RECORD NOS. 13-2178(L), 13-2182, 13-2183

IN THE UNITED STATES COURT OF APPEALS FOR THE FOURTH CIRCUIT

M.C., a minor by and through his parents Pamela Crawford and John Mark Crawford, parental natural guardian Pamela Crawford, parental natural guardian John Mark Crawford

Plaintiff-Appellee

v.

DR. JAMES AMRHEIN, DR. IAN AARONSON; DR. YAW APPIAGYEI-DANKAH; KIM AYDLETTE; MEREDITH WILLIAMS; CANDICE DAVIS, a/k/a/ Candi Davis; MARY SEARCY; DOE 1, Unknown South Carolina Department of Social Services Employee; DOE 2, Unknown South Carolina Department of Social Services Employee; DOE 3, Unknown South Carolina Department of Social Services Employee

Defendants-Appellants

ON APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF SOUTH CAROLINA
AT CHARLESTON

AMICUS CURIAE BRIEF IN SUPPORT OF THE PLAINTIFF-APPELLEE M.C. FOR AFFIRMANCE OF THE DISTRICT COURT DECISION

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UNITED STATES COURT OF APPEALS FOR THE FOURTH CIRCUIT
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No. 13-2178L Caption: M.C. v. James Amrhein, et al.

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AIS-DSD Support Group
(name of party/amicus)

who is Amicus, makes the following disclosure:
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1. Is party/amicus a publicly held corporation or other publicly held entity? ☐ YES ☑ NO

2. Does party/amicus have any parent corporations? ☐ YES ☑ NO
If yes, identify all parent corporations, including grandparent and great-grandparent corporations:

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If yes, identify all such owners:

4. Is there any other publicly held corporation or other publicly held entity that has a direct financial interest in the outcome of the litigation (Local Rule 26.1(b))? ☐ YES ☑ NO
If yes, identify entity and nature of interest:

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If yes, identify any publicly held member whose stock or equity value could be affected substantially by the outcome of the proceeding or whose claims the trade association is pursuing in a representative capacity, or state that there is no such member:

6. Does this case arise out of a bankruptcy proceeding? ☐ YES ☑ NO
If yes, identify any trustee and the members of any creditors' committee:

Signature: /s/ Suzanne B. Goldberg Date: April 9, 2014

Counsel for: AIS-DSD Support Group

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I certify that on April 9, 2014 the foregoing document was served on all parties or their counsel of record through the CM/ECF system if they are registered users or, if they are not, by serving a true and correct copy at the addresses listed below:

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I hereby certify that on April 9, 2014, the foregoing document was served on all parties or their counsel of record through the CM/ECF System if they are registered users, or if they are not, by serving a true and correct copy at the addresses listed below:

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STATEMENT OF INTEREST

AIS-DSD Support Group is a national nonprofit organization comprised of intersex individuals, parents of intersex children, and medical professionals who work together to promote better lives and informed decision-making for hundreds of intersex people and their families. The group, which is dedicated to helping people living with Androgen Insensitivity Syndrome (AIS) and other Disorders of Sex Development (DSD), offers resources about medical diagnoses and scientific advancements, educational programs for health care providers and therapists, an annual international conference for intersex people and their parents and families, informational newsletters, and a forum for helping its constituents connect with other intersex individuals, parents of intersex children, and medical professionals.

AIS-DSD Support Group also endeavors to educate the public and promote understanding and acceptance of intersex individuals who live with diverse sex characteristics. As intersex individuals, parents of intersex individuals, and medical professionals, AIS-DSD Support Group possesses both professional and personal expertise regarding the issues related to intersex children that are central to the case before this Court.[1]

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[1] No counsel for a party authored this brief in whole or in part, and no counsel or party made a monetary contribution intended to fund the preparation or submission of this brief. No person other than *Amicus*, its members, or its counsel made a monetary contribution to its preparation or submission.

SUMMARY OF ARGUMENT

When a baby is born with an intersex condition, parents and doctors cannot readily identify the child as male or female. In the past, doctors sometimes recommended surgery to change the appearance of a child's genitals, even though an intersex condition does not typically present any medical threat to the child's health. Although these doctors may have thought they were aiding parents who initially found their child's intersex condition alarming, there was never evidence that parents had difficulty accepting or bonding with their intersex children.

Instead, medical practitioners have recognized the assumption that intersex babies need "correction" as outdated and demonstrably damaging. The problem is that this irreversible surgery is known to cause intersex persons extensive physical and psychosocial harm, including infertility, depression, and diminished or lost capacity for romantic relationships and sexual pleasure. Moreover, when this surgery is performed during infancy or early childhood, there is a heightened risk that surgeons will "assign" the wrong sex, because it is not possible to determine whether intersex infants will identify as male or female as they mature. Consequently, medical experts and intersex individuals have long recommended that any contemplated cosmetic genital surgery be postponed until a child is old enough to participate in the decision.

ARGUMENT

I. Intersex Is a Condition in Which a Person's Anatomy at Birth Does Not Fit the Typical Definition of Female or Male.

Intersex is a collective term describing a spectrum of conditions; infants born intersex may have physical, genetic, or chromosomal characteristics that vary from the typical conceptions of female and male. *See* N.R. Maharaj et al., *Intersex Conditions in Children and Adolescents: Surgical, Ethical, and Legal Considerations*, 18 J. Pediatric Adolescent Gynecology 399 (2005).

The medical community estimates that the prevalence of intersex conditions is approximately one in 2,000 live births. Catherine L. Minto et al., *The Effect of Clitoral Surgery on Sexual Outcome in Individuals who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study*, 361 Lancet 1252, 1252 (2003). This means that intersex differences occur more frequently than cystic fibrosis, a well-known autosomal recessive disease that affects 1 in 3,500 American infants. *See* Cystic Fibrosis Found., http://www.cff.org/aboutcf/.

In most cases, intersex conditions do not directly threaten the child's health and do not require immediate surgery.[2] *See* Ida Ismail & Sarah Creighton, *Surgery for Intersex,* 5 Reviews Gynaecological Practice 57, 62 (2005) ("[V]aginal surgery can be deferred until later in life in the majority of cases."). In fact, as one urologist

[2] Some intersex conditions correlate with medical complications that do require surgical treatment. *See* Ismail & Creighton, *supra*. But cosmetic genital surgery is never necessary.

observed, nearly two decades ago doctors were already starting "to realize that [performing genital surgery on infants] may be potentially devastating." Justine Schober, *Early Feminizing Genitoplasty or Watchful Waiting*, 11 J. Pediatric Adolescent Gynecology 151, 155–56 (1998).

When surgery is performed, estimates show that in ninety percent of cases, doctors alter intersex infants' genitalia to appear female (albeit imperfectly, as discussed below) because it is less expensive and less invasive to remove a penis and build a vagina than it is to remove female reproductive organs. *See* Nancy Ehrenreich & Mark Barr, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices*,*"* 40 Harv. C.R.–C.L. L. Rev. 71, 105 (2005).

II. Performing Irreversible Cosmetic Genital Surgery on an Infant Causes Long-Term Physical and Psychosocial Harms, with No Evidence of Benefit to the Child.

A. Genital Surgery on Infants Causes Physical Harms, Including Scarring, Sexual Dysfunction, and Infertility.

The process of altering a child's genitals usually involves multiple invasive surgeries. *See* Maharaj et al., *supra*, at 400. An average of three to five surgeries during childhood is typical, and some children endure more than twenty. Ehrenreich & Barr, *supra*, at 105. These surgeries often persist into puberty. *Id*. at 107; *see also* Sarah Creighton & Catherine Minto, *Managing Intersex: Most*

Vaginal Surgery in Childhood Should be Deferred, 323 BMJ [formerly Brit. Med. J.] 1264, 1265 (2001) ("Recent work has shown that most children undergoing vaginoplasty will require another operation to permit use of tampons and sexual intercourse."). For each one of these surgeries, the child bears the risks inherent to any surgical procedure.

In addition, the procedures are painful, can create scarring of the genitals, and often result in genitals that do not have typical appearance or function. *See* Katrina Karkazis, Fixing Sex: Intersex, Medical Authority, and Lived Experience 133 (2008). Other serious medical consequences associated with cosmetically-altered genitals include, for example, abnormal narrowing of the vaginal opening and loss of genital sensitivity. Suzanne J. Kessler, Lessons from the Intersexed 56–57, 60–64, 72–73 (1998).

Moreover, loss of fertility or loss of potential fertility often results from this type of genital surgery. In many cases, intersex people born with penises have the capacity to reproduce as males. Alice Domurat Dreger, *"Ambiguous Sex"—or Ambivalent Medicine?*, 28 Hastings Ctr. Rep. 24, 28 (1998). In addition, where an aspect of the intersex condition impedes fertility, medical treatment later in life may allow for full reproductive function. *Id*. But when doctors remove functional genital tissue, as they typically do when remodeling the appearance of an intersex person's genitals, they often irreversibly terminate that person's reproductive

capacity. *Id.*; *see also* Schober, *supra*, at 155 ("Removing gonads may deprive fertility potential . . . .").

Diminished or lost capacity for sexual pleasure is another serious physical harm resulting from feminizing genital surgery. *See, e.g.*, Minto et al., *supra*, at 1256 ("[I]ndividuals who have had clitoral surgery are more likely than those who have not to report a complete failure to achieve orgasm and higher rates of non-sensuality."). Scar tissue, interference with delicate nerves, and the removal of certain tissues can all impede genital sensation and sexual function. *See* Kessler, *supra*, 56–57, 60–64, 72–73; *see also* Creighton & Minto, *supra*, at 1265 ("[A]ny surgery to the clitoris, which risks vascular, anatomical, or neurological compromise, could alter sexual response.").

B. Genital Surgery on Infants Can Also Cause Psychosocial Harms Ranging from Shame and Distrust to Depression and Trauma.

In addition to negative physical consequences, intersex children who have undergone cosmetic genital surgery endure a range of serious psychological and social harms.

There is ample evidence that subjecting children to constant examination and manipulation of their genitals, which is necessary for surgeons to complete the alteration process, increases feelings of shame and humiliation. *Cf.* Ehrenreich & Barr, *supra*, at 107. Further, there is *no* evidence that surgery leads to better

psychosocial outcomes and results in a more "typical" childhood, as some earlier proponents of surgery had maintained. *See* Minto et al., *supra*, at 1252.

The psychological harms resulting from childhood genital alteration continue into adulthood. For one, because this surgery is irreversible, an intersex individual whose altered anatomy does not match his or her gender identity cannot undergo further reconstructive surgery to correct the doctors' mistake. *See* Ehrenreich & Barr, *supra*, at 105. This dissonance between gender identity and anatomy caused by the surgery can result in additional, long-term psychosocial problems. *See generally* Julie Greenberg, *Defining Male and Female: Intersexuality and the Collision between Law and Biology*, 41 Ariz. L. Rev. 265 (1999). Yet even when doctors perform surgery that turns out to be consistent with the intersex person's gender identity, the individual may continue to experience feelings of deceit, betrayal, and outrage as an adult. *See* Creighton & Minto, *supra*, at 1265 ("Some articulate feelings of anger, distrust, and betrayal directed towards their doctors and families.").

For many intersex people, childhood surgeries thus elevate their risk of depression and other psychosocial difficulties.

> Too many patients I encountered who had been surgically . . . managed . . . did not behave as they were supposed to behave: they became quite isolated at puberty; they did not integrate successfully into society as adults, comfortably assuming their assigned gender identities/roles; they were estranged from their families; they did not

> pair-bond; they were not happy with the outcomes of their surgeries; their sexual functioning was severely impaired . . . .

Schober, *supra*, at 155 (quoting Dr. Martin Malin, a psychotherapist).

Difficulty forming romantic relationships is another harm from genital alteration surgery. One study found that intersex individuals who have undergone feminizing surgery overwhelmingly report a lack of enjoyment in sensual affection with their partners. *See* Creighton & Minto, *supra*, at 1252 ("Of the 39 individuals enrolled . . . 18 women who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than did the ten who had not had surgery (20%).").

Further, children who undergo cosmetic genital surgery experience many of the same types of trauma as children who are sexually abused. *See* Tamara Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse*, Intersex Soc'y N. Am., (1997), http://www.isna.org/articles/analog.html. The effects of the surgery are analogous to those of sexual abuse because of the secrecy and shame of being forced to have one's genitals periodically examined. *Cf*. Ehrenreich & Barr, *supra*, at 107–08. In some cases, doctors have even masturbated young intersex boys to check post-surgical penile function or forced dilations of young intersex girls' surgically constructed vaginas. *Id*.

III. Medical Experts and Intersex People Recommend Postponing Surgery Until the Child Can Participate in the Decision.

A. Because the Surgery is Irreversible, the Child's Participation is Essential to Avoid Sex-Assignment Errors and Other Long-Term or Permanent Harms.

Leading medical experts recommend that doctors who contemplate providing surgery postpone that decision rather than performing unnecessary, irreversible sex-assignment surgery on intersex infants. *See* Consortium on the Mgmt. of Disorders of Sex Differentiation, Clinical Guidelines for the Management of Disorders of Sex Differentiation in Childhood 20 (2005) [DSD Clinical Guidelines]; *see also* Peter A. Lee et al., Am. Acad. Pediatrics, *Consensus Statement on Management of Intersex Disorders*, Pediatrics 118 (2006) [Am. Acad. Consensus Statement] (recommending postponing certain procedures until a child is old enough to participate in the decision).

These experts agree that an intersex patient's participation in the decision to undergo surgery to change the appearance of the patient's genitals is paramount. *See* DSD Clinical Guidelines, *supra*, at 29 ("Healthy, functioning gonadal tissue should remain in place unless the patient, fully advised of risks and options, requests it be removed."); *see also* Am. Assoc. Pediatrics Comm. on Bioethics, *Informed Consent, Parental Permission and Assent in Pediatric Practice*, 95 Pediatrics 314, 315 (1995) (urging medical practitioners to prioritize gaining a child's assent to medical treatment, even if this means delaying non-urgent

treatment); Am. Acad. Consensus Statement, *supra*. While doctors have not specified a particular age when a child might participate in this decision, they recommend a formal assessment of a child's cognitive status to assist in determining the extent to which a child is capable of taking part in the decision-making process. *See* DSD Clinical Guidelines, *supra*, at 29.

Intersex people express similarly strong preferences to make their own decisions about their bodies and, in particular, the appearance of their genitals. Many intersex individuals report resentment that doctors performed irreversible operations on them before they could choose whether to undergo surgery. *See* Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics & The Law*, 11 Annals Health Law 195, 213–14 (2002). David is one such intersex person who expresses resentment that doctors reconstructed his genitals during his infancy before he could decide what was best for himself:

> What is done to these children, what was done to me, is legally and scientifically sanctioned traumatic sexual abuse. We are sexually traumatized in dramatically painful and terrifying ways . . . [and] this trauma is carried out by trusted authorities...and against our will, as we are incapable of understanding "choice" as a helpless infant.

David, *I Am Not Alone!*, Hermaphrodites with Attitude, Winter 1994, at 4, *available at* http://www.isna.org/files/hwa/winter1995.pdf.

Additional anecdotal evidence reinforces this view that intersex individuals should be able to decide themselves whether to have surgery to alter their genitals.

See, e.g., Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 Berkeley J. Gender L. & Just. 59, 70 (2006) (noting that intersex people who have spoken out have made it "resoundingly clear" they believe the decision to undergo cosmetic genital surgery should be made by the individual); *see also* Eli Nevada, *Lucky to Have Escaped Genital Surgery*, Hermaphrodites with Attitudes, Fall/Winter 1995-96, at 6, *available at* http://www.isna.org/files/hwa/winter1996.pdf ("As an intersexual who has been fortunate enough to escape surgery . . . I cannot see how my life would have been improved in the least by genital surgery."). Intersex individuals whose gender identity aligns with their surgically constructed genitals have likewise indicated that they would have preferred to have chosen whether to undergo cosmetic genital surgery at all. *See* Hermer, *supra*, at 213–24.

Strikingly, all intersex people who have spoken publicly about cosmetic genital surgery have expressed opposition to it. *See, e.g.*, Emily Greenhouse, *A New Era for Intersex Rights*, New Yorker Online Newsdesk, (Dec. 30, 2013), http://www.newyorker.com/online/blogs/newsdesk/2013/12/a-new-era-for-intersex-rights.html; *see also* Marcus de María Arana, San Francisco Human Rights Comm'n, A Human Rights Investigation into the Medical "Normalization" of Intersex People (2005); Barron H. Lerner, *If Biology is Destiny, When Shouldn't It Be?*, N.Y. Times (May 27, 2003), *available at*

http://www.nytimes.com/2003/05/27/health/behavior-if-biology-is-destiny-when-shouldn-t-it-be.html.

By contrast, there is no record of any intersex person publicly expressing satisfaction with the results of cosmetic genital surgery. *See* Greenhouse, *supra*, ("I don't know one intersex individual who is happy with the treatment they have received from physicians . . . not one." (quoting Howard Devore, a clinical psychologist)); *see also* de María Arana, *supra* (noting that a leading proponent of surgery on intersex children has been unable to produce any statements from patients satisfied with cosmetic genital surgery); Lerner, *supra* ("I have yet to read about, hear or meet an intersex person who is grateful for surgery done on them as an infant." (quoting Dr. Monica J. Caspar, sociologist and former Director of the Intersex Society of North America)).

That no intersex person has spoken publicly in favor of cosmetic genital surgery is especially telling as the internet provides ample opportunity to speak to a wide audience publicly and anonymously. Instead, intersex people have risked stigma and relived painful memories to come forward and condemn these invasive surgical changes to their genitals. *See generally* de María Arana, *supra*; *see also* Greenhouse, *supra*; Zoran Stefanovic, Hermaphrodites Speak 1996, YouTube, https://www.youtube.com/watch?v=VMER3_nxlN0 (published June 5, 2013). Presumably, intersex people who believe cosmetic genital surgery improves lives

would come forward in a similar manner. However, to amicus's knowledge, no intersex person has done so.

B. Postponing Surgery Preserves the Child's Medical and Social Options and Has Not Been Shown to Cause Harm.

Postponing surgery benefits an intersex child because it ensures that all medical and surgical options are available after gender identity has manifested. This matters because, as noted earlier, there is no guarantee that an intersex child will adopt his or her surgically-assigned gender. Some intersex children do not. *See, e.g.*, Chanika Phornphutkul et al., *Gender Self-Reassignment in an XY Adolescent Female Born with Ambiguous Genitalia*, 106 Pediatrics 135 (2000); *see also* Melissa Hendricks, *Into the Hands of Babes*, Johns Hopkins Magazine, Sept. 2000. If an intersex person's gender identity does not match the surgically-constructed genitals, then he is a male who has female genitals, or vice versa. Because these surgeries are not reversible or correctible, a person's genitals cannot be realigned later with the person's gender identity. In addition to this fundamental reason for postponing surgery well past infancy, the individual who ultimately opts for surgery benefits from surgical advances that emerge during the intervening period.

Further, all available evidence shows that an intersex person who forgoes cosmetic genital surgery does not suffer physical or psychological harm. *See* DSD Clinical Guidelines, *supra*, at 28. Indeed, intersex individuals who have publicly

addressed their decision not to undergo surgery have been outspoken about their satisfaction with their bodies and their lives. *See, e.g.*, Hermaphrodites Speak, *supra*; Nevada, *supra*; de María Arana, *supra*, at 32; Cheryl Chase, *What is the Agenda of the Intersex Patient Movement?* 13 Endocrinologist 240, 241 (2003).

IV. The United Nations and the Parliamentary Assembly of the Council of Europe Denounce Cosmetic Genital Surgery as a Human Rights Violation and Call for Its End.

The United Nations (UN) and the Parliamentary Assembly of the Council of Europe (PACE) have both denounced and called for the end of cosmetic genital surgery; they consider it to be a human rights violation that infringes an intersex person's right to bodily autonomy.[3] Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1, 8–9, 23, Human Rights Council, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013) (by Juan E. Méndez);

[3] The Swiss National Advisory Commission on Biomedical Ethics agrees that performing cosmetic genital surgery on children runs counter to their welfare. The Commission urges doctors not to perform this irreversible elective surgery until the person being treated can decide the treatment him or herself. Swiss National Advisory Commission on Biomedical Ethics, *On the Management of Differences of Sex Development: Ethical Issues Relating to Intersexuality*, Opinion No. 20/2012 (2012). A recent Australian Senate report also agrees that medical treatment of intersex people should be managed within a human right framework and recommends postponing surgery until an intersex person decides the course of treatment himself. Australian Senate Community Affairs References Committee, *Involuntary or coerced sterilisation of intersex people in Australia*, Oct. 25, 2013, *available at* http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index.

Parliamentary Assembly of the Council of Europe, Children's Right to Physical Integrity, Resolution 1952 (2013).

When a doctor performs an intrusive and irreversible medical procedure that serves no medical purpose without the free and informed consent of the patient, this "may constitute torture and ill-treatment." United Nations Committee Against Torture, General Comment No. 2, CAT/C/GC/2 (2007). As such, the UN considers sex-assignment genital surgery to be a form of health-care abuse tantamount to torture and other cruel, inhuman, or degrading treatment and calls for the repeal of any law that permits doctors to perform these intrusive and irreversible treatments without the free and informed consent of the person concerned. *See* UN Torture Report, *supra*, at 1, 8–9, 18–19, 23. PACE similarly directs European Union member states to ensure that no intersex child undergoes cosmetic genital surgery. *See* Parliamentary Assembly of the Council of Europe, *supra*.

CONCLUSION

For the foregoing reasons, AIS-DSD Support Group respectfully requests that this Court affirm the district court's denial of the defendants' motion to dismiss.

Respectfully submitted,

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UNITED STATES COURT OF APPEALS FOR THE FOURTH CIRCUIT

No. 13-2178L **Caption:** M.C. v. James Amrhein, et al.

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I hereby certify that on April 9th, 2014, the foregoing document was served on all parties or their counsel of record through the CM/ECF System if they are registered users or, if they are not, by serving a true and correct copy at the addresses listed below:

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