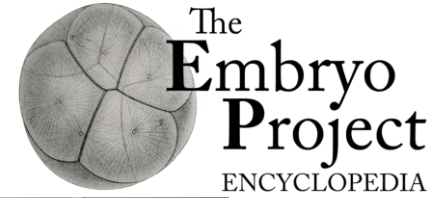


PROSAYLA



# Rainey's Story

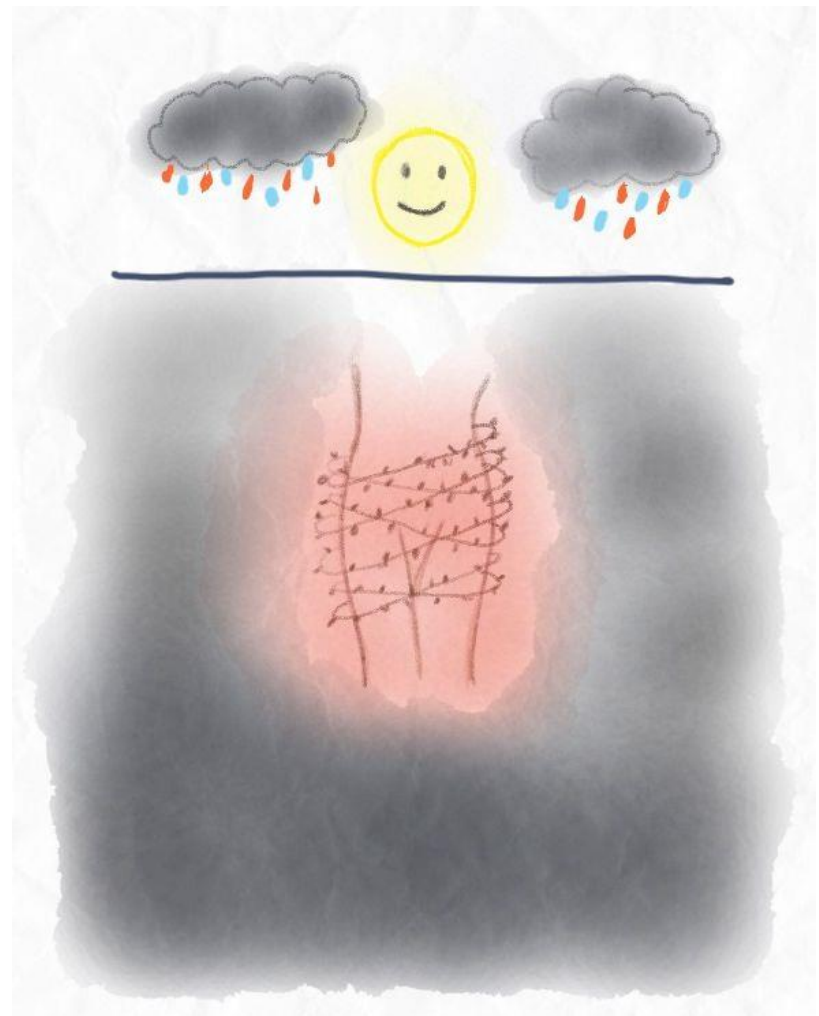
- Medical Education Journey
  - BS Biology, MS Biology and Society, Medical Doctorate, Urology Residency loading...
  - The Embryo Project
  - Sexplained Med
- When the young doctor becomes the patient
  - “It’s all in your head,” “if anyone knows what is wrong, it should be you, “you should know better”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

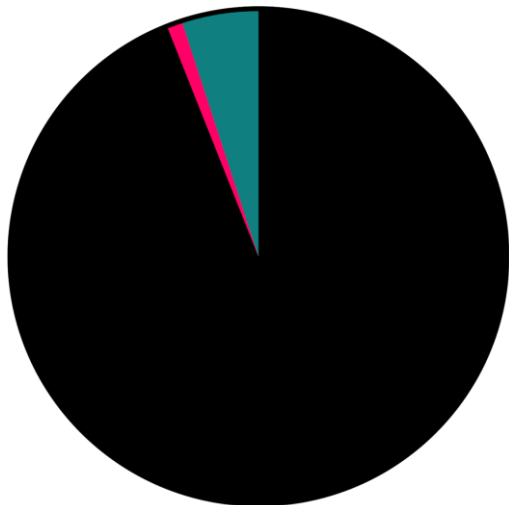
“You cannot diagnose what you do not (know how to) look for.”

- Rachel Rubin, MD

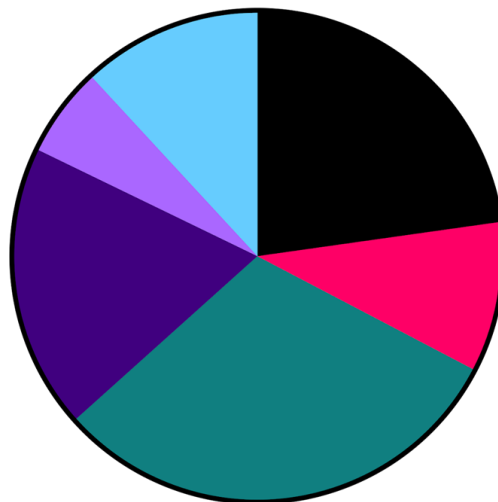


# Information for patients is hard to find online

**Patient Search Terms  
(Poll Results)**



**Website Keywords  
(Average)**



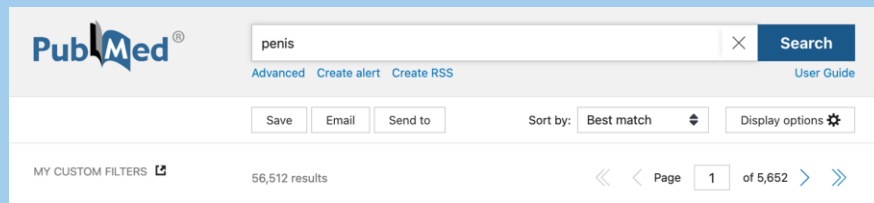
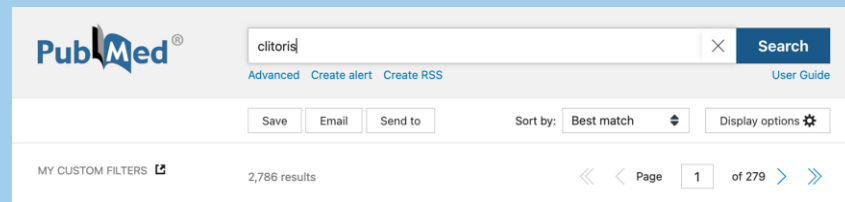
- Symptoms
- Non-medical Terms
- Medical Terms
- Anatomy
- Provider & Society Names
- Other

# 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



# What can you do to best help your patients?

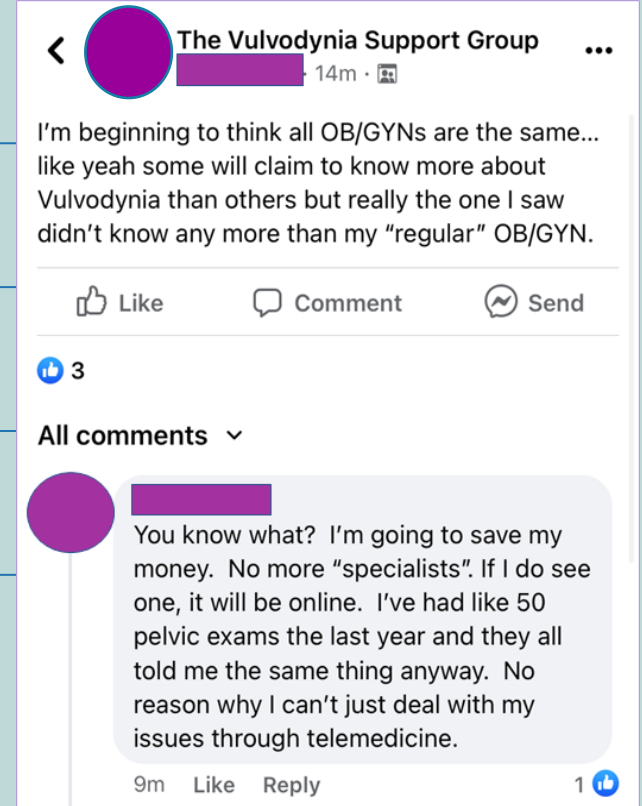
# Be honest

Don't oversell

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

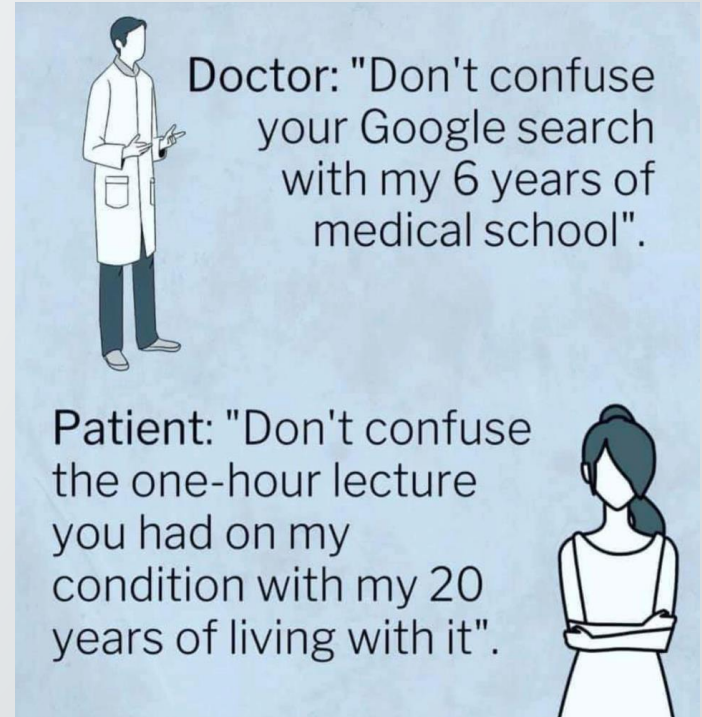
Share the data we do have

Discuss treatment options and ideas



# 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

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Chronic pain is traumatic

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Not being believed is traumatic

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Medical care is traumatic

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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



Your trusted source for women's  
sexual health information

**Prosayla.com**

Tell your patients!

Be an author!

**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**

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- ISSWSH Public Outreach Committee

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