

## Podcast Transcript

**UNMC Chancellor Jeffrey P. Gold, MD:** Today, our guest is Dr. Geeta Rathore, who is an assistant professor at the University of Nebraska Medical Center in the division of Pediatric Neurology. Now, Geeta has recently won a national patient advocacy award, and we are all here today to talk about patient advocacy and the role and the responsibilities of physicians and others in advocacy efforts. So, Geeta, thank you so much for joining us today and of course the first and most important question I think that our audience is interested in is what is patient advocacy?

**Dr. Geeta Rathore:** Thank you for having me here today, Dr. Gold and for bringing up this important topic of patient advocacy. So just as advocacy means to support, support the cause, or something that we think is important to us or the patients we serve, patient advocacy is supporting our patients for what they need. So, it could be something simple as, listening to what they have to say or what the challenges that they're facing and trying to help them find a solution. Or you could go all the way up to the legislature and try to change health care policies. So, just supporting what they need.

**Dr. Gold:** Well, you know, it's very interesting to me that somebody such as yourself is so interested and so involved in this area. As you may know that I spent a large portion of my clinical life taking care of newborns and kiddos with congenital heart disease and have had the pleasure of working with pediatric cardiologists and neurologists and nephrologists for, you know, decades of my life. So, how is it that somebody, uh, with a specialty as highly refined as pediatric neurology gets involved in this kinds of area, and more importantly, perhaps, what have been your experiences that led you to the leadership of this that is now recognized on a national level?

**Dr. Rathore:** I think my leadership, or I wouldn't say starting with leadership, just advocacy in general. Started about a couple months after I started as a pediatric neurologist and, I saw a baby diagnosed with spinal muscle atrophy and just giving that diagnosis to those parents, you could just see the devastation in the eyes of those families, and you feel so helpless, you can't give them anything, to help them. You just give a diagnosis that changes their life, and you say, I'm sorry, I can't do anything about it. And that was just, it really hit me. And my husband said, why don't you do something about it? And I said, what can I do?

I'm like, a junior faculty, I'm barely getting my feet wet. I can't do anything. And I am very grateful, I think, to the leadership of our department. I think our organization, the director of advocacy, Liz Lyons, they all got me involved and

they said, you know, they helped me get involved and testify and advocate for a bill that we could get spinal muscle atrophy on our newborn screening in the state. So, that was kind of my starting point. And we were able to then get gene therapy in the state. We built a neuromuscular clinic where a wonderful colleagues, like you mentioned, pediatric or orthopedic physicians, pulmonologists, cardiologists, they all joined me and helped me take care of these patients. And it kind of helped me down the line where one person can make an impact. If you see a problem and you say, I want to do something about it and just ask for help. Everybody is ready to jump in and everybody helps you and you find a way to fix it. And after that I got involved with our stroke program. We kind of started building pediatric stroke program and our epilepsy program. And I recently, I went to Washington to advocate at a national level to improve neurological care, not just in our state, but throughout the nation. So, I think now it's become a passion of mine now that I've learned that I can do it and it makes an impact.

**Dr. Gold:** Well, I think that's really the message Geeta, is that it makes an impact and I'm sure you're aware that I've spent more than my time in the beltway on Capitol Hill. Plenty of time in the Pentagon, in the White House, et cetera. And it gets to my next question to you is that all of us large organizations like Children's hospitals, academic medical centers, et cetera, have a typically a well-defined government relations team of professionals. Many of us have advocacy firms that we work with in Washington or in our respective state capitals. So, why is it that, at least, that you believe, and I have my own opinions on this, but why is it that you believe that the voice of a physician, a frontline health care professional, who actually had to deliver that message to that family on that tragic day is so important as part of this process?

**Dr. Rathore:** I think as physicians it's part of our profession to advocate for our patients. That's kind of why we went into this profession we wanted.

**Dr. Gold:** It's actually in the hippocratic oath that all of us took when we became a physician.

**Dr. Rathore:** Correct. Yes. So, and we don't think of advocacy as part of it, but we're doing it every day when we are, you know, advocating for our patients in simple sense. But to your question, why is it important for us to step up a little bit higher and where the policies are being made? Because I think the policymaker, and you've probably had a lot more experience, but the people that are actually involved in policymaking don't have understanding or as much of an in-depth knowledge of what involves a day-to-day working or functioning of a health care system. I mean, like you said, a child, what it takes to take care of

a congenital heart child who can understand it better than a pediatric cardiologist or a cardiothoracic surgeon, or the whole ICU team that's taking care of them. Or an ALS patient, you know, a neurologist will probably have the best understanding. We see the challenges that the patient or the family is facing every day. You know, we can't get a medicine for them cause insurance won't approve it. Like those simple things, I don't think the policymakers understand. So, it is our job to be a voice for our patients at that table where decisions are being made for them. And I think, you know, the policymakers, like our interactions with them at the Hill, they appreciate that. You know, we can educate them about how these policies or the decisions that they're making are impacting our patients or their families. So, I think that's where our role is to educate them and help those policies benefit our patients.

**Dr. Gold:** And, you know, I would add in addition to providing them with the necessary information they need to be effective, giving them real life examples that they can repeat as part of their efforts to bring their colleagues along. Because you know, anything and everything that happens on a governmental level happens as a result of building energy and building enthusiasm across a body, whether it's the United States Congress or the Unicameral legislature. Or even a local county government. If we want to affect change, we need to not just convince an individual, but convince a cohort. And there are no stronger voices that occur than a real-life example of what happens to a patient who would benefit from the results of your advocacy. So, let me ask you this, Geeta, you know we are fortunate in that we are graduating every year well over a hundred medical students, hundreds of nursing students, pharmacists, dentists, physical therapists, physician's assistants, others, all who have that frontline experience of having to deliver care and seeing real time where the gaps are and where advocacy could possibly be helpful. But perhaps most of them have never had an experience in advocating for an important area. So, if you had some advice for them as to how to get started, how to, if you will just put their toe in the water to have an experience very similar to your early days of doing it. What kind of advice would you share?

**Dr. Rathore:** I think I would start with telling them they're already doing it. I think we start advocating day one when we're calling the pharmacy after hours and saying, our patient needs this medicine, or calling the insurance and saying, we need this, or calling schools or work or nursing homes asking for modification. So, we're already advocating. So, everybody should feel that they're doing it if they want to go a step ahead. I feel like for me, it was helpful that I had a very supportive leadership that kind of helped me with this. And we have trained people like advocacy directors who understand the law making and they kind of guide you how you can do it. So, I think if somebody's identifying something that they want to help or make change, or they see a barrier or a

problem in a system, start with talking to people that could help and maybe they can't, but they will direct you to somebody that can help. And then, you could go as far as you want to. The other thing I feel, which I've talked a little bit with the dean and our leadership, is the American Academy of Urology has been very visionary in building leadership programs for advocacy. So, they are training people that are interested in it. How do you advocate, you know, at your organization level or at the hill. So, they give you those tools and skills. I think first of all know you can do it. And then if you're interested, kind of talk to leadership and talk to people that are more experienced in it. And then go as far as you want to.

**Dr. Gold:** You know, I think you make a number of critically important points. And one of them is when you're advocating for our patients, when you're advocating for the communities that we serve, it is a much easier message to deliver than when professional organizations or large healthcare organizations advocate for what they need to be successful. Because at the end of the day the entire healthcare system of our nation is focused on making our nation healthier, preventing disease, providing access, providing equity and quality of care. And that really needs to drive the decision making around policy and frankly, not just policy, but around what we pay for and how we use those precious resources to deliver that care. And, you know, I think if I had a message to share with an evolving or a young professional and certainly, I think you've learned this as well, that the sins of omission are typically far greater than the sins of commission. And what I mean by that is that the risks of advocating for our patients, for our communities, families, of our patients are very, very small. And that the potential benefits are great. Now, not every opportunity to advocate results in an immediate response. I'm sure you have experienced that as well, but ultimately it does add up. And my own personal experience is that when you can talk about a patient or a family as you did as that child that you described early, and I'm sure you've had many others in your career, as have I had, it really makes a huge difference. So have you, you know, perhaps, what are the limitations or how do you perceive the, you know, the push back to your efforts because I think it's important for the next generation of health care professionals and those of us who deliver care every day or have administrative responsibilities to understand how well you're received when you brought these efforts forward.

**Dr. Rathore:** Like you mentioned briefly, not an image effect that sometimes you see, and that can be frustrating sometimes, you know, you go and say, oh, I testified, and okay, this should be happening like fast. And a year later you're still like, so what's going on? Like, everybody voted unanimously, so why is it still not happening? So, just realizing that sometimes change is slow. But it can happen, and you have to just keep, you know, pursuing it and keep asking for it and when the change happens, you'll see the reward. It might just be slow and

sometimes the impact, even though the change has been made, you're not seeing the downstream effect until years later, you know, spinal muscle atrophy was one example I gave that was a disease that's very fast progressive. So, you can see the benefits soon, but certain disorders or even policies or system changes can take almost a generation to see an impact. So, um, I think that would be one thing. If you truly believe in something, don't get, don't get disheartened if you believe it's the right thing, continue to do it. I feel like I was fortunate that I got people ready to help me every step I went. So, personally I don't think I can say I got a barrier, but there can be places where, you know, that you might not get the support. So maybe ask, you know, a second person or a third person, one barrier that I think all of us face is time, because we have so much effect, you know, we're so free. So that was one barrier. And again, you know, you're taking time. You can't go back on your clinical duties, so you're still doing your clinical duties, you're doing your family duties, and then you're taking on more. So, so that I feel is a big barrier I felt guilty sometimes about, but I think, you know, my family thankfully was very supportive, and my work was very supportive. So those are some barriers I can foresee for some people that may not be as fortunate as I was.

**Dr. Gold:** Well, Geeta, we could have this conversation forever, but I want to take this opportunity to thank you and to thank your family for all that you have done, and to provide not only leadership in your field of expertise, of course, but to inspire others to have this role to participate in advocacy. You know, I will tell you my own experiences are not only is it greatly rewarding to see these changes occur over a period of time, albeit you need patience, but it's actually fun. And you'll find for those of us who have this opportunity that it's very well received and it's very heartfelt in so many ways. So, thank you for all that you do, and thanks for joining us today on this Heart-to-Heart podcast.

**Dr. Rathore:** Thank you, Dr. Gold, for having me.