REQUEST FOR APPLICATIONS (RFA)

Name of Project	Expanding Access to Sickle Cell Disease Care in California – Education and Awareness
Request for Applications (RFA) No.	NCSCC-07012021
Date of Issue	3/1/2021
Letter of Intent (Required)	4/1/2021 (due by 5pm Pacific)
Closing Date for Receipt of Applications ***(Late applications will not be considered)***	5/7/2021 (due by 5pm Pacific)
Announcement of Awarded Grants. *All applicants are notified of their status on their applications.*	6/15/2021
Grant Year	07/01/2021 – 6/30/2022
Reporting • Mid-Year Report Due • Final Report Due	• 01/31/2022 • 07/31/2022
Questions on this solicitation should be submitted to e-mail address provided no later than the date indicated.	E-mail: grants@c3dibd.org No later than: 3/12/2021
The project will hold a briefing for interested parties on the date indicated. Those interested **must** register through the link provided.	3/16/2021 Register by 3/12/2021: https://www.surveymonkey.com/r/NCSCCRFA Call in information will be sent to all registered participants 24 hours prior to the call

I. PROGRAM DESCRIPTION AND OBJECTIVES

This announcement will initiate a request for applications (RFA) in these three areas of need in California's sickle cell disease (SCD) population: 1) Emergency Room education, 2) pain management, and 3) quality of life.

Background:

Individuals with SCD have inherited a genetic variant in both of their hemoglobin A genes which results in loss of red blood cell flexibility especially in conditions of low oxygen. [i] Eventually, the red blood cells become irreversibly distorted and assume a "sickle-like" shape resulting in severe anemia and pain due to obstructed blood flow to tissue and organs throughout the body. Individuals with SCD have a significantly shortened life expectancy[ii] and encounter pain as well as a multitude of serious health problems throughout their lifespan.

SCD impacts all facets of an individual's life to include physiological, psychological, and their social well-being. Health-related stigma refers to a form of devaluation, judgment, or social disqualification of individuals based on a health-related condition.[iii] People who have SCD experience health-related stigma for a variety of reasons including race, disease status, socioeconomic status, and/or having chronic and acute pain that needs to be managed with opioids.[iv]

In the United States, SCD occurs most commonly among people of African ancestry: one in 365 African American births. In California, approximately 133 cases of SCD are identified per year among approximately 500,000 births.[v] Often overlooked, there is a significant incidence of SCD in the US Hispanic population where approximately 1 in 16,300 births result in SCD.[vi] In 2016, California's Sickle Cell Data Collection Program estimated there were nearly 5,000 individuals with SCD in the state. California's costs for sickle cell were estimated at $740 million for inpatient hospitalizations and emergency room visits, not including HMO systems.[vii] SCD disproportionately impacts populations of African, Hispanic, Mediterranean, Middle Eastern, and Indian descent. These same populations historically experience substantial socio-economic, geographic, cultural, and language barriers to healthcare and social services.[viii]

In 2020, the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine (NASEM) developed a strategic plan and blueprint to address SCD in the United States.[ix] NASEM identified key gaps in SCD care, including inadequate care delivery combined with the absence of guidelines and healthcare infrastructure, unrecognized burden of pain, fatigue and emotional distress, and the lack of dedicated facilities and personnel caring for adult patients. Pain is the most common complication of SCD, and the number one reason that people with SCD go to the emergency room or hospital.[x] These challenges are amplified when coupled with the stigma, racism, and discrimination faced by affected individuals within the health care setting. These challenges and gaps in our healthcare delivery system can be bridged through partnerships with a wide array of partners including community-based organizations (CBOs) who deliver effective follow up and provide education and support services.

Networking California Sickle Cell Care (NCSCC):

In June 2019, Governor Newsom included as part of the California state budget, funding to support the expansion of SCD services throughout the state. This appropriation stemmed from information gathered in the California Sickle Cell Action Plan (CA-SCAP)[xi], and addresses priorities to expand adult clinics in areas of need, expand workforce, including community health workers to enhance care coordination; expand surveillance to monitor healthcare utilization, complications and costs. Additionally, funds have been set aside to support novel proposals for outreach to promote SC education and awareness.

Grant Objectives & Priority Areas

This RFA cycle seeks applications in three areas: Emergency Room education, Pain Management, and Quality of Life.

This call for proposals requests applications from eligible organizations and institutions, not individuals. Only one application per institution is allowed; further information is outlined in *Section II. Award Information*.

Sickle Cell Disease & Emergency Department Care: In 2014, the National Heart, Lung, and Blood Institute's (NHLBI) 2014 guidelines for the care of SCD, included recommendations for the management of acute sickle cell pain in the emergency department (ED).[xii] Various factors may affect healthcare access and increased utilization of the ED, such as patients' perception, insurance, availability of transportation, and disease related factors.[xiii] The Sickle Cell Data Collection Program (SCDC) found that in California, people with SCD seek care in the ED an average of three times a year from their late teens to their late 50s.[xiv] Pain is the most common complication of SCD, and the number one reason that people with SCD go to the emergency room or hospital.[xv]

Given the frequent use of the ED, it is key to ensure healthcare providers are providing unbiased, evidence-based care. Educational gaps and biases among healthcare providers, staff, and patients create barriers to communication and trust and erode the provider-patient relationship.[xvi] Documented deficiencies in adult SCD care include poor access to knowledgeable providers and inadequate treatment in emergency departments.[xvii]

Examples of applications submitted under this priority area may focus on developing, testing, and evaluating projects that assess current implementation of NHLBI guidelines within the ED; develop and test quality improvement initiatives (to decrease variability of care between providers and increase metrics related to guideline adherence); improve provider attitudes within the ED through education and training. Applications may target physicians, residents, nurses, and advanced practice providers working in the ED.

Pain Management: Many individuals with SCD have been battling pain crises throughout their lives and have built a high tolerance for pain medications; combined with misinformation, stereotypes, and negative provider attitudes[xviii] toward individuals with SCD, impedes implementation of evidence based care guidelines. Furthermore, a lack of institutional and departmental treatment protocols can lead to wide variability in the quality of care, resulting in patient and provider frustration.[xix]

Possible proposals might examine how best to implement pain guidelines in the ED, or at home via telehealth to empower patients with early interventions.

Sickle Cell Disease & Quality of Life: Measuring the impact of a health condition on quality of life within an individual or specific population can be used to influence the decision-making and/or disease management approach taken by healthcare providers, patients, and policymakers. Individuals with SCD experience a myriad of complications throughout their lives. Most adults experience more than one SCD-related complication and have more than one affected organ system.[xx] The Pain in Sickle Cell Epidemiology Study (PiSCES) study assessed Health Related Quality of Life (HRQOL). Results found that SCD patients experience health related quality of life worse than the general population.[xxi]

Applications submitted under this priority area may focus on assessing the needs within the SCD population and developing and testing innovative approaches to improve the patient's experience with the care they are receiving, including ability to cope with complications resulting from their SCD diagnosis.

We expect evidence based evaluation tools be used to assess impact of all proposed projects.

Cost Reimbursable Grant Activities and Results

Applicants should propose results-oriented objectives to address the priorities described above. Objectives should be quantifiable and measurable. It is recommended that the applicant use S.M.A.R.T. Objectives (S.M.A.R.T. is an acronym that is used to guide the development of measurable goals. Each objective should be: **S**pecific, **M**easurable w/Measurement, **A**chievable, **R**elevant, and **T**ime-Oriented)

At a minimum, applications must contain the following key elements:

- Identifies specific and quantifiable results to be achieved and steps (e.g. general strategies/processes) to achieve the intended results;
- Performance management system to measure and assess achievement of results. System should include proposed goals/results with a timeline;
- Identify specific person(s) accountable and responsible for performance.

No cost sharing is required

A Review Committee, made up of SCD experts, will review and evaluate all complete applications submitted by the deadline.

II. AWARD INFORMATION

The award ceiling for all applications submitted is $75,000. The project period will extend for 12 months, from July 1, 2021 to June 30, 2022.

III. ELIGIBILITY OF PROSPECTIVE APPLICANTS

Applications from eligible entities are encouraged. All applicants and grantees must be able to demonstrate that they meet the following mandatory eligibility requirements:

1. A legally registered 501c3 in good standing for the past five consecutive years.

2. Have an active conflict of interest policy

3. Confirm the Principal Investigator, other employee(s), contractor(s), or any other participants(s) engaged in this project are not presently debarred, suspended, proposed for debarment, or declared ineligible for award of state or federal contracts

4. Have an accounting system with the capability to identify the receipt and expenditure of awards separately

IV. APPLICATION AND SUBMISSION INFORMATION

A. Letter of Intent (required)

The letter of intent will help us to be sure we have an adequate number of reviewers and ensure there will be no conflict of interest for the review committee members. The Letter of intent should not exceed one page and be emailed to grants@c3dibd.org by 5pm PST on April 1, 2021. The document should be labelled according to the priority area for which you are applying. Please label your letter of intent as follows:

"LOI_NCSCC-07012021_[abbreviated name of applicant organization]"

The applicant MUST use the template provided as Appendix A when developing their letter of intent.

B. Format

1. Applicants must use the application templates provided on the website (https://sicklecellcare-ca.com/outreach-education-overview/) and noted in the Application Instructions for the Letter of intent, cover letter, narrative, and corresponding budget.

2. Each application must be submitted as one PDF document, except for the budget, which should be submitted in an excel format.

3. The application must be signed by an officer of the Applicant organization who is duly authorized to represent the organization in further discussions and/or negotiations on the application.

4. Applications should not exceed 10 pages (not including attachments, budget, or budget justification), should be single spaced, and in 11 point font (Times New Roman, Calibri, and Ariel style fonts are acceptable).

All applications should be submitted to grants@c3dibd.org by 5pm Pacific on May 1, 2021 clearly stating the "[abbreviated name of applicant organization]: Application in response to RFA #NCSCC-07012021" in the subject line.

C. Additional Instructions for Budget Section

1. Applicants should propose only those costs that are necessary and reasonable to perform the activities described in the application. Guidance on certain limitations are provided in the Section II, Award Information.

2. Applicants are required to submit a budget narrative that explains and justifies the need for the costs proposed in the budget. The narrative should help the reviewer understand ***why*** ***an item of cost is necessary and how it will be used for the activity for which it will be incurred***. The budget narrative should demonstrate the relationship between the proposed activities and the budget.

3. All costs associated with responding to this solicitation shall be the sole responsibility of each applicant.

V. EVALUATION

Applications will be evaluated against the evaluation criteria in the table below. Only applications with a combined average total score of 80 points or higher will be considered for funding.

Criteria	Maximum Score
Organizational capacity & Past performance	15
Cost Effectiveness & Practicality	25
Proposal & Technical merits	60
Total	**100**

These evaluation criteria elements are described more fully below.

A. Organizational Capacity and Past Performance (1 page): Evidence of the applicant's capability to undertake and accomplish the proposed grant activities. The application should demonstrate the organization's effectiveness in terms of internal structure, technical capacity, and key personnel, in meeting the grant objectives and goals. In addition, the organization must demonstrate adequate financial management capabilities. Grantee to demonstrate a program coordinator or administrator dedicated to project oversight and implementation. **Total of 15 points.**

B. Cost Effectiveness and Practicality: The degree to which budgeting is clear, reasonable, and reflects the best use of organizational and grant resources. **Total of 25 points.**

C. Proposal and Technical Merits: The quality and feasibility of the application in terms of 1) the feasibility of the proposed approach, (i.e., the proposed technical approach can reasonably be expected to produce the intended outcomes); 2) appropriateness of the proposed methodology; 3) innovativeness, and 4) the work plan for achieving project objectives. Proposed mechanisms for monitoring and evaluation with objectively measurable indicators. **Total of 60 points.**

VI. AWARD AND ADMINISTRATION INFORMATION

A knowledgeable committee representing experts in SCD care and implementation science will be assembled to review these applications and prioritize funding based on score. None of the reviewers will be employees of CIBD or the Sickle Cell Disease Foundation. Applicants will be informed in writing of the decision made by the reviewers regarding their proposal. All costs funded by the grant must be allowable, allocable and reasonable. Grant applications must be supported by a detailed and realistic budget as described in Section IV.

APPENDICES

A. Letter of Intent TEMPLATE & Instructions
B. Cover Letter TEMPLATE
C. Budget TEMPLATE
D. Application Format & Instructions

REFERENCES

[i] Benson, J.M. and Therrell, B.L. History and current status of newborn screening for hemoglobinopathies. Semin Perinat. 2010; 34: 134–144

[ii] Cynthia S. Minkovitz, Holly Grason, Marjory Ruderman and James F. Casella, "Newborn Screening Programs and Sickle Cell Disease," *American Journal of Preventive Medicine* 51, no. S1 (June 2016): S39-47

[iii] Weiss MG, Ramakrishna J, Somma D. Health-related stigma: Rethinking concepts and interventions. Psychol Health Med. 2006;11(3):277–287.

[iv] Bulgin D, Tanabe P, Jenerette C. Stigma of Sickle Cell Disease: A Systematic Review. Issues Ment Health Nurs. 2018;39(8):675-686. doi:10.1080/01612840.2018.1443530

[v] R. Bryant and T. Walsh, "Transition of the chronically ill youth with hemoglobinopathy to adult health care: an integrative review of the literature," *Journal of Pediatric Health Care* 23, no.1 (January – February 2009): 37-48.

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[viii] The American Society of Hematology. "The State of Sickle Cell Disease: 2016 Report." 2016.

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[xv] Center for Disease Control and Prevention. https://www.cdc.gov/ncbddd/sicklecell/treatments.html. Accessed 12.09.20.

[xvi] Glassberg, Jeffrey. Improving Emergency Department-Based Care of Sickle Cell Pain. *American Society of Hematology*. 2017. P412-417.Ibid.

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