

## **The Dex Diaries, Part 9: The Real Silent Majority**

*A legal advocate speaks out about the real silent majority in the dex story. Post published by Alice Dreger Ph.D. on Oct 30, 2012 in Fetishes I Don't Get*

The entry of the Dex Diaries is written by Anne Tamar-Mattis, JD, ([link is external](#)) Executive Director of Advocates for Informed Choice ([link is external](#)), and co-author of our recent paper ([link is external](#)) on prenatal dexamethasone for CAH. AIC advocates for the civil rights of those born with bodies other than the standard male or female, and has been a key player in our joint work to secure the rights of pregnant women offered dexamethasone for CAH.

There's a theory floating around the world of medicine that goes like this: while it is widely known that patients with disorders of sex development (DSD) are unhappy with the treatment they have received – cosmetic genital surgery, unwanted hormone treatment, and humiliating genital exams top the list – they can be safely ignored because there is actually a “silent majority” of patients out there who are doing just fine. This is a comforting idea. It justifies the mistakes of the past, and it allows current practice to continue without all the discomfort of change.

Those of us who work in DSD advocacy hear the theory of the satisfied silent majority all the time. But no one can find them. After almost two decades of patient advocacy ([link is external](#)) and active debate, decades in which hundreds of affected people have spoken out against the treatment they received, not one person with a DSD has spoken out publicly to say that normalizing treatment is just great. Not one.

But there is a silent majority out there in the world of DSD treatment. And I have found them. They are the clinicians, the researchers, the junior practitioners, the social workers, the nurses, the psychologists who know or suspect that there is something very wrong with current treatment models, but keep their thoughts to themselves. Or word them carefully, in deferential terms, to avoid making waves. My experiences investigating dexamethasone treatment and “clitoral sensitivity testing” brought this home for me.

I got involved in the dexamethasone wars when Alice Dreger asked me to sign a letter. She had been approached by numerous physicians and researchers who wanted her to “do something” about Dr. Maria New. For years, many in the medical academy had been alarmed at Dr. New's widespread promotion of prenatal dexamethasone as “safe and effective,” and at her continual production of shoddy research on the subject. There had been many polite calls for restraint in the medical literature, and even some pointed exchanges. But Dr. New was a prominent, and well-funded, researcher, and the culture of medicine does not encourage challenging such figures. In 2010, though, after she refused to answer one courageous researcher's public questions about what she was telling her pregnant subjects, many finally felt she had gone too far. Something had to be done.

Still, though, even her strongest critics were hesitant to stick their necks out too far. Alice is an academic in the field of medical humanities, known to be unafraid of controversy, and doctors and researchers in the field asked her to take the risk of bringing what had been a behind-the-scenes discussion into the public square. What happened next is well-chronicled elsewhere. ([link is external](#)) What surprised me, though, was how many professionals were ready to jump on the bandwagon once a few people expressed their concerns about Dr. New's work.

In a matter of months, voices of dissent in the medical world grew stronger. Many who politely questioned use of dexamethasone in the past now condemn it in the strongest language. One published paper (link is external) stated: “We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up.” Multiple academic societies published new guidelines (link is external) underscoring the experimental nature of the treatment. Some of these statements were brewing before we took any action. But what I observed is that, after our group of advocates and academics spoke up and named New’s practices as unethical, many others found their voices. The silent majority had been there for some time, all waiting for “someone” to do something.

This wasn’t the first time I had encountered the silent majority in DSD treatment, but it did highlight something I already knew: there are a lot of people in medicine who are uncomfortable with the things they and their colleagues are doing to kids with DSD. And a lot of them aren’t speaking up. Some of them approach me after I give presentations to medical audiences, to tell me about a case they saw that troubled them. Some invite me to speak at their hospital or campus – to say what they aren’t comfortable saying, or to give them backup so they can say it more strongly. Some just email me to tell me how glad they are that “someone” is doing something.

How does this happen? Medical professionals are, by and large, an ethical group. I don’t believe there are many who would consciously keep silent while patients are harmed. But it is hard to speak up, and easy to rationalize. I saw this when we raised the alarm about Dr. Dix Poppas, who was doing post-surgical “clitoral sensitivity” tests with vibrating devices on young girls with DSD. I had conversations with doctors around the country about this, and most could see the problem right away. Many of those discussions would go like this:

Doctor: “You’re mistaken. No one does that. It would be damaging and unethical.”

Me: “But you see, here is the published study, where Dr. Poppas and colleagues write about doing just that.”

Doctor (looking doubtful): “Well, it was published, so they must have had approval from an ethics board.”

Me: “No, you can see here that they only got approval for chart review.” (for looking at the charts after the tests had been done)

Doctor: “But it was done in a medical setting. So it must not have been harmful. The kids knew it was a doctor doing the testing.”

See how that works? At the beginning of the conversation, my conversation partner knows that putting vibrating devices on a young girl’s clitoris and asking her to report on the sensations could obviously be harmful. But he doesn’t want to believe that is what is happening. So he tries a number of rationalizations to explain the problem away, and finally decides that maybe it’s really not so bad after all.

This kind of rationalization happened all around when we sounded the alarms about dexamethasone and clitoral sensitivity testing. Everyone wants to believe the systems that are meant to protect us must be working, that it would be impossible today to have another Tuskegee or DES. The only way to prevent that kind of tragedy, though, is for individuals to speak up (link is external) when they see something wrong. To do that, we have to be willing to see what is in front of us.

I can’t prove there is a silent majority in the world of DSD treatment who believe that medicine is failing these kids, any more than I can prove that there is no silent majority of happy DSD patients. But experience tells me that it is so. And history tells me that as more people begin to question current practice, many of the silent will find their voices.

My thanks to Anne Tamar-Mattis for this contribution to the Dex Diaries.

<https://www.psychologytoday.com/blog/fetishes-i-dont-get/201210/the-dex-diaries-part-9-the-real-silent-majority>

Alice Dreger Ph.D.

Alice Dreger trained in History and Philosophy of Science at Indiana University (aka the Land of Kinsey), but she hasn't let her Ph.D. in those disciplines stop her from wandering far afield. Most of her academic work has centered in history of medicine and medical ethics, particularly as they concern sexual minorities and people with body types that don't fit social norms.

Lately, under the auspices of a Guggenheim Fellowship, she's been writing a walk-about history of scientific controversies in the Internet age. The book includes her own experiences in intersex rights work (she helped lead the Intersex Society of North America for about seven years) and in having done historical research that ticked off a number of transgender activists. Now Professor of Clinical Medical Humanities and Bioethics in Northwestern University's Feinberg School of Medicine, Dr. Dreger has published two books with Harvard University Press: *Hermaphrodites and the Medical Invention of Sex* and *One of Us: Conjoined Twins and the Future of Normal*. Always up for a task beyond her skill set, she also coordinated and edited well-received clinical guidelines and a parents' handbook on disorders of sex development (see [dsdguidelines.org](http://dsdguidelines.org)).

Dr. Dreger publishes in journals in medicine, the social sciences, and the humanities, and also writes for the mainstream press. Her op-eds have appeared in *The New York Times*, *The Washington Post*, *The Wall Street Journal*, and the *Chicago Tribune*. She has appeared over three dozen times as a talking head (and once as a dancer) on various broadcast programs, including on CNN, BBC, CBC, HBO, *Good Morning America*, and the *Oprah Winfrey Show*. She is a guest advisor to *Savage Love*, and her essay, "Lavish Dwarf Entertainment," was chosen for Norton's annual Best Creative Non-Fiction volume of 2009. In her free time, Dr. Dreger provides private, pro bono, personalized medical history recovery work for people who have suffered medical trauma. At the moment, she doesn't have a lot of free time because she's leading a push for a federal investigation into a disturbing case where hundreds of pregnant women may have been experimented upon without their knowledge. Dr. Dreger lives with her mate of fifteen years, their ten-year-old son, and two surprisingly charming rats, one hooded and one from a lab.

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