



Advocacy Day 2020 Sponsor Prospectus

April 20-21, 2020



Greetings!

Dear Supporter and Friend of SCDA:

On behalf of the sickle cell community, we are pleased to extend greetings to all prospective participants of our 2020 Advocacy Day event to be held in Washington, DC from April 20-21, 2020 at the Kellogg Conference Hotel at Gallaudet University and on Capitol Hill.

For 48 years, Sickle Cell Disease Association of America, Inc. (SCDAA) and its member organizations have provided national leadership in building advocacy campaigns and increasing awareness of the impact of sickle cell disease (SCD) on the health, economic, social and educational well-being of the individual and their families. Our collective efforts have provided effective direction in positioning sickle cell disease and its related problems as a major public health care concern and a global problem.

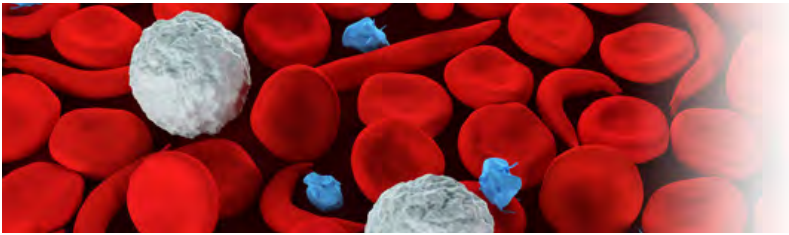
Advocacy Day plays a significant role in extending our outreach strategy to further engage elected officials on the multi-factorial aspects of sickle cell disease. Our two-day event brings together individuals representing our 46 chapters, affiliates and supporters representing 35 states from across the country to meet with Members of Congress and staff members, and to connect with one another. Participants will meet with their representatives or congressional staffers to share their stories about the impact of sickle cell disease on their lives and to advocate for key legislation that would address research funding, community health responses, and improved treatment options affecting the sickle cell community.

We invite you to join SCDA as a valued partner in building the next generation of leaders and advocates, as we work together for a sickle cell disease-free future. We look forward to your support and participation at our 2020 Advocacy Day!

Sincerely,



Beverley Francis-Gibson
President/CEO
Sickle Cell Disease Association of America, Inc.



What is Sickle Cell Disease (SCD)?

Sickle cell disease (SCD) is an inherited blood disorder which constitutes a global public health problem. At least 100,000 Americans live with the disease. Many more Americans - as many as 2.5 million - including 1 in 12 African-Americans, are carriers for Sickle Cell (also called sickle cell trait or SCT). SCD affects African Americans, Hispanics and is common among those whose ancestors come from sub-Saharan Africa; regions in the Western Hemisphere; Saudi Arabia, India; and Mediterranean countries.

SCD causes the destruction of red blood cells due to the presence of the abnormal hemoglobin S, resulting in anemia and vaso-occlusion (blocking of blood vessels by sticky and inflexible red blood cells).

Complications include early childhood death from infection, stroke in young children and adults, infection of the lungs similar to pneumonia, pulmonary hypertension, chronic damage to organs such as the kidney resulting in chronic kidney failure, and frequent severe painful episodes. These unpredictable, intermittent, devastating pain events can begin as early as six months of age and can span a lifetime, impacting school attendance and the work force.

While the physical aspects of SCD are formidable, advances in the reduction of morbidity and mortality have provided the opportunity for a person with the condition to experience a prolonged and improved life.

However, there remains a significant lack of progress in the broader public health and social issues of educational, vocational, support for personal, family and community relations, practitioner and public education and mental health aspects of the lives of these individuals. There is an emerging body of promising experimental and practice-based research that suggest improvements in the overall quality of life for persons with SCD and their families. However, the relative lack of resources for such efforts remains problematic.

Federal resources directed to surveillance, research, newborn screening, follow-up, and ongoing treatment strategies such as analgesics and the medication hydroxyurea have been key to recent advances in fighting SCD.



SCD affects an estimated 100,000 Americans



Individuals with SCD avg. 200,000 ER visits annually



Worldwide 300K+ infants are born with SCD per year



1,800- 2,000 infants are born with SCD each year in the US, primarily African American and Hispanic



People with the most severe form of SCD may have a 2-3 decade shorter life expectancy



65%-70% of those with SCD are classified as low income or economically disadvantaged



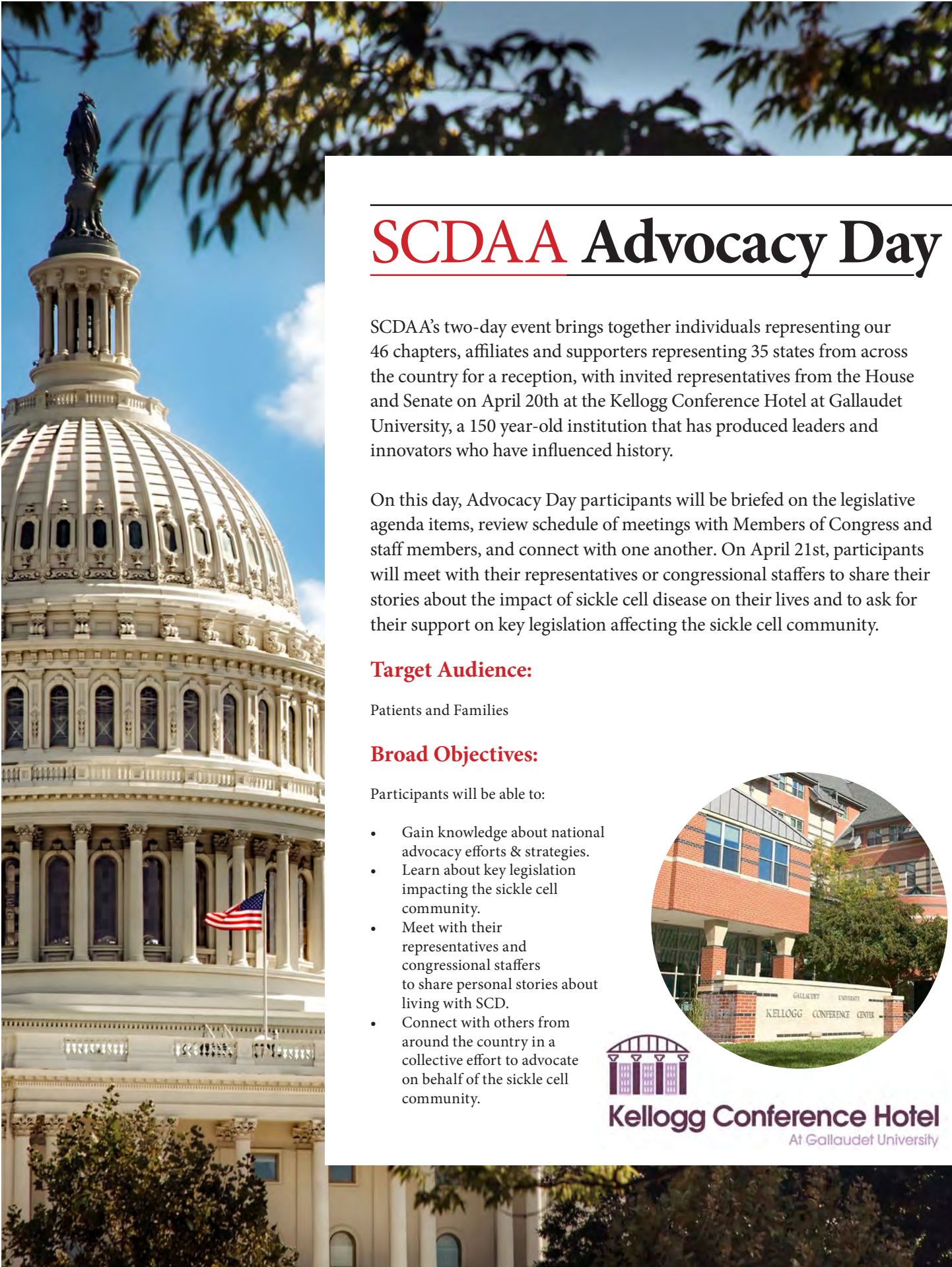
SCD patients experience 18K – 20K or more blood transfusions per year



20%-30% of children encounter stroke and cognitive impairment



Approx. 3 million people in the U.S. and 300 million worldwide are carriers



SCDAA Advocacy Day

SCDAA's two-day event brings together individuals representing our 46 chapters, affiliates and supporters representing 35 states from across the country for a reception, with invited representatives from the House and Senate on April 20th at the Kellogg Conference Hotel at Gallaudet University, a 150 year-old institution that has produced leaders and innovators who have influenced history.

On this day, Advocacy Day participants will be briefed on the legislative agenda items, review schedule of meetings with Members of Congress and staff members, and connect with one another. On April 21st, participants will meet with their representatives or congressional staffers to share their stories about the impact of sickle cell disease on their lives and to ask for their support on key legislation affecting the sickle cell community.

Target Audience:

Patients and Families

Broad Objectives:

Participants will be able to:

- Gain knowledge about national advocacy efforts & strategies.
- Learn about key legislation impacting the sickle cell community.
- Meet with their representatives and congressional staffers to share personal stories about living with SCD.
- Connect with others from around the country in a collective effort to advocate on behalf of the sickle cell community.



Kellogg Conference Hotel
At Gallaudet University



SCDAA Advocacy Day Sponsorship Package

As a SCDAA Advocacy Day partner, you have the unique opportunity to support sickle cell disease, SCDAA member organizations, and patients and families. As one of our partners, you will have the chance to connect with 46 member community-based organizations from across the country, meet individuals and their families and be a part of a national movement to advance key legislative issues important to the sickle cell community!

Please complete this form and send to SCDAA by March 15, 2020

CONTACT INFORMATION

Organization/Company Name _____

Primary Contact Name/ Title _____

Address _____

City/State/Zip _____

Phone Number _____

Email Address _____

SPONSOR LEVEL: \$10,000

METHODS OF PAYMENT

CREDIT CARD

Please charge my credit card in the amount of \$ _____

Visa Mastercard American Express Discover

Credit Card Number _____

Expiration Date _____

CHECK

Enclosed is my check made payable to SCDAA for the amount of \$ _____

Check Issuer Name / Signature _____

Please send completed form along with a high-resolution logo of your company to:

MAILING ADDRESS:

Sickle Cell Disease Association of America, Inc.
ATTN: Beverley Francis-Gibson
7240 Parkway Drive, Suite 180, Hanover, MD 21076

410.528.1555 • BFrancis-Gibson@sicklecelldisease.org



SCDAA Advocacy Day Sponsorship Package Benefits

Below is a brief description of the sponsor level and benefits that our partners will have access to in return for their generosity!

- Sponsorship recognition announced during Advocacy Day reception
- Prominent signage at Advocacy Day reception
- *Logo placed on Advocacy Day promotional materials to include, but not limited to:
 - o Advocacy Legislative Briefing
 - o Press releases
 - o Website
 - o Social media
 - o Eblast
- Speaking opportunity at Advocacy Day reception

*Logo must be high-resolution and sent along with application to BFrancis-Gibson@sicklecelldisease.org

Sickle Cell Disease Association of America, Inc. is a 501(c)(3) nonprofit organization. Donations to this organization are tax deductible to the fullest extent allowed by law. A copy of our current financial statement is available upon request by contacting the Sickle Cell Disease Association of America, Inc. at 7240 Parkway Drive, Suite 180, Hanover, MD 21076. Documents and information submitted to the State of Maryland Charitable Solicitations Act are available from the Office of the Secretary of State for the cost of copying and postage.