

The McCourty Twins & Friends Shine a Spotlight on Sickle Cell Disease ^[1]

Education & Awareness ^[2]



Imagine having a chronic disease that affects almost every organ in your body and can lead to intense, debilitating pain episodes that often send you to the ER.^{1,2} What's more, there are generally no warning signs, making it difficult to not only plan ahead for special events, but to keep up with the day-to-day activities most people take for granted. Too often, this is a recurring cycle for people with sickle cell disease (SCD).

To spread awareness of this problem, professional football players and SCD advocates Jason and Devin McCourty teamed up with Novartis to hold an educational Spotlight on Sickle Cell Disease Facebook ^[3] Live broadcast panel discussion.

- Watch ^[4] the full video

The McCourty twins joined Dr. Biree Andemariam (Director, New England Sickle Cell Institute and Chief Medical Officer of the Sickle Cell Disease Association of America) along with SCD patient and aspiring actress KC Morse to raise awareness of and open a forum for this often misunderstood disease. The panel's purpose was to help the public understand not only the

chronic pain that SCD patients experience, but the emotional and social impact of the disease that are regularly overlooked.

During the broadcast, the panelists provided some key learnings:



"Your support team can reach so many different dynamics. If you have a kid with sickle cell disease who is playing a sport and if you're a coach, don't be mad if they can't make a sprint or can't run when they have a condition ... let them know that they aren't alone."

Devin McCourty

"Transitioning from pediatric to adult care is difficult ... You have to gain as much knowledge of your own medical history as possible so when you are at school and you're going to see doctors, you can knowledgably talk about what you've gone through."

Jason McCourty

"As a physician, taking care of individuals living with sickle cell disease, I don't just discuss their medical issues – we talk about their lives. 'How is it impacting you? What's your stress level? How can we help you?' We're here to talk about more than just usual care, we're here to talk about your life because it's a life-long disease that you have to manage."

Dr. Biree Andemariam

"It's difficult in situations where you have people that you feel that you trust and love to look at you and say 'but you look fine, you look okay' or 'you were okay 20 minutes ago, how are you all of a sudden sick?' But symptoms of the disease come on that quickly, and are that debilitating – so the support system is paramount, whether it's your doctors, family, friends or meeting up with the community."

KC Morse

Facts About SCD:

- SCD is one of the most common genetic disorders in the US³
- About 100,000 Americans are currently living with the disease²
- Approximately 270,000 babies worldwide are born with SCD every year¹
- African Americans are disproportionately affected by SCD, which also impacts those of

Latin American, Indian, Mediterranean and Middle-Eastern descent²

- 1 in 365 African American babies is born with SCD, 1 in 13 is born with the trait²

Show support for the SCD community and learn more about the disease by liking and sharing the [Spotlight on Sickle Cell Disease Facebook page](#). [5]

References:

1. Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of World Health Org.* 2008(86):6:480-487.
2. Centers for Disease Control and Prevention. Sickle cell disease data & statistics. Last updated: August 31, 2016. Available from: <https://www.cdc.gov/ncbddd/sicklecell/data.html> [6]. Accessed on January 1, 2018.
3. Mandal A, Leger R, Graham L, et al. An overview of human genetic disorders with special reference to African Americans. *Journal of Bioprocessing & Biotechniques.* 2015 October 27. doi:10.4172/2155-9821.1000e139.

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[2] <https://www.novartis.us/stories/education-awareness>

[3] <https://www.facebook.com/SpotlightOnSickleCellDisease/>

[4] <https://www.facebook.com/SpotlightOnSickleCellDisease/videos/1894020867337773/>

[5] <http://www.facebook.com/SpotlightonSickleCellDisease>

[6] <https://www.cdc.gov/ncbddd/sicklecell/data.html>