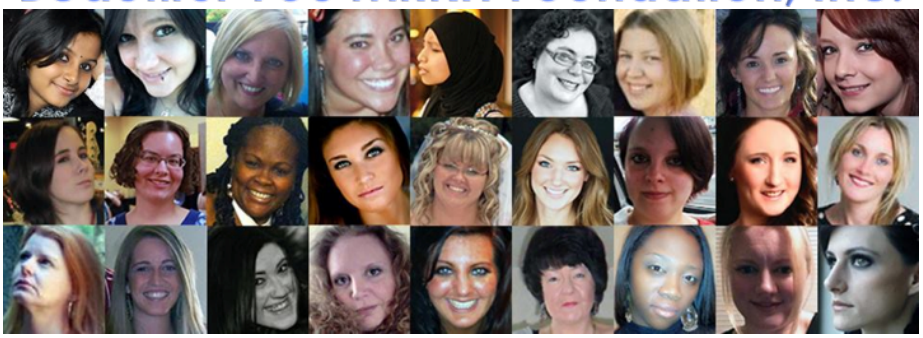
MRKH Syndrome

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?

Named for the four physicians who first diagnosed the condition, Mayer–Rokitansky–Küster–Hauser Syndrome (MRKH) occurs in ~1 in 5000 females. Other common terms are Müllerian Aplasia and Vaginal Agenesis.

MRKH is a congenital condition (which means it is present at birth) that results from the incomplete development of the female reproductive tract. People with MRKH have two X chromosomes and a typical female chromosome analysis (i.e. 46, XX). They have functional ovaries that can be located in unusual places in the body. Typically, women with MRKH lack a functional uterus, cervix and upper vaginal canal. They have normal external genitalia and breast development, and often have a small external vaginal opening, called a 'dimple' that looks like a hymen. MRKH can encompass additional symptoms including: kidney abnormalities, ear problems, skeletal malformations and heart defects.

What to expect

The primary reason that teens and women with MRKH seek a physician's care is because they fail to menstruate. The first physician most teens see is a local family physician or gynecologist.

Many general practitioners are not familiar with MRKH (although they will diagnose a patient with Müllerian Aplasia or Vaginal Agenesis). This can prolong the time to obtaining a diagnosis of MRKH and increase anxiety. In many countries, females will usually be referred to several specialists at the nearest teaching hospital. Most patients see at least a geneticist and a gynecologist; some will also see an endocrinologist, surgeon and urologist. It is becoming more common for clinics to offer psychotherapy with a clinical psychologist who specializes in fertility/reproduction.

The patient will be examined by these specialists, and an ultrasound, MRI or laparoscopic surgery is usually done during this time. This process can take weeks or months, and can be very stressful, traumatic and invasive. It has been our experience that an MRKH diagnosis opens up support networks for females and provides a sense of community.

Treatment options

~ *Nothing*. Many women decided to leave their bodies as they are.

~ *Dilation*. You can lengthen your vagina using dilators that stretch your existing tissue over time.

~ *Surgery*. The McIndoe uses a split skin graft to create a neovagina. The Vecchietti is a quick, traction-mediated dilation surgery that requires diligent, long-term post-op care. Bowel vaginoplasty is when a portion of the bowel is used to create a neovagina. The Davydov procedure uses the woman's own peritoneum to create a vaginal canal. Most, if not all, of these require and benefit from post-surgical dilation.

~ Since treatment options depend on where you live and which type of surgeon or physician you see, it is worth getting a second opinion.

Fertility and MRKH

In vitro fertilization

Many women with MRKH have been able to have biological children using *in vitro* fertilization and gestational surrogacy.

Adoption

Adoption is another option for women with MRKH.

Visit us at:

www.beautifulyoumrkh.org

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MRKH Support and Awareness

Moms for MRKH Support Group

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