

The quarterly

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Intersex Society

of North America

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Hermaphrodites with *Attitude*

We want our medical records!

Many of us have found it invaluable to obtain copies of our medical records, especially those of our births or early genital surgeries. The medical information and the emotional confirmation of what was done to us as children and how we were evaluated by medical personnel helps us to heal. With this information we can better know ourselves and understand who we are.

During the seventies, American laws regarding patient access to medical records changed. If an institution or a physician has your records, you have a legal right to a copy of those records, no matter how old. Hospitals rarely discard old records, but they may move them into warehouses or onto microfilm.

You may be able to obtain your records easily by having a physician request them. Don't have a physician you trust? ISNA member physicians with appropriate specialization can write the letter and act as your requesting physician. Contact the ISNA office if you need this help.

If your records are not easily found and your first request is refused or ignored, you may be able to enlist the help of a records clerk. Try telling your story; if you can enlist his or her sympathy, the clerk may be willing to look harder for records misfiled or stored in a warehouse or on microfilm. Showing up in person at the hospital or office may help.

If these efforts fail, ISNA member attorneys have volunteered to consult with you regarding your right to demand your records, and may be willing to call or write letters on your behalf.

If you feel ready to know this information about your early treatment, we encourage you to pursue getting copies of your medical records. If you need the help of an intersexual physician or attorney, contact the ISNA office.

What has ISNA been up to?

In the months since the Winter 94 issue, we have been working hard to publicize ISNA's existence in places where intersexual adults can locate us. By the time you read this, ISNA should be registered with the National Organization for Rare Disorders and the American Self-Help Clearinghouse.

You can help with this effort. Write and let us know where you looked for information about intersexuality. We'll try to get ISNA mentioned there.

We have produced and are now mailing a new pamphlet addressed to professionals in medicine, sexology, and mental health. We have appointed several mental health professionals to our Board of Directors, to act as liaisons with the professional community.

The SF Weekly, widely distributed in San Francisco, carried on February 1 a

front page article on intersexuality. The article contrasted statements of intersex specialist physicians from UCSF and Johns Hopkins with the personal experiences of three ISNA members. The abominable graphic on the cover is balanced by a beautiful photo of strong, proud intersexual Morgan Holmes and her son. The article brought several new members to the second Bay Area ISNA meeting in March.

Morgan Holmes has been addressing the academic community. In March she presented "Queer Cut Bodies: Homophobia in Medical Treatment of Intersexuality," at the Queer Frontiers Conference at USC. In June she will deliver "Enforcing Borders: A Discussion of Abjection and Intersexuality" to the Canadian Sociology & Anthropology Association Meetings during the Learned Societies Conference at the Université de Québec à Montréal. And look for her essay "In(to)visibility: Intersexuality in the Field of Queer," expected next year in Dawn Atkins' anthology *Looking Queer*.

Jane Carden attended the first meeting of the AIS Support Group in England (story page 2), and hopes to gain entrance to a closed Royal Society of Medicine symposium on "The Management of Intersexuality into Adult Life" in April. The symposium includes a session titled "Revelment or Concealment of the Diagnosis." A member of the AIS Support Group (see story page 3) is scheduled to present her views on the emotional damage inflicted by secrecy.

Learning to Speak at 36

Jane Carden

Twenty five years ago, as my girlfriends were getting their periods, I was told a lie. It went something like this: “When you were born, your ovaries were twisted. And a very smart doctor discovered this because he saw that you had hernias. Well, these twisted ovaries were at risk for becoming cancerous. So, to prevent this from happening, when you were just a baby, they removed your ovaries, to make sure that you didn’t develop cancer.” I have an IQ in the top one percentile. Something in this story just didn’t make sense.

That night my father told me that he was proud that I didn’t cry when my mother told me the lie. He was proud; I was numb.

A few weeks later my mother took me to a reproductive endocrinologist. He wrote a prescription for Premarin, told me I

would have to take it for the rest of my life, that I would never have babies and never have a menstrual cycle. From that day forward, no one in my family has ever again spoken to me about my medical condition. Not my parents and not my elder brothers, one of whom is a medical doctor and one of whom is a clinical psychologist.

At age 20, I was in my first year of law school and in the habit of studying in the medical school library. I visited the library late at night to avoid being seen poking around the stacks. In those days before computerized medical databases, I worked with the huge Index Medicus, beginning with the extensive entries for “oophorectomy.”

After several weeks of poring over medical texts and comparing the appearance of my body with the clinical photographs, I reached a firm diagnosis: testicular feminization. Not an oophorectomy, as my parents had told me. The doctors had removed my—*testes*. Alone and

frightened, in the deserted stacks of the medical library in the wee hours of the morning, I learned that I was a “male pseudo-hermaphrodite.”

This discovery didn’t really change my course of treatment. At age 17, I had decided to stop taking Premarin and stop going to doctors. I stopped taking the hormone because no one had ever given any reason why I needed it other than the absence of ovaries. If I needed a pill to make me “female,” then I preferred to allow myself to be whatever I would be. Quite honestly, there was no perceptible change after I stopped the prescription.

My decision to drop all medical care was the direct result of the humiliation and obfuscation I had been subjected to over the prior seven years. Interns were paraded past my vagina at age 14 or 15. I was never told about my prospects for sexual intercourse. Not once was I asked how I felt about any of what had transpired. I was a patient with a terrible

continued next page

Can/should doctors counsel?

from ALIAS, with permission

AIS experts Williams, Patterson, and Hughes have written, “Management of complete AIS is relatively straightforward as the sex of rearing is always female. However, appropriate counseling of parents in which clear and accurate information is given about longer term issues of hormone replacement and fertility must be carried out by an experienced endocrinologist.” Another journal article from the same clinical department says, “The counseling of parents whose child is born with AIS is difficult and requires an experienced pediatric endocrinologist and urologist.”

It is then suggested what medical explanations should be given to the parents. Later in the same paper ‘counseling’ for the patient is covered in two sentences:

“Counseling is also required for girls with complete AIS. At an appropriate age in adolescence they should be given simple explanations for their lack of pubertal development and menstruation and the need for hormone replacement.”

Counseling is not about helping people to understand medical concepts. It is not over and done with in a fifteen minute consultation, with the doctor doing most of the talking.

It is important that parents and patients should be given this information, but this is not counseling. Why do clinicians invariably think they can (or have to) do everything on their own? What about employing experienced *counselors* to counsel? Since when have pediatric endocrinologists and urologists been trained in counseling skills? And does “simple

explanations” mean half-truths? Do clinicians think that counseling just involves *explaining* things to people? Counseling is not about helping people understand medical concepts. It’s about helping them come to terms with how they *feel* about things and to assign their plight some ‘meaning.’ It’s not something that is over and done with in the course of a fifteen minute consultation, with the doctor doing most of the talking.

Doctors must realize that the healing process which aids in the ultimate acceptance of bad news does not come suddenly, through their own magical pronouncements and hand-waving, but through the patients and parents having an opportunity, over the course of time, to articulate their fears and uncertainties under the guidance of professionals trained in psychological counseling.

see related story, page 3.

Learning to speak

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secret that even the doctors and my own mother couldn't or wouldn't discuss.

Last year I resumed medical care, because I decided that I needed to start dealing with all of this. I learned that years of hormone depletion had caused my bones to lose mass. My bone density is now so low that I am at immediate risk of spontaneous spine and hip fractures. I had been completely unaware of the connection between estrogen and osteoporosis. I also learned that I needed to use a series of increasingly large lucite "tampons" to dilate my vagina, if I wanted to be able to have vaginal intercourse.

I would have liked to believe that the medical community is now more in touch than it was when I last saw a doctor 18 years ago. It isn't. The first three times I visited my new endocrinologist, the intake nurse asked when my last menstrual cycle was. When I answered that I thought the doctor wouldn't need to know that, she told me, "Oh yes, Dr. — specifically asked me to inquire." When I told her I didn't have menstrual cycles, she said, "Oh, hysterectomy, huh?"

To those who have experienced menarche, this might not seem like much of an issue. Some might think it a relief not to have periods. But imagine everyone from gym teachers to best friends asking about your nonexistent periods. I simply do not know how to answer such questions.

Since resuming medical treatment I have repeatedly and persistently asked to be put in contact with other AIS patients. The answer I always got was "why would anyone want to talk about it?" I was regarded with suspicion for even asking.

For the past twenty five years I believed I would live my life never being able to share my secret with anyone. I had never discussed this syndrome with any person other than doctors until last year. I had hit a wall and felt that my life wasn't work-

ing and I didn't see much point in continuing. I sought professional counseling, taking care to avoid psychiatrists, who are medical doctors.

The social worker I turned to has been quite helpful in allowing me to express the thoughts that have been bottled up within my mind for most of my life. But still I was unable to locate another soul who knew what it *feels* like to inhabit my body.

Then, on December 26, 1994, *something* called me to return to the medical library. I discovered in the British Medical Journal three articles describing, not case studies, but real human beings with AIS. One included the phone number of a new support group in England.

For two days, I rehearsed what I would say to the contact at the support group, how I would maintain my composure; talking about this condition inevitably reduced me to tears. Somehow I got the words out in between sobs. I was amazed to learn that *most* people who contact the group are in a near hysterical state because of the complete lack of emotional support they have received.

In March the inaugural issue of their newsletter, ALIAS, announced that their first meeting would be held on March 15. Within the hour I was booked on American Airlines flight #105 to London.

Next week, for the first time in my life, I will meet other people with AIS. I will meet others who understand the fear, humiliation, shame and secrecy which surround my status. I have been locked in a closet for 36 years. But from this moment I am committed to dedicating all my resources, emotional and financial, to ensuring that no one suffers a lifetime of emotional neglect because of a ridiculous social taboo. I welcome the friendship of all ISNA members as I undertake this journey.

You can contact the AIS Support Group at 2 Shirburn Avenue, Mansfield, Nottinghamshire, NG18 2BY, UK. Send £2.50 for a copy of ALIAS, their newsletter. If you have AIS, ISNA can connect you to Jane Carden.

British AIS support group

The Androgen Insensitivity Syndrome Support Group was started in 1988 by Mrs. Jackie Burrows, the mother of a 6 year girl old with AIS.

With androgen insensitivity, the body's cells fail to respond to testosterone. Individuals with the complete form of AIS are born with internal testes and female genitals. Their vaginas may be short or nearly absent, which is related to their absent uterus and cervix. Without medical intervention, these girls usually experience feminine puberty, because testes produce estrogen as well as testosterone. For this reason, AIS used to be labeled "testicular feminization."

The Support Group publishes a quarterly newsletter titled ALIAS, with news and information about AIS and the support group, and first hand experiences of people with AIS.

ISNA member Jane Carden (see article on page 2), flew to England in March to attend the Support Group's first-ever meeting. Jane hopes to return to England in April to join a Support Group member who will address a closed Royal Society of Medicine symposium on "The Management of Intersex Problems into Adult Life." Jane, of course, will bring ISNA literature with her.

The AIS Support Group's aims

- ▼ To reduce the secrecy, stigma, and taboo that has existed around AIS and other intersex states, by encouraging doctors, parents, and society to be more open about it.
- ▼ To encourage the provision of psychological support within the medical system, for young people with AIS and their parents.
- ▼ To put parents and people with AIS in touch with each other and to encourage them to seek support and information.
- ▼ To increase the availability of information on AIS both verbal (from health professionals) and written (from the support group and other sources).
- ▼ To encourage improvements in vaginoplasty techniques and research into why

*Can you sue your doctors?
One ISNA member decided to try. Her lawyer's opinion, reproduced at right, is that the chances of success are slim, and the emotional and financial costs high.*

Dear Ms. Matthiessen,

I will attempt to assess the legal remedies you may have for damages sustained in connection with your medical treatment, or lack thereof.

The procedures in question are the removal of clitoral tissue by Dr. Heartless during infancy; the failure of Dr. Heartless to know or familiarize himself with the consequences of such a procedure; and the failure of physicians to provide adequate counseling to the parents which in turn prevented them from properly seeking help for their child. The damages appear to be catastrophic, both physically and emotionally.

These events occurred over two decades ago. There has been no continuous treatment by the physicians sufficient to invoke an exception to the statute of limitations. There appears to be no fraud in concealing the alleged malpractice. There was no incompetency. The discovery of the alleged malpractice appears to be more than six months ago. Under these circumstances, the applicable statute of limitations appears to militate against any action.

Some legal scholars are advocating an extension of the statute of limitations in cases where the aggrieved party is mentally incapable of acting upon the alleged wrong because of the damage inflicted. The reasoning is that the tort-feasor (Heartless) should not be shielded from prosecution because of a circumstance he engineered, i.e., his malpractice.

There is little or no legal precedence in this regard. If the lawsuit was defended on Statute of Limitations grounds, the matter could be dismissed by the lower courts and may end up in the appellate courts. I can offer you no guidance on the outcome except that others before you have not been successful.

Assuming you can clear the statute of limitations issue, you have equally significant proof problems. Many witnesses would be unavailable or may not remember the circumstances of your treatment. Moreover you would need

expert testimony to establish that the Doctor violated standard accepted medical practices, as existing when treatment was rendered. You will need an expert to give his opinion before you could commence a lawsuit.

As to your physical damages, they are easily and visually documented. Every member of a jury will be able to relate to what was done to you. With respect to emotional damages, a sharp defense attorney would claim that these damages are speculative. The attorney would cite your stellar academic and social adjustment in support of this theory. Your eloquence, intelligence and communicative skills could work against you.

Financially, an enormous burden would have to be met. Expert testimony does not come cheap, assuming such experts are available and willing to assist you. I estimate that initial expert fees will be \$10,000.00 and could go up to \$20,000.00 or higher as court proceedings progress. Legal fees could go up to \$35,000.00, or higher. Initial costs (court fees, service of process, etc.) will be approximately \$650.00. These expenses could go as high as \$7500.00 depending on the number, length and location of the depositions. Accordingly, your total outlay could be as low as \$20,650.00 and could go up to \$62,500.00 or higher.

Emotionally, the burden would be greater. You would be required to relive your traumas in great detail; you would be subject to genital examinations; your privacy would be compromised. You would be expected to continue with psychiatric care to document your damages.

All told, I see many obstacles in your path. The significant outlays of money, time, and emotional energy, when weighed against the possibility of success on the merits, appears to weigh against the institution of a lawsuit. The decision on how to proceed, however, must be yours. Feel free to contact me in this regard.

Very truly yours,

J. Barad

This letter is reproduced for informational purposes only, and is not intended as legal advice.

If you have had bad surgery...

Jeff from Michigan

Plastic surgery of the genitalia is considered art within the world of plastic surgeons, in the same class with experts who work on restoring the function and appearance of hands. Lofty as it sounds, in practice this uniqueness also leads to a lack of general experience and of agreement regarding standards for good versus bad surgery.

Bad surgery—surgery that is not the most modern technique, or is performed by a doctor who has never done genital surgery before in his history of practice, or which leaves the patient in worse function or appearance than before—is allowable. It will be defended by other doctors as OK to do, and can be seen as excusable because of the rareness and level of expertise necessary to do this kind of work at all.

Worse, doctors are a powerful fraternity which will close ranks against the accusations of any patient. Because malpractice insurance is so expensive, they will go to extremes to avoid being sued.

Let me tell you what happened to me. My genitals were severely damaged by a series of surgeries during infancy and childhood. Because my penile urethra was surgically constructed, I had frequent urinary infections, which produced urinary discomfort and occasional bladder and kidney infections. As a young adult, I thought that I could shop for better, more modern surgery that would undo some of the damage to my urinary tract.

I found a doctor who told me he was an expert. When I asked to see photos of his previous work, or talk to others he had done genital surgery on, he said he couldn't do that because of those patients' privacy, and he doubted any doctor could put someone in touch with previous patients as I was requesting.

After surgery, I was left in much worse condition. There were now pockets in my penis that regularly became infected

and filled with puss, causing tissue destruction. Urine leaked through holes along the shaft, into the body of my penis.

I determined to sue him for what seemed to me to be obvious malpractice. At first, no lawyer would take the case. When I found one who would, because I had no money I was on my own to find medical experts to support my claim.

I interviewed many urologists and surgeons. All said that they couldn't judge, solely by comparing the result to my recollection of my condition before this surgery, how bad the surgery had been. One urologist even insisted that the surgeon had helped me by performing any surgery on me at all! Many doctors told me I would be lucky to find *anyone* who would testify against another doctor.

But I did find experts willing to testify, and the suit was filed, and then—my lawyer disappeared. Because I was a contingency case, and couldn't pay up front, I thought that I shouldn't hassle the lawyer too much. Still, many phone calls and letters from me to the lawyer were never returned.

Then two years passed, and I received notice that my case had been dismissed. The lawyer had let a "toll" pass, a limit of time by which a case must be brought to court. I would now have to sue the lawyer, I would never be able to sue the doctor for what he had done to me. I cannot prove it, but to this day I believe that the surgeon paid off the lawyer to avoid being sued.

So hermaphrodites, beware. Don't let this happen to you. If you must have surgery, be sure to check out your doctor's credentials. Please try to remember that any surgeon's promise of beautiful looking and feeling genitals is probably exaggerated, and you would be better off not to have surgery at all. I wish that Hermaphrodites with Attitudes and ISNA had been around to give me warning.

*“Promises of beautiful
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*“I wish Hermaphrodites
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Legal sex change, no surgery

Lynn Edward Harris

Recently I had the pleasure of meeting sexologist Bo Laurent, at the International Congress on Gender, Cross-Dressing, and Sexual Issues where we were both scheduled program speakers on intersex. While her lecture dealt with the management of hermaphroditic children, my own presentation delved into my personal experiences as an hermaphrodite.

Born with hermaphroditic genitals, I was assigned and raised female. I fought the progressive virilization of my body by emphasizing my femininity. I was even crowned the 1968 Junior Miss of Newport Beach, California!

My parents were indifferent to, and have never acknowledged, my obvious hermaphroditism. My mother had abused me emotionally, and my father was essentially absent. Especially in terms of my medical care, he deferred to my mother, though he was probably better qualified to deal with it. Of course, in their ignorance, they did me a favor; I'm very happy not to have suffered genital surgery. Only one of my three younger sisters, all fully-functioning females, was at all sympathetic.

Finally, at age 29, after years spent wandering in an emotional quagmire, I made the mammoth switch to becoming a man. I did it cold turkey, almost overnight. I just stopped taking estrogens and let my beard grow in. Much psychotherapy helped me work my way through the vegetative depression that accompanied my "molting process." I'm now a gay man, looking for another gay man with whom to share my life.

Being a pragmatist at heart, I decided against "corrective" plastic surgery of the genitals. Sure, my penis is just about the size of my thumb when erect, but it has a lot of good feeling, and I wouldn't trade it for a bigger one with no feeling, or for no penis at all. I don't think like a lot of transsexuals. I don't want to alter

it. I rejected any kind of surgery after I investigated the pros and cons. I've heard of more people being unable to urinate, or unable to climax, after surgery than before.

I spent the next four years (1979-1983) in a sexual legal limbo, living as a man, but with all of my documents bearing a female identification. I decided to approach the court to legally formalize my preferred middle name (Edward) and sex. Based on my unusual medical history and hospital records of exploratory surgery and laboratory tests done at age 23 in 1973, the Superior Court of California, County of Los Angeles, granted my petition (Case #437625). Lynn Eliza-

“Sure, my penis is just about the size of my thumb when erect, but it has a lot of good feeling, and I wouldn't trade it for a bigger one with no feeling, or for no penis at all.”

beth Harris became a legal non-entity, replaced by Lynn Edward Harris.

I filed with Sacramento to have my birth certificate reissued, in accordance with the Court's decision. The Sacramento bureaucrats rejected my filing because my petition was not accompanied by the customary plastic surgeon's affidavit of "radical sex reassignment by surgery," indicating that I had "manufactured characteristics of the opposite sex".

I had already demonstrated to the Court that Nature herself had bestowed such characteristics upon me at birth! I asked the bureaucrats to explain exactly what *my* opposite sex was. Furthermore, there was nothing written in their Health and Safety Code that mandated one go under the knife for such purposes. Finally, they issued a birth certificate bearing my new name, Lynn Edward Harris. But it still stated the sex as female.

Controlling my suicidal feelings, I considered my options. Perhaps I would sue

the State. Or perhaps I would hire a lawyer to take my case to an Appellate Court for enforcement. After several more go-rounds with Sacramento, I received not an amended, but a new Certificate of Live Birth for Lynn Edward Harris, male. I believe mine is the precedent case in the nation.

Since then, I've appeared on over 60 nationally-syndicated radio and television shows, at colleges and medical seminars, in international print media and anthologies. I've participated in medical research projects. And I've penned my autobiography, "More Lives than One."

Why do I go out of my way to seek this kind of publicity? In one way, it's a kind of reaction to the years, the decades, of denial and repression. But more importantly, I believe that it is my mission to educate and enlighten both the general populace and especially the medical profession. They don't want to believe that intersex exists in humans. This subject

deserves to be brought out into the open. Intersex children should be protected and loved and allowed to assume whichever gender they like. What if you perform surgery during infancy, then during adolescence the child goes in the direction of the other gender? You've already cut off the wrong parts of their genitals. I'm glad that didn't happen to me.

On a number of occasions, parents of intersex children have approached me for advice. I tell them that they should certainly have their child examined, but to stay away from genital surgery.

Last year I appeared on a syndicated television show where I argued with a physician, from Cedars-Sinai Medical Center in Los Angeles, who specializes in treating intersex children. He says that children with ambiguous genitals under his care must have at least two surgeries before age two! I've met several other hermaphrodites who had surgeries during infancy, and I can tell you that they are miserable. The surgery is just barbaric.

What would you say to these parents?

Suzanne Kessler

I'm a social psychologist and have been talking with parents of young intersex children. I speak to them, not as a clinician, but as someone who is interested in gender and intersexuality. They talk to me about their experiences with the medical profession, most of which they think of as good—cutting edge (no pun intended). Presumably, their children will be the recipients of additional medical attention.

I've gained some understanding of what it was like for them to give birth to an infant who was deemed "genitally ambiguous" and to raise that child. These parents are well-meaning, reasonably liberal about gender issues, and most importantly, want the best for their child. They are not, however, gender radicals committed to helping create a transgender world. I've told them about ISNA and listened to their reactions. In part, they think your goals are idealistic. Although they acknowledge that their children have one of the conditions that receives an intersex label, they don't think of their children as "intersexuals" and would not exactly see the point of communicating with members of ISNA. On the other hand, many are actively seeking out each other for support and advice about issues involving their children.

I don't believe these parents would welcome hearing that they made a big mistake some years ago in handing their children over to the surgeons, but they are receptive to ideas on how they should talk to their children about their conditions and about the surgery. I've shared with them what I've learned from members of ISNA about the damage that secrecy and shame can create and the importance of parents offering safe places for their children to talk openly about sexuality and desire. I'd be interested in hearing what you think about all this. What would you say to these parents?

You can email me at skessler@purchase.edu or write me: Dr.

Suzanne Kessler, Division of Natural Sciences, Purchase College, SUNY Purchase, N.Y. 10577.

In the delivery room

Kaye

From 1978 to 1988 I worked in Labor and Delivery, first as a staff nurse and later as a nursing professor in charge of R.N. nursing students. During that time, I saw many babies born with what were termed "congenital anomalies" of various types.

The birth of an infant with such a "congenital anomaly" was always a devastating outcome for everyone involved in the delivery process, especially the parents. All staff were committed to healthy outcomes, and anything that deviated from this goal sent shock waves throughout.

A certain percentage of these births were of babies who had ambiguous genitalia. This was clearly noticed right away by the physicians and the nursing staff, but often the parents were not immediately told. The nurses, myself included, simply whisked the child off to the infant warming unit.

If the parents asked about their baby, we told them that the baby needed to be checked out and would be with them as soon as possible. A pediatrician was always summoned and inspected the genitalia. Often, but not always, the parents were told at this point that there was something wrong with the baby's geni-

tals, but more examination and testing would need to be done. They were reassured that otherwise the baby was fine.

The parents generally reacted with extreme grief and fear. Grief over the loss of a "normal" baby and fear that the baby would never be "normal."

Once the pediatricians had finished evaluating the baby, they would come to the parents' room and describe the extent of the "problem." Most often the pediatricians were very kind and empathetic, and sincerely felt that they were helping the parents with the baby. They indicated that once chromosomal analysis had been done, they would be able to make further recommendations, but that in these situations, surgery was generally warranted.

The surgery would make the baby resemble others in the genital area. The parents were most often reassured that with surgery their baby would look "normal" and could be raised "normally."

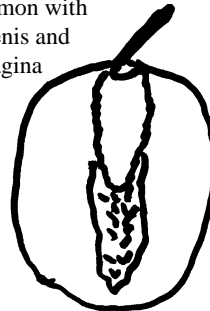
In all of the cases that I saw, the parents were greatly relieved by this news. They were grateful that someone would make their baby okay. They never appeared to have any other thoughts or reservations about this. They completely trusted the pediatric staff. The doctors and nurses involved also believed in what they were doing. They felt that surgery was best for the baby and for the family and felt that they were being helpful. I never heard a discussion of what the surgery might mean to the baby in later years in terms of gender identity or sexuality.

Lynn Harris shared with us these drawings of wonderful "hermaphroditic fruits" he has known. The lemons grew in Lynn's own back yard.

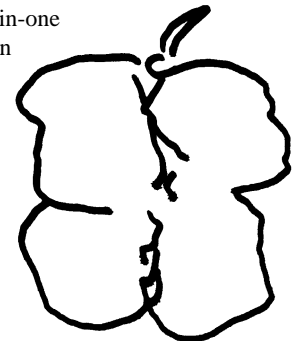
persimmon with penis



lemon with penis and vagina



four-in-one lemon



The healing journey

Saraswati

I was late as usual, I could not wait for this first time. There! IQ was waiting for me in front of her house. I felt desire burning in my body.

I was the sex teacher, the rescuer. I would just give her a lot of love, a space to express her feelings, to cry. I would use my skills around sexuality and everything would be all right. Little did I know that IQ would become my life partner, and how deeply the wound of genital mutilation would affect my life and my own sexuality.

Someone once said, "if you want to know what you are working on, look at who is knocking at your door." So I have not fixed anything, and now I share a healing journey where I question deeply my own sexuality, my own gender identity.

It was easy at first to focus my attention on my partner's wound (that has been part of my training), a good way to forget my own issues, to stay in control. It worked for some time and it provided space for much grief and for a great passion to blossom.

On an archetypal level I was holding the space of the healer for my partner to go into her wound. I believe that only a person who has been deeply wounded can understand the depth of the affect of sexual wounding and hang out in the well of emotions that can surface. At the same time, when both partners go into their wound together, the potential for explosion is high.

To witness healing is a beautiful gift. We spent many hours together making love with great passion. Pain, grief, rage appear, the surgeons intrude into our private space, together with the isolation, the loss of parenting.

The challenge for me was to let those moments be there and pass, and not to withdraw my sexual energy and desire. After the passing of the wave we may

find ourselves with deeper intimacy and passion. There is a fine line in letting sadness be there together with desire and yet not eroticizing the pain.

I still marvel at the fragility of this time. IQ loved to be petted and touched. So many partners in her life had wanted her to make love to them, but could not or would not spend the time it takes for her to get aroused. I had to understand that for us, making love was about giving her pleasure, regardless of what it might look like. It was not easy to remember sometimes that simply stroking her feet and shoulders for an hour might be just what she needed.

Making love was an adventure of many hours. I had been searching for deeper intimacy and connection at the level of the heart, my soul was hungry. My lust became our lust; my desire was there for both of us. This doesn't mean that I was solely responsible, it is clear that the space and the emotional content provided by IQ were vital components of our dance.

I felt so vulnerable exposing my orgasm when my partner could not have orgasm. Sometimes my orgasms reminded her of what had been taken from her, and often we looked at each other so intensely, I knew that we would travel together as far as we could.

I like IQ's genitals, because they are hers. It was the first time I had seen female genitals without a clitoris. I like the way they get wet, it is my cue to know that somewhere there is arousal happening. They reassure me.

Sometimes I feel sorrow at what has been robbed from her, robbed from us. Sometimes I wish so much she would feel desire for me, that I could see her coming to orgasm at the tip of my finger. That was taken away from me, too. It is not her wound only, I now live with it as well.

Then one day a little voice spoke to me. "What about me, what about my wounding? She is not the only one who is hurt."

The next step into intimacy was to speak my wound and how it had affected my sexuality. A part of me had been seeing IQ as broken, in need, with few social skills, and I was getting off on it. I realized that I had fetishized her as being broken.

I had to painfully look at my own issues about self-esteem, fear of abandonment, and my need to have a partner whom I could control. I had to journey into my own rage and shame. I have never felt so naked in front of another person.

When I go into those places, my sexual desire nearly disappears, and this threatens my very sense of identity, for being highly sexual has been my survival tool. At the same time, when I am not lost in the descent into the underworld, I know that in this relationship I have found my wish for the next decade of my life: to know what love is.

The journey is long, difficult, exciting, painful, unpredictable, rewarding, uncomfortable. Sometimes when it is particularly difficult, when I wonder if it is worth it, the only thing I have is to remember my commitment, my choice to be with my beloved and to share this journey. It will take time to build trust. I believe that there is abundance of pleasure waiting for us, that reclaiming bliss and connection with our spirit, body, and each other is part of our journey.



Thinking of more surgery?

IQ

I write to relate to ISNA members my experience searching for surgery to undo the damage of early “genital reconstruction.” I had a near miss, and I want to warn away others who may not be so lucky.

As a consequence of “reconstructive genital surgery” during infancy, I have no clitoral sensation, and have never been able to experience orgasm. After many years of denial, I had a severe emotional crisis, with suicidal feelings. I decided that there *must* be some way to get back what had been robbed from me. Perhaps the sort of microsurgical techniques used to reconnect fingers severed in industrial accidents could restore the sensation of my clitoris.

Study in the medical library told me that it was theoretically possible. After a long search, I located a surgeon who had encouraging news. “Yes,” the Virginia surgeon told me. “We can take a section of skin from your hand, transfer it into your perineum, connect the conserved nerve to the severed pudendal nerve, and the conserved blood vessels to an artery which we will bring down from your abdomen, and you should have sensation. In fact, I’ve done this for several other women who were treated just as you were, lost their clitoris during infancy because they were intersexual.”

Not only was there hope for getting back the genital sensation that had been robbed from me, but this surgeon actually knew others! I would get him to introduce me to them! No longer alone in the world!

However, the surgeon hemmed and hawed when I asked to be introduced to these other women. Privacy considerations, he said, would not allow him to introduce me until I had flown across three time zones to visit his office, been examined, discussed surgical possibilities, and officially become his patient. I completed these tasks, allowed him to examine and to photograph me.

I discussed the possibilities for success and the risks. This would be major surgery. I would have a “secondary defect” on my arm and hand, scarring and loss of feeling where the surgical team would remove skin, nerves, blood vessels.

Could they locate my severed pudendal nerve? The surgeon was confident that he could. Would the newly connected nerve actually transmit feeling to my brain? “Yes, yes,” he was certain that it would. Not as sensitive as a real clitoris, perhaps, but he was confident. Would the grafted skin heal and thrive in its new position, or would it fail, turn black, and slough away? “No, no,” very little chance of that, he assured me. Would my brain, which had not experienced since infancy the sensation of having my clitoris touched, be able to interpret the strange new signals, understand them as erotic? Would I be able to have orgasms? “Well, the brain is very plastic,” he explained. “There will be some sensation there, and you will have to learn to interpret it as sexual.”

What about the likelihood of making things worse? I knew that sometimes such transplants have only painful sensation. I wouldn’t like to spend \$20,000, undergo major surgery, trade my intact arm and hand for a Frankenstein-styled one, and wind up with genital pain rather than numbness. The surgeon had nothing convincing to say about this.

I knew that nerves are elastic, and that the severed pudendal nerve had probably retracted considerably. Would he find it? How much would he have to cut up my perineum in order to do so? Would there be more nerve damage? Perhaps my labia would become insensitive. Worse, perhaps I would become incontinent, unable to hold my urine. I knew of an intersexual woman whose control of her sphincter muscles had been damaged by early genital surgery, and as an adult was forced to wear a diaper.

The surgeon estimated most of the risks that I asked him about at 5%—*each*. That doesn’t sound negligible to me. I got the distinct feeling that he didn’t actually know what the probabilities were at all, or understand how probabilities multiply together.

Of course, I wanted more than theoretical evidence that this might work. I was anxious to meet other women whose clitorises he had restored, to talk with them about their experiences of intersexuality, of sex without a clitoris, and especially, whether the surgery had improved their experience of sex.

The surgeon now conceded that he had never done such a surgery, that I was the first adult intersexual he had seen. He performs surgeries on female-to-male transsexuals, and claims that the surgically created phallus has sensation. Predictably, he won’t introduce me to any of these patients.

Wait a minute. These guys are not like me. They are taking testosterone. They have grown up with an intact clitoris, so their brains know what orgasm feels like, how to get there. I talked to many transsexuals and some therapists and sexologists, and I am not convinced that anyone who allows the surgeon to sever his pudendal nerve, even if he attaches it to the skin graft that forms the phallus, has erotic sensation or can achieve orgasm.

In the end, I decided that the likelihood of improving my erotic sensation by surgery was minute, and that there was a good chance of doing more damage. I have abandoned the idea of surgery, and know that I must live all my life without learning what a clitoris feels like.

Here is my advice to other readers who might be considering surgery: don’t. Unless your genitals are causing you pain or making you ill, you are probably better off not letting a surgeon touch you again.

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever does.”

Margaret Mead

Letters



Hermaphrodite and damn proud!

Thank you, thank you, thank you for the best Christmas present I've ever had or ever could have. As soon as I saw the title *Hermaphrodites with Attitude* I cried aloud for sheer joy. I mean, I've known that there were other people like me, but to find that they also have *attitude*; that they also are ready to stand up and shout, "I'm here, I'm angry and I'm not going to take it any more!" It's better than real, it's better than anything I dreamed, it's sheer paradise on earth. No more secrets, no more shame, guilt, dread, fear, self-loathing or hatred. Finally I can say, "I'm hermaphrodite, I'm intersex, I'm transgender, I'm queer and damn proud," as the tears of joy and belonging stream down my face.

Hello to my family, hello to you all and thank you again and again for sharing your stories! You have told my story, you have portrayed my pain, you have struggled with the same self-doubts and fears and... We have survived. We have more than survived, we are actively reclaiming our birthright and heritage and we are healing ourselves. Your few pages have done more to heal 'my condition' than all the surgical interventions, the many books I've read or the counselors I've seen; you've shown me that the tentative steps I've taken to reclaim my wholeness are the right ones, and that there are many others like me on the same journey.

When I first wrote to you I was worried that your organization would be simply an extension of the medical profession and toe the accepted medical line. I've been going to a cancer support group which is shunned by mainstream medicine because it uses New Age techniques

to supplement cancer management. It doesn't oppose medical treatment but sees it as dealing with only one part of the experience of cancer, the physical, so the group works to heal the emotional and spiritual. I've been disappointed in my attempts to contact the Congenital Abnormality Association, which seems to be very suspicious of any direct criticism of medical intervention. Because it is run by parents who are trying to do the best for their children with severe handicaps, this is perhaps understandable, if somewhat unfortunate for those of us at the receiving end of medical intervention.

Having calmed down somewhat from when I first opened your wonderful Christmas present I still have to say, like David in the last HWA, I'm blown away by it all (he said everything I've felt and am feeling now). I've been busy photocopying your newsletter and putting it in letters to people that I, like David, have spent the last couple of years quietly trying to come out to as an hermaphrodite.

Yours, smiling (thanks to you) in the summer sunshine,

Broken by God, fixed by surgeons?

I am a monster. I would like to join your monster club.

I was most fortunate, when, at age 5, my parents astutely perceived that God had made a mistake, and brought me to the eminent Dr. Charhack of Children's Hospital of Los Angeles. Dr. Charhack wrote

the famous medical treatise *God Broke It; I Fixed It*, by George Charhack.

After only three short years of surgery, my "hernia" was cured. I pray that I will have the means to repay, in some measure, the American Urological Association, for all they have done for my benefit. I am having some trouble, though, in connecting the timing mechanism to the fuse.

Please tell me more about ISNA.

Your Servant,

Just us as we are

Who we are is not defined by our gender! Who we are is not limited by our bodies, by our genitals, by our sexual characteristics or by our biology. Who we are is not limited by the roles we have taken on, by the roles society expects of us, or by our ideas of male and female. Who we are is not limited by our sexual preference, our desires, or our own self-image; it is not limited by our abilities or our disabilities, by our talents or our gifts or our faults or our problems. Who we are is not limited by our feelings or our sorrows or our ecstasy.

Who we are is the essence of life itself, equally the same for all, pure and sacred and simple and absolutely ordinary. Who we are is just this. Nothing peculiar or special at all. Spectacularly wonderful and profoundly unknowable. Indefinable and unnameable and utterly safe and untouched. Who we are can never be soiled, never be harmed, never be damaged, never be broken.

Who are we then? Just me as I am, just you as you are, just this as it is.

Send letters to ISNA, PO Box 31791, SF, CA 94131. Letters may be edited for length and clarity. HWA does not publish anonymous letters, but you may specify a pseudonym.

What I wish my parents had been told about hypospadias

I would like to speak to parents about hypospadias. In 1970, when I was 7 years old, I was brought to a doctor. The reason was never fully explained, but the primary focus of these visits was my penis. After several visits, the doctor concluded I needed surgery to expand the urethral opening of my penis. Prior to that time, I had neither recollection nor awareness that anything was wrong with me.

Before surgery, my normal urine flow was only downward; now the flow follows the natural course through the tip also. More often than not, at the start of the flow, the two streams fail to converge, and I am shooting in two directions at nearly right angles.

The doctors never consulted me other than to ask if I had any discharge or pain. The idea of asking for my opinion about having my penis surgically altered apparently never occurred to them. To the doctors I was nearly a non-entity. All decisions were made by others; how I *felt* about it all was inconsequential.

Putting all these details on paper is tough for me. I have never elaborated on my problem to others, for fear of possible ridicule. It seems almost absurd if it were not the sad truth. It is very difficult to be in the dark about your own body. I appreciate ISNA giving me the chance to recognize the missing piece of this puzzle.

Here is my advice to parents about hypospadias. If the condition is not health-threatening, no action should be taken without the explicit consent of the person concerned. I feel the same way about circumcision. It is the afflicted person who has to live with the condition, *not* the parents or doctors. Far too many people allow social "stigma" to cloud their judgment. It's OK to be different.

The parents should wait until the child, health permitting, reaches a level of maturity so he can decide for himself whether or not to opt for surgery. Of

course, education is very important. If parents are made aware that hypospadias is not rare, that their child is not the only one, they may consider the alternatives. The child has accepted his condition; it is all he has ever known. Make him aware of his choices and let him make up his own mind.

If it will help, please feel free to give out my name to other men with hypospadias, or parents whose children have hypospadias.

Thanks,



Me and the medical community

I am intersexed, and was treated at various clinics at Johns Hopkins. I have written to all of the groups registered with the National Organization for Rare Disorders, but I only received responses from parents. Cheryl Chase asked me if I would be willing to write; I'll try.

It seems that the best way to describe my intersexuality is "immature." Because my body is immature, people have treated me as if I were younger than I was, and told me that I was immature. My attitude today is that children will always be able to have more fun than adults, so let me be this way.

I went to four clinics at Hopkins, including the Endocrine Clinic, and Dr. Money's Psychohormonal Research Unit. At the Endocrine Clinic, they performed "hernia" surgery on my undescended testicle, and continued to see me because I didn't grow or sexually mature normally. During the time I was going to this clinic, I never understood what was wrong with me. It was only after I was released from this clinic that I understood my diagnosis. When I was most interested in going and learning about myself from this clinic, they released me.

Dr. Money's clinic was for the psychological problems associated with my slow development and mental immatu-

ry. At the time I was going to Dr. Money's clinic I never really understood why I was going, until just before they released me. Still, I had no hard feelings toward this clinic.

It was Dr. Money's clinic that referred me to a psychiatrist, Dr. Lowden. My parents brought me to her for quite a few years. I feel I would have been better off if I had never gone; actually I feel damage was done. She made me feel inferior, and that everything was my fault. I was so glad when my parents stopped taking me to her.

I was also brought to an institute for children with learning disabilities. They tested me and found that I had dyslexia, but I was just above their enrollment standards, so they refused to admit me. Every year my parents, who thought I was retarded, would have me tested at that institute, and every year I would score just high enough not to be enrolled.

After a major surgery I was not well enough to attend school, and had a home tutor. He taught me how to read, write, and spell, and got me out of having to go to the learning disabilities institute every year for testing.

This brings me to my bad attitude toward Dr. Lowden. After eight years of going through school not being able to read, suddenly I could. But she thought it no big deal, and said that my tutor had overrated my progress. She had the test to prove it.

To this, I have two things to say. 1) Fuck you, Dr. Lowden. 2) The reason she belittled my progress under my tutor was because she tried to teach me to read and could not.

That pretty much sums up me and the medical community. I have one question, though, for other ISNA members. As a sexually intermediate person, have you ever encountered a psychiatrist who was helpful and not hurtful?

Sincerely,



I am intersex

Lee

i was not born male
i was not born female
my mother screamed
the doctor rubbed his hands with glee
my father spat with disgust
the doctor rubbed his hands with glee
interesting, he mused, interesting
he looked at my penis
interesting, he mused, interesting
he looked at my vagina
an interesting medical problem
what do we do said my mother
trust me said the doctor
what we have here is... yes...
he poked and he prodded
what we have here is... a...
he tested and studied
boy, simply a boy with a problem
a very, very interesting problem
don't worry, just trust me
he picked up the scalpel
i know what to do
he stole my vagina from me
don't worry, i'm the expert
he stole my breasts from me
i'll just fix nature's mistake
he stole myself from me
i was not born male
i was not born female
i was made, created male
made to fit into your world
your limited, two-gender world
your frightened, unnatural world
i am your shame
so you make me feel ashamed
i am your fear
so you make me feel afraid
i am your hidden self
so you make me need to hide
i am the mystery you hate
so you make me hate myself
i was not male
so you said i had a problem
i was not female
so you said i had a problem
you stole myself from me
you are my problem
your small two-gendered world
you are my only problem
i am your other
i am not male
i am your other
i am not female
i am your other
i am intersex
i am hermaphrodite
i am your other
and i celebrate

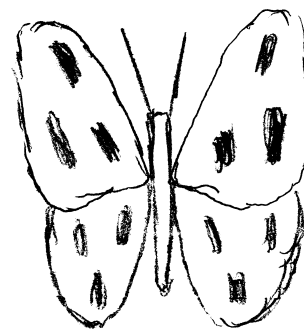
◆
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i was not male
so you said i had a problem
you stole myself from me
you are my problem
your small two-gendered world
you are my only problem
i am your other
i am not female
i am your other
i am not male
i am your other
i am intersex
i am hermaphrodite
i am your other
and i celebrate

Did you know?

Before her ill-fated stint as Surgeon General, Joycelyn Elders' specialty was—pediatric endocrinology. An article in last year's *The New Yorker* quotes Dr. Elders: "If you have a boy thinking he's a girl, then all you can really do is just **take out everything** and make a good vaginal pouch, and the child can function very well as a female" (emphasis added).

Dr. Elders taught these "rare" surgical procedures at the University of Arkansas. "I always taught my students, 'I can make a good female, but it's very hard to make a male.'"

The New Yorker writer characterized Dr. Elders as one who appreciates healthy sexual development. She was ultimately dumped as Surgeon General for having the gall to speak openly about healthy masturbation. We wonder if any of the hermaphrodites made into "good females" by Dr. Elders or her students are **able** to masturbate today.



Hermaphrodites with Attitude

Editor Cheryl Chase

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