The Missing Vagina Monologue
 . . . and Beyond

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ABSTRACT. The author, a middle-aged woman, was originally diagnosed with “Congenital Absence of Vagina”—at age thirteen. Since that time, she underwent four exploratory and corrective surgeries, without ever receiving a correct diagnosis that explained her condition, Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH). The author describes personal experiences with the medical profession and her emotional response to the diagnosis and treatment. The author made contact with an 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. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2006 by The Haworth Press, Inc. All rights reserved.]

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

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Curious to learn what other women were talking about, I read the *Vagina Monologues* (Ensler, 1998). I was not curious about the play, but about vaginas. I am a woman who was born (in 1956) without one. Although that topic was briefly discussed in the book, there was not a monologue in the woman’s voice—so I decided to write one myself. Think of this as the *Missing Vagina Monologue*, or the *Monologue of Missing Vaginas*. Either way, this is a monologue that deserves more attention.

Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH) is a condition that involves congenital absence of the vagina, fallopian tubes, cervix and/or uterus. Some women have uterine remnants, called horns. External genitalia in MRKH are considered “normal” female. The chromosome karyotype is 46XX and the incidence rate is between one in 4000 to 5000 (Carmil, 1975; Foley and George, 1992; Kutile and Weijenborg, 2000). Other associated symptoms, to varying degrees, include kidney abnormalities, skeletal problems and hearing loss. The cause of MRKH is somewhat unclear, but the physical manifestations occur sometime during the fourth through sixth week of fetal development. There is little research on the other symptoms of MRKH. What research does exist is primarily about creating vaginas for “normal sexual function.” My main concern is not how MRKH develops, but how women are transformed by it.

This is hard to talk about because most people know little about MRKH. Those of us who have it do not necessarily have the wherewithal to educate others. We withdraw to fight the daily battles associated with our anomaly and the health issues that accompany it. This is a lot of work to keep up with, because none of the doctors I had worked with was able to connect my symptoms as being part of a larger syndrome. I ask myself, “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?” I may never know the answers but I will have to live with the consequences of past treatments and limited information.

My life completely changed when I was thirteen and sent home from camp with abdominal pain. When I was examined, the doctors discovered an imperforate hymen prohibiting the flow of menstrual fluid. I had my first surgery to open my hymen so I could bleed. But they found that nothing was there. I had no vagina, just a dimple, and the doctors could detect no uterus. I had secondary sex characteristics—body hair and breasts—so they assumed I had ovaries. However, no one knew where they were. Although the medical profession has known about MRKH since 1838, I was diagnosed with “congenital absence of vagina.” To
me it seems it was because the absence of vagina is all the doctors 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? My parents proceeded to do 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 and the dream of having children. I received sympathy and even pity about that, but the doctors’ most pressing concern was to create my vagina as soon as possible.

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. My chromosomes were counted and discussed in front of me. “Got to run that test again just to make sure.” There were no women physicians involved in any of my treatment. Apparently, there were not enough other signs for the guys to determine my gender. They repeatedly examined my breasts, labia, clitoris, and vaginal dimple with blind eyes. They did not see what they either wanted to see or expected. Instead, they saw a narrow version of normal—to which I did not conform.

I was too young to know I had the right to ask questions, or the right to slow the process down to suit my own state of mind. I had major doubts about what was going on, and what was being done to me. However, 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. My relationship with my body ended. Suddenly, I had no right to keep 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 the doctors determined that I was officially to be female, my reconstruction was arranged. This way I could adopt children and life would be just fine. In 1972, I had my second and third surgeries. I was fifteen. That summer everyone was told 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 . . .
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 seventeen days, I shared a room with countless women having babies. I had no visitors since I was supposed to be on a trip. My cousin worked in the hospital and stopped by often, but my reason for being there was never discussed. So it was mostly 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 seeking to satisfy their curiosity as I slept.

Two weeks later, I had Phase Two—my third surgery—to have the mold and stitches removed. Then I was told about postoperative therapy to keep my vagina “functional.” As I have been repeatedly told by my various physicians over the years, a functional vagina is one “that will be able to accept a normal size penis.” I was given vaginal dilators for postoperative therapy, and brief instruction to insert one 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. To him, I was another surgical success.

I was introduced to anger two years later when I started having sex. After all the trouble I had gone through, I discovered that a penis would respond to anything. I felt abused in the most intangible way, a victim of other’s arrogance and assumptions. Although I could not identify it then, I became an instant survivor.

Why was my gender questioned in the first place, and then why did it have to be “confirmed” as if it were something I did not 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, an action which actually neutered my soul? I was not 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 about the fact that I did not really care that I was born without a vagina.

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 five thousand is not that rare. I just did not 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 could not 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 a stoic, intellectual method of coping. I strapped myself in. It was going to be a bumpy ride.

As I grew older, 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 tracked 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 body with no place to go. And I was having other physical problems that needed attention as well.

At age 34, I was living in Boston in 1991 when I had another medical work-up done. Technology had changed and the doctors were able to find one of my ovaries. Two years later they found the other one. The report I got back from the specialist restated what my physicians had said twenty years earlier, but this time it was given a fancier name: Müllerian/Vaginal Agenesis. The specialist also noted that my vagina had shrunk. It was recommended that I undergo 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 undergoing a laparoscopy to remove the cyst, the surgeon told me that the procedure had not worked. But he confirmed my suspicion that I had a uterus. Imagine my surprise when he told me he found two. I had a functioning uterus growing from my left ovary and a uterine remnant on the right ovary.

How did my body parts suddenly appear? Or had they been there undetected all these years? Could my neovagina have been connected to a uterus in a way that would have enabled me to have children? Were these new findings the cause of the crippling pain I have lived with since I can remember? I thought all of this had been taken care of decades earlier. So why was this coming up now? Ironically, my fifth surgery was for two hysterectomies; so back to the bell tower I went.

Every time I get depressed about this experience, 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 physician I have ever seen. My sister sent me an article and in the year 2000 where I learned about MRKH for the very first time. I got a copy of my latest work up from eight years earlier and saw Mayer-Rokitansky-Küster-Hauser syndrome written there too. The report my specialist sent me had left that diagnosis out. However, he had been quick to point
out that my vagina had shrunk. Apparently, the state of my vaginal function was all he thought I needed to know. Apparently, other parts of the syndrome were not of concern to him. Although I was disabled with back problems at the time—another symptom of MRKH—any connection between my symptoms was not discussed.

Hoping for a possible diagnostic answer, I went to the medical library to research articles on MRKH. I was in my forties and finally had something to call my experience other than “bizarre.” That is when I discovered the other symptoms associated with the syndrome. Discovering there was a connection to my years of disability and my hearing problems left me numb. If I had known I was predisposed to hearing loss and back problems, I would have made different decisions about my life. But nevertheless it was still a joy to know that I had not brought my disabilities on myself.

However, the most important discovery I made was to learn that there are many variations of gender. For example, I had been labeled female—although at times I feel more like an it. I came to understand that my feeling was a result of being forced into rigid gender standards. A whole new perspective was emerging from very old emotions.

Reading the articles on MRKH made it painfully clear to me that this was not just about bodies, and that a “corrective” approach to genitals should not immediately be adopted. 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. What made me feel abnormal was not knowing the truth about my body, but the idea that I had to be fixed. My feeling of being different is a result of my surgeries, not my vaginal dimple. Being born without a vagina was not my problem. Having to get one was the real problem. It is not that my vagina has shrunk that now alarms me; but the fact that we make judgments about the size of vaginas—or genitals—at all.

I am an adult now so I do have choices—and a library card! I no longer trust without question. I no longer believe without verifiable information. I have researched the various surgeries and dilation treatments used to create vaginas. I found that surgery is recommended for a person with no vagina, or when dilator treatment does not work.

Various body parts can be surgically transplanted to create “normal sexual function.” The bowel and intestine have been used to make vaginas, though this is not done as 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, one still
has to keep one’s vagina functional with dilators if one does not have regular intercourse. Now who benefits most from that?  
Dilator treatment is less risky than surgery—but still invasive, and just as emotionally difficult. The basic method of dilation is to apply enough pressure with the different sized dilators to stretch the vaginal dimple enough to achieve an “acceptable depth.” It takes anywhere from two to eighteen months to complete the procedure, depending on how often it is done. I gave up using my dilators after the first few years. Even after my surgery, dilation was painful. And it was not stretching anything. It felt emotionally self-defeating for me to continue. So I gave the dilators names, and hid them in the attic.

There are a few studies on the psychosocial development of women born with vaginal agenesis. In the literature, physicians tend to 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 do not fit in are reshaped until we do. As one doctor wrote, an “angry, withdrawn, muscular girl” was transformed into “a woman responsive in coitus and eager to adopt children” (Kaplan 1968). I have no doubt that she worked much harder than her doctor did.

Purely by luck, 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 by this discovery. 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. They challenged me to recognize that their trauma was also mine. These women taught me more about treatment and courage in a week than any stack of articles or any doctor ever could. To the physicians, our dysfunction had been treated. Our success rates were tallied. Then we were sent out on our own to make peace with it all. However, I felt driven to fill in some gaps, and so I asked some questions of my own.

I compiled a set of questions for a survey and e-mailed it to the group. When twenty-one women responded, I realized this experience could not be captured in a questionnaire. There is so much more to MRKH than “normal sexual function.” So much more to the women I am listening to now. We each have our personal experience and cope in our own valid ways. As it turns out, I got most of my valuable information from the question: “What Else Would You Like To Say?”

Every woman who answered my survey wanted her doctor to be more informed about MRKH. Of the twenty-one women who responded, only four of their physicians had heard of MRKH before their initial pelvic exam. Two of those four had limited experience or knowledge of
vaginal agenesis. The rest of the doctors were “shocked” or “excited” about treating us; and one woman’s physician “ran into his office to look a few things up.” Other women were referred to specialists without explanation from their primary care doctor. Most of us never knew we had a syndrome or given any explanations until years after our vaginal procedures.

One woman’s physician gave her a vaginal dilator which he compared with a shoe stretcher. He also told her she could become a nun. Another young girl’s doctor told her, “Some species respond to overpopulation by producing sterile females.” Some doctors only asked about the sexual pleasure of husbands and boyfriends and gave no regard to the feelings of 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 indicate to me that there have been too many slips in the operating room.

Many women have had true success stories that included supportive doctors and positive experiences. Yet even in those cases, something is 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 is what scars us the most. We battle frequent depression. We hate being told how lucky we are by people who do not 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 and sensitize doctors.

The survey found that twelve of the fifteen women who completed treatment felt it was necessary in order to be sexually active, normal, or loved. The other three felt correction was “somewhat required,” but they nevertheless still 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 physicians that their procedures had been successful. However, not all the women agreed. One woman had two surgeries before she felt happy with the result. Two women tried different procedures before finding treatments with which they could live. 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. One woman said she 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 did not 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 worried whether their vaginas would not feel normal to their sex partners. Usually the partners did not notice. One woman was called a “freak” by a partner and another 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 there is a broader challenge. Our existence challenges the roles designated for women and the concept of normal gender and sexual activity. We threaten cultural beliefs about gender and that makes people very nervous.

Although we are indeed atypical, we are women all the same. Most of us do not realize we pose any threat at all. We start out our lives as normal little girls. Then suddenly something suggests that perhaps we are not. The foundation of our identities crumbles when we do not measure up to gender expectations. We are literally molded to fit societal values.

How does one deal with not fitting into the mold? I “come out” about my own surgery in carefully selected ways. Unfortunately, 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 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 transgendered and thought I was being 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 could not find the words. Knowing other MRKH women has finally given me a voice. But I do not want it to stop there. My condition seems extreme only because most people have not heard of it. Many of the women I surveyed want knowledge about MRKH to become more public. We hope to open the door to our secret lives. Our knowledge is powerful but hidden in embarrassment and shame. The approach to our treatment is very extreme but affects all women in subtler ways. For example, while advances in medicine offer men Viagra, women still get the knife. However, scar tissue does not enhance sexual pleasure.

I want people to understand that doing the “right thing” can often do more harm than good. The standard of normal for which we aim is imaginary. We are altering women’s bodies when it is social and medical attitudes that need adjusting. Surgically correcting our genitals tells
us that they are wrong. However, different is not wrong. Different is just
different. Women should not have to endure so much emotional and
physical pain just to perform one sexual act when other options are
available. Yet 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.

Women with MRKH should be treated as women with a syndrome
rather than isolated with the label of “sexual dysfunction.” My “absence
of vagina” posed less of a threat to my health than the parts of the syn-
drome that disabled me. So why was a vagina all that I was given to cope
with a much greater loss?

**BEYOND THE MONOLOGUE**

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 frag-
mented 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 freak-
ish 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 condi-
tions that causes harm. Some conditions are discovered at birth and oth-
ers 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 hospi-
tal. As infants, no one asks them for their consent. Other people become
convinced later in life that altering their bodies will make them “nor-
mal.” Usually the focus of treatment is genital appearance, or defini-
tions 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, some-
times even surgery. But the standard medical practice of “normalizing”
surgeries must be questioned. Corrective procedures are meant to pre-
vent 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 by cosmetic treatment or by altering our appearance. 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 stigma that can contribute to a 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 Horejsi 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 online. 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 an 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 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 to do that on my own.

REFERENCES


Accessed March 24, 2006

**INTERNET RESOURCES**

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


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: [www.isna.org/node/83](http://www.isna.org/node/83).
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