

Lillian Gould



**ASSIGN  
BUSTER**

Lillian Gould Professor: Dr. Faye Ran Arts Administration July 10, 2012

Advocacy Proposal The Sickle Cell Thalassemia Patients Network 1139 St.

John's Place Brooklyn, NY 11213-2617 Telephone: 347-533-8485 Fax: 718-

789-5767 Email: info@sctpn.org URL: www.sctpn.net Type of Grant maker:

Public Charity IRS Exemption Status: 501(c) (3) Financial Data (yr. ended

2012 can't find) EIN: 990: 2011 2010 2009 2008 2007 2006 2005 2004 2003

2002 Last Updated: Background: Established in 1989 in Brooklyn, NY

Limitations: Giving primarily in the Brooklyn, NY area Purpose and Activities:

Dedicated to improving the quality of life for individuals and their families

living with sickle cell disease, thalassemia, and other hemoglobin variants

providing services that will help to reduce the negative physical, emotional,

social, and economic impact of this debilitating blood disorder. SOCIAL

JUSTICE ADVOCACY In the pursuit of influencing outcomes, including public

policy and resource allocation decisions within political, economic and social

systems and institutions that directly affect people's current lives. I have

chosen a medical issue that needs a different approach in the way of change

to be brought to society in a form of social injustice advocacy. Sickle Cell

Disease (SCD) is the most common inherited blood disorder in the United

States, affecting 70, 000 to 80, 000 Americans. Statistics shows that the

disease is estimated to occur in 1 in 500 African Americans and 1 in 1, 000 to

1, 400 Hispanic Americans. So because of this data, it is extremely vital to

provide the much needed education on how to deal with sickle cell disease

and how it impacts families. In addition to uncovering the underlying

prejudices, attitudes and supplementary needs of those stricken with sickle

cell anemia. Sickle Cell Thalassemia Patients Network (SCTPN) began in 1989

at Brooklyn Jewish Hospital (now known as Interfaith Medical Center) located

<https://assignbuster.com/lillian-gould/>

in Brooklyn, NY as an adult and parent support group for individuals with inherited blood disorders. This organization was incorporated in 1993 as a volunteer, not for profit organization by its founding members to serve the larger community by providing a face and a voice for these underrepresented health issues, but more is needed. WHAT IS NEEDED & WHY More funding is required to help those who have sickle cell disease as well as the general public to better understand this disease so that they can make well informed decisions about their care and their lives. Furthermore, additional information is needed to provide knowledge and the service of the benefits of non-drug treatments such as: 1) Physical Therapy- gentle exercise and heat and cold treatments can help with sickle cell pain. 2) Relation Techniques- learning how to relax can help patients cope better with the illness and pain. 3) Massages —especially at the first signs of a sickle cell crisis. Massages can decrease muscle stiffness and potentially reduce pain. 4) Acupuncture- can also be useful in helping to relieve stress and manage pain as well. FURTHER CHANGES NEEDED a) Encourage academic excellence in children and young adults living with sickle cell disease and other hemoglobin variants through tutorial services, achievement awards and college scholarships. And this is very important factor because according to the National Association for Sickle Cell Disease, 70% of those with sickle cell anemia, either partially or totally depend on public assistance or their families for financial support. b) The development of additional Comprehensive Medical Care programs for adults with sickle cell disease. Oftentimes patients are too poor to afford private insurance (or the supplemented care required). So they find themselves switched from doctor to doctor, struggling to get referrals to specialists who are skilled to

<https://assignbuster.com/lillian-gould/>

monitor their care effectively. c) Make Genetic Counseling available with family planning. And this aspect of knowledge is very important to a person who has the sickle cell trait because it can make the difference in caring for a child who will be sick all the time for the rest for the rest of their life as oppose to not. FUNDING: I would like to hold a fashion show at Brooklyn Tech College in September which is the month for sickle cell awareness, to help raise money in order to sponsor cost for non-drug treatment care for sickle cell patients such as acupuncture, relaxation techniques and massages. My company would like to do something to help pay for a good cause so that when sickle cell patients encounter severe pain, they can receive effective care to help control or counter act the symptoms of their disease without taking synthetic drugs oftentimes with harsh side effects. In addition to their mobility and quality of life being compromised. Tickets are \$25 before the show and \$30 at the door. Proceeds will be donated to Sickle Cell Thalassemia Patients Network located at 1139 St. Johns Place Brooklyn, NY11213. For more information on the fashion show, please 347-533-8585. CONCLUSION New strategies are needed to enhance more awareness of Sickle Cell Disease among African & Hispanic Americans adults as well as bringing more attention to the alternative methods in efforts to fight aggressively and better treat the complications of this blood disorder which can provide patients with a better quality of life.