

Mayo Clinic Q & A - Dr. Noelle Larson - Patient Advocacy Gro...

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SPEAKERS

DeeDee Stiepan, Narrator, Dr. Noelle Larson

N Narrator 00:01
Coming up on Mayo Clinic Q&A,

D Dr. Noelle Larson 00:03
My goal in life is to make new stuff for patients to make the treatment less burdensome, and to make their lives better. And so, if we really want to make new drugs, new devices, new treatments, we all have to work together.

N Narrator 00:17
That collaboration often comes by working with patient advocacy groups. The results can lead to new advancements and treatments for patients.

D Dr. Noelle Larson 00:26
I mean, there's no one that cares more than the patient right and the patient's family. And so, to bring the patients together allows them to work together and let us as the researchers and the doctors serve them, is a really powerful force.

D DeeDee Stiepan 00:38
Welcome, everyone to the Mayo Clinic Q&A podcast, I'm Deedee Stiepan sitting in for Dr. Halena Gazelka. Patient advocacy and support organizations play an important role for patients suffering with diseases or conditions. The goal of these groups is to connect with others who

may be in similar situations and to help locate resources and manage or treat their condition. But patients aren't the only ones who benefit from these connections. Physicians and researchers can benefit too from getting involved. Here to discuss is Mayo Clinic orthopedic surgeon Dr. Noelle Larson. Dr. Larson, welcome to the program. Thanks so much for joining us.

D Dr. Noelle Larson 01:14

Really a pleasure to be here with you this morning, DeeDee.

D DeeDee Stiepan 01:17

So, tell me how did you start becoming more involved with groups for patients and their families?

D Dr. Noelle Larson 01:24

From my standpoint, taking care of patients is my passion. So, it really comes naturally to be interested and involved in my patient's lives. My primary clinical and research focus is scoliosis. So, I see a lot of young teenagers, primarily girls and their parents and really feel for them as they go through their walk in life. Oftentimes, for non-operative management of scoliosis, children are being asked to wear a brace to school, which is very difficult particularly for a young teenage lady. And so, I think my first introduction was really getting involved with Curvy Girls Scoliosis Support Group, which is a state-based and national organization, actually global organization, which helps children with scoliosis develop supportive strategies as far as how to wear a brace, how to wear clothes that fits over a brace, how to prepare for surgery, how to go through the recovery following surgery. And I saw that a lot of my patients were benefiting from these networks. So, that was kind of the first group that I have become involved with. I had the pleasure of going to their national meeting a couple years ago prior to COVID, and spent the weekend with over 100 lovely young ladies and their mothers at a hotel in Long Island and really got a chance to listen to our patients. So often, our encounter in clinic is quite short, it's a 10 to 15 minute encounter. And you don't get a sense of the impact of what our treatment has on that child's overall life and well-being. So, it was really a change in my practice and my change of how I view each patient encounter to spend a couple of days on-site with families and children affected by scoliosis.

D DeeDee Stiepan 03:14

Well, that's wonderful. Would you say is it common to have Mayo MD faculty such as yourself attending these organization meetings for patients and their families?

D Dr. Noelle Larson 03:23

I think it's becoming increasingly common, and I would be a huge advocate for it. I would recommend it to my colleagues, and then I'd recommend patients, if you're struggling with a condition and you only get to see your physician once or twice a year, yet you're having

challenges in your own life, that ability to reach out, and I think a lot of that reaching out is now occurring through social media, and through internet and through online connections. I mean, there's a huge ability now to make contact with others. And that gives power, and education, and networking to the families. And I think physicians, if we're not involved then that's a real shame. Because again, these patients know more about their condition and living with their condition than we do at some level.

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DeeDee Stiepan 04:10

Oh, absolutely. And you touched on it a little bit, but can you speak more about how patients and families benefit from these groups?

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Dr. Noelle Larson 04:18

I think there's a lot of word of mouth happening nowadays where new treatments arise. And really the poster child for all of this is a group that I'm not particularly involved with at the moment that I admire, and it's Cure SMA. So, spinal muscular atrophy is a relatively common condition that can be life threatening and affects children. And there was a parent who had a child with spinal muscular atrophy and wished to do research. So, they set up a large research fund and actually funded University of Massachusetts and some other partners, and they actually developed a drug that cures SMA, so spinal muscular atrophy, now if the children get the drug prior to, you know, one year of age, the children are now walking, they're not needing ventilators, they're up living a much more normal life, because of this patient organization that achieved the dedicated funding that then was transferred into a pharmaceutical product. So, I mean, that really is the gold standard, right? And I think there hadn't, I mean there's no one that cares more than the patient, right? There's no one that cares more than the patient and the patient's family. And so, to bring the patients together, allow them to work together, and let us as the researchers and the doctors serve them, is a really powerful force. So, I'm hoping we'll see those same kind of developments for scoliosis. I would love a medical cure for scoliosis where we don't have to put children in a hard plastic brace, and we don't have to do surgery on their spines. So, I think we should do it.

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DeeDee Stiepan 05:54

I agree, it sounds incredible. Talk a little bit more about how the medical community benefits from these organizations.

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Dr. Noelle Larson 06:01

I think at the end of the day, we want to see fast, safe innovation. And so, from our standpoint if we have patient organizations and patient networks to work with, we can meet more patients who might be interested in enrolling in a study. When we have patients that are enrolled in a study, again if they're invested and interested or better, yet, their support group is funding the study, you know, they're going to do their best to make the best possible data that will then help the FDA decide whether or not to approve that treatment, which will then help insurance companies decide whether or not they're going to approve it. So, again about five years ago I

decided I had published enough papers, I got my little professorship, you know, I ticked all the boxes. And really my goal in life is to make new stuff for patients to make the treatment less burdensome, and to make their lives better. And so, if we really want to make new drugs, new devices, new treatments, we all have to work together. Because what I think might be a good idea, a patient might say, No way, I will never wear a brace that looks like that. I would never want to go through a surgery that involve that. So, that partnership between the families, and the patients, and the researchers and the doctors all working together is really critical. Same thing for an engineer. An engineer might have a great idea for a new spine device, but as a physician, if I come in there and say, well that means the family has to travel here four times a year, and we have to do surgery, you know, eight times, I can say hey, no that's not feasible. You know that that's not a feasible treatment, go back to the drawing board. So, at the end of the day any one group alone is not going to make as much progress as if we all can work together, and again make lives better for kids.

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DeeDee Stiepan 07:52

Absolutely. Well said. Can you share any other examples of how these collaborations lead to research discoveries and medical advances?

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Dr. Noelle Larson 08:01

Well, my main journey over the last six years has been on fusion scoliosis treatment. And fusion surgery has been around for 40 years. It's very predictable. All the pediatric orthopedic spine surgeons, we know how to do the procedure very well. There are 15,000 papers published in medical literature talking about fusion surgery. But what I started hearing from my patients five to seven years ago was that they don't want a fusion, and that they don't want to have rods in their back. And I can, again have this long discussion with families, and say it's very reliable, it's a great solution. But they want to preserve their child's growth and mobility. So, there was a procedure that was developed in the U.S. that was not approved by the FDA. So, we did a handful of those procedures at Mayo, and at that point I ethically didn't feel comfortable continuing doing non-fusion scoliosis surgery without a study. So, I went and talked to my first handful of patients, and I said, Hey, would you be willing to be in a study if we are able to get FDA approval for it. So, we did a surgeon sponsored investigational device exemption study at Mayo, and I really have to thank all my patients for being willing to come and do the follow up, and do the patient reported outcomes. And it was really an outgrowth of hearing from my families that they want an option other than fusion. And then right now we're really kind of at an ethical standpoint, because the non-fusion surgeries have a higher failure rate. So, there's a higher chance of needing a second surgery with non-fusion. But like the fusion, you know, you put a rod, right. You put a rod and the kids back, and you pull the spine straight, and it's great. And then the non-fusion devices are like a plastic cord. So, you have like a plastic cord, you know, where the child's back still bends, and moves, and twists. But as you'd imagine, the rod, it's going to be quite hard to break it right? But a little plastic cord, this is going to brake at some rate, the device is going to fail, and are families willing to accept that higher failure rate for the cost of motion and growth? So, really, as a surgeon, I find that a very hard decision to make. Most surgeons are very conservative, we want to do a procedure that's going to work, and the patient doesn't ever have to come back with more problems. So, again, this is another threshold in time where we need that feedback from families about what do they value and care about. So, right now we're doing a FDA sponsored study with Setting Scoliosis Straight

Foundation. So, the first aim of the study was to survey 300 patients and families about their values regarding fusion versus non-fusion surgeries. So, we've just completed aim one of the study. And then the second aim is actually through the Mayo Knowledge Education Research Unit, with Dr. Juan Brito. And basically, we're developing a shared decision aid that doctors can use when they're sitting with their families talking about fusion versus non-fusion, and use that aid to help inform patients. But I'd say for right now there are these very involved social media groups that are interested in fusion versus non-fusion, and they really would benefit from some of the data. So, like tomorrow night, I'm doing, with Setting Scoliosis Straight, we're doing a webinar for patients and families with kind of the latest updates on non-fusion scoliosis surgery. And again, trying to work with patient groups so that they have an informed ability to decide what's best for their child.

D DeeDee Stiepan 11:45

That's a great example. Thank you for sharing that. And I love a visual aid. So, I appreciate that. Dr. Larson, are there any recent activities that you've been involved with, with these organizations and support groups?

D Dr. Noelle Larson 11:58

This fall, I had an amazing opportunity to go to the Children's Tumor Foundation Neurofibromatosis Walk, and I actually ended up going to the one in Iowa and also to the one in Minneapolis. And I had a couple of my patients that I had treated with a newer procedure on the shin bone on the tibia. One was age three, the other is about age five, and both the little boys were there at the walk, and they were running around together and meeting each other. And one little boy was in a brace, and the other boy due to our interventions is now out of the brace. So, it was really sweet to see the two of them, you know, share bracing tips, and meet their families, and see them playing together at this walk. It was really like one of the highlights of my life, I have to say, to see these two children living and playing together. And I think neurofibromatosis is another very common genetic condition, and Children's Tumor Foundation is very active both as far as research, developing research standards. So, I sit on a couple of committees where we have patients with neurofibromatosis, and PhD's who research neurofibromatosis, and clinicians who treat patients with neurofibromatosis, all working together to figure like, if we do a study what kind of outcomes should we look at? What's important to families? What makes a difference in their lives? Rather than just me as a doctor, as the orthopedic surgeon, I care about the x-ray. That's our typical study. We care what the x-ray looks like. We don't necessarily know how to study the function, which at the end of the day is what's important, right. The function is important, not the x-ray.

D DeeDee Stiepan 13:44

Our thanks to Mayo Clinic orthopedic surgeon, Dr. Noelle Larson, for joining us today. Dr. Larson, thank you so much.

N Narrator 13:51

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