

## The Missing Vagina Monologue and Beyond

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*Curious to learn what women were talking about 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. That monologue was shared from a father's perspective so I would like to give you my own. This could be the Missing Vagina Monologue, or the Monologue of Missing Vaginas. Either way it's a monologue that deserves more attention...*

*Mayer-Rokitansky-Kuster-Hauser Syndrome is a condition that involves congenital absence of the vagina, fallopian tubes, cervix and/or uterus. Some women have uterine remnants, or horns. External genitalia are normal. Chromosome karyotype is 46XX(normal female). The incidence rate is approximately one in 5000. Other symptoms involved to varying degrees are kidney abnormalities, skeletal problems and hearing loss. The cause is somewhat unclear, but the Syndrome occurs sometime during the 4th-6th week of fetal development. There is not much research on the whole body, it's mostly about creating vaginas for "normal sexual function". My main concern is not how the Syndrome develops, but how women are transformed because of it.*

This is the part that makes me so crazy. It's hard to talk about because too many people are uninformed about MRKH. And those of us who have it don't have the heart to take that on. We retreat to fight the daily battles of our anomaly, and the health issues that go along with it. It's a lot of work to keep up with because none of the doctors I've worked with have been able to connect my symptoms to the Syndrome. Could I have avoided years of disability had I known I had a condition that was not suited for my chosen profession? Could I have avoided hearing aids had I known I had MRKH, and that hearing loss was part of it? These are things I will never know but always have to live with.

Trauma. It spirals, touching down at different times in my life. In a scary way I hope it never ends. True, the conflict and shame I would be well rid of, but the presence of mind keeps me holding on, ever hoping to grasp or accept my origin of being. Wishing I could have had choices... The chance to desire change on my

own - embracing opportunity rather than fleeing who I was and fearing who I was supposed to be. Too much focus on making me right when I was quite content with myself, thank you very much.

My life completely changed when I was 13 and sent home from camp with abdominal pain. When I was examined they discovered an imperforate hymen prohibiting the flow of menstrual fluid. I had my 1st surgery then, to open my hymen so I could bleed. But they found that nothing was there. I had no vagina, just a dimple, and they could detect no uterus. I had secondary sex characteristics, body hair and breasts, so they guessed I had ovaries but no one knew where. The medical profession has known about MRKH since 1838, but I was diagnosed with "congenital absence of vagina" because that's what they cared about. My abdominal pain was quickly forgotten. I was suddenly and shamefully different. Puberty was over for me. I went from selling Girl Scout Cookies to correcting my sexual dysfunction in one afternoon.

My doctors talked to my parents about vaginal reconstruction so I could have a normal sex life with my husband. What husband? And why couldn't he adjust as he would for any other "birth defect"? My parents did the right thing. They took me down the only path available, the path of "corrective" surgery. But I was staggering from the loss of my fertility, the dream of having children. I received sympathy and even pity about that, but the most pressing concern was to create my vagina ASAP.

I spent the next few years going to specialists, having tests to confirm my gender, being probed by curious doctors and interns with multiple instruments in multiple holes at multiple times. There were no women doctors involved in any of my treatment. My chromosomes were counted and discussed in front of me. "Got to run that test again just to make sure." There were not enough other signs to determine gender for these guys. They examined my breasts, labia, clitoris, and dimple with blind eyes.

Not seeing what they wanted, they saw a narrow version of normal, and I wasn't it. I was too young to know I had the right to ask questions. Or the right to slow the process down to fit my own state of mind. I had major doubts about what was going on, and what was being done to me. But I was not yet capable of wondering who was having the biggest problem with my body. Was it me or the people treating me? Frightened in a cloth hospital gown I did what I was told. And my relationship with my body ended. Suddenly I had no right to have it in the state it was in. Like an android on an assembly line, I had no concept of feeling that this

body was mine. There was so much focus on the woman I should be that I lost all knowledge of the girl that I was.

Once I was officially determined female my reconstruction was arranged. Then I could adopt children and life would be just fine. In 1972 I had my 2nd and 3rd surgeries. I was 15½. That summer I took a "trip" for three weeks to avoid explaining why I had to go to the hospital. I missed family weddings and graduations for my McIndoe surgery. *"...a slight dimple was present where the vagina was expected to be. A transverse incision was made. By means of sharp and blunt dissection a very adequate vagina was developed... a split thickness skin graft was obtained from the left buttocks and attached to the mold... The Balsa mold was then inserted into the cavity... The skin graft that extended was attached to the vaginal introitus... The vagina was closed... All sponges were accounted for."*

After my surgery I was sent to recover in the maternity ward. For 17 days I shared a room with countless women having babies. I had no visitors since I was on a "trip" and no one knew to come visit me. It was me and my mom, and a lovely nurse named Donna who would wake me in the morning sitting quietly by my bed holding my hand. I later realized that she was protecting me from nightly visitors wanting to satisfy their curiosity as I slept. My cousin worked in the hospital and visited often, but my reason for being there was never discussed.

Two weeks later I had Phase Two- my 3rd surgery, to have the mold and stitches removed. Then I was told about postoperative therapy to keep my vagina *functional*. A functional vagina is *"a vagina that will be able to accept a normal size penis"*. I was given vaginal dilators for postoperative therapy, and brief instruction to insert one and wear it every night. The problem was solved, for everyone but me. I was left out of the experience. The whole shebang was over. I never had a chance to deal with any of it. I had two follow-up visits with my surgeon and never saw him again. I was another surgical success.

Why was my gender challenged in the first place, then confirmed like something I didn't already know? Why was my body taken away and rearranged like a sexual Action Figure by men with knives? What was the need to feminize my body, which actually neutered my soul? I wasn't able to see what all the fuss was about. All the excitement just reinforced my despair. I was living within this anomaly and feeling terribly wrong for the fact that I didn't really care that I was born without a vagina.

I was introduced to anger two years later when I started having sex. After all that trouble I discovered that a penis would respond to anything. I felt abused in the most intangible way, a victim of arrogance and assumption. I couldn't identify it then; I became an instant survivor. And I was told that I would never meet another woman like me. Big time isolation. Divide and conquer? Well I don't know, but one in 5000 is NOT that RARE. I just didn't know that then. I denied my depression. Like the Hunchback in the Bell Tower, I found a place to hide when normalcy failed me.

Tidbits of emotion overwhelmed me in very big ways. I was learning that normal was merely a concept for people who couldn't cope with anything different. I alienated myself from peers who would rightfully complain of menstrual cramps and NO I don't have a tampon! I mastered the stoic, intellectual method of coping and strapped myself in. It was going to be a bumpy ride.

As I grew older I realized I was faced with many questions. How will I experience menopause? How do I monitor the health of my ovaries? How many ovaries do I have and where are they hiding? What about pap smears? I was tracking my cycle with notes on the calendar so I could attempt regular breast exams. I was tired of all this and really pissed that I had to ask all the questions. I was caught in this funky body with no place to go. And I was having other physical problems that needed attention now too.

I finally had another medical work-up done in my early thirties. Technology had changed and they found one ovary. (Two years later they found the other one.) The report I got back from the specialist restated what my doctors said twenty years earlier, but with a fancier name: Mullerian/Vaginal Agenesis. He also noted that my vagina had shrunk. I was recommended for annual ultrasounds to monitor for ovarian cancer. I religiously compared my test results from year to year. In 1997 I noticed a change in the report and called my doctor about it. I was referred for follow-up and another round of tests. They thought I had an ovarian cyst.

After a laparoscopy to remove the cyst the surgeon told me that the procedure didn't work. But he confirmed my suspicion that he would find my uterus. Imagine my surprise when he told me he found two. A full sized uterus on the left ovary and a uterine remnant on the right. So why do my body parts suddenly appear, or have they been there undetected all these years? Could my neovagina have been connected to a uterus enabling me to have children? Was this the cause of the crippling pain I have lived with since I can remember? I thought this was taken

care of decades ago; so why are things acting up now? Ironically, my 5th surgery was for two hysterectomies; and back to the Bell Tower I went.

Every time I get depressed about this I take some little action. Fifteen years ago I got my hospital records and read about my surgery. I have also gotten medical records from every doctor I have ever seen. My sister sent me an article and in the year 2000, I learned about MRKH for the very first time. I got a copy of my latest work-up from eight years before and saw Mayer-Rokitansky-Kuster-Hauser Syndrome written there too. The report my specialist sent me had left that diagnosis out. But he was quick to point out that my vagina had shrunk. Apparently, vaginal function was all he thought I needed to know. Apparently, other parts of the Syndrome were not of concern. I was disabled with back problems at the time, but the connection was never discussed.

Guided by a possible diagnosis, I went to the medical library to research articles on MRKH. I was in my forties and finally had something to call this other than bizarre. That is when I discovered the other symptoms associated with the Syndrome. The connection to years of disability and hearing problems made me numb. If I had known I was predisposed to disabilities I would have made more appropriate decisions about my life. But what a joy to confirm that I hadn't brought them on myself. The most important discovery I made was to learn that there are many variations of gender. This revealed how we are forced into incredibly rigid standards. Even though I was labeled female, I feel more like an *it* at times. To ignore most of the possible genders is to ignore diversity altogether. Those who don't fit the traditional male-female dichotomy may seem few, but maybe not if we allowed ourselves to see them; to respect diversity. A whole new perspective was growing from very old emotions.

Reading the articles on MRKH made it painfully clear that this wasn't just about bodies, and that the "corrective" approach to genitals should not immediately be assumed. Emotional and sexual counseling would have provided me with a more permanent and accepting solution. If I wanted surgery later in life then I could work toward that. I feel abnormal because I had to be fixed, not for the truth about my body. I feel different because of my surgeries, not because of my vaginal dimple. Being born without a vagina was not my problem. Having to get one was the real problem. It's not that my vagina has shrunk that alarms me now; it's the fact that we judge vaginas (genitals) at all. People don't fail to meet the definition of normal gender, but the confines of the definitions fail to meet the people. Even with the benefit of normal female chromosomes I feel oppressed by this. Too many people are turned into "freaks" when we refuse to see them as they are. But our

genitals are also our privates and they are not to be discussed. Or different. Wishing again to have had choices...

I am an adult now and I DO have choices. I no longer choose to trust without question. I no longer choose to believe without information. I am an adult now and I have a library card! I have researched the various surgeries and dilation treatments used to create vaginas. Surgery is used for a person with no vagina-or when dilator treatment doesn't work. Dilator treatment is less risky, but still very invasive and just as emotional. The basic method is to apply enough pressure with the different sized dilators to indent your tissue enough to achieve an "acceptable depth". It takes anywhere from two to eighteen months depending on how often you can do it. I gave up using my dilators after the first few years. Even after my surgery it was painful. And it wasn't stretching anything. It felt emotionally self-defeating for me to continue. So I gave them names, and hid them in the attic.

Various body parts can be transplanted for "normal sexual function". The bowel and intestine have been used to make vaginas, though not so much anymore. I read one case where an actual vagina was transplanted from the patient's mother. My mother's used vagina?! And regardless of the procedure or the treatment you have, you still have to keep your vagina functional with dilators if you don't have regular intercourse. Now who benefits most from that?

There are a few studies on the psychosocial development of women born with vaginal agenesis. The doctors more or less credit themselves for making us feel normal again. But they are the ones who lock us out with their categories of normal and abnormal. Those of us who don't fit in are reshaped until we do. One doctor wrote how an *"angry, withdrawn, muscular girl"* was transformed into *"a woman responsive in coitus and eager to adopt children"*. I can assure you that she worked much harder than he did.

Five months ago I found an online support group for women with MRKH. Having believed that I was the only woman I would ever know with this experience, I was totally overwhelmed. The case studies I had been reading about became real women who finally humanized this experience for me. Some of their stories seemed so traumatic that it challenged me to recognize that their trauma was also mine. What a wealth of information when compared to medical journals. These women taught me more about treatment and courage in a week than any stack of articles or any doctor ever could. Our dysfunction has been treated. Our success rates have been tallied. Then we are sent out on our own to make peace with it all. I felt driven to read between the lines, so I asked some questions of my own.

I compiled a survey of questions and emailed it to the group. When twenty-one women answered my survey I realized this experience could not be captured in a questionnaire. We each have our personal experience with this and cope in our own valid ways. I got most of my information from the question: "What Else Would You Like To Say?" There is so much more to this than "normal sexual function". So much more to the women I am listening to now.

Every woman who answered my survey wanted her doctor to be informed of MRKH. Of the twenty-one women who responded only four of their doctors had heard of MRKH before the initial pelvic exam. Two of those four "*hardly knew anything*". The rest of our doctors were "*shocked*" or "*excited*" about treating us. One woman's doctor "...ran into his office to look a few things up." Other women were referred to specialists without explanation. Most of us never knew we had a Syndrome until years after our vaginal procedures.

Many women are true success stories with supportive doctors and positive experiences. Yet even then there is something missing. Most of us feel that our lack of body parts threatens our identity. We get that message loud and clear and for some that scars the most. We battle frequent depression. We hate being told how lucky we are by people who don't have a clue. We are saddest about infertility but there is no procedure to give us wombs.

The women in the group are passionate about helping other women, and for the need to educate doctors. One woman's doctor gave her a vaginal dilator and compared it to a shoe stretcher. He then told her she could become a nun. A young girl's doctor told her that "*some species respond to overpopulation by producing sterile females*". Some doctors only ask about the sexual pleasure of husbands and boyfriends with no regard to the patient. Some women have needed additional surgeries because their skin grafts grew hair inside their vaginas. The reports on how to avoid colostomies during bowel transplants tell me there have been too many slips in the operating room.

In regard to treatment, twelve of the fifteen who completed treatment felt it was required to be sexually active, normal or loved. The rest of the women felt correction was somewhat required, but they added that they wanted it. Some women question the importance of intercourse. "What's the point? I'll never get pregnant... We share pleasure in many other ways..."

Of the women with medical procedures-all were told by their doctors that their procedures were successful; but not all of those women agreed. One woman had two surgeries before being happy with the result. And two women tried different procedures before finding treatments they could live with. For some women intercourse is too painful or not possible at all. Only three of the twenty-one women were told there were alternative sexual practices besides vaginal penetration. And one woman was cornered by her doctor and told "...how men like oral sex and different positions". Three women were given treatment options but most of us didn't know options were available. One woman had a medical procedure to prepare her for self-dilation. She added, "*I didn't know about the slit*".

Most of the women were worried that their vaginas would not feel normal to their sex partners. Primarily the partners didn't notice. But one woman was called a "*freak*" and one woman was asked why her vagina was "*so shallow*". Another woman was bluntly asked, "*Can't you fix that thing?*" Until that moment she thought she had.

I have read a lot about the "medical challenge" of treating women with vaginal agenesis but I think the challenge is broader than that. We challenge the role presented to women and that makes people very nervous. We challenge the concept of normal for gender and sexual activity, and that makes people fanatic. Indeed we are atypical but we are women all the same, with test results to prove it. Most of us don't realize we pose any threat at all. We start out our lives as normal little girls. Then suddenly something suggests that maybe we're not. The foundation of our identities crumble when we don't measure up. We are literally molded to fit societal values. We accommodate sexual standards to phenomenal extremes with a determination never dreamed possible. We are faced with questions of our most vulnerable selves during our most formative years. But how can you follow your heart to the answer when the process has ripped out your heart?

I come out about my surgery in carefully selected ways. I have seen the response of too many twisted faces telling me that they have never heard of such a thing. They show me pity. They tell their friends this great gossip and strangers ask intrusive questions on the street corner. One medical practitioner told me I was "*just too weird*". I have been physically assaulted by women who presumed I was transgender and too active in the women's community. I have been asked if this is what made me a lesbian, by lesbians who were born with vaginas.

Questions have haunted me for too many years because I couldn't find the words. Knowing other MRKH women has finally allowed me a voice. But I don't want it to stop there. My condition seems extreme only because it's unheard of. Many of the women I surveyed want MRKH to become more public. The hope of opening the door to our secret lives in most of us. We exist in a conundrum because our knowledge is powerful but hidden in embarrassment and shame. The approach to our treatment is very extreme but effects all women in subtler ways. Advances in medicine offer men Viagra, but women still get the knife. Scar tissue does not enhance sexual pleasure.

I want people to understand that doing the right thing often does more harm than good. The standard of normal that we aim for is imaginary. We alter women's bodies when attitudes need adjusting. Correcting our genitals tells us they are wrong. Different is not wrong. Different is different. Women shouldn't have to endure emotional and physical pain to perform one sexual act when so many options are available. I understand why we do that as much as I resent it. I resent it because of the price we pay for society's lack of creative thinking.

Identity shouldn't be centered around body parts; missing, constructed, or removed. Women with MRKH should be treated as women with a Syndrome rather than isolated by *sexual disorder/dysfunction*. My "absence of vagina" posed less of a threat to my health than the parts of the Syndrome that disabled me. Then why is a vagina all I was given to cope with a much greater loss?

The complete survey, article, and links to resources can be found at [www.mrkh.org](http://www.mrkh.org)  
or Email: [info@mrkh.org](mailto:info@mrkh.org)

**BEYOND THE MONOLOGUE**

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coedited by Vernon Rosario and Jack Drescher

Please read the [Missing Vagina Monologue](#), published in Sojourner 2001 available at [www.mrkh.org](http://www.mrkh.org)

**ABSTRACT.** *The author, a middle-aged woman, was originally diagnosed with sexual dysfunction--also known as "Congenital Absence of Vagina"--at age thirteen. Since that time, she underwent four exploratory and corrective surgeries, without ever receiving a correct diagnosis of the syndrome that explained her condition. The author describes personal experiences with the medical profession and her emotional response to the diagnosis and treatment. The author made contact with a MRKH Internet support group and conducted a survey of its members. This paper discusses the qualitative results of this survey, confirming the need for awareness of atypical reproductive issues. This paper concludes with recommendations on the medical and psychological treatment of MRKH.*

**KEYWORDS.** *Congenital absence of vagina, corrective surgery, genital surgery, intersex, Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH), McIndoe, Mullerian agenesis, vagina, vaginal agenesis, vaginal dilation, vaginal treatment*

Writing this Missing Vagina Monologue is the first time I ever looked at my medical history from beginning to the present. It is the first time I have ever considered this experience in terms of my life. My MRKH has always been treated as a physical issue, to be dealt with medically and surgically. In the process, my feelings have been fragmented by procedures, opinions and missing or measured body parts. The more I learn, the more I realize what I need is to UNlearn what I have been taught. Society and medicine experience the intersex population as a freakish and unacceptable physical phenomenon. Our bodies are perceived to need "correction." However, it is not intersex conditions themselves that are harmful. It is the way society treats people with intersex conditions that causes harm. Some conditions are discovered at birth and others later in life. Some people are informed of their physical histories or syndromes, but most of us are not. Some infants are considered to have a medical emergency that must be "corrected" before leaving the hospital. As infants, no one asks them for their consent. Other people become convinced later in life that altering their bodies will make them "normal." Usually the focus of treatment is genital appearance, or definitions of sexual function rather than medical need. However, when bodies are dissected to correct physical "flaws," emotional attachments are also cut. Occasionally there are medical needs that require intervention, sometimes even surgery. But the standard medical practice of "normalizing" surgeries must be questioned. Corrective procedures are meant to prevent emotional trauma for patients, or parents who may not be able to bond with an atypical child. Before we can prevent the trauma, we must examine what provokes it. The silence around atypical genital and reproductive development contributes greatly to the problem. The real phenomenon is the prevalence of genital and reproductive variation. Doctors will admit that there is a

wide range of variation, but their standard for what is acceptable has been determined by the values with which they are comfortable--rather than the variations in genital appearance that actually exist. Excluding the variables of differentiation tips the scale in a way that promotes medical and social values and overrides human realities. Variations are so quickly "disappeared" that we do not get a chance to know about them, or how they might mature. We lose the opportunity to get comfortable with our options. There is entirely too much stigma around genital body parts. We teach our children to respect the differences in others, yet adults create a state of emergency over the size and shape of genitals. When I talk to people about intersex they are stunned by what they did not know. Their ignorance is genuine and their concerns hopeful. They see the benefit that intersex awareness can liberate everyone from rigid standards. History reminds us that social values can change with awareness. Homosexuality is no longer listed in the *Diagnostic and Statistical Manual of Mental Disorders*. It is time to realize that intersex cannot be "cured" either. Cosmetic treatment will never change who we really are it only prevents others from seeing us.

Most of us want to love our bodies but everything we are taught forbids us to do so. Living in bodies that raise all these questions puts too much responsibility on the patient. Knowing that people so rarely talk about genital or reproductive development makes it even harder to be scrutinized in the medical environment. We leave the ordeal of the doctor's office and return to the world of hushing our experience because, "Sshhh, it makes people uncomfortable." We are isolated without emotional support because we are not supposed to talk about ourselves. This is a result of limiting awareness. If people were told how common intersex conditions are, there might not be such panic around personal discovery.

Upon reflection, my own emotional development was interrupted when my doctor told me I was infertile and labeled me with "sexual dysfunction." I was medicalized out of experiencing puberty. My first experience with vaginal penetration was under anesthesia. My first vaginal encounter was a piece of plastic prescribed as postoperative therapy. All the attention to prepare me for sexual intercourse was done prior to my having any interest in a sex-partner. All this was done to prevent emotional trauma, and make me feel "normal." In fact, it did just the opposite. I never had a chance to want a vagina, I simply had to have one.

My trauma started with the value judgment overriding my sense of myself. It was about denying adequate health care because an "adequate vagina" was more important. It was about discovering that all my physical differences were part of a syndrome that nobody previously told me about.

My personal privacy was first violated in the hospital the night after my McIndoe Surgery. I was awakened by the touch of someone spreading my thighs; and looked down to discover a light under my sheets. When I objected, he replied, "I didn't think you'd mind." When I asked if he was the resident who was working with my doctor he explained he was a podiatrist who was, "Just curious."

Considering the amount of time I have spent with doctors, I marvel at the fact that my sister was the one who told me about MRKH. Most of our doctors have only read one

or two pages about atypical development in medical school. When differences become evident, we are not told of the frequency, we are told how to "correct" them. We are rarely told what to expect after treatment. We are not told to explore our own desires; we are told what is "normal" and how we "should be." Most importantly we are not told that we are viable just the way we are. Patients and families are forced into irreversible decisions while in a state of panic without complete information. Society and medicine focus on procedures to correct intersex conditions, not advice for living with them.

People have to know the values of correction to determine if they want to adopt them. It seems fair to ask some questions. Why is a woman's sexual function defined by her relationship to a penis rather than her own sexual body? Are women without vaginas "dysfunctional," or do other people become dysfunctional when their expectation of a vagina has let them down? Why are we suddenly different when we learn about our anatomy as though who we were before never mattered? And why are young women making drastic and permanent decisions about their sexual bodies before they become sexually active?

Before making any decisions, patients and clinicians should be aware of not only what is in medical articles or textbooks, but about what can be learned from the personal experiences of adults in our community:

- Medical procedures are irreversible. Research on long-term results is inadequate because adults are "lost to follow-up."
- Terms such as "abnormal", "disorder" and "dysfunction" reinforce negative stigmas that can contribute to negative sense of self.
- Scarred or removed organs and nerves do not feel pleasure, but they often experience pain.
- Rearranging tissue can cause lifelong malfunctions and/or infections.
- Neovaginas have been punctured during intercourse.
- Society and medicine limit us to two chromosome types when there are at least five different chromosome variations. In reality 1:1600 people have chromosomes other than XX or XY (Blackless, et al., 2000).
- Increased social inclusion and exposure would help to prevent emotional trauma without creating scar tissue.
- Many women, and their partners, have satisfying sex lives without vaginal penetration.
- "Corrective" procedures should be presented as a final option, not the first.
- Patients will eventually learn about their medical history or syndrome, and inevitably resent being lied to and having to find out on their own.
- No one should determine gender, or define sexual function for another person without their direct participation and informed consent.
- Patients need time to make their own decisions about their bodies.

It has been argued by the doctors that the reason for "corrective" treatment is to prevent emotional trauma. Yet the mental health profession has been left out of our care.

Becoming part of an active community is the first experience I found that has offered

me any validation. I was left to think that I had failed drastically because my neovagina did not make me feel "normal." Yet I never received any emotional care for my fears or anger, the loss of who I was, or the loss of my natural body. Once deemed a "medical success," my feelings became irrelevant. Since success meant transforming into someone I am not, I have avoided success from that moment on.

There is a great disparity in the information available to medical and mental health providers. The medical database, PUBMED, turned up one-hundred-fifty-six articles on MRKH while a search in the PsycInfo database found only four, the most recent being 1986 (Lewis and Money 1986, Money, Schwartz, and Lewis 1984, Raboch, and Horeisi 1982, Tucker 1941).

Support groups are the best resource for information and emotional support. Patients usually find them on their own, or long after treatment. Some groups are offered in hospitals--gatherings that are organized by patients--and also on-line. Some groups are closely moderated while others are not. The common theme is that without each other we would be doomed to a life of ignorance, isolation and shame. These groups are where the experts are found. They are the survivors, the researchers, and provide the follow-up so desperately needed. Support groups offer patients and families a chance to hear from adults with real life experiences. This is what the survivors have taught us:

- People lose ownership of their bodies when they are subjected to treatment without options, knowledge or consent.
- Patients need emotional care before physical treatment.
- Squeezing an individual with an atypical anatomy into standardized categories can undermine identity and self esteem.
- Being lied to, or misinformed about one's medical history can irrevocably destroy one's ability to trust doctors and parents. It can compromise these relationships beyond repair.
- Children may find it difficult to discern sexual abuse from a uncomfortable examinations or painful genital treatments in a professional environment. The same may be true for parents who are instructed to dilate children after early vaginal surgeries as well.
- Medical examinations and procedures can be subjectively experienced as "sexual abuse." Patients with unusual presentations are often put on display as teaching tools for medical students, interns, and residents. Doctors need to *feel* as often as they touch.
- Daily reminders that one does not fit into social or medical standards are emotionally exhausting. When one is treated as a threat to the culture, the burden may feel overwhelming. Patients need help in carrying that burden.
- The need for surgical "correction" is often more important to other people than it is to the patient. A heightened focus on genital appearance or sexual function can overemphasize the importance they have in an individual's life.
- Most people with intersex conditions have undergone more procedures by their teens than other people do in a lifetime. A history of pain or genital surgeries

can lead patients to ignore important warning symptoms of other health related matters. Patients need support to pursue all their health needs.

- Sexual self worth can be damaged by professional interventions and opinions. A focus on "correction" can leave a patient feeling dysfunctional, abnormal, inadequate, too big or too small; or totally disinterested.
- Some patients are forced into a world of "little lies" to cover up their medical histories. As a result, they are denied access to emotional support and may feel cheated out of a sense of wellness. They may also struggle with the conflict of lying.
- Families are affected by the medical treatment of members with atypical development. Parents need support to decide how to care for their children and accept atypical anatomy. Children need support to decide what is best for them. Partners need support to help them deal with the way intersex treatments affect their relationships.
- It can be painful and difficult to "break in" and educate new physicians, especially when the patients medical histories are not been completely explained to them. Mental health clinicians must learn as much as they can about intersex conditions and treatment. Given the medical secrecy surrounding intersex, they may not be able to rely on their patients/clients for basic information.
- Coming out is the greatest gift we can give ourselves. I now have the support of friends, family, therapist, doctors, medical allies, church, college professors, boss and coworkers, and an entire community. Patients need support to determine when and where to come out; and how to make that feel safe. It took me thirty years do that on my own.

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**INTERNET RESOURCES**

Information on MRKH: [www.mrkh.org](http://www.mrkh.org)

MRKH Survey: <http://mrkhorg.HOMESTEAD.com/files/home/SummarySurvey.htm>

Information about intersex, in general, can be found at the Intersex Society of North America online library (which includes videos and books):

[www.isna.org](http://www.isna.org).

Care and counseling of a patient with vaginal agenesis:

<http://www.isna.org/articles/foley-morley.html>