

MRKH Syndrome

What is MRKH syndrome?

MRKH (Mayer Rokitansky Küster Hauser) syndrome, also called müllerian or vaginal agenesis, is a condition that causes a baby to be born with a small or not fully developed vagina. There may also be a small or absent uterus. Most teens and adults with MRKH have a typical female chromosome pattern (46 XX). Their ovaries work normally, and they experience normal puberty, but they never have a period.

How common is MRKH?

MRKH syndrome affects about 1 in 4,500 newborn female babies.

What causes MRKH?

Sometimes mothers wonder whether they caused this in their child. There is no single environmental or genetic cause for MRKH. There is also nothing that you did during your pregnancy or during your childhood which would have caused this.

How is MRKH diagnosed?

Most teens find out that they have MRKH when they go to the doctor because they have not started their period. Your doctor will do a physical exam. They may use an ultrasound to see if there is a cervix or uterus. The doctor may also want to do an MRI (magnetic resonance imaging) to see a more detailed picture of your reproductive tract.

Some teens and adults with MRKH may have issues with other parts of their body, like their kidneys, spine, or hearing. You will be tested to check for any of these other problems.

How is MRKH treated?

Treatment is used to make the vagina longer.

There are 2 treatment options:

- Vaginal dilation
- Surgery and vaginal dilation

To Learn More

- Adolescent Medicine
206-987-2028
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

Creating a vagina with dilation

Most people with MRKH will have a dimple of the lower vagina. Using dilators, this tissue can be stretched to a length to have comfortable sexual intercourse. This is called vaginal dilation. The dilators are made of smooth plastic and shaped like a taper candle. It can take 2 to 15 months to create a functioning vagina. The amount of time it takes depends on how often dilation takes place. You can stop dilating once you are having sex regularly.

Deciding to use dilation to make a vagina longer is your decision. It is also your decision when to start. We recommend that you wait to start dilation until you are completely ready. Your healthcare provider will help you make decisions about dilation. They will show you how to dilate and will support you throughout the process. You will visit with your doctor often while you are dilating to make sure it is going well for you. See our handout “How to Use Vaginal Dilators.” seattlechildrens.org/pdf/PE1292.pdf

Creating a vagina with surgery

Almost all people will have success with dilation alone and will not need surgery. However, if dilation does not work, a vagina can be formed using surgery. In most cases, a vagina is created with a graft. A graft is a thin piece of tissue from another area of your body. After the surgery, you will continue dilation to keep the area open.

Will I be able to have children?

Most people with MRKH cannot get pregnant, but their ovaries work normally. This means you may produce eggs. It is possible for you to have a baby through in vitro fertilization if your ovaries produce eggs. Your eggs can be fertilized by your partner’s or a donor’s sperm outside the womb and implanted in another person’s uterus (gestational carrier). A gestational carrier is a person such as your sister, friend or another person you choose, who agrees to carry the pregnancy for you. You would be the biological parent of this child. Many people with MRKH also become parents by adopting a child.

Who can I talk to about my diagnosis?

You may feel very saddened when you learn that you have MRKH. You may feel shocked, numb and angry. It is normal to feel sad about not being able to carry your own pregnancy. You may also feel confused or have questions about how MRKH affects other parts of your life. We recommend close counseling with a psychologist to help you cope with your diagnosis. We can help you find a psychologist who understands MRKH.

You may also feel isolated when you learn that you have MRKH. However, we care for many people with MRKH and you are not alone. Ask your healthcare provider about how we can connect you with support from other teens and young adults with MRKH.