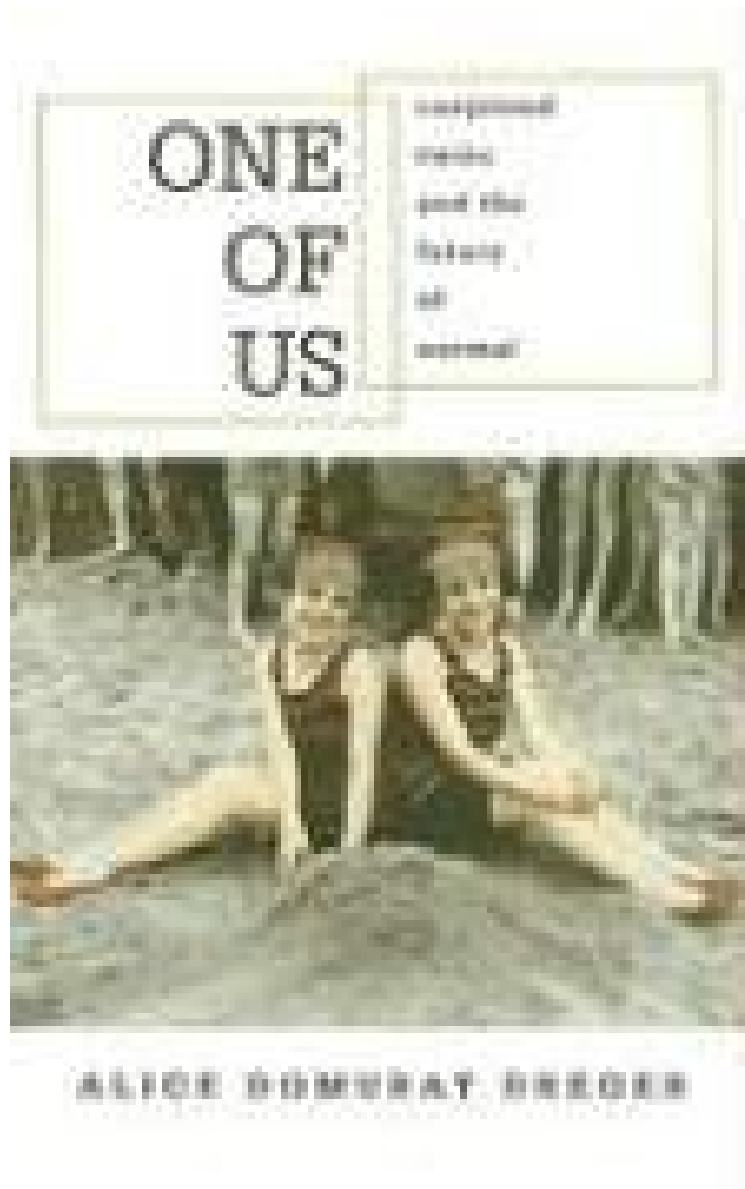


[FREE] One of Us: Conjoined Twins and the Future of Normal

## One of Us: Conjoined Twins and the Future of Normal

*Alice Domurat Dreger*  
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**Alice Domurat Dreger** : **One of Us: Conjoined Twins and the Future of Normal** before purchasing it in order to gage whether or not it would be worth my time, and all praised One of Us: Conjoined Twins and the Future of Normal:

7 of 7 people found the following review helpful. TrifectaBy Aurora GraceDreger hit the trifecta here. Her book was

informative, thought-provoking, and engaging. The pages are filled with anecdotes of the lives of conjoined twins throughout history, the decisions they've made and the lifestyles they've lived. It offers up some fascinating questions of morality. My favorites were these three: (1) Why do many people consider it wrong to exploit conjoined twins by putting them on display for their unusual bodies? Isn't that exactly what we do in the modeling industry? (2) Why is there this pervasive theory that conjoined twins should offer up their bodies for the advancement of medicine? Doctors usually don't offer proper monetary compensation to twins or their families for access to the corpses of twins or for hordes of medical students to watch separation surgeries take place. Isn't this sense of entitlement, in a sense, worse than offering payment? (3) Under what circumstances would it be morally acceptable to sacrifice one twin for the sake of the other twin's well-being? It examines the idea of disability versus differences, and whether performing normalizing surgery is really a healthier course of action than becoming more adaptive and accommodating to one another's differences as a society. This book was well-researched, and I kept telling my boyfriend about the stuff I was reading in the book, asking his opinion on philosophical questions and saying "Hey, did you know that ...?" I highly recommend this book. 4 of 4 people found the following review helpful. fascinating read By HTCI really enjoyed this book. Though slightly outdated, (for example, conjoined twins Abby and Brittany Hensel are no longer children... they're twenty-somethings with a reality show and an elementary school teaching job), the book is still fascinating and relevant. I was taken by comparisons between society's common over-enthusiasm for separating conjoined twins (often creating two disabled or even dead individuals in separate bodies instead of two often otherwise healthy individuals in one body) and society's misguided need to "fix" the genitals of babies born with unusual genitalia (leading to adults who often have lower sexual feeling and who are sometimes made into a gender that feels wrong...) I hope the author updates this book to account for some of the stories of conjoined and separated twins featured on TLC and the former Discovery Channel in recent years... 0 of 0 people found the following review helpful. More Than Data, One of Us Tells How Twins Live as One By Al Oickle Author Dreger gives an informative, yet at once scholarly, understanding of the human entrapment that is conjoined twins.

Must children born with socially challenging anatomies have their bodies changed because others cannot be expected to change their minds? One of Us views conjoined twinning and other "abnormalities" from the point of view of people living with such anatomies, and considers these issues within the larger historical context of anatomical politics. Anatomy matters, Alice Domurat Dreger tells us, because the senses we possess, the muscles we control, and the resources we require to keep our bodies alive limit and guide what we experience in any given context. Her deeply thought-provoking and compassionate work exposes the breadth and depth of that context--the extent of the social frame upon which we construct the "normal." In doing so, the book calls into question assumptions about anatomy and normality, and transforms our understanding of how we are all intricately and inextricably joined.

From Publishers Weekly Analyzing case studies past and present, Alice Domurat Dreger, an associate professor of science and technology at Michigan State, questions assumptions about anatomical norms in a solemn and politically passionate exploration of separation surgery on conjoined twins. Providing historical and contemporary evidence that most adult conjoined twins do not desire to be separated, and that many surgeries are carried out on children too young to object, Alice Domurat Dreger voices distaste for Americans' failure to tolerate anatomical difference and instead fetishize individualism at all cost. Making ample use of her previous study of hermaphrodites, she likens separation surgery to reconstructive surgery on the sexually ambiguous genitalia of "intersex" children. Both types of surgery, she argues, share the dubious social rather than strictly medical goal of making such children appear more "normal." Aided by statistics that bespeak a high mortality rate, Alice Domurat Dreger mines cases of separation surgery around the world for the rational and ethical flaws in medical decision making, building a strong case against intervention. At the heart of her moral questioning is suspicion of the institutions involved, and of parents who may be motivated more by ill-conceived feelings about normality than by rational consideration for the children's futures. This pithily provocative critique of medical paternalism and society's blind spots vis--vis anatomical standards provides a valuable opportunity to ponder the high-profile surgeries on conjoined twins that most of us know only through the news headlines we habitually fail to question. 13 illus. Copyright Reed Business Information, a division of Reed Elsevier Inc. All rights reserved. From The New Yorker Part history of medicine, part consciousness-raising freak show, this surprisingly entertaining book examines cultural reactions to conjoined twins and other anatomical anomalies. Dreger argues that Victorians were more appreciative than moderns of people born "different," viewing them as "authorities on a unique and strangely attractive experience." Nowadays, pediatric surgeons so prize normalcy that they perform sexual surgery on infants without concern for adult function; they may also withhold information from parents, and even override their consent, when dealing with birth defects. Dreger sometimes strays into lit-crit goofiness for her, conjoined twins call to mind every "crazy-in-love" song you've ever heard but her examples persuasively make the case that the anatomically different feel normal to themselves. Copyright 2005 The New Yorker From The New England Journal of Medicine "Why not change minds instead of bodies?" asks Alice Domurat Dreger in her new book in reference to people who are born with bodies different from those of us who consider ourselves normal. Her primary subject is

conjoined twins, one of the most extreme examples, but she also brings into the story people with cleft lips, dwarfs, giants, and hermaphrodites. Since we cannot conceive of being willing to live with these abnormalities, we usually think that such conditions should be fixed by modern medicine, if possible. That, says Dreger, is the problem. Normalization procedures may sometimes be the best choice, but they are not the only option. Many people with unusual anatomies are completely comfortable with their bodies and derive their personal identities from them. It is the discomfort of their families and communities that most often exerts the pressure to change them. (Figure) Conjoined twins are in some ways the most urgent issue to confront, since high-risk separations are more often life-or-death situations than are other corrective procedures. Dreger understands the reasons for such separations, especially the fact that modern medical techniques have made them possible and usually successful, but she challenges our idea of what constitutes success. She finds it is often limited to the brief survival of one or both twins or subjecting survivors to years of hospitalizations and surgeries. Separations that require the deliberate sacrifice of one child in order to increase the viability of the other also force us into extremely difficult ethical decisions. To support her case for alternatives, Dreger looks at present-day and historical conjoined twins who have lived to adulthood. She finds that they all, with one recent exception, would not want to be separated even if they could be. Dreger makes telling analogies between people with these conditions and those whose "different" anatomies provoked discrimination in the past -- women, blacks, and homosexuals. In these instances, it was society's attitude that changed, and Dreger would argue that the same change could occur in the way we think and feel about the "differently bodied." She sees hopeful signs that this process is beginning. Documentaries and even tabloid-television talk shows that allow audiences to see how these people live and hear them speak for themselves can serve as sources of empowerment, rather than exploitation. Medical schools are inviting people with these conditions to talk to medical students about disability and difference. Families can be helped to adjust to a "different" child and encouraged to postpone some treatments until the child is old enough to participate in the decision. Long-term follow-up studies of corrective surgeries, although still too few, have made some physicians wary of routinely proceeding with normalization procedures "at all costs," because in some cases practitioners now see the costs as too high. Discourse on disability is a growing phenomenon in academia and in the popular press, but Dreger's book stands out for her extensive use of both historical literature and the current media. More important, she draws on her personal relationships with many of the people she writes about and even her experience as a relatively new mother. She believes that our ignorance about the differently bodied is often the biggest impediment to their ability to lead happy and productive lives, and she provides ample reasons to ask ourselves the question "Why not change minds instead of bodies?" Gretchen Worden, B.A. Copyright 2004 Massachusetts Medical Society. All rights reserved. The New England Journal of Medicine is a registered trademark of the MMS.