Millions Of Women Face Astonishing Pain When They Have Sex. Why Don't Their Doctors Take Them Seriously?

A writer ventures out of his "male bubble" to find a medical jungle crowded with toxic treatments, false diagnoses, and shame

by Maxwell Williams

The case of the vulva that stabbed itself

BRITTANY JONES HAS BEEN TRYING TO SOLVE A MYSTERY since she was 17 years old: Why did having sex feel like getting stabbed?

"I remember the first time," she says. Now 28, the inquisitive Los Angeles–based actor who asks me not to use her real name says that back then, she was just striving for digital penetration. Even so, there was "this feeling of a knife. I literally mean a *sharp* pain."

When Jones related her agonizing experience to her friends, they told her the pain was ordinary, that she was probably just tense, and anyway, it always hurts at first. But as she continued to experiment with her sexuality, the alarming ache remained. She pondered the prospect of a life without sex, which ultimately contributed to a depression that drove her into a dark nightlife scene in New York.

"I started to use a lot of drugs. I was constantly around people on drugs, and I was sexually assaulted many times," she says. "But I never had sex. I always would fight it off. So I was a virgin in this seedy underground scene."

Until, one night, a man raped Jones while she was unconscious. "Sex just became such a negative scary thing, so after that happened, I swore it off for … years, worked on myself, and moved across the country to California," she says.

For a while, the move encouraged her. She eventually figured it was the right time to start over with sex. "I didn't have a negative view of sex anymore. And guys in California are really cute."

There was only one problem: The stab-like pain persisted. "[One guy] had to force himself into me. Trust me, I've been through uncomfortable things, but that was the most painful activity I'd ever experienced," she recalls. "It felt as if I was getting split apart from the inside, like muscle was getting torn apart."

That's when Jones finally worked up the courage to go get treatment. Because of her past sexual assaults, Jones's gynecologist encouraged her to see a sex therapist. She wasn't quite sure where to look, so she made an appointment with one she'd spotted during a segment on "Dr. Phil." That doctor referred her to an expensive hypnotherapist, who she says charged $300 an hour to tell her that the gaps in her memory likely stemmed from a childhood molestation.

But Jones knew in her gut that the hypnotherapist was wrong — that her pain stemmed from physical causes, not mental. Since no one seemed to believe her, she turned to self-medication, using information she found on a website describing vaginismus, a vaginal disorder known to cause spasms and the clenching of pelvic muscles. The recommended cure? A set of incrementally larger dilators that would, in theory, strengthen her vulvar muscles and eventually ease her pain.

So Jones sat in her bedroom and forced the instruments inside of her, starting with the smallest one. That it would even "go in," she says, felt like a sign of progress. But her agony persisted, and the dilators seemed to have triggered a new problem: She felt like she had to urinate all the time.

"I was getting very depressed again," says Jones. "I didn't go out. I had to stop working. You just isolate yourself from the world because you're feeling this pain. It's like knowing there's a bee around you at all times."

The spasms and clenching of vaginismus never did feel like the right words for what she was feeling, either. For the time being, the mystery went unsolved.

When a woman hurts

JONES WASN'T THE FIRST WOMAN TO TELL ME about how hard she had to fight for relief of astonishing sexual pain. She wouldn't be the last, either. All told, I've gathered about a dozen similar accounts, all of them remarkable and heartbreaking in their own ways. But none have shaken me as much as my close friend's, who sat next to me in a car one night, unspooling the distressing story of a curious pain that had destroyed her marriage.

I'd been out with 25-year-old painter Lila Murphy (also not her real name) for hours, so it could have been the liquor talking, or simply the candor that befits an artist. Either way, she got around to admitting that sex with her ex-husband had burned for years, leaving her completely uninterested in the act. Eventually, he left. I almost couldn't believe how long Murphy had suffered in her relationship, but I was even more shocked when she told me how unhelpful her doctors had been when it came to addressing her health concerns. Like Jones, she approached the medical industry warily, as if she were about to be stung — a standard state for many women, it turns out.

I like to think of myself as a sensitive guy, and intellectually, I knew that the health care system was stacked against women. But I lived in what I'll call the 'male bubble." My worst experience with health care was having to go to a primary care physician to get a referral to a specialist because I have an HMO. Annoying but not that bad.

Yet it's a cruel fact that men and women are treated differently when they get sick. In her 2014 essay "Grand Unified Theory of Female Pain," now a classic in the growing canon of ghastly tales about feminine agony, Leslie Jamison writes powerfully about how women are "minimized, mocked, coaxed into silence" when they seek care.

For my friend, the quest for a cure was almost as torturous as the pain itself. Murphy saw four different gynecologists, who each gave her various misdiagnoses and mistreatments before she hit a dead end. "I felt a little too comfortable with the pain," she says. "I had accepted the compromised position and felt like giving up and living with it was the only option."

Murphy's divorce might have been inevitable — she opines that some things aren't meant to last — but she believes the lack of sex was certainly a factor. And the stress of a dissolved marriage caused her overall health to take a turn for the worse. She started losing weight, she was often thirsty, she was lethargic, and the pain throbbed at all hours of the day — even when sexual activity was the furthest thing from her mind. She knew she had to figure it out. So, she went on an "internet research K-hole," eventually finding several glowing reviews for Dr. Joshua Gonzales, a urologist in Encino, California.

Murphy drove deep into the Valley, took the elevator up to the eighth floor, and walked down the hallway to Gonzales's office. She immediately took a shine to him. It was the day Prince died, she recalls, and he was playing "Purple Rain" into computer speakers. He was handsome in a Zachary Quinto kind of way, and he spoke with a bedside manner that she recalls as confident and trustworthy.

More importantly, Gonzales actually listened. He quickly made a diagnosis for a real medical condition and not some emotional tick, introducing Murphy to a new disorder: hormonally mediated vestibulodynia, a subcategory of vulvodynia. The same enigmatic condition that also plagued Jones.

Sitting in the car that night listening to Murphy was my first exposure to the words vulvodynia or vestibulodynia. Why didn't I know about it? And more importantly, why didn't she?

Vulvodynia obscura

VULVODYNIA AND VESTIBULODYNIA ARE MERELY BLANKET TERMS, like fibromyalgia or shin splints: the prefixes "vulvo" and "vestibule" refer to the locality, while the suffix "odynia" is Latin for pain. As many as 16% of women — about 14 million of them — will experience the condition in their lifetimes. By comparison, an estimated 11% of women experience endometriosis, and 12% are diagnosed with breast cancer.

So why isn't the term integrated into our shared cultural lexicon? Murphy says she once came across it in a 2001 episode of "Sex and the City" where Charlotte is diagnosed with vulvodynia, but the show cruelly plays the disorder for laughs, suggesting that Charlotte has a "depressed vagina," for which her doctor prescribes the antidepressant desipramine. Though experts now know this treatment does nothing for vulvodynia, the condition is still listed in the latest Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), released in 2013.

When I looked up vulvodynia up on the internet, I found myself on YouTube, where the entire first page of results featured videos from the heavy metal band Vulvodynia, save for two exceptions: a well-intentioned man giving a flawed definition of vulvodynia under the guise of "health & wellness" (he recommends "avoiding intercourse" and bathing in baking soda) and a Pilates instructor named Laura Lebrbauge dangerously claiming to have cured her vulvodynia with something called the Acid Alkaline Diet.

Phyllis Mate, co-founder, board president, and one-time executive director of the National Vulvodynia Association (NVA), tells me from her winter home outside Fort Lauderdale that she isn't surprised: Various diets have been associated with treating vulvar pain since well before she co-founded the NVA in 1994.

One diet in particular, the "low-oxalate diet" — oxalates are a molecule found in nuts and spinach — is commonly thought to reduce kidney stones, though there've been few published studies clearly establishing its efficacy against stones, let alone vulvodynia.

"Before the NVA was founded, there was another association out there that claimed the only cure was a low-oxalate diet," Mate, a snowbirding Bernie Sanders supporter with a gentle voice, tells me. "Some women will swear by it because they started the diet, and they got better. But women can get better doing nothing. Unless you have a controlled study comparing a random group of women taking the low-oxalate diet to a random group of women on a normal diet and then analyse the results, you can't prove anything."

From the top down, reliable information about the condition and its causes isn't readily available, which Mate attributes to the fact that vulvar pain treatment has a funding problem.

"It's not taught in medical schools, it's not taught in residency training programs, it's not available as a topic at the NIH to have grants funded for," says Dr. Irwin Goldstein, the director of a prominent Southern California clinic called San Diego Sexual Medicine, as well as the International Society for the Study of Women's Sexual Health.

It's frustrating, he says, that there are more vulvodynia cases than those of breast or even "prostate cancer. That doesn't mean we shouldn't study those, but that doesn't mean we should not study people with sexual problems. Relationships are very important, people's quality of life is very, very important — all of that suffers."

I WANTED TO KNOW WHY RESEARCHERS WHO FEEL SO MUCH EMPATHY for women like Jones and Murphy couldn't seem to fund studies about what ails them. So I decided to call up the government and ask. The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) seemed like the right place to start; there, Dr. Lisa Halvorson serves as the first-ever chief of the Gynecological Health and Disease Branch, established only four years ago.

"I don't mean to be defensive [and say], 'We're doing what we can,' but the truth is, to a degree, we are doing what we can," she tells me over the phone from the NICHD's office in Bethesda, Maryland. "We've got a very, very broad mission, and we are restricted, of course, to funding the science that is the most competitive, doing our best to be sensitive to the fact that there are some fields that are not as

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well developed — that are in their early stages."

What that means is that over the past decade, the NICHD has, according to Halvorson, funded approximately 20 grants in the treatment, identification of risk factors, classification, and diagnosis of vulvodynia — to the tune of about $3 million annually. By comparison, a search on the NIH's website for "erectile dysfunction" turned up 629 grants awarded from 2007 through 2017, including 52 currently funded projects (though the amount of money specifically allocated to this disorder, described on the NIH website as a "significant public health concern," is unlisted).

To be fair, it's not entirely the NICHD's fault — they've put the word out that they are looking for grant applications for vulvodynia studies, and Halvorson's desire to get government money into the hands of researchers is there. But she points out that the NICHD funds fewer than 10% of the top-scored applications as ranked by a peer-review panel.

"So, in order for us to fund grants in the area of vulvodynia, we need to have a 10-to-1 ratio of applications coming in," Halvorson says. "Again, this is a great group [of doctors and researchers], but there aren't enough of them submitting enough grants in order for us here at NICHD to be able to fund more grants."

That said, there has been much advancement in the field, in large part due to Dr. Andrew Goldstein (no relation to Dr. Irwin Goldstein), who co-authored the 2015 "Consensus Terminology and Classification of Persistent Vulvar Pain and Vulvodynia" paper, which attempts to codify the language used around vulvodynia. This has helped lead to quicker diagnoses and better treatments while many previously common but ineffective treatments have begun to be ruled out.

That includes Charlotte York's desipramine, which was used off-label as a treatment for vulvodynia for years and has the distinction of being examined in one of the only two treatment studies I could find with funding by the NICHD. In a 2010 study led by David Foster, called "Oral desipramine and topical lidocaine for vulvodynia," the conclusion was that "oral desipramine and topical lidocaine ... failed to reduce vulvodynia pain more than placebo."

The other study, according to Mate of the NVA, investigated Neurontin (also known as gabapentin), an anticonvulsant produced by Pfizer thought to block the pudendal nerve, which branches down into the urethra and the bladder. A 2007 paper describes it as an effective treatment for generalized, unprovoked vulvodynia, with few side effects. Murphy was once given the drug; she says it just made her groggy and unable to drive.

"The vulvodynia study on Neurontin started in 2009 or '10," says Mate. "David Foster and Candy [Candace] Brown — they work together — I keep begging her for her results. But the results haven't been published yet. The study's been over for at least a year and a half."

Halvorson at the NICHD wasn't able to confirm the status of the study when we spoke on the phone. Once published, the research may scrap a first-line treatment for a common sexual-dysfunction; already, the organization's most recent vulvodynia research plan doesn't list Neurontin as a priority.

These delays and lack of clarity remind me a lot of what happened with "female Viagra," or Addyi. The drug, rarely insured, cost as much as $1,000 per month as recently as last year. For women who want to enjoy sex, treatments of any kind remain a scarce and all-too-often unaffordable luxury.

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The $12,000 solution

EVER SINCE MELISSA PANZER WAS 17, WHEN SHE BECAME SEXUALLY ACTIVE, she "grins and bears it" when she has sex. For the first few years, the now 33 year-old Los Angeles-based film producer tells me that she used to chalk up her discomfort to the age-old warning that breaking the hymen hurts. And when sex continued to be painful into adulthood, she just assumed that it was built into the act.

Like Jones, "I was under the impression, incorrectly, that sex just hurt," she says. "For most of my life, I thought, 'He's much bigger than I am,' or, 'I can't handle the girth' — that's what's causing the pain — so I'm just going to deal with it."

And because Panzer thought it was normal, she never said anything to anyone about it — not her parents or any doctors or even her boyfriends. Still, she'd managed to find some joy in the act with Jonathan Barenholtz, the man who proposed to her in 2015. She was thrilled to say yes — but she wanted to add more sex to her wedded bliss. Not only that, she longed to start a family. So she mustered up the courage to tell Barenholtz the truth about her pain, and like any good fiancé, he was game to support her. They tried everything to make sex enjoyable for Panzer, from lots of lube to kegels — a pelvic floor exercise recommended to them by a sex-shop employee. (Panzer says this only caused her more discomfort.)

Then last year, at her regular physical, Panzer's determination for a healthy sex life with Barenholtz spurred her to ask her internist offhandedly if pain during sex was normal. "I'm, no," the doctor told her. But he misdiagnosed Panzer with a partially torn hymen and sent her to an OB/GYN at Cedars-Sinai Medical Center, who told her the issue was psychosomatic.

"He said to me, 'This is definitely in your head,'" says Panzer bitterly. "He was like, 'I can see your hymen is broken; I think this is probably in your head.' I was like, 'Listen, I will tell a stranger I have this condition. It's not in my head.'"

After seeing several doctors, Panzer was referred to Dr. Irwin Goldstein — yes, the same Goldstein we've met before, of the San Diego Sexual Medicine clinic. The two started with a 10-minute phone meeting, in which Goldstein asked her to press on her belly button. This guy is a quack, Panzer thought, until the same pain twinged inside her vulva; it was a feeling she normally encountered only during sex. Goldstein told her that the nerve endings in the belly button are connected to something called a vestibule.

"I think I can help you," he told her before their 10 minutes were up. A month later, she saw him in his San Diego office, where he recommended she get a surgery called a vestibulectomy.

IF YOU'RE A LITTLE LOST ABOUT WHERE OR WHAT A VESTIBULE IS, don't feel bad. The nerve-rich opening is located just inside the labia and outside the hole that leads to the urethra, the vagina, Bartholin's glands, and Skene's glands. The tender ellipse is pretty easy to find once you know where it is, but even health care professionals tend to bypass it.

"The gynecologists that I saw [before] didn't even look at the vestibule: 'Let's just get right to the cervix,'" says Jones, the actor, whose vestibule was also inflamed. Though she'd looked at her vulva in the mirror a number of times while trying to treat herself using dilators, she didn't know about her vestibule until she'd spent two years receiving misdiagnoses and unhelpful treatments.

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Then, Jones ended up in the office of Gonzalez (the one with the Zachary Quinto looks and calm bedside manner), who referred her to a physical therapist, who referred her to Dr. Irwin Goldstein in San Diego, who immediately spotted how "red and swollen" she was. "Whoa," he told her. "When do you want the surgery? Tomorrow? Holy shit."

Jones had her vestibulectomy six weeks before we first spoke; three months later, her recovery has been going well, though she's dealing with the new lingering yeast infection that irritated her vestibule before it was removed. She says physical therapy and botox, which has been studied alongside Neurontin as a treatment for vulvodynia, have helped her heal. "I appreciate what everyone did for me, but if I could have gone to Goldstein from the beginning, I would be in a much different place right now," she says.

Panzer agrees; she says getting the surgery was a no-brainer. She had it done March 8 in San Diego at Alvarado Hospital, a tiny facility where Goldstein performs all his surgeries. She tells me he's "the weirdest human being. I would say that to his face. I'm getting prepared for the surgery, and they're putting my IV in — he comes in with his laptop, and he goes to me and my husband and my mom and the nurses and to his fellow, 'Do you guys want to see a fish have an orgasm?'"

Despite his oddness, Panzer says she's a "huge advocate" of Goldstein, calling him "shockingly good" at what he does. Even her anti-vestibulectomy gynecologist admitted that the surgery was skillfully done. Though tight scar tissue has made sex a little painful, she says "the original pain is gone, which is amazing. I can see the light at the end of the tunnel. It's really up to me how fast I heal."

Panzer adds that she was only able to find about five other surgeons who perform vestibulectomies, and she'd heard frightening post-op stories about their patients, related to "bad stitching." But Goldstein doesn't come cheap: He says he doesn't accept insurance because, according to him, his methods are considered unorthodox and insurance won't pay him back, though companies like Cigna and Aetna, which neither Panner nor Jones use, list vestibulectomy as an insurance-covered option.

"I was lucky to pay for the surgery out of pocket on my own, but I also recognize many [girls] do not have $12,000 that they could just pay for this," Panner says. Depending on your plan, some insurance companies will cover a procedure that's out of network, particularly if no one else within a specified distance performs it. So Panner filed a claim. At first, her insurance company has insisted that the surgery should have cost $750. She appealed, and the appeal went through. But, she says, "They told me that they would pay me back. ... Now I've called five times, and the woman I need to talk to is never in the office. ... They told me that I'd get $7,500 [of the $12,000], but nothing has happened."

Jones says her parents paid for her surgery because her insurance wouldn't cover it. Despite all of his referrals to Dr. Irwin Goldstein, however, Gonzalez doesn't believe that a surgery, which no matter how expertly performed is bound to result in complications, is the only answer. For him, and for my friend Murphy, there may be a less invasive solution. But it requires untangling the complex history of women's sexual freedom.

A bitter pill

BEFORE ORAL CONTRACEPTIVES. MEN EITHER PULLED OUT or rolled a condom on. Then, the pill was introduced in the early 1960s. By 1967, Time magazine featured it on its cover. Renowned economist Claudia Goldin has famously written about how the pill gave women agency over their own bodies, and Nell Irvin Painter (author of "The History of White People") has credited the birth control pill with allowing her to delay pregnancy and pursue her career.

Thanks to birth control pills, women have been able to finish school and enter the workforce in greater numbers, making the method perhaps the strongest link between the first wave of feminism and the current push for gender equality in the workplace. As recently as 2016, a Guttmacher Institute study found that nearly 10 million women in America use hormonal birth control pills. But not everyone knows how they work.

Essentially, the pills function by overloading the body on estrogen or progestin in order to stop ovulation, which tricks the pituitary gland into not producing certain hormones that would cause the egg to be released. For a subsurgery of women, this works like a charm.

For many other women, however, the pill can cause imbalances: weight gain or mood swings, blood clots and strokes, or — this one is often missed — decreased libido.

The side effect is mentioned on the packaging: Hormonal oral contraceptives increase the production of a protein called sex hormone binding globulin, which is made by the liver. Dr. Irwin Goldstein estimates that birth control "raises SHBG a [to] 10 times the normal value," binding onto the free testosterone in a woman's body, rendering it useless — this can decrease the sex drive and cause extreme dryness, leading to sustained pain.

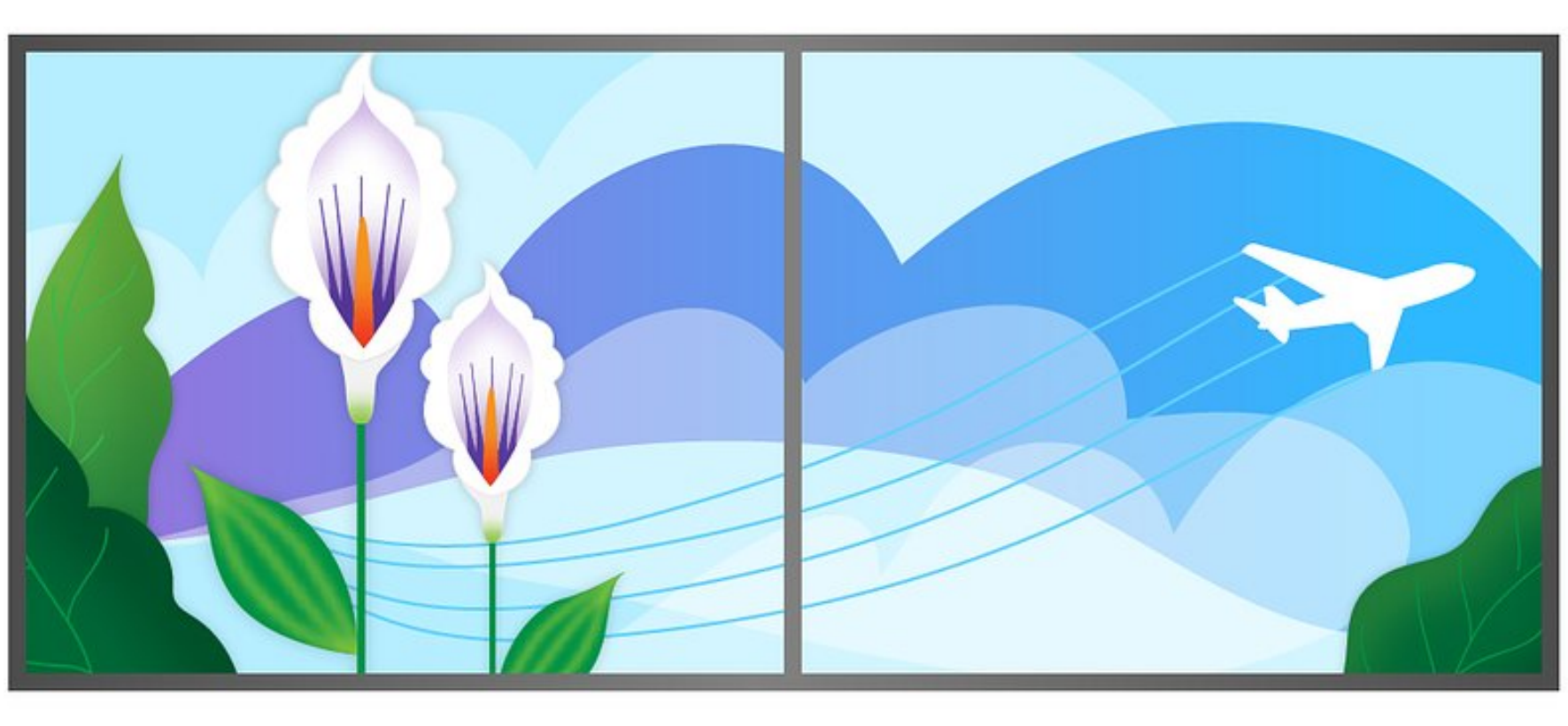
Gonzalez, who was Dr. Irwin Goldstein's fellow in 2014 and 2015, has been pushing for more research into the link between oral contraceptives and vulvodynia, though at least one longitudinal study found that birth control pills do not increase (and may even decrease) one's risk for the condition.

Murphy had taken birth control pills for over a decade and Plan B once or twice (she has since chosen to stop taking any form of oral contraceptive). She tells me that, no matter the cause, Gonzalez found that her SHBG levels were elevated, which he told her led to her low sex drive, vaginal dryness, and, ultimately, her vulvodynia.

Gonzalez prescribed my friend a simple testosterone gel — one dollop on the calf (anywhere else on the body could lead to unintended masculinization in women, he says) each day. Often thought of as a "male" hormone, testosterone has been linked time and again to libido in women. But as a treatment for hormonal imbalance in women, testosterone is heretofore unstudied and therefore unapproved by the FDA.

But in Murphy's case, it has been just the right thing. Within weeks, she says she regained her energy. Even her circulation improved; she used to get cold all the time and had long attributed it to her gender. Most importantly — even more than the pain, she says — is that for the first time in her life, Murphy has a libido. Or, as she told me that night in the car, "I want to fuck all the time." She's even had her first orgasm.

The change was so drastic that I went to see Gonzalez at his office in Encino on a warm day in February. Could there really be such a simple fix?



The testosterone debate

GONZALEZ'S DESK IS HIGH UP IN A COMMERCIAL OFFICE BUILDING, the Van Nuys Airport visible in the distance. As we talk, he smiles easily, airplanes cutting through the blue sky beyond his shoulders.

"In the same way that estradiol, the primary estrogen, is recognized as a female hormone, [it also] exists in the male body," he says, pointing out that low levels of estrogen can lead to osteoporosis in both men and women. "If I see a man who is taking some sort of estrogen blocker [for bodybuilding] and has undetectable levels of estrogen, that's a really bad thing."

Gonzalez says that most of his younger patients with vulvodynia have some amount of hormonal imbalance. He has partnered with a number of area pelvic floor physical therapists who he's trained to look for the signs of a hormone problem in their patients. Gonzalez has also written impassioned screeds against birth control pills. He's very much a proponent of testing a patient's hormones as almost a rote activity in his practice.

Gonzalez refers some women to Dr. Irwin Goldstein if he thinks they're in the neuroproliferative category — which means there is a high density of nerves in the vestibule causing sensitivity and pain. Those patients (like Jones and Panzer) are sometimes eligible for a vestibulectomy, but he often finds himself giving those under his ward (like Murphy) testosterone as a first-line treatment.

"We just obviously use it in much lower does than a man would get," Gonzalez tells me. "Over the course of weeks to months, sometimes longer, then you get reversal of the problem that's been going on." But he thinks that most of these cases could be eradicated with a simple shift in birth control from pills to IUDs.

"Having sex should feel good. That should be my motto."

"Number one, they've been shown to be more effective than oral birth control pills," he says. "Number two, ACOG (The American Congress of Obstetricians and Gynecologists), which is essentially the governing gynecological body, recommends them as first-line therapies. They don't cause the same hormonal problems that oral birth control pills cause. So those three things put together, I don't know why anyone would not get an IUD."

He shows me his examination room. He laments the stirrups, so cold to the touch, while explaining the ins and outs of IUDs. I tell him I'd always thought that IUDs also used hormones, and he says that they do but that they're so much more localized than the pill — laser focus: a pinpointed, targeted hormonal attack.

Still, I have my doubts, in part due to my girlfriend, who reads (and then tells me all about) way too many IUD horror stories: ectopic pregnancies, painful insertions, infections, and more. So, after leaving Gonzalez's office, I reach out to Dr. Irwin Goldstein for his thoughts. He explains to me that long-acting reversible contraceptives like IUDs and implants (better known as LARCs) don't boost SHBGs.

"Most societies that are engaged in women's health advise physicians and patients who use contraceptive to use LARCs, not birth control pills," he says. "For many reasons, but in particular the vestibular health risk."

Dr. Irwin Goldstein may be one of the world's biggest advocates of the testosterone treatment; another is Dr. Andrew Goldstein — the one who wrote that big "Consensus Terminology" report. Dr. Irwin Goldstein likes to call Dr. Andrew Goldstein "a brother from another mother," and it's been said that if you're west of the Mississippi, you see Irwin; east, you see Andrew. Between the two of them, they've co-written two books, including "When Sex Hurts," as well as a multitude of scientific papers about vulvodynia and other sexual medicine topics.

"Andrew is cutting-edge," says Mate of the National Vulvodynia Association. "He's been talking about this for the last 10 years. Irwin is also very into this hormonal area, but usually [gynecologists] are not. I don't think the majority of gynecologists would get a woman with vestibulodynia and immediately check her hormones."

NOT EVERYONE IS CONVINCED. "I think that's purely hypothetical at this point, personally," says Halvorson at the NICHD.

But Mate points out that testosterone treatments might not be accepted because of the niggling status of vulvodynia studies. "Compared to the other treatments, it's newer," she says, "so we don't have any research that proves that it works. But then again, there are very few research studies that have proven physical therapy works, so that can give you an idea of how slow this moves. We've been banging on their doors [to get more studies done] for 20 years."

Whether or not Gonzalez (or either of the Goldsteins) is right, he also treated Jones for a hormonal imbalance (she's still on that treatment) and referred her to a vaginal wall physical therapist — the one who helped her realize she needed that vestibulectomy. And though she was soon in Dr. Irwin Goldstein's office getting surgery, she believes that the journey to proper treatment had become a much more straight line long before.

Yet we may never find out if either a $12,000 surgery or a testosterone gel is really the key to eliminating a disease impacting millions of a women a year — or if these methods are a bunch of hooey. It all comes back to a lack of funding. (And not just because of America's predilection for healing male bodies over female.)

"After surgery, I was like, 'Oh, so this is what a vagina feels like.' I had one my entire life, but it felt different."

Fringe benefits

"WOMEN'S GYNECOLOGICAL DISORDERS THAT CAN'T KILL YOU, that are not life-threatening, have gotten minuscule amounts of money from NIH," says Mate. "That includes endometriosis and uterine fibroids and vulvodynia. The stupidity of it is that gynecological disorders are lumped with pediatrics in the same institute. So, you're competing with funds for [studies for] children."

Haunting the research of any women's sexual dysfunction done by the NIH is that the Gynecological Health and Disease Branch is couched within the NICHD, which means that women's sexual health studies are drawing from the same money needed to support obstetrics and pediatrics.

Halvorson says that part of the fault lies with the researchers like Dr. Irwin Goldstein — and not because they explore oddball treatments. "There aren't enough of them submitting enough grants in order for us here at NICHD to be able to fund more grants," she says. "We're certainly interested in it. We've had meetings on it. It's on our web page, and it's definitely part of our mission."

Yet I can't shake the feeling that as much as the Goldsteins and Gonzalez are trailblazers in the field of sexual medicine, their ideas — not to mention their fondness for understanding fish orgasms — sound a little out there, a little fringe. Though "free-spirited genius" German cardiologist Andreas Roland Grüntzig, who developed balloon angioplasty in his kitchen in the late 1970s, was a little fringe, too. Initially rejected, his treatment has become one of the most common of all operating room procedures.

Someday, these treatments may be thought of as similarly groundbreaking. But the pace of female sexual medicine remains glacial, even when compared to the medical-industrial complex as a whole — one of the few that still relies on fax machines.

"It's very sad," says Dr. Irwin Goldstein. "For whatever reason, even though people practice sex from early puberty to almost until they are in their grave, a lot of people don't find the quarterbacks to help them navigate ways to diagnose a problem." He sees sexual health as part of a human right intrinsically linked to our overall health, and for him, the lack of emphasis on sexual pain in women is devastating.

"If you were a woman and you were asked, 'In your last sexual encounter or your last series of sexual encounters, did you experience pain?' what would you think the answer would be?" he says. "It's a little over a third. That's a freaking epidemic. One third of women in our environment are having pain during sex. That's an unnecessary, bothersome, distressing issue. We need a lot more effort in understanding it."

"It's not a psychological thing; it's not your childhood. You have a physical issue."

Yet vulvodynia remains a condition that not many people have heard of. And Murphy, Jones, and Panzer demonstrate just how often the American health care system fails women in dire pain. These three have been lucky to afford the help they received, but there are many women who never will. Months after Murphy's car confessional, I find it mind-boggling how screwed up this is, and how hard it can be to apply Occam's razor. Why can't we simply go with whatever treatments work and cause the least amount of harm?

As a man, I'll never have vulvodynia. Neither will Gonzalez or the Goldsteins, who I believe genuinely care about their patients. Dr. Irwin Goldstein especially is a warm guy when we talk on the phone — he's actually on his way home from Boston, where he sat in on a few patient screenings with Dr. Andrew Goldstein. My gut tells me he's a kind and considerate soul. His patients Jones and Panzer have painted a portrait of him as a loveable goofball who just happens to be their guardian angel.

But an awful lot of men are working in women's sexual medicine (not to mention all those male journalists telling readers like you what ought to be done about the problem). From my admittedly limited perspective, even those with the will to treat women with the same respect that they would treat men are finding that their studies aren't taken as seriously, perhaps because women's sexual health issues aren't deemed a priority.

Gonzalez, who originally set out to focus on men's urology, says he stumbled into his chosen field. He's pragmatic about it, and in his office, he tells me something that resonates as the catalyst driving each of these doctors: "Having sex should feel good." Then, to himself, he whispers, "That should be my motto."

IT'S TEMPTING TO LEAVE THE STORY THERE, WITH SO MANY MALE CHAMPIONS of female health. But I can't help but think about Jones, the actor, who told me about her vulvodynia "quarterback" — and she wasn't Dr. Irwin Goldstein. No, Jones's female physical therapist, Stephanie Prendergast of the Pelvic Health and Rehabilitation Center, is the person she thanks for first guiding her on the path toward sexual health, telling her, "'We deal with people like you all the time. It's not a psychological thing; it's not your childhood. You have a physical issue.'"

Jones's mom was helpful, too; she'd pushed Jones to tell Prendergast that nothing in their sessions had eased her pain so far. Before that moment, Jones says, "I'd felt so disconnected from my vagina. I didn't feel like a woman. I felt like half a woman. ... [Then my physical therapist said], 'OK. Let's re-examine the situation.' She felt all my muscles, and then she was like, 'How does this feel?' 'Good.' 'How does this feel?' 'Good, no pain.' 'How does this feel?' And I was like, 'Oh my god, oh my god! That's an 11 out of 10. That's the most painful thing ever.' And she said, 'Yeah, this is your vestibule, do you want to remove it?' I was like, 'Yes. Are you fucking kidding me? Yes, please.'"

The surgery, despite lingering issues, was monumental for Jones. "I was like, 'Oh, so *this* is what a vagina feels like.' I had one my entire life, but it felt different." But when a medical professional — a woman — finally took her seriously, "*That* was the best day of my entire life. Period."

***Clarification 8/4/2017**: One passage about Panzer's insurance-claim experience was clarified and, upon the request of Brittany Jones, the name of her physical therapist was added.*

Illustrations by Stephanie Kubo. Share image by Aurelien Glabas/Flickr.