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

- 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, NJ, Sept. 20, 2018 – 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 SCDAA. "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 SCDAA 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

Located in East Hanover, NJ Novartis Pharmaceuticals Corporation is an affiliate of Novartis which provides innovative healthcare solutions that address the evolving needs of patients and societies. Headquartered in Basel, Switzerland, Novartis offers a diversified portfolio to best meet these needs: innovative medicines, cost-saving generic and biosimilar pharmaceuticals and eye care. Novartis has leading positions globally in each of these areas. In 2017, the Group achieved net sales of USD 49.1 billion, while R&D throughout the Group amounted to approximately USD 9.0 billion. Novartis Group companies employ approximately 125,000 full-time-equivalent associates. Novartis products are sold in approximately 155 countries around the world. For more information, please visit http://www.novartis.com.

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References

- 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
- American Society of Hematology. State of sickle cell disease 2016 report. Available from: http://www.scdcoalition.org/pdfs/ASH%20State%20of%20Sickle%20Cell%20Disease%202016%20Report. pdf. Accessed on July 17, 2018.
- 3. Steinberg M. Management of sickle cell disease. N Engl J Med. 1999;340(13):1021-1030.
- 4. Jain D, Lothe A, Roshan C. Sickle cell disease: current challenges. *Journal of Hematology & Thromboembolic Diseases*. 2015 Nov 10. Doi: 10.4172/2329-8790.1000224.
- Adams-Graves P, Bronte-Jordan L. Recent treatment guidelines for managing adult patients with sickle cell disease: challenges in access to care, social issues, and adherence. Expert Review of Hematology. 2016:9(6):541-552.
- Anim M, Osafo J, Yirdong F. Prevalence of psychological symptoms among adults with sickle cell disease in Korie-Bu Teaching Hospital, Ghana. BMC Psychology. 2016;4(53):1-9.
- Yawn B, Buchanan G, Afenyi-Annan A, et al. Management of sickle cell disease summary of the 2014 evidence-based report by expert panel members. *JAMA*. 2014;312(10):1033-1048.
- 8. Puri L, Nottage KA, Hankins JS, et al. State of the art management of acute vaso-occlusive pain in sickle cell disease. *Paediatr Drugs.* 2018;20:29-42.
- Centers for Disease Control and Prevention. Sickle cell disease data & statistics. Last updated: September 16, 2011. Available from: http://www.cdc.gov/ncbddd/sicklecell/data.html. Accessed on August 4, 2015.

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