

# I Think I May be Intersex

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**S**o you think you may be intersex! Whether it's from weird doctor visits as a kid, a partner making a comment, or reading your own medical records, you're suspecting something might be up. This guide exists to help you through the process of figuring out if you're intersex. This may be a fresh diagnosis for you, something your family knows and hasn't told you, or even a new understanding of a condition you've had your whole life. Maybe you're experiencing (or not experiencing) puberty right now. While this is a confusing time, you are in no way alone. Intersex people make up about 1.7% of the population, which is as common as redheads or people over 85. You've definitely met an intersex person before even if you didn't know it!

**What is an intersex variation, really?**



**E**very investigation needs to start somewhere, so here's that start! Intersex is a medical umbrella term that includes dozens of potential diagnoses. Rather than run down a huge list of conditions (check out interACT's excellent "Intersex Variations Glossary" for that), we will explore common signs of intersex variations

as they relate to how the human body develops and differentiates. But first, some disclaimers:

- ◊ We are not doctors and this booklet cannot give you a concrete diagnosis.
- ◊ Intersex variations can show up anytime—at birth, at puberty, in old age.
- ◊ More variations are being found all the time.
- ◊ Plenty of knowledge about what it's like to be intersex can only be found in community, not with doctors.
- ◊ The medical framework of intersex is not the only way to understand human sex variation, nor even the best way.
- ◊ The infinite diversity of the human body is impossible to capture in a series of boxes, no matter how many boxes there are.
- ◊ Many cultures throughout human history have had unique roles for intersex people.

In many medical spaces, the only things considered truly intersex are chromosomal differences. The intersex community overwhelmingly rejects this and considers physical and hormonal variations to be intersex as well. If you have a sex variation, you are not required to self-identify as intersex, but we strongly encourage you to seek out intersex people who share similar experiences with you either way. Being intersex is not an entirely separate third category that excludes you from identifying as a member of the male or female sex—although you can absolutely just say you're intersex—and your gender can be influenced by a diagnosis as much or as little as you want. Doctors cannot dictate your identity. You get to decide what feels safest and best for you.

# SOME COMMON POTENTIAL SIGNS

Like most binaries, female and male are somewhat useful intersex variations can show up in people with different at birth) section may apply to someone **AFAB** (assigned female at

## AFAB

- ◊ Webbed neck
- ◊ Lack of a period
- ◊ Being taller than average
- ◊ Ovotestis
- ◊ Cliteromegaly (large or permanently swollen clitoris)
- ◊ Broad chest with widely spaced nipples
- ◊ Short fingers and toes
- ◊ Large breasts
- ◊ Extra facial and body hair
- ◊ Partial fusion of the labia
- ◊ Genital growth
- ◊ Speech issues
- ◊ Irregular periods
- ◊ Hypergonadism
- ◊ Arms that turn out at the elbows
- ◊ Kidney issues
- ◊ Ovarian cysts
- ◊ Abdominal pain
- ◊ Lack of breast growth
- ◊ Deepening of voice
- ◊ Pain during sex
- ◊ Heart issues
- ◊ Muscle mass increase at puberty
- ◊ Bone density issues
- ◊ Early-onset osteoporosis
- ◊ Height discrepancies
- ◊ Fast and early growth spurts
- ◊ No growth spurt
- ◊ Delayed or absent puberty
- ◊ Early puberty
- ◊ Scarring on the abdomen or genitalia
- ◊ Issues with incontinence
- ◊ Low libido
- ◊ Acne
- ◊ Fatigue
- ◊ Balance issues
- ◊ Infertility

## EVERY

# OF AN INTERSEX VARIATION

categories that ultimately just generalizations, and many assignments. Some symptoms in the **AMAB** (assigned male birth), but these categories are based on what is most common.

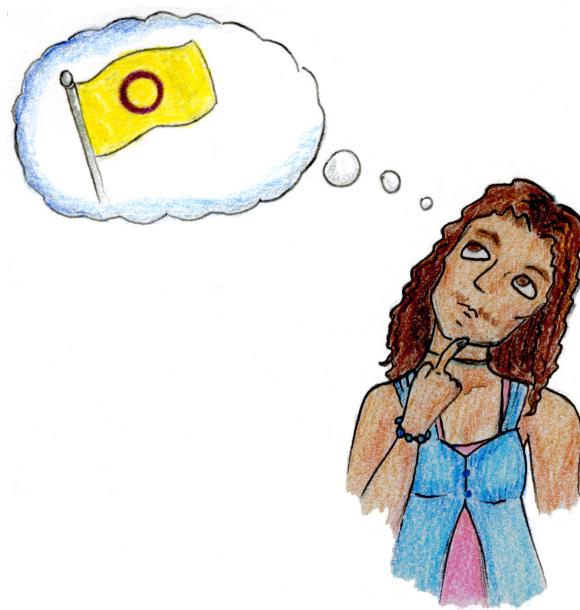
## AMAB

- ◊ Gynecomastia (breast growth)
- ◊ Undescended or partially descended testes
- ◊ Delayed tooth growth
  - ◊ Poor motor control
- ◊ Crossed eyes
  - ◊ Wide-set eyes
- ◊ Issues with reading, writing, and math
- ◊ Erectile dysfunction
- ◊ Hypospadias (urethra not on the tip of the penis)
  - ◊ Congenital anorchia (absence of testes at birth)
- ◊ Small testes
- ◊ Low sperm count
- ◊ Balance issues
- ◊ Lack of muscle mass or inability to create muscle mass
- ◊ Bent pinky
- ◊ Congenital chordee (a bend in the penis)
- ◊ Low muscle mass
- ◊ Small penis

## BODY

- ◊ Ovotestis
- ◊ Hair loss
- ◊ Low set ears
- ◊ Numbness or sensation issues in genitals
- ◊ Patchwork skin coloration/ discoloration
- ◊ Autoimmune disorders
- ◊ Different colored eyes
  - ◊ Less body hair than average
  - ◊ Aromatase deficiency
    - ◊ Hearing issues
    - ◊ Low set ears
    - ◊ Ambiguous genitalia
- ◊ Weight gain
- ◊ High blood sugar
- ◊ Fatty livers
- ◊ Glucose intolerance
- ◊ Dyspraxia
- ◊ Hot flashes
- ◊ Development delays
- ◊ Hypertension
- ◊ Issues with fine motor skills

# CONVERSATIONS WITH FAMILY AND LOVED ONES



**C**onversations with people about your body can be alienating and awkward. It can be especially hard to ask a guardian about concerning things you found in medical documents or scars you want answers for. The first step we recommend when approaching these situations is remembering to ground yourself. Take deep breaths, situate yourself in your body, observe and acknowledge how you feel, and stay resolute. You deserve answers, you deserve to share your truth, and you deserve to be treated with respect. Unless your family is very casual and open, we suggest going in with a list of specific questions you want to address so you can refer back if you start to feel overwhelmed by the myriad emotions these conversations can bring up. We also recommend firmly setting your boundaries and sticking to them.

## GETTING ANSWERS

We recommend going into conversations with family with bullet points so you have something to refer to when you are feeling shaky, defensive, forgetful, or any other strong emotion. We also suggest firmly setting your boundaries and sticking to them. There will often be invasive questions about your reproduction, body parts, and feelings—think about what you feel safe and comfortable sharing beforehand. And remember one of our favorite memes: you can just leave! If it sucks, hit da bricks!

You deserve answers, so be ready to drag the conversation back on topic if they keep changing the subject. and if they keep changing the subject, bring it back. If an immediate guardian refuses to give you the answers you're looking for, consider an aunt, uncle, grandparent, or family friend that was around when you were a kid who might be able to help.

When investigating medical documents, both your own and your family's, here are some things to look out for:

- ◊ Diagnoses of sex variations, “hermaphroditism” or “pseudohermaphroditism,” polycystic ovary syndrome (PCOS), “hormone imbalance”
- ◊ Childhood surgeries, especially during infancy, often described as hernia surgeries
- ◊ Hormone replacement therapy, birth control, and/or puberty blockers
- ◊ Fertility issues
- ◊ Strange descriptions of genitalia, especially “ambiguous”
- ◊ Abdominal masses, especially on the ovaries
- ◊ Abdominal and/or pelvic imaging, usually ultrasounds
- ◊ Crossed-out and rewritten sex assignment on birth records

## COMING OUT AS INTERSEX

You can expect invasive questions about your anatomy, sensation, memories, trauma, experience with doctors, experience with self exploration, experience with partners, how you go to the restroom, how you found out, why you expect this, and more. It's also safe to expect reactions that range from defensiveness, disgust, fear, guilt, anger, curiosity, or the most hopeful of all: acceptance! If a guardian did do any sort of medical or social intervention, they may feel like you're going against their wishes or turn aggressive to hide their guilt. They may make it all about themselves and their feelings, instead of how you feel about your body and the situation. Reminding them this is about you and not them may make them angry, so only do so if it is safe, but always remember that you are the person most affected and it is not your job to handle their guilt or feelings for them. Your bodily autonomy comes before their feelings.

If a family member or loved one reacts with disgust, remind them that your variation is natural, nothing to be afraid of, and not contagious. They're not going to "catch being intersex" from you (oftentimes, you caught it from them!). Maybe bring a statistic about how common your variation or suspected variation is.

After the conversation, take time to regulate, self soothe, or reach out to other intersex peers, friends, or family. These conversations can be extremely hard or plain old anxiety inducing, and you deserve to take care of yourself and get the acceptance and support you need. Gearing up for a hard conversation and having it go easy can also throw you for a loop—your feelings are valid no matter how confusing to others they may be!

# DIAGNOSIS AND TESTING

**T**he first step is doing research into your past medical history. You can request your medical records from your medical provider.

*Laws and an in-depth explanation on how to access medical records as well as frequently asked questions can be found at:*

**<https://www.health.state.mn.us/facilities/insurance/clearinghouse/medrecords.html>**

*More information can be found at:*

**<https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html>**

There are lots of different kinds of tests for different variations. They can take some time, and some are more invasive than others.

## HERE'S A RUNDOWN OF A FEW:

### KARYOTYPE TEST

- ◊ Good for chromosomal variations

### GENETIC TEST

- ◊ Good for CAH
- ◊ Good if there is a known history of intersex variations in the family

### BIOCHEMICAL TEST

- ◊ Check levels of luteinizing hormone, follicle-stimulating hormone, anti-Müllerian hormone, testosterone

## HCG STIMULATION TEST

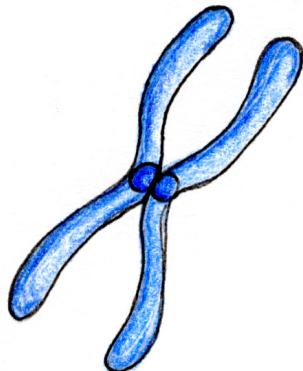
- ◊ Series of intramuscular injections, many different protocols for different variations

## ACTH STIMULATION TEST

- ◊ One hour, one injection
- ◊ Measures the ratio of different hormones in the production pathways of the adrenal gland
- ◊ Tests the hormone “assembly line”—what specific steps are not working as expected?

## IMAGING TEST

- ◊ Ultrasound, MRI
- ◊ X-rays with contrast dye in bladder used to be common



## DIRECT EXAMINATION

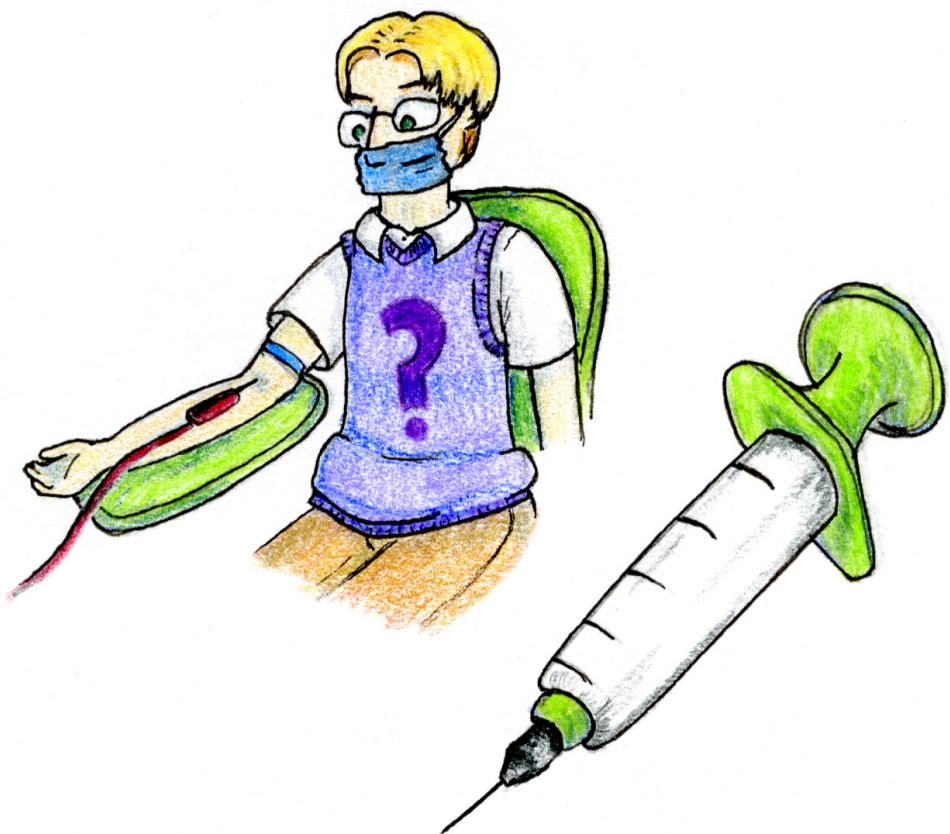
- ◊ Gynecological pelvic exam
- ◊ Abdominal laparoscopy
- ◊ Biopsy

## DEXA SCAN (dual-energy X-ray absorptiometry scan)

- ◊ Scans for bone density with low dose X-rays
- ◊ Extremely important, as many intersex folks have poor bone health
- ◊ Try starting these fairly young if you have an intersex variation or suspect you are intersex

You are more than welcome to have someone come with you or have the doctor explain everything to you before and/or during the test. You can refuse a test or treatment at any time. TIGERRS recommends always getting a second opinion on your test results when possible.

Most of these tests aren't done at your average clinic and will require a referral to get them. A prior authorization may have to be done to get insurance to cover a test, and in some cases, they may not cover it at all if there is no recorded family history of a variation.



# ADVOCACY IN MEDICAL SETTINGS

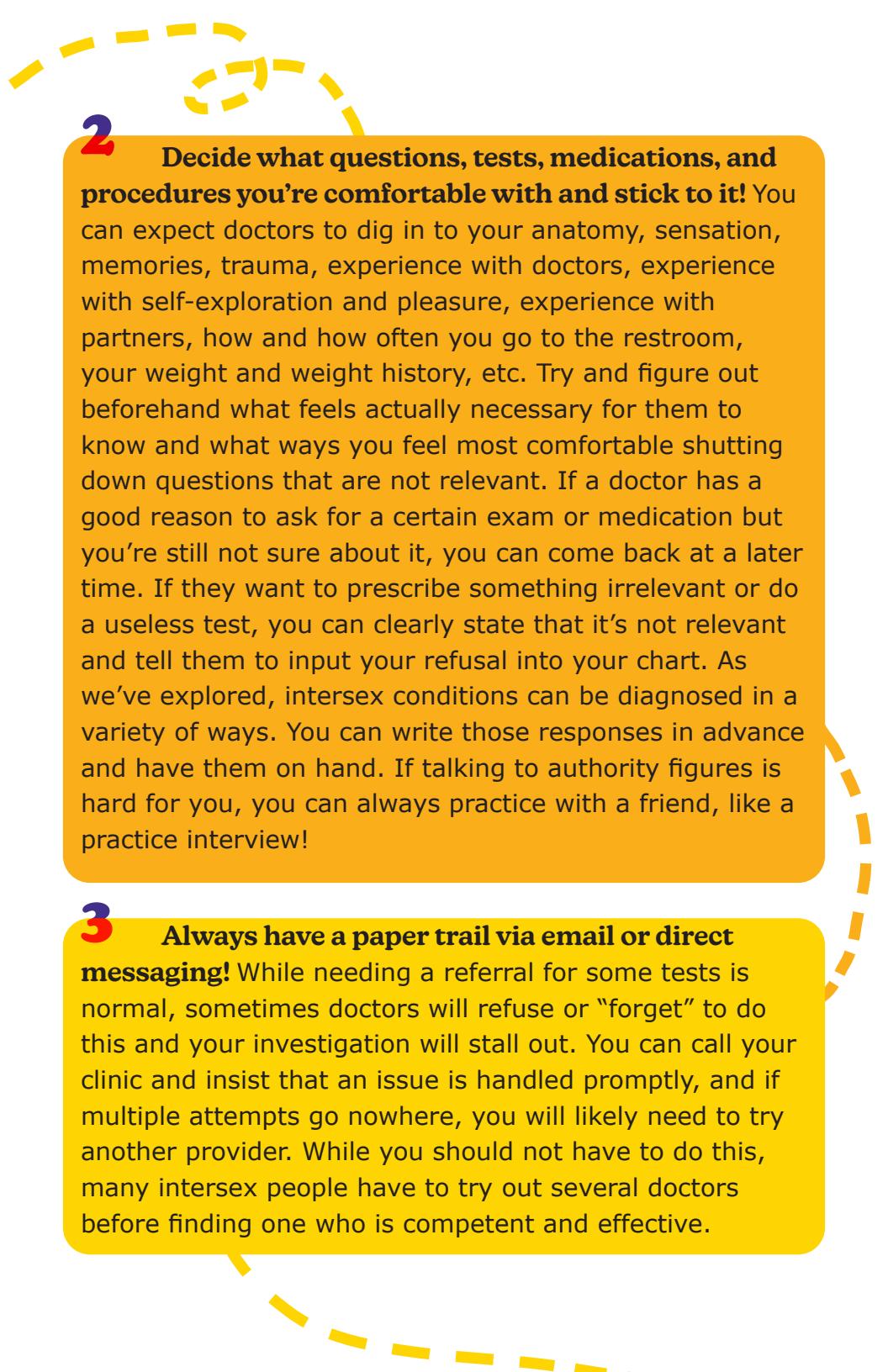


**U**nfortunately, getting diagnosed and treated effectively is an uphill battle. Most doctors do not have expertise in intersex care and many doctors will be indifferent or outright hostile. Even if you come to an appointment with very strong evidence of a potential intersex variation, you are fairly likely to be treated as someone who looked up one symptom and thinks they have every disease under the sun. Here are our suggestions for self-advocacy in the medical space:

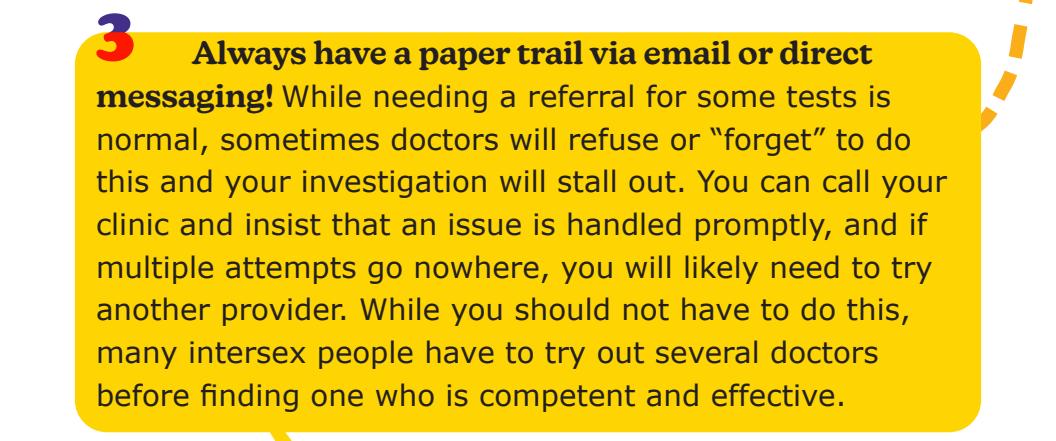
## I

### **Write things down before the appointment!**

Whether it's due to nervousness or just the natural flow of the conversation, you may forget to bring things up. Tracking your concerns and the doctor's responses can show you what's being addressed and what isn't. A written list can help make your provider slow down and prevent them from "forgetting" or moving on. You are the world's foremost expert on your own body and your concerns deserve to be addressed comprehensively.

**2**

**Decide what questions, tests, medications, and procedures you're comfortable with and stick to it!** You can expect doctors to dig in to your anatomy, sensation, memories, trauma, experience with doctors, experience with self-exploration and pleasure, experience with partners, how and how often you go to the restroom, your weight and weight history, etc. Try and figure out beforehand what feels actually necessary for them to know and what ways you feel most comfortable shutting down questions that are not relevant. If a doctor has a good reason to ask for a certain exam or medication but you're still not sure about it, you can come back at a later time. If they want to prescribe something irrelevant or do a useless test, you can clearly state that it's not relevant and tell them to input your refusal into your chart. As we've explored, intersex conditions can be diagnosed in a variety of ways. You can write those responses in advance and have them on hand. If talking to authority figures is hard for you, you can always practice with a friend, like a practice interview!

**3**

**Always have a paper trail via email or direct messaging!** While needing a referral for some tests is normal, sometimes doctors will refuse or "forget" to do this and your investigation will stall out. You can call your clinic and insist that an issue is handled promptly, and if multiple attempts go nowhere, you will likely need to try another provider. While you should not have to do this, many intersex people have to try out several doctors before finding one who is competent and effective.

**4**

**Consider bringing someone else with you!** Now that COVID restrictions have eased, there should be no issue with having another person in the room, but you could also have them on the phone if they can't be there physically. You can also record your appointment—Minnesota is a one-party consent state, so your doctor doesn't need to know. Calling someone before or after, having comforting foods, or a fidget toy can also help.

**5**

**Remember that you are a patient, not a science experiment or a learning opportunity!** You do not have to educate your doctor on the condition you think you might have. If you feel like you are being treated with anything less than full human dignity, you can say so. If your provider invites other people into the room and you're uncomfortable with that, you can insist that they leave. Healthcare happens on your terms.

**6**

**If a doctor hears you describe your body and immediately suggests physical or hormonal intervention, press pause!** Take your time to seriously look into what that would look like for you and if it aligns with what you want for your body and life. The sense of urgency is usually fabricated, and there is no actual need to start taking medication that day. Even puberty can be put off for a few months to make a decision about if you want hormone replacement therapy.

**7**

**Prepare for potential harassment from providers!** People in our community have been repeatedly harassed by medical providers, including getting calls and emails at

home and having their information shared with other doctors without permission. It is important to brace yourself for this and be ready to hang up and block numbers.

Entering a medical facility can put you in a rough position. Beyond the extremely common trauma response many intersex people feel, the current model of healthcare generally demands intervention and “correction” of intersex variations. We encourage you to remember that you have power in those situations, especially the power to refuse treatment and the power to leave, and always make decisions based on what you truly want.

For more info on your legal rights, see the Minnesota Patient Bill of Rights: <https://bit.ly/MN-patient-rights>

## RESOURCES

interACT, a national intersex advocacy organization and knowledge hub:

<https://interactadvocates.org/>

interACT’s primer on intersex traits and variations:

<https://bit.ly/interACT-glossary>

TIPS (TIGERRS Intersex Peer Support), our social support group for adult intersex Midwesterners:

<https://bit.ly/intersex-tips>

InterConnect, a national intersex support group:

<https://interconnect.support>



# CREDITS

**TIGERRS** is a **nonhierarchical collective** dedicated to delivering programs and resources that build solidarity and safety among transgender, intersex and gender-expansive Minnesotans. To learn more, donate, or volunteer, head to: <https://tigerrs.org>

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