

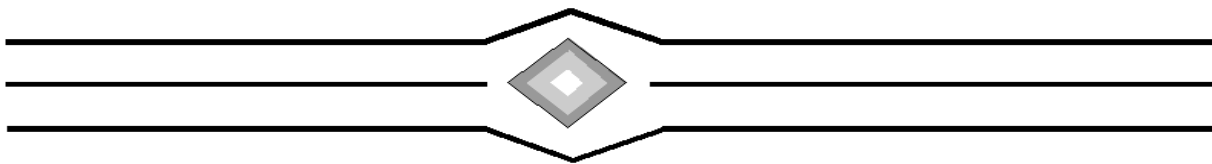
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MRKH.org was started to offer a place for the MRKH community to network about activities; and to work with the public and medical professionals towards a better understanding of the needs of women with mrkh. This is a new endeavor. MRKH.org incorporated in June 2001, but the web site has been online for 9 months. In that time the web site has received over 5400 hits and 5 requests a week for information. One of the requests was from **Good Medicine** in Australia. They

wanted to include a woman with MRKH for their segment, *Good Sex*. That outreach has introduced the public to MRKH, and we have heard from women who “*Never knew there was a syndrome connected to this. I thought I was the only one.*” Gee, where have we heard that before?

We couldn't contact the woman who appeared for permission to use her name but many wonderful compliments followed her appearance; for which the MRKH community is most grateful.

IN THIS ISSUE:

Regions are forming
Montreal Pediatric Endo Conference
MRKH gets airtime in Australia

Denise Burnson has established regions so women can get together for support and activism. Many women volunteered to be regional coordinators (yea team). A few regions have already met and others are setting dates. If you want to know about the region that would be most convenient for you, check the link at <http://home-stead.juno.com/mrkh1/about.html>

Women in Paris Texas (Region 5) will be meeting on August 3-4th. They intend to work on a project for Frequently Asked Questions.

Austrilia (Region 12) in will be meeting in Sydney on Nov 9-11 2001.

Calif, Nevada, Arizona (Region 10) will be meeting again on September 15, 2001

Women in Wichita, Kansas(Region 6) will be meeting on August 18, 2001

After years of email communication this is very exciting . Most women with MRKH have never met anyone else with the syndrome. It's nice to know this is changing.

Women are free to join any group they want. The decisions about the members and activities will be determined by each group.

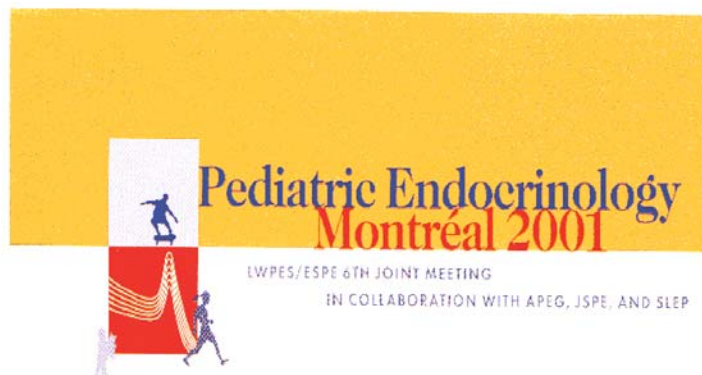
Mrkh.org has offered web space to post these regional events, but we are not sponsoring or coordinating them. Anyone is welcome to report about what your regions is doing, or any event you would like to announce, by sending a blurb to the newsletter info@mrkh.org.

After a slew of calamities I arrived in Montreal in one piece. I had worked an 8 hour day, shuttled through the Big Dig in Boston only to be told at the ticket counter that my flight was booked for 'yesterday'. (So much for confirming ahead of time). Five minutes of dramatic conversation ensued and I was booked on the next flight with just enough time to go to the bathroom – where I almost lost my ticket to the whirl of an overzealous automatic toilet. Then there was customs... I had been told repeatedly that I did not need a passport to fly to Canada but no one told Canadian Customs Officials. After explaining 50 copies of the *Missing Vagina Monologue*, 50 copies of the MRKH Survey, 50 copies of the ISNA newsletter and NOW endorsement, I was finally allowed to pass.

I have never done this before. I am newly empowered by my MRKH diagnosis and still amazed by it. MRKH.org was merely weeks old and I had only a few days to prepare for the largest International Pediatric Endocrinology Conference ever held. I shuttled to the hotel, stashed my stuff and tried to prepare for the days ahead. ISNA had done all the preliminary work arranging for space and lodging; fundraising and networking. I was there to make a collective presence. My worries entailed feeling exposed, personally threatened, doctor phobic, and uncontrollably sarcastic. I was simply too busy for any of that so I put my worries aside. Besides, I had to find the Jacuzzi.

As a conference exhibitor you get nothing. I couldn't get a program

for the weekend, directions to our table; and I had to beg for a chair. Most of ISNA's stuff was in a postal abyss so I needed to resolve that as well. I got friendly with the folks at the table next to me and put out my limited display of materials. I had a sign with the introductory sentence of my Monologue for MRKH.org and conference staff made a sign for ISNA. If you want to get the attention of a hall full of mostly male MD's, stand under a sign for Intersex Society and advertise you were born without a vagina.



This being an international conference, language was a challenge for me. I saw name tags from Australia, Brazil, Canada, Singapore, India, UK, Netherlands, Peru, Italy, Germany to name a few. I tried to strike up conversations and doctors tried their best to communicate. I would watch them read the signs for "The Intersex Society of North America" AND "... I read the Vagina Monologues. I wasn't curious about the play, I was curious about vaginas. I am a woman who was born without one...." They would read, and then STARE at me. Only a few shuttered and scurried off. Some wouldn't engage at all, and many came back later to stare ever harder. It was interesting to be examining doctors for a change; watching them as they were watch-

ing me. Here I was- a personable individual making a presence about a medical reality that medicine has tried to dismiss. I smiled a lot.

It also gave me the chance to think about how doctors perceive their work with our bodies. Medicine is a reactive science. When you break a bone the doctor will set it. When you have a wart the doctor will burn it off. When we are born *abnormal* the doctor will *correct* that too. Doctors treat our genitals with medical procedures, but those medical procedures treat our souls with invasion, confusion and despair.

Clearly some of them will never get it, but some are clearly trying. Yet one woman proclaimed "I am a Pediatric Endocrinologist. I don't need information from you." I couldn't help myself. "Then you may find this survey interesting. I

work with a group of over 400 MRKH women and most of our doctors have never heard of it." I handed her the survey before she got away. Smile, Smile, Smile.

The docs would come by in groups between programs. At times I spoke with four or more people at once. I was fairly impressed by their sincerity; and the humble few who asked for advice with certain cases. I passed out lots of business cards, Monologues, Surveys, and newsletters. Whether they ever read any of this stuff will take time to know but 50 copies of each were gone by the end of the day.

The only negative response came from two young docs who read the title of the *Missing Vagina Mono-*

logue and quipped, "That sure limits things." Their smarmy looks waned when I pointed out how "It can actually open up a whole new world of possibilities". Smile, Smile, Smile. A few docs sputtered cryptic sentences as they passed. "I'm from UC Davis." "Thanks for the work you are doing." "I haven't heard MRKH referred to in years." "I'll be referring to your (ISNA) work in my presentation tonight." I appreciated seeing them in a group rather than the one on one personal experience I am used to. I watched their curiosity and their concern. Not only was I appearing human to them in our in-

teractions, but they became human to me. The difference being that doctors have the option to determine sexual function and appearance when patients always do not. I learned a lot on this trip and I feel good about making an appearance. The mere fact that I was there exposed medicine to the fact that we are here in numbers AND we are organized for our own wellbeing. They were curious about the concept of exploring nonphysical treatment and receptive to consider our emotional needs as part of our medical care.

It was a hit and run event but one that I hope will live with the docs as long as it will live with me. I thank everyone who donated to help with expenses, ISNA for making all the arrangements and getting funds, and the very kind doctor who was willing to share her room with a stranger from Boston

esther morris

In the next issue: THE PATHOLOGY OF VARIATION

Your contribution will:

- ◇ Increase the awareness that atypical gender / reproductive development is not uncommon –just unheard of.
- ◇ Help inform young women about treatment so they can make appropriate decisions about their lives with a patient centered approach.
- ◇ Help us continue to network with Medical Professionals to make the best care available for all women.
- ◇ Collaborate with other groups organized for atypical gender and sexual awareness.
- ◇ Get information to the health communities where it can be available to everyone.

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Please send this form along with your generous donation to:

MRKH.ORG ***** P.O. Box 1494 ***** Jamaica Plain, Ma 02130

NAME _____

ADDRESS _____

EMAIL _____

WOULD YOU LIKE TO BE LISTED AS A SUPPORTER ON OUR WEBSITE? **YES NO**

HOW WOULD YOU LIKE TO BE LISTED? _____

SUGGESTIONS OF WHO ELSE WE SHOULD CONTACT _____