

MRKH VOICES

There are some experiences in life that you can't begin to imagine until you've had them. The MRKH Event this past October was one of those experiences. The MRKH Organization hosted the 2nd Annual MRKH Event, co-sponsored by The Institute of Leadership and Change at Simmons College. We are very grateful to this collaboration for providing a safe and comfortable place for us to meet. Women traveled from California, Connecticut, Florida, Massachusetts and New York to meet face to face. We came from many races, religions and cultures. We represented a wide range of age, class and experience. The thing that really impressed me was how we nurtured what we have in common when we live in a world that prefers to focus on what might keep us apart. It helped me remember that community is an expression of attitude and we can create community wherever we are. Each of these voices touched me in a special way and I hope they will inspire others to attend next year.

esther morris leidolf, age 50, founder and president, MRKH Organization- Boston MA

As it has been said before, the MRKH Sunday was truly amazing; kind of tops any Oprah show!

I actually came home as if I received a new diagnosis of MRKH all over again. For whatever reason, I have been walking around with this half-belief (for 17 years, mind you :-)) that any minute now, I will turn "normal" and this was like a dose of reality for me. And reality is sinking in, and it's sad. Therefore, I would like to cheer up. I really like what one of the women wrote in her email about treating one's self well.

All my best to my newly found MRKH sisters! I cherish each one of you.
from LOS ANGELES, age 33.

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From New York,

I was born without a vagina or a uterus, and since have felt like less-than-a-woman. I was told by doctors that I was a rare case, and that they'd never seen anything like it before. I wasn't even given a name for my syndrome. I immediately had surgery to construct a

vagina-it didn't work to say the least. Coming to terms with the reality that I can't carry children has been a mind-boggling struggle all on its own. I have since struggled with depression and self-esteem issues that I only now recognize. Now I know a little more about my body. I know that my syndrome is MRKH, and I know that I am not alone. Through online research I found MRKH.org and have attended the 1st and 2nd annual MRKH conferences. The relief and hope I feel for those few hours that I get to sit in a room, and connect with other women who know exactly what it is like to forget who they are and fear where they're headed is immeasurable. That feeling stays with me, as I now have someone to email or call when I am having a hard time.

This year, I took a 16 hour train ride, rode the subway from one line to another and another, carrying 3 suitcases in heels, and every single moment of it was worth the experience of being face to face with these women. It has helped so much to know that I am not alone.

So thank you to all of you brave women who shared your stories with me, and listened when I was angry, or scared. You're helping me to take a step in the right direction-toward a greater love and appreciation for myself and my body, despite its differences. I'm learning that is all my body is- it's different. Different doesn't have to be a bad thing.
age 22

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Deborah in NYC

I was diagnosed when I was 16, had the McEndoe procedure at 17. I am now 41. Meeting with other women who have MRKH was a wonderful experience that finally gave me a sense that I am not alone in the world. There was both pain and joy, struggle and acceptance but most importantly, there was a sense of belonging that I never expected to have. We are strangers who have lived similar experiences, in different places and at different times, yet somehow we could just sit and talk for six hours. What a rare opportunity to connect with others who share an experience that has shaped our lives when most of us thought we would sit with MRKH alone forever. I am very grateful to have had this opportunity.

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It was truly a wonderful experience to meet other women like myself and chat

with them face to face. In only a few hours, I feel like I made friends for life. We all share the same struggle in life and listening to everyone's stories and sharing everyone's tears made me realize that I am not alone. None of us are alone. – Melanie, Connecticut

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"I couldn't imagine in a million year that I'll ever get a chance to meet my fellow MRKH sisters until the conference. I was very happy to find two support groups online but even more ecstatic to meet in person. Honestly, I was very nervous and anxious yet excited at the same time. I didn't know what to expect, guess this was a huge step in dealing with my MRKH.

It was overwhelming and mind-boggling (in a good way of course) to be in the presence of all the wonderful ladies that travel all over the country to meet, share and listen to each other's experiences with our common bond, MRKH. It was an emotional and inspiring weekend for me. I'm planning to stay in touch with the other ladies I've met at the conference. Thank you again for facilitating this wonderful event!

With love,
Melissa A
dx 18, now 25, NYC

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