

**Inter/Act** is a national project led by young people with DSD/intersex conditions, ages 14-25.

## WE FEEL IT IS TIME WE *TOLD OUR OWN STORIES* AND **SPOKE OUR OWN TRUTHS.**

In 2012, we started a series of conversations about what we wish our doctors knew, and what we are glad our doctors knew. We're sharing that with you, and we hope you'll *pass it on.*



### Support Groups

- \* I need you to keep me informed about existing peer support.
- \* Being part of a community of women with DSD really gave me a sense of belonging.
- \* My doctor gave my parents a pamphlet for a support group, but advised them not to go because they were "crazy."
- \* The fellowship I found with other women going through this struggle really helped me grow.
- \* The mental health aspect of having a DSD is bigger than the physical aspect.
- \* My parents never told anyone else, and their silence affected my entire family.
- \* The support groups are great because they are just that: support! A unique support that we can't get from our doctors or families.
- \* Some of the best healing I have done is through support groups.



[inter-actyouth.tumblr.com](http://inter-actyouth.tumblr.com)

### Disclosure

- \* Be honest. Why would you not want to tell me something about myself? Why should you know when I don't know? Honesty makes this not shameful.
- \* I knew when I was 16, but my parents thought I didn't.
- \* I wish that I had known about everything at age 13, and had gone to conferences immediately.
- \* My peers were experimenting sexually while I was scared of my own body.
- \* I don't think my parents knew they had a choice.
- \* We aren't fragile. Tell us the truth.

### Communication & Therapy

- \* Do not tell me you know how I'll turn out. My DSD doesn't mean I'll be gay/straight or identify as a boy/girl. Just tell me the facts about my body.
- \* Do not lie to me.
- \* Do not lie to my parents.
- \* Do not speak in absolutes, i.e. "This vagina will never be sufficient for marital relations."
- \* If you know I don't get my period, don't ask me when I had my last period.
- \* Do not assume I want a husband at all.
- \* Do not assume I am heterosexual.
- \* Know what you're talking about. We shouldn't have to educate our doctors.
- \* Do not try to convince me how terrible it is to have a period.
- \* Please tell me what's good about having my condition. For example, not having to shave my armpits.
- \* Do not emphasize how rare this is.
- \* My doctors told me I'd never meet anyone else like me, but it was a big turning point for me when I did.
- \* I wish my parents could have had access to therapy. They felt so alone.
- \* Do not ask me if I feel like a boy/girl.
- \* Do not question me like I'm an anomaly, or a once in a lifetime opportunity.
- \* Do not ask young kids if they have any questions right after they've been shell-shocked from the genital exam you just gave them.
- \* Encourage us to email you. Encourage us to express ourselves. Draw, write, paint—anything. Sometimes it feels impossible to ask someone, "Where did my clitoris go?"

[CONTINUES ON REVERSE >>>](#)

**Inter/Act** is a place for young people with intersex conditions or DSDs to come together, express themselves, and unite their individual stories to develop a voice for a new generation. We don't always agree with each other, and we don't expect you will either.

**Inter/Act** is a project of Advocates for Informed Choice (AIC), [www.aiclegal.org](http://www.aiclegal.org), and is funded through a grant from the Ms. Foundation.

“I remember THE FIRST TIME I said the words ‘I have PAIS.’ ***I was so jealous.*** All these girls had known about themselves at a much younger age and *I had been stuck in this dark place.*” –Shana

## Surgery

- \* Do not tell a child a surgery is the only way they will be able to have “normal sex with their husband.”
- \* Always offer a nonsurgical solution. Surgery is a last resort for everyone else. Why should it be different for us?
- \* Surgery on my genitals wrecked my sense of self, my confidence as a partner and a lover.
- \* It’s painful to have something happen to you that you don’t want.
- \* I had surgery done in 1990, when I was 3. I still wish my parents were given more options. I regret that I have a huge scar and I regret that I had no say about having my gonads removed.
- \* There are times I think that if they had been more realistic about the surgical successes of what they wanted to do with me, my parents would have cautioned me regarding the extent of what I wanted done, and how soon I wanted it done. We all made mistakes.
- \* Do not tell us that only a professional medical eye could tell the difference between “normal” women and us. It’s devastating to learn that it’s completely untrue.

“I know plenty of people who’ve had POOR EXPERIENCES with intersex surgeries. ***Doctors need to be honest about the frequency of failures and complications.***”

–Sarah

## Examination Room

- \* Brief the nurses who are going to work with me.
- \* Have a pediatric speculum nearby.
- \* Ask the patient how they would like the exam to go.
- \* It’s crazy to think genital exams wouldn’t bother a child. Even grown women hate them!
- \* Engage with patients as experts on their own experiences.
- \* Do not patronize us by speaking to our guardians instead of us.
- \* Do not stick your fingers up a little girl’s vagina if it’s not required.
- \* It can be hard for a child to distinguish between a standard genital exam and molestation.

“After MANY YEARS OF COMPLICATIONS, I was referred to a doctor who was one of the finest people I’ve ever met. **SHE CARED FOR ME.** She would sit with me for an hour and just talk... What was I feeling? What did I want? What worked and what didn’t? ***It made all the difference in the world.***” –Monica

This brochure was produced with support from the Ms. Foundation.

For more of our thoughts on medical care, see “The Writing on the Wall”

[interactyouth.tumblr.com/the-writing-on-the-wall](http://interactyouth.tumblr.com/the-writing-on-the-wall)

**Contributors:**  
Abby, Imogen, Lexye,  
Lucy White, Monica,  
Pidgeon, Sarah, and Shana

Thanks for listening!

