

## 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-07012020
Date of Issue	3/2/2020
Letter of Intent (Required)	4/1/2020
Closing Date for Receipt of Applications <i>(Late applications will not be considered)</i>	5/1/2020
Announcement of Awarded Grants. <i>All applicants are notified of their status on their applications.</i>	6/15/2020
Grant Year	07/01/2020 – 6/30/2021
Reporting <ul style="list-style-type: none"> <li>• Mid-Year Report Due</li> <li>• Final Report Due</li> </ul>	<ul style="list-style-type: none"> <li>• 01/31/2021</li> <li>• 07/31/2021</li> </ul>
Questions on this solicitation should be submitted to e-mail address provided no later than the date indicated.	E-mail: <a href="mailto:grants@c3dibd.org">grants@c3dibd.org</a> No later than: 3/12/2020
The project will hold a briefing for interested parties on the date indicated. Those interested must register through the link provided.	3/16/2020 Register by 3/12/2020: <a href="https://www.surveymonkey.com/r/CASCD">https://www.surveymonkey.com/r/CASCD</a> Call in information will be sent to all registered participants closer to the date

## I. PROGRAM DESCRIPTION AND OBJECTIVES

This announcement will initiate a request for applications (RFA) to promote outreach, education and awareness of Sickle Cell Disease and Trait in: Healthcare Systems, Teaching Institutions, Community, and Newborn Screening Programs

### **Background:**

Patients with Sickle Cell Disease (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. <sup>i</sup> 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<sup>ii</sup> and encounter pain as well as a multitude of serious health problems throughout their lifespan.

In California, approximately 133 cases of SCD are identified per year among approximately 500,000 births.<sup>iii</sup> In the United States, SCD occurs most commonly among people of African ancestry: one in 365 African American births. Moreover, 1 in 13 African-American babies born are carriers of the Sickle Cell Trait (SCT)<sup>iv</sup> In addition, nearly 3,500 newborns per year are identified with Sickle Cell Trait, where only one of the two hemoglobin genes carry the Sickle Cell variant. Often overlooked, there is a significant incidence of SCD in the Hispanic population where approximately 1 in 16,300 births result in SCD.<sup>v</sup> In 2010, the 1,500 Hispanic infants who did test positive for trait made up 37% of the 4,000 babies identified with sickle cell trait.<sup>vi</sup> Sickle cell disease 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.<sup>vii</sup>

In 2016, the Sickle Cell Data Collection Program estimated there were nearly 5,000 individuals with SCD in California. California’s statewide costs for sickle cell are very high, at an estimated \$740 million for inpatient hospitalizations and emergency room visits, not including HMO systems.<sup>viii</sup> A growing percentage of adults and young people at transition are losing services due to the absence of a strong network of providers. One way these challenges and gaps in our healthcare delivery system can be bridged are through partnerships with community based organizations (CBOs) to deliver effective follow up and provide education and support services throughout an individual’s lifespan.

### **California Sickle Cell State Action Plan, (CA-SCAP):**

In a landmark meeting of over 50 sickle cell stakeholders in Sacramento in 2018, public health gaps and priorities were identified to improve the health of Californians affected by SCD and SCT. The CA-SCAP’s committees’ draft report was finalized and disseminated in December 2018 after incorporating substantive input from a broad array of stakeholders (found at <https://ca-actionplan.pacificscd.org/california-action-plan/>). The California Sickle Cell Action Plan also creates a roadmap forward, presenting long term goals and strategies to improve healthcare systems. Key to this effort is the need to increase education and awareness about sickle cell disease and sickle cell trait in California. Its ultimate aim is to improve the quality of life and longevity of those living with sickle cell disorders now and in the future.

### **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 of California. This appropriation stemming from CA-SCAP

addresses priorities to expand adult clinics in areas of need, expand workforce, especially community health workers to enhance care coordination; expand surveillance to monitor healthcare utilization, complications and costs; and **through a granting process, conduct outreach to promote SC education and awareness through a series of grants in 3 major categories: Healthcare Delivery Systems, Healthcare Provider training programs, and Community Based Organizations.**

This request for grant applications is one of the first and most important steps in Networking California Sickle Cell Care and operationalizing the California Sickle Cell State Action Plan, Goal 2, and strategies 2.1 – 2.3. Specifically, to “...engage entities to implement outreach and education activities that increase education and awareness of SCD and SCT and provide information about clinical and support services...”

### Grant Objectives & Priority Areas

The RFA requests applications from organizations and institutions in three priority areas; a **separate application is required for each area**; further information is outlined in *Section II. Award Information*. Applications are welcomed from entities in one or more of the following priority areas:

A. ***Education and Awareness of SCD and Its Complications in Healthcare Delivery Systems:***

Applications will propose to conduct activities that would raise education levels and awareness among clinicians and staff who work in settings frequented by people with SC, i.e. hospitals and emergency rooms, primary care clinics, Healthcare Networks and federally qualified health centers (FQHCs). Awareness and education is particularly needed in preventive ambulatory SCD care, many of which do not know that key federal agencies<sup>ix x</sup> have exempted individuals with SCD from current restrictions in opioid prescriptions. This lack of understanding inappropriately limits access to treatment for debilitating SCD- related pain and wrongly stigmatizes people with SCD as drug seekers. Education is also needed on the importance of referring patients, particularly adults, to the growing network of knowledgeable SCD teams for ongoing comprehensive coordination of care. Clinical settings, such as FQHCs are mandated to provide care to medically underserved communities, and thus are also valuable in the effort to address health disparities.<sup>xi</sup> Given that there are nearly 5,000 individuals diagnosed with SCD in California establishing and strengthening partnerships with FQHC’s is imperative to improving health outcomes for individuals with SCD and SCT.

Grants will be provided to qualified entities that can raise awareness and educate practicing health professionals about the needs of people living with SCD and their families, including trait testing and trait education. Increasing education and awareness about SCD as a vital health equity concern in California and committing resources to eliminate disparities are key elements of this priority area. Public and health care provider awareness about sickle cell disease is limited; particularly that sickle cell disease affects Hispanic populations, which is California’s largest ethnic group. While national figures indicate that one in 10 persons with sickle cell disease is Hispanic, that rate may be higher in California, given the state’s increasingly large numbers of residents declaring more than one race or ethnicity.

Our goal is to increase the number of knowledgeable healthcare providers that care for individuals with SCD, and also contribute to improving the health outcomes and quality of care provided to individuals with SCD. We will fund projects that commit to the following activities:

- Implement a training/education mechanism (e.g. lectures and/or workshops on SCD and SCT) that target primary care physicians, nurses, social workers, case managers, etc.;

As part of the primary proposal we encourage:

- Commitment to participating in monthly telementoring calls;
- Commitment to collecting and reporting the following data:
  - Numbers of sessions and participants, dates, locations, learner demographics (e.g. discipline, numbers of years in practice, # of individuals with SCD treated in the reporting period);
  - Types of education events: live in person or video, archived, or other;
  - Pre and post test results (or explanation of other type of evaluation method)

B. *Education and Awareness of SCD and Its Complications in Healthcare Provider Training programs:*

Teaching hospitals are well known for providing high quality and highly specialized care. Other distinctive missions of teaching hospitals include medical education, innovations in clinical care, and treatment of indigent patients, particularly at public teaching hospitals.<sup>xii</sup> Despite this robust training structure, there are few hematologists' trained and willing to care for adults with SCD, resulting in the majority of care being delivered in emergency departments (EDs) and other non-specialty settings.<sup>xiii</sup> Poor access to knowledgeable care and life altering therapeutics has limited the impact of innovative therapies for the majority of person with sickle cell disease.

Healthcare professions associations are also in a unique position to educate large groups of healthcare professionals and link them to training resources. Workforce development and training has not matched the increasing numbers of individuals with SCD reaching adulthood. Thus health and quality of life has critically diminished for patients unable to access appropriate treatment to prevent pain and disease related organ damage. Our goal is to increase the number of knowledgeable healthcare providers that care for individuals with SCD through training, education, and mentorship. We will fund projects that commit to the following activities:

- Implement an innovative and robust education mechanism (e.g. lectures and/or workshops on SCD and SCT) to target students / residents **in training** such as primary care physicians (family practice and hospitalists), nurses, social workers, case management staff, etc.;

As part of the primary proposal we encourage:

- Commitment to participating in monthly telementoring calls;
- Commitment to collecting and reporting the following data:
  - Numbers of sessions and participants, dates, locations, learner demographics (e.g. discipline, numbers of years in practice, number of individuals with SCD treated within the reporting period);
  - Types of education events: live in person or video, archived, or other;
  - Pre and post test results (or explanation of other type of evaluation method)

C. *Education and Awareness of SCD [in, via] Community Based Organizations (CBO):* Community-based organizations are critically important health system stakeholders as they can assist patients with health decision making and provide highly valued programs and services to the members of their community.<sup>xiv</sup> Community-based organizations are well positioned to deliver

such services to the public because they understand their local communities and are connected to the groups they serve.<sup>xv</sup> In addition to providing important health services and programs, community-based organizations often play important advocacy roles with the aim of strengthening the health systems in which they work.<sup>xvi xvii xviii xix</sup> Sickle cell based CBO's are historically underfunded and under recognized. Even so, CBOs have still been highly effective in working with the clinic social workers and providers to identify community resources and aid in building trust between patients and the clinic team. As patients are most comfortable with the CBO in their local area, these organizations have also been key to identifying persons with SCD who are seeking knowledgeable SCD healthcare services.

CBOs are also taking the lead in successful transition programs which are challenging for the healthcare team, but which must be integrated with clinical care to assure that young adults find an excellent medical home with SCD services. Most importantly, the disparities in health and health care that have pervasively affected individuals with SCD ultimately prevent them from obtaining the highest quality of healthcare, quality of life and the best health outcomes.

Funding provided to CBOs should focus on educating providers and the community in these areas and to propose successful collaboratives with healthcare teams to improve patient outcomes, transition, and quality of life. *Grantees funded under this priority area will be expected to work in conjunction with the Sickle Cell Disease Foundation, the CBO lead for the Networking California for Sickle Cell Care Initiative.*

We will fund projects that focus on implementing the following activities:

- Conduct outreach on SCT and SCD,
- Educate community members to increase awareness of SCT and SCD. Topics should be based on a needs assessment.
- Material development (as needed). Evidence should be provided to demonstrate that materials do not currently exist or are inadequate. Materials are expected to be bi-lingual (English/Spanish).
- Address barriers to access SCD subspecialty comprehensive care.
- Increase capacity for self-advocacy and empowerment among Patients and families
- Provide training and support to adolescents and young adults to increase readiness for transition from pediatric to adult care.
- Demonstrate best practices in patient support and transition or projects that integrate community resources with the clinics in order to overcome challenges which limit the effectiveness of preventative care such as economic status, lack of access to transportation, homelessness, cultural and language barriers.
- Link individuals to social support and clinical services.

### 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

CIBD will review and evaluate all complete applications submitted by the deadline.

## II. AWARD INFORMATION

<b>A. Education and Awareness of SCD and its complications for Healthcare Delivery Systems</b>	
Projected number of grants to be awarded	Approximately 2-4 in total
Projected not-to-exceed amount of an individual grant/year	\$20,000-\$40,000
Anticipated period of performance of an individual grant	Up to 12 months, with possibility of renewal for 2 additional years based on performance
Anticipated start date of performance	07/01/2020
<b>B. Education and Awareness of SCD and its complications in Healthcare Provider training programs</b>	
Projected number of grants to be awarded	Approximately 2 in total
Projected not-to-exceed amount of an individual grant/year	\$27,500
Anticipated period of performance of an individual grant	Up to 12 months, with possibility of renewal for 2 additional years based on performance
Anticipated start date of performance	07/01/2020
<b>C. Education and Awareness of SCD in Community Based Organizations</b>	
Projected number of grants to be awarded	Approximately 2-5
Projected not-to-exceed amount of an individual grant/year	\$30,000-\$75,000
Anticipated period of performance of an individual grant	Up to 12 months, with possibility of renewal for 2 additional years based on performance
Anticipated start date of performance	07/01/2020

### III. ELIGIBILITY OF PROSPECTIVE APPLICANTS

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

1. A legally registered 501c3 for at least two 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
5. If selected, agree to be subject to a pre-award assessment to examine its possession of or ability to obtain the necessary management competence to plan and carry out the activities to be funded.
6. If selected, able and willing to sign and submit the following required certifications:
  - *Assurance of Compliance with Laws and Regulations Governing Nondiscrimination*
  - *Certification Regarding Lobbying*



## IV. APPLICATION AND SUBMISSION INFORMATION

### A. Letter of Intent (required)

The letter of intent will help us to be sure we have adequate reviewers and to be sure there will be no conflict of interest for the members of each granting section. The Letter of intent should not exceed one page and be emailed to [grants@c3dibd.org](mailto:grants@c3dibd.org) by 5pm PST on April 1, 2020. 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-07012020\_[priority area number]\_[abbreviated name of applicant organization]”

If an organization is applying to more than one priority area, a separate letter of intent should be submitted for each area. 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), 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](mailto:grants@c3dibd.org) by May 1, 2020 clearly stating the “Application in response to RFA # NCSCC-07012020.”

### 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.

Criteria	Maximum Score
Organizational capacity & Past performance	15
Cost Effectiveness & Practicality	25
Proposal & Technical merits	60
<b>Total</b>	<b>100</b>

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. **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 in any of the three categories. 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

- 1) Letter of Intent TEMPLATE
- 2) Application Cover Letter TEMPLATE
- 3) Grant Application Instructions
- 4) Budget TEMPLATE

## REFERENCES

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- <sup>i</sup> Benson, J.M. and Therrell, B.L. History and current status of newborn screening for hemoglobinopathies. *Semin Perinat.* 2010; 34: 134–144
- <sup>ii</sup> 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
- <sup>iii</sup> 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.
- <sup>iv</sup> Centers for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/sicklecell/data.html>
- <sup>v</sup> Ibid.
- <sup>vi</sup> <http://casicklecell.org/cadata/>
- <sup>vii</sup> The American Society of Hematology. “The State of Sickle Cell Disease: 2016 Report.” 2016.
- <sup>viii</sup> Sickle Cell Data Collection Program. What are the costs of Sickle Cell Disease: <http://casicklecell.org/cadata/> accessed 7.13.2019
- <sup>ix</sup> Dowell D, Haegerich TM, Chou R. CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016. *MMWR Recomm Rep* 2016;65(No. RR-1):1–49. DOI: <http://dx.doi.org/10.15585/mmwr.rr6501e1>
- <sup>x</sup> U.S. Department of Health and Human Services (2019, May). Pain Management Best Practices Inter-Agency Task Force Report: Updates, Gaps, Inconsistencies, and Recommendations. Retrieved from U. S. Department of Health and Human Services website: <https://www.hhs.gov/ash/advisory-committees/pain/reports/index.html>
- <sup>xi</sup> Roland, KB. Eta al. “Use of Community Health Workers and Patient Navigators to Improve Cancer Outcomes Among Patients Served by Federally Qualified Health Centers: A Systematic Literature Review.” *Health Equity.* 2017 May 1;1(1):61-76. doi: 10.1089/heq.2017.0001. eCollection 2017.
- <sup>xii</sup> Blumenthal D, Weissman JS, Campbell EG. The Social Missions of Academic Health Centers. *New England Journal of Medicine.* 1997;337:1550–3
- <sup>xiii</sup> Hemker BG, Brousseau DC, Yan K, Hoffmann RG, Panepinto JA. When children with sickle-cell disease become adults: lack of outpatient care leads to increased use of the emergency department. *Am J Hematol* 2011;86:863-5.
- <sup>xiv</sup> Wilson, M., et al. “Community-based organizations in the health sector: A scoping review,” *Health Research Policy and Systems.* 2012 10:36. <https://doi.org/10.1186/1478-4505-10-36>
- <sup>xv</sup> Chillag K, Bartholow K, Cordeiro J, Swanson S, Patterson J, Stebbins S: Factors affecting the delivery of HIV/AIDS prevention programs by community-based organizations. *AIDS Educ Prev.* 2002, 14: 27-37. 10.1521/aeap.14.4.27.23886.
- <sup>xvi</sup> Blas E, Gilson L, Kelly MP, Labonte R, Lapitan J, Muntaner C: Addressing social determinants of health inequities:

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what can the state and civil society do?. *Lancet*. 2008, 372: 1684-1689. 10.1016/S0140-6736(08)61693-1.

<sup>xvii</sup> Carey GE, Braunack-Mayer AJ: Exploring the effects of government funding on community-based organizations: 'Top-down' or 'bottom-up' approaches to health promotion?. *Glob Health Promot*. 2009, 16: 45-52.

<sup>xviii</sup> Doyle C, Patel P: Civil society organisations and global health initiatives: problems of legitimacy. *Soc Sci Med*. 2008, 66: 1928-1938. 10.1016/j.socscimed.2007.12.029.

<sup>xix</sup> Nathan S, Rotem A, Ritchie J: Closing the gap: building the capacity of non-government organizations as advocates for health equity. *Health Promot Internation*. 2002, 17: 69-78. 10.1093/heapro/17.1.69.