

# Dr. Alexandra Kornbluh

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[00:00:02] **Krissy Dilger:** Welcome to the "Community Meets Clinic" series, a collaborative podcast to introduce the clinicians, clinician scientists, and healthcare personnel working directly with individuals and families facing a rare neuroimmune diagnosis. Hear directly from those in the clinic and connect with the individuals whose focus is promoting quality of life for those diagnosed with a rare neuroimmune disorder.

[00:00:28] SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our web site at [wearesrna.org](https://wearesrna.org). "Community Meets Clinic" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; UCB; and Genentech.

[00:00:52] My name is Krissy Dilger and I moderated this episode. Today we meet Dr. Alexandra Kornbluh from Children's National Hospital. Dr. Kornbluh is the Director of Investigational Therapeutics through the Pediatric Neuroimmunology Program and is the principal investigator for clinical research studies in pediatric demyelinating conditions. You can view her full bio in the podcast description.

[00:01:19] Thank you so much for joining me today, Dr. Kornbluh. I am excited to be able to speak with you and to learn a bit more about you as well as the clinic at Children's National Hospital. To start, can you tell me a little bit about yourself and what led you to neurology and in particular neuroimmunology?

[00:01:43] **Dr. Alexandra Kornbluh:** Absolutely and thank you for this opportunity. It's a pleasure to speak to the community about my background and our clinic. I became interested in medicine early on in high school and quickly found fascination with the brain as a neuroscience major in college.

[00:01:59] In medical school, my passion for how the brain works quickly turned very clinical, and I knew early on that I wanted to go into neurology as a field. It did take me some time to decide between adult and pediatric neurology, but I ultimately chose to work in pediatrics because of the amazing neuroplasticity that children have.

[00:02:18] I love to see them improve from their neurologic issues and get back to themselves over time. And then in working with different child neurology populations in my residency at Nationwide Children's [Hospital], I was really drawn to neuroimmunology from the patients I cared for and ultimately decided to pursue some additional subspecialty training in that field.

[00:02:38] Neuroimmunology interested me for a lot of different reasons, but one main reason is that I like the pace of patient care that neuroimmunology brings. Our patients are typically acutely ill in the hospital and can sometimes require intensive care and immediate interventions. But then it's amazing to see that those interventions tend to work, and we can see great improvement in their illnesses from the effects of our immunomodulators.

[00:03:03] I get the opportunity to follow families longitudinally in the clinic and build long-lasting relationships over time as we do disease surveillance and support their growth and development after the initial illness.

[00:03:17] **Krissy Dilger:** That sounds great. We're lucky that you decided to go into this field because you're an amazing asset to this field and to our community. What led you to focus on the rare neuroimmune disorders specifically, and also do you have any particular interest areas that you are working on in research specifically?

[00:03:43] **Dr. Alexandra Kornbluh:** The fast-paced advances in neuroimmunology research really drew me into the field. We've learned an immense amount about rare neuroimmune disorders in the past several years. In particular, I've always had a research interest in MOGAD. Clinical MOG antibody testing didn't become commercially available until I was partway through my residency.

[00:04:04] Then suddenly we were able to diagnose one of the most common pediatric acquired demyelinating disorders and learn all about that broad spectrum of clinical presentations. I've really been interested in pushing forward our understanding of different MOGAD presentations and outcomes with my clinical research.

[00:04:23] **Krissy Dilger:** Awesome. That sounds great. That's a common thing I hear about people who go into this field, the fact that there's still so much to learn and there are so many new things coming out. MOG wasn't officially coined until I think 2017, or so. That's relatively recent in the world of medicine, and it's exciting to be a part of that, so I totally understand where you're coming from.

[00:04:54] **Dr. Alexandra Kornbluh:** Absolutely, and it's informative in my training and interest.

[00:04:58] **Krissy Dilger:** Can you share more about your specific neuroimmunology multidisciplinary clinic team at Children's National? What other specialists might a new patient expect to see if they have an appointment with you? How does a new patient typically get connected with you, and what might that look like?

[00:05:22] **Dr. Alexandra Kornbluh:** The Neuroimmunology Program at Children's National is one of the only pediatric neurology programs that cares for children and adolescents with neuroimmune disease in the greater Washington, D.C. metropolitan area.

[00:05:34] We serve children from the broader region. Patients come from throughout Washington, D.C., but also Maryland, Virginia, West Virginia, Pennsylvania, and other surrounding areas. Our clinic is really grounded in multidisciplinary care. We're comprised of three pediatric neurologists with sub-specialization and interest in neuroimmunology, also a pediatric neuroimmunology fellow, and rotating adult-trained neurology fellows from surrounding academic centers. We really have education and training as one of our core tenets of our clinic.

[00:06:04] In addition, we work closely in the clinic with other pediatric subspecialists, and that includes physical medicine and rehabilitation, and neuropsychology. We can pull in colleagues from other subspecialties like psychiatry, rheumatology, complex care, infectious disease, all depending on what a patient specifically needs. We have an embedded nurse manager who helps with care coordination and a clinical research coordinator

[00:06:32] That allows us to embed research efforts and clinical trial opportunities to all the patients that we see in our clinic. We work very hard to make research opportunities fully embedded and accessible, woven into all aspects of our patient care. New patients are often seen in follow up after they've been admitted to our hospital or one of our partner community hospitals after they initially present with their neuroimmune illnesses. We also see second, third, and fourth opinion referrals from other centers, both nationally and internationally. Once they're put in touch with our clinical nurse manager, then they can be scheduled to see our multidisciplinary group for their evaluations.

[00:07:10] **Krissy Dilger:** Wow, that sounds amazing. I particularly love that you use research pretty much throughout your clinic and have it interwoven as the experience. I know research is such a big thing for our community and really gives everyone a lot of hope. Also, I can imagine as a clinician, especially when you're dealing with so much unknown with these disorders, that it can be potentially difficult to deal with the emotions every day. How do you take care of yourself and what do you do in your free time that helps you relax or reset?

[00:07:54] **Dr. Alexandra Kornbluh:** I would say that our neuroimmunology clinical team is very tightknit. We really lean on each other to talk through patients with difficult conditions, and we support one another. Outside of work I spend all my time with my family. I have a kindergartner and a six-month-old. We love to hang out at the park and spend time outdoors to unwind.

[00:08:13] **Krissy Dilger:** I love that, and I know that area has some great outdoor places to be. I like to hear that you have a place to decompress outside of work. Is there anything you'd like to share for a family with a child with one of these disorders who's considering your clinic for care? Anything they should know or anything you'd want them to know before coming?

[00:08:41] **Dr. Alexandra Kornbluh:** Just emphasize that we do believe very strongly in that multidisciplinary model at our clinic, and with each patient we work to provide big picture and holistic care. For example, that includes offering all of our patients access to neurocognitive evaluations so that we can help with providing school accommodations if they need it. We also focus on addressing any concerns about mood and fatigue and other holistic resources in addition to their neurologic care.

[00:09:09] **Krissy Dilger:** Awesome. And I do want to also plug the fact that Children's National is a recognized SRNA Center of Excellence which means that you do excellent comprehensive care for patients, and we really appreciate the work that you do and are happy to collaborate. I can attest from the SRNA standpoint that Children's National is an excellent place to go for care.

[00:09:37] **Dr. Alexandra Kornbluh:** Thank you.

[00:09:39] **Krissy Dilger:** To wrap up this discussion, I like to end on a note of positivity on these podcasts. What are you hopeful for in the future of rare neuroimmune disorders?

[00:09:53] **Dr. Alexandra Kornbluh:** I think there is so much to be hopeful for. From the standpoint of being a pediatric neuroimmunologist, I'm hopeful that the exciting research advances in immunotherapies that have been approved for adults will continue to become more and more available in children. I'm also really excited about the discovery of new biomarkers that may help us more accurately diagnose and predict treatment response in patients with rare neuroimmune conditions. And that's with the ultimate goal of providing more targeted and patient tailored therapies for our patient populations.

[00:10:27] **Krissy Dilger:** Awesome. We're excited as well, and hopefully in the next five to 10 years we can come back and talk about all the advancements that have been made since this discussion. I look forward to that.

[00:10:41] **Dr. Alexandra Kornbluh:** Me too.

[00:10:45] **Krissy Dilger:** Thank you to our "Community Meets Clinic" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; UCB; and Genentech. 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.

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