

# Reflections on Conjoined Twins

The doctors say, this is not so  
Some cry out humbug, till they  
When they say-great mystery!

Two heads, four arms, four feet  
All in one perfect body meet;  
I am most wonderfully made  
All scientific men have said.

None like me, since the days of  
None such perhaps will ever be.

By Naoe Suzuki

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## Historical and Contemporary Views

The perpetual wonder and fascination of conjoined twins can be found throughout history, from the Biddenden Maids born in 1100 AD to the current media frenzy over separation surgeries. There are numerous drawings and prints of conjoined twins from the Renaissance period, and there are a number of photographs from sideshows and medical textbooks. Similarly, literary works have featured conjoined twins, including Mark Twain's *Those Extraordinary Twins* and Lori Lansens' *The Girls*. Throughout history, artists and writers depicted conjoined twins with wonder, fantasy, desire, fear, despair, courage, and destiny.

Within medicine, doctors and scientists have treated conjoined twins as the "most extraordinary" cases. "In the nineteenth century, there was a great upsurge in interest and knowledge in both normal and abnormal human anatomy. This was the heyday of scientific teratology (study of malformations), particularly in Germany and France. In addition to dissecting every malformed infant that came into their hands, the pioneer teratologists reviewed the old annals of strange births to discover historical cases of rare malformations. By this time there had been several dissections of stillborn dicephali (two-headed humans). One of the most detailed ones, by the obstetrician Dr. Bland, was described in the *Philosophical Transactions* of the Royal Society of London on 1781." (Bondeson 2000, p.168) People from the eminent and wealthy to ordinary working class paid money to take a peek at individuals with unusual anatomies presented at sideshows. During the Victorian period, people collected *carte de visites* (souvenir photographs that were popular in Europe and America) of sideshow characters. In a strange way, people with unusual anatomies were more visible in the Victorian household, but were contained within the safety of photo albums or scrapbooks. Also, the sideshow platform that was used to showcase individuals with anomalous anatomy was morally questionable.

The visual presence of conjoined twins touches our deepest psyches. It challenges the distinction between self and other, and questions our understanding of "normal" anatomy. It also stirs our curiosity about sexuality and intimacy. In 1904, the Giacomo and Giovanni Tocci brothers created a controversy by getting married to two separate women. Their marriages were cause for much discussion because it was a well-known fact that the brothers shared their genitalia. "Some newspaper correspondents found the marriage of the Tocci brothers too disgusting to speculate on further, and their wives were blasted as vulgar curiosity seekers, particularly as most medical experts were of the opinion that the Tocci brothers were impotent. The simple explanation that the twins felt a need for human company in their lonely life, after their long and dismal career as sideshow monsters, does not seem to have entered anyone's mind." (Bondeson 2000, p.181) Because we cannot imagine being conjoined, we cannot even think that conjoined twins can flourish the same way as "singletons" do. We see conjoinment as trapped, and view their lives as horrible and miserable. "Because most singletons—by which I mean people born with no anatomical bond to anyone but their mothers—understand psychosocial individuality as *requiring* anatomical individuality, they tend to assume that conjoined twins are trapped in such a way that makes a happy, normal life impossible. Only surgical separation could truly make them free." (Dreger 2004, p.7)

## **“Normal” Body**

I’ve been fascinated with twins for a number of years, and I can recall watching a short video about a boy with severe mental and physical disabilities. The title of the video was *Two Boys*, but only one disabled boy was depicted along with his mother’s voice over. Towards the end of the video, the mother revealed that she had in fact carried twins, but had chosen to terminate one of the twins based on prenatal screening data. The story unfolded further when the mother described in a non-accusatory narrative how the doctor mistakenly terminated the “normal” embryo. The video ends with more questions than answers. Since watching that powerful video, a picture of the two boys comes to my mind often, and I create drawings of them from time to time.

While I’ve been interested in technological advancements in medicine and science, I’ve also incorporated these issues into my work with a healthy dose of skepticism. Advancements in biotechnology and genetic engineering have contributed to the changing notion of enhancement and what makes a “normal” and “perfect” body. As a species, we have more choices and options, and can even opt to terminate “abnormal” babies. But when society constructs the notion of “normal”, how do we begin to make these decisions? At the same time, I fully understand that every parent wants healthy babies and do not wish their children to go through obvious hardships that may come with anatomical, developmental, or biological challenges.

Conjoined twins are an extraordinary form of human anatomy. When I encountered some photographs of conjoined twins presented at sideshows, I first thought, “How can they live attached to another person like that?” As an artist, I cherish solitude and feel that I need to be *alone* often. As an avid dancer and hiker, I could not imagine being attached to someone else and still be able to go dancing or hiking on mountains. Yet, I learned that Millie-Christine were great dancers, and Chang and Eng performed amazing gymnastic feats on stage during their youth. (Martell 2000, p.121) Dr. John Barnard Sweet Jackson, professor of morbid anatomy at Harvard, wrote in 1869, “Millie-Christine not merely walk rapidly about the room, but they waltz together, and rather gracefully.”

Reba and Lori Schappell, say that one of them blocks out when the other one needs privacy. Lori says Reba doesn’t interfere when she’s on a date. “She can’t see us anyway (the Schappell sisters are conjoined at the head, but face opposite directions). “If we’re on a date, she will bring something along that she has to do, or else she’ll read. She totally blocks us out.” (Brown 2006, abcNews.com) Alice Domurat Dreger, a professor of clinical medical humanities & bioethics at the Feinberg School of Medicine of Northwestern University and the author of *One of Us* says, “What really surprised me is when I looked back through history, I found that over and over again they (conjoined twins) said that not only were they OK with being conjoined, many of them actually felt that this was a superior state that was better because they went through the world with somebody with them, with somebody very close to them.” Dreger continues, “The conjoined twins that I’ve studied say that in fact, the way that they feel about themselves is that the body that they were born into is the body that is theirs. And in that sense, it’s a normal body for them.” (Brown 2006, abcNews.com)

## Conjoined Twins Prenatal Survival

Fetuses with unusual anatomies are often terminated before birth due to advancements in prenatal screening. “The number of children born with obvious disabilities is declining as the resolution of prenatal ultrasound and other fetal diagnostic procedures improve, allowing parents to abort abnormal fetuses. What we’re seeing now with conjoined twins is a lot of termination of these pregnancies,” said Dr. James A. O’Neil Jr., chief surgeon at Vanderbilt University School of Medicine in Nashville. (Angier 1997) Conjoined twins are a rare occurrence. “Estimates of the incidence of conjoined twinning in humans vary from 1 in 25,000 births to 1 in 200,000,” and “40 percent or more of conjoined twins are stillborn; another 35 percent die within one day as a result of profound medical problems stemming from their anomalous development.” (Dreger 2004, p.31)

Because of advanced technologies involved in prenatal screening, another type of stigmatization could be emerging: parents who choose to give birth to conjoined twins or babies with other “abnormal” anatomies could be held responsible for giving horrible and miserable lives to children with unusual anatomies. “In sum, the dominant culture appears to be moving in two contradictory directions: more accommodating of disabilities in adults, but less tolerant of *imperfections* in children (my emphasis in italic). “I’m concerned that as more abnormal children are prevented through abortion and testing, we’ll be less tolerant of abnormality,” said Dr. Alan R. Fleischman, a bioethicist and senior vice president of the New York Academy of Medicine in Manhattan. “We’ll blame families if they knew there would be an abnormal child but chose not to abort.” (Angier 1997)

## Normalization and Separation Surgery

In her book, *One of Us*, Alice Domurat Dreger writes that anatomy matters because it influences the assumptions people make on the basis of our anatomies. “The truth is, most of us go through minor anatomical ‘normalization’ procedures every day, changing our bodies ever so slightly to fit the identity we wish to present socially.” (Dreger 2004, p.3) People with unusual anatomies do not easily fit into standard categories of anatomy and identity, and they test the limits of our understanding of who we are as an individual human being.

According to Dreger, normalization of our children occurs in many ways, ranging from teaching simple manners to rebuilding the genitalia of child. Parents genuinely want the best for their children. “When a child is born with an unusual and potentially stigmatized anatomy, the parents’ desire to normalize that child can be especially strong. Parents also tend to see nearly everything anatomical as a medical issue. Weight, hyperactivity, circumcision, menopause, depression, birth, death—all of these things, for better or worse, have come to be seen primarily as individual medical issues. In this context a child with an unusual anatomy seems to be a child, who, regardless of her actual health, is first and foremost in need of a doctor to “cure” her.” (Dreger 2004, p.55-56)

Historically, many conjoined twins who remained joined lived long lives. Chang and Eng Bunker, the original Siamese twins, lived to be 63-years-old and together fathered 22 children(!). Both conjoined twins, Millie-Christine McKoy and Daisy and Violet Hilton, lived to be 61-years-old.

Despite the appearance of unusual anatomy, the actual health of these conjoined twins was good. On the contrary, separation surgeries of conjoined twins bring high costs and risks, often requiring many follow-up surgeries and procedures, and may not even make the child look “normal”. Sometimes the child’s actual health may even decline, and occasionally the surgeries may result in death. There can also be significant psychological damage from being separated from “the other half”.

Because many separation surgeries are performed on infant conjoined twins, it is usually the parents who make these decisions. According to Dreger, in 2003 Ladan and Laleh Bijani of Iran were the first twins in history to consent to be separated. The Bijani sisters were craniopagus, which means they were joined near the top of the head. They were well-educated women who lived conjoined for twenty-nine years. Despite recommendations from physicians who deemed the surgery to be too dangerous, the sisters pursued the surgery aggressively. The sisters finally found a doctor in Singapore who was willing to perform the surgery. The neurosurgeon, Dr. Goh, repeatedly tried to talk the women out of having the surgery, but ultimately, he consented to perform the separation. Dr. Goh was reported to have said, “....to give these girls some measure of a decent, normal life as we know it.” (Dreger 2004, p.42) Sadly, the operation failed and both sisters died after fifty hours. Dr. Goh told the press, “At least we helped them achieve their dream of separation.” (Dreger 2004, p.42)

The Bijani case raised ethical questions about whether doctors should allow patients to undergo such risky procedures. The Bijani twins had asked doctors to proceed with the separation surgery even after they were warned that there was at least a 50 percent chance that one or both of them would die or suffer severe brain damage. Alireza Safaian, the twins’ adoptive father, said, “They were victims of a big propaganda in Iran and Singapore. They were used as laboratory mice.” He also said the twins had led normal lives before the surgery, having lived alone, done their own shopping, and cooked for as many as 20 guests. (Arnold and Grady 2003) The definition of “normal life” was clearly very different: the physician interpreted separation as a normal life and tried to give it to them, and the father of the twins claimed that they already had normal lives. This prompts us to ask: What is “normal” life then? Also, how do we interpret the sisters’ decision to be separated even though there was a high risk for death or severe brain damage? The media lauded the sisters’ heroism and bravery, and the physician’s willingness to follow his patients’ wishes was applauded. But, the Bijani sisters’ choice to be separated was radically different from other conjoined twins. “Indeed, many conjoined twins often explicitly say they do not want ever to be separated, since this would result in a profound change of identity or the death of a twin’s other half.” (Dreger 2004, p.43)

### **More Questions Than Answers**

Do we pay as much attention to conjoined twins who choose to remain joined? Do we accept those twins who remain joined, or do we condemn them for not wanting to be separated to pursue a “normal” life? Most importantly, do healthcare professionals seriously pay attention to the claims made by conjoined twins who choose to remain joined? Our view on independence and normal life needs to be altered when we consider the lives of conjoined twins. “In the United States, conjoinment might be especially challenging because American

culture equates individualism with independence, and interdependence with weakness.” (Dreger 2004, p.31)

### **Consider This.....**

Here is an interesting idea on normalcy that made me think twice about the social construction of what “normal” means. Jonathan Glover, author of *Choosing children: The ethical dilemmas of genetic intervention*, describes a blurred boundary in flux between normality and disability. “If a widespread mutation (or widespread use of genetic engineering) gave most people wings, those of us unable to fly might start to count as disabled.” What counts as “normal” today may change tomorrow, depending on the numerical and the normative. “Its possession by a reasonable sized group is needed if something is to count as normal functioning. The central idea seems to be that of a benchmark of human potentiality, demonstrated by some sizeable past or present population.” (Glover 2006, p.12) We never think of ourselves as disabled because we don’t have wings. If we were to be surrounded by people with wings or any other extra functions (think super-humans) in the future, would we feel disabled and disadvantaged, and even discriminated against?

In an article written by David Wasserman in *Cutting to the Core: Exploring the Ethics of Contested Surgeries*, the author imagines the lives of Chang and Eng in our present time. “Had Chang and Eng been born in contemporary Thailand, they might well have enjoyed a different, lesser celebrity than they in fact did. Instead of being displayed to the king of Thailand and then taken on tour, they might have been flown to Johns Hopkins Hospital for highly publicized surgery by an entrepreneurial star like Benjamin Carson. Or perhaps, given the fairly easy surgical challenge they posed, they would have been separated by a less celebrated surgeon in a more obscure hospital, perhaps even in Thailand.” (Wasserman 2006, p.136)

### **Perfectly Cheerful in Their Strangely Blended Condition**

While researching historical descriptions about conjoined twins, I found many documents written by doctors. In the 1867 book, *Medical Description of the Two-Headed Girl*, there were accounts of how well these sisters were adjusted to living as conjoined twins, and it also said that they did not wish to be separated. “They seem perfectly cheerful in their strangely blended condition; declare that they know of no inconvenience resulting from it, and protest that they would be unhappy if they were separated, were such a thing possible.” The title of this installation comes from this phrase, *perfectly cheerful in their strangely blended condition*. This phrase reflects the contradiction between what we as “singletons” imagine the lives of conjoined twins must be like in contrast with actual observation of their lives. Ironically, the title still bears observation by others and not the actual voices of conjoined twins. This reminds us that we must create space for conjoined twins to be heard in our society.

## Artist Statement

### ***Perfectly Cheerful***

Mineral pigment (iwaenogu) on Japanese paper (mashi) over panels, typed text on found paper, mineral pigment on BFK Rives paper. Size variable. 2008—2009.

The title ***Perfectly cheerful*** derives from the text in the *Medical Description of the Two-Headed Girl* from 1867. The editor of the *Daily Evening Bulletin* of Philadelphia described the conjoined twins attitudes in “their strangely blended condition.” The entire text from the same book was typed on the found old paper, representing the voice of cultural authority and medicine. In response to these voices, the verses of the two-headed girl; Millie Christine are also included in this installation.

All the figures of conjoined twins are based on historical documentation including one of the earliest printed illustration of conjoined twins from *Carmen heroicum de partu monstriifero* by Jacob Locher (1471–1528), to more recent conjoined twins, Yvonne and Yvette McCarther, a craniopagus (joined at the head) born in 1949. I often visited the American Antiquarian Society in Worcester, Massachusetts for my research on sideshow people and people with unusual anatomies. While conducting my research at the American Antiquarian Society, I was also able to find the original *carte de visites* of many sideshow characters collected by an antiquarian named Nathaniel Paine (1831–1917).

In this installation, small paintings of conjoined twins fill one wall. Their unique shapes are made more distinct by their graphic and abstract presentation. Patterns, dots, and occasionally flowers and roots inhabit their bodies; sometimes depicting romantic views on conjoinment and sometimes suggesting separate individuality. On the other wall, the drawing of a skeleton of conjoined twins reminds us of that many conjoined twins were intensely studied throughout their lives and even after their death.

### **Acknowledgements**

For two years I have been collecting images of sideshow people. A year ago, an artist friend of mine suggested that I visit the American Antiquarian Society in Worcester, Massachusetts, to see their collection on sideshow people. I was very excited when I first saw Nathaniel Paine’s scrapbook of various sideshow characters, and many other circus and sideshow related documents. I am grateful for the resources and helpful guidance provided by the American Antiquarian Society. I am also thankful to Sue Johnson for suggesting that I visit the Society. Andrew Mroczek, a curator at the Art Institute of Boston, forwarded me some links to helpful websites, including Morbid Anatomy. And I am especially grateful for the book, *One of Us* by Alice Domurat Dreger. I only just read this book a month ago when I was getting close to finishing the paintings for this installation. I was very excited to read the book, and found Dreger’s narrative to be the most articulate text on this topic. Much of what Dreger wrote

echoed my own feelings about conjoined twins and the many issues surrounding their placement in our society and history.

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