

# Five nonprofit organizations to receive up to \$250,000 through Novartis STEP Program™ to support sickle cell patient initiatives

May 16, 2019

- -The Solutions to Empower Patients (STEP) Program™ continues to help nonprofit organizations deliver new solutions to address unmet patient needs
- -This year's focus is on addressing some of the most pressing issues in the sickle cell disease (SCD) community

EAST HANOVER, N.J., May 16, 2019 /PRNewswire/ -- Novartis today announced that five nonprofit organizations will receive a total of nearly \$250,000 in funding through the company's STEP (Solutions to Empower Patients) Program™. Now in its second year, the STEP Program supports nonprofit organizations by funding innovative programs that empower patients with significant unmet needs to navigate a path to better care. This year's focus is on addressing some of the most pressing issues in the sickle cell disease (SCD) community.

"People with sickle cell disease continue to face significant gaps in care which can be detrimental to their physical health and overall well-being," said Ameet Mallik, Executive Vice President and Head, US, Novartis Oncology. "Through the STEP Program, we aim to help make a difference in these patients' lives by supporting innovative programs developed by organizations in the best position to tackle these challenges."

This year's funding recipients will work to address these difficulties by encouraging self-advocacy, providing resources to help SCD patients better navigate the healthcare system, and supporting patients as they transition from pediatric to adult care. The diverse group of recipient organizations includes patient advocacy groups and research institutions, representing the broad impact of this disease.

The organizations and innovative SCD initiatives include:

- All One Blood's commercial campaign series, which will reveal powerful stories and conversations with those living with SCD.
- Children's Research Institute's INSERTT (ImproviNg SickIE TRansition Through Telemedicine) study, which will evaluate the impact of telemedicine on improving health outcomes for SCD patients as they transition to adult care.
- Sickle Cell 101's FACTSS (FACilitating Communication BeTween PatientS and ProviderS) program, which will provide patients with a digital toolkit containing customized communications strategies.
- The Sickle Cell Foundation of Georgia, Inc., which will host interactive workshops to provide adolescents with tools to successfully transition from pediatric to adult health care.
- The Georgia Health Policy Center at Georgia State University, which will create educational videos to help patients and caregivers understand the benefits and potential complications of therapeutic blood transfusions.

Proposals were evaluated by an external review committee made up of experts in the fields of advocacy, psycho-social support and multi-cultural health, as well as an SCD practitioner and patient.

"The volume, breadth and quality of the proposals we received this year speaks to the deep need within this community to remove the hurdles people with sickle cell disease face every day," said Charles Jonassaint, PhD, MHS, Assistant Professor of Medicine, Social Work, and Clinical & Translational Sciences at University of Pittsburgh and a member of the STEP Program external review committee. "It was inspiring to see the passion of so many organizations dedicated to improving the lives of those impacted by the disease, and on behalf of the entire review committee, we congratulate the five recipients. We look forward to seeing the impact their initiatives have on the lives of patients and their families."

SCD is a genetic blood disorder that causes ongoing damage to blood vessels and organs<sup>1</sup>. It is a lifelong illness that places a physical and emotional burden on patients and their families as they manage issues dealing with work, school and family.

#### About Novartis

Novartis is reimagining medicine to improve and extend people's lives. As a leading global medicines company, we use innovative science and digital technologies to create transformative treatments in areas of great medical need. In our quest to find new medicines, we consistently rank among the world's top companies investing in research and development. Novartis products reach more than 750 million people globally and we are finding innovative ways to expand access to our latest treatments. About 105,000 people of nearly 140 nationalities work at Novartis around the world. Novartis Pharmaceuticals Corporation, a US affiliate of Novartis, is located in East Hanover, NJ. Find out more at [www.novartis.com](http://www.novartis.com).

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#### References

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