

# Yale University

## President's Public Service Fellowship

### Proposal for Fellowship Placement Summer 2024

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#### Organization information

<i>Name of organization</i>	Sickle Cell Disease Association of America of Southern CT
<i>Full street address</i>	1389 Chapel Street, New Haven, CT
<i>Website or link to social media page</i>	<a href="http://www.michellesHousect.org">www.michellesHousect.org</a>

#### PPSF Fellow's direct supervisor

<i>Name</i>	James Rawlings, R.PH,MPH
<i>Title</i>	President/ CEO
<i>Cell phone number</i>	203 8595355
<i>E-mail address</i>	<a href="mailto:Jamesrawlingsscdaa.sc@gmail.com">Jamesrawlingsscdaa.sc@gmail.com</a>

**What is the best way for prospective student applicants to contact you with questions about your proposal?**

- Send an e-mail with questions

or

- Send an e-mail to set up a 15-meeting phone call to discuss

**Placement dates (8-11 weeks between Tuesday, May 28, 2024 through Friday, August 9, 2024)**

May 28 2024-August 9, 2024

**Are placement dates flexible? Are there any dates on which your Fellow must work?**

Yes

**Proposed work schedule (*work week should equal (and not exceed) 37.5 hours per week*)**

7.5 hours per day x 5 days per week

**If a hybrid schedule is offered at your site, please describe:**

At least 80% of the time on site since there are many collaborators.

**Organization description (*mission statement, population served. 1,000 characters or less*)**

At Michelle's House, home of the Sickle cell Disease Association of America Southern CT and statewide we embrace prevention, new clinical options and strategies to enhance the quality of life and well being of the community affected by Sickle Cell Disease and equally since it is a genetically transmitted disease we drive awareness of Sickle Cell Trait carriers.

We also incorporate into our charge the sequelae of down field negative impacts of the disease such as educational challenges of our youth and the employability of everyone who lives with Sickle Cell Disease and are therefore medically compromised.

Since most of our clients are on Medicaid they are burden with poverty and have unstable housing.

Since there is no cure and live expectancy is 20 years less than their cohorts we must negotiate the sources and highest correlations of social determinants. Our goals are to publish our findings and pilot programs to become an exemplar nationally for change.

**Write a 1-2 sentence summary of the work that the Fellow would be conducting.**

Since this is the second year of this longitudinal study we finally have the data from DPH including all the state wide acute care data the actual report writing will began. This will include the data analytics and the complementary interviews of many of our clients. We hope to publish "The Report on the status of SCD in CT with support from the YCA and support from the Smilow Cancer

Center, The SCSU School of Health and Human services and the School of Public Health at Yale.

**Write a more complete description of the specific project you propose and list the duties/outcomes expected of the Fellow.**

The PPSF will be to draw from the data to help coordinate and write a report on the Status of Sickle Cell Disease in CT and to add to the armamentarium of tools to improve the lives of all affected by this disease and drive and improve awareness of all stake holders.

The embedded charge and goals of this report will be to highlight that there is a Canary in the Mine Shaft and to:

1. Document through data analytics the barriers to access issues of appropriate and preventable clinical care
2. The role of Sickle Cell Trait carriers and the stigma associated with sharing and or knowing ones SCT as it relates to the generational impact of new borne with SCD
3. Issues related to the quality of life of the Sickle Cell Community(SCC)  
Examples of these sequelae are excessive academic failure of children who too often suffer through the burden of school days loss based on frequent acute care admissions and emergency room visits
4. The inability to maintain employment , to be able to meet the day to day basic needs and are too often homeless.
5. The lack of development and philanthropic support to address many of the needs of the SCC especially in relation to all other genetic disease such as Cystic Fibrosis which receives up to 12 times the financial support of SCD and is only 1/3 the affected population demographics.

**List any specific skills/experience required for the project**

Good writing skills.

Good collaborations insights in working with other researchers.

Interview skills to research data and other variables.

Some analytical skills and strengths to inform the project with graphic presentations.

**Additional requirements**

NA

**Briefly describe any work that Yale PPSF Fellows and/or Yale students have done with your organization.**

Over the last three years have:

1. Supported the development of prevention program targeting SCT issues such as SCT testing awareness and developing surveys focusing on individuals of child bearing age
- 2, Supported the development of development and executing a capital campaign
3. Developing a legislative Agenda and the execution and presentation of at the LOB
4. Grant writing
5. Updatig website
6. Donor engagement and outreach programs to community-based organizations
7. Developed our first education poster, profiling and highlighting trend data that captures graphically pictures of SCD/SCT both nationally and within new Haven County and statewide
8. Helped organize a planning committee to produce a 5-year strategic plan for SCD in CT