



Fierce Advocate

A MinneStory

Rae talks with her son's medical specialist, Dr. Nelson, about how her son's diagnosis of sickle cell disease as a newborn has shaped her into the advocate she has become today.



Rae: Alright, well I am Rae Blaylark, and I am talking with my partner here, Dr. Stephen Nelson.

Dr. Nelson: Yes, my name is Stephen Nelson. I'm 53 years old. I feel like I've been a provider and a partner in the care of her son over these years.

Rae: That's absolutely true.

Dr. Nelson: It's really hard to believe.

Rae: I know.

Dr. Nelson: That it's been 17 years that I've really had the pleasure and honor really of helping to take care of your son. And I think not just your son, but you and your family, and your mom, and I've gotten to know your brother, so much of your family.

Rae: And the one thing that I can say is that from the beginning I felt like we had a mentorship relationship. And I didn't realize how new you were to the field.

Dr. Nelson: I've been here 21 years, so I actually was only a little over two years out of training.

Rae: But I think that's why we could have such a mentorship relationship because you were only relaying what you were newly taught.

Dr. Nelson: Yeah. We were both learning.

Rae: Yes!

Dr. Nelson: On some level, actually.

Rae: But yeah, it's amazing that relationship has taken many turns, welcome turns along the way and has grown and matured in ways that involve Treyvon and his care, and in ways that go beyond Treyvon. I mean I don't think that I would have been able to find my place in the sickle cell community had I not been on the 8th floor. I watched so much. I didn't know the right questions to ask. I didn't know what to expect.

Dr. Nelson: You were such a fierce advocate for your son on the 8th floor. You continued, and still continue to advocate for your son in a calm, respectful, but fierce way. For you it's, it's, I don't know if difficult is the right word, but I want to hear what are the fears you have?

Rae: My greatest fear is that Treyvon will second-guess his purpose in life. That his health challenges – he will see his health challenges as a curse upon his life. Not wanting him to fall victim to hopelessness (crying).

Dr. Nelson: Right.

Rae: Wanting him to get through college without the setbacks that having any kind of an illness like sickle cell can bring because college is difficult enough. Staying focused is difficult enough. So him being, you know, an hour away was reasonable. He's far enough away that he can't call me for a ride.

Dr. Nelson: Right.

Rae: But close enough to where I can get to him, or he can get to me.

Dr. Nelson: Right.

Rae: And he can get to you, and he can get to his specialist.

Dr. Nelson: Right.

Rae: Which is critical.

Dr. Nelson: What I hope you will feel also is such pride, such pride in your son for the really fine young man that he is becoming, but also pride in yourself. I personally have learned much from you and Treyvon about what's really important in life, and I'm so honored (crying) to have been a part.

Rae: I am very, very proud of Treyvon. He has taught me so much about life and resiliency, and finding strength within yourself. He'll say little things and I'll smile to myself and say, "Oh, thank God. He was listening." (Both laugh.) And so, I look forward to the man that he's going to become. And those sprouts have everyone's names all over him, and I'm grateful to so many people, you included, and we could never, ever, ever have done it without you.

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