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HEALTH

This Sexual Development Disorder Is More Common Than You Think

“It affects every important developmental milestone of a woman’s life.”

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MRKH syndrome is a rare disorder where the uterus, cervix, and vagina aren't fully developed.

That means incomplete reproductive organs, not getting a period, and not being able to carry children. It's a congenital disorder, meaning it's present at birth, and it's estimated to affect between 1 in 4,000-5,000 women.

The name, MRKH, is actually an acronym for the doctors who first discovered it: Mayer-Rokitansky-Kuster-Hauser syndrome. It's also sometimes referred to as Mullerian Agenesis, Vaginal Agenesis, or Vaginal Aplasia. Experts aren't sure what causes it, but genetics seem to play a role. For some, MRKH can also be associated with kidney, hearing, skeletal, or heart complications, which is referred to as MRKH type II or [MURCS Association](#).

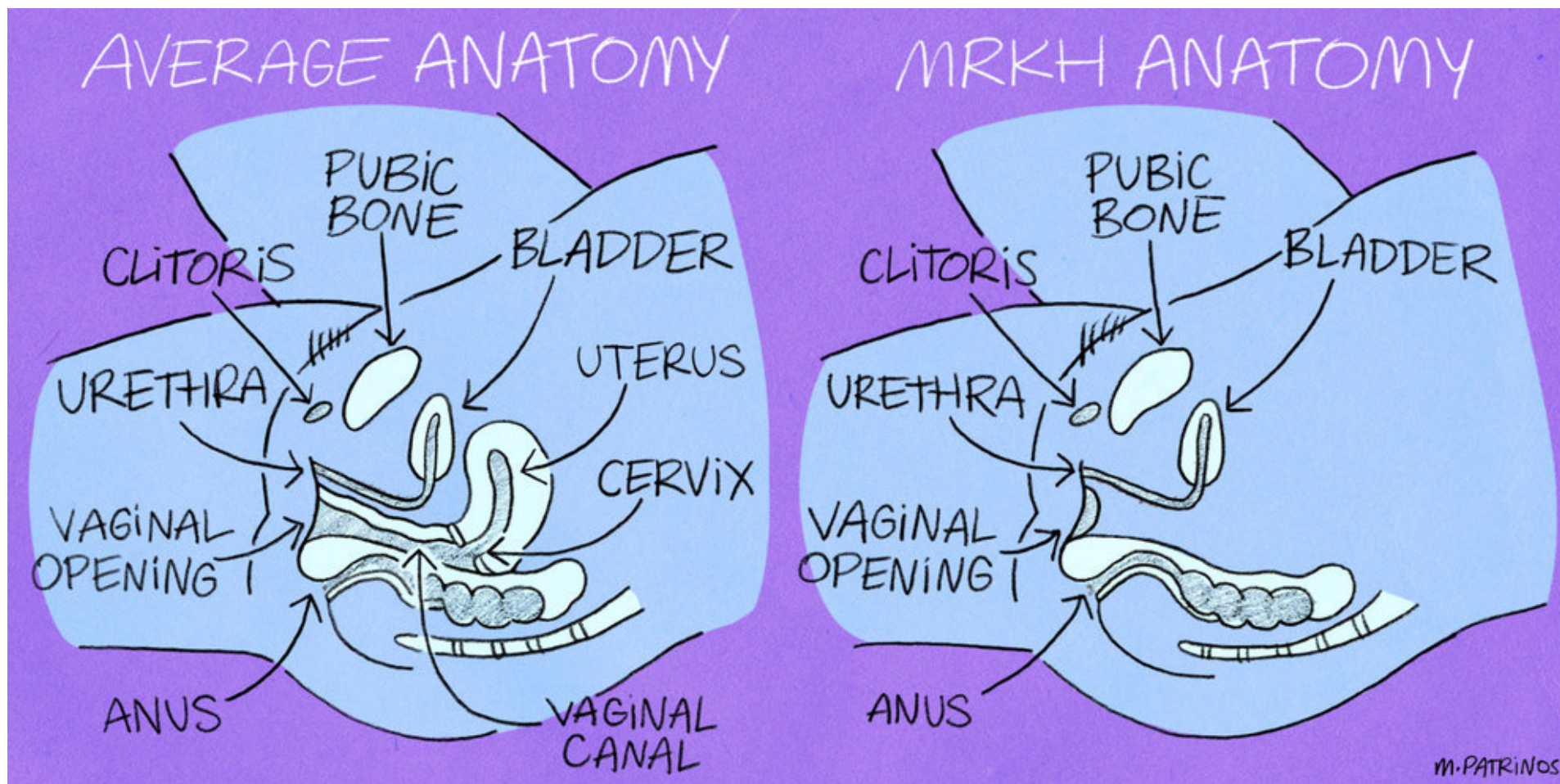
But despite an “incomplete” anatomy, women who have MRKH lead complete, rich, fulfilling lives.

We spoke to two women with MRKH: Laura, co-founder of the [Mid-Atlantic MRKH Foundation](#) and Amy Lossie, Ph.D., president of [Beautiful You MRKH Foundation](#). Both of them were diagnosed at age 16. Now, they run organizations aimed at connecting women with MRKH and providing helpful resources they wish they'd had when they were diagnosed. Here's what they want people know about it.

1. It doesn't mean someone is missing a vagina or vulva.

MRKH affects the development of the *internal* reproductive tract, not the *external* genitalia, so it has nothing to do with the vulva, clitoris, pubic hair, etc. It can also present very differently in different people — so one woman might have a small vaginal opening while another might have a fully functioning vaginal canal that's slightly shorter or narrower than usual. Some women are missing their entire uterus, while others might have some remnants still there.

“Some articles will say ‘women born without vaginas,’ like it's a freak factor, an abnormality,” says Laura. “I think the way it's presented is a little bit hurtful. We're also people — it's not just about our sexual organs.”



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Due to the range of different presentations of MRKH, this diagram does not fully represent every person's unique anatomy.

2. And it doesn't mean you're "any less of a woman," if that's something you're worried about.

Of course gender is about identity, not physical characteristics, but in terms of chromosomes, people with MRKH have what's considered a normative chromosomal makeup for a cisgender woman (46,XX karyotype).

Still, it can be confusing and scary as a teen to wonder with what this diagnosis means for your identity and sexuality. “I thought, *am I really a female? Am I really a woman if I don’t have a uterus? Am I really a woman if I can’t bear children?*” says Amy.

3. Someone is usually diagnosed when they don’t get a period.

Laura was 16 and still hadn’t gotten her period, so she went to a specialist who put her on hormones to induce it. When that didn’t work, they did an MRI and discovered she was missing parts of her reproductive tract.

Amy was also period-less at 16 when she was diagnosed. “I had uterine remnants — very small uterine horns. I had a mini cervix and I was missing the upper portion of my vaginal canal.”

4. But because you still ovulate, you’ll still get all the cramps and other annoyances of PMS.

Since the ovaries typically aren’t affected by MRKH, ovulation still occurs every month. And after that comes the PMS symptoms, like cramps and bloating. “It’s essentially the same period as people off birth control have, but no bleeding,” says Laura.

5. Finding out you have MRKH can be scary, confusing, and isolating.

As if those teenage puberty years weren’t hard enough, imagine finding out that you were different, infertile, and may even need surgery to have sex. “The life you thought you had, you no longer have,” says Amy. “You have to figure out how to live this life that’s very different than the one you had planned.”

“It affects every important developmental milestone of a woman’s life,” says Laura. From the moment your friends are first getting their periods, to when they lose their virginity, to when they’re having kids... “It’s this continuous cycle of dealing with these challenges and feeling different and feeling alone.”



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6. Finding the right doctor and therapist is key — but it might not be easy.

“A pediatric gynecologist would be best, but there are not a lot of us around,” says Dr. Veronica Gomez-Lobo, director of pediatric and adolescent OB-GYN at Washington Hospital Center. That’s because it’s a new but growing field, with just nine fellowships dedicated to it in North America, she says. In the past, MRKH was typically treated by pediatric surgeons or reproductive endocrinologists, but neither field is really a perfect fit for a disorder that affects the reproductive tract of a teenager.

“You might have to travel in order to see a specialist but in the long run I think it’s worth it ... to have a doctor say ‘I’ve seen a lot of people like you and you’re not alone.’ They know how to treat the patient and they know what’s going to be triggering for them. They know how to put their patients at ease. To me, that’s important.”

And because this can be such an emotional diagnosis, Laura suggests finding a counselor or therapist who can help.

7. It’s definitely possible to have a healthy, happy sex life with MRKH.

Having penetrative sex can be anywhere from uncomfortable to almost impossible for someone with MRKH, depending on how far their vaginal canal stretches. For some women, the penis (or dildo, toy, whatever) can help dilate the vagina, says Gomez-Lobo. For others, sex might be limited to oral and manual contact only.

But this is important: MRKH doesn’t directly affect your ability to feel pleasure, have an orgasm, and have really great sex. “I had a lot of great boyfriends who were very supportive and that was huge,” says Laura. “Them willing to have a healthy sex life in other ways was really helpful.”

8. And there are options available to make vaginal intercourse more comfortable.

There are a few types of vaginal reconstructive surgery available, but even though it might seem like the fastest and most convenient option, it’s not always right for everyone. “I kind of felt this desperate need to fix this part of my body, but it was really intense, I wish I had thought about dilation first,” says Laura.

Dilation is usually suggested as the first line of treatment — stretching the vaginal canal with dilators (basically small plastic tubes, sometimes vibrating ones to make it a little more comfortable). It can take a few months to almost a year of very frequent therapy, but it’s been shown to be a successful, nonsurgical option for most women. Plus, dilation is part of post-surgery treatment anyway, so Gomez-Lobo strongly suggests it to anyone considering surgery.



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9. But you also don't have to change your body at all if you don't want to. Ever.

Getting a diagnosis this life-changing can send you into fix-it mode. What are your options? What can you do right this second? What will make this better? “You don’t have to do anything ever. You are absolutely perfect just how you are,” says Amy. “Any decision, unless it’s medically necessary, can wait. A lot of people think *I have to fix this now*. MRKH isn’t something you fix, it’s something you learn to live with.”

Even exciting and promising options — like IVF, vaginal reconstruction, or the clinical trials of [uterine transplants](#) that could allow women with MRKH to carry their own children — aren't necessarily right for everyone. "There's this misconception that we're going to fix these women born without uteruses," says Laura. "But you can never fix something that's happened to you. That's a part of who you are."

10. You also don't have to tell anyone about MRKH until you're ready.

"While MRKH is not shameful, it is private. And as anybody who's survived high school knows, one month you're friends with somebody and the next month they hate you," says Amy, who suggested opening up to the close people in your life when you feel safe and ready.

11. For people who want to bear children, dealing with the reality of infertility can be the biggest challenge.

At 28, Laura says she's now going through the hardest phase of her diagnosis as she watches her friends start families of their own. "Some people will say 'At least you're not dying. At least you don't have cancer.' I know that and I'm obviously grateful for that, but I think there's a big misconception of how difficult dealing with infertility is."



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12. If you have MRKH, know that you are not alone.

Laura initially connected with other women over Facebook, then put together her first MRKH meet-up in D.C. Then another one in New Jersey. “We started to realize there were women who were just desperate to meet each other and wanted these opportunities.” You can find out about upcoming events [here](#).

“I wish I had known there are women with MRKH in my own city that I could have met or tried to meet up with. It seemed like such a

me issue, I felt so isolated,” says Laura. “You don’t even think about the fact that, because it doesn’t have a specified cause, there are women who have it all over the world.”

13. MRKH is a part of you, but it doesn’t have to define you.

“My life is so much richer than I ever could have imagined it could be. To be honest, a lot of that is because of MRKH,” says Amy, who ended up getting her Ph.D. in human genetics and founding [Beautiful You MRKH Foundation](#).

“It has been really devastating and hard, but it has honestly made me a very strong person and has taught me to appreciate everything I have,” says Laura. “Because you never know when you’ll be pulled into a doctor’s office and get some crazy diagnosis you’ve never head of.”

14. But most of all, people with MRKH just want you to know that it exists.

“In my perfect word, people would learn about MRKH when they learn about health in school,” says Amy. “Sometimes development isn’t just this way or that way — it’s variations on a spectrum.”

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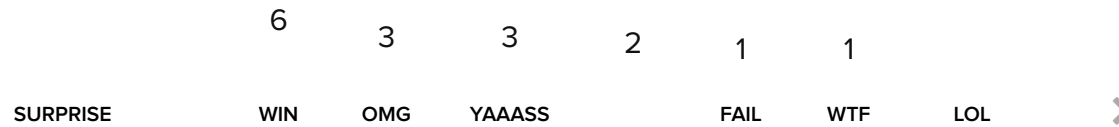


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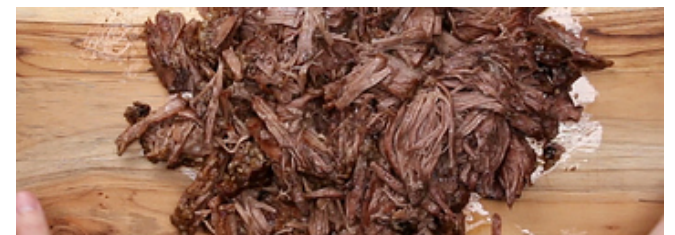
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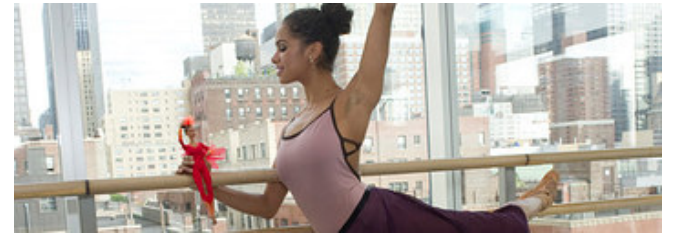


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