

Announcement of Requirements and Registration for the

Hope for Sickle Cell Disease Challenge

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

Authority: 15 U.S.C. 3719

Billing Code: 8470187 / 121212

Date of Announcement: September 1, 2020

DESCRIPTION

The National Heart, Lung, and Blood Institute (NHLBI), an institute of the National Institutes of Health (NIH), announces the NHLBI “Hope for Sickle Cell Disease Challenge” to help increase awareness about [sickle cell disease](#) and its associated complications. Sickle cell disease (SCD), also known as sickle cell anemia, is the most common genetic disorder in the United States.¹ About 100,000 Americans are thought to be living with SCD and each year another 1,000 babies are born with it.²

A specific single mutation in the gene for hemoglobin, when inherited from both parents, causes SCD. The hemoglobin in people living with SCD distorts the shape of the red blood cell into a ‘sickle’ or crescent moon shape that flows poorly through small blood vessels. This can cause problems in virtually any organ by reducing the delivery of oxygen and inflaming the surrounding tissue. The organ damage caused by SCD can result in strokes in the brain, kidney damage, or complications in other organs. SCD also causes significant pain in the affected tissues. This pain, which can begin in childhood, often escalates as people age, severely affecting

¹ Tanabe, P., Spratling, R., Smith, D., Grissom, P., and Hulihan, M. CE: Understanding the Complications of Sickle Cell Disease. *American Journal of Nursing*. June 2019; 119(6): 26-35.

² Bulgin, D., Tanabe, P., and Jenerette, C. Stigma of Sickle Cell Disease: A Systematic Review. *Issues in Mental Health Nursing*, April 13, 2018; 39: 675-686.

the quality of life of individuals with SCD.^{3,4,5} SCD affects the quality of life for those living with it, and the lives of their families and caregivers. They may experience psychological stress, financial problems, medication management pressures (e.g., administering daily medications and managing pain episodes through behavior or lifestyle changes), and conflicts between job obligations and medical appointments because of the unpredictable nature of SCD and its associated complications.⁶

A lack of awareness about SCD and its associated complications among the public and affected communities,^{7,8} can contribute to stigmas associated with SCD, a lack of understanding of how the disease affects individuals and families, and to less than optimal care experienced by many patients.⁹

The [SCD Implementation Consortium](#) (funded by the NHLBI) is testing new approaches to enhance care for SCD and improve health outcomes in eight geographically diverse areas, particularly for young adults. The [Cure Sickle Cell Initiative](#) is an NHLBI-led collaborative research effort accelerating the development of genetic therapies for SCD. And the NHLBI's intramural researchers have developed gene therapy advances using a vector system to deliver a normal hemoglobin gene to blood-forming stem cells more efficiently.

The NHLBI supports these and other innovative research activities for SCD and is seeking to foster improved awareness about SCD and address the associated [myths](#) and stigmas by launching the NHLBI Hope for Sickle Cell Disease Challenge. This Challenge incentivizes

³ Kato, G.J., Piel, F.B., Reid, C.D., Gaston, M.H., Ohene-Frempong, K., Krishnamurti, L., Smith, W.R., Panepinto, J.A., Weatherall, D.J., Costa, F.F., and Vichinsky, E.P. Sickle Cell Disease. *Nature Reviews: Disease Primers*, March 15, 2018; 4: 18010, 1-22.

⁴ Aich A., Jones, M., and Gupta, K. Pain and sickle cell disease. *Current Opinion in Hematology*. May 2019; 26(3): 131-138.

⁵ Tanabe, P., Spratling, R., Smith, D., Grissom, P., and Hulihan, M. CE: Understanding the Complications of Sickle Cell Disease. *American Journal of Nursing*. June 2019; 119(6): 26-35.

⁶ Madani, B.M., Raddadi, R.A., Jaouni, S.A., Omer, M., Awa, M.-I.A. Quality of Life Among Caregivers of Sickle Cell Disease Patients: A Cross Sectional Study. *Health and Quality of Life Outcomes*, September 10, 2018; 16(1): 176, 1-9.

⁷ Smith, M. and Brownell, G. Knowledge, beliefs, attitudes, and behaviors regarding sickle cell disease: Implications for prevention. *Social Work in Public Health*, May 16, 2018; 33: 299-316.

⁸ Wesley, K.M., Zhao, M., Carroll, Y., and Porter, J.S. Caregiver Perspectives of Stigma Associated with Sickle Cell Disease in Adolescents. *Journal of Pediatric Nursing*, Jan-Feb 2016; 31(1): 55-63.

⁹ Bulgin, D., Tanabe, P., and Jenerette, C. Stigma of Sickle Cell Disease: A Systematic Review. *Issues in Mental Health Nursing*, April 13, 2018; 39: 675-686.

college and graduate students to develop innovative Tools that build awareness of evidence-based information about SCD. Examples of such Tools include, but are not limited to, a video (documentaries, testimonials, etc.), a software application, a game (board, computer, interactive, etc.), a website, a book (children's books, k-12 learning tools, etc.), a marketing campaign, a social media campaign, music or a song, a grassroots campaign, or an exhibit. The Tools created for this Challenge should undergo pilot testing and be evaluated using a rigorous scientific assessment. Knowledge dissemination and transfer may improve patient outcomes by (i) increasing public awareness of SCD, particularly those who have been underserved and including young adult populations and K-12 youth; (ii) providing individuals, caregivers, and families affected by SCD accurate and easily understandable information about SCD and its complications; and (iii) educating healthcare providers about pain and opioid management.

This Challenge is open to college and graduate students to promote the field of implementation science to the next generation of researchers and offer mentoring and research training.

Implementation science is the scientific study of methods and strategies that facilitate the uptake or adoption and integration of evidence-based practices, interventions, programs, policies, and research into regular use by practitioners, health systems, communities, and policymakers. The training and mentoring experiences of the Challenge will enhance SCD research knowledge for students through the creation of Tools for sickle cell disease education. The Challenge is in line with the NHLBI Center for Translation Research and Implementation Science (CTRIS) roadmaps to build capacity and increase awareness of sickle cell disease. This Challenge also encourages "team science" by providing students valuable experiences to pursue science collectively as they engage in complex problem solving to improve outcomes.

Dates

- **Challenge Launch:** September 1, 2020
- **Registration Period:** September 1, 2020 – February 26, 2021
- **Submission Period:** September 1, 2020 – March 26, 2021
- **Judging Period:** April 2021 – May 2021
- **Winner(s) Announced:** June 2021

Statutory Authority to Conduct the Challenge

The general purpose of the NHLBI is the conduct and support of research, training, health information dissemination, and other programs with respect to heart, blood vessel, lung, and blood diseases and with respect to the use of blood and blood products and the management of blood resources (42 U.S.C. 285b). The mission of the NHLBI is to promote the prevention and treatment of heart, lung, and blood diseases and enhance the health of all individuals so that they can live longer and more fulfilling lives. In order to fulfill its mission, the NHLBI stimulates basic discoveries about the causes of disease, enables the translation of basic discoveries into clinical practice, fosters training and mentoring of emerging scientists and physicians, and communicates research advances to the public.

The NHLBI is conducting this Challenge under the America Creating Opportunities to Meaningfully Promote Excellence in Technology, Education, and Science (COMPETES) Reauthorization Act of 2010, as amended [[15 U.S.C. § 3719](#)]. In line with these authorities, this Challenge will lead to increased public awareness of SCD, provision of accurate and easily comprehensible information about SCD and its complication to individuals living with SCD and their caregivers and families, and improved understanding by healthcare providers about pain and opioid management for those living with SCD.

PRIZES

Amount of the Prize

The NHLBI will award up to a total of \$50,000. Up to three winners will be selected. Fewer than three winners will be selected if there are fewer than three participating teams that qualify for the Challenge. The NHLBI reserves the right to announce honorable mentions. Honorable mentions will not receive cash prizes.

- **1st Prize** - \$25,000
- **2nd Prize** - \$15,000
- **3rd Prize** - \$10,000

The NHLBI will announce the results of the competition and publicly display the winning Tools.

Presentation of Winning Tool

The team that wins first place in the Challenge will be invited and highly encouraged to present the winning Tool at a forum selected by the NHLBI (*e.g.*, the NHLBI Annual Sickle Cell Disease Research Meeting, the SCD Consortium, or the American Society of Hematology). Second and third place teams may also be invited to present their Tools at the forum.

Award Approving Official

The Award Approving Official will be Gary H. Gibbons, M.D., Director of the NHLBI.

Payment of the Prize

Prizes awarded under this Challenge will be paid by electronic funds transfer and may be subject to Federal income taxes. The prize will be awarded in one payment to the designated “Team Captain.” HHS/NIH will comply with the Internal Revenue Service withholding and reporting requirements, where applicable.

NIH reserves the right, in its sole discretion, to (a) cancel, suspend, or modify the Challenge, or any part of it, for any reason, and/or (b) not award any prizes if no entries are deemed worthy.

RULES

Eligibility Rules for Participating in the Challenge

This Challenge is open to any “Student Team,” which is defined as a group of at least three and not more than five adult (18 years of age or older at time of submission) individuals. Each team member (“Participant”) of the “Student Team” must be currently enrolled as a full-time undergraduate or graduate student (someone who has earned a bachelor's degree and is pursuing additional education in a specific field at a graduate school) at an accredited university or college or community college. Team mentors, including those who are both graduate students and teaching or graduate assistants, are not members of Student Teams.

The Student Teams are encouraged to be multidisciplinary, composed of students from diverse disciplines. Collaborations across programs that are novel and creative may include fine arts, performing arts, humanities, psychology, science, engineering, graphic design, IT (hardware and/or software), mathematics, statistics, environmental science, computational modeling, and others. Undergraduate students or graduate students (with or without graduate or teaching assistantships), except those that are designated as mentors for Student Teams, may participate in the Challenge in any combination.

To participate in and be eligible to win the Challenge, the Student Team must also:

- a. Have as a mentor to the team a faculty member employed at a Research Funding Organization, an Organization with Funded Research Grants, a Research Organization (i.e., academic research organizations, research institutes, or research centers), or a Department within a college or university, who has mentored undergraduate or graduate students in the past. The mentor will encourage success and provide ongoing guidance, support, and encouragement for the Student Team members.
 - i. The mentor should hold the position, including, but not limited to: Dean, Lecturer, Professor, Associate Professor, Assistant Professor, Research Assistant Professor, Instructor, or Teaching Assistant within a Grant or Research Organization or Center, Institute, or Department at a college or university in an academic setting similar to or the same as the Student Team.
 - ii. A Teaching or Graduate Assistant who is also a graduate student and is designated as a mentor for a Student Team cannot participate in the Challenge also as a member of the Student Team.
 - iii. Each mentor may only work with one team; however, a team may have more than one mentor. Co-mentors may be located at different institutions.
- b. Agree to submit only one entry into this Challenge through one student member of the Student Team that is appointed as the “Team Captain” by that Student Team. The Team Captain will carry out all correspondence with the NHLBI regarding the Student Team's entry. On behalf of the Student Team, the Team Captain must certify the Student Team's eligibility as part of the submission process.

In addition, the following rules also apply:

(1) To be eligible to win a prize under this Challenge, each Participant (team member):

- a. Shall, through a Team Captain, have registered to participate in the Challenge through the Team Registration Process under the rules promulgated by the Department of Health and Human Services (HHS), National Institutes of Health (NIH), National Heart, Lung, and Blood Institute (NHLBI) as published in this announcement;
- b. Shall have complied with all the requirements as set forth in this announcement;
- c. Shall be a citizen or permanent resident of the United States. Non-U.S. citizens and non-permanent residents are not eligible to win monetary prizes (in whole or in part). Their participation as part of a winning team, if applicable, may be recognized when the results are announced.
- d. Shall not be a federal entity or federal employee acting within the scope of their employment and further;
- e. Shall not be an employee of the Department of Health and Human Services (HHS, or any other component of HHS, such as NIH) acting in their personal capacity;
- f. Shall, if employed by a federal agency or entity other than HHS or any component of HHS, consult with an agency ethics official to determine whether the federal ethics rules will limit or prohibit the acceptance of a prize under this Challenge; and
- g. Shall not be a judge of the Challenge, or any other party involved with the design, production, execution, or distribution of the Challenge or the immediate family of such a party (i.e., spouse, parent, step-parent, child, or step-child).

(2) Federal grantees may not use federal funds from a grant award to develop their Tools or to fund efforts in support of their Tools.

(3) Federal contractors may not use federal funds from a contract to develop their Tools or to fund efforts in support of their Tools.

(4) Federal awardees may not use federal funds from an other transaction (OT) award to develop

their Tools or to fund efforts in support of their Tools.

(5) By participating in this Challenge, each Participant agrees to assume any and all risks, and waive claims against the federal government and its related entities, except in the case of willful misconduct, for any injury, death, damage, or loss of property, revenue, or profits, whether direct, indirect, or consequential, arising from participation in this Challenge, whether the injury, death, damage, or loss arises through negligence or otherwise.

(6) Based on the subject matter of the Challenge, the type of work that it will possibly require, as well as an analysis of the likelihood of any claims for death, bodily injury, property damage, or loss potentially resulting from Challenge participation, no Participant in the Challenge is required to obtain liability insurance or demonstrate financial responsibility in order to participate in this Challenge.

(7) By participating in this Challenge, each Participant agrees to indemnify the federal government against third party claims for damages arising from or related to Challenge activities.

(8) A Participant shall not be deemed ineligible because the Participant used federal facilities or consulted with federal employees during the Challenge if the facilities and employees are made available to all Participants participating in the Challenge on an equitable basis.

(9) By participating in this Challenge, each Participant in the Student Team warrants that the Student Team is the sole author or owner of, or has the right to use, any copyrightable works that the Tool comprises, that the works are wholly original with the Student Team (or is an improved version of an existing work that the Student Team has sufficient rights to use and improve), and that the Tool does not infringe any copyright or any other rights of any third party of which the Student Team is aware.

(10) By participating in this Challenge, each Participant grants to the NIH an irrevocable, paid-up, royalty-free nonexclusive worldwide license to reproduce, publish, post, link to, share, and display publicly the Tool on the web or elsewhere, and a nonexclusive, nontransferable, irrevocable, paid-up license to practice, or have practiced for or on its behalf, the Tool throughout the world. Each Participant will retain all other intellectual property rights in their Tool, as applicable. To participate in the Challenge, each Participant must warrant that there are

no legal obstacles to providing the above-referenced nonexclusive licenses of the Participant's rights to the federal government. To receive an award, participants will *not* be required to transfer their intellectual property rights to NIH. However, Participants must grant to the federal government the *nonexclusive licenses* recited herein.

(11) Each Participant agrees to follow all applicable federal, state, and local laws, regulations, and policies.

(12) Each Participant in this Challenge must comply with all terms and conditions of these rules, and participation in this Challenge constitutes each such Participant's full and unconditional agreement to abide by these rules. Winning is contingent upon fulfilling all requirements herein.

(13) Each individual Participant in this Challenge must be 18 years of age or older.

(14) The NHLBI reserves the right to disqualify a Tool if the Tool fails to function as expressed in the description provided by the submitting Student Team or if the Tool provides inaccurate or incomplete information. Tools must be free of malware. The NHLBI may test the Tool to determine whether malware or other security threats may be present and reserves the right to disqualify the Tool if, in the NHLBI's judgment, the Tool may damage government or others' equipment or operating environment.

JUDGING CRITERIA

Basis Upon Which a Winner Will be Selected

Federal employees serving as judges will select up to three Challenge winners, subject to a final decision by the Award Approving Official.

Basis Upon Which Tools Will Be Evaluated

Significance (15 points)

The Tool will be evaluated for significance by the following:

- a. Potential impact of the Tool in reducing stigma and bias by building awareness of SCD

(pain, genetics, symptom identification, associated health issues, coping mechanisms, etc.) among the target audience(s).

- b. Inclusion of scientifically accurate information, including SCD evidence-based guidelines (e.g., reference [NHLBI SCD guidelines](#), websites from NIH, the [National Library of Medicine](#), etc.)

Innovation (20 points)

The Tool should be innovative and creative. This will be evaluated by the following:

- a. Novelty or distinctness from existing SCD-related awareness tools. Incremental advancements that improve awareness of SCD among the target audience are discouraged.
- b. Methodology for reaching the target audience, delivering the Tool to the target audience, and acceptability by the target audience.

Design, affordability, and usability (20 points)

The submission should exhibit user friendliness, cost-friendliness, and user comprehension. This will be evaluated as follows:

- a. Functionality - generates the expected output efficiently
- b. User Centricity
 - i. Evidence of co-design with and support from users of proposed Tool (e.g., patient, family, caregivers, community, and healthcare providers)
 - ii. Representation of diversity (sex/gender, racial/ethnic, cultural, and linguistic)
- c. Understandability
 - i. Appropriateness of images/messaging for the intended audience
 - ii. Clear, concise, and well-organized messages
 - iii. Clarity of images and/or audio
- d. Accessibility
 - i. Available readily (ease and breadth of dissemination) and affordable for end-users

- ii. Written or composed in English
- iii. Compatibility with section 508 accessibility standards and guidelines

Approach and quality of tool testing and outcomes (25 points)

The approach of the Tool should include and will be evaluated on the following:

- a. Research Objectives/Research Question/Literature Review
- b. Study Methods/Study Design
- c. Data management tool to collect information about study participants, dissemination of the Tool to study participants, impact of the intervention with study participants, etc.
- d. Variables/Data Collection (Qualitative, Quantitative, or Mixed-Methods)
- e. Statistical Analysis and Sample Size
- f. Results and discussion of pilot test outcomes (interpretation of the results in light of scientific literature and conclusions)

Feasibility: Outreach, Communications, and Dissemination Plan (20 points)

- a. Methods for outreach, communication, and dissemination of the Tool. Tools that include proposals on how to reach a range of users, including those with disabilities and from underserved populations are encouraged.
- b. Likelihood of future adoption of Tool (delivered as intended to target population and adopted by those audiences).

HOW TO ENTER

Team Registration Process

Teams must register to participate in the NHLBI Hope for Sickle Cell Disease Challenge by emailing SCDChallenge@nhlbi.nih.gov, indicating intent to submit an entry (the “Tool Submission Package”), and including the following information:

- Tentative title and one-paragraph summary of the planned Tool
- Identification of the Team Captain who will serve as a point of contact and submit the Tool on behalf of the team
- Name and school affiliation of every team member
- Name, school affiliation, and position of the team mentor(s)

Emails registering teams must be submitted to SCDChallenge@nhlbi.nih.gov by 11:59 PM EST, February 26, 2021.

Tool Submission Requirements

Each Tool submitted for this Challenge requires a complete “Tool Submission Package.” The Team Captain identified through the Registration Process should submit the Tool Submission Package on behalf of the team and will serve as a point of contact. Only complete and correctly formatted Tool Submission Packages will be reviewed. Detailed instructions on the content of the Tool Submission Package are listed below.

Submit the Tool Submission Package to SCDChallenge@nhlbi.nih.gov by 11:59 PM EST, March 26, 2021. The Team Captain will receive notification by email that the Team’s Tool submission Package has been received.

Each Student Team will submit a creative and innovative Tool using any combination of media that is designed to increase public awareness of SCD. Examples of include, but are not limited to, a video (documentaries, testimonials, etc.), a software application, a game (board, computer, interactive, etc.), a website, a book (children’s books, k-12 learning tools, etc.), a marketing campaign, a social media campaign, music or a song, a grassroots campaign, or an exhibit. All original materials must be written or composed in English. A complete Tool Submission Package is defined as including the following:

- A fully functional Tool developed and tested by the Student Team. The Student Team must provide the NHLBI with continuous access to the Tool after submission and until winners are announced. As applicable, include separate from the written entry and its six-page limit a detailed description of the Tool, instructions on how to install and operate it, and its system requirements. If electronic, the Tool must be designed for use on one or

more of the most widely-available computing platforms including, but not limited to, Windows-based Operating Systems, Mac OS X, iOS mobile computing platforms, and Android mobile computing platforms.

- A written entry (not to exceed six pages, single-spaced, between 10-point font and 12-point font, 1-inch margins) that clearly and concisely includes the following.
 - a. A concise and informative title (150 characters or less).
 - b. A description of the Tool, why it is innovative, the problem that the Tool addresses, and the expected outcomes (goals) of using the Tool.
 - c. A summary of the science and/or technology underlying the Tool and its development.
 - d. A description of how the Tool was tested among the population(s) of interest (e.g., urban/rural/socioeconomic populations, patients, clinicians, caregivers and/or researchers). Include a description of the study design and why it was selected to test the Tool.
 - e. A description of the populations/communities involved in the Tool design and testing.
 - f. Preliminary data describing the outcome(s) of testing the Tool in the population of interest and whether the Tool met the anticipated goals. Were any outcomes unanticipated and what can be learned from them? What challenges or barriers were faced and what improvements could be made?
- A video (not to exceed two minutes in length) that clearly articulates the problem and how the Student Team's Tool addresses the problem. The video must deliver a clear and understandable message using non-technical language. It should emphasize insights that are not provided in the written submission, tell a compelling story, be visually striking, and be well-edited (e.g., high quality/consistent audio, limited use of jump cuts, complete transitions, suitable music inputs, consistent graphics, etc.) It must not include any sensitive information. Participants should be aware that this short video is required even if the Tool being submitted is also a video. If the video is too large to upload via email, then post the video on [YouTube](#) as an unlisted video and provide a link to the video in the submission email. "Unlisted" means that only people who know the link to the video can view it (such as individuals to whom you send the link). An unlisted video will not appear

in any of YouTube's public spaces (such as search results, your channel, or the Browse page).

- A set of ten slides (approximately 15-minute presentation) in PDF format that describes the Tool. The slides must address the judging criteria and describe the key features of the Tool as they relate to the goals of the Challenge.

The Tool must not use HHS, NIH, or NHLBI logos or official seals. The Tool must not claim endorsement by HHS, NIH, or NHLBI. Each Student Team is required to make the Tool compliant with Section 508 accessibility and usability requirements at their own expense.

ADDITIONAL INFORMATION

Supplementary Information

The following online resources provide information to help Challenge participants better understand SCD, its effects, and treatment options:

- Cure Sickle Cell Initiative: <https://www.nhlbi.nih.gov/science/cure-sickle-cell-initiative>
- National Heart, Lung, and Blood Institute/National Institutes of Health: What is Sickle Cell Anemia, <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/>
- Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014, <https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease>
- National Human Genome Research Institute/National Institutes of Health: <http://www.genome.gov/10001219>
- Centers for Disease Control and Prevention: <http://www.cdc.gov/ncbddd/sicklecell/index.html>
- National Library of Medicine/National Institutes of Health: <http://ghr.nlm.nih.gov/condition/sickle-cell-disease>

The following online resources are software programs that can be used by the Challenge participants to help create and test their tools:

- GSA Government-wide IT Accessibility Program: Create Accessible Digital Products, <https://section508.gov/create>
- Communication and video conferencing platforms:
 - Skype, <https://www.skype.com/>
 - Slack, <https://slack.com/>
 - Webex, <https://www.webex.com/>
 - Zoom, <https://zoom.us/>
- Creating online surveys and polls:
 - Doodle, <https://doodle.com/>
 - Google Forms, <https://www.google.com/forms>
 - Qualtrics, <https://www.qualtrics.com/>
 - SurveyMonkey, <https://www.surveymonkey.com/>
 - Typeform, <https://www.typeform.com/>
- Marketing to and/or communicating with the public (social media):
 - Facebook, <https://www.facebook.com/>
 - Instagram, <https://www.instagram.com/>
 - LinkedIn, <https://www.linkedin.com/>
 - Twitter, <https://twitter.com/>
- Organizing, brainstorming, and prioritizing projects:
 - Asana, <https://asana.com/>
 - Miro, <https://miro.com/>
 - Trello, <https://trello.com/>
- Photo and video stock:
 - Adobe Stock, <https://stock.adobe.com/>
 - Pixabay, <https://pixabay.com/>
 - Shutterstock, <https://www.shutterstock.com/>
- User or A/B testing platforms: