

# Transitioning from Pediatric to Adult Care with NMOSD

You can watch the video of this podcast at: [youtu.be/O7RItAoMPh8](https://youtu.be/O7RItAoMPh8)

[00:00:02] **Intro:** “ABCs of NMOSD” is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder or NMOSD, a rare, relapsing, autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. “ABCs of NMOSD” is hosted by SRNA, the Siegel Rare Neuroimmune Association, and in collaboration with the Sumaira Foundation and Guthy-Jackson Charitable Foundation. This education series is made possible through a patient education grant from Amgen.

[00:00:42] **Krissy Dilger:** Hello and welcome to the “ABCs of NMOSD” podcast series. Today's podcast is titled “Transitioning from Pediatric to Adult Care with NMOSD.” My name is Krissy Dilger and I moderated this podcast. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at [wearesrna.org](https://wearesrna.org).

[00:01:10] For this podcast we were pleased to be joined by Dr. Jonathan Galli. Dr. Galli is a neurologist at the University of Utah in Salt Lake City, Utah. You can view his full bio in the podcast description. So, welcome, and thank you for joining me today. Can you begin by just briefly giving an overview of neuromyelitis optica spectrum disorder?

[00:01:35] **Dr. Jonathan Galli:** Yeah, sure, absolutely, and thank you for having me. It's an absolute pleasure to be here. So, neuromyelitis optica spectrum disorder, or shortened to NMOSD. It's a historically kind of fallen into several different areas of characterization or families of diseases if you will. Actually historically it was thought to be a MS variant way back in the day, which we know certainly isn't the case now. But really kind of at its core, NMOSD falls into the syndromes that are mediated most classically by the presence of the aquaporin-4 antibody.

[00:02:28] Which actually causes damage to supportive cells in the central nervous system called the astrocytes. And then there's some downstream immunological effects that damages most often the optic nerves. So the nerves that take information from the eyes back into the brain or the spinal cord. In rare cases, it can affect the brain as well, but typically we think of it as primarily optic nerves or spinal cord.

[00:02:59] Kind of most recently within the field there's also generally the idea of what we call seronegative NMOSD, which are patients who meet specific diagnostic criteria with optic nerve, spinal cord involvement, but don't have the presence of the aquaporin-4 antibody. There's a little bit of debate within the field, but generally, we think of seronegative NMO as a similar-ish disease entity in some ways as patients with aquaporin-4 although there are some differences that we aren't going to get too far into today.

[00:03:37] **Krissy Dilger:** Okay, thank you. So, today we're talking about pediatric transitioning into adulthood with NMOSD. So just to start us off on that topic, are there differences in how pediatric and adult NMOSD present?

[00:03:59] **Dr. Jonathan Galli:** Yeah, it's a great question. In general, you can still see some of our classic presentations and that includes optic neuritis. And typically it's or oftentimes I should say it's bilateral or both optic nerves being affected. You can also see again spinal cord involvement and typically that's what we call longitudinally extensive. So, those are longer spinal cord lesions than say those that we see with patients with multiple sclerosis. Both the bilateral optic neuritis and transverse myelitis are presentations that we can see in our pediatric populations.

[00:04:46] Interestingly though, in the pediatric population, there have been more cases reported of both hypothalamic involvement where patients will have inflammatory damage to their hypothalamus, which can actually cause issues with hormones, hormone productions that we'll call endocrinopathies. Our pediatric patients do tend to have a little bit more what we call cerebral involvement. So, involvement of the actual brain itself rather than just optic nerves or spinal cord.

[00:05:22] You can see brainstem involvement in adults, but it does seem to be a little bit more prevalent in kids. In adults typically we'll see what we call area postrema syndrome where the area postrema specifically has inflammatory damage. Kids can also have brainstem involvement. So, certainly, we can see the same kind of presentation in pediatric patients that we see with adults, but a little bit more broad range of presentation.

[00:05:54] **Krissy Dilger:** And in a similar vein, are there differences in how pediatric and adult NMOSD are treated?

[00:06:04] **Dr. Jonathan Galli:** Yeah. So, in adults and children I think the big take home point regardless of pediatric versus adult is aggressive therapies upfront are incredibly important. And so, in the pediatric population, I would still recommend aggressive treatment. So, in some ways, the treatment is very similar. So, the typical recommendation for treatment in patients is high dose IV steroids usually for three, I prefer five days.

[00:06:43] And then most of the time we will also implement plasmapheresis or plasma exchange in patients, because we know that NMOSD is an aggressive disease and that left inadequately treated you can still have a lot of long term disability. I tend to recommend aggressive treatment with at least steroids and plasmapheresis. We know that in children, plasmapheresis is very safe even down into young ages.

[00:07:13] So, I would say for the most part in the acute setting, they're relatively similar. As far as maintenance treatment, the mainstay of treatment in the long term is what we call steroids sparing treatment where we're having patients on immunosuppressive medications to decrease the immune response and therefore decrease the risk of relapse.

[00:07:44] I'd say the biggest difference at this point is several of the newer FDA-approved medications, at least for seronegative aquaporin-4 mediated NMOSD, those are still in trials for pediatric populations. Whereas in adults we have several FDA-approved medications. That being said, I wouldn't say that's a dismal thing for our pediatric patients. We still have several medications that we use off label.

[00:08:20] The most common one I'd say in our clinic for our under 18 patients is probably Rituximab, which is a CD20 inhibiting medication. I also use that most commonly in my adult patients just because it's not been proven to be less effective than some of these other newer medications at this point. So for me, most of my patients whether you're 15, whether you're 35, whether you're 60, I probably would tend more towards starting patients on Rituximab anyway personally.

[00:08:59] So, there's a few nuanced differences, but I think for the most part we're able to manage patients pretty well, whether they're on the pediatric side or adult, both in the acute and the longer-term phase.

[00:09:14] **Krissy Dilger:** Thank you. So, for someone who is diagnosed with NMOSD as a child, are there any concerns about effects of the disorder on development or effects of the medications?

[00:09:29] **Dr. Jonathan Galli:** It's a great question. So, potentially depending on where the lesion occurs, there could be some long term trouble with mobility, ambulation, or walking, things along those lines. Especially if there's a longitudinally extensive spinal cord lesion that can lead to longer-term trouble with things along those lines. Same if there's optic neuritis, you can have long-term visual impairment again depending on how you respond to the acute therapies.

[00:10:08] But other than that, it's nothing that would really change cognitive development, other development, anything along those lines. As far as the treatments are concerned, with any immune therapy, there's the concern about potential increased infectious risk, slight increase in blood-borne malignancies and things along those lines. But really even the medications themselves really shouldn't cause any significant developmental concerns in our patients.

[00:10:45] **Krissy Dilger:** Got it. Good to know. So, for a child with NMOSD who is in their teens and nearing adulthood, what are some of the ways in which they can start preparing for that transition? Are there any tools you use in your clinic to help children and their families with the process?

[00:11:07] **Dr. Jonathan Galli:** Yeah, it's a great question. So, at our institution, we have a pretty interesting model where our pediatric patients are seen in one medical system and then our medical system is a separate one on the adult side. So, our colleagues that are seeing our patients with either MOG, even MS, they're the ones that are oftentimes transitioning to us.

[00:11:39] What we're working on right now is actually kind of an intermediate clinic where our pediatric provider will come over to the adult clinic physically, see their patient one last time, have one of us, one of the adult providers meet and greet with the patient and then basically do a gentle handoff in the adult side. So, it's kind of an overlap-type model.

[00:12:11] The discussion occurs initially on the pediatric side with our pediatric providers where they start actually having the discussion as our patients move into kind of the adolescent age where they start talking about the transition of clinics and things like that. So that patients aren't just caught unaware of making that transition. I think, as far as patients who are in their teens, I think as you start to get closer to the magical age of 18 where all the transition really happens and suddenly you go from the pediatric side and then are all of a sudden considered an adult.

[00:12:53] I think the biggest thing that you can do is make sure that you just talk with your current pediatric neurologist about, "What does this look like, who's taking care of me once I hit 18? Will that continue to be you? Am I going to transition to the adult side? If I do that what does that look like?" So, I think having that conversation around the age of 15, 16 just so that you're aware and you're not again caught all of a sudden being like, "I'll see you later," I think is probably the best thing to do.

[00:13:26] And then also having that conversation with family. You know, not to get too far into logistics, I think maybe not necessarily on our adolescent patients, but certainly for families, thinking about what does

insurance look like for me? Certainly, if there's a two-system model like we have switching from the pediatric side over to the adult side isn't just like changing clinics.

[00:13:55] It could be actually changing insurance providers and things like that. So, I think that's something for families to keep in mind as well as, "Do I need to look at my insurance options as well?" So that that doesn't end up being a big hang-up.

[00:14:11] **Krissy Dilger:** Yeah, that makes sense for sure. So, just talking more about this transition process in your clinic. So, you said that 15, 16 is when the process starts. Can you tell us more about the timeline, like at 18, is that a hard line or is it kind of gradual? What's the timeline for the transition?

[00:14:37] **Dr. Jonathan Galli:** It's a great question. To be honest, there's no hard and fast. I've had a couple of patients transition over around 15 or 16. And this was kind of prior to us having a little bit more standardized model. Dr. Melissa Wright is our pediatric neurologist who's autoimmune trained, who's kind of pioneering things from the pediatric side. And when we discussed this last, it's kind of around this age 16, 17. I'm sure if somebody wasn't quite ready she'd wait.

[00:15:12] Knowing her, she's not going to rush to get anybody out. I'd say 16 to 18 is probably around the typical age where we'll start at least having the conversation, and then probably 17, 18 is around when we'll have them come over to that transition clinic over on the university side. That being said, a lot of times, it comes down to the comfort of the pediatric neurologist of what age they want to treat up to, which ours are I think very comfortable treating to 18 and a little bit beyond.

[00:15:50] Part of it comes down to the comfort as well of the adult neurologist and what age they're comfortable treating. I have a couple of patients who are 14 to 15 that I'm very comfortable treating. So, for me, it's very much comfortable. They just came straight over at that age. That'd be fine as well. So, really it's kind of more a readiness from the patient and family. I think that helps guide that a little bit.

[00:16:18] And then, as far as what the process looks like, the support staff on the pediatric side make sure the patients scheduled over the adult side clinic, they'll see Dr. Wright. And then again, we'll do the meet and greet. And then on our end of things, we have clinic nurses who are very involved in our patient care that oftentimes will help coordinate the family conversation and move over to the adult side as well.

[00:16:52] And certainly one of the first things that we'll address with a family is what needs do we need to meet in the immediacy of changing over, because obviously, it's a big transition for everybody.

[00:17:07] **Krissy Dilger:** Yeah, for sure. And you mentioned support staff that helps with that transition. Another one of the questions I was going to ask is just like the role of social workers or nurses. What place do they have in this transition? How long will they stick with that patient before letting them loose in your clinic. Can you speak to that experience?

[00:17:39] **Dr. Jonathan Galli:** Yeah, absolutely. Again, it's probably clinic-dependent on what staff are available and what their rules are. At least for our clinic, our nursing staff are very, very involved with patient care. I can tell you whether you're a new young adult patient, or if you're just transitioning over from the pediatric side, or if you are an adult with a new diagnosis, our nursing staff is still very involved either way.

[00:18:17] And really they stay integral in the kind of patient care experience all along. I mean, our nursing staff is incredibly important and integral where a lot of times they're the ones that are triaging our messaging inbox, taking calls and things like that where they may be the point person that our patients are talking with

a little bit more even than our providers. And again, that's not something that typically goes away. I always joke with my patients that my clinic nurse Tracy is the real superstar that they'll oftentimes still like her more than me in the long run.

[00:18:56] So, it is something that I think is really important and integral to that first meeting where you get to meet the staff that you're going to be working within the long term, get a chance to know them, get comfortable with them. We don't have a huge social work involvement in this specific process. It's certainly something that I think can be beneficial. Again, I think that need oftentimes is met by our nursing staff more than anybody.

[00:19:26] **Krissy Dilger:** Awesome. And obviously, it's a transition for your clinic from totally different centers. So, your care team will have a lot of changes. So, your neurologist will change. Any other, I guess, care team differences or changes that happen between pediatric and adult? Is there anybody that a pediatric patient may need to start seeing or may not need to see anymore now that they're an adult?

[00:20:00] **Dr. Jonathan Galli:** Yeah, it's a good question. Like you said, certainly kind of new faces show up across the board even as simple as new nursing staff, you'll have new medical assistants in the clinic, new phlebotomists in the clinic. You may have gotten used to staff for years and years in the pediatric side and everyone's new even down to pharmacy and things along those lines.

[00:20:34] Generally, at least in our clinic I think the biggest thing is just making sure that our patients are meeting especially the individuals who they're going to be communicating with a lot. Part of the transition as well into the adult world oftentimes sees our patients becoming more independent and potentially parents aren't going to be there as much as a part of their visits.

[00:21:01] So, that's the other thing that we're finding as we're making this transition is not necessarily just to note that specific example, but all kind of saying, right now that we're entering the adult side, "What needs do you have?" because they certainly can be different from the pediatric side where we don't necessarily have the same support staff to help with like things like school and things along those lines.

[00:21:29] We have more social work support staff for things like that, that may focus more on what does employment look like? What is moving forward into the adult world look like? And things like that. So, it certainly can be a big shift. And I think the biggest way to make that a success is really just meeting everybody involved early on and just being comfortable with them in that transition.

[00:21:54] **Krissy Dilger:** Yeah, that's important, definitely. So, after transitioning into adult care, what are the things that you as a neurologist have to evaluate and take stock of? For instance, are there things like medication dosages that change or are re-evaluated? Anything like that?

[00:22:16] **Dr. Jonathan Galli:** Yeah, for sure. So, anytime I'm transitioning any patient, I'll always take a look at their medications just to make sure that we're all on the same page. Certainly, medication dosing can change. In the pediatric side oftentimes medications are weight-based, especially at younger ages now. In an adolescent to kind of young adult population, generally, it's a little more straightforward. I remember trying to do math back in my pediatric neurology rotations and I brought my calculator along with me at times because it racked my brain a little bit.

[00:22:57] So, certainly one of the things that I'll look at is to make sure that for an immunotherapy standpoint dosing is okay. Make sure that I'm in agreement with the current dosing or current immune therapy that the patient's on. And then even something as simple as symptomatic medications, I'll take a look at the dosing

and make sure that we're on an adequate enough dose and just make sure that we're not actually under-dosing medications.

[00:23:30] Generally, when patients were transitioning over, they're already on really appropriate immune therapy. So, I don't actually have to spend a ton of time reinventing that wheel. We're very lucky that we have a fantastic pediatric neurology group over at primary children, and to be honest I don't worry too much when they come on over that we're on the wrong medications or we have to redo anything. Really what I'll spend the most time checking in with is what are your immediate needs from a symptomatic standpoint.

[00:24:08] What can we do to really kind of keep the ball rolling really with the goal of what can we do to get you feeling your best to get you functioning your best despite having this condition? So, that's honestly when I'm transitioning patients over where I will focus the most, "Is there something missing in your medication regimen that would really make your life easier?"

[00:24:38] **Krissy Dilger:** Got it. Thank you. Are there differences in the frequency of appointments with neurologists once a person with NMOSD becomes an adult?

[00:24:49] **Dr. Jonathan Galli:** I don't necessarily think so. I think most patients see their neurologist about every six months or so. Certainly, in younger pediatric patients, it would be reasonable to see them more if somebody is early in the course of their diagnosis. Sometimes we'll do every three-month visits, things along those lines which I personally will still do in somebody if it's really necessary, especially from a symptomatic management standpoint.

[00:25:39] I don't think from our standpoint at least it's something that you go to the adult side and you get ignored or forgotten about. I think it's a pretty much the same frequency that you get in with.

[00:25:39] **Krissy Dilger:** Well, thank you so much for answering all of our questions about this topic. To leave us, is there any advice or tidbits of information you would like to share with children or their families who are transitioning into adult care?

[00:25:57] **Dr. Jonathan Galli:** Yeah, for sure. So, my biggest piece of advice and this is probably advice from a lot of patients that I've heard at some point along the lines of just advocating for yourself. I think within that -- I think the biggest thing you can do is, again, once you start hitting that adolescent period where you say, "I'm going to be an adult in a couple of years," just having that conversation, "What does the future look like for me when I hit 18?" So that you're allowed to get prepared for that.

[00:26:36] And I think really the biggest thing is while the pediatric world can be a little different than the adult world, I would not be scared to make a transition over to the adult side. I can tell you we all love, obviously, our adolescent patients, but we love our adult patients and enjoy taking care of them. And I think it can be a big jump with all new faces. Everybody that's on the adult side is excited for it as well.

[00:27:16] And I think we all take a lot of joy in kind of taking over and as exciting as your teenagers are I think for me personally one of my most rewarding things about taking care of a younger population of patients is really watching my patients kind of grow up into young adulthood. It's something I truly enjoy. So again, making sure that you advocate for yourself is always very important. I'd say that in someone who's 10 years old up to 85, it's always important, but also just it's not something you should be scared of.

[00:27:58] Be informed, make sure that if you are looking at providers, trying to find reviews and things on if a provider is more comfortable with younger patients or in this transition period. Doing that I think is really

important as well. Just to make sure again, just to reiterate, making sure I think the most important thing is finding a knowledgeable provider, but one that you're also comfortable with is important.

[00:28:27] **Krissy Dilger:** Awesome. Well, thank you so much. That's all I have for this podcast. But we really appreciate your time and you joining us today.

[00:28:37] **Dr. Jonathan Galli:** Yeah, absolute pleasure. Thank you.

[00:28:42] **Krissy Dilger:** Thank you to our "ABCs of NMOSD" podcast series sponsor, Amgen. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.