

The Role of Physicians and Patients in Legislative Advocacy

You can watch the video of this podcast at: youtu.be/_V8IKqkS8y8

[00:00:02] **Krissy Dilger:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This episode is titled, "The Role of Physicians and Patients in Legislative Advocacy." My name is Krissy Dilger, and I moderated this podcast. SRNA is a nonprofit focused on support education and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. "Ask the Expert" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and UCB.

[00:00:36] For this episode, we were pleased to be joined by Dr. Shuvro Roy. Dr. Roy is an assistant professor of neurology at the University of Washington, specializing in neuroimmunology. You can view his full bio in the podcast description. Welcome, Dr. Roy and thank you so much for joining me today.

[00:00:57] **Dr. Shuvro Roy:** No, thank you, Krissy. It's a pleasure to interface with the SRNA community finally.

[00:01:05] **Krissy Dilger:** And so, today we're talking about the role of physicians and patients in legislative advocacy. So, to start us off, do you mind just explaining why legislative advocacy is important in health care?

[00:01:21] **Dr. Shuvro Roy:** Yeah, absolutely. As long as you promise to cut me off, if I'm talking too long because the short answer is everything. When it comes to practicing medicine or even just being a patient, we're so used to certain rules on how things are conducted, whether it be, how often you're able to see your provider or what medications you can be on, or which doctors you can see or what order of medication you can be on or how much time you can take off from work if you're unfortunately hospitalized. All of that is really determined by health care policy.

[00:02:05] And importantly, those rules are basically constantly in flux and are constantly impacting what it means to be a physician, what it means to be a patient. It is constantly impacting the patient-provider dynamic. And so, I think it's really important as patients and providers to have a say in trying to shape those rules so that they can be as beneficial to both of those parties as possible.

[00:02:44] **Krissy Dilger:** I think those are all great points and will be a great introduction into this topic for this podcast. So how can physicians such as yourself effectively engage in legislative advocacy?

[00:03:03] **Dr. Shuvro Roy:** Well, I would say, for us, I feel like it - I always say that it's a bit of a cheat code and I'm always talking to other practitioners, other physicians who feel intimidated about the idea of engaging in health care policy because, well, oftentimes people get bogged down. And what I think are maybe the less important details of, "Well, I don't know the exact bill. I don't know all the exact steps of prior authorization, or I don't know all of the details that go into the specific bill or the specific law that is impacting my practice."

[00:03:44] And what I tell folks is, what's more important is that honestly, you have the story of your practice, your job is not to be a legislator. And thankfully, I mean, I'm very grateful that I'm not a legislator or part of a legislative staff, but what I can provide instead is technical expertise in a very specific area being a subject matter expert on neurology and rare neuroimmunologic disease and especially I have the stories of all of my patients of being able to tell them, "Well, here is why step therapy or fail first therapy, while that sounds like a great idea in practice, this idea of utilizing less expensive medications up front to minimize the cost on the health care system. Here's the real-life impact that has on my patient with NMO who all of a sudden now cannot walk because she had a breakthrough attack."

[00:04:53] And when the staffs hear our stories and the stories of our patients, that is what they then carry over to our legislators. And that is what then is incorporated into legislation. And it really helps I think translate for folks, "Here's what this policy that we're working on, at this 5,000 foot view, here's what it's actually doing on the ground."

[00:05:27] And so when we're able to go and provide that context as physicians, one it's something that is coming hopefully from a trusted voice of somebody who genuinely - we're doing this because we care about our patients. We're doing this as folks who really understand the issue at hand and we're doing this with the hope that we can build a better health care system together.

[00:06:02] **Krissy Dilger:** Awesome. Thank you. And so, leading off of that, obviously, physicians play a very important role in this topic. But what role do patients have in legislative advocacy?

[00:06:20] **Dr. Shuvro Roy:** That is a great question and I'm really glad you brought it up because I think oftentimes patients aren't even aware how much power they hold because it's one thing for me to show up and say, "Okay, well, here's the story of this patient, here's the story of this patient. Here's what happened." And yes, that carries a certain amount of weight. But I would argue it actually carries so much more weight when you are a constituent and you are a patient who has this condition and you can go and meet with a staffer or even the legislator that represents you and say, "Hey, here's my story and here is beyond just"—because as physicians, we see patients at a snapshot in time, basically during our appointment visit.

[00:07:16] But as patients, you're able to just share the story of what it truly is to live this condition and what it means to have all of the little complications that that changes with quality of life. And I think that just carries even more weight. And so, as patients, I think it's just as important, if not more important to try to engage in advocacy.

[00:07:49] **Krissy Dilger:** So, can you share examples of successful advocacy efforts that have been achieved in the past, in health care advocacy?

[00:08:02] **Dr. Shuvro Roy:** Absolutely. I mean, and many of these are—I think maybe the bright spot and the dark spots of being in health care advocacy is you might have a win but then the same thing comes up again in the following year. So, one example I think of that is pretty successfully advocated for every year is the changes in telemedicine that have occurred since the pandemic.

[00:08:36] So, some background context at the start of the pandemic, basically, there were these wholesale federal changes that allowed patients to be seen outside of their state via telemedicine, which I think especially for patients in the rare neuroimmune community, that is huge. The idea that, I mean, if you're not fortunate enough to be born near a postal academic center, it's pretty hard to find a specialist in these conditions. And so now all of a sudden with these changes in telemedicine, it became much easier, for example, for my patients in Alaska to be able to see me in Washington.

[00:09:22] But as some of those changes lapsed as we got further from the pandemic, all of a sudden, we see people are trying to put the genie back in the bottle where all of a sudden, "Well, yes, I know that you"—I used to live in Baltimore for my fellowship training—"I know that you as a patient may live in West Virginia and I know your doctor is in Maryland, but you can't see them over telemedicine." And so, we would have these crazy situations where patients would just drive over the border, pull over to the side of the road, and then do their telemedicine appointment that way, which is crazy.

[00:10:06] And so what many different groups in neurology have advocated for is trying to maintain those cross-state agreements to try to continue to see patients over telemedicine. So that's one thing. Other things would be limiting the cost of prescription medications to a certain out-of-pocket cost, certainly increasing the amount of funding that goes into medical research, especially in neurosciences, and actually especially relevant for the SRNA community is really pushing for actually PCORI the patient outcomes, NIH cohort, they now actually have an emphasis on rare neurologic diseases that is actually actively looking for applications.

[00:11:04] So, those are certainly some of the wins on a year-to-year basis. Other things include basically trying to expand the neurologic workforce as well as step therapy relief, which I can talk to you for an hour about that. But those are all ongoing issues.

[00:11:31] **Krissy Dilger:** I can see how even things you might not think about in terms of legislation playing such a huge role. It really does take over everything at the end of the day and that's why this is important. So, you mentioned a lot of examples there, are there any key current legislative issues impacting the rare neuroimmune community right now?

[00:12:01] **Dr. Shuvro Roy:** Yeah, I would say actually something that just happened, that's actually up right now is there is a new bill that's looking at step therapy reform. So basically, prior authorization reform. So essentially, patients ask me all the time, for example, if I have a new patient with NMO, "How long is it going to take me to get the Soliris or Ultomiris or Uplizna approved?" And I tell them, "Hey, we're going to submit the paperwork today before you're out of here, I will have the paperwork done to get that submitted to you for prior authorization."

[00:12:52] But what can get slowed down is that the prior auth of submitting and then say you get a—we send these forms out into the ether and we don't know when we're going to hear back and you might get a denial and then we appeal immediately the same day or the next day and then you're still waiting for, who knows how long. And unfortunately, I've had patients who have had to wait months to just get started on treatment.

[00:13:24] And so one of the bills, HR 8702 is looking for patients, for example, on Medicare Advantage plans and really when it comes to Medicare, we find that a lot of the insurance companies follow suit with those policies basically limiting the amount of time that insurance companies have to respond to an authorization. So, if we send an appeal, you have 72 hours to respond. And so, we're hoping that that can just speed the process along of getting patients on treatment faster.

[00:14:09] One other thing that I didn't mention but was a win was just increasing medical leave availability for caregivers beyond just the patient. And so, if you are a caregiver for somebody with say, NMO or MOGAD, or transverse myelitis, or optic neuritis, you have at least six weeks of paid medical leave available to you. And in some states, we've actually been able to push that to 12 weeks, but those are just a few of the issues. I mean, really at any given time there can be any number of issues and then they all matter for patients with rare neuroimmunologic disorders just given research matters. Certainly, things like prior authorization, as we talked about, access to care, telemedicine, even just increasing the neurologic workforce, which is often an area of emphasis. All of these I think can really make a difference for patient outcomes.

[00:15:26] **Krissy Dilger:** Thank you. So, in your experience, what are the most effective ways to communicate healthcare concerns to legislators and policymakers?

[00:15:38] **Dr. Shuvro Roy:** So, this is I think the part that can be a little bit tricky, but what I always tell people what is most important is your authenticity, is that you are sharing what your experience is because that's really what people want to know. I think what's important to understand just before I get into maybe some nuts and bolts is how do these legislative teams work.

[00:16:09] And admittedly, a lot of times, actually, you're not meeting with your senator or your congressperson. Frankly, you may be meeting with someone more important and that is say their health care staffer there, a person who really is then in the legislators' ear of, "Okay, I am taking this information from that I've heard in the community" and then translating that into, "Okay, well, here how this fits into this point of this bill. Here's how this is impacted by this point of this bill."

[00:16:41] And so what's important is just delivering that information. The caveat I have—and I am not good at this—is keeping it tight. So ideally, you want to be able to tell your story in 30 seconds to a minute, mostly just because these meetings can be a little bit short. These folks are seeing and meeting with a lot of different folks throughout the day. And so, you want to make sure that you're able to convey your story clearly and ideally, if possible, give them a clear ask.

[00:17:26] If that means that there's a specific bill, whether it's HR 8702 or some other bill that ties into your point like, "Okay, here's my story, here's how this impacted me, and because of that, I'm asking that you support this or actually don't support this, or be a cosponsor of this bill that is actually not up for vote yet." But again, I think sometimes people can get a little too weighed down by how intimidating all these bills can be. I think the most important thing is just delivering your authentic story as succinctly as you can.

[00:18:14] **Krissy Dilger:** Thank you. And then what are the potential barriers or challenges faced by physicians and patients in advocating for legislation and policy changes?

[00:18:26] **Dr. Shuvro Roy:** I would say, number one is something we mentioned earlier on which is just folks feeling like, "Oh, I'm not a good advocate or that I can't be a good advocate" and that is just the wrong message to take away. You absolutely can be whether you're a physician or a patient. And you have a story to tell. You do not need to understand where all the money flows. You don't need to understand necessarily, who is in charge of what, overseeing what aspects of what committee, you just need to tell your story.

[00:19:08] I think the other thing that can be intimidating is people can feel, "Well, I'm not part of some advocacy program. And as a result, I don't feel like I can advocate effectively." And there is a certain advantage to having strength in numbers. I have done some work with the American Academy of Neurology. Certainly, the National MS Society has a program engaging patients to go and advocate in groups, but you don't have to, you are a constituent and that with it carries a certain amount of power.

[00:19:52] If you are reaching out to your local representatives and saying, for example, for these upcoming August recesses, "Hey, I'm a constituent. I would love to talk about some of the challenges facing myself and my medical community. And I would just love to know what the senator, the congress person, what city council is doing to help patients like myself or people like myself really." So, I think those are two misconceptions that can really get in the way of effective, otherwise excellent health care advocates.

[00:20:35] **Krissy Dilger:** So, what role does medical research play in supporting legislative advocacy?

[00:20:43] **Dr. Shuvro Roy:** So, I would say they both feed into one another. So, every year, for example, when I'm doing work with the AAN, they have certain tangible areas they want to target. But one of them without fail is we need to continue funding medical research, and we need to continue funding neurologic research. And this is something that frankly anyone can advocate for it because it's always really important because what's key is, yes, there is a certain amount of medical funding that goes into the NIH. But within that, I think it's important to remember there's the NINDS, the National Institute of Neurologic Diseases and Stroke and making sure that that institute is also receiving just the same proportionate funding every year as the NIH.

[00:21:43] And I think that's really important for the sake of making sure that the pipeline for neurologic research stays strong. And especially now that—I mean, we're really fortunate we have this focus on rare neurologic disorders. The NIH has developed this network of clinical trial sites called NeuroNEXT, for the sake of more easily doing clinical trials on rare neurologic conditions. And so, it's really always something that's important to advocate for because it's always something that I think if we don't, we risk losing funding and obviously that just affects not just patients, but so much of the pipeline of these brilliant physician-scientists who may be—or forget it, not even physicians, just scientists who are really changing the face of management of these conditions.

[00:22:57] Think about how different things were for the management of NMO 12 years ago. I'm hoping that we are going to be in that same place for MOGAD in the next few years as we continue a lot of these clinical trials. So, I guess, I could have just given you the short answer that it's incredibly important, but they are incredibly intertwined.

[00:23:25] **Krissy Dilger:** No, I appreciate the full explanation because I do agree, it's so important, not just for the small future, but the larger future down the road, how our understanding of these disorders progresses.

[00:23:42] **Dr. Shuvro Roy:** Absolutely.

[00:23:44] **Krissy Dilger:** You already touched on it a bit, but how can physicians and patients collaborate with other stakeholders such as healthcare organizations, nonprofits, policymakers to advance healthcare legislation?

[00:24:02] **Dr. Shuvro Roy:** I think this is my favorite question. I mean, because I think what's also misunderstood is that this is not a one-way street, you're not just going and making a bunch of asks and saying, "Hey, see, I'll be back when I have more things to ask of you." And this also goes into, how can you most effectively convey your message. I think it's important to present ourselves as resources. A lot of times I think what I try to do when I meet with legislators and their staff is just, "Okay. Yes, here's what I'm here to talk to you about today. But I go home, I'm a neurologist full time. So, if you have questions about neurologic conditions, especially neuroimmunologic conditions, but really how this affects our practice, here's my contact info, please feel free to reach out any time."

[00:25:05] And so with the policy folks, I think that's the easiest thing, is just cultivating that relationship of just, "Hey, wanted to stop by say hello, tell you what's going on my end. Just give you some insight into what things are looking like for me as a constituent." And then whether you have an ask or not just presenting yourself, "Please feel free to reach out if you have more questions." And then shooting probably a follow-up email after that meeting just to thank them for their time. But also again, reiterating.

[00:25:47] And sometimes they may even just ask you a question in the meeting. And I think this is a perfect opportunity if say you don't know the answer. Well, you can go home, and this is another opportunity to

collaborate with medical professional societies, reaching out, say to someone in the SRNA, "Hey, this is something that came up about optic neuritis. I actually don't know the answer, but do you all?" And then you can then later provide that answer to a legislative staff member and all of a sudden, yes, they have that information, they know that you can be trusted as a source and trusted as someone who can provide them high-quality information.

[00:26:32] Beyond that, many different organizations have dedicated advocacy pathways, whether it is something like the National MS Society or otherwise, even things like I think the—I actually don't know if the Sameera Foundation—I should know—does actual policy work. But I think when it comes to the rare neuroimmune space, I think there's certainly an opportunity to push it even further. So those are all, I think opportunities to try to serve as an advocate and then also bring that information through the pipeline to those staffers.

[00:27:18] **Krissy Dilger:** And I can only say on our end as SRNA as a nonprofit in this space, we will always try our best to support anyone who comes to us with intentions of moving legislature for this cause. So, we welcome any inquiries or anyone who wants to talk about it. And I know that we've talked a lot today about the benefits and the challenges and how the process works. But what advice would you give to maybe other medical professionals or say a patient who's never engaged in legislative advocacy before? What advice would you give them to become more involved in advocacy work? Where can they start if they're maybe overwhelmed and don't know where to start?

[00:28:18] **Dr. Shuvro Roy:** I think the easiest and first step is just to figure out who are your representatives. I think that is the key, to just understand, "Okay, who is it that is supposed to be advocating for me, at the local level, the state level" and just looking that up to start because I have to admit I was pretty bad about this. When I was a kid, I had no idea who my legislators were at a local level. I thought everything was run by the president and that's not how government works. And so, I think understanding that to start.

[00:29:09] And then from there, if you want to get involved, and again, we've got the August recesses coming up right before things gear up for the election. So, I think it's actually a great time to reach out and just shoot an email and just try to set up a meeting. Again, you don't have to come in with one particular ask, if you do, great, but you don't have to. And I think just think about, "Well, what is it that is impacting my life the most in terms of my medical care? Is it the fact that I have had trouble not just getting on my therapy but staying on my therapy? I am having trouble being able to see my doctor on a regular basis?" Is it issues with just even getting your diagnosis, access to care, even just little things like, just your out-of-pocket costs?

[00:30:23] I think it's perfectly reasonable to set up a meeting be like, "Hey, my medications cost more than what is remotely reasonable for me to afford." So, trying to figure out who is, for example, the health care staffer, the person you want to meet with, shooting them an email, trying to get something on the books, mention that you are a constituent because that word carries a lot more weight than people think. And then try to come in with just your story and really what is impacting you the most. And I think that's a great place to start.

[00:31:00] If you're interested in working with other organizations, I think you can always reach out to local nonprofits and see if there is an advocacy arm. But like I said, I think even if there's not, your story is the most powerful thing that you have. So that is I think the main piece of advice I would give people.

[00:31:25] **Krissy Dilger:** Awesome. I think that's great advice. And one that I think everyone would be able to do, it's a tangible step you can take if you want to get involved. That is the end of my questions. But I did want to open the floor in case there was anything else you would like to add before we close our discussion.

[00:31:47] **Dr. Shuvro Roy:** I mean, honestly, I think we covered a lot of it really in depth. You asked some really excellent questions. But I think my main takeaway is just for members of the rare neuroimmunologic community, I mean, the stories you have of what you're facing, whether it is, "Oh, my goodness, I woke up one day and I was blind" or "within a few days, I was blind in one eye," or what it's like to experience transverse myelitis and to go from, "Hey, I am in a normal state of health and all of a sudden within a few days I keep feeling I'm paralyzed in one leg or I couldn't even use the restroom." Those are powerful stories that really speak to what it means to be a patient facing these conditions.

[00:32:50] And there's so much with coordination of care, access to care. So many of the many, many, many complex facets of health care, whether fortunately or unfortunately are represented in these stories. And so just because you have a rare condition does not mean that your voice matters any less. If anything, it matters even more. And again, if you think you're not a good advocate or you're not ready to engage in advocacy, I bet you're probably just the type of person actually that folks are trying to hear from.

[00:33:33] And so I encourage everyone, just because we face these conditions does not mean that we are bound to the rules in the rulebook, we can change the rules in the rulebook. We just have to make sure that our voice is heard, right?

[00:33:54] **Krissy Dilger:** Well, thank you so much, Dr. Roy, for joining and sharing your expertise on this topic. It's something that I know I learned a lot about today and I hope our listeners do too. And I think you've invigorated me at least into maybe reaching out to my representatives about my concerns. So, thank you so much. Hopefully, we can have another conversation soon to continue this discussion.

[00:34:24] **Dr. Shuvro Roy:** I would love that and that's what they're there for, is to listen to us. And so, thank you, Krissy. This has been a lovely discussion on my end.

[00:34:41] **Krissy Dilger:** Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; and UCB. 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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