Questions for your medical care provider

1. Do you know the **exact diagnosis** of my child's condition? If so, will you write it down for me and tell me where I can learn more about it? (Be aware that sometimes it takes weeks or even months to figure out the correct diagnosis, but while this is happening, you should ask your child's doctors to write down for you the diagnoses they are considering. If your doctor is genuinely uncertain and shares that uncertainty with you, that's OK! Uncertainty is normal and inevitable in medicine. But if your doctor is unnecessarily keeping you uncertain in order to control the situation, that's not OK. Assure your doctor you do not need to be "protected" from the facts of your child's anatomy.)

2. May I have **copies of all of my child's medical chart and lab results?** (Having this will allow you to consult with others easily, and will also mean your child will have easy access to his or her own records when he or she grows up. This will be very helpful in the long run. If your doctor resists letting you see the chart, remind him or her you can care best for your child if you know exactly what is going on.)

3. Who really needs to examine my child personally? Be aware that, especially if your child is in a teaching hospital, she or he is likely to be used as a teaching tool for medical students, nursing students, residents, etc. You may find this repeated display of your child's genitals very disturbing, and your child will certainly find it disturbing once she or he is old enough to understand what is happening. You should therefore limit examinations to those medical care **providers who really need to examine the child for true medical reasons.** (If your doctor is a resident, you should also permit the supervising attending physician to examine your child.) You should also limit how many pictures are taken of your child's genitals, and who has access to those pictures. We have heard from many adults with intersex conditions that repeated medical displays of their genitals harmed them irrevocably.

4. Would you please give my name and number to other parents who have been through something similar, and ask them to call me? It's OK if their children didn't have the exact same condition—I just want to talk to other parents who have older children or adult children with intersex. (We have learned that peer support is probably the MOST important thing for parents. **Meeting another parent who has lived for years with intersex will help you realize you are not alone,** and that your rollercoaster of emotions and experiences is normal. They'll also help you navigate the medical and school systems.)

5. Would you please give me a **referral to a psychologist, psychiatrist, and/or social worker who has experience dealing with gender issues and birth anomalies,** so I can get someone experienced to help me with my mixed emotions—fear, confusion, guilt, joy, curiosity, etc.? Ideally I would like to speak with someone who cares for adults with intersex conditions, so I can learn more about what happens as a child grows up with intersex. (Note that caring medical doctors—including endocrinologists, urologists, and surgeons—may try to provide counseling to you and your child on the fly, but most have neither the time nor training to do it well. Push for professional psychological support for yourself and your child. Getting that doesn't mean you're crazy or weird; it means you have found yourself in an unusual situation and you know how to get and use the resources available to help your family)

6. Is my child having any **immediate medical problems?** If so, what are they, and what are the treatment options? (Most children born with intersex conditions are healthy; that is, they have no immediate medical problems. Most can be taken home safely and joyfully as soon as test results show there are no immediate medical problems. Examples of immediate medical concerns in cases of intersex are: failure of the urine to drain out of the body and salt-wasting in congenital adrenal hyperplasia. Let your care providers know you want to take your child home as soon as possible, so you can get on with the business of getting to know your precious new family member.)

7. Which gender identity (boy or girl) should this child be given—that is, **which gender is my child most likely to feel as she or he grows** up? (Doctors can use what is known about various intersex conditions to help you figure out if your child is likely to feel like a girl or boy in the long run. One of the things they should take into account is to what extent your child's brain was exposed to androgens before birth. Evidence suggests that children exposed to higher levels of androgens prenatally are more likely to grow up to feel masculine. Keep in mind your child doesn't need any surgery to be labeled a boy or a girl, and be aware that surgery doesn't cement gender identity—but it does irrevocably take away parts that may matter to your child in the future. Don't let anyone tell you that delaying surgery is equal to "raising your child in a third gender." It isn't. Choosing a gender—boy or girl—for your child is like choosing a gender for any child; you use what is known to make an informed choice. If your child grows to act gender "atypical," that's not because you've done anything wrong, and it doesn't mean your child is diseased; it just means your child is a little different from the statistical average, and the best thing you can do for him or her is to provide love and support for the child's individuality. Surgeries don't, by the way, prevent children from acting gender atypical; they just take parts away.)

8. If the doctors are pushing for genital surgeries designed to change the way your child's genitals look, ask: Why do you think my child needs to have his or her genitals changed? **Is there a reason you think I can't love my child the way she or he is?** What evidence do you have this will help my child in the long run? (A surgical "reconstruction" may sound like it will make intersex go away, but it doesn't, and it may leave a child with diminished sexual sensation, scarring, and a poor cosmetic outcome. There are parents who have raised their children as boys and girls with genital ambiguity because they decided against elective genital surgeries; their adult children have told us they are grateful for their parents' decisions. Regardless of your decision, you should ask your doctors to provide you with proof that the procedure they're offering leads to the outcome you want—your child being healthy and well in the long term. Avoid having one or two scary anecdotes stand in for real evidence. If the doctor says "your child will need this when she or he becomes sexually active," ask why the surgeries can't wait until that point. After all, as Sherri Groveman points out, your kid is also going to need a computer when she goes to college, but that doesn't mean you need to buy her one now! Computers and surgeries keep getting better and better; waiting will likely benefit your child.)

9. If the doctors are pushing for genital surgeries designed to change the way your child's genitals look, also ask: **Genital surgeries risk health, sensation, and life, so why can't we wait until my child can decide whether she or he wants to have cosmetic genital surgeries?** (Waiting until a child can decide about optional procedures is supported by the American Academy of Pediatrics' policy on informed consent (children's participation in decision-making about their medical care; see www.cirp.org/library/ethics/AAP). The AAP also says that you and your child have the right to know everything you can about the procedure being offered. We recommend you download a copy of the AAP policy and go over it with your child's doctors.)

10. If the doctors are pushing for genital surgeries designed to change the way your child's genitals look, also ask: **How many of these particular surgeries have you done, and how many had positive outcomes and poor outcomes**—both in terms of physical well-being and psychological well-being? (If the surgeon tells you "this always works," run to another surgeon! No surgery works every time; find someone who is honest and realistic. Also avoid having your child be an experimental subject; if you decide to go with a procedure, choose the one that has been shown to work for people with your child's condition. If there's no evidence about what works, think about waiting until your child can decide whether to risk an experimental procedure. Again, if you wait, the procedure might not be experimental when you child is ready to decide—it may have been proven or disproven at that point to result mostly in good outcomes.)

11. Regardless of what your doctor advises, ask: **Can you introduce me to someone with a similar condition** who has been treated the way you recommend, and someone with a similar condition who was treated with an alternative?

12. If there are problems you should consider talking to **patient relations or perhaps the consult liaison psychiatry service.** CL psychiatry not only addresses psychiatric and psychological issues of patients; it also addresses problems between patients and physicians or between different medical services. When multiple services are involved (urology, endocrinology, surgery, medicine) it is be very likely that your wishes will not be communicated to all. CL psychiatrists can work to get the different teams speaking to one another.

We hope these questions will be helpful. If you are a parent, please feel free to write to us with suggested revisions, additions, or feedback about who you found helpful. If you'd like to help us push to have all medical care providers move to the Patient-Centered model of care for intersex, please make a donation! With your help, we can make the world a safer place for families dealing with intersex conditions.

MEDICAL ADVISORY BOARD

Intersex Society of North America
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Since our founding in 1993, the Intersex Society of North America has been offering policy advice, positive advocacy, and caring support for individuals and families dealing with intersex.

A decade ago, nearly all medical providers were using a treatment system that was based on incorrect facts and outdated ethics. The standard of care featured the "concealment" approach, which unintentionally harmed many individuals and families.

The good news is, many medical teams now use the Patient-Centered Model of care we advocate.

Unfortunately, if you're a parent of a child with an atypical reproductive anatomy (an intersex condition), you may find yourself still treated with part or all of the outdated "concealment" system. If you print out the following list of questions, bring them to your medical providers, and take notes, you can find the best care possible for you and your child.

Tips for Parents