ORAL HISTORY INTERVIEW WITH DEANNA ADKINS

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COLLECTION SUMMARY

This collection features an oral history I conducted with Dr. Deanna Adkins on 02 12, 2024 for the Bass Connections Agents of Change oral history project. The 90-minute interview was conducted in the Duke University Medical Library. Our conversation explored Dr. Adkin's childhood and family, her pathway into endocrinology, how she became involved in gender-affirming care, her interdisciplinary approach to gender-affirming care, her legal advocacy work, and her advocacy to ensure the Duke Hospital system is welcoming to LGBTQ+ patients. The themes of these interviews include medical care for LGBTQ+, trans rights, and the relationship between medicine and advocacy.

This document contains the following:

- Short biography of interviewee (pg. 2)
- Timecoded topic log of the interview recordings (pg. 3-4)
- Transcript of the interview (pg. 5-23)

The materials we are submitting also include the following separate files:

- Audio files of the interview*
 - O Stereo .WAV file of the original interview audio
 - o Mono .MP3 mixdown of the original interview audio for access purposes
- Scan of a signed consent form
- Photograph of interviewee (credit: Duke Department of Pediatrics)

^{*}At the end of the interview recording, we recorded a self-introduction and room tone for use in a production edit of the interview.

BIOGRAPHY

Dr. Deanna Adkins is the director and founder of Duke Child and Adolescent Gender Care Clinic. Her mother was an accountant for a rural health system, and she instilled in Dr. Adkins that, if she was going to become a doctor, she needed to truly care for her patients. Dr. Adkins originally began practicing endocrinology because she wanted the chance to see her patients all throughout their youth and work with "the whole spectrum of kids." In 2013, a primary care doctor needed to refer a transgender patient to an endocrinologist, and my sheer chance and "fate," Dr. Adkins received the referral. Afterwards, she began to take more transgender patients upon realizing they were having to travel states away to access medical care. She found the work "incredibly rewarding" because of the lifesaving effect it had on her patients and chose to commit to specializing in gender-affirming care. When she founded the clinic, she quickly realized quality gender-affirming care would require a multidisciplinary team and began to recruit more practitioners. For the first few years, the clinic was the only option for genderaffirming care for transgender youth in the Southeast, and the number of patients multiplied. When one of her patients sued a Florida school system for the right to use the bathroom corresponding with their identity, Dr. Adkins became an expert witness for the case. This led to a close relationship with the ACLU and involvement in more cases as an expert witness. Additionally, Dr. Adkins became involved in LGBTQ+ advocacy within the Duke medical system by ensuring medical staff were trained in practices such as pronoun sharing, and that medical data systems were designed with LGBTQ+ patients in mind.

INTERVIEW TOPIC LOG (Adkins Interview.wav)

- 0:28 Growing up, impact of family, decision to become doctor, mother's negative impression of doctors
- 1:31 Early advocacy sentiment
- 1:53 College education at Georgia Tech, engineering and molecular biology background,
- Medical College of Georgia, residency in North Carolina
- 3:06 Interest in preventative healthcare, influence of older sister
- 4:04 Interest in endocrinology, diabetes in family
- 5:47 First referrals of transgender patients
- 7:09 Realizing similarities between gender affirming care and general endocrinology
- 7:44 Decision to permanently train in gender affirming care
- 8:01 Connection to patients
- 8:13 Experience with multidisciplinary medical teams, gender clinic founding in 2015
- 8:37 Interdisciplinary recruits and volunteers, social worker Chris Russell, religious care
- 11:25 Other interdisciplinary teams in Duke Medical pediatrics
- 12:30 Pure chance or "fate" of original involvement in transgender care
- 12:59 Rewarding nature of gender affirming care, excitement from patients
- 14:37 Relationship with patients' parents, use of medical data and information to ease concerns
- 16:58 Effect of North Carolina House Bill 808, pain of turning away prospective patients
- 19:23 Power of being advocate and speaking up
- 20:12 Support from Duke, benefits of working in a private institution
- 21:02 Involvement in legal system, anxiety, support from legal experts, learning about legal system
- 24:06 Support from Duke Communications, vetting of media outlets and organizations to talk to, Human Rights Campaign
- 25:55 Challenges of advocating for transgender youth as a ciswoman, empowering transgender youth voices
- 27:17 Advocacy to make hospital system and staff more accepting to transgender people, pronoun training and sharing
- 29:41 Work with Epic medical records system
- 30:31 LGBT+ advocacy at Duke School of Medicine, Sex and Gender Diversity Inclusion Council, inclusivity training
- 32:32 Sex and Gender Wellness Clinic, LGBTQ+ unity, LGBTQ+ organizing with entire Duke community
- 32:24 Clinic growth, importance of recruiting from within own medical trainees
- 35:34 Need for more administrative support, pressure on social worker
- 36:06 Interest from medical students, Cultural Health and Health Disparities Course
- 37:10 North Carolina "Bathroom Bill," protective feeling towards patients
- 38:24 Increased awareness of gender clinic from "Bathroom Bill"
- 39:23 Policy vs advocacy work, learning how to be an advocate
- 41:22 Learning from others, American Academy of Pediatrics advocacy course
- 42:10 Learning how to convince with data and stories
- 43:08 First legal cases, Lambda Legal, ACLU, being an expert witness and care provider, Adams
- v. The School Board of St. John's County, Florida
- 44:37 Positive relationship with legal experts, Pauli Murray Award

- 46:26 Effect of wide geography region of care, effect of legislative attacks on other clinics
- 48:39 Future of gender affirming care at Duke. adult gender-affirming care, hope
- 50:16 Talking to patients about having to wait to access care
- 51:40 Recognition for work, learning to accept recognition
- 53:22 Learning from other disciplines, reliance on other providers, limitations of subspecialties
- 55:17 Continued work in inpatient services and general endocrinology, division of clinical time
- 56:09 Effect on advocacy of being from the South
- 57:22 Involvement with Equality NC, talking to state legislators, counteracting misinformation
- 59:38 Learning from patients, importance of staying informed on gender affirming care
- 1:01:15 Learning from parents, empathy for parents, education sessions for parents in the right setting
- 1:03:18 Importance of understanding patients' self-identification and terminology, separation of gender identity and sexual orientation
- 1:05:25 New research, long history of affirmative care data, limitations of data, combatting skepticism of gender affirming care research
- 1:08:09 Overwhelming volume of work, extremely rapid growth in involvement in affirmative care
- 1:09:29 Setting boundaries, small size of department, setting limits on advocacy work
- 1:11:45 Patient voices, involving patients in medical school education, patient feedback, community advisory board
- 1:12:57 Registries to track long-term outcomes, tracking geriatric and adult outcomes
- 1:13:29 UNC Master of Social Work study for patient feedback, electronic health records (EHR) training, training modules for staff
- 1:15:15 Expansion of training modules over time, requirements to display ally symbol
- 1:16:40 Learning from early patients, designing treatment plans to meet patients goals
- 1:17:44 Learning about everyday struggles for transgender youth, training exercise for medical students to understand struggles of daily life
- 1:20:35 Joy of successfully helping patients transition, life changing effect of gender affirming care, patients becoming advocates
- 1:23:08 Empathy for reluctant parents, overcoming parent fear with education, fear for children who do not access clinic at all

TRANSCRIPTION (Adkins Interview.wav)

CO 0:06

It's February 12 at 3:09pm, and we're here with Dr. Deanna Atkins. And again, thank you so much for being here with us. And to start off, what was your- Can you tell us a little bit about your life growing up? What some of your early influences were?

DA 0:28

Yeah, so I grew up in Georgia. My family were primarily farmers. But my mom was an accountant, and she actually worked in hospitals. And she worked for a company that moved us around from rural hospital to rural hospital every few years. And so I spent a lot of time in hospitals growing up and hearing about them. And then my sister, who's 12 years older than me, became a nurse. And I think between those two things, it was destiny that I'd be [laughter] a doctor. But my mom, being an accountant, didn't really- wasn't a real big fan of the idea, to be honest. She- in fact, she did speak to me for about three months after I told her I wanted to be a doctor [laughter]. But I think when we chatted about it. I'm like, "Mom, I'm not gonna be like those doctors. I'm gonna be a good doctor. I'm gonna listen to my patients. I'm gonna-" you know. So anyway, I think those early things were from a long time ago, as far as being an advocate and listening to my patients and mom instilling that into me, "If you're going to do this, you need to do a good job."

So, then I went to college as an undergraduate at Georgia Tech, and thought, "Well, I'll do engineering as a backup, just in case," and then discovered engineering is really hard. So my actual undergraduate degree is in molecular biology and genetics, which serves me really well. A lot of what I do involves genetic conditions and things like that. So also, my undergraduate research was in the early days of researching HIV infection and understanding what the virus looked like and how it worked. And so again, another little thread weaving its way into kind of where I've been and come to. And then I went to the Medical College of Georgia, and I wound up in North Carolina for a residency and fellowship. So I stayed [laughter].

CO 2:51

And of course, molecular biology isn't hard at all.

DA 2:54

[Laughter] Right? Yeah, of course not.

CO 2:56

So what was- What drew you to becoming a doctor given your mom's negative experiences with them?

DA 3:06

Yeah, I think it was- I knew I wanted to- I saw a lot of the things that happened to people as they grew older. And it seemed to me that preventing that was a key part of medicine that at that time, a million years ago, people weren't paying attention to. And it was really something that my sister also talked to me a lot about. She was a P.E. instructor before she became a nurse. And so she was big into teaching kids how to be athletic and eat well, and she did the same for me. And

that kind of- I think my sister had more of an influence on me than my mom. She was like my other mother because she was 12 years older than me.

CO 3:58

Yeah. And what led you to endocrinology in particular?

DA 4:04

Yeah, more family stuff I guess. My grandmother and my mother both had diabetes. And soboth the preventable kind. And so again, leading into the trying to stay healthy and get ahead of things that might be a problem and learning how that all worked. And then pediatric endocrinology in particular because that puberty thing was a rough time for me. And I wanted to really know what are these hormones and what are they doing to me? So, all of that led me down the road to endocrinology. And it's also- I didn't- I wanted to do a subspecialty where I got to take care of the whole spectrum of kids. It's not just babies. A lot of specialties are NICU or just babies or just this one thing for this short period of time. And endocrinology, once the patient has the endocrine problem, it's with them forever. And so you get the whole, whole gamut, and you see them all the time. It's just like being a general pediatrician with all the good stuff without having to do the like, ear aches and the vaccines and [laughter] things like that, to me. And the physiology was great. I think that endocrine- The latent engineer and me wants to tweak this, and then that goes up, and tweak that and then this goes down.

CO 5:41

And how did you first get involved in working with transgender patients?

DA 5:47

Yeah. So around 2013 or so, a local mental health provider, just referred a patient to me, and I was reviewing the information, and I was like, "This is great and all, but I don't know how to do this. I've never done this before." And so I called her and I said, "I'll try and hook them up with someone out of- that knows-" and then realized that they were gonna have to go to Boston, or Toronto. At that point in time, there weren't a lot of places that were doing this work, and nowhere convenient or close. And so- And then shortly after that, I got a call from another endocrinologist working at Columbia who was seeing patients from here who said, "This patient's really traveling to New York every so often to see me, and I'd be really grateful if you would help me take care of this patient." And I was like, "I don't know what to do." And it turns out, he was a person that wrote all the papers on transgender care and youth at the time. And so he's like, "I'll send you all my papers. If you have any questions you can call me." And I said, "Okay, fine." And so I started taking care of that patient, and I read all of his articles.

And when I read all these articles, realized this is stuff I'm already doing. This is what I do with my cisgender patients. I've used these medicines for 15 years now. I know how they use them, what their side effects are, the dosing. This is not going to be anything hard, and it really is needed. And by that point in time, I had gotten more requests. And I was like, "Okay, somebody's got to do this work. I know how I figured this out, I understand it, I'm gonna go dig in and do my own training. And so I started going to different trainings and learning the specifics of- The patients are amazing. Once I started seeing the patients I was done for. I was like, "Okay, I could just do only this. This would be great." So, they have a lot of challenges, and I'm used to

working in a multidisciplinary team. Just like diabetes, we have a multidisciplinary team. And so I created that in my own work. And that started in 2015, and been ever since.

CO 8:33

What kind of other professionals were involved in the team?

DA 8:37

So my first partner was our pediatric urologist. And primarily, we started a combination clinic for kids with differences of sex development to start with, and combined it with our transgender patients. And he was taking the lead on those in that area, and then I took the lead in the other half. And that allowed us to basically get clinic space because it's hard to get clinic space here at Duke. But we did that. And then once I got that space, I started to talk about the kind of team members I wanted. And out of what must have been my dreams, our social worker that works with us, Chris Russell, came up and was like, "I hear you're starting a kid clinic for transgender kids and I want to be involved." I'm like, "Well alright then." Because I knew I needed a mental health provider. It was absolutely key to have that if nothing else in your multidisciplinary team. So she was my second recruit, and then we had a psychiatrist and a psychologist in the early years all, working together in clinic together. And then we started to get like GYN and nutrition. And the chaplain actually came to us and said, "We really want to be involved." We know these kids are going to often struggle with that religious part of their identity too, and maybe not wanting to- wanting to know how to weave that all together. And so then we got- adult endocrinology started a clinic a few years after us. We kind of recruited them in, and physical therapy and voice therapy. And I'm working with someone in orthopedics now because we do things with breastplates that are fun and interesting when you put them through different puberty. But so, I'm sure they are more that I'm missing, but like, broad people.

CO 10:56

Were these largely people that came to you, or- What was it like trying to recruit people for this?

DA 11:01

Yeah, pretty much everybody came to us. Like they heard about our work and came to us and said, "I really want to be involved. This is-" Which was not the way it usually is when you're trying to partner with something, someone. It's like pulling teeth. "Who wants to be involved with this study?" But no, we've just- it's been great.

CO 11:22

And was there anything like this available at Duke before?

DA 11:25

No. Yeah, there were a few multidisciplinary teams for other kinds of things, but certainly not this. And I think we were only the third group to put together a multidisciplinary team within pediatrics. They had a long standing one at- for kids with [pause] spinal disorders. But they didn't really have one for much of anything else. And since then, we've been able to help replicate other teams to make it a better process. Like for kids with Duchenne muscular dystrophy. They have a team now. And then for- CF [cystic fibrosis] had a team, but- I think

they were one of the other groups that had a team before us. But I think it's been helpful for us to lead and figure that all out.

CO 12:20

And if you don't mind me looping back a little bit, your friend who started referring these patients to you, do you know why she chose you to be the person to refer them to?

DA 12:30

I have no idea. My guess might be that my last name is "A" and I was first on the list. But you know, you may have just gotten lucky. I don't know. I may have even just been on call. It was fate. We'll go with fate.

CO 12:45

And you're talking- I've read in some of your interviews that you are really clear about how the work that you do is life saving. And what is it like to provide a treatment like that?

DA 12:59

Yeah, it's amazing. It's so rewarding. When you talk to the patients, and you're getting- We do a lot of work with them before, but when they realize that they're actually going to get to take gender affirming hormones, it's really going to happen, they are so relieved, and so happy and excited. And tears of joy. I've seen- in having them come back and say that they finally feel like they see who they are in the mirror, and they hear in their ears who they were meant to be. It's just incredible, incredibly rewarding.

CO 13:53

So with your involvement with the patients, you- I saw on your video on the Duke Medical website, in the little intro video, you talk about how it's really important to you to, as a pediatric doctor, listen to the children in addition to the families. How- What is that like in terms of trying to work with parents, as well as- How do you- I'm sorry, I'm phrasing this strangely [laughter]. But what is it like trying to prioritize the voice I guess of the children that you work with?

DA 14:37

Yeah, it's one of the hardest things I do really honestly, especially in this area. I mean, it always is in pediatrics. There are a lot of adult providers. If you ask them what were the things that they went into adult medicine [for], [it] is because they wanted to have only one patient and instead of three. But so, in pediatrics we're kind of used to having to deal with another set of thoughts and ideas and- But in this scenario, sometimes not all the parties, not parents and the child or the youth are on the same page. It's great when they are. And I would say, most of the patients who come to see me are, but we do have some who are not on the same page. And I think presenting the facts, the medical data, helps, but it's also making that relationship [that] is the most important part. If you don't make a solid relationship with that parent and let them know that you're not going to do anything a) without their permission, because it's their child, unless you think that the patient is in danger, then they can relax. And they can listen and absorb a little bit better. It's when they come in, and they're first very defensive, and they don't understand. I'm not there to make people transgender. [Laughter] I can't do that. That's not possible. I'm there to help people who are transgender become the person who they were meant to be and explain the pluses

and minuses of all the ways that you get there. And that, generally, will win people over, most of the time.

CO 16:37

That makes sense. And how have you noticed for your patients, how over time- Has it changed over time, the care that's available to your patients outside of the clinic as well? Or differences in what their lives are looking like outside of the clinic, in terms of care that you provide?

DA 16:58

Well- We are no longer able to provide gender affirming hormones to patients who've never been on them before. That started this August, and that's been a really horrible situation. It's been gut wrenching. For families who didn't know and weren't paying attention, and they come in, and we have to tell them. And it happens over and over again every week. There's somebody who comes in and had no idea that our legislature was passing laws that restricted this care. And so, luckily for us, the patients who were already in care can still get care in the state of North Carolina, but we've been having to help patients find other places to get care outside of North Carolina if they hadn't started on treatment before. And many of these patients wait six months to see me and they've often waited years to tell their parents, and then their parents make the appointment. And then it's six months, and then they find out they have to wait another three to six months to see another provider in another state. And sometimes it's just hard to bear, especially for those who are seriously struggling with depression and anxiety and may be suicidal in that timeframe. And we've lost patients in that wait time, trying to get them to care. And they didn't make it. So that part is just excruciatingly painful knowing that could have been prevented specifically. But we'll do the best we can to try and mitigate what we can.

CO 18:57

That makes sense. And speaking of which, the work that you do in being an advocate for those patients, in light of how politically charged your work has gotten, is it- Does it feel more overwhelming or empowering for you to be providing that kind of care?

DA 19:23

[Pause] There's an element of overwhelm in that you just don't know the outcome. But I definitely feel empowered knowing how to talk to the people that I need to talk to and how to reach out and who to reach out to to get support, both legally and financially for some of our patients. And just knowing that- I guess that my- that me speaking up means something, and it's going to amplify those voices of my group is huge. And I think a big part of that has been my ability to do that here because it's a private institution. That gives me a little more leverage. Were I in the same position at a state funded institution, it would be more difficult. And also, Duke has been great about supporting our work and being behind what we do. And so I'm super appreciative of the fact, and the privilege I have of being able to do that.

CO 20:49

And along those lines, what has it been like to have to transition into being a legal advocate in some ways? Like, what has it been like being an ACLU [American Civil Liberties Union] expert witness?

DA 21:02

Yeah. It's not something I ever wanted to do. In fact, one of my goals in life was never to have to be involved in the legal system in any way. [Laughter] And I don't enjoy it. I have some baseline anxiety that I've had to learn to really channel to be able to do some of the work in a most effective manner. And learning to be very careful about how you word things and how you answer things. And learning what the process is for a trial even. I had no idea. I'm like, "I don't know what that means. I'm sorry." But the folks that I work with have been fantastic about helping me with that process, which is great. And some of the smartest human beings I've ever met in my life, which is awesome. And I feel really grateful to have been involved and learn from them. But I would say it's definitely been something that I have to be careful about how much of it I do to keep my life in balance. But- And knowing that trying to get other people involved is important as well. So that we, all of us who are doing this work, can show up for our patients. And helping them learn the ropes without maybe some of the trip and fall that I might have had has been really good, too. So I've been trying to help other people that are doing this work help out.

CO 22:52

Was it- Did you ever- Were you ever uncertain about becoming one of the expert witnesses?

DA 23:06

I would say that yeah, I have had some concern. I think it was already in it before I realized [Laughter] what I had done. And then was like, "Oh, wait a minute. This is gonna be challenging." But also, seeing my patients get what they need out of those particular forays into into my work was really helpful and reinforced thatit was worth it.

CO 23:44

That makes sense. Speaking- You talk about having to be a little bit careful about not- Like giving yourself space to say no to some of them. How do you decide what causes to get involved in, what news organizations to agree to speak to?

DA 24:06

Right, that last one's probably a little easier to answer. Duke Communications actually will vet anybody that asks to speak to me, and they'll read all of their previous writings and see what they're- ask them what they're here to talk about and guide the conversation as well so that there's less risk of being- making a mistake there. So that's been really helpful. I would say that trying to figure out what- Otherwise, just being careful about looking at who it is that you're working with. Like when the Human Rights Campaign came to me and asked me to help with writing their school information for parents. And at first, I was like, "Who are you? And give me a minute. And-" But of course, once I had seen their work, I was like, "I'm in," or, "When are we meeting?" [Laughter] "How do I help?" But you just have to be very careful.

CO 25:35

And I was wondering, too, about you yourself being not transgender. What has that been like to be asked by news organizations to represent what transgender youth say and need? Has that been difficult to navigate?

DA 25:55

Yeah. Certainly I feel weird being the person to answer those questions. Certainly I would much prefer the community be the ones that are speaking for themselves. And I definitely advocate for, when I am asked to speak, allowing voices of the community to be involved. And we have had a lot of our patients who have shared their stories with different outlets to try and help with that. I think that it's- You have to be very careful about that. And I can tell you the stories that I've heard and how they've influenced me and that sort of thing, but I have to be honest and say, "This is what I'm hearing, but if you want- You gotta go to the source sometimes." And yeah, I try to be careful about that.

CO 27:01

That makes sense. And have you been involved in any advocacy outside of the clinic With the broader transgender community or the LGBTQ community?

DA 27:17

It's a good question. I feel like - Other than the policies and trying to get some of the laws turned over, I think that's been my biggest focus, after directly working within the hospital system to change some things there. Because systematically, there's just a lot of not optimal systems for patients with chosen name. And getting the system up to date with their gender marker and all of those things. As well as just the basic care for when the patient comes in, and using the right name and pronouns, and how to ask those questions, and teaching people how to be comfortable with that. And knowing that it can change from was one visit to another because that's a whole other thing that people are like, "That can change?" I'm like, "That can change." So that has been another thing, to remind people that every time you meet a patient, you should introduce yourself, and ask, and share, and that reciprocation opens a dialogue and makes people feel comfortable about chosen name and pronouns. So, I've done a lot of that within Duke.

And it's harder than you would think. In a health system too there are lots of- We have our computer system, and we've been able to change that main medical system. But the lab has a different program written by a different company with a different set of rules who may not have any idea anything about LGBT. "You mean you can have two mothers? Oh, you can have two fathers. Wow," when you start digging in the weeds. So I've done a lot of digging in the weeds. I have one more project to tackle, one company that still kind of a burr in the system. Finally weeded out the rest, but that's where I am.

CO 29:35

And has most of that been at Duke, or does it ever have to Ibranch out to many other-?

DA 29:41

Yeah, for the other companies, right? Yeah, I'm like- I've worked with Epic, who is one of our medical record systems and they're out of [pause] Minnesota, I believe. And I was on their Pediatric Endocrine Steering Committee for a while and worked through that way and then- So you definitely have to go different routes depending on where things are sourced and stuff.

CO 30:09

That makes sense, yeah. And you mentioned before they you've been really lucky to be working with the Duke administration. And I was wondering how that's changed over time, or just general education about what people know about transgender youth or the LGBT community from the administration, from the hospital? Has it changed?

DA 30:31

Oh, yeah. I think it's definitely changed. I feel like we've made a lot of progress. I feel like when I first started this work, it was barely on the radar. They had- The medical school had a committee, a council, and still does, and I'm a part of it. Sex and Gender- Sex and Gender Diversity and Inclusion Council. And we- they had been around for a while, and they had started the groundwork for the LGBTQ+ group within the medical school, and that started to branch out more into the health system. And getting involved with them is where I've made most of my forays into making improvements within the overall system. And now we have trainings that anyone who's hired has to go through to understand what our values are around inclusivity with the LGBTQ community, which we had nothing like that before. I helped with making thedesigning the scenarios and making the videos and talking- getting the right people in to do thewhat's the word I'm looking for? Contracting, that's the word. I knew it was like a C word. Contracting groups that we knew did a good job with the LGBT community at other places and getting them involved at Duke. So it's been really rewarding to see it progress for sure.

CO 32:19

That makes a lot of sense. And sort of along those lines, it listed- You're also involved in the Sex and Gender Wellness Clinic, and I was wondering if that's also focused on LGBT related issues, or if it's-

DA 32:32

Yeah, so that's inclusive of the whole LGBTQ+ group. We are- because I grew out of that bigger partnership, that I developed in clinic once I started meeting people in other areas of clinical care. And we realized that the whole- the L, G, and B, and the Q and the I and the A, and the SS+ were- They needed us too. And each of us had our own expertise. We started to really bring that together. And then we had some folks in the global health area that were doing broader work across the world with the LGBTQ+ community. And so they really helped us organize that group and bring in people from policy and from the law school and the undergraduate school to include with the medical school and the clinical part, to really build up our whole group so that we can be a bigger group at Duke. I wanted to tackle all the things, not just patient care.

CO 34:01

And you've mentioned before, too, in some of your interviews that you've worked over the years with an enormous number of patients, and some of which in a relatively short amount of time with the growth of the clinic. What has it been like to be dealing with such a huge geographic area? With the clinic to be handling so many patients?

DA 34:24

Yeah, it's - The first few years, we doubled our capacity every six months for probably the first two years. The first year, we had a half a day, a clinic a month. And then within a few months, we had two half days. And then within another six months, we added a full day. And then

another six months, another full day. And we've had on average about 100 new patients a year. And some graduate out and more come in. And so we probably are seeing- around 400 or so? On an ongoing basis, roughly. But I also have a fellow who's very interested in this work who is graduating this year from our program, and we're- we've made our own offer, and she's planning to stay. And so train your own. I highly recommend it [Laughter]. So, that has helped a lot. Because the last three years- it's a three year training program- she's been able to help me and see patients in addition to myself. So, there's some logistical things, and I would love to have like a patient navigator, some other administrative assistance with it. I think those have fallen a lot on my social worker, and she's got a lot- enough going on with helping with the mental health stuff. So, we're working with Duke to hire somebody for that kind of a position now. So, hopefully, we'll have more help.

CO 36:00

And has interest from medical students changed over time?

DA 36:06

Yeah, I've certainly had interest from students all along, but it's definitely been more frequent in the last five years or so. I think- I've been teaching in the School of Medicine as part of the Cultural Health and Health Disparities course, and taught that course four years and helped with the fifth year, and the curriculum development when they were changing it over this last year. So I think being a part of that and being in front of the first year medical students makes a difference. They see your face, they know what you're talking about, they know what you're like, and they come up and ask, and so that has helped a lot with that process.

CO 36:52

That makes sense. And I was wondering, too, about the effect of the North Carolina Bathroom Bill [Public Facilities Privacy and Security Act] on your work and what it was like trying to run the clinic through that year.

DA 37:06

Yeah, that was our first year [Laughter]. Our first official year, and so it was quite- I think that was formative into the- into me being part of the process of standing up for my patients. Because right away, one of my patients was literally involved with that case. And in a- I don't know. I'm a very protective person of my patients, and I felt like that, "I'm not gonna let you harm my patient." And it was a very harmful bill. And really frustrated me with- So yeah, I think that energy is easy to harness and push back against it and motivated me. And it still motivates me some, but I tried to move to the more positive view of it rather than the negative kind of stuff these days just to help my own sanity [laughter]. But, it- Yeah, and I think, honestly, that part of it helped trans kids find us, which is an interesting plot twist, right? They were out there to squish this group of people in our state. And because they tried, and I'm out there saying, "No, you can't do this. This is not helpful. This is harmful. This is dangerous," people all over the state were like, "She has a clinic. We can go there." And they would have not otherwise known that we were there. And so I think that actually helped us grow and helped us help a lot of people.

CO 39:14

What was it like first transitioning into the role of almost having to go from doctor to political advocate?

DA 39:23

Yeah, I'm still learning, and it's challenging. Learning the difference between policy and advocacy was also another challenging bit that I had to learn. The policy is what the government decides that should be done because they are recommended by medical data. But advocacy is what we do for our patients to help them get the care that they need not necessarily related to what the government plans to do for them. So there's a different approach, a different way of thinking about it, I guess, that I had to learn about. And- But I feel like that they're so interrelated, that you can't have one without the other for sure. Most policy is reliant on the advocacy of the people that are doing the work and the research to make sure that the patients get the best care. But you have to- I had to learn that. That was one of the weird things to learn about. And now, I've lost my train of thought. [Laughter]

CO 40:58

That was very interesting. So do you feel like- You've mentioned the anxiety provoking side of this, but also the side that really brings out a protective side. Do you feel like it came naturally to you in the end? Or do you feel like it was a persona that you had to foster?

DA 41:22

No, I think it's just part of who I am. And I guess finishing up the weaving of that last question in this question is that learning- I have learned from all kinds of different areas. I've learned from the attorneys that I've worked with on different cases. I have learned from some of my predecessors who did policy work. I've learned from advocacy organizations. I am doing an advocacy course with the American Academy of Pediatrics in the spring where we're going to be able to go and actually meet with our representatives and talk to them about what are- we want to- our issues are for them. And so that's a whole other line of learning about how to do it. And I think a lot of it is knowing what people want to hear. Stories work well. And that- Being sure that you know the data behind what you're doing. I think if you lead with a story, and you give them the data, that gives them an opportunity to hear what you have to say and understand that we're talking about science, and we're not- So we're trying to help our patients with science.

CO 42:54

That makes sense.

DA 42:55

Yeah.

CO 42:56

And so were your first court cases that you got involved with with the ACLU?

DA 43:01

Yeah the first one. What was the first one?

CO 43:06

Was it by any chance Overs v-?

DA 43:08

Overs v. was a different case. That one was a child who had- parents had been accused of abuse. The first one was with Lambda Legal, who often works with the ACLU, and they partner on a lot of cases together. And that one was actually in Florida. A Jacksonville school board and the bathroom bill in Florida [Adams v. The School Board of St. John's County, Florida]. And one of my patients was coming from Florida to see me, and so I got involved as the provider. And then they asked me to also be the medical expert. In that case, you're not usually both. Usually you're either the- involved with talking about the patient, that is your patient and that information, or you're telling the medical evidence for whatever's going on. But for that particular case, I was both. And then they introduced me to the folks at the ACLU. The second one, after that one, was with the ACLU [Hecox v Little].

CO 43:48

And what kinds of things do you feel like you- You mentioned learning a lot from the attorneys.

DA 44:30

Yeah.

CO 44:31

What was- What kind of relationship did you end up having with them?

DA 44:37

Yeah. I really, really trust them. I am- I have a lot of respect for them and what they do, and I now understand how important our legal system is, far more than I really understood before. And that's probably my naiveness growing up, just not paying attention. But I- Anytime I have a question or a concern in that area, I totally feel comfortable with reaching out to any of them. And one of the main attorneys that I've been working with actually was involved in the- what I- this year, and the Sex and Gender Wellness Symposium that we had. He was one of the ones that came on and spoke about me after the- I received an award, the Pauli Murray Award for advocacy this year. And so, yeah, it's been a good relationship, still.

CO 45:57

That makes sense.

DA 45:58

Yeah.

CO 45:59

I know we touched on this a little bit before, but given the Duke clinic's place, as originally- I think it was referred to by- Was it NPR?- as the only gender clinic in the South as of like, 2016. What has it been like in terms of doing your legal advocacy and having to think about, essentially the entirety of the Southeast, like Florida and North Carolina?

DA 46:26

Yeah I think luckily, after- shortly after that, a number of other clinics opened up around the Southeast. But they were- We're still the biggest multidisciplinary clinic. Many of the other places have only been able to have the endocrinologist here, do that, or the adolescent medicine doctor. I think Vanderbilt was also growing a lot right around the time that we were. So it's been a- It's been a relief to have other places, but they're all struggling now with what's been going on. And that's been a hard process to manage too because even our in-state partners, because of the recent law, are concerned that they are not able to provide care because of the way the law's written. It says, "No state funds shall be used for." And so we've been receiving patients from the public institutions. And so the growth has been a bit- been an administrative challenge, I'll say that. And making sure that everybody gets what they need, and trying to work that out. And it was- It's been hard to be the person that's in Florida, and in Alabama, and in Tennessee, and in West Virginia. And so like I said, if you need help, train your own. So that's what I've been doing.

CO 48:21

And given North Carolina's turn of- trying to make a lot of the work that you do illegal, what do you envision for the future of gender care at Duke, gender affirming care here?

DA 48:39

Right. Well, we certainly have developed a strong program on the adult side as part of our growth. And so I don't see, hopefully, that there'll be any issue with adults getting the kind of care that they need, and that will remain strong. You know, I have patients that are under care and- So we'll definitely be taking care of them for years, right? I'm hopeful that the work we're doing will make a difference, and that the- what is considered the standard of care for transgender care will continue to be offered at our institution, and that we will not be restricted by legislation. It's maybe longer than I hoped for that [it] takes to get to there, but I'm hopeful. And I'm going to keep working at it.

CO 49:49

Is it- I'm sorry if this is sort of a strange question, but how do you- Or what strategies have you developed to maintain hope for yourself with it? Or how- In addition to that, how do you- What is it like talking to your patients about the future of that type of care?

DA 50:16

Yeah. Transgender care is not going to go away. It may be more difficult to get to where you can get it, at least for a while. So I just try to help them focus on, a lot of the times, the same sort of thing that I say to kids who come to me and whose parents aren't ready. It's like, "We're not saying never. We're saying not now. But, yes, just not now. And we know how to make this happen for you, and it's gonna happen. It's a process, try and maintain hope, and we can get you there." So that's what I keep telling myself.

CO 51:14

Has it- Has it helped at all with the recognition that you've gotten as an advocate?

DA 51:27

Helped my ability or-?

CO 51:30

Yeah, the ability to maintain that kind of stressful work? What is it- I guess what is it like getting recognition for it?

DA 51:40

Yeah, I'm not one of those people who has often gotten recognition for things and has always just been the, "on the treadmill and keep on moving. I'm just doing this because I like doing it." So getting recognition is nice, and it certainly makes me happy. I didn't ever anticipate it. And I think it's a little bit like, "Duh. I'm just doing the right thing. And thank you." I don't know, it's a very hard thing to mentally get my head around. I have a bit of, as they say, impostor syndrome, where I'm like, "Hmm, are you sure you're talking to the right person? Because I think I'm just a pediatric endocrinologist over here seeing patients." And so I have to- I'm learning to give myself credit for the work that I do, and I think that it helps when other people recognize it. So it's a growing process.

CO 52:49

That makes a lot of sense, yeah. And I was wondering, too, about- Obviously, a lot of the strength in the Duke Gender Clinic is the multidisciplinary approach and the inclusion of social workers and mental health practitioners, but does some of that still- Do you still find yourself sometimes having to fill in other roles that you wouldn't usually be filling as an endocrinologist?

DA 53:22

I definitely have learned some skills from my mental health team, for sure. And I, as an endocrinologist, in general learn a lot from the other people I work with. Like I've learned a ton from our nutritionists and our diabetes educators on that multidisciplinary team. So I definitely feel like my abilities, working with a team of different folks, have expanded a lot. But I know I've figured out kind of where my limits are. And I'm like, "I think we're past where I feel comfortable dealing with this. And I'm going to 'phone a friend," as they say. [laughter] And that's been one of the great things too at Duke is learning who knows how to do everything. Because I feel like it's a little bit more of making me almost a primary care provider, part of it too. When you're a primary care provider, you need to know this much about everything. But when it gets out here, you've got to know who to send people to. And in endocrinology and in other subspecialties, you're often in such a hole that you're like, "I don't know where you need to go. You need to go see your PCP and have them send you somewhere." But I feel like I'm a better doctor to learn a lot more.

CO 54:47

That makes sense. [10 minute break]

So I was wondering too, given that you have also just a general passion for endocrinology, is it hard- Do you have time or a desire to treat general endocrine disorders? Or is that something hard to fit into your schedule?

DA 55:17

Right now I'm 90% clinical, which means I am about a third gender medicine, a third diabetes, and a third general endo. So even with all of that other stuff, I'm still doing equal amounts of the other things. And I still cover the inpatient service at Duke for our endocrine, with an equal share with my partner. So I'm just busy. [Laughter]

CO 55:51

And I was curious too about- You're from the South, and do you feel like that impacts at all the relationship you can have with the legislators here or your perspective on doing your work here?

DA 56:09

I think it definitely gives me a perspective that I wouldn't have had otherwise, having a long history and knowing a lot personally about how things have changed over time in the South. Which is a bit different than it is in other parts of the country. I don't know. I haven't gotten any feedback about how it might or might not affect my relationship with our legislators. But-I don't know. It is a good question. I've often wondered that myself. I don't feel like a person just strutting in with outside values, telling people what they should and shouldn't do. No, I'm homegrown. Yeah, I suspect it makes a difference, but I don't know for sure.

CO 57:11

And for the most part, are there legislators that you feel you're able to have close relationships with?

DA 57:22

I wouldn't necessarily say close relationships with, but I have been able to talk to several. We were involved in the Equality NC's Legislature Day [Advocacy Day], or whatever they called it, where we actually did set up meetings with our own personal representatives. And so my representatives that I met with that day were fantastic, and they were very open and listened to what we had to say and were very receptive. But they represent the community in our bubble here in this area. And so they're not the people who are writing the House Bill 808 [An Act to Prohibit Gender Transition Procedures for Minors] kind of things, so. I would love to have opportunity to talk with more, and we did get a chance to do some teaching that we arranged. Duke's legal legislative liaisons helped us try and teach some folks who were interested what we really do and dispel some of the misinformation that was out there. And I don't- I hope it helped. I feel like we had some folks who were not on the same page counter our information as usual by sending messages to the whole legislature saying a whole bunch of things that were untrue, which is really frustrating. But all you can do is tell the truth and- yeah. But it's hard. I don't like that part.

CO 59:30

And you mentioned before that you feel like you've learned a lot from your patients. What kinds of things do you feel like you've learned from them?

DA 59:38

Yeah, so much stuff. [I'm] learning new language every day because the language is always changing. Anytime I hear something new I ask, "What does that mean to you? I've not heard it used that way," or, "That's a new one for me. I'd love to get a better understanding." So a lot of

language, which is awesome. A lot of- What's the word? [Pause] Goals, aspirations. Some of my patients, even some endocrinology to be quite honest. [Laughter] Patients who are like, "You know, I was reading such and such and so and so uses such and such." And then I'll go dig, and sure enough, there it is. I try not to let that happen because then that puts me in the position of-What I hear a lot is that, "I hate having to tell my doctor how to take care of me." Because I don't want to be that person. But I am the person who is open to hearing about new things and learning about it and reading about it. So it's a balance between those two things. [Laughter] I want to learn as much as I can on my own without my patients having to teach me, but I love it when they do teach me things.

And I think, parents- What I've learned a lot from the parents is they love their kids. They want them to be happy and healthy, and a lot of times, they're afraid. They're afraid. And if you can dispel that fear, then you're good. And you're helping them understand. Sometimes it just takes time. That's the other thing. Working with time is a hard thing to do. Having someone wait, when they're feeling awful, for the time for their parent to feel okay, is a stressful time period. And the goal is to shorten that as small as possible. So one of the things we've done is getting ahead of that. One of the things we've learned is let's not do that in the visit with me, right? There's so much more we've got to talk about when it's you and me, and we're talking about your healthcare. So my team has put together education sessions for parents, and if we can get the parents caught up with the kids before the visit, then we can make a lot more progress once they've come to see us. And so that's made a huge difference to give them time with it, without their kids, with a professional, to ask questions, has made a world of difference. So, those are lessons learned. [Laughter]

CO 1:02:53

It sounds like you're alluding a lot to just getting people real evidence-based information-

DA 1:03:03 Right.

CO 1:03:03 -as a huge part of this.

DA 1:03:04 Absolutely. Yeah.

CO 1:03:07

And I was wondering, too- You mentioned- I was curious- language that you learn for your patients- I was wondering if you could give an example of-

DA 1:03:18

Most often it's around their gender identity. So- Gosh, there's just so many different ones. Like, for some people, they don't understand "genderfluid." Well, "genderfluid" has a general term, meaning that you may waver in your gender identity a bit, day to day, but for not every person. That might not be exactly what they mean. So they- I might get them to walk me through that. Or, for some folks, "non-binary" is different. And some- what's the word? Older ones, like

"demiboy" or "demigirl," or- What are some of the newer ones? "Gender non-binary femme," or- Every day, there's a new thing. And it's subtle, but it's important to that person, and they have chosen a very specific thing to label themselves. And it's because it really means something to them, and it's important that I understand it, especially if I want to try and match their body to that identity.

And then even sexual orientation, which is, of course, a whole other category, which is a whole other thing that I get frustrated with parents about. Because parents often conflate the two and it's like, "Hmm, no." So we have that conversation a lot. But I've learned a lot about all of that as well because they're going through the development of both of those things at the same time. And so working through that and hearing what they are learning about, and asking questions about that's always good.

CO 1:05:13

What is it like having a field where, from what you're describing, there's new research all the time, a quickly developing field. What is that like to be a practitioner within that?

DA 1:05:25

It's good, it's good, because we're getting more and more information. But it also means that we didn't have it before, and that's the hard part when you're talking to people. They've had data in this area, and had been doing this work with hormones in particular since the 80s. And when you start talking to people, and- Well, really even longer than that, but definitely since the 80s. When you start talking to people about the duration of- that's 43 years now, right? And that's a long time. Most of the drugs that we use right now have not been around for 43 years. I mean, aspirin, sure. Penicillin, yes, but barely. Almost all the other antibiotics are newer than that. The heart drugs, they're all newer than that. Blood pressure. So it's when you normalize it against other things, people sort of get that there is more data. It's just smaller numbers of individuals who were getting that care because no one knew where to go, or how to do it, to get that care.

And I think I would love- I wish I could magically- like magic wand retrospectively make enough data that makes everyone comfortable. But what is nice is that at least we're getting newer stuff. And it's good to be able to be part of that process to learning how to really make sure that you are being very careful with collecting your data, and monitoring your patients, and talking about your limitations. Every study on the planet has a limitation, and just because it has a limitation doesn't mean that it's not useful information. You just have to know that and help apply it. And so, it's been a really good learning experience, from that point of view, too.

CO 1:07:36

That makes sense. And thinking too about the timeline that we've been talking about where, correct me if I'm wrong, but you got involved in a lot of this in 2013, and so we're only 11 years removed from that. What has it been like to, within such a short span of time, become so deeply involved in this type of care and research?

DA 1:08:09

I mean- [Pause] It's been weird to see it grow around me. I feel like that I was starting this work and found it very interesting, and that was great. And I was- and then all of a sudden, it just

"whoo" around me. And I think that has been interesting to see. I think there's- It can be overwhelming to try and make sure you meet the needs of all the patients. Like you mentioned before, at the point where we were looking at having patients come from as far south as like, Central Florida, that was hard. But I think just learning that what you can and can't do and setting boundaries is another thing that you learn.

CO 1:09:18

And how do you- or what does setting boundaries look like for you at this point?

DA 1:09:29

Yeah, it's a good question. [Laughter] [Pause] Right now, it's honestly been in the clinical space, just literally physical constraint. We had a very small department division when I came to Duke, and we have grown a lot since I've been here. And so now, there are other folks within our division who can take over this stuff that I- it's not my gender stuff. In a lot of places, people have their focus, and they may only see those patients, or they do very little other work. But I haven't been able to do that, until the last probably five years to allow me to do that, which has been good. And so setting- Some of them have been set for me. But I think in the space where I have to do it the most often now is my advocacy work. Yeah, right now, I can't. I'm doing this and this, and maybe come back to me in six months if you have something else. And that's what's been nice about knowing people and knowing that they will, if they really need help, come back. I think early on, I was worried that maybe, I would lose opportunity or missed that connection, or whatever. But now I know that all of- It'll all work out in the end. Those are solid relationships, and I'm happy to help whenever and however, and I think they know that. So I'm not worried so much about that anymore. But there was a point in time where I was like, "Ooh, if I step back from this, am I ever gonna have this opportunity again to help my patients?" Because I don't want to lose that ability to reach out to people on their behalf.

CO 1:11:36

So are there patients where even once they reached adulthood- Do you still keep up with any of those patients?

DA 1:11:45

Yeah, we definitely do. I have- When I teach the class in the med school, we actually have several of our patients come back and teach. And that's another way that I feel [it] is really important that when we're teaching, it's not just me talking about it, that we bring their voice in. So I'll do my schpeel, or I'll give them written stuff to read. And then we bring the patients in to talk and tell their own story, and their own truths, and their ups and downs. And we hear back the things that we did wrong, and that helps us move forward. And so I keep up with them that way, primarily. And we also have a community advisory board, which some of them participate in to help direct the clinic and some of our research as well. Because I think it's important to have the voices of the folks in the room when you're talking about what do they want us to do. Like, what is not working for you right now, and how do we make that better? And so that's an important part of keeping up with them. And then, in a broader perspective, our adult colleagues who I work with also have a registry which we have as well of our patients so that we can objectively follow outcomes long-term. And they're actually working through even through geriatrics, so we get the lifespan of the patient in between the two registries. So that's really been awesome.

CO 1:13:25

What kind of feedback have you had from patients before?

DA 1:13:29

Yeah, we did a really in-depth study, probably three or four years in. We had a team from the master's program at UNC, in social work, do a deep dive on what it was like to be in our clinic, what things we did well, what things we could do better. And it was really interesting to get that feedback. We figured out early on that we had a lot of work to do. Re-educating folks in the clinic is an ongoing thing because frontline jobs in a clinic turnover a lot, and so it's not something you can just do once and let it go. You need to have a system. So we built that system. And that's what led us into that getting into the EHR [Electronic Health Records] and developing the educational modules for new hires and stuff. So that is a direct component from our patients, and this happened [laughter] like a direct line. And still we have work to do there but at least we know. And certain areas of the hospital are more problematic than others as far as some of the things that happen and some of the attitudes that we're still needing to work on, but we're getting there. I'm optimistic.

CO 1:15:05

Over time, have you had to change at all what kinds of things the modules focus on compared to-

DA 1:15:13

Yeah.

CO 1:15:13

what used to have to-?

DA 1:15:15

Yeah, I feel like they used to be much more basic. Now, we've been able to expand and add more modules for folks and have goals of setting up a series so that you can display your little ally in your window if a whole group has done all of these modules. Because the worst is, for me- One of the worst things is to have your patients show up somewhere, and it looks to be LGBT friendly because they have something up that looks like that, and then it's a bad experience, and they really have no idea what they're doing. That's not at all a good thing. So there's a bit of a balance of wanting to make sure that we get everybody on the same page and making sure that people are behaving with the right values- with the values that Duke has, as far as diversity and inclusion.

CO 1:16:22

That makes sense.

DA 1:16:23

Yeah.

CO 1:16:24

Have there been any experiences with patients or their families that were particularly memorable? Or where you really feel like you learned a lot from them?

DA 1:16:40

So many. Yeah. [Pause] The early ones, obviously, because I had such a big learning curve. I learned a ton from those patients. Learning what their expectations were, what they wanted to-and learning what expectations were available from the tools that I have. You want to make sure that everybody's aiming for the same target. Or understanding that this medication's only going to get you here, and if you want more than that, then there's other things that we have to do to get you to that next step. Is it voice coaching? Is it nutrition? Is it weight training? Is it surgery?

I think- [Pause] I learned so much about, also, what it's like to function in school, or not function in school, when you're in a minoritized identity and facing that struggle every day. You read about, and you hear about, but until you've- I've talked to 800 patients now about everyday life, and what every day, every little thing, and one of- That was a huge thing for me to really grasp, and I think it's still hard for parents to understand. And one of the things we used at one point in time to teach our med students the same sort of thing is an activity where you stand in a group and you pass the ball around. First, there's one ball going around. And then, okay, "This is prom," pass the prom ball around. And, "This is grades," "And this is homework," "And this is dating." And then you hand them all a ball that they have to hold and pass all these other balls. That's their identity struggle. Dealing- And then you add three or four more of those things because it's not just one part, one thing, of that struggle that is challenging. And then you suddenly realize that I have to hold all of this in and on me and still deal with all of this. And all of that's not a lot of fun when you're an adolescent. It's super challenging. Your whole job is learning that, all of- dealing with all of those things, and learning to be a person in the world, and how to function long-term. I think that was the biggest, biggest thing. When that clicked I was like, "Oh, okay. I get it." Because I have a lot of privilege as a cis white woman, and it didn'ttook me a while to figure that out.

CO 1:20:12

That makes a lot of sense, yeah.

DA 1:20:13

Yeah.

CO 1:20:16

Is there anything that I didn't ask you about yet they you would like to mention or to tell me about?

DA 1:20:24

[Pause] I don't know. I think, thinking back about some of the highlights, I think about the patient who was literally in tears, and insisted that they come back up to the clinic and give their first injection in front of me. And they were so excited. They were FaceTiming their friends. And just, that feeling over and over again, and knowing that you're making that kind of an impact in that person's life. And that person, I know right for a fact is still an advocate. They're an adult now. They've gone to college. They're out there, fighting windmills or whatever, with me.

They're out there doing this. Anyway, just seeing the joy. And that's just amazing. And then, the pain sometimes of the roller coaster is challenging, but it's- Yeah, I've had some patients who came in who had been harming themselves extensively because they had been waiting so long, and their parents couldn't get them in or didn't get them in, or whatever the circumstances were. And just seeing that pain, when it's there on the surface, literally, you can see it, is heartbreaking. And then knowing- And then you see them four years later, and they're all healed. They still have scars that they'll never be able to get rid of, but they are flourishing. They've graduated from high school, and they've got a job. I've got patients that are married. I have patients who are having kids. I have patients who are involved in their- as mentors, in their different programs. And we're developing a mentorship program too for folks. And- I don't know, those are the highlights, I guess. The highlight reel. [Laughter]

CO 1:22:56

I guess one last question about that. Is it hard not to resent parents sometimes with- How do you?

DA 1:23:06

It can be very frustrating. And it's difficult, but I put myself in their shoes. I'm a parent. I just know that they're afraid of the unknown. And if I can, in some way, close the knowledge gap so that it doesn't feel unknown to them anymore, then I can make them come around and feel better. I think one of the things is that a lot of the patients who aren't on board, those kids aren't getting to me. Those kids are never making it to clinic, and those are the ones I worry about the most, ones who are out there who aren't- have no access. At least if they're coming in, the parents are-At least the parents are coming. They're trying. Hopefully they'll listen. But I just try to always put myself in someone else's shoes when I am encountering a frustrating situation, and oftentimes I can learn from that.

CO 1:24:14

That makes sense. Thank you so much for coming and talking to us.

DA 1:24:19

Sure. Absolutely.

CO 1:24:21

Yeah, it was an honor to get to talk to you.

DA 1:24:24

Thank you. It's a privilege to be here. I'm so excited.

My name is Dr. Deana Adkins. I'm an Associate Professor of Pediatrics specializing in pediatric endocrinology at Duke Children's.