Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/medical-industry-feature/expert-insights-on-adult-congenital-adrenal-hyperplasia-care/26275/

ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Expert Insights on Adult Congenital Adrenal Hyperplasia Care

ReachMD Announcer:
You're listening to ReachMD. This medical industry feature, titled "Expert Insights on Adult Congenital Adrenal Hyperplasia Care," is sponsored by Neurocrine Biosciences, Inc.

Here's Dr. Sara Lubitz.

Dr. Lubitz:
I am Sara Lubitz. I'm an adult endocrinologist at Rutgers Robert Wood Johnson Medical School.

There's a couple of different ways that the patients come into our practice for management of congenital adrenal hyperplasia (CAH). So, the first way, and the way that's the nicest transition wrapped up with a little bow, is when we get the patient directly from the pediatric endocrinology specialists and they're transitioned with this is what their regimen is, this is what their goals of care are. Sometimes, my pediatric endocrinologists even give me goals for adrenal androgens or 17-hydroxyprogesterone levels, they tell me what's worked or not worked in the past.

And again, that's, you know, the adult endocrinologist's dream is to get this smooth transition. The other group of patients I'm seeing, sometimes they were followed really, really closely when they were under the care of a pediatric endocrinologist and they're on that regimen and then life gets in the way. Sometimes, they're not coming to seek out the adult endocrinologist until they've hit some sort of rock bottom where they're still on the same hormone regimen that they were on since they were a kid, even though they're in an adult body and their goals of care are very different.

And they might show up saying, "I'm here now because I was told I have type two diabetes, or I'm obese, or I'm not able to conceive, and this is the time to get back into endocrine care." So, I'm going to say it's about, like, a third of the patients come from pediatric endocrinology with this nice transition, and the rest of the patients are referred from, sometimes from, reproductive endocrinology, sometimes from primary care doctors, or kind of just show up and say, "I'm ready to get back into care with an expert specialist, with an endocrinologist."

Ideally, every pediatric endocrinologist and adult endocrinologist has some sort of relationship for these transitions of care. You want to make sure that nothing is lost in that transition, especially with a complicated, rare condition like congenital adrenal hyperplasia. I suggest that everybody have some pediatric endocrinologist that they work with and work with closely, that they could provide those transitions.

It's really important for the physician, first of all, to have a good relationship with the patient where they could bring up anything. I say to people, you can always tell me. It might have nothing to do with my field of endocrinology, and I might not know about that dental thing. But you know what?

It also might be. It might be high doses of steroids is affecting even your dental health or affecting your mood or something like that. I think it's really important to take a good review of systems where, you know, if the patient is not very forthcoming about how they're feeling on a day-to-day basis and what might be concerning them, then that's why we have the review of systems to fall back on where you make sure you're addressing mental health, and sexual health, and appearance, and hair, skin, and nails, and all these other things that somebody might not bring up to you or even know might be a side effect of the disease or the treatment.

In the first visit, I'm really trying to get the history of what, especially like, what medication regimens they've tried in the past, what kind of side effects they've had from those medication regimens. What are the comorbidities? Is there depression, mental health issues going

on?

Is there metabolic syndrome-type stuff going on? Have they had their bone density checked?

Have they been assessed for adrenal rest tumors? A lot of times that is way overdue and hasn't been done in a while. And what are their goals of care?

I want to know the history, I want to know what's worked in the past, but then, moving forward, what is the goal of care? What are they trying to get out of the treatment regimen and the visits with the specialist?

A typical patient visit, we'll get height and weight on everybody, whether they want to get it or not, because that's an important part about deciding if we're doing a good treatment regimen. We'll go over labs. So, I want someone to come to the office with new blood tests done. And that's a whole, you know, rabbit hole of trouble in itself in that, what blood tests are you doing and what is the timing of when it's being done? And what's the timing of when the hormones are being checked in relationship to what steroid regimen you're using? And are they doing it at the same time each visit, or is it at totally different times and you're comparing apples and oranges? So, I want to have the labs with, in front of me.

When they're sitting down at that visit, I want to have the vital signs, I want to know what other medications they're on, I want to also ask what's been happening in between the last visits. How often are they having to stress dose their glucocorticoid?

Are you compliant, even, with your steroid regimen? If it's one of these regimens that we're trying to use lower doses of steroid spread throughout the day, it's really hard to take a medication multiple times a day. So, I try to establish that relationship that we could even be honest. Like, how often are you missing that midday dose?

A lot of times, it's just, they're not happy with, again, gaining some belly weight or changes in hair and skin or having a little bit more acne, a little bit more hirsutism. So, you have to get into that uncomfortableness with the patient to get them to speak up and tell you what's really bothering them and what may require a change in the treatment regimen.

This is a multidisciplinary condition that requires multiple specialists to be involved. So, we need to be on the same page as the primary care doctor.

So, it really takes communication with the primary care doctor, who may not understand that this is not the same as everybody else who's developing insulin resistance or high cholesterol, high blood pressure.

There is, a lot of times, people seek out reproductive endocrinology or they'll go to urology having sexual dysfunction. A lot of times, the doctors in the other field, as soon as they hear “congenital adrenal hyperplasia,” a lot of them are just like, “okay, hold off. Well, you know, like, you need to go see a specialist or we need to communicate with a specialist.”

And it's a good way to establish a line of communication with other specialists in our area. The coordination of care with other specialists and with the primary care doctor is so important.

So, one of the wonderful things about being a physician and being an adult endocrinologist is I get to have a long-term relationship with my patients, so we get to have that long view of goals of care and how it changes. So, it's wonderful for me as I watch a person go through each of their fertility, having a baby, and then, as they're aging, being able to think about what they're at risk for, how to make them have as little morbidity and mortality so that they can watch their grandchildren.

It's such a gift as a physician to be able to treat somebody through all of their life stages, to go through that with them.

ReachMD Announcer:
This medical industry feature was brought to you by Neurocrine Biosciences, Inc. If you missed any part of this discussion, visit *Industry Features* on ReachMD.com, where you can Be Part of the Knowledge.