



intersexcritiques

volume iii : from controversy to consensus



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Dedicated to Logan & Luke,
who could have been me if I didn't become an activist.

"20,000 Americans have died of AIDS and
not one of them committed political assassination.
If they all had, America would have been
a better place for those of us left behind."

— Sarah Schulman, 1992

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From Controversy to Consensus: An Activist Perspective

by Emi Koyama, Intersex Initiative

Below is a text of the flier prepared for the October 2004 annual meeting of the American Academy of Pediatrics.

INTRODUCTION

This year marks the eleventh year since the first intersex patient activist organization was founded, and the eighth since the first- ever public demonstration was held by activists and allies at the annual meeting of American Academy of Pediatrics in order to challenge the AAP's official position at the time, which called for normalizing genital surgeries to be performed between 6 weeks to 15 months of the birth of a child with an intersex condition, particularly those born with atypical or "ambiguous" genitalia.

Today, patient advocates and medical professionals have a lot more knowledge about how people born with intersex conditions have been impacted by various medical procedures. And yet, there is a lot more we wish we knew. Many of us have strong views about how intersex children should be treated, and sometimes we fiercely disagree because none of us have all the data to fully convince "the other side." But **it is time that we move beyond these areas of contention, and find areas we can work together** for the betterment of the medical and social treatment of children born with intersex conditions.

MAKING INFORMED CONSENT GENUINE

In the past, some in the medical community called for withholding information from the parents of intersex children under the premise that too much information could lead them to reject or question the gender assignment. Today, many people consider it unjustifiable to withhold information or mislead parents about the risks and benefits associated with these surgeries (and the lack of complete knowledge about both). While recent medical journal articles call for a more honest approach to communicating with the parents of an intersex child, many parents continue to report that they had to go out of their way to find the kind of information they wanted to know because their child's physician did not discuss them.

Informed consent is more than just signing a paper. In order for parents to make a decision they and their child can live with, they need to know more than what they are being told today at hospitals across the country. Providing parents with more information would protect physicians from potential future liability as well. Such information should include:

- diagnosis and its impact on the child’s health beyond the irregular genital shape
- whether a suggested procedure addresses biomedical problems or psychosocial ones
- whether a procedure is necessary for biomedical reasons or for social ones
- whether a procedure is a response to a true medical emergency or it can be postponed until later
- likelihood that repeated surgeries might become necessary
- that surgical assignment of sex is not necessary for gender assignment
- that surgery does not guarantee that the child would grow up to identify with the assigned gender
- that some preliminary follow-up studies have shown potential adverse physical, emotional and sexual impacts resulting from normalizing genital surgeries on children
- that normalizing surgeries on intersex children is controversial, with experts arguing from both pro and con sides of the debate
- availability of less drastic alternatives to surgery, including counseling and support groups to deal with psychological difficulties
- referral to knowledgeable counselors, support groups, patient advocacy groups, and/or other families with similar experiences.

KEEPING THE CHILD’S BEST INTEREST AT THE CENTER

All of us involved in this “debate” are here because we all want what is best for the child. None of us want to hurt, damage, shame, isolate, or humiliate children, even though these words are exactly what some adult intersex individuals use to describe how they have been impacted by some of the medical procedures. While we may hold different views in terms of how surgeries might improve or diminish one’s quality of life, there are other areas in which we can work together in order to reduce pain and suffering.

1. “Medical display” is a phrase used by some advocates to refer to the seemingly routine and widespread practice of using an intersex child as a live educational tool. Upon arriving at the hospital to see an endocrinologist or for a routine exam, the child is stripped to nude or semi-nude and displayed to a large number of doctors, medical students, interns, and others “for the advancement of science and medicine.” Many intersex adults recall this experience as extremely humiliating and sexually traumatic, and that it contributed to their sense that they are freakish or shameful. Further, it may lead some adults to refuse to seek medical care altogether because they associate medical care with this type of traumatic experience.

This practice is clearly harmful to any child, let alone the ones who are taught strictly by their parents to hide their bodies from other people to keep the “secret”

safe. We urge the medical community to utilize photo and video educational materials that have already been produced instead of putting the live child on display.

2. In the past, physicians advised parents of an intersex child to keep the diagnosis hidden as much as possible because the child would be confused and ashamed if they found out. We now know that children feel confused and ashamed because their doctors and family members kept secret from them and nobody told them what was going on. As young adults, many intersex people research their own histories and are often severely shocked and upset when they learn about what was kept secret from them by people they trusted—their doctors and parents.

Many studies on the psychological adjustment of children with severe disabilities have shown that how well a child can adapt to living with that condition depends more on how open and supportive his or her family members are than the severity of the disability itself. We feel that this holds true for families with an intersex child also.

In order to end shame, secrecy and isolation, physicians should advise the parents to tell their child about their condition and what it means throughout their development in age-appropriate and non-shaming ways. Just few years ago, everyone thought that this was impossible—and yet, we know many parents who are doing just that today. There is a lot to be learned from these pioneer parents—which is why we need to establish more support groups and networks for parents.

3. Parents' authority to make medical decisions on behalf of their minor child is well founded in the U.S. legal tradition, but it is not meant to be absolute or unlimited: physicians have the obligation to refuse to participate in medical procedures if they believe that they are contrary to the interest of the child. In the case of intersex, however, parents' need for comfort is often cited as the primary justification for the surgical intervention at the earliest stage of the child's life, rather than giving a more careful consideration for the child's long-term quality of life, including her or his adult sexual functioning.

While we may have different opinions about normalizing surgeries on intersex children in general, we should all be in agreement that if any surgery is to take place, it has to be because careful examination of available evidences suggest that surgery is in the best interest of the child, and not because parents would have difficulty accepting and raising the child without it. Some might argue that surgery is indeed in the child's interest if it makes the parents accept him or her, but this is insufficient justification because there are far less invasive and risky alternatives to address parental anxiety and frustration (e.g. counseling and support group for the parents) that should be sought first.

We would further argue that it is not in the interest of the child to grow up in a family that suppresses anxiety and frustration with concealment and silence.

Like all children born with disabilities and atypical bodies, intersex children deserve parents who are open and supportive of their unique conditions, whether they have surgery or not.

CONCLUSION, OR A PERSONAL APPEAL

Over the past decade, genital normalizing surgeries on intersex children have become a site of increasingly heated debate within the medical community and beyond. Paper after paper call for “more follow-up studies” to find out whether we should continue to perform these procedures or to abolish them, but we have real live intersex babies born every day across the country who cannot wait until we have all the data. Activists and medical professionals need to put aside our differences and find areas in which we can come together to think about what we can do to improve the lives of five or so intersex children born every day.

This article is an attempt to open such dialogue from the activist side. Personally, I am highly critical of normalizing genital surgeries on intersex children and wish to put an end to them if I could; however as an activist I know that real changes often happen not through heated screaming matches, but through finding a common ground with those I disagree.

Whether you happen to endorse surgeries or oppose them (or occupy a space in between), I trust that you want to take away the pain in the world as much as I and other intersex activists and allies do. It is in this trust that I also trust that we can work together to make small changes in the lives of our children as we push for more and better follow-up studies.

Ultimately, the goal in my activism is to make intersex normalizing surgeries obsolete. By that, I do not mean some top-down decision from the AAP or the Congress or the Supreme Court to step in and solve our problem; what I mean is that I would like to help build a society in which intersex bodies are not considered shameful, so that parents would not even think about cutting into the child’s skin unless it is medically necessary.

In that society, the cloud of shame and secrecy no longer surrounds intersex; instead, it is approached with openness, honesty and support. I believe that the medical community—along with activists, families, scholars, and other allies—will have a pivotal role in moving our society closer to that vision. I invite you to join us.

Is “Gender Identity Disorder” An Intersex Condition?

by Emi Koyama, *Intersex Initiative*

Is “gender identity disorder” an intersex condition? The short answer is no—at least under the current definition. “Intersex” refers to “congenital anomaly of the reproductive system” (National Institute of Health) and does not include “gender identity disorder” (GID) or transsexuality. Some people have said that GID is a “brain intersex” condition, but it makes no more sense than calling headache a “stomachache in the head.”

More importantly, why do some people want GID to be considered intersex? There are a couple of reasons. First, the fact GID is treated as a “psychiatric condition” makes some people feel like they are being told that “it’s all in your head.” Many transsexual people feel that their gender identity is more than just “in their head,” that is, they feel that gender identity is something as biologically concrete and “hard-wired” as our body parts.

Two responses can be made to this sentiment: first, many “psychiatric” conditions are indeed biologically based but we still consider them “psychiatric” as long as the biological events take place within a brain; and second, something being biologically rooted is not the same thing as being intersex. One could even argue that intersex is not biological but social, since it is not how large someone’s clitoris is that qualifies it as an intersex condition, but how large the society thinks it should be, for example.

Second, some people believe that being re-classified as intersex would lead to greater acceptance of transsexual people and more services being offered to them. Indeed, sometimes intersex individuals who transition from one gender to another as adults are treated more favorably than a non-intersex individual doing the same, which is unfair.

But at the same time, being categorized as intersex comes with its own stigma and barriers. For example, a transwoman who discovered her intersex status during her transitioning from male to female was told by a doctor that she needed testosterone, not estrogen which she requested, because the only reason she did not feel like a guy was because she did not have enough testosterone in her blood. Being intersex in this society too often means that your right to self-determination is routinely neglected and violated—which is the last thing a trans person needs.

Also, the vast majority of people born with intersex conditions identify with the gender in which they were raised, with only small (but noticeable) minority electing to transition to another gender or otherwise live as trans or genderqueer. Activists oppose non-consensual genital “normalizing” surgeries on intersex children primarily because they are harmful physically, emotionally and sexually, and not necessarily because they might get the gender of the child “wrong.”

In general, issues faced by intersex people are very different from those faced by transgender and transsexual people (although there are people who are both

intersex and trans). One of the misperceptions that plague the young intersex movement is the notion that intersex is all about gender. It is not. For many intersex people, the problems they face are shame, secrecy, isolation, and the history of sexual trauma within medical settings. When some trans people and their advocates conflate intersex and trans, it sends the wrong message about what intersex is all about and what intersex activists are fighting for.

Of course, when the medical community began diagnosing GID at birth and “fixing” and eliminating them through invasive brain surgeries on transsexual infants, perhaps our issues are similar enough that we would come together to form a unified movement. We certainly hope that this will not become reality though—trans people and intersex people both deserve to be accepted fully into the society without shame, secrecy, or attempts at eugenicist elimination.

Recommendations for the SF Human Rights Commission

September 1, 2004

1. Restoring “Best Interest of the Child” Principle

Human Rights Commission should proclaim that any “normalizing” genital surgeries that are performed for the sake of parents, relatives, or others rather than in the best interest of the child (patient) are in violation of the child’s human rights. Parents should not be given an unmitigated power to “consent” to such surgeries on behalf of their child because there is a clear conflict of interest between the parents and the child.

Physicians should never accommodate parents’ request for “normalizing” or cosmetic surgeries on an intersex child unless evidence suggests that it would be in the best interest of the child. However, physicians routinely perform such surgeries for parents’ comfort rather than that of the patient, as endorsed by some medical journal papers and medical teaching materials.

There is a conflict of interest when parents request medical procedures that are not in the best interest of the child or when parents refuse medical procedures that are in the best interest of the child. When serious conflicts of interest occur regarding a medical procedure, it is generally up to the physicians to bring the case to the attention of the Court, which would rule on the basis of what is in the best interest of the child. This legal safe harbor designed to protect children’s human rights is not available for intersex children because physicians do not question parents’ requests for surgery, even when the primary purpose for demanding it is to improve the parents’ (and not necessarily the child’s) psychological well-being and comfort.

Therefore, it is recommended that the Human Rights Commission call on the legislature to mandate judicial review (by a judge who has received a special training on intersex) before any medically unnecessary “normalizing” genital surgeries on a non-consenting child can take place. Such legislation would not prohibit “normalizing” genital surgeries in any way; instead, it puts the burden of proof on the party that seeks to impose this procedure on a non-consenting child, which is only fair considering the invasive and irreversible nature of such surgeries.

In addition, many adult intersex individuals report that the seemingly routine practice of showcasing intersex children’s naked or almost naked bodies to large number of professionals, medical students and others while in the medical examination room has been sexually traumatic to them, and it should be found in violation of the child’s human rights. While this practice may have some educational or training value, it is clearly against the best interest of the child/patient and must be minimized and made much more discreet and less traumatizing. For educational purposes, there are already enough video and photo materials available.

2. Restoring Informed Consent Standard

Under the U.S. legal system, “informed consent” standard is understood to mean that physicians are only required to disclose as much information as others in the same field do. While this standard may be sufficient in the treatment of most medical conditions, many parents of intersex children feel that they were deprived of the kind of information they would have wanted to know before having to make a life-altering decision of having “normalizing” surgeries performed on their children.

Medical ethicist Alice Dreger explains: “Since the overarching rule of this system is ‘avoid psychological confusion about the patient’s gender identity,’ doctors often do not tell intersexuals and their parents all that the doctors know, lest information about intersexuality confuse or complicate the family’s understanding of gender.” She further states, “in no other realm in medicine do doctors regularly argue for active, nearly wholesale deception.”

While some of the recent medical journal articles call for more honest approach to treating intersex children, we still hear from parents who have received absolutely no information about risks of surgeries, non-surgical alternatives, availability of support groups, or even the fact that “normalizing” surgeries are optional and are in fact controversial. Parents want and deserve these information; the Human Rights Commission should find it a violation of patients’ (and parents’ by proxy) human rights to have these vital information systemically concealed from them.

We also recommend that the Human Rights Commission establish a list of criteria for which relevant information must be provided in the treatment of intersex children. The list of physicians’ responsibilities may include:

- disclose diagnosis and explain what it means
- distinguish biomedical issues from psychosocial issues
- distinguish medical emergency from things that can be dealt with later
- distinguish medically necessary treatment from cosmetic or “normalizing” treatment
- explain that surgery is not necessary for gender assignment, nor does it guarantee that the child would grow up feeling comfortable as the assigned gender
- discuss less drastic alternatives to surgery, including counseling and support groups to address psychosocial difficulties that may arise
- acknowledge that we do not yet have sufficient follow-up studies to know whether intersex surgeries are more helpful or harmful to the child’s well-being; that some adults who experienced these surgeries as children feel physically, emotionally and sexually damaged by them
- offer referrals to knowledgeable therapist, support groups, advocacy groups, and others with similar experiences

In order to further ensure that every parent of intersex children receive the above information, the Human Rights Commission might consider seeking the legislature to enact a statute requiring specific list of criteria (such as the list above) for which information must be provided before any “normalizing” genital surgeries can take place on a non-consenting child. In addition to protecting intersex children’s human rights, such legislation would protect honest physicians who follow the statute from possible liability by removing uncertainty around what information should be provided.

3. Ending Shame, Secrecy and Isolation

Many intersex individuals have been harmed not only by the invasive medical procedures, but by the shame, secrecy and isolation that were imposed on them through the system of humiliation and erasure. Public health administration has the obligation to end these shame, secrecy and isolation through public education, support services, and other approaches.

To that end, the Human Rights Commission should seek the City and County of San Francisco to proclaim October 26 as the Intersex Awareness Day (www.intersex-awareness-day.org) and sponsor public education events on or around that date. In addition, it should collaborate with intersex groups, public health administration, sexual and human rights groups to continue to raise the public awareness of intersex.

Fundamentalists Pick Its Newest Enemy: Intersex People

ipdxWIRE Intersex News

www.intersexinitiative.org/news

March 28, 2004

Prompted by the widely read intersex article in *TIME* magazine (March 1, 2004 issue), the right-wing Traditional Values Coalition issued a news alert attacking intersex activists. Strangely, though, TVC seems to have no clue as to what intersex activists are actually working toward, despite the fact they have browsed the web long and hard enough to find and criticize a report co-authored by Intersex Initiative director Emi three years ago.

Titled "Intersex Activists Push Multiple Gender Theory," the alert states: "The gender confusion movement is now openly promoting the idea that there are more than two sexes. The Intersex Society of North America is leading this effort... ISNA has produced a curriculum for college courses that describes the objective of 'deconstructing' what it means to be male or female."

The curriculum TVC is referring to is part of "Teaching Intersex Issues," a booklet co-produced by Emi. Contrary to TVC's claim, however, the main report from the booklet criticizes feminist and gender theorists for exploiting intersex existence as a theoretical device to "deconstruct" binary gender categories, arguing that the focus should be on the real-life experiences of people born with intersex conditions and social and medical issues they face.

TVC is also wrong in that intersex activists are advocating for more than two genders. We oppose cosmetic surgeries on intersex children because they are medically unnecessary and harmful to their physical, emotional and sexual functioning; however we are not advocating that intersex children be raised without a gender or as a member of the third gender, at least as long as our society operates under the two-gender system. As ISNA and others have repeatedly stated, we are recommending that an intersex child be raised either as a boy or as a girl, depending on what specific condition the child has and what gender the child is most likely to function well.

We do not frankly care that the Traditional Values Coalition has chosen to expand the targets of their hate beyond LGBT people and women seeking abortion (among others) to include intersex. We also feel that it is TVC's prerogative to oppose our goal of ending the medical abuse of intersex children, if so they choose (but I bet they'd be demanding that it be stopped if surgeries were being performed in utero).

We do wish, however, TVC would stop misrepresenting facts about intersex conditions and about our movement, because there could be many supporters of TVC who have an intersex condition or a child with one, who could use some accurate information. Conservative Christians or not, nobody deserves to have their genitals mutilated against their will.

“Most Intersex People Support Surgery” Claim Disputed

ipdxWIRE Intersex News

www.intersexinitiative.org/news

April 17, 2004

Heino Meyer-Bahlburg, Claude Migeon and other intersex medical specialists are the co-authors of “Attitudes of adult 46,XY intersex persons to clinical management policies,” arguably the first-ever follow-up study in which they actually asked intersex individuals what they thought about the cosmetic genital surgeries performed on them. According to the study, which was published in the April 2004 issue of *Journal of Urology*, “the majority of respondents [...] did not agree that corrective genital surgery should be postponed to adulthood and stated that their genital surgeries should have been performed before adulthood,” despite intersex activists’ criticisms of such surgeries in the past decade. However, a close examination of survey questions reveal how this finding does not necessarily contradict the position of the intersex movement.

The study involves 72 participants with 46,XY chromosome pattern, who are divided into five groups depending on the nature of their intersexuality and their assigned gender. Those who exhibited visibly intersex genitalia at birth are categorized either as “ambiguous genitalia” or “micropenis,” each of which are divided into those raised as women and those raised as men. The last group is the people born with unambiguously female external genitalia who are nonetheless intersex because they have 46,XY chromosomes (all but one of them have complete androgen insensitivity syndrome).

Part of the study confirms what doctors and intersex activists already agree on: that the majority of intersex individuals feel okay about the gender in which they are raised, while some of them wish to transition to another gender, or that the majority of them do not think assigning intersex children to a “third gender” is a good idea. The controversial part is where the study reports that the majority of 46,XY intersex people (by the margin of two-to-one) disagree with the notion that cosmetic surgeries on non-consenting children should not be performed.

The actual question here is phrased this way: “Some people argue that children born with unfinished sex organs (ambiguous genitalia) should not be surgically corrected before they are adult and can fully understand and consent to the procedures. Do you agree?” Already, there are two distortions of intersex activists’ positions: first, intersex activists want surgeries to be postponed until the child can participate in his or her own treatment, but not necessarily until adulthood; second, we want surgeries to be replaced with counseling, support groups, and other less invasive solutions, rather than just leaving the child alone.

In addition, looking at specific distribution of “disagree” answers to this question, you would recognize that women from “ambiguous genitalia” and “micropenis” groups are far more likely to support surgeries than the rest. This is perfectly understandable when you realize that these are women with functional

testes that could cause the body to masculinize unless they are surgically removed at or before puberty: no wonder they don't want to have to wait until adulthood before they can consent to the surgery to remove their testes! But is it really necessary to remove their gonads during infancy or early childhood, long before we even know that the child actually identifies as a girl? Certainly, "surgery" and "no surgery until adulthood" are not the only options.

Indeed, intersex activists have demanded not just an end to cosmetic genital surgeries on children, but replacing these surgeries with social and psychological support to end shame, secrecy and isolation that are socially and medically imposed on intersex children. And yet, the only question doctors asked was whether or not surgery is a good idea; why do they continue to forget to ask us what kind of support and information might have been helpful as we grew up? Fundamentally, the question should not be framed in terms of surgery vs no surgery, but rather how to improve overall quality of life for those impacted by intersex conditions.

To the question regarding at what age surgeries should be performed, respondents are evenly split between wanting it to have happened during infancy and wanting it to be postponed at least until adolescence. It is hard to interpret this information because researchers did not ask at what age they actually had surgeries, but one possible explanation is that the majority of people received surgeries somewhere in the middle (between toddler age and adolescence) and really hated whatever they went through.

Researchers concede that findings on the small and selective (1/4 of the patients could not be contacted, and another 1/4 refused to participate) sample from one clinic could not be generalized to the population, but caution that "the representativeness of the case histories on which activists base their critique and suggestions for change is totally undocumented and suspect." That is true: however, it is doctors' job to have studied potential negative consequences of intersex cosmetic surgeries before it is widely practiced—a responsibility they have evaded for five decades in violation of the public trust on their profession.

Toward the end, researchers state: "It is quite conceivable that the activist material is too negative and the data from clinic samples are too positive. Thus, collaboration between clinicians and activists is called for." But if that is what they truly believe, how come none of them invited activists to help devise the survey or to interpret the data? There are many activists as well as professional members of activist groups who are trained professionally to do take on such tasks, myself included.

Yes doctors, let us collaborate. We welcome the fact that you are finally asking patients what we feel about the treatment we have received, but we think it could be even better. Next time, please invite us to help design and conduct the research, rather than merely treating us as the research subjects. By working together, we will be able to ask the right questions and find out how to improve the treatment of children born with intersex conditions.

Meyer-Bahlburg HFL, Migeon CJ, Berkovitz GD, Gearhart JP, Dolezal C, Wisniewski AB (2004). "Attitudes of adult 46,XY intersex persons to clinical management policies." *Journal of Urology*. 171: 1615-1619.

Intoxicated Sex Advice Columnist Ponders on Intersex

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www.intersexinitiative.org/news

April 13, 2004

Controversial sex advice columnist Dan Savage responds to an intersex reader's letter in this week's *Savage Love*. The reader is "a twentysomething legal female" who feels like a bisexual man in a woman's body, who found out recently that he had been born intersexed and was operated on to be raised as a girl. He feels fine about being intersex, but he is frustrated that gay and bisexual men view him as female—hence the letter to the advice columnist. Before answering the question about how to approach gay and bisexual men, Savage gives a three-paragraph Introduction To Intersex speech in case any reader is not aware of what it is. Citing the positions posted on the website of Intersex Society of North America (some of which was written by Intersex Initiative director Emi while she was an intern at ISNA), Savage writes: "ISNA's absolutely right. I agree 100 percent. You go, girls. And boys."

The rest of his response, however, were classic Dan Savage: depicting trans (and now intersex) people as unreasonable and easily offended, insisting that "most gay men want to be with other men, not with trannies, bois, the intersexed, or legal women who can pass for bi males," and telling the reader that gay and bisexual men are unlikely to find him attractive. Hmmm, you mean bisexual men are only attracted to people who have standard male body? He is, of course, merely expressing his own sexual preference—must have a non-surgical penis—and applying it not just to all gay men, but also to bisexual men. It's somewhat understandable, although not right or correct or anything, that he, a gay man, would generalize his preference to other gay men; but where did he get the idea that he and bisexual men like the same thing? Sure, some bisexual men might find the reader attractive "as a woman" and that would not be a good relationship for him to be in; but many bisexual people identify as bisexual because what matters to them is the personality, not the shape of their genitalia.

Savage's final advice for the reader is to go to a place like San Francisco, where "FTMs (female-to-male transsexuals), the intersexed, and the men who love them are more vocal and visible." In other words, he is admitting that the problem is not that gay and bisexual men simply don't like them; the problem is the lack of voice and visibility in most part of the country. Skip closed-minded gay men like Savage (and here, I'm not blaming him for not being turned on by something that doesn't turn him on; I'm blaming him for making unwarranted generalizations that deny the existence of people who are different from him); we should make some noise to increase our voices and visibility everywhere so that more people will respect who we are and stop being afraid of our queer bodies.

Ian Anderson at AUA: “Doctors Should Stand In Shame”

ipdxWIRE Intersex News

www.intersexinitiative.org/news

May 10, 2004

Doctors “should stand in shame” at the lack of follow-up studies on the cosmetic genital surgeries on intersex children they have been performing for decades, proclaimed Dr. Ian Aaronson of the Medical University of South Carolina. The strong words came during a presentation titled “Gender Reassignment: Yea or Nay?” at the American Urological Association conference currently being held in San Francisco. This is an interesting change of heart for a doctor who stated “to advocate nonintervention in intersex infants until they are old enough to make up their own minds about what gender they want to be signifies a return to the ‘dark ages’ of intersex management, which has given rise to a host of psychological cripples” in 1999. Perhaps the “dark ages” wasn’t so bad after all.

However, in the discussion of available follow-up studies, Aaronson seemed to solely focus on defining a “success” as a “correct” gender assignment, in that the person maintained her or his gender identity over the period studied—an incredibly narrow way to measure success, and certainly not the most important factor impacting the person’s overall quality of life. This is concerning, considering the fact that Aaronson is in charge of the largest follow-up study currently being conducted on the intersex patients’ psychological and sexual well-being after surgery.

From the activist point of view, the title “Gender Reassignment: Yea or Nay?” is a very limited way to frame the question. What is important here is not whether or not surgery should be performed, but what the overall treatment strategy should be in order to allow maximum participation of the patient and to reduce shame, secrecy and isolation. Activists do not argue for simply eradicating surgeries; we want full disclosure, counseling, peer support, true informed consent, and education.

Also of interest to intersex activists and allies: In an earlier presentation at the same panel, Dr. George Kaplan from University of California San Diego gave a lecture titled “Complications of Neonatal Circumcision.” In this talk, Kaplan discussed “mistakes” that can occur in routine circumcision and how to resolve them. One of the points he made was that it is now very clear that reassigning boys who are victims of botched circumcision to be raised as girls is a really bad idea. Coming only few days after the suicide death of David Reimer, the subject from John Money’s infamous “John/joan” experiment, we can’t be more thrilled that they finally got the lesson that had been obvious to many from the beginning.

Unanswered Questions in the Psych Study of CAH Women

ipdxWIRE Intersex News

www.intersexinitiative.org/news

June 13, 2004

In the paper published in *Journal of Pediatrics* (June 2004; vol. 144, no. 6), Penn State University psychologist Sheri Berenbaum and others report that children and young adults who have congenital adrenal hyperplasia do not show any more psychological problems compared to their siblings and relatives of similar age. Authors claim that the data indicate that psychological adjustment is not negatively affected by either the condition itself or its treatment, which often includes clitoral recession and vaginoplasty surgeries in girls with CAH. Astonishingly, however, the research omits investigation of the psychological aspect of sexual functioning as experienced by women whose genitals have been repeatedly operated.

In addition, the instruments being used to examine psychological adjustment are designed to detect psychological pathologies, and not necessarily harms to one's quality of life. In fact, most people who experience traumatic events do not exhibit any detectible "psychological adjustment" problems in the long-term, but that obviously does not mean that their lives are unaffected by the traumatic events or that their quality of life do not suffer because of them. It would be a stretch to use this data to claim that surgeries and other invasive medical treatment is harmless to children born with CAH.

And besides, that is not how medicine is done. You do not perform medically unnecessary procedures on a non-consenting child just because it does not cause adjustment issues; you do so only when there is a medical need that can be alleviated by the procedure. Showing that the treatment does not result in psychological dysfunction is not enough to justify it; they must first show that children experience dysfunction without the treatment.

In conclusion, authors state that "these data strongly suggest that the presence of this intersex condition per se does not place a child at risk of psychologic disturbance." I hope that this is how medical professionals would interpret the finding, but they could also argue that the study did not find any psychological disturbance because most of the patients with atypical genitalia received surgeries to fix them. We hope that future researches would be designed so that they can separate harms caused by the condition itself (if any) and those caused by the treatment.

Berenbaum SA, et al. (2004). "Psychological adjustment in children and adults with congenital adrenal hyperplasia." *Journal of Pediatrics*. 144(6):741-746.

Dear LGBT Community Center

October 17, 2004

Hello LGBT Community Center,

My name is Emi Koyama and I am the director of Intersex Initiative, the Portland, Oregon based advocacy group for people born with intersex conditions.

I'm contacting you regarding a presentation one of your staff members has been presenting at various conferences and I hope that you can help me, or forward this email to whoever can help.

This past August, I saw a presentation titled "[DELETED]" by Mr. [DELETED] who works for the LGBT Community Center, at the LGBTI Health Summit in Boston. The presentation was a dissapointment, to say the least.

The entirety of Mr. [DELETED]' knowledge of intersex issues consists of having provided substance abuse counseling to a single individual over eight sessions who stated that he was intersex. He does not know basic facts that even casual participants in an "Intersex 101" workshop would understand. He does not recognize the names of prominent intersex activists, nor has he ever contacted them to receive assistance or to get educated. In fact, he did not attend any of five other intersex workshops during the conference.

I found his presentation offensive and damaging to intersex people everywhere, and I am not alone. Several intersex individuals in attendance, including Betsy Driver (the director of Bodies Like Ours, who is speaking on a panel at the LGBT Community Center later this month) felt the same way.

Recently, I found out that Mr. [DELETED] is planning to present the same workshop at the upcoming GLMA (Gay and Lesbian Medical Association) conference, despite the fact several intersex individuals have confronted him about it. This is even more troubling than the LGBTI Health Summit, because his presentation is promoted as the only workshop about intersex at the entire conference, whereas the Health Summit had other workshops where participants could learn accurate information.

I don't know if he is attending these conferences as part of LGBT Community Center (i.e. if he is paid to attend them, or if any expenses are being paid by the Center), but I am very frustrated that a staff member of LGBT Community Center is using his position to do something so irresponsible.

Is there any way to stop this campaign of ignorance and misinformation? I realize that he has the constitutional right to speak his mind as much as anyone else, but what he is saying in these workshops are clearly contrary to the mission and goals of the LGBT Community Center. I appreciate the Center for sponsoring an intersex panel for the Intersex Awareness Day, and I hope that it would also stop its staff members from spreading inaccurate or misleading information at conferences.

Best,

Emi Koyama, Director, Intersex Initiative

Intersex “Caught in Crossfire” Between Talk-Show Hosts

ipdxWIRE Intersex News

www.intersexinitiative.org/news

June 2, 2004

On June 2, former “Saturday Night Live” comedian and the progressive radio talk-show host Al Franken made a joke reference to intersex that many felt was hurtful. The comment came during his three-hour weekday show, *The O’Franken Factor*, in a segment titled “Fighting (conservative pundit and FOX News host Sean) Hannity’s Lies With Lies About Hannity.” Below is the excerpt of the transcript from the show:

Host Al Franken: We caught [Sean] Hannity in another lie. The guy just will not stop... Let’s play this, this is from May 26th. [...] And Hannity knows this, and it’s just tiresome. We continuously debunk Hannity’s lies but it doesn’t make any difference. He keeps on repeating lies we debunk and then he tells other lies that he knows are lies. And he forces us to resort to the only weapon... welcome to today’s edition of “Fighting Hannity’s Lies With Lies About Hannity.”

AF: Okay, today’s lies about Hannity. Remember this isn’t true. That’s important—this is a lie. Not true. *Hannity was born a hermaphrodite.*

Co-host Katherine Lanpher: What?

AF: It’s not true. Not just a hermaphrodite, but a conjoined twin who is also hermaphrodite. They were conjoined at both sets of genitals. Remember this isn’t true, it’s a lie. The doctor in delivery room said he’d never seen a more hideously freakish creature in his life, Sean and Shawn, S-H-A-W-N.

They were separated at age 14 by drunk carnival barker using a [inaudible] stolen from bearded lady, who was Sean’s mother and father. Remember, none of this is even remotely true, it’s a lie. Anyway, Sean nearly bled to death but survived and now has a quarter of a vagina and three-quarters of a penis. Remember this isn’t true.

But in a sense it is far less [inaudible] lie than the lies this three-quarter man tells everyday. And we here at *The O’Franken Factor*, we feel that it’s our duty to keep lying about Hannity as long as he insists on lying to America. That was today’s Fighting Hannity’s Lies With Lies About Hannity.

KL: Al? What happened to Shawn, S-H-A-W-N, Shawn?

AF: Katherine, it’s a lie, there were no twins. But your asking demonstrates how insidious these lies could be. He-she bled to death.

KL: Oh, that’s terrible.

AF: But Sean didn’t seem to care, he’s never even mentioned her on the show as his sister.

KL: That’s terrible.

Concerned about the depiction of children born intersexed (or conjoined) as “hideously freakish creature,” Intersex Initiative director Emi Koyama immediately sent a letter to Air America Radio, which broadcasts Franken’s show. So far, we have received no direct response. However, when other activists wrote Air America (prompted by the transcript we forwarded them), many activists received sincere apologies from the show producer Ben Wikler, who said “There’s no reason intersex people should be caught in the Al Franken-Sean Hannity crossfire, and they won’t be again.” It appears that they didn’t think to respond to the first complaint they received, but changed their minds after a slew of them began flooding in. Folks, this is the power of collective action: we can do things together that we can’t do alone.

Personally, I appreciate Franken’s work, both his stint at the Saturday Night Live and his more recent role as the progressive talk show host. I also enjoyed his most recent bestseller, “Lies and Lying Liars Who Tell Them: A Fair and Balanced Look at the Right,” which thoroughly documents how conservative pundits (such as Ann Coulter, Sean Hannity, Bill O’Reilly, et al.) and media outlets (FOX News, Washington Times, Clear Channel, etc.) spread unsubstantiated stories and outright lies. But that does not mean that we need to tolerate offensive “jokes” about intersex children.

On the website of The O’Franken Factor, Wikler states: “[If] you hear something inaccurate on our show, it isn’t a lie—it’s an error. We want to correct it. And we need your help. If you hear a mistake, an inaccuracy, or a falsehood—no matter how boring or technical—send it to [email address deleted].” Franken insists on air that this is the difference between his show and that of Hannity and others. We hope that the same standard holds for offensive and bigoted commentary—after all, nobody expects Rush Limbaugh to publicly retract or apologize all of his racist, sexist, homophobic, etc. statements, but we want to believe that Al Franken is different.

UPDATE on June 4, 2004:

Today, Al Franken publicly apologized on air for the insensitive “joke” he made about intersex people and conjoined people. Below is the official statement of apology from Franken:

“On Wednesday’s ‘Fighting Hannity’s Lies with Lies About Hannity’ segment, I falsely claimed that Sean Hannity was born a hermaphroditic conjoined twin, and that the doctor who delivered him and his twin reacted in horror at their birth. I would like to apologize to members of the intersexed and conjoined-twin communities for furthering the unjustified stigma attached to these conditions. An estimated one in 2000 people are born with atypical genitalia, which, like conjoinment, is a naturally-occurring bodily variation. I am sorry for the ill-considered joke. — Al Franken”

We’re good enough, we’re smart enough, and doggone-it, people like us!

Open Access to Publicly-Funded Researches Benefits Patients

ipdxWIRE Intersex News

www.intersexinitiative.org/news

September 6, 2004

The September 6, 2004 edition of *The Washington Post* reports that the National Institute of Health (NIH) is accepting public comments over the next 60 days regarding the proposal to make all results from NIH-funded (i.e. taxpayer-funded) medical researches available online for free. Currently, patients and their family members seeking latest research about the condition they are dealing with would have to pay large fees to download published research papers, including those researches they participated—and that is if they are available for download in the first place.

The issue surfaced in the U.S. House Appropriations Committee this past July, whose recommendations for the FY2005 budget for the NIH included the following language: “The Committee is very concerned that there is insufficient public access to reports and data resulting from NIH-funded research. This situation, which has been exacerbated by the dramatic rise in scientific journal subscription prices, is contrary to the best interests of the U.S. taxpayers who paid for this research. The Committee is aware of a proposal to make the complete text of articles and supplemental materials generated by NIH-funded research available on PubMed Central (PMC), the digital library maintained by the National Library of Medicine (NLM). The Committee supports this proposal and recommends that NIH develop a policy, to apply from FY 2005 forward, requiring that a complete electronic copy of any manuscript reporting work supported by NIH grants or contracts be provided to PMC upon acceptance of the manuscript for publication in any scientific journal listed in the NLM’s PubMed directory. [...] NIH is instructed to submit a report to the Committee by December 1, 2004 about how it intends to implement this policy, including how it will ensure the reservation of rights by the NIH grantee, if required, to permit placement of the article in PMC and to allow appropriate public uses of this literature.”

As patient advocate organization, we believe that publicly funded researches belong to everyone, not just those who conduct them, and especially to those who will most benefit from learning the findings: patients and their family members and friends. We search the PubMed Central database daily for new research papers that are of interest to intersex individuals and our families so we can publicize important findings, but often we find it hard to get our hands on them (yes, some of our members work at medical schools, but even their libraries don’t carry everything). We support the work of Open Access Working Group which is promoting open and public access to the scientific and scholarly knowledge and the plan to require all NIH-funded researches to be “open.”

Opponents (sadly headed by the highly respected former Congresswoman and a fellow Portland, Oregon native Pat Schroeder, who currently heads the

Association of American Publishers) worry that the move—especially if other funders follow suit—would bankrupt medical journals and the professional medical societies that publish them. But the simple idea that papers based on taxpayer-funded researches should be free to taxpayers makes imminent sense, as does the idea of making them available on PubMed, which is what everyone in the field uses to locate papers in the first place.

Regardless, the business model of scientific journals—which is that they charge enormous fees for researchers to publish their papers, and then charge more fees for other researchers to read them—seems archaic. As the director of NIH is quoted as admitting in *Washington Post*, “the status quo is not an option.” We feel that the proposed “compromise” of delaying PubMed’s publication of new papers by up to six months is both reasonable and sufficient.

Patients pay for researches via taxes we pay, and via our blood—that is, through our participation in the medical studies. Don’t make us pay for the third time just because we want to learn everything there is to learn about the conditions we have.

Intersex Experts Call For “Culture of Full Disclosure”

ipdxWIRE Intersex News

www.intersexinitiative.org/news

December 30, 2004

Aphallia is a very rare condition summarized as the congenital absence of the phallus in a genetically and hormonally “normal” male child. Under Dr. Money’s now-debunked theory that any child could be reared either as a boy or as a girl with appropriate surgeries and socialization, doctors traditionally instructed genetic males with aphallia to be raised as girls, simply because gonadectomy and vaginoplasty were easier to perform than phalloplasty. But now that we know we cannot rely on Money’s theory, how should these children be raised? That is the question addressed in the recent issue of *Pediatrics*. (The discussion originally appeared earlier in *Journal of Developmental and Behavioral Pediatrics* but we didn’t notice it the first time. D’oh.)

Dr. Erica Eugster from Riley Hospital for Children in Indianapolis discusses possible treatment scenarios for the case of aphallia. First, there is the traditional protocol, which calls for surgically assigning the child as a girl and follow up with estrogen injection starting at puberty. Second, the child could be raised as a boy, possibly preserving his fertility; phalloplasty would be performed, although it is “technically difficult.” Third, the “option promoted by patient-advocacy groups” (that’s us!) is to “defer gonadectomy and genital surgery” whether the child is assigned male or female, until the child can participate in the decision-making in an meaningful way. Eugster however urges that gonadectomy be considered in the case of female gender assignment, because the presence of testes could stimulate further masculinization of the brain.

What is remarkable about this dialog is the refusal of each participating experts—Drs. David Sandberg and Tom Mazur from the Children’s Hospital of Buffalo, Dr. Jorge Daaboul from University of Florida College of Medicine, and Dr. Eugster—to give simple answers. “In light of contemporary controversy,” writes Eugster, few would hazard the assertion that there is an absolute ‘right’ or ‘wrong’ answer regarding optimal sex assignment in this case.” According to Daaboul, “the current medical model with its focus on diagnosis and medical-surgical treatment does not assure the best possible outcome... The appropriate care model is one in which the focus is shifted away from the precise medical diagnosis and toward the parents’ conception of [...] how they see their child’s future in the context of their family and society.”

The general consensus here is that there is no systemic way to ascertain any particular recommendation regarding the appropriate sex of rearing. Instead, Daaboul and others are urging physicians to facilitate case-by-case determination in terms of gender assignment through full disclosure of information, including those information that may be “arguably biased” (i.e. those coming from patient-advocacy groups—that’s us!) and with the assistance of experts in psychology and

counseling.

Eugster points out that “a consistent source of dissatisfaction among adult intersexuals, even among those for whom the psychosexual outcome appears favorable, has been the lack of disclosure by medical professionals (and often parents) regarding their diagnosis and treatment.” “The ideal time to establish a culture of full disclosure is in the initial discussions with parents,” she writes.

We agree: what we need now is to end the culture of shame and secrecy that has been imposed on children with intersex conditions and their families, and transform it to the culture of full disclosure and respect for everyone. While long-term outcome studies are important, even in their absence we can begin improving the lives of intersex children and their families through honesty, respect and support.

Source:

Stein MT, Sandberg DE, Mazur T, Eugster E, Daaboul J. (2004). “A newborn infant with a disorder of sex differentiation.” *Pediatrics*. 114(5):1473-1477.

NBC's "Law & Order" Episode Based on "John/Joan" Case

ipdxWIRE Intersex News

www.intersexinitiative.org/news

January 20, 2005

The January 18, 2005 episode of NBC's "Law & Order: Special Victims Unit" (Season 6, Episode 12) featured a plot based on the true story of the "John/Joan" twin case, which was made famous by John Colapinto's book, "As Nature Made Him." In the true "John/Joan" case, the genetic male who was raised as a girl after the circumcision accident burned off his penis was later told of his medical history and chose to go back to living as a man; however, in this television program, the medical history is exposed in the course of crime investigation in which the genetic male being raised as a girl is a sexual assault victim.

At the beginning of the episode, investigators find the body of a dead man, a known sex offender, who apparently fell off from the roof when his victim bit his penis in self-defense. From the DNA sample in the victim's saliva, which clearly included a Y chromosome, they determine that the fourteen-year old boy Logan was the victim—but it was his twin sister Lindsey who confessed to having been assaulted at the scene. Investigators initially suspect that Lindsey was covering for Logan by telling stories that only he could know, until their old medical record reveal the "shocking" truth, which was that Logan and Lindsey were born identical twins.

Investigators confront the parents: "What happened? Is it that you just had to have a boy and a girl?" "It was a freak accident. They do it hundred times a day. It's supposed to be a routine procedure." "What?" "Circumcision... They used some sort of device to remove foreskin—it malfunctioned. Burned him severely. We spoke to all those experts, and they all said that he will never be normal... Imagine the abuse he'd take in locker rooms. Humiliation of explaining it to the girl he fell in love with. We couldn't put him through that." "Did you think that sex change operation would be easier for him?" "What else could we do? Dr. Blair convinced us that it was the only hope our child had for a normal life... He promised us that it would work. He promised us, as long as we are committed to raising him as a girl."

Next, investigators visit Dr. Blair, a character obviously based on psychologist/sexologist John Money. "Any plastic surgeon would tell you that it's easier to dig a hole than to build a pole... In order for the experiment to work, she has to look like a girl, be treated like a girl, and taught to act like a girl... Children are born psychosexually neutral, a blank slate. Gender identity is determined by nurture, not nature."

Investigators then go back to Lindsey to tell her that they would not press charge against her because it was self-defense, but Lindsey is rightfully confused about what had happened. "But I don't understand... You said my brother had to have done it. Just tell me what's going on! I feel like I'm going crazy. Please." It is

at this point Lindsey is finally told the truth despite the objection of Dr. Blair. “You were born a boy. There was an accident right after you were born.” “I knew it! I never once felt right! Why didn’t anybody tell me? Why didn’t you tell me? What was my name?” Almost immediately, Lindsey stops taking estrogen and chooses to transition back to his genetic sex.

But that is not all: Logan wishes to press charge against Dr. Blair. “He molested us. He used to show us these pictures of adults having sex. He pushed us into positions. He used to make me and my sister pretend we are having sex.” This is the detail similar to Dr. Money’s practice as described in “As Nature Made Him.” In response, Dr. Blair insists that everything was necessary part of the treatment. “It was important to differentiate their gender roles... It clarified things for Lindsey. She had to be programmed. It’s perfectly normal for children to explore each others’ bodies.” “So you are not denying any of the allegations Logan made about your practices?” “Denying? I’m writing a book about it.”

In the end, however, Dr. Blair is found murdered in his office. They find the DNA and security camera evidences indicating that either Logan or Lindsey—now going by Luke—must have committed the crime, but they cannot figure out which one did it. “They came up with a perfect crime.” “Until you get one of them to flip.” “That’s not going to happen. They are too close.” The scene pans out as Logan and Luke, now wearing similar clothes and hairstyles, feel each other’s presence through the holding cell wall.

This was one piece of amazing television program. It’s a sad and devastating story that is too familiar to many of us, told through a very sympathetic voice. Producers should be commended for not presenting the story simply as a freaky episode about gender, and depicted the real-life pain arising from secrecy, betrayal and sexual abuse. Unfortunately, in the real “John/Joan” case both twins—Brian and David Reimer—have committed suicide, as did many others who were treated similarly by the medical system because of the accidental loss of penis or because of a congenital intersex condition.

Here at Intersex Initiative, we are doing our part of avenging the wrong that has been done to us and our friends through our activism (so join us!). Meanwhile: doctors, take note. While we don’t advocate violence as a solution, believe us when we say that Logan and Luke aren’t the only ones who felt the urge to murder their doctors.

UCLA's Eric Vilain Expresses Support for Intersex Movement

ipdxWIRE Intersex News

www.intersexinitiative.org/news

February 2, 2005

This past weekend, UCLA's Center for Society and Genetics hosted a public symposium on "Sex, Science and Society," part of which addressed the science and ethics of intersex medical treatment. Among other things, we have been pleasantly surprised by Dr. Eric Vilain's candid and forthcoming support for the goals and positions of the intersex movement, whereas his previous comments on the topic has often been confusing or overstatements (apparently, he feels misrepresented by presses, including the communications office of his own institution).

Below is a note from moof, who attended the symposium:

[Dr. Vilain] agreed that if there were a way [to determine one's gender identity at birth], that determination should be used only to help with gender assignment (rearing), and not to justify surgical reconstruction. He sees gender assignment and surgery as two very separate issues. Actually, Eric took a significant amount of time to talk about the patient-centered approach to treating intersex children. He said that no one has the right to say what the upper bound on clit size is.

He also said that there's a wide spectrum of phenotypes, showed pictures of intersex people's genitals (only to contrast the traditional model of treatment versus the patient-centered one), and stated that the frequency of intersex births ranges from 1/4000 to 1%, depending on who is included in the definition of "intersex." He brought up that there's controversy over clinical management of intersex cases around precise diagnosis, gender assignment, and genital surgery. He asserted that due to their own ignorance, many doctors contribute to the stigmatization of intersex children. He went on to explain what the traditional therapy is for intersex cases, citing concealment, early plastic surgery, and later exogenous hormones. Then he stressed that we have to remember that the patient in these cases is the child, not the parents, and sometimes the parents wishes may conflict with the patient's, and that informed consent is NOT obtained from the patient in these cases.

Then he mentioned ISNA and that gender should still be assigned, and that gender is probably not socially constructed so performing genital surgery won't be a successful way to force a gender upon a child. Next he showed two videos, one from ISNA (featuring clips from Hermaphrodites Speak) showing intersex people talking about their experiences, and then a contrasting training video from the American College of Surgeons that was very much in favor of the traditional treatment model.

Then Eric said something along the lines of “I’ve been showing you lots of genitals, but it’s important to show images of intersex people, who are not just walking genitals.” At that point he had up a slide of various pictures of people smiling, some with partners/families, and stated their names and that he had gotten permission from them for them to be a part of his presentation.

In response to our follow-up email, Dr. Vilain wrote: “I am very supportive of your work in the intersex movement. There is always the risk that surgeons will use the work on gender as an argument for surgery, but they would use any arguments anyway. Gender assignment and genital surgery are two independent parameters in my mind. I don’t think a possible misuse of science should block the science. There will always be someone doing the science. It might as well be someone sympathetic to the cause, who can explain what it means and avoid misinterpretations. I think that the main reasons to be against unwanted genital surgery are the absence of outcome data and the absence of consent. Helping predict gender should certainly not be used as an argument for surgery! Plus, genetics or no genetics, there will always be errors in gender assignment, because gender is just so complex.”

Thanks, Dr. Vilain, for your understanding and support.

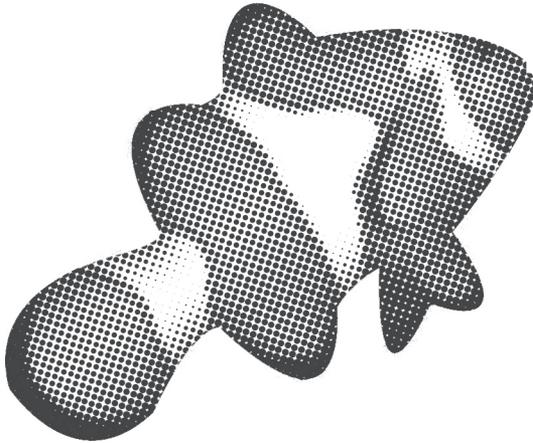
About Intersex Initiative

Intersex Initiative is a Portland, Oregon based national activist and patient advocacy organization for people born with intersex conditions. Intersex Initiative was founded in January 2003 by Emi Koyama, the multi-issue social justice activist and a former staffer of Intersex Society of North America. Please visit www.intersexinitiative.org for more information.

About Emi Koyama

Emi Koyama is a multi-issue social justice slut who synthesizes feminist, Asian, survivor, dyke, queer, sex worker, intersex, genderqueer and crip politics. Emi is the founding director of **Intersex Initiative** and has present extensively on intersex activism, working-class sex worker feminisms, and the domestic violence “industry.”

Emi is also the founder of **Confluere**, the alternative “speaker’s bureau without the centralized bureau” and is responsible for putting the “Emi” back in “feminism” via her personal website, eminism.org.



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