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Green Park Collaborative and Sickle Cell Disease Association of America, Inc. Launch coreSCD to Develop Consensus on Critical Outcomes in Sickle Cell Disease Clinical Research

Baltimore, MD (April 2, 2019) – The <u>Green Park Collaborative (GPC)</u>, a major initiative of the <u>Center for Medical Technology Policy (CMTP)</u>, is partnering with Sickle Cell Disease Association of America, Inc. (SCDAA), to develop a core set of outcomes to be used in clinical trials of new therapies for sickle cell disease (SCD). This initiative, coreSCD, will engage patients, clinicians, regulators, payers, health technology assessment groups, product developers, and other key stakeholders in a structured consensus process to develop the core outcome set.

Sickle cell disease is the most common inherited blood disorder in the United States and affects millions of people worldwide. Despite the severity of the disease, treatment options have remained limited. Encouraging recent developments include FDA approval in 2017 of the first new drug for SCD in 20 years. In addition, rapid advancement in gene therapy for SCD holds the promise of a cure.

"With multiple new therapies in the pipeline, the timing is ideal to determine how best to assess the impact of these new treatments," said Donna Messner, President/CEO of CMTP. "coreSCD will help to assure that patient-important, stakeholder-relevant information is consistently available for decisions about new SCD therapies."

"SCDAA is excited about this new partnership that will help us identify the most critical outcomes for clinical trials in sickle cell disease," says SCDAA President/CEO Beverley Francis-Gibson. "With the advancement of new therapies and research for sickle cell disease, the work that we are doing together is increasingly important, and we look forward to the findings."

About the Green Park Collaborative (GPC)

<u>GPC</u> is a major initiative of <u>CMTP</u>, an independent 501(c)(3) non-profit organization dedicated to improving the quality, relevance, and efficiency of clinical research. GPC is a multi-stakeholder forum for developing conditionand technology-specific study design recommendations to guide the creation of evidence needed to inform both clinical and payment decisions.

About Sickle Cell Disease Association of America, Inc.

Project partner, <u>SCDAA</u>, is a non-profit organization promoting and advancing initiatives focused on people affected by sickle cell conditions worldwide. The mission of the SCDAA is to advocate for people affected by SCD

and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

Contact

Green Park Collaborative

Susan Reed 410-547-2687 ext. 114 susan.reed@cmtpnet.org

SCDAA

Beverley Francis-Gibson
410-528-1555
bfrancais-gibson@sicklecelldisease.org