SICKLE CELL DISEASE ASSOCIATION OF AMERICA .SOUTHERN CT

Yale University Presidents Public service Fellowship

Proposal for Fellowship Placement  2019

Sickle Cell Disease Association of America Southern CT(SCDAAS.CC)

1389 Chapel Steer New Haven CT

scdaaofsouthernct.org

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Placement dates open

Placement are flexible

Proposed week 9-4:30 daily with 1/2 hour for lunch negotiable

- Mission... The mission of the SCDAAS. Southern CT is to provide health advocacy, community health awareness education, screening, counseling and support services to persons and families impacted and affected with sickle cell disease and sickle cell trait. Our goal is to ensure a support network of community partners dedicated to promoting a healthy lifestyle for the entire sickle cell community.

- Summary:

  Our organization thrives to address the unattended broad issues that impede the quality of life of the
sickle cell community. Therefore
two programs need significant leadership

1. Continue to build a tutorial program for at risk youth
   SCD youth.

2. The need to produce a documentary to address
   the stigma of SCD that suffocates the
   quality of life of those impacted.

- COMPREHENSIVE DESCRIPTION OF OPPORTUNITY
  Tutorial Program. Last year a Yale fellow initiated a framework to establish a tutorial program to address the academic needs of sickle cell youth based on the significant number of school days loss due to frequent hospitalization. One of the goals was to engage local universities to enter into a Memorandum of Agreement (MOA) to engage their faculty and student body to mentor and supplement their academic deficiencies. To continue this program we have with the support of our previous Yale fellow through a FOI process documented that the national rate of annual repeat of grades is 4.5% whereas national rate for sickle cell disease impacted disease is 40%. We need to establish a baseline for New Haven schools relative to failure rates and establish and formalize a program to quantitatively improve the academic success of these youth.
Documentary...One of the overriding challenges within the sickle cell community is the oppressive burden that members of the sickle cell community deal with daily. Members of the medical community too often see sickle cell patients with their heavy opioid prescription profile as simply drug seeking and therefore under prescribe future medications.
Some of the latter interactions results in avoidable and preventable admissions due to delayed standard of care practices. Additionally and even more significant can be the degree of stigma within the communities the clients/patients live. Our experience has been that all too often members of these communities deny their sickle disease and trait status. The latter therefore indirectly suppresses positive dialogues within the community and forcing others through this behavior to pull away from social engagement in a community that all too often already suffers a large degree of shame and burden. We believe a documentary detailing these internal and external factors will help to produce healthy dialogue with the medical theater and impacted communities and families locally and nationally.

SPECIFIC SKILLS ETC

Creative, committed and with high degree of interest in social justice.

Additional Requirements NA
Past PPSF Fellows

Over the past two years we have been blessed to have two great scholars who have advanced our mission mightily.

The first year our fellow established the first in the nation high risk focused screening program in partnership with the New Haven Department of Health.

The second fellow working with the State Department of Health and the Department of HHS and utilizing the FOI process developed one of the first educational posters nationally that has mobilized many sectors and new partners to advance Sickle Cell Disease studies and initiatives especially as it brings national data and marries it with state data to promote awareness.