

Beautiful You MRKH Foundation, Inc.



Beautiful, just as you are

Creating a supportive community that partners with health care professionals to empower all women with MRKH to feel beautiful, just as they are

What is MRKH?

Mayer-Rokitansky-Küster-Hauser (MRKH) Syndrome is a congenital condition characterized by underdevelopment of the female reproductive tract. Approximately 1 in 5000 females are born with MRKH.

Typically, people affected by MRKH have functional ovaries and develop breasts and other secondary sex characteristics. The majority find out they have MRKH after seeking medical advice due to a lack of a period.

MRKH Type I affects the Müllerian tissues (fallopian tubes, uterus, cervix, upper portion of the vaginal canal, and). In some people, the uterus develops an endometrial lining that grows during their hormonal cycles. This can be painful and lead to endometriosis.

MRKH Type II/MURCS occurs when other organs are affected; kidney and vertebral system anomalies are the most common. Some have heart defects and hearing loss.

Klippel-Feil & Ehlers-Danlos Syndromes are also seen in people with MRKH. These musculoskeletal syndromes can be accompanied by distinct facial and skeletal features, connective tissue problems, and pain.

Mental Health and Wellbeing

MRKH can be a difficult diagnosis. People often experience shock, feelings of loneliness, and isolation. It is common to question gender identity and to have feelings of anger and sadness.

People often seek mental health care when their friends start building families. This can be an isolating and lonely time for people with MRKH. Many people have found mental health care to be an important part of their healing process.

Sexuality

Many have a shortened vagina that can lead to painful attempts at intercourse. The choice to or not to lengthen the vagina is a personal one that is best decided by the person who has MRKH. Some choose to create a vaginal canal shortly after diagnosis; some wait until they are much older; and some choose to not undergo any treatment.

Dilation is recommended as a low-risk, first line of treatment by the American College of Gynecology. The person with MRKH gradually stretches the lower portion of the vaginal canal using plastic or silicone dilators. This should be done under the care of a physician, who can teach the individual optimal methods and techniques.

There are multiple surgical methods that can be used to create a vagina, and there is no consensus on what method is best. Each surgeon typically focuses on one type of surgery, and most people must dilate after surgery to avoid complications.

Family Building

The options to build a family vary depending on where you live, your religious and cultural values, and your personal preferences. As people with MRKH typically have functional ovaries, it is possible to have biological children through *in vitro* fertilization using a gestational carrier or a uterus transplant. Many people have chosen to adopt and/or foster adopt. Some create a savings account to help with these costs.

Living Your Best Life

Accepting MRKH is often a grieving process. It's rarely linear, and MRKH can pop up in your head when you least expect it, even when you thought you've accepted it. There are many in the MRKH Community who lead happy and fulfilling lives – with and without children. We wouldn't trade MRKH for anything.

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