Placement Description

Sickle cell disease is a global health problem, having direct impact on our greater New Haven communities. In the United States it is estimated that over 100,000 people live with sickle cell disease and one in ten African Americans and one in thirty Hispanics carry the trait. Currently the while the average life expectancy in America has improved—it is now in the mid 40 years of age range, however, the challenge currently is increasing the life expectancy threshold through medical intervention and awareness. While people of African descent suffer from the disease and carry the trait disproportionately other groups also present with the disease and trait such as Hispanics, Portuguese, French Corsicans, Sardinians, Sicilians, mainland Italians, Greeks, Turks and Cypriots. Sickle cell disease also appears in Middle Eastern countries and Asia. Currently, there is no universal cure for sickle cell disease.

In the absence of a cure SCDAA of Southern CT will need to continue our work with the city of New Haven through a model pilot program to drive awareness of those carrying the trait and specifically targeting the age group of child bearing age who plan to marry. Last year our Yale Fellow establish an innovative program in partnership with the Department of Health, Division of Vital Statistics which is responsible for marriage license process. One of the projects and or initiatives would be to continue to oversee this project and work with our Medical Advisory Committee to further advance this program by introducing a genetic counseling arm for those seeking screening/testing and working with our Medical Advisory Committee to analyze the rich amount of data relative to lessons learned from a survey of this high risk urban population. This work may also involve publishing the findings of such data from our survey tool developed by the FY 17 Yale Fellow.
SCDAA is also working to further develop our tutorial program for those youth who fall behind academically. The fellow will further develop and solidify our tutoring program to offer this service by furthering these efforts to develop MOAs with local colleges and Universities to provide resources for high risk sickle cell youth in need of critical academic support. (3) Beyond continuing to help develop these programs, launched by our FY 17, the FY 18 Yale Fellow will help plan our open house this summer since this event, featuring the first Sickle Cell Community House in the Northeast, will be a very highly visible program because so many constituents are involved and engaged inclusive of locally, regionally and national stake holders. (4) Finally the FY 18 Fellow will serve as the project manager to support our first Regional (Southern CT) Bike Ride and our first major 1/2 or full Marathon as a complement to our Annual Sickle Cell Walk.

**Continuation Plan**

SCDAASC’s request support will be underpinned by an upgrade in technology offered by Yale IT that focuses on both, fund raising, and expansion into our social media needs and further development of our programs and services—creating donor value and recipient value. The latter framework was developed after a year of careful research and study of successful nonprofit models common in the United States.

- **Specific skills/experience required for the project (Please list):** writing skill, know word, excel, google doc.

- **A car is not a necessity however, there may be some weekend work as far as community Health Education Outreach events. Any transportation expenses will be reimbursed.**

- **Briefly describe the work that Yale PPSF Fellows have done with your agency in the past and present. If you have not worked with Yale Fellows, please describe any work that Yale students have done with your agency. Volunteer with our annual Walkathon.**

As noted our FY 17 fellow advanced our new Prevention Program in concert with the Director of Health /Department of Vital Statistics

Additionally the FY 17 Fellow has built and launched MOAs with many of the contiguous Universities and Colleges to build a vibrant, continuous and seamless tutorial support base.

The FY 17 Fellow has also help launch our first Capital Campaign Project and developed a very successful template for success.