

MRKH Resources from the Beautiful You MRKH Foundation

Disclosure

Want to know more about disclosure? Click on the QR Code to download MRKH & Friends: The Journey of Disclosure with MRKH.



MRKH Videos



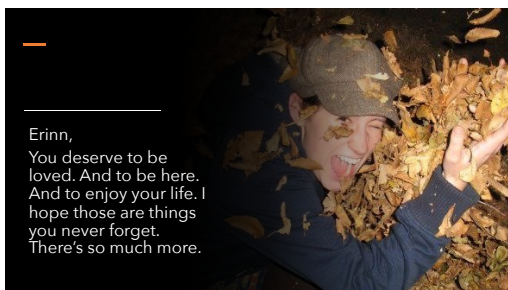
Do you have urinary symptoms? Check out the video highlight from Dr. Christine Pennesi's 2021 study exploring urinary and fecal symptoms in people with MRKH.

Have you wondered how MRKH can affect mental health and wellbeing? Check out the video highlight from Dr. Susan Carroll's 2020 paper exploring how MRKH affects your mental health.

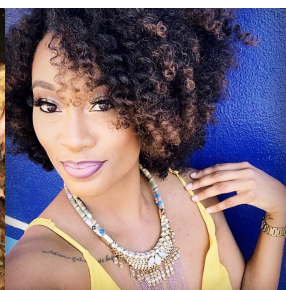
Sunni Speaks: A video series exploring Disclosure and Müllerian development from Sunni Anne Ball, MRKH Canada, and BYMRKH



The Empowerment of the Silent Sisterhood: The BYMRKH Blog
Excerpts from *Letters to my 17-year-old Self*



Erinn,
You deserve to be loved. And to be here. And to enjoy your life. I hope those are things you never forget. There's so much more.



Janay,
You've spent years blending in with white walls, but now you paint beautiful brush strokes in every space you enter. Remember, everything isn't perfect, but it's still beautiful. Don't ever scale back from being YOU.



The tears you shed, wanting to be "normal," will eventually be replaced with tears of joy. You learn that you are special to God, your family, and friends. You learn that your uniqueness is the very thing that allows your light to shine.
- Badia

The only way out is through

There are no shortcuts, the only way to get out of this phase is to go through it. You will feel uncomfortable, but it is when you are out of your comfort zone where you really grow and become confident.
-Sabine





Beautiful
you
MRKH Foundation

Research and Policy Publications on MRKH:

Fischer N, Xun H, Lossie A, Fadavi D, Darrach H, Yesantharao P, Kraenzlin F, Singh B, Sacks JM, Segars JH. Perspectives of 281 patients with Mayer-Rokitansky-Küster-Hauser Syndrome on uterine transplantation. *Fertil Steril*. 2021 Apr;115(4):1074-1083. doi: 10.1016/j.fertnstert.2020.10.044. Epub 2021 Jan 16. PMID: 33468312.



The major conclusions from this paper are that there is a strong desire for uterine transplants to become widely available, safe, and affordable. However, uterine transplant programs should consider the vulnerability of this group in regards to informed consent and thorough evaluation prior to acceptance into the program. Providers who care for people with MRKH should prepare to be able to engage with their patients regarding uterine transplants, and care should be taken to ensure all educational materials use evidence-supported information.

Mikhael S, Dugar S, Morton M, Chorich LP, Tam KB, Lossie AC, Kim HG, Knight J, Taylor HS, Mukherjee S, Capra JA, Phillips JA 3rd, Friez M, Layman LC. Genetics of agenesis/hypoplasia of the uterus and vagina: narrowing down the number of candidate genes for Mayer-Rokitansky-Küster-Hauser Syndrome. *Hum Genet*. 2021 Apr;140(4):667-680. doi: 10.1007/s00439-020-02239-y. Epub 2021 Jan 19. PMID: 33469725.



In this genetics study of 111 people with MRKH, we identified 72 candidate genes to be involved in MRKH. Ten of these showed evidence of being involved in Müllerian development or causing an MRKH-like outcome using animal models or showed that they were involved in processes important for uterine development in studies using human cells.

Pennesi CM, English EM, Bell S, Lossie AC, Quint EH, Swenson CW. Prevalence of urinary, prolapse, and bowel symptoms in Mayer-Rokitansky-Küster-Hauser syndrome. *Am J Obstet Gynecol*. 2021 Jul;225(1):70.e1-70.e12. doi: 10.1016/j.ajog.2021.02.020. Epub 2021 Feb 20. PMID: 33621544.



In this international survey of 615 participants, we found that urinary symptoms, vaginal prolapse, as well as bowel symptoms, are common in people with MRKH, and people with MRKH should be evaluated for these symptoms in clinic. Check out the video from the QR code above.

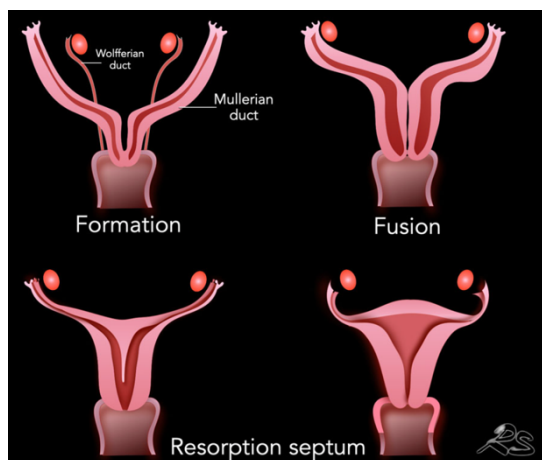
Mind Over MRKH Podcast from Ella Mae Fullalove:

Checkout podcasts from leaders in the MRKH Community. Hear about uterine transplants from Marianne Wood-Clark (West Coast Ambassador), Badia Atcherson (BYMRKH Advisory Board Member, and Belonging Team members) and Amy Lossie (BYMRKH President and co-founder), along with many others.

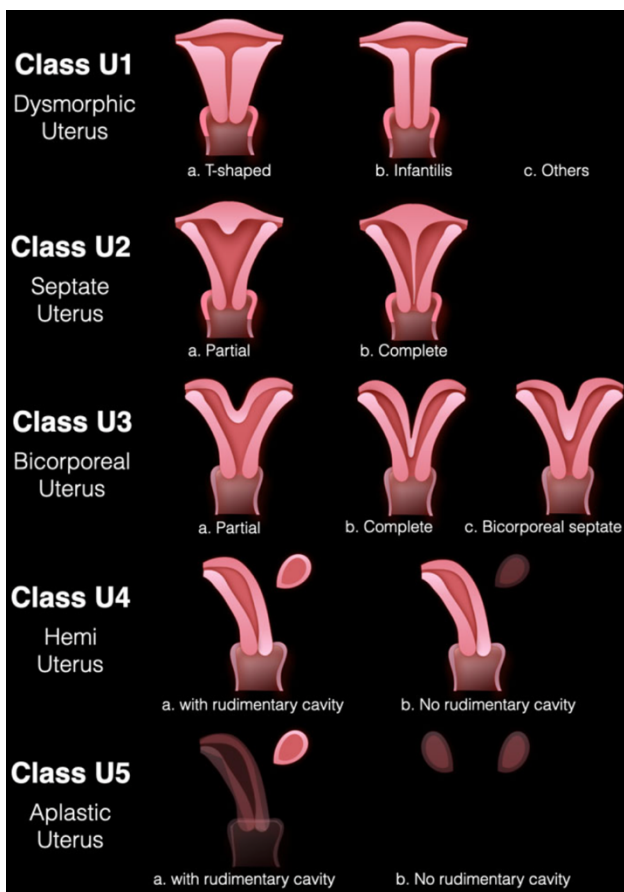


The Spectrum of Müllerian Development:

Embryology



Spectrum of Development



MRKH Coaching through Sumaavi Trusted Circle:

Rima Zigaitis is a passionate MRKH Coach who provides private coaching and structured group coaching through Trusted Circle by Sumaavi. Rima Zigaitis uses her extensive knowledge of creating training modules to Sumaavi Trusted Circle. Her programs are created with an end-goal in mind and are designed to “help you transform how you feel about yourself, your body, and your future while living with MRKH.” – Rima Zigaitis



Find YOUR Regional MRKH Support Group:

Find Christie Laggis during the meeting. She is the Midwest BYMRKH Ambassador. She can help you become more involved in meet-ups, Zoom support groups and our online groups. We host Zoom Support Groups (regional and international) at least monthly and Parent Support Groups quarterly.

