

Ashley Meyers
Narrator

Andrea Jenkins
Interviewer

The Transgender Oral History Project
Tretter Collection in GLBT Studies
University of Minnesota

January 13, 2016



The Transgender Oral History Project of the Upper Midwest will empower individuals to tell their story, while providing students, historians, and the public with a more rich foundation of primary source material about the transgender community. The project is part of the Tretter Collection at the University of Minnesota. The archive provides a record of GLBT thought, knowledge and culture for current and future generations and is available to students, researchers and members of the public.

The Transgender Oral History Project will collect up to 400 hours of oral histories involving 200 to 300 individuals over the next three years. Major efforts will be the recruitment of individuals of all ages and experiences, and documenting the work of The Program in Human Sexuality. This project will be led by

Andrea Jenkins, poet, writer, and trans-activist. Andrea brings years of experience working in government, non-profits and LGBT organizations. If you are interested in being involved in this exciting project, please contact Andrea.

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- 1 AJ: My name is Andrea Jenkins and I am the oral historian for the Transgender Oral History Project
2 at the University of Minnesota and today is January 13, 2016. I am here today with Ashley
3 Meyer . . . is it Meyer or Meyers?
4
- 5 AM: Meyers with an “s”.
6
- 7 AJ: With an “s”. All right. So Ashley, I’m going to ask you to introduce yourself. State your name,
8 your preferred pronouns, your gender identity and your gender assigned at birth.
9
- 10 AM: OK. My full name is Ashley Elizabeth Meyers. Let’s see . . . my preferred pronouns are she, her,
11 hers.
12
- 13 AJ: Great.
14
- 15 AM: And my gender identity, I usually describe it as intersex woman. That’s probably the simplest
16 way of putting it. And my gender assigned at birth was female.
17
- 18 AJ: All right. Thank you. Can you share with me, Ashley, what’s the earliest thing that you
19 remember in life?
20
- 21 AM: That’s an interesting question. I guess the earliest thing I can remember distinctly in actually
22 place and time is probably when I was pestering my mother for a dog. One day dogs were just
23 appearing on cartoons and I really wanted one, my mother is allergic to dogs so she kept on
24 having to say no, and one day I finally broke her resolve because she kind of wanted a dog too.
25 And my dad didn’t really want one, he’s more of a cat person, but my mother is also allergic to
26 cats - basically any pet with fur that sheds she’s allergic to. So he didn’t really want one and
27 eventually my mother broke down and was like, “OK, talk to your father.” And got him on the
28 phone, at work, and instead of asking him for a dog, I said, “Dad, don’t you think it’s weird that
29 we don’t have a dog?” It just seemed to be the thing that people just did – the parents, the kids,
30 and the dog. That’s what I kept on seeing at age five – or four . . . yeah, age five or four. And
31 then my dad said, “I’ll think about it.” My mother knew in my dad-speak that means, “Yes.”
32
- 33 AJ: Oh wow, OK.
34
- 35 AM: Yeah, in his speak that means yes. And so she was all surprised and then got on the phone with
36 him and was like, “Are you sure?” and everything. I told her, “Mom, get off the phone because
37 dad has to think.” So that was one of my first memories.
38
- 39 AJ: Really.
40
- 41 AM: Well at least one I can place in time. There might be ones that are earlier but again, they’re not
42 very . . .
43
- 44 AJ: Super fuzzy.
45
- 46 AM: Right, they’re kind of fuzzy and I don’t remember it too well, but that’s one I can say was when I
47 was four or five. So that’s probably the most distinct, early memory I’ve got.

1
2 AJ: Interesting. Did you get the dog?
3
4 AM: Yes, I did get the dog and unfortunately had to be put down about a year ago.
5
6 AJ: Oh, wow. So you guys kept it for a long time.
7
8 AM: Yeah, 16 years. He was 16 and just wasn't doing very well. We think he might have been having
9 small strokes. He didn't seem to know what was going on and confused all the time, just felt like
10 he would break if you picked him up. But his name was Tommy. I still do not know why I named
11 him that, I picked the name.
12
13 AJ: You picked the name.
14
15 AM: Yeah. And whenever somebody would ask, I would just put my little hands on my hips and say,
16 "I just thought it was a good name for a dog." And later I wish I had been more explicit because
17 I asked mom, "Were we watching Rugrats at the time?" Because Tommy Pickles, I know at one
18 point in our childhood my brother and I did watch Rugrats sometimes and so was it that, was
19 there a boy at preschool named Tommy, where would I have even heard this before? And she
20 was like, "Nope," you would have watched Rugrats later and she didn't remember any boy
21 named Tommy or how I would have known the name. So I guess I must have picked it up from
22 somewhere and just thought it would work, but I can't imagine him being by any other name.
23
24 AJ: That is quite an interesting name for a dog.
25
26 AM: He was a little white fluffy Bichon Frise, my mother could handle him because he didn't shed,
27 which was a blessing because we wouldn't have to . . .
28
29 AJ: Yeah, I've heard they're the hypoallergenic dogs.
30
31 AM: Exactly. My mother didn't have to worry about it. Well, OK – she'd have to make sure after
32 playing with him or petting him, she washed her hands before touching her face because her
33 eyes would get itchy and everything. But other than that it was fine and we didn't have to pick
34 up dog hair.
35
36 AJ: Yeah, that's kind of nice.
37
38 AM: So that was good.
39
40 AJ: Bichon Frise. What about elementary school? Where did you go to elementary school?
41
42 AM: I went to elementary school at Oxbow Creek. It was an elementary school not too far from my
43 house. It was a good place.
44
45 AJ: How do you spell that? O-x . . .
46
47 AM: O-x-b-o-w.

1
2 AJ: Oh, Oxbow.

3
4 AM: Oxbow Creek. Yes. I had some good teachers there, I especially remember my first grade
5 teacher, Mr. Kohvik and we called him Mr. K. He was the one who kind of noticed I was having
6 some learning difficulties. My kindergarten teacher had noticed but felt that it was too early to
7 really do much about it or bother with a diagnosis, but by that point Mr. K was like, "Well maybe
8 we should check this out." At first they kind of thought maybe I had dyslexia but we didn't
9 bother doing a whole diagnostic at that point but they got me in touch with a reading teacher
10 and I would go out with her a few times a week and we would sit together and she would have
11 me write out these little booklets with stickers and then we would have to go through a lot of it
12 with white stickers so that way I could fix the backwards letters and things. B and D were a
13 nightmare.

14
15 AJ: Oh really.

16
17 AM: Yeah, well the lower case ones look so similar and trying to remember which one is in which
18 direction.

19
20 AJ: Which direction, yeah.

21
22 AM: Right. And eventually I got the strategy of during a spelling test writing the word bed at the top
23 and remembering that when you write it out it kind of looks like a bed and you can draw a little
24 person right there. In fact one of my . . .

25
26 AJ: And you came up with that idea on your own?

27
28 AM: Actually I can't take total credit for it, one of my special ed teachers thought of it – Mrs.
29 Paulsted. She was the one that I had in 2nd or 3rd grade. I really liked her, she was very nice and
30 I was disappointed when she had to go to another school. And after that it was Mrs. Green and
31 she was very good as well. So yeah, I was blessed with a lot of help in that area.

32
33 AJ: So there was a little bit of dyslexia?

34
35 AM: Yeah. Eventually we did do a whole diagnostic years later and they said that I had non-verbal
36 learning disorder. So, in the end, I've just learned not to be too concerned with the label –
37 mostly it's looking at how it affects me. Even now sometimes when I'm writing by hand,
38 sometimes the backwards letters will come up after I write for a while. I discovered this when I
39 had to do a travel journal for one of my trips abroad and we hand wrote those. My mom looked
40 at it later and was like, "Yeah, this reminds me of when you were little and doing all your
41 backwards letters and things." She helped me transcribe them all to show family members. But
42 luckily when I'm typing it's fine.

43
44 AJ: It doesn't appear.

45
46 AM: Yeah. So that's an interesting thing I've noticed as far as the letter thing. And also I've noticed
47 that I tend to be a slower reader still. Even now in college I still have some accommodations –

1 they'll scan my books and I have a special reader on my iPad that will read it all to me. And also
2 it has like a little red cursor above the word to help me follow along and things.
3
4 AJ: Oh, so you can follow along with the audio.
5
6 AM: Exactly.
7
8 AJ: And read the words.
9
10 AM: And I can also adjust the pitch of the voice, which is good because I noticed one time I had to
11 listen to the audio book of *The Grapes of Wrath* for my 10th grade English class. The voice on the
12 audio book was super low and it made me fall asleep. So now I adjust it to be a higher voice
13 because I don't fall asleep to those.
14
15 AJ: So Orson Wells was reading *The Grapes of Wrath* or somebody.
16
17 AM: I think so. Yeah, somebody with a very low soothing voice. I just couldn't stay awake. My
18 mother would come by and shake me awake, just on the chair. "How long were asleep?" "I
19 don't know." And then the voice would still be in my ear and I'd be like, "OK, where was I?"
20
21 AJ: That's quite funny. You're in this great elementary school and the teachers are really helpful,
22 what about the kids? I know that sometimes . . . kids can be kind of cruel when there are
23 learning disabilities present and that kind of thing.
24
25 AM: I think that the teachers kind of helped by . . . they acted as kind of a buffer and they were very
26 good explaining why I would leave class. That was probably the biggest thing, otherwise I was
27 able to hide it from . . .
28
29 AJ: Sure, nobody really knew.
30
31 AM: Those were the only times when maybe I felt a little awkward or the kids were wondering how I
32 was different because I had to get up and leave. Again, luckily the teachers were very good at
33 explaining what was going on. I was lucky that I was able to avoid that part and actually many of
34 the kids were surprised when they discovered I had a learning disability because I've always had
35 . . .
36
37 AJ: They couldn't tell.
38
39 AM: They couldn't tell. I always had a big vocabulary, which sort of masked it – because you don't
40 expect somebody with a big vocabulary to have a learning difficulty. Back when my mother was
41 concerned, when I was really little, she brought me into the pediatrician's office and I was
42 talking to the doctor, just yapping away using all my \$10 words. And he was like, "OK, why did
43 you bring her here?" And she was like, "She still doesn't know how to count or do her letters."
44 He was like, "Oh," and was kind of surprised. So I think in the end the fact that it was pretty
45 invisible sort of was a shield in the end and people would easily forget until I had to leave or I
46 was struggling to read something and then they would remember. So I did have some friends
47 who would have to do the same thing – go out to the reading tutor. I remember my friend,

- 1 Maggie, she also would have to go out to the same tutor sometimes when we were in 4th and 5th
2 grade. So that was good to have somebody else . . .
3
- 4 AJ: Somebody else who was experiencing some of the same kinds of things.
5
- 6 AM: Yeah, or at least similar things.
7
- 8 AJ: So no bullying then in school?
9
- 10 AM: No. I was very, very fortunate not to have to deal with that.
11
- 12 AJ: And you had lots of friends and good social interactions with kids?
13
- 14 AM: Yeah, I would have to say that making friends was always . . . that's always been kind of a
15 challenge, which I discovered is not uncommon. That's something a lot of people might struggle
16 with and also the neuropsychologist who did my test much later said it's not even uncommon
17 for people with non-verbal learning disorder. I think a lot of it is because we tend not to notice
18 non-verbal cues as well as we notice verbal ones. So sometimes people would be giving me
19 signals non-verbally and cues and stuff and I would just not be . . .
20
- 21 AJ: Just not be aware of it.
22
- 23 AM: Not be seeing them. Luckily most of the time a verbal cue comes pretty quick but sometimes . . .
24 I can remember sometimes . . . what I would receive as a weird reaction and now I look back and
25 it's like oh, I probably just missed a verbal cue for sometimes – to stop talking or whatever. So,
26 that was kind of a struggle. So, yeah, there was no bullying but still it was sometimes hard to
27 make friends because of that. And that's gotten better as I've gotten older and I've become
28 more aware. I try to really be conscious of OK, am I receiving a non-verbal cue and just trying to
29 understand that a little bit more.
30
- 31 AJ: Well it sounds like you grew up in a pretty intact home environment – both of your parents have
32 been together for the entirety of your life, right?
33
- 34 AM: Right.
35
- 36 AJ: And, they were very supportive of helping you through some of the challenges with the learning
37 disabilities and such. Tell me about your identity as an intersex woman and how does the
38 learning disabilities play into that. And I want to talk a little bit more, as we get a little deeper
39 into the interview, about invisible disabilities and how people just don't recognize it and sort of .
40 . . what are some of the challenges and getting help when people can't see it. It's clear when
41 somebody is in a wheelchair and hey, I might need to hold the door open for them. Or, they're
42 blind or hearing disabled. So – we'll talk about that in a little bit, but . . .
43
- 44 AM: Well, as far as the intersex identity, I became more aware of it as I started reaching the age of 11
45 or 12. In fact, I believe it was my 12-year-old appointment with a pediatrician when something
46 was noticed. I wasn't growing, I was leveling off already on the growth chart and not going
47 through a growth spurt.

1
2 AJ: So at 12-years-old, how tall would you say you were?
3
4 AM: Let's see, I was probably a little over four feet at that point. My parents weren't really
5 concerned because they're not very tall themselves, they're pretty average height and so they
6 weren't really thinking too much about it but the pediatrician pointed out how I was leveling off
7 and said, "We should probably have you see a specialist." And so I was referred to an
8 endocrinologist by the name of Dr. Creigo.
9
10 AJ: How do you spell that, do you know?
11
12 AM: I think it's spelled C-r-e-i -g-o.
13
14 AJ: OK.
15
16 AM: I'm not entirely sure.
17
18 AJ: That sounds pretty close.
19
20 AM: We went to see her that July, so the appointment probably was May, around my birthday. So
21 July sounds right anyway. When I got there they asked a bunch of questions, I can't remember
22 what they all were. I just remember being very nervous because we didn't know what they
23 were going to find.
24
25 AJ: And you probably had never been to an endocrinologist before.
26
27 AM: No, I didn't even quite understand what she was. Later I figured out her specialty is the growth
28 system and hormones – particularly with children and adolescents. So we talked for a while and
29 she made this list of things that it could be, some sounded not too bad and others just sounded
30 just terrible. I can't remember everything – I think that I tried to block that out at the time. She
31 told me that we would have to do some blood tests and by this point, 12-year-old me is freaking
32 out because that's a scary thing and I'd never had a needle in a vein before. So that was very
33 scary. So they brought in a nurse with this numbing solution to put over my arm and that takes
34 a while to work.
35
36 AJ: Like a topical anesthetic.
37
38 AM: Yeah, something like that. Yeah, so we had to wait a little while for that to work and meanwhile
39 I didn't get a very big breakfast before coming in that morning and my parents weren't thinking
40 about the fact that oh, she hasn't had a lot of food and they were just trying to keep me calm.
41 And also, we didn't know they were going to be taking 12 vials of blood out of a really small kid
42 – I wasn't even 100 lbs. I was probably more . . . I don't even know, maybe somewhere between
43 75 and 80 . . . probably more like 80.
44
45 AJ: You were a tiny kid, huh?
46

1 AM: Yeah, I've always been tiny. Even as a baby I was 5 lbs. 5 oz. My mother was surprised after
2 such a long labor, she thought I was going to be huge – and she said I felt huge, but then she
3 saw this tiny thing.

4
5 AJ: And out popped this tiny little thing.

6
7 AM: And the nurses called me peanut. So I've always been tiny. Again, they're taking all this blood
8 out of a very tiny kid and I fainted in the waiting room. Luckily I had already sat down in a chair
9 so I didn't fall or anything, but I started twitching and hitting the person behind me. My mother
10 was like, "What are you doing?" and then saw my eyes and got a nurse. I remember waking up
11 with my mom right in front of me and then the nurse on the other side. It didn't take long to
12 realize what had happened. I had fainted before once coming out of a hot tub from the
13 temperature change. It was winter time up at my grandparent's house and they have a hot tub,
14 and so I got out of this warm hot tub into the cold and back to the warm, so I already knew what
15 that sensation was like – to pass out. So yeah, I put it together and then they gave me this
16 powdered orange juice . . . it was not good. Yeah, my mom was like, "OK, I'm going to get
17 something better," and went to the vending machine and got some Chips Ahoy cookies.

18
19 AJ: So that got your blood sugar back up a little bit.

20
21 AM: So I saw in a chair for a while until I was ready to walk out again and then I remember we went
22 to McDonald's right after that because there was one right by the doctor's office. So filled up
23 there and went back home. I didn't really think a whole lot about it and it was going to take
24 some time for the tests to come back. I didn't know this at the time but my mother heard, way
25 before I did, the answer and they explained to her that the test came back positive for Turner's
26 Syndrome, which is when somebody who is typically assigned female at birth, although there
27 might be some exceptions to that rule, but most of the time assigned female at birth, is born
28 with one X chromosome or one X chromosome and then kind of a partial, smaller second one.
29 And so that causes the ovaries to be non-functional, it affects things like growth hormones,
30 which is why I wasn't growing, and we also discovered that besides that I also wasn't going
31 through puberty, which was another concern. They thought I was because apparently I got
32 some baby fat on my chest and so they thought that oh, I must be starting.

33
34 AJ: Puberty is happening.

35
36 AM: Right. And the doctor looked at it and was like, "Oh actually, that's just baby fat." So that was
37 kind of . . .

38
39 AJ: Disappointment.

40
41 AM: A little bit. Slight. And they expected then . . . that it was puberty because, also, my mother
42 went through puberty early – really early, like age 11, so they expected I would be an early
43 bloomer like her because kids take after their parents in this way.

44
45 AJ: But you were 12 and you weren't menstruating or . . . ?
46

- 1 AM: No, nothing like that. And again, they thought that I was on track because of my chest but . . .
2 yeah, that turned out to be the case. And so the doctor had to explain some of this to her and
3 further explanations were given at an appointment the next month, that my parents attended.
4 In the meantime, my mother was going off into a room to cry by herself because . . . it kind of hit
5 her hard.
6
- 7 AJ: So she didn't tell you about it?
8
- 9 AM: Not at first. Basically she let my brother and I have free reign with the computer and we had
10 just rediscovered his Harry Potter computer games that we used to play. So we were having the
11 time of our lives with that, I wasn't thinking about the fact that, "Oh wait, mom is letting us have
12 more screen time than she usually will let us have and she's going up into her room." I didn't
13 even . . .
14
- 15 AJ: You didn't make those connections.
16
- 17 AM: I was just having fun playing these games and was totally distracted.
18
- 19 AJ: You were 12.
20
- 21 AM: Yeah, I was 12. And so my mother's tactic worked, she figured that would keep us busy. So I
22 had just started middle school that September – yeah, I think it was September 5th when my
23 parents told me after they had gone to an appointment with the doctor themselves for further
24 explanation.
25
- 26 AJ: Oh, so you didn't go to the second appointment?
27
- 28 AM: No. My parents thought it would be better to protect me because they didn't know totally what
29 she was going to say. They had some idea from the phone conversation but they wanted to
30 hear more and explain it to me themselves, not in a doctor's office. Which in a way was kind of
31 better. I could be at home hearing about this instead of being in a doctor's office, which can
32 sometimes be an uncomfortable and intimidating place. Not that doctors are bad but . . .
33
- 34 AJ: No, but they're an authority figure and the walls are sterile typically.
35
- 36 AM: Right, all that. I remember they had me stay after school with a friend of the family – in fact,
37 their son was friends with my brother. So we were over there after school and they picked me
38 up later that evening and then explained it to me. Yeah, I remember being very sad because I
39 was hoping it was not going to come up with anything. And so that was difficult and some of
40 the memories are a little hazy – of that first hearing.
41
- 42 AJ: Can I ask you this, Ashley? So Turner's Syndrome, which is one aspect of intersexuality, right?
43
- 44 AM: Right.
45
- 46 AJ: Are you aware or familiar with other forms of intersex?
47

1 AM: Well, I've been slowly becoming more aware. In fact, I didn't even hear the term until my senior
2 year of high school, which . . . that came about because my grandmother and I, who you know,
3 is a transgender woman, and we were about to do this whole panel with some of the women in
4 my family about transitioning and family and things like that. Always with these panels they
5 have some information about each of the panelists. And so, she filled it out for me with what
6 she thought would best describe me at that point and she put down cis gender female at the
7 time and heterosexual and asked me, "Does that fit?" And I said, "Well, it seems to," because at
8 the time I didn't know what other terms might be out there. And, of course, with the sexuality
9 part I wasn't thinking too much about that at the time. Yeah, so anyway . . . and I said, "Well it
10 seems to be." And she was like, "Oh, well, I was wondering if you might prefer intersex." And I
11 was like, "What is that?" And then she . . . I don't even remember totally how she explained it
12 but I think that she explained it as somebody who is born with ambiguous . . . well some
13 ambiguous sex characteristics and we sort of left it at that. I remember being a little thrown,
14 but eventually . . . I started doing my own research and figured out that there are a whole host
15 of conditions and things that are out there. So that was interesting to hear about and to
16 explore.

17
18 AJ: You know the most common type of intersex identities that most people think about is sort of
19 this . . . the sex characteristics or genitals of both "sexes". With Turner's Syndrome, you didn't
20 necessarily experience that?

21
22 AM: No, not that part. Most of the ambiguities with me had to do with hormones and chromosomes
23 than it did with anything external that people could see, which is why the doctor just looked at
24 me and assigned me female at birth – because everything looked typical. I didn't get any of the
25 physical characteristics that some Turner's women might get – you know, sort of droopy eyelids,
26 naturally small fingernails is another one.

27
28 AJ: Really?

29
30 AM: Yeah, apparently. Or a web neck is another one.

31
32 AJ: What's a web neck? I don't . . .

33
34 AM: It's when you have some excess skin right here. And often they'll get that removed, as far as I
35 know, once they get older. So doctors usually, when they see those things, will test right away.
36 But, for me, that just wasn't showing and so we didn't really think about it. In fact, I later
37 discovered when a lot of people hear the phrase intersex, like you said – they think of people
38 with the genitals of both sexes or somebody who has something ambiguous that you can
39 actually see if you took off their pants.

40
41 AJ: Right, yeah.

42
43 AM: It was interesting to hear stories – later in my sociology class we had to read an article about
44 intersex people and identities. In fact, some of the stories I heard about were stories of people
45 who were typically assigned female at birth but had an unusually large clitoris and then surgery
46 was done to them because . . . I guess the doctors felt that that should be done. It wasn't
47 harming the infant at all or anything like that, talking about that aspect of what some intersex

1 people may experience. So those are stories I remember because quite a few of those came up.
2 There were others about other chromosomal variations – there may be somebody born with
3 XXY or something like that, or people who had to take hormone replacement therapy like I did.
4 Or you also did hear about androgynous sensitivity disorder, that was another one.

5
6 AJ: What is that?

7
8 AM: That is a condition where somebody who looks female externally has XY chromosomes and what
9 happens is they don't have receptors for androgens in their body, which is why despite the XY
10 chromosomes they turn out looking like a typical female at birth and then later, as they go
11 through puberty, it's discovered that oh there is something different. There's been a lot of
12 stories that I've heard about and I don't know if this is every case, but some of the cases I heard
13 about there were internal testes and typically the doctor would tell them, "Oh your ovaries are
14 twisted and prone to cancer and we have to remove them." They wouldn't actually say what
15 they were or why they wanted to remove them. Yeah, in fact, I think I just recently read a book
16 written by somebody with androgynous sensitivity disorder who had that kind of experience and
17 didn't discover what she had until she read her medical records for another reason years after
18 she'd gone to surgery at 17. Yeah, I wish I could remember the name . . . but I think that the
19 first name was Regina.

20
21 AJ: So a question, when you were doing this research, were there people who were "assigned
22 female at birth" and had sort of extraordinary large clitoris, had it removed, but regretted that
23 or were disappointed?

24
25 AM: Yeah, quite a few of them were very disturbed by all this and they had trouble sexually later.
26 Also they didn't consent to it, they were babies at the time and so that wasn't a very good way
27 to go about it. So they regretted that the doctors had done that once they discovered what had
28 been done.

29
30 AJ: And doctors were pretty . . . up until very recently, sort of pretty much in control of that
31 situation, right?

32
33 AM: Right. Exactly.

34
35 AJ: They sort of spoon fed the parents and didn't include the children in many of the conversations.

36
37 AM: No, usually not at that time anyway. I have been hearing about changes . . . they're good to
38 hear about. But as far as these . . .

39
40 AJ: Like what kind of changes?

41
42 AM: Well, I've been hearing more about doctors who are now saying that they wouldn't do surgery
43 on an infant unless, of course, you have a situation where it's actually life threatening. There is
44 actually one condition that is that way that I read about in which the child is born with no
45 genitalia and no way to pee. So they have to . . .

46
47 AJ: That's a problem.

1
2 AM: Yeah, so in that case they would be like, “Yes, we would do surgery in that case but otherwise if
3 it’s not hurting the child we’ll just leave it alone.”
4
5 AJ: Wait until they can sort of figure out which direction they want to go.
6
7 AM: Right, exactly. So that’s at least a good thing.
8
9 AJ: So what is the no genitalia called? I’m going to make a really bad joke here – is it the Barbie
10 Syndrome?
11
12 AM: I think I have heard it called that as a nickname. But I wish I could remember. It’s a medical
13 name, but it’s a long name that sounds kind of Latin.
14
15 AJ: X’s and o’s.
16
17 AM: I’ll have to look it up. But I didn’t even know that that was possible.
18
19 AJ: I’ve never heard of that before.
20
21 AM: And from what I’ve read it’s pretty rare, it doesn’t happen very often. I just remember it came
22 up in a book I was reading about biology and gender and sex and all that.
23
24 AJ: But actually, intersex identity is much more common than many people think.
25
26 AM: Oh yes, for sure.
27
28 AJ: Do you have any idea of the numbers or the percentages of the population?
29
30 AM: I’ve heard widely varying ranges of estimates. I think the lowest I ever heard was one in 2000.
31 In fact, women born with Turner’s Syndrome – that’s the rate just with this one condition.
32
33 AJ: That is actually a fairly good-sized portion of the population.
34
35 AM: Right. So that was interesting. With that estimate they were going by how many cases in which
36 doctors will notice something with the genitalia right away, right at birth or are confused about
37 what sex to assign the baby. So that was interesting and that’s still a pretty good size, even with
38 that. And even with just my own condition. So that was the lowest estimate I’ve ever heard, it
39 definitely seems to be more than that from what I can tell. The highest I’ve ever heard is like
40 1%, but again I think it can be hard to tell – especially since a lot of people . . . if I didn’t have
41 Jamie Ann as a grandmother I may never have realized that this description even existed or this
42 identity was even possible. In fact, a lot of the women and girls who I’ve met who do have
43 Turner’s Syndrome, like I did before, don’t really know about the wider intersex community – or
44 even that the word exists, which is interesting. Again, without Jamie Ann I probably never
45 would have heard it. So that’s another thing – and then also biology is so complicated, just in
46 and of itself and there’s so many things that can happen and then also not everybody has had
47 their chromosomes tested so if we’re going to go with “abnormalities”.

- 1
2 AJ: Air quotes, yes.
3
4 AM: With chromosomes or anything unusual with sex chromosomes, we would probably find a lot of
5 people who maybe didn't know but had something going on there. But yeah, there's just so
6 many things.
7
8 AJ: Is there a strong sort of advocacy community around intersex identities that you're aware of?
9
10 AM: Well, let's see. I did hear about . . . well, in fact the website that I went to to research this was
11 the Intersex Organization of North America, which I know is no longer in operation.
12
13 AJ: Oh really.
14
15 AM: They shut their doors in 2008. But their website still exists, so that's where I went to do
16 research because they had a whole bunch of things and there was a whole page about Turner's
17 Syndrome and all the different ways it can manifest. In fact, now that I'm thinking about it,
18 there is another way it can manifest in which a person might have some cells that have part of Y
19 chromosome even so. So that's another way, but it's more rare than the other two I just
20 described, but it's still a thing. I didn't know that until I read that page . . .
21
22 AJ: On this website.
23
24 AM: And that's also how I figured out more about the androgynous sensitivity syndrome as well and
25 other conditions. So I do know that that existed and their website is still in existence. The book
26 that I read, *Intersex: the Dubious Diagnosis*, talks about the history of that organization and why
27 it shut its doors.
28
29 AJ: Why was that?
30
31 AM: From what I remember from what I've read, it shut down shortly after this conference was being
32 done with people from the medical community about intersex conditions and care. This
33 organization was known for protesting in front of such conferences and not receptive to the
34 medical community. And so, the leader . . . oh, I wish I could remember her name, the person
35 who started it – her name . . . I think the first name was Christine . . . I think it was Christine
36 Chase.
37
38 AJ: Chase?
39
40 AM: I believe so. I'll have to look it up again . . . don't necessarily take my word for it, but she
41 decided that thanks to this organization's reputation now, and the fact that doctors were not
42 receptive, it would be best to shut the doors, start over, and she also supported the change for
43 intersex language within the medical community to disorders of sexual development, which was
44 very surprising for me to read about a bunch of people who are intersex themselves supporting
45 such a change and saying, "Oh, it's OK to call my body disordered." So that was kind of strange.
46
47 AJ: Very interesting, because most people with "disorders" are not fond of that.

1
2 AM: No – no, not at all. And I didn't even like the term when I first read about it, even though I know
3 I probably have to interact with it every time and to some level when I go into a doctor's office
4 about my condition. Probably the doctor has heard this term and is operating with it, even
5 though they may never say it to me. I know that they have probably heard it in medical school
6 or probably have heard about Turner's Syndrome under that umbrella.

7
8 AJ: Again, it's a sexual . . .

9
10 AM: Development.

11
12 AJ: Sexual development disorder.

13
14 AM: Yes, disorders of sexual development. That's their big umbrella term within the medical
15 community to describe . . .

16
17 AJ: So that covers this wide range of intersex identities and genetic sort of "abnormalities."

18
19 AM: Yeah, so that was interesting to read. And again, it seemed to be more about making
20 themselves more receptive to the medical community so that way they would even listen.

21
22 AJ: So tell me this, Ashley, how was your diagnosis treated?

23
24 AM: Well, my parents explained it to me, and they didn't get into all the complexities and all the
25 different ways that this could manifest. They just explained that I was missing part of an X
26 chromosome, and luckily I had heard about this in Biology class – just a brief tidbit about, you
27 know, XX and XY. And so that part I understood and then they explained that my ovaries were
28 non-functional and that later I would need to go through estrogen therapy to even go through
29 puberty. They also explained that to make sure that I grew that I would have to take growth
30 hormone injections. Now when they were first explaining this whole diagnosis and the
31 treatment, my brain, of course, went straight to the injections again . . . needles. No.

32
33 AJ: The last time I had an injection I passed out.

34
35 AM: Exactly. So I was not happy with that news, but I still wanted to read 5'. And also I think that
36 there, oddly enough, was some pressure to make sure that I got to at least the short end of an
37 adult height. I have the feeling that if I had piped up and said, "No, I'm not interested in that
38 part." And I've even heard of Turner's women who have said that and doctors are like, "Are you
39 sure?" and would really want them to do it. Now, luckily I have no regrets about doing that –
40 that's one of the things I speculate if I had said something, but I didn't want to . . .

41
42 AJ: That you may have been able to not do that.

43
44 AM: Right. And just wondering what would have happened in that scenario but we'll never totally
45 know. I'm just going off from what I've heard from other stories. But still, we did the growth
46 hormone injections for three years – I made it to the goal of 5'. That was very exciting.

- 1 AJ: You achieved your goal.
2
- 3 AM: Yeah, and I'm glad that I did. In the end it's good to have some more height. And, I remember
4 the last injection too . . . I think it was sometime in . . . I think it was February of my 8th grade
5 year . . . or maybe it was later than that, I just remember it was winter. My Grandma Peggy did
6 that since she is a nurse she wanted to . . . every time she was over, she would just do it because
7 she's had experience with this. My parents were . . .
8
- 9 AJ: Also, these injections . . . you have to do these at home? You didn't go to the doctor's office.
10
- 11 AM: Yeah, we did them at home because they had to be done every day – every evening we did that.
12
- 13 AJ: For three years?
14
- 15 AM: Yeah, all through middle school.
16
- 17 AJ: Oh, you must have had a sort little bum.
18
- 19 AM: Actually they were done in my thigh and luckily the needle was tiny. But still, I remember seeing
20 little red marks on my thighs. My parents were also not thrilled with the news that they would
21 have to do these themselves. When the doctor first mentioned that there were growth
22 hormone injections and they were like, "So we have to take her in from time-to-time to do this?"
23 They were like, "No . . ."
24
- 25 AJ: "Here's the needle, do it yourself."
26
- 27 AM: Yeah. At first I was thinking maybe I can learn how to do it. In fact, I remember Grandma Peggy
28 brought over an orange once because it kind of has a similar texture and everything and
29 thickness to skin and it's a good thing to practice on. So I practiced on that and then I remember
30 once, after a few months of getting these injections, I tried it myself and my hand was shaking
31 and my dad was just like, "OK, I'll just do it." And they pointed out, "It's not like you're a
32 diabetic and going to have to do this all your life."
33
- 34 AJ: Right, it's going to end at some point.
35
- 36 AM: Right. So then I just let them and Grandma Peggy do it for the rest of those three years and that
37 was fine. I even remember the first ones I had to do. It was MEA break and I was in 6th grade
38 and my mother decided it would be a good idea to go and visit her brother in Cleveland. She
39 had to do it on her own for the first few days because my dad couldn't come because he still had
40 to work. I remember being at my aunt and uncle's house and crying and everything and my
41 mother gave me a pillow because my cousin was a baby at the time and she didn't want me to
42 wake the baby. And then after a while I would be so anxious, just all day, about this injection
43 and she suggested, "OK, for a while why don't we do them in the mornings, just get it done right
44 away and that way you don't have to think about it all day." I remember after a couple of weeks
45 of that, I got up once and decided, "You know what? I'm just going to do it in the evening." By
46 that point I was starting to get used to it and it was becoming more like brushing my teeth. I
47 also remember having this ice pack . . .

1
2 AJ: To keep the swelling down.
3
4 AM: And to put it on before so that way my thigh was numb by that point.
5
6 AJ: You had to do it in the same injection site every . . . was that a part of the . . . ?
7
8 AM: No. In fact there were a couple of options. It could be done in the arm, either side, and it could
9 also be done in the stomach but I was so skinny at the time that the nurse did not recommend
10 that. I was fine with that, I did not want that.
11
12 AJ: The needle going right into your solar plexus.
13
14 AM: Yeah, and so I felt most comfortable with either of my thighs. So we just alternated them – and
15 to make me feel better, I'd put on an ice pack beforehand, for a while. I remember having my
16 ice pack on me, sitting in my underwear in front of the TV watching *The Suite Life of Zach and*
17 *Cody*.
18
19 AJ: Getting ready for another injection.
20
21 AM: Yeah.
22
23 AJ: So when did you start the hormone therapy?
24
25 AM: That's harder to remember because that was just a pill. I think I was 14 . . . yeah, 14 at the time
26 when they started giving me Premarin.
27
28 AJ: So after the growth . . .
29
30 AM: Yeah, the reason why they did it after the growth hormone is because if you start doing
31 estrogen, the growth plates will begin to fuse and they wanted to make sure I would be able to
32 get as much height as possible. So they waited until they saw the growth plates were fused,
33 because by that time it's just like injecting nothing – it's not going to do anything. Yeah, and so
34 once the growth hormones was coming to an end, then they started me on Premarin for awhile .
35 . . I think for a year. I think it was Premarin. The start of it doesn't stick out as much to me
36 because it was just a pill every night so that wasn't a big to do.
37
38 AJ: So around age 14.
39
40 AM: Yeah, it started them.
41
42 AJ: Do you still take hormones now?
43
44 AM: Yes, now I'm on a type of birth control and that can be interesting to talk with doctors because
45 they assume that I'm taking . . .
46
47 AJ: That you're sexually active and you're taking these because you don't want to get pregnant.

1
2 AM: Right, and that I can get pregnant because physically that's impossible.
3
4 AJ: So you are not able to have children?
5
6 AM: No, and I discovered that when I was 12, shortly after diagnosis happened. My mother didn't
7 plan on telling me but when they were explaining the estrogen therapy . . . I don't know where I
8 got this idea but I figured it would help with that because it would enable me to have a
9 menstrual cycle. And so it seemed that, well oh . . .
10
11 AJ: Everything is going to be . . .
12
13 AM: It seemed like I should be able to experience a pregnancy because of this and they want me to
14 have that option and so that's one of the reasons why we're doing this and my mother
15 corrected me and said, "No, it can't do that because your eggs are not viable – they're
16 misinformationing you."
17
18 AJ: How do you feel about that?
19
20 AM: Well now it's not as big of a deal, simply because I'm not in a relationship right now or really
21 anxious to get back into one. Also, when you're 22 and you don't want to have kids, but you
22 may want to be sexually active, the idea of I never will have to worry about it . . .
23
24 AJ: Is a relief.
25
26 AM: Yeah. I remember early on in my first year of college my roommate had a pregnancy scare,
27 luckily everything was fine, but the condom broke and she got really worried and got a
28 pregnancy test and everything. I remember thinking, "Thank God."
29
30 AJ: I don't have to go through that.
31
32 AM: No, I do not. But when I first heard about it I was pretty devastated. It was an interesting
33 reaction of people because they kept on saying, "Oh, don't worry about it, you're too young to
34 even think about it." It was like, "This is a pretty big deal. The way that I thought my adult life
35 should go . . ."
36
37 AJ: It can't happen.
38
39 AM: Right, it's not going to happen – at least not the traditional way. There are things like IVF and
40 there's adoption but still a pretty big deal.
41
42 AJ: Would IVF be a possibility?
43
44 AM: Maybe. It would depend, I would need to have some tests done to see the condition of my
45 womb. They didn't really look at that so much when they did an ultrasound but my ovaries are
46 mainly trying to see . . . there is a small chance, there's like 5% of women with Turner's

1 Syndrome who can get pregnant spontaneously, although usually it's not recommended
2 because they're more prone to have complications and things like that.

3
4 AJ: And ovaries, I think, have some connection to the womb and how the production of the
5 hormones and all of those things is what sort of . . . in my unscientific thought process, helps
6 that to develop.

7
8 AM: Right, exactly. So I would need to ask a lot more questions to try to understand how that all
9 works. But I was told that some women with Turner's Syndrome are able to go that route. In
10 fact, when I went on a support website shortly after I was let in on the diagnosis, there were
11 women who came and told me their stories about going through IVF and having children that
12 way. But again, I would need to probably speak with a doctor when the time comes.

13
14 AJ: So you are on estrogen therapy for probably the rest of your life.

15
16 AM: Yeah.

17
18 AJ: Which is the same sort of treatment that transgender women deal with in terms of their own
19 transition from male to female. Do you think that is one of the reasons why intersex identities
20 are connected to the transgender community? Do you think it should be connected to the
21 transgender community? How do you feel about that?

22
23 AM: Well, very complicated questions. I would say that would be one of the reasons why. It
24 sometimes can be useful to connect them. In fact I even saw that when Jamie Ann first came
25 out to me and we were able to talk about hormone replacement therapy.

26
27 AJ: So Jamie Ann is your grandmother and identifies as a transgender woman.

28
29 AM: Yup, that's correct.

30
31 AJ: I just want to clarify that.

32
33 AM: Exactly. That was interesting for me because it was good to have another woman around who
34 knew, to some degree, what that's like. Because when I tried to talk about it with the cis gender
35 women in my family, they were like, "Well, it's basically the same." And in many ways they're
36 right and certainly from an external point of view it looks very much the same and has similar
37 effects. But, you know, still – it was good to have somebody who I could talk to about all that.
38 And even though her experience as a transgender woman and estrogen replacement therapy
39 differs from mine, there was a parallel there.

40
41 AJ: There is a parallel.

42
43 AM: What was interesting is when the rest of the family was like, "Well, why does she have to go
44 through all these physical changes," and particularly my great aunts were that way. To me, that
45 just seemed ludicrous because I could . . . all it took for me was to imagine what if I ended up in
46 some family who doesn't believe in western medicine and forbid me from getting estrogen
47 replacement therapy. Yet in my case, not doing it seemed . . . well, first of all, it would probably

1 not be the best idea because from a health perspective, simply because there can be certain
2 risks in not doing it – like increased risk for early onset osteoporosis and there’s a higher risk of
3 cancer, or at least as far as I understand it. I should check all this, but that’s how they explained
4 it to me. Again, the only reason why I would imagine somebody with Turner’s not going through
5 would be if they didn’t have a female identity and, in that case, we would have to go through a
6 different set of procedures to manage all that. But in my case, that made sense.

7
8 AJ: Do you think that . . . well, have you ever met another intersex person?

9
10 AM: I actually haven’t met anybody who . . . at least not that I know.

11
12 AJ: Openly identifies.

13
14 AM: Right, who will openly say it?

15
16 AJ: Which is one of the reasons why I’m so thrilled that you’re willing to talk about this on camera,
17 Ashley. I really appreciate it. It’s an identity that is just so foreign to people and so many
18 misconceptions about it. So, just really appreciate your willingness to sit down and share so
19 openly. Any thoughts about being engaged in activism or advocacy around intersex identities?

20
21 AM: Yeah. Well I would certainly love to get involved with something like that, it’s just the challenge
22 of finding it – because again, I haven’t met somebody who actually will openly say. I very well
23 could have met somebody and I know I’ve met other women with Turner’s Syndrome, but again
24 – they were probably like me . . . well, how I was before Jamie Ann told me about it, knowing
25 about their own condition but not about any others, and not even knowing that this word exists.
26 At least I’m pretty sure that’s how with went with the girls with Turner’s Syndrome who I met in
27 the support group that I went to over at the doctor’s office . . .

28
29 AJ: So there was some support – with your peers.

30
31 AM: Right, a little bit. However, it wasn’t as helpful as it could have been because . . . and it’s hard to
32 describe. I think it was mostly that there was a lot of talk of normalization, a big focus on that,
33 and while, again, I certainly do not regret going through estrogen therapy, it’s interesting to
34 hear people talk about it because a lot of it . . . they’ll talk about, “Oh, well you can look
35 normal.” Where it’s like . . . OK, what’s normal anyhow? What is that? And so that was
36 interesting. I remember one time this one doctor came in and said something about how there
37 are studies that show that women with Turner’s Syndrome don’t live as long and that freaked
38 me out. And then of course right after he said, “But, those studies aren’t very good.” So I was
39 thinking, “Why did you . . .?”

40
41 AJ: Even bring it up.

42
43 AM: Yeah. And I think the reason why is because in the more severe cases there can be heart and
44 kidney problems. So what they’re seeing in those statistics is probably women with Turner’s
45 Syndrome who have maybe something going on with their heart or their kidneys and that ended
46 up resulting in their death – but that might not be the case for women like me who don’t have
47 any of that. In fact, they did a whole . . . they did ultrasounds and all that stuff with my heart

1 shortly after my diagnosis – just to make sure there was nothing else happening. I got a clean
2 bill of health. I got it checked again recently because a doctor noticed a heart murmur, but then
3 they checked it again and everything was fine. The technician told me actually it's not
4 uncommon for people under the age of 30 to have small heart murmurs. She said, "I often get
5 kids sent in here about a heart murmur, but that's not unusual." So that made me feel better
6 because here I was like, "Oh, am I not going to get off on that." But then it was fine. But it's
7 been an interesting road with health. Sometimes whenever something happens I'm wondering .
8 ..

10 AJ: Wondering is it's related.

12 AM: Right. And most of the time it's not. But I just remember for a while there I had episodes with
13 back pain – right around where the kidneys are, and that freaked me out. But they checked and
14 it was like, "No, you're fine there." And then . . . what's interesting is the pain was kind of like
15 severe menstrual cramps, and this is before I went on the hormone replacement. We asked the
16 doctors who I went to see could this be related to Turner's or anything like that and they said,
17 "Well not that I know of." Again, the pain would be so bad that I would throw up. And this
18 happened for a while – sometimes through middle school where these random episodes of back
19 pain and vomiting would happen. We have no idea why they happened. But then once I got to
20 high school – it ended. We have never really bothered to investigate it. But still, sometimes
21 when I feel a bit of pain there . . .

23 AJ: Do you menstruate now?

25 AM: Oh yes, now I do. Which is why, sometimes, when I wonder if it's something to do with it
26 because they stopped once that happened – which is interesting. I remember, I started
27 menstruating at 16 and the episodes went away – they were gone. The doctor said, "Oh, well,
28 you must have just outgrown it." I'm sure I'm not being lied to . . . yeah.

30 AJ: Ashley, thank you so much for, again, being willing to be a part of this. We are a little over an
31 hour so we're going to have to end this now. But, you have brought some fascinating new light
32 to this project. Thank you very much.

34 AM: Thank you.