

Creating Peer Support

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How do you rise above years of self-doubt in just one afternoon? How do you know when you're ready for change when you don't quite know who you are? How do you open your heart for emotional support when you're used to being alone? These are a few of the questions that ran through my head while preparing for the two MRKH conferences that recently took place in Boston.

The first conference was at **Boston Children's Hospital**, sponsored by the Center for Young Women's Health. The workshops and groups were facilitated by a creative mix of medical and mental health providers familiar with MRKH, as well as adult educators who also have MRKH. The participants included young women recently

diagnosed, women in different stages of treatment and women not in treatment. There were also groups for family members needing to learn and connect with others. This gathering was long overdue. I don't think any of us were prepared for what that day would unfurl. The following letter from a college student who attended best describes the success...

"Walking in was such an incredible experience. I was late, and as I stepped into the conference room, I could hear a doctor explaining what I know so well about my own body to a room full of alert, attentive people. It was such an incredible feeling to realize that people were interested in this, and that people spend time studying it, and trying to understand this part of me. It was unbelievably reassuring and empowering. I felt so understood. We also had a support group where we talked more generally about living with MRKH. I felt like I really helped people feel better about MRKH, all while feeling better and better about it myself through other peoples stories and ideas. This conference meant so much to me. I cried about it later. Just because I felt so comfortable. It's so nice to be able to discuss it without having to explain every detail. I had an unparalleled experience. I'm full of feelings about it. Thank you, thank you, thank you."

The next day, The **MRKH Organization** held a gathering for adult women with MRKH sponsored by the Institute for Leadership and Change at Simmons College. The age range of the participants was 20-55. People traveled from Mississippi and Texas to meet another woman with MRKH for the very first time. The group was an amazing mix of cultures, class, sexual preference, surrogate and adoptive parents, women who don't want kids, artisans and professional women. We didn't have a set program but we had a collective agenda. Every woman who walked in the door sat down, introduced herself, and told her story with power and pain.

We heard about the mutual frustration of providers who don't know how to talk to us, or see the entirety of our syndrome. We felt each other's difficulties and shared knowledge and experience. We laughed. We cried. And we listened.

In both these events, formal and informal, the successful element was the women who made the day rich. Spanning age, background and experience these brave women came together to share what they know, what they fear, and what they have overcome. They gave so much of themselves. We wrestled with our sadness and loss throughout the weekend, which made it even more magical to watch these amazing women give each other life.

Every one of the attendees hopes Young Women's Health at Boston Children's Hospital and the SILC will sponsor similar events. (MRKH Org and SILC gathering is tentatively planned for the Spring of 2007) We hope to expand on our vision to create a visible presence in the world of women's health and

sexual awareness.

Thank you one and all for making this happen!

esther morris leidolf

Founder and president, MRKH Organization

Contact info@mrkh.org to create or contact a regional gathering in your area.

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