

Novartis teams up with recording artist and actress Jordin Sparks and SCDAAs to launch Generation S, an inspiring new sickle cell storytelling project

Sep 20, 2018

- - Generation S offers the sickle cell community a powerful new way to share personal experiences and rewrite the story of an often-misunderstood disease
- - Singer-songwriter and actress Jordin Sparks spearheads project, sharing emotional story of her stepsister's battle with sickle cell disease
- - Learn more at JoinGenS.com and register for a chance to meet Jordin live

EAST HANOVER, N.J., Sept. 20, 2018 /PRNewswire/ -- Novartis is teaming up with Grammy[®]-nominated singer, film and Broadway star Jordin Sparks and the Sickle Cell Disease Association of America, Inc. (SCDAA) to launch Generation S, a national sickle cell disease (SCD) storytelling project that will help rewrite the SCD story for generations to come. Generation S encourages anyone touched by SCD to help inspire the sickle cell community and educate the nation by sharing their story.

"Although I didn't have the honor of knowing her throughout her journey, my stepsister Bryanna battled sickle cell disease her entire life," said Jordin. "Even though we were stepsisters for a short period of time, it was the closest I've ever come to the disease and its struggles. I hope that Generation S will help to change how we think about sickle cell and I am proud to lend my voice to our collective stories."

People can go to JoinGenS.com to share their experiences with sickle cell disease starting today through the end of November – as written stories, photos, or audio or video recordings. Submissions will start to be shared later in the fall, and the collection of stories from around the country will come to life in Feb. 2019. A few participants will also have the opportunity to meet Jordin in person and to work with a professional storyteller on a video to capture their personal experience with sickle cell disease.

"Through Generation S, we hope to help people understand more about sickle cell disease, including their family genetic risk factors for passing the disease on to their children," said Beverley Francis-Gibson, President and Chief Executive Officer of SCDAAs. "We are thankful for the opportunity to work with Novartis to share powerful stories about sickle cell disease that too often have gone unheard."

While SCD is considered a rare disease, it is one of the most common genetic disorders in the US, and nearly 100,000 Americans are living with the condition.^{1,2} SCD is a lifelong condition that causes ongoing damage to blood vessels and organs.³ While people of all ethnicities can have the disease, people of African descent are disproportionately affected.⁴ People with SCD often experience recurrent episodes of acute, severe pain, which can eventually become chronic.⁵ Importantly, pain is more than a physical symptom – it can impact emotional and social wellbeing.⁶

"Working with the sickle cell community, we hope to educate people about the disease and raise awareness of the significant impact it has on the lives of patients and their loved ones," said Ameet Mallik, Executive Vice President and Head, US Oncology at Novartis. "In partnership with SCDAAs and Jordin Sparks, our goal is to inspire people who are touched by this difficult condition to help them to lead strong, vibrant lives."

About Sickle Cell Disease

Sickle cell disease is a genetic blood disorder marked by painful crises, also known as vaso-occlusive crises (or VOCs).⁷ These crises are the main reason why patients go to the hospital, and are linked to increased morbidity and mortality.⁸ Although sickle cell disease occurs predominantly in individuals of African descent, sickle cell disorders are also prevalent throughout the Mediterranean, the Middle East, parts of India, the Caribbean, and South and Central America.^{4,9}

About Novartis

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