Building Your Health Care Team

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[00:00:00] **Roberta Pesce:** Our final talk for the day is incredibly important, and it is about building your healthcare team. I am joined by GG deFiebre, my dear colleague and friend and Director of Research and Programs at SRNA, and Dr. Benjamin Greenberg, also a friend, professor at UT Southwestern Medical Center and Director of the Transverse Myelitis and Neuromyelitis Optica Program, and Director of the Pediatric Program at Children's Health. He's also one of our Board members at SRNA. GG, Dr. Greenberg, over to you.

[00:00:42] **Dr. Benjamin Greenberg:** Thank you.

[00:00:42] **GG deFiebre, PhD:** Thank you, Roberta. Oh, hello. So, thank you for joining us for this last talk of the day about building your healthcare team. And so just to give a little bit of some background, we're going to be having a conversation. I'm the Director of Research and Programs, here at SRNA, but I'm also someone who is diagnosed with transverse myelitis, so I'm kind of talking through some of my experience through building a healthcare team with Dr. Greenberg. So, thank you, Dr. Greenberg, for joining us.

[00:01:10] **Dr. Benjamin Greenberg:** It's a pleasure. Thanks for putting this together.

[00:01:13] **GG deFiebre, PhD:** Yep. So, to start, I guess kind of the first time someone is having to deal with building a healthcare team or has a healthcare team dedicated to their care when one of these disorders is at onset, right, so the onset of symptoms and whether that is them presenting to the emergency room or maybe their primary care physician. So, what kind of goes into that beginning phase of someone's diagnosis, and who's really involved in their care at that point in time?

[00:01:48] **Dr. Benjamin Greenberg:** Yeah, it's a great question. In what's called the acute setting, meaning when you're first becoming symptomatic and first becoming ill, there is a tremendous diversity from institution to institution on who might be involved in a person's care. And so, I'll go through a list of doctors that people may have met during their acute setting and give an explanation as to why people were present or not present in any given situation. When you present to either an outpatient clinic, your internist or pediatrician, or to an emergency room for an evaluation, the first thing that clinicians do is try and get an accurate diagnosis. Once they identify what's wrong with the person, is it a problem with the person's heart, their lungs, their brain, their kidneys, or spinal cord, then they move on to what is causing the problem.

[00:02:41] So for most of our patients who ultimately get admitted to a hospital, and usually that's via an emergency room, they will meet potentially an internal medicine physician or hospitalist. Those are individuals trained in general medicine and the management of admitted sick individuals, and often act as the overseer, the conductor of the team. For almost all if not all of our patients, a neurologist would've been involved in the diagnostic evaluation and/or management of a patient. If you're a child, it would've been a pediatrician and a pediatric neurologist.

[00:03:23] And then we have families who meet all sorts of other clinicians in the hospital for various reasons. If you're in the intensive care unit, an intensivist or critical care attending would join. And then, during the diagnostic process, while trying to understand what's wrong, some of our patients have been evaluated by infectious disease physicians, individuals who focus on viral and bacterial infections of human beings. And if the team was questioning whether or not the brain issue or spinal cord issue was actually an infectious process instead of an autoimmune process, they may have brought on an infectious disease physician to help guide testing that could be done to prove or disprove an infectious issue.

[00:04:05] I will say the group that is to be consulted enough early on for our patients are our physiatrists, our physical medicine and rehabilitation doctors who are often thought of as down the line. So, after the acute setting, we will have a child or adult transition to rehabilitation medicine. But, in actuality, we try to get our physiatrist involved early in the care of our patients, even when they're still in an ICU because there are things we can be doing to help maintain and ultimately restore function, even as early as those first few days in the hospital. So, folks will meet a lot of different doctors in the hospital, but, in general, a pediatrician or internist and a neurologist is involved in almost every if not every case that's admitted to a hospital.

[00:04:53] **GG deFiebre, PhD:** Great. And then what if someone is getting something like an angiogram or doing something like plasma exchange or IVIG, is there any sort of additional specialist who might be involved in that?

[00:05:02] **Dr. Benjamin Greenberg:** Yeah. Great question. So for diagnostic imaging, there are always radiologists in the background interpreting images, but if you need a procedure that requires an interventional neuroradiologist, meaning, in the example you gave an angiogram where a catheter is inserted into a blood vessel in the leg and contrast is injected into the arteries that feed the spinal cord, that's not just a radiologist, it's not just a neuroradiologist, but it's someone who went on to do specialty training in interventional neuroradiology to complete that diagnostic procedure.

[00:05:36] And then, for individuals who are getting plasmapheresis or plasma exchange, depending on the hospital you're at, you might meet one of two different clinicians. In some hospitals, the plasmapheresis unit or service is run actually by pathologists who specialize in what's called transfusion medicine. So, these are physicians who went on to do pathology as a specialty, but often they oversee the blood banks and blood products. And since plasmapheresis is often used in individuals with blood-based disorders, in some hospital settings, pathology oversees the plasmapheresis unit.

[00:06:16] In other settings, it's actually the kidney doctors because the machine is kind of a cousin of dialysis. And so, in some hospitals they said, "Well, the kidney doctors know how to do dialysis. They're going to take on plasmapheresis." At my institution, it's run by the pathology department, and so individuals who are getting plasmapheresis or plasma exchange will meet the team, which involves a plasmapheresis technician and a supervising physician, which comes from the Department of Pathology here at UTM Children's.

[00:06:46] **GG deFiebre, PhD:** Okay, great. Thank you. And so, people will maybe be in an ICU or just a regular hospital, and then move over to a rehab hospital where they will then be more likely to be seeing a physiatrist,

as you said. Usually, we should maybe involve them a little bit earlier than we do. But then, so once someone is finally kind of released from the hospital, they're able to go home, how is this building a healthcare team really supposed to work?

[00:07:15] **Dr. Benjamin Greenberg:** Yeah.

[00:07:16] **GG deFiebre, PhD:** Kind of who fills in what roles, and how is it supposed to work? And then, we'll kind of go into what actually maybe happens.

[00:07:22] **Dr. Benjamin Greenberg:** Yeah. So, I think this will be fun. I think I can sculpt through what's supposed to happen, and I'll be curious to turn the tables on you and hear about, in your experience and what you hear from our community what actually happens. So, I want to go through a list of different physicians, different healthcare providers, different specialties and explain what their traditional role is. And we can take it from there. So, first, being a neurologist, I'll start with my specialty.

[00:07:56] So neurologists across the country undergo uniform training in terms of general neurology. We are all required to do a year or internal medicine followed by three years of neurology. That's after graduating, though, from school. So, we all do four years of a residency. And, in that time, we get trained in both the diagnosis and management of individuals who have brain, spinal cord, nerve, muscle-based diseases. And during the post-acute setting, so the person has got their diagnosis. So, the diagnostic issues should be completed. We are now into the management phase. And, neurologically, the patients in our community really often need help with two aspects of management.

[00:08:45] So the first is, for our community, individuals who have conditions that could recur over time. So, the best example is neuromyelitis optica disorder or anti-MOG associated disorder. The neurologist will usually take the lead, if not always take the lead, on helping craft the management plan for the prevention of relapse. So that's one aspect of their care.

[00:09:09] But on the other side are the symptomatic management that is required after whatever attack had occurred. So, if somebody has ongoing issues with sensory loss, pain, spasticity or tight muscles, weakness, vision changes, cognitive changes, the neurologist is supposed to help guide the management of all or the majority of those symptoms.

[00:09:36] Now this is where a gray area comes in because a lot of those symptoms can and are often managed by physiatrists. And so, one of the questions that comes up all the time is at what point should a neurologist take the lead on some sort of symptomatic management versus the physiatrist. And I think as we'll hear from you, depending on where people live and the institution they're at, it can be six of one, half dozen of another. It ends up, I think, being more dependent on the person in the specialty.

[00:10:05] But the physiatrist is trained both in rehabilitation medicine in terms of what are the things people can do to improve function or adapt to a deficit. They're trained in symptomatic management, including bowel/bladder function, as well as pain control and spasticity control. And, additionally, physiatrists will often undergo training for certain interventional procedures that may be useful for managing certain symptoms. Botox injections, the management of intrathecal pumps that may help with spasticity. Those are things that, traditionally, the neurologist doesn't do but a physiatrist does.

[00:10:43] In the team, after the acute care setting, we also find ourselves working with urologists, so individuals who help manage bladder function. And it's actually critically important for any of our patients, especially who had spinal cord events, to, at some point, have a urologic evaluation to make sure that they

are completely emptying bladders and completely emptying bowels, and that they know that their function is intact and that they're not risking any kidney damage from a bladder that is incompletely emptying.

[00:11:14] And, often, urologists will manage neurogenic bladders and will help us both with the medical management, if catheters are needed, the catheter management, or, if certain interventions could be used to the benefit of our patients, bladder Botox injections or even sometimes stimulate placements, it's the urologists who help manage that side of things.

[00:11:36] And between that team, the physiatrist, the neurologist, and the urologist, we cover a lot of bases, but I'm going to point out there are certain things we are probably not aggressive enough with. For instance, working with psychologists. It is important for everyone to remember not just the potential impacts on cognition, but the emotional impact that these diagnoses carry, not only for our patients, but the families that are around our patients, the caregivers, and the loved ones.

[00:12:08] And so even though when somebody comes to me, I am their physician, it is up to me to at least make sure I'm raising to any family members who are there, the possibility that they should independently seek support, emotional support, for what the whole family is going through. I think a lot of our patients and families suffer in silence, and I would encourage anybody who's listening to this who is struggling in even the smallest way, to not be afraid to ask for help, not be afraid to talk to your neurologist and get a referral to a psychologist or a counselor to make sure you're getting supported in the way you need. We often focus on the physical at the expense of the emotional and the mental, and it's something I need to remind myself of on a regular basis to make sure my patients get adequate complete care.

[00:12:57] And so just between those four specialties, I think we cover probably 95 percent of the issues. I will point out, in more complex pain situations, we might bring in other experts in the pain management side of things. These are often anesthesiologists who can help us manage more complicated pain situations. But between a physiatrist, a neurologist, a urologist, and a psychologist, we cover the most. It sounds like the beginning of a bad joke. Four doctors walk into a bar.

[00:13:26] But that's the way things are supposed to work, and the person I left off is the general practitioner, the internist, or the pediatrician. And often I'll hear from my patients all the time, "Dr. Greenberg, you're my general doctor," to which I say, "No, I am not. I am not scheduling your colonoscopy. I am not making sure you're getting mammograms or pap smears. I'm not doing colon screening or cholesterol screening."

[00:13:50] Everybody still needs a general practitioner, and it's up to that general practitioner to decide how much they want to be involved in the management of neurologic issues, but absolutely there needs to be a conductor of the orchestra, a general practitioner there to make sure that everything is being facilitated. So that's the way it's supposed to work on paper. I'm curious, GG, either if you're willing to speak about your experience or the stories I'm sure you get told on a regular basis from our community. Often that's not how things go. So, what's been your experience with this?

[00:14:24] **GG deFiebre, PhD:** Yeah. I would say I would agree that the physiatrist, neurologist, urologist are kind of the main team that I see. But I think I personally end up seeing my physiatrist most often because I have a baclofen pump, so the intrathecal baclofen pump you talked about. So, I see them every 3 to 6 months just to get that refilled. And so, in that time, we talked about other stuff. And so, I end up seeing them the most because of that. And then, as someone with idiopathic TM that hasn't recurred, I see my neurologist about once a year just to check in and see if she wants to do anything new, any new testing, any stuff like

that. But I think that if someone doesn't really have a pump that they're managing, I could see why they might go to a neurologist more frequently for some of that symptom management stuff, whereas I just go there because I ask him about other things too.

[00:15:18] And I think it's also important that you noted the still need for a primary care physician, you're still a person outside of the diagnosis that you have, so you still can have, you still need your colonoscopy or your pap smears or those sort of preventative health measures. So, it's important to see a primary care doctor who's looking at that as well and hopefully looking at you as kind of that whole picture and making sure that you're doing all, none of those stop just because you get a diagnosis of a rare neuroimmune disorder. So, I think it's important to mention that as well.

[00:15:52] And then, physical, and occupational therapists. I'm someone who's been diagnosed for almost 12 years now. I don't really see a PT or OT that frequently. I go for care twice a year usually and see someone and kind of get my home program set up. And I do stuff at home, and so that might look different kind of depending on where you are in your diagnosis, how far you're out from your onset and all of that. So, I don't know if that's also kind of your experience with your patients as well, Dr. Greenberg.

[00:16:24] **Dr. Benjamin Greenberg:** Yeah, no. I'm glad you brought it up. It was definitely remiss on my part not bringing up our therapy colleagues and PT and OT who play such a critical role, particularly in the beginning as folks are getting a regimen down and then episodic check-ins. I will say probably the biggest question I get, and I know it's come up for you, is, "What should people do?"

[00:16:45] So we have these roles that are supposed to happen, and then we all come together with a Frankenstein of what actually happens. But a lot of times I get the question of, "What do I do if I live somewhere where these people don't exist, where either there isn't a neurologist or there isn't a neurologist with a background in myelitis or NMO or whatever the case may be?" And we've talked in the past in this forum and in others on how you can build a team even remotely and get people the help they need.

[00:17:23] And I'll tell you from, from my perspective, I'm sure as from yours, what I've found over the years is it's probably less important to live near an "expert" in one of these conditions, and it's really important to live near a healthcare provider, whoever that may be, who's willing to partner up with experts. I give the foundation immense credit, what Sandy and Pauline built over the years and partnered with in the medical community, and really grew the medical community.

[00:17:57] When we started having these symposiums years ago, there were six of us showing up from the healthcare provider side. And I look at the speakers through these three days, coast to coast from all specialties, and that's really being driven by the association. There's now an opportunity not just to be closer to folks, but all of these individuals who are speaking to each and every one of them are willing to partner with folks remotely.

[00:18:22] So as patients come to see me and they're living in an area where there isn't someone familiar with transverse myelitis, I am always willing to work with their primary care physician or local neurologist, or whoever that may be, and communicate electronically or by phone to help manage things at a distance. And so, I encourage people to focus more on the type of person the healthcare provider is. Are they willing to collaborate versus what their background is or what their expertise are. I will take an accessible, smart, caring clinician any day over a supposed expert who isn't accessible or caring or invested. You really just want that investment made, and it sounds like you've pieced together folks because you're in an area of the

country that has no experts. New York's got, no, I'm just kidding. New York's got a lot. But we have lots of families who come from a distance where they don't have the same access.

[00:19:22] **GG deFiebre, PhD:** Yeah. And even with that, even being somewhere where I have a great neurologist, there have been times where there's been some weird stuff that's happened with me, and I've consulted, I've traveled to Johns Hopkins because Baltimore is not that far away from New York City. And so, they have consulted with them there. So that's a great thing. So, thank you so much, Dr. Greenberg. I think Roberta is going to join us.

[00:19:43] **Roberta Pesce:** Yes. Thank you both so much. This was such an interesting and nice, good conversation to have, important conversation to have. We received a question. "Almost 2 years from my onset of TM. Is it too late to get a physiatrist on board?"

[00:20:02] **Dr. Benjamin Greenberg:** This is such a good question. The answer is an unequivocal no. It is not too late. The issues that come up after a spinal cord injury and particularly transverse myelitis evolve over time, and the window of opportunity for meaningful improvement and meaningful symptom management to occur really doesn't close. And so, it is definitely a worthwhile evaluation to have to see what are the opportunities for improvement or improved symptom management. So, I definitely would encourage people to seek out, even if it's been 10 years since the onset. If you haven't done it before, it's worth touching base.

[00:20:42] **GG deFiebre, PhD:** Yep, and I completely agree with that for sure. It's never too late. Sorry, there was honking happening outside, but yep.

[00:20:50] **Roberta Pesce:** Excellent. Well, thank you both so, so much for this talk. It was great having you on here and seeing you.