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President  
William E. Proudford Sickle Cell Fund, Inc.

Presentation to  
National Minority Quality Forum  
Leadership Summit and Spring Health Braintrust  
Adult Sickle Cell Satellite Meeting  

Washington D.C.  
April 25, 2017
Vision and Mission

• **Inspiration** – William E. Proudford

• **Vision** – a world without sickle cell disease

• **Mission** - To support sickle cell awareness, education, state-of-the-art treatment and research, and to bring hope to families affected by this devastating disease

• **Focus**: Awareness, Education
History and Background

• Established in 2005
• Witnessed first-hand the difficulty families face in getting proper treatment
• Held small fundraiser in Delaware
• All volunteer organization
• Board of Directors (6 people)
• Active in Maryland, Delaware and Washington, D.C.
Activities - artSPEAKS

• artSPEAKS™ –
  – Mechanism for giving sickle cell families a voice
  – Artwork used to educate the public
  – Model: Engagement, Education, Empowerment
  – Art on display at Johns Hopkins, duPont Hospital, Georgetown Hospital, Children’s National Medical Center
  – Sessions in Maryland, Delaware and Washington D.C.
  – Reached 500+ people annually
Activities – Annual Event

• Unsung Hero Awards
  – Honored broad group of stakeholders who have advanced sickle cell efforts as “Unsung Heroes”
  – Support awareness, advocacy and art programs
  – Support comprehensive care at Nemours duPont Hospital for Children, Sickle Cell Center for Adults at Johns Hopkins, Sinai Hospital
  – Raise visibility during National Sickle Cell Awareness Month
Sickle Cell
Northeast Regional Collaborative

• Sickle Improvement in the Northeast Region through Education (SiNERGe)

• 20+ Community Based Organizations in DE, DC, MD, NJ, NY, PA, VA, Virgin Islands
  – Webinar Series
  – Annual Meetings
  – Small Grants
  – Collaboration on advocacy efforts
Online Presence

• Website
  – Traffic
  • 2010 – 6,899 clicks; 651K impressions
  • 2016 – 57K clicks; 1.7M impressions

• Leveraging website to increase awareness, with emphasis on clinical trial participation
STRUGGLE CREATES ABILITY
What We’ve Learned

SEE PEOPLE

TREAT DISEASE
Awareness. Education. Hope.