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ECHO: CARING FOR TRANSGENDER YOUTH IN CHALLENGING TIMES

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ECHOCaring for Transgender Youth in Challenging Times
[video transcript]

00:08

So thank you again, for having me this is for caring for transgender youth. in challenging times, I have no disclosures. So I'm just going to do the background information, the summary of the current legal landscape, the strategies for working with parents and the cases, just before we get into any backgrounds. These are the kinds of the sources of information, you can get all of these easily by Googling them. So the World Professional Association for Transgender Health has released its long awaited standards of care, version eight, this fall within the past month or so there's an entire chapter on adolescents. And you can get it at this link or just Google it and you will get to this link. Also, the American Academy of Pediatrics has a policy statement from 2018 with lead author, Dr. Jason Rafferty, and this is the link and that has to do with ensuring and for affirming care for LGBTQ youth, especially for transgender youth. There are also treatment guidelines from the Endocrine Society, most recently updated in 2017. And they're available at that link. And finally, a lot of us use, and you probably know about the UCSF guidelines that you can just find online, I believe there were less updated 2016. But they're very easy to access and easy to navigate through. So you can click to masculinizing hormones, and kind of get an outline of dosing and, and adverse effects and things like that. So if for some reason you have to log off, or kids stay for the whole presentation, this is really, if you're looking for information, these are great, great sources. Okay, so I just did one slide on transgender children. So there is no medical intervention for transgender children. And something that's pretty shocking and kind of some of the legal controversies is how much misinformation there is out there and and kind of bad science that is used to then try to justify sort of what seems to be kind of some biased opinion. So it's important that we all kind of spread the word. Young children are not getting hormones, and they're not getting surgery. So what do we recommend for a transgender child? And and these kids can present with their gender? The youngest I've heard is 18 months, certainly we hear 345 Fairly often that they tell their parents, why do people think I'm a girl, I'm actually a boy. And so we recommend affirmation, allow them to explore as we would for any child, try to promote their resilience and emotional well being as best we can use the name that they request and the pronoun. Consider age appropriate psychoeducation about gender diversity, for the youth. And for the whole family. There are many, many books, I can't even keep up with all of the books that come out, we do have a list we give to patients, and we try to update that as we can. And I got that from the psychiatrist. And then I try to keep up with it as best I can myself. So we don't want to conflate gender diversity or gender, gender in congruence with mental health, but we may want to consider individual or family therapy, you know, if needed, or if the gender and congruence or gender dysphoria is a source of significant distress. And then when would they get referred to a specialist if they were going to be a candidate for medical treatment, that would be Tanner stage two, ideally early Tanner stage two or before and we can monitor them for that, or Tanner stage three, but ideally, Tanner stage two. And so what age is that? So I use this acronym SAV, that sex assigned at birth girls, the average is 10 and a half years that they start puberty and if they were assigned male at birth, the average is 11.5 years, there's a range for both of those, say nine to 13 in the in the kids assigned female at birth and 10 to 14 in the kids assigned male at birth. And as I was writing that I just threw this box in here, the term genetic female is often used, it's a little bit problematic

because their gender identity is also genetic. They identify as a male say they were assigned female at birth, they identify as male that is genetic, it's coming from their head, there are studies showing the genetic there's there is some biology to it. So a lot of people replace that with sex assigned at birth instead of the term genetic female. And while I was on that, mentioning that I thought I would point out the term transition is often used. But for the kids, they don't see it as a transition. They see it as affirmation of who they are. They don't see it as a change in any way. It's just who they are and their ability to be themselves. So then, as puberty gender dysphoria may emerge, or worsen with puberty. And so some youth are candidates for for suppression of puberty. The best suppression is the GnRH agonists are also called GnRH analogs. Starting at Tanner stage two there has to be something to block before we give the blocker so we started at Tanner stage to clinically the first sign in sex assigned at birth girls is breast buds. That's the first sign of central puberty and in boys it's testicular enlargement in the girls the ovaries are good getting larger, but we can't see that clinically. So we go by the breast buds or Tanner stage two breasts and in the boys testicular enlargement, like for MLS, we can usually pick it up biochemically before we can pick it up clinically. So we do order the LH and FSH. What are the benefits of the blockers, they may eliminate the need for future surgery, you have a better long term outcome. And there are some pretty good Dutch longitudinal studies. No adolescents regretted their decision all went on to gender affirming hormone hormones. I didn't know we should mention that that's a selected population they've been assessed, they've been they're considered good candidates. For for this treatment, okay, so puberty continued the risks of GnRH agonists costs, they're very expensive. And it's insurance, we're lucky in New York State, we almost always can get insurance coverage. injection site reaction can happen, I've seen it once or twice a sterile lab says we usually if it happens once, we'll just treat it as you would any sterile lab says, Say ice packs and time. And then we'll try one more time at a different site. And if they have the same reaction, then we either have to switch their formulation or use something else for a blocker, you can have an initial flowering of puberty because of the mechanism of action because these are flooding the receptors in the pulsatile release of GnRH that triggers puberty. And so when you flood the receptors, you're you're shutting down the pulses, but that initial dose could feel like one big pulse and so you could have an initial worsening of puberty. After that first dose. Weight Gain is sometimes seen bone density you hear a lot about that does catch up once the hormones are started just being you're blocking puberty, puberty. Steroid hormones do promote bone mineral density accrual. If you're stalling if you're delaying puberty, you're not going to have that pubertal bone mineral density accrual, you're just going to stay as you were pre puberty and then once you start the hormones, it does seem to be there is catch up. But that is a reason not to delay starting hormones too long. The effects on fertility, your if you're not allowing endogenous puberty to ensue, you're not allowing fertility to develop and that's an important conversation. And then the other important piece to discuss as these are temporary so that you give the injections. We usually do the three month formulation, but it's also there's a one month formulation, there's a four month there's a six month there's an implantable subdermal device. But as soon as you take it away, it doesn't have long term effects. Puberty endogenous puberty then ensues. So it's completely temporary. It's often described as a pause button. There's a study that just came out recently that I thought I would add, it was 720 youth using GnRH agonists for gender dysphoria. The median age at the start was 14, and they followed them out to 19. And 98% had continued in gender affirming treatment. It's worth mentioning also, as we're talking about background, progestins predestines

are often used in this population. Sometimes it's used for non binary individuals or transgender males who don't have access to the GnRH agonist maybe for cost reasons. They can be used for menstrual suppression in trans males. Often norethindrone 0.35 milligrams is used the mini pill birth control pill for example, Micronaut, or there are many other brand names. Another one that works very well as a Justin or norethindrone five milligrams once a day or twice a day, if the five milligrams once a day isn't working. And then Provera or medroxyprogesterone acetate, Po is often used various doses 2.55 10 depo provera is another another option. These pedestrians are also used in transgender males who have persistent vaginal bleeding or who have a need for contraception. If they're having sex with someone with a functioning penis, they're on testosterone, the testosterone is not adequate contraception, so we usually give them the mini pal. Oops, my computer just shut down. I don't know if people can still see Hang on. Okay.

09:10

Okay, finally, the last few slides on the background just to talk about hormones. So, the kids have to meet criteria to get hormones and that includes a marked gender incongruence that is sustained over time. Any mental health problems are reasonably addressed. Not that they're, they're cured, but they're being addressed. And they have the emotional and cognitive maturity to assent. We have a fertility conversation first, the patient needs support from the parents. We not everyone requires this but we do still require a supporting letter from a therapist that they've worked with and says that they're a good candidate. And then for the transgender males, usually the earliest. We start as age age 14, they can get testosterone injections, usually subcutaneously can also be given I am transdermal once they're older, and then the sub The transdermal would be daily. The subcutaneous is every one to two weeks. And the adverse effects acne is pretty common. And then increased red blood cell count or polycythemia is something we watch for transgender females take estrogen, the earliest we start at age 13, and select cases, usually starting with an oral daily preparation. transdermal is is also a great way to give estrogen it's harder to get the lower doses. And it's sometimes harder to get insurance coverage. But there is some emerging evidence that the transdermal formulation confers a lower risk of blood clot. So certainly as they get older, if they're smokers, if they have other risk factors, transdermal estrogen is a great way to go for these patients. In terms of the kids taking testosterone, the transdermal testosterone, the gel is daily preparation, usually the levels aren't quite as high and there's sometimes inconsistent absorption depending on how quickly they spread it out. I believe some of them really like it, I think there's more consistent levels, although they may not be as high and then some patients don't care for the transdermal testosterone, injectable estrogen is really tough, you can get pretty high levels initially. And I think that, you know, we all worry there's a higher risk of blood clot with injectable estrogen harder to keep steady levels Occasionally, when you really can't get a level with with oral or transdermal I have used it. So the ICD 11 has gender incongruence as the term meaning there's a mismatch. It's not a mental health diagnosis. And here it's it's just I just quoted it, you can Google this and find this yourself. But it's a marked and persistent in congruence between their experience gender and their assigned sex. And it leads to a desire to transition which they put the word transition in quotes, in order to live and be accepted as a person of their experience gender, to make the body align to diagnosis can't be assigned prior to the onset of puberty, there's another diagnosis for children. And just gender variant behavior and preferences alone are not a basis. So the youth will say they are that gender, not they want to be that gender, but they truly are that

gender, they experience life as that gender. And then I put the childhood definition also very similar, except that they include included that it should have persisted for two years to get the diagnosis. And it's very classic. And children and children often don't know the word transgender, or they don't know any sort of LGBTQ terminology or any they don't have a sexual orientation yet, or sexual preferences. They'll just say, I don't know what you're talking about. With all that stuff. I'm just telling you, I'm a girl, or I'm a boy, I think we all know, sexual orientation and gender identity are two separate two separate items. Okay, so here's some of the legal slides. These were initially written by Abigail English, who's an attorney who is the director of the Center for adolescent health and the law in North Carolina, and she's an adjunct professor of Public Health and the School of Public Health at UNC. She's a former president of the Society for adolescent medicine. And we did a presentation together at the Society of adolescent medicine and at the American Society for bioethics and humanities. And this was sort of her part of that workshop. I just took a few few slides with her permission. So it's hard for me to keep up with this. And I think it's nice to have it summarized. So first of all federal protections in health care. So there's section 1557, of the Affordable Care Act, in which discrimination in health care is prohibited based on color, national origin, sex, age or disability, then the big question is what is meant by the term sex here, so that was interpreted to include sexual orientation and gender identity in 2016, under the Obama administration, then that was rolled back in 2020. Then it was revived in 2021 by the Biden administration and in 2022, revised regulation was proposed by the Department of Health and Human Services, to reinstate the protections as HHS had them back in 2016. So there was some potential protection in the Affordable Care Act. There's also the proposed federal equality act, and that provides protection against discrimination on the basis of sexual orientation and gender identity that passed the House of Representatives in 2021, but has been pending in the Senate. Okay, so some barriers and protections at the state level that was a brief summary of federal level. So half of states do not prohibit discrimination against LGBTQ individuals in private health insurance, and approximately 1/5 The states explicitly exclude transgender coverage in Medicaid. On the other side, there are protection so about half of states explicitly prohibit health insurance providers from refusing coverage of transgender care, and approximately half of states do explicitly provide coverage in Medicaid for transgender care. are so it's so tough on these kids because their access really depends on where they live and what state they're, they're born in. Okay, and now finally the the last two slides on the the legal aspect is this these bans on gender affirming care for youth. So three states this was as of October 29, three states have enacted laws banning gender affirming care for youth. First was Arkansas in 2021. They banned all gender affirming care for youth puberty blockers, hormone therapy and surgery and referrals. Then Alabama and 2022 went a little bit farther, they banned all the things that Arkansas banned, but they also instituted criminal penalties for anyone to engage or cause us to receive these, these treatments, which I think included 10 years in jail. There have been federal lawsuits challenging the constitutionality and medical basis of both of these laws. In Arkansas, an injunction was granted so the law could not be implemented. And there's a trial currently underway in Alabama. injunction was granted to to prevent the enforcement of the ban on puberty blockers and hormones and appeal is pending. And then society of adolescent medicine the American Academy of Pediatrics and other health care organizations have filed amicus briefs or friend of the court briefs in Arkansas and Alabama supporting gender affirming care and access for youth. And then Arizona in 2022, banned gender affirming surgical treatments for minors, which

in practice is rarely done, or almost never done, except for with the exception of occasional top surgery for transgender males a mastectomy for transgender males. And even that is done in select cases with you know, at least a year on hormones and parental consent and two letters of support. And in those cases, those youth are living as a male in living as a male to have female breasts contour is very difficult. They can't swim, they can't go outside. They're wearing binders. They're duct tape or these stick tight tight binders with a lot of sweating and uncomfortable a skin breakdown underneath sometimes chest pain. So those those kids, it really is medically necessary. Finally, the last legal slide is this gross mischaracterization of gender affirming care is child abuse. This isn't a legal thing or a law. It's just a Texas attorney general opinion then that that was then supported by a directive from the governor of Texas. So they said gender affirming puberty blockers hormones and surgeries may constitute Child Abuse and Child Protective Services was instructed to investigate reports of gender affirming care as child abuse, and that these investigations may include both health care professionals and parents. This has been challenged in court with two lawsuits. Temporary injunctions have been issued. So this cannot be enforced. Right now. Litigation is ongoing. With these. I don't know if they're going to end up in the Supreme Court at some point at all of these the Alabama and Arizona etc. The department federally the Department of Health and Human Services issued guidance in opposition to the Texas policy in March of this year. But that guidance was vacated by federal court in October. This litigation is ongoing. Okay, so here are four cases feel free to jump in with thoughts, questions or comments. At any, any time. The first one is about kind of working with parents.

18:35

Okay, this is an 11 year old boy. He was assigned female at birth, he's been identifying as a boy since age two. He wears his hair short and as stereotypically male style. Typical male clothes plays on boys sports teams, most of his friends are male. They don't know that he was assigned female at birth. He has many good friends. He has no psychological symptoms or concerns. He presents to our office with his mother asking for blockers he's terrified of quote turning into a girl before puberty. The if the kids cut their hair in a stereotypical style and we're by their clothes in the boys section. They'll look like a boy even though he's had no you know, no medicine. So typically we we gather the history we get the perspective of the patient and the guardian. In this case, the gender identity has been insistent, persistent and consistent. Over years, the intensity of his dysphoria has worsened recently, with the possible onset of puberty, we would want to assess the stage of puberty by physical exam growth chart and biochemically and we order a pediatric LH, which for us is a standout test, but it's very sensitive and it's the earliest way we can catch the beginnings of puberty. But in this case, the mother said the father is completely opposed to treatment. He thinks dG is a tomboy, he'll outgrow this. He's too young to know what's best. And a father found something online from something called the ACP which is the American College of Pediatricians, which has been able to hate group by the Southern Poverty loss loss society and is is actually an anti LGBTQ group of a small group of pediatricians who are against things like the HPV vaccine adoption by gay and lesbian parents, and transgender care. So how do we handle this? How do we talk to parent, in this case, the parent was estranged hadn't spent a lot of time with the boy. So hadn't lived with it to see most of the parents who are living with it over the years come to see how very real and powerful how consistent, insistent and persistent this is. So a few talking points, I certainly don't have all the

the answers here. And these, these conversations are delicate and challenging. So one thing we do know parents cannot control the child's gender identity. But their reaction, their response does influence a child's mental health. We also know we want to have an affirming proach, for approach for the parents as well as for the youth, the parents are going through a big change, they need time and support. Sometimes patience is what's needed. And that's one thing we tell the kids so we want to try to foster support and affirmation in the parents so we can explore their concerns. And then we can share information. One key point is doing nothing is not neutral, the youth is suffering, there's a risk for suicide, there's ongoing puberty, that's ensuing that some of its irreversible. For example, in an identified female, the deep voice the Adam's apple, those are things we can't get rid of ever. We can discuss the medical risks and benefits and psychological risks of not of no treatment and benefits of treatment. And we can refer to specialized therapists who have really there are many who have expertise in this art and are comfortable working with families. And also we can refer to transparent support groups often to the cue center. The Family Acceptance Project is a great source of information. And you can find this by googling it. They suggest recognizing that that parents and caregivers were seen as rejecting their LGBT child. These parents are motivated by care and concern. They want to help their child fit in have a good life and be accepted by others. And they believe that this behavior is is actually helping. So we need to support there needs to be heard and understood. We need to understand that the parents experienced their own lack of knowledge about LGBT issues as an inadequacy that feels disempowering and can be shameful or embarrassing. So we want to try to build a strong alliance with the family. And then we want to help them be aware of the consequences of their behavior in terms of how that influences the child and the youth mental health. So socially transitioned children who are supported in the gender identity have developmentally normative levels of depression, and only minimal elevations and anxiety, suggesting that psychopathology is not inevitable. especially striking is the comparison with reports of children with this as the old with gender identity disorder, socially transitioned children have notably lower rates of internalizing psychopathology than previously reported. So this is also from that Family Acceptance Project. And the most striking piece is this attempted suicide here. So trans youth with support it with supportive parents 4% have attempted suicide, trans youth with unsupportive parents, almost 60% have attempted suicide. And so again, the parents can't control the gender identity, but they do have an influence over the mental health. So we we try to let them know that reactions that are experienced as rejection, contribute to serious health concerns and inhibit the child's development and well being all children need affirmation at home. We do know that rejecting families tend to become less rejecting over time, and access to accurate information is critical in this process. It's important to tell the youth that that there is hope, and that we can continue to meet with a family and we can have a therapist involved. So why not just wait until they're adults? What if the parent says, Well, fine, this kid's transgender, but we're not going to do anything until they're 18. So a few points here, puberty causes irreversible changes. It can be extremely distressing even unbearable for these children, allowing it to progress is not neutral. And studies have shown that GnRH analogues decreased suffering decreased depressive symptoms, improvement in general mental health functioning, and all patients went on to gender affirming hormone treatment. So the the blockers are reversible, temporary and no long term harms. Sometimes it's helpful to talk about the MRI studies. There are structural brain differences between the sexes and transgender individuals have brains that more closely match the affirms gender We there are also some in addition to

these structural studies, there are some functional studies having to do with hypothalamic activation to odorous steroids. And it it more matches the the affirms gender. And then this other sort of functional study adolescents with gender dysphoria Phoria had MRI activation responses similar to those of their affirms that gender and not to sex assigned at birth. That can be helpful in terms of understanding there's a biological basis. And then finally, here's a quote from a parent when my daughter was little I spent so much time fussing over how she looked, I should have been concerned about how she felt we didn't know about transgender, but I know how sad and depressed she got right before middle school, the school helped us find a counselor and that's when we found out how hopeless she felt. I wanted to make sure she wasn't rejected by others, but instead, I was the one rejecting her. I'm so grateful I could change things before it was too late. So just having parents work with a therapist or joining a transparent group and seeing other parents that have gone through this and seeing that you can live a full and happy and healthy life as a transgender individual is is so helpful.
[End Transcript]