



47th ANNUAL NATIONAL CONVENTION

October 9-12, 2019
Baltimore, MD



**SICKLE CELL COMMUNITY
EMBRACING CHANGE TOGETHER**



Kyle



Tiahna



Amiya

Pfizer is proud to support

THE SCDA 47TH ANNUAL NATIONAL CONVENTION

Sickle cell disease (SCD) is the most common rare inherited blood disorder in the United States affecting nearly 100,000 Americans. Greater education and improved treatment options are desperately needed.

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04	President Greeting
05	Chairman Greeting
06	Chief Medical Officer Greeting
07	Congressman Cummings Welcome
08	MD Health Secretary Neall Welcome
09	SCDAA Board of Directors
11	Who We Are
12	National Child Ambassador
14	Celebrity Ambassadors
17	National Highlights
20	Access to Care
21	Lonzie Lee Symposium
23	Whitten and Reid Honor Lectures
26	SCDAA Chapters
29	Chapters in the Fight
42	Awards
44	SCD Advocate
45	Unity Soiree
46	We Believe
47	Sponsor/Exhibitors
48	Convention Committees



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Our Mission

To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

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Welcome to SCDAA's 47th Annual Convention!



Thank you for joining us for this year's event "Sickle Cell Community Embracing Change Together" with our Board of Directors, Community-based member organizations, staff and supporters.

I want to personally welcome you back to Charm City, which is a perfect backdrop for both work and play. The Renaissance Baltimore Harborplace Hotel offers an exceptional hotel experience along the waterways of Baltimore's Inner Harbor. It stands to offer a blend of urban luxury and local charm and is the perfect convention destination. This week you will be able to participate in inspiring and educational workshops, but you will also be mere steps from exciting museums, historic landmarks and attractions including the National Aquarium, Reginald F. Lewis Museum, Horseshoe Casino and a host of restaurants!

Once again SCDAA has organized an outstanding agenda with the hope it will quench your educational thirst. I would like to personally thank all of our presenters, panelists and speakers for their willingness and participation in making this experience a success! I would like to express my special gratitude to Dr. Marie Russell and Dr. Amanda Brandow, our keynote speakers this year. I am certain you will walk away inspired after listening to these amazing speakers. We anticipate having a great time at the Unity Soiree on Friday evening—so come ready to dance to Caribbean music while feasting on Caribbean delights and then we round out the Convention on Saturday with our popular Lonzie Lee Symposium.

I cannot express how proud I am of the work the SCDAA team has done this year and the planning by our Convention Planning Committee to ensure your experience is both rewarding and productive. Together, we will show the world that united, we can and will move forward in providing quality service, treatment, and programs for those living with and affected by sickle cell disease and trait. Your presence and support are always greatly appreciated.

Again, on behalf of the Board of Directors, staff and members of SCDAA, thank you for joining us for what I anticipate will be the best convention yet. Furthermore, thank you for supporting us as we continue to make a difference in the lives of those individuals and their families affected by sickle cell disease and the many communities serving and advocating on their behalf.

Sincerely,

Beverley Francis-Gibson

Beverley Francis-Gibson
President & C.E.O.



Chairman's Greeting



Welcome to the Sickle Cell Disease Association of America's (SCDAA's) 47th Annual National Convention. On behalf of the Board, I extend our heartfelt greetings to all of you. Thank you for joining us in what will surely be a productive week of dynamic forums for education, research, learning, community, and fun!

SCDAA's 47th National Convention, our signature event of the year, is themed: 'Sickle Cell Community Embracing Change Together,' which recognizes the strength of our Sickle Cell Stakeholder Community. It is about teamwork to support one another, to learn

about new advances, to find and give inspiration, and, of course, to enjoy each other in the process. I want to recognize the hard work that has gone into the quality planning of this convention by **Dr. Biree Andemariam** and **Dr. Lewis Hsu**, our Convention Committee Program Co-Chairs, together with SCDAA National Staff, Sponsors, our member organizations, and all of the wonderful and dedicated volunteers. If you happen to see any of these folks, please share your appreciation as well.

We're proud to celebrate the launch of coreSCD, an alliance between Green Park Collaborative and SCDAA to develop consensus on critical outcomes in sickle cell disease clinical research. In addition, SCDAA together with Sickle Cell Foundation of Georgia, Inc is partnering with the American Red Cross to host 100 blood drives across the country throughout the year. There are also a number of new media partners (Ebony Magazine, Emerge Woman Magazine, Monarch Magazine, BLACKDOCTOR.org, and African Sickle Cell News & World Report) helping to raise awareness this year about Sickle Cell Disease and Sickle Cell Trait. All of this is in addition to SCDAA and our Sub-Awardee's successful implementation of a Health Resources & Services Administration (HRSA) Grant, aimed at making a material impact in selected Sickle Cell Disease (SCD) communities through the partnership between SCDAA and the HRSA Grant Sub Awardees. We've partnered on engaging community members to train Community Health Workers (CHW) across the country, assisting people with SCD to find medical homes, and engaging in many other support services to improve the quality of life for those affected by SCD.

On behalf of the Sickle Cell Disease Association of America, Inc., including our Board of Directors, our staff, our partners, sponsors, and volunteers, thank you for your continued dedication and work towards bringing greater education and awareness to the world surrounding this life impacting illness.

Sincerely,

David N. Braxton

David N. Braxton
Chairman, Board of Directors

Chief Medical Officer's Greeting



Welcome to the 47th annual SCDA convention! I have had the privilege of serving as convention program chair once again and am confident that this will still be the best convention ever!

Our convention planning committee has been hard at work all year to insure we still honor our pledge to provide something for everyone. We have an outstanding cadre of individuals living with sickle cell disease, advocates, caregivers, nurses, social workers, psychologists, physicians, researchers, industry leaders and national partners who will provide the most up-to-date information on

the ongoing multi-dimensional advances in sickle cell disease.

We have scores of individuals who have volunteered their time to help us make this convention another success. We are fortunate to have individuals in attendance from all over the country and all over the world, truly representative of the global nature of sickle cell. I hope that every single attendee will feel, as they head home from the convention, that they learned something new, embody a renewed sense of hope and commitment, and identified at least one new friend. For it is only armed with knowledge, passion, hope and a very large family of committed individuals that we can truly move our mission forward as a community.

We are living at the dawn of a new day as dozens of new therapies for sickle cell disease are under discovery and it is quite conceivable that by next year's convention, we will have new treatments approved for use.

I thank all the individuals and caregivers who agreed to take part in clinical trials to find new therapies for sickle cell disease. Without you, new drugs and treatment strategies could never be developed. Your sacrifice, faith, and deep-rooted trust will never be forgotten.

I would also like to thank all of our sponsors. Your generosity is deeply appreciated and represents a clear commitment on your part to help the community move forward toward better days that are brighter, less painful, more fulfilling, healthy, and not needlessly foreshortened. I hope you each experience a fantastic three days and that you keep returning every year having brought at least one new person with you! Enjoy!

Sincerely,

Biree Andemariam, MD

Biree Andemariam, MD
Chief Medical Officer





HOUSE OF REPRESENTATIVES
WASHINGTON, D.C. 20515

ELIJAH E. CUMMINGS
SEVENTH DISTRICT
MARYLAND

October 9, 2019

Dear Friends:

I am writing to welcome you to the Sickle Cell Disease Association of America, Inc.'s 47th Annual National Convention, held here in downtown Baltimore's beautiful Inner Harbor. This year's theme: "Sickle Cell Community Embracing Change Together" speaks to the challenges, successes, and undaunted spirit exuded by the Sickle Cell Community.

Sickle cell disease is the most common inherited blood disorder affecting more than 100,000 individuals in the U.S. — the majority of them African-Americans — and millions more worldwide. It is a painful, debilitating disease that can impact every organ system in the body and has historically been very difficult to treat.

The Sickle Cell Disease Association of America, Inc. (SCDAA) is a national nonprofit whose mission is to advocate for people affected by sickle cell disease and empower community-based organizations to maximize quality of life and raise public awareness while advancing the search for a universal cure.

Formed in 1971, SCDAA is tireless in its pursuit to provide a national coordinated approach to address all issues related to sickle cell disease. Headquartered here in Maryland, SCDAA works with its 46 affiliated chapters across the country to meet the many challenges of sickle cell disease.

As you connect with others afflicted with this devastating disease as well as colleagues, it is my hope that this convention helps expand your knowledge base and inspires you with its focus on providing an essential forum for education, learning, and community involvement.

I commend the Sickle Cell Disease Association of America, Inc. for its dedication and continued hard work, and I thank all of you for your efforts and commitment to support one another.

Congratulations on hosting the Sickle Cell Disease Association of America, Inc.'s 47th Annual National Convention.

Sincerely,

Elijah Cummings
Member of Congress



MARYLAND
Department of Health

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Robert R. Neall, Secretary

October 9, 2019

Dear Convention Participants,

Welcome to Maryland and the 47th Annual National Convention of the Sickle Cell Disease Association of America, Inc. This year's convention theme, "Sickle Cell Community Embracing Change Together," is exactly the spirit needed to support individuals affected with Sickle Cell Disease and to advance the work toward achieving a universal cure.

The Sickle Cell Disease Association of America, Inc. (SCDAA) is a national nonprofit which advocates for people touched by this debilitating disease. SCDAA educates individuals, families, and caregivers, as well as the professional medical community, about Sickle Cell Disease and Sickle Cell Trait. It works with 46 member chapters across the country to raise public awareness, lengthen quality of life, and aid research for treatment options and ultimately to find a cure.

Affecting millions of people worldwide and more than 100,000 people in the United States, Sickle Cell is a crippling, inherited blood disorder for which, currently, there is no cure.

This Convention provides a great opportunity for the Sickle Cell Community to come together, learn the latest medical information, and offer support and comfort to those suffering from Sickle Cell Disease. And just as important, it provides a forum for every stakeholder in the battle against Sickle Cell disease to be heard!

To the Sickle Cell Disease Association of America, Inc., I want to offer my thanks for all the hard work you do, both here at the National Convention and all year long.

Sincerely,

Robert R. Neall
Maryland Secretary of Health

MEET OUR BOARD OF DIRECTORS



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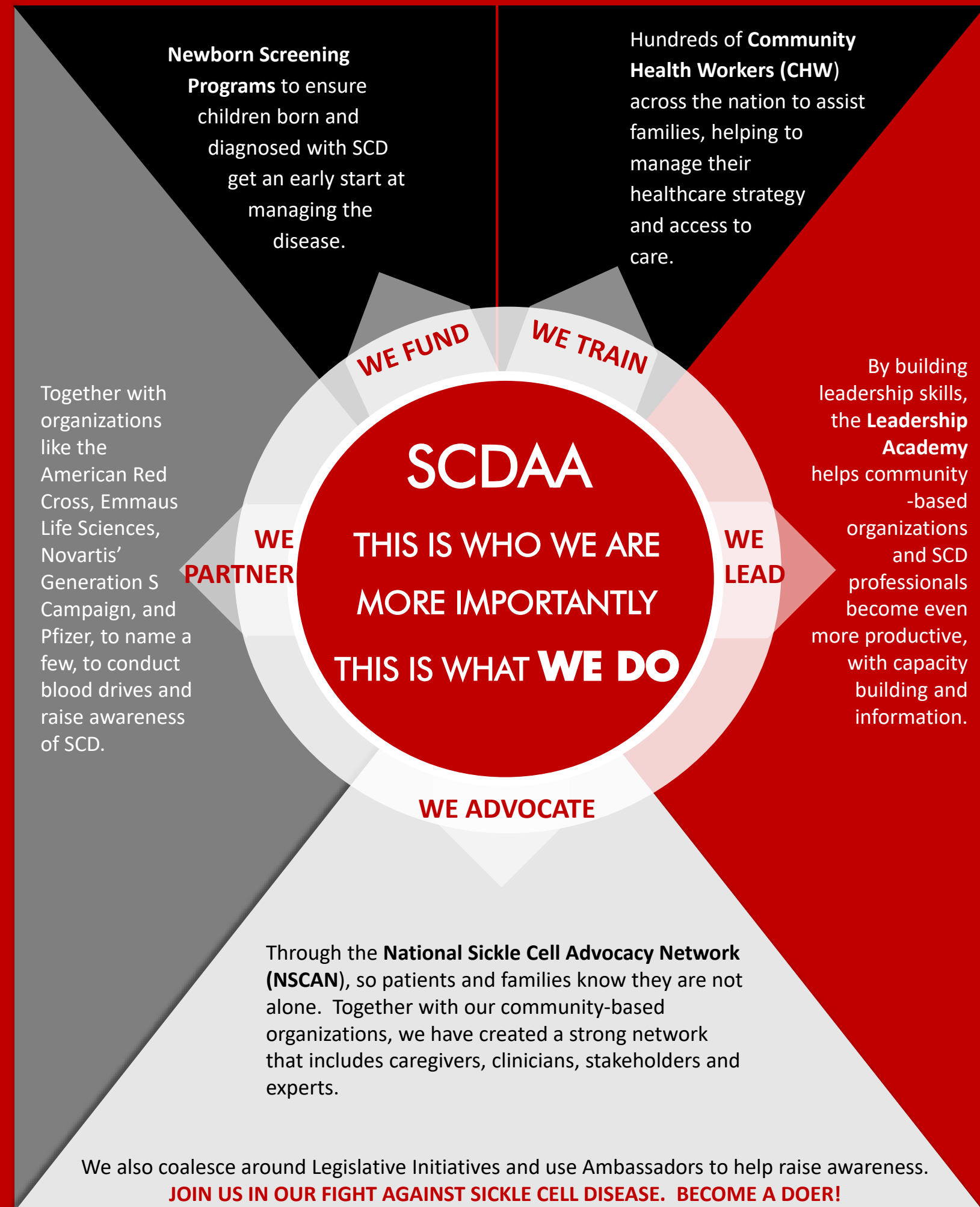


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National Child Ambassador **Kiarra ROSEBURGH**

"I may have sickle cell, but sickle cell does not have me."



It's clear why Kiarra Roseburgh, SCDA's National Child Ambassador for the second year in a row, is so tough. She's had to be, as her motto reflects. Only 10 years old, Kiarra is talented and tireless in a role forced upon her by genetics.

Yet, it has given the Sickle Cell Community a powerful advocate in tiny Kiarra. "Having sickle cell has never been a disadvantage for me," says Kiarra. "It actually has helped me become one with the most important factor of my life – my body. I am fortunate because my health has been stable allowing me to accomplish everything I set out to do at this point."

This year, Kiarra was able to join her school's basketball team and be an AAA School Safety Patrol, all while maintaining good grades. She graduated from two modeling schools and became part of an "amazing hip hop dance team where I found out that my teacher has sickle cell disease, as well."



More recently, Kiarra is doing well with yoga and breathing exercises, which are "helping tremendously," say her grandparents, Tanique and Robert Mitchell.

"In the first few weeks after Kiarra's diagnosis, our family's schedules and routines got turned inside out. No one is ever prepared to hear that their (grand) child has a life-threatening illness," they say, but note that parents have many things they can do to help children with Sickle Cell Disease (SCD) overcome their challenges.

"It is very important to make sure you get the support you need first, because when you're looking after a child with SCD, taking care of yourself is not a luxury or an act of selfishness—it's a necessity. Being emotionally strong allows you to be the best parent you can be to your child in need."

If your child has been diagnosed with SCD, there is no right or wrong feelings, they've learned. "Some parents have trouble believing that this is happening. We cried... a lot! But our main focus was on:

- making treatment decisions;
- using support from social workers, nurses, psychologists, and doctors;
- leaning on family members and friends;
- using and/or learning strategies to reduce anxiety, such as exercising and listening to music;
- finding strength in religious beliefs by speaking with our pastor;
- taking care of and teaching Kiarra to eat right, get rest, and take lots of breaks.

Something that doesn't get talked about enough is "expressing anger in a healthy way." The Mitchells find a private space to vent their feelings. Sometimes they shout, sometimes it's a scream, and other times they just break down and cry. "I have done those 3 a lot," says Tanique Mitchell.

What also helps, they say, is talking with other parents of children with SCD, listening to what Kiarra and other children like her say about changes in their bodies, and lastly, learning all you can about treatment. "This is what helps us!!" It's what they call, "creating the new normal."

For Kiarra, "Having sickle cell has motivated me to do my best. Why? Because, I see so many warriors doing their best to show me that I can do my best also."



**MY
DREAMS
WILL NOT
BE STOPPED
BY SICKLE
CELL.**

Come learn more
at the GBT booth or at
SICKLECELLSPEAKS.COM



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“Keep going, don’t ever give up. Everything you dream of will come to you.”



London Knight, famous fashion model, knows what it’s like to live with sickle cell disease (SCD). Diagnosed at three months of age, it’s been a constant presence, but one she faces head on each and every day. It’s why she volunteers in children’s hospitals, to show young people how to become sickle cell warriors, like her. “Keep going, don’t ever give up,” says London. “Everything you dream of will come to you.”

That’s a mantra London follows, becoming a successful model and gracing the pages of such magazines as Elle, Cosmopolitan, Glamour, and Marie Claire; as well as international runways; commercials and movies.

While the latest medical treatments get most of the attention in the SCD Community, and deservedly so, London also advocates for SCD warriors to get tough, mentally.

Most of the difficulties London has experienced with having sickle cell, she says, directly relates to her mental health. “I think it’s important to keep a positive outlook on dealing with sickle cell disease,” she says. “Only those of us living with sickle cell disease know the true pain and mental strengths it takes to be a sickle cell warrior.”

As a SCDAAs Celebrity Ambassador, London is committed to increasing awareness about sickle cell disease and to giving kids and young adults, just like her, a voice. “God has a plan for you,” she says. “And having sickle cell shouldn’t give you doubt. It should be the thing that drives you. God has chosen you as one of the stronger soldiers to teach compassion and love because you never know what other people are going through!”

“I believe in giving back ... and using my platform to engage a broad audience in how others can get involved...”



Dexter Darden was already singing in the church choir when he was just three years old. Talent stands out, and in Dexter’s case, his gifts were recognized by none other than the late actor, Paul Newman. Dexter performed in star-studded galas and Broadway shows to raise money for children with blood diseases and cancer. The rest, as they say, is history, thanks to Newman’s faith in Dexter and his own hard work.

You might recognize Dexter from the series of Maze Runner movies, among other notable films.

Honoring Newman, “I believe in giving back,” he says, providing the kind of encouragement that he received. In addition to becoming a

Celebrity Ambassador for the Sickle Cell Association of America, Inc. (SCDAA), Dexter is actively involved with the Sickle Cell Anemia Foundation, Children’s Hospital of Philadelphia, The Hole in the Wall Gang Camp, The Ranfurly Home Orphanage, The Boys and Girls, and The Heart Foundation.

The talented actor has been an advocate for the sickle cell community for several years, participating in SCDAAs Annual National Convention co-hosting the Lonzie Lee Jones Symposium.

“I am honored to serve as an ambassador for SCDAAs and to assist them in their mission to increase awareness about this life-threatening disease,” says Dexter. “I look forward to using my platform to engage a broad audience about how others can get involved in our worthy cause to make a difference in the lives of those affected by SCD.”

A CLINICAL STUDY

STRONG
SCD

SICKLE CELL DISEASE

WON'T STOP ME.



I AM STRONG.

That's why I am learning about the STRONG SCD study. It's evaluating an oral investigational drug for treating sickle cell disease (SCD). Researchers believe it may be able to reduce SCD complications, including pain crises.

All participants receive, at no cost:

Investigational Drug or Placebo

Study-related Care

Visits with the Study Doctor

Participants may be reimbursed for their time and travel.

To see if the STRONG SCD study may be an option for you, speak with our staff.

iamStrongSCD.com

AWARD

Sickle Cell Disease Association of America, Inc. (SCDAA) President and CEO Beverley Francis-Gibson honored with an award recognizing her contributions to the sickle cell disease community from the National Association of Real Estate Brokers.

“I am very excited to be honored for my work in the community,” Francis-Gibson said. “Individuals suffering from sickle cell disease (SCD) and sickle cell trait (SCT) rely on community leaders to support and advocate for them. The NAREB understands how important it is to be the voice of sickle cell patients, which is why this award means so much to me.”

8th ANNUAL SCD THERAPEUTICS CONFERENCE

As part of National Sickle Cell Awareness Month, Global Blood Therapeutics (GBT) together with Sickle Cell Disease Association of America, Inc. (SCDAA) hosted the 8th Annual SCD Therapeutics Conference in Washington DC, with U.S. Representative Robin Kelly, chair of the Congressional Black Caucus Health Braintrust, delivering the keynote address.



SCDAA President Beverley Francis-Gibson moderated as patient advocates, healthcare providers and policy makers gathered to discuss the latest advances and future trends for treating patients with sickle cell disease. The program featured panel discussions, some led by SCDAA’s Chief Medical Officer, Dr. Biree Andemariam, and presentations from leading members of the SCD Community on a range of issues and topics, including the impact of SCD on the brain and cognitive function and hot topics in SCD from the perspective of patients and caregivers.

SCDAA MOVES INTO NEW NATIONAL HEADQUARTERS










Hosting an Open House, SCDAA welcomed community based organizations, patients, colleagues, office neighbors and others to its brand new headquarters in Hanover, MD.

SICKLE CELL SATURDAY HIGHLIGHTS VALUE OF CLINICAL TRIALS

The Sickle Cell Foundation of Georgia, Inc. and SCDAA, Inc. hosted a special luncheon for the SCD community. Called Sickle Cell Saturday, the day featured presentations by SCDAA President and CEO Beverley Francis-Gibson; Dr. Milford W. Greene, Director of Health and Clinical Services at the Sickle Cell Foundation of Georgia; and a Clinical Principal Investigator from Children’s Healthcare of Atlanta. The theme of the luncheon was Working for Solutions: The Value of Clinical Trials to the SCD Community.

National Highlights, cont'd

NEW SCDAA MEDIA PARTNERS

				
African Sickle Cell News & World Report	BLACKDOCTOR.org	Monarch Magazine	Ebony Magazine	EMERGE Woman Magazine

NEW STRATEGIC PARTNERS



SCDAA Partners with The Pain Community to support the Sickle Cell Community by providing comprehensive integrative pain management educational information and wellness to support individuals living with sickle cell disease (SCD) and their family members. The partnership will use digital platforms and other collateral to share important resources and to engage those affected by SCD in achieving better health and wellness in partnership with their healthcare providers.



Sickle Cell Disease Association of America, Inc., the Sickle Cell Foundation of Georgia, Inc., and the American Red Cross partner on national blood drives initiative to host 100 blood drives across the country.

AWARENESS CAMPAIGNS



In partnership with community organizations, Global Blood Therapeutics (GBT) is directing a national campaign to raising awareness and understanding of sickle cell disease, including among health professionals focused largely on pain crises, with the goal of patient care.

Called Sickle Cell Speaks, the campaign highlights diverse stories told by patients, caregivers, friends, and family to educate others, and to help eradicate disease stigmas. SCDAA President Francis Gibson and Mapillar Dahn completed 22 radio and television interviews to promote this campaign. At least 10 of the 22 interviews have reached an estimated 16 million viewers, to date.

WORLD SICKLE CELL AWARENESS DAY 10TH ANNIVERSARY



In partnership with SinERGE, SCDAA launched the “Shine the Light on Sickle Cell” Campaign in celebration of the 10th Anniversary of World Sickle Cell Awareness Day. Collaborating with sickle cell advocacy groups, community-based organizations, hospitals, governments and other key stakeholders in the sickle cell community, Shine the Light on Sickle Cell is a 24-hour awareness campaign to celebrate the 10th anniversary on June 19, 2019.

Designated by the United Nations as World Sickle Cell Awareness Day, the international awareness day is observed annually with the goal to increase public knowledge and an understanding of sickle cell disease (SCD) and sickle cell trait (SCT), and the challenges experienced by patients and their families and caregivers. It is a day of unity and purpose.

6TH ANNUAL WALK WITH THE STARS



Each year, we have organizations take part in this event that want to share information with our walk participants and their friends and families. We want to thank Medunik, Global Blood Therapeutics and the Maryland Sickle Cell Disease Association for joining us at our event.

SPONSOR SHOUT-OUT

SCDAA thanks our sponsors for their ongoing support of the work we do and for their commitment to the sickle cell community! The 2019 Walk with the Stars sponsors include Pfizer, Novartis, Sanofi Genzyme, Global Blood Therapeutics, Wegmans and Giant!

The event celebrates movement in any form, whether it's walking, running or jumping rope.

Walk With the Stars, SCDAA's second largest event, has raised more than \$500,000 since its inception. Funds support the work SCDAA does both at its Baltimore headquarters and at chapters across the nation, providing direct services, information and referrals.

ADVOCACY



SCDAA Joins Alliance to Fight the 40 | Don't Tax My Health Care National Family, Patient, Public Sector, and Multi-employer Groups Join Effort to Protect Health Care Coverage



Launch of coreSCD
Green Park Collaborative and Sickle Cell Disease Association of America, Inc. launch coreSCD to develop consensus on critical outcomes in Sickle Cell Disease Clinical Research.

ADVOCACY DAY

SCDAA hosted its Annual Advocacy Day in Washington DC with more than 200 in attendance, representing SCD patients/caregivers and supporters from 18 states.

LEGISLATION

The President signs the Sickle Cell Treatment Act of 2018 into law on December 18, 2018.

MAKING HEALTH CARE MORE ACCESSIBLE, AFFORDABLE, AND REPRESENTATIVE



For Congresswoman Robin Kelly (D-IL), healthcare is at a critical focal point, one where everyone needs to strategize the most effective path forward.

Each year, more than 2,000 babies are born with Sickle Cell Disease, said Kelly, speaking at the GBT Therapeutics Conference in Washington, DC and hosted by the Sickle Cell Disease Association of America, Inc. (SCDAA).

Worse, 4 million live with Sickle Cell Trait. “That’s 2 percent of the population or 1 in 12 African Americans. The challenge of addressing sickle cell disease is large.”

She called Sickle Cell Disease one of the most “underfunded and under researched genetic diseases” of our time. The reasons are many, but mostly, she said, due to the low level of private and foundation funding; the low level of African American researchers in the biomedical community; and just plain “lack of interest.”

This is a disease that disproportionately impacts African Americans and other people of color because there is less money for research, not a lot of disease awareness, and a lack of faith in the healthcare system.

Of the top ten killer diseases in America, African Americans die from 8 of them, and in disproportionately higher rates than their white counterparts. “We’re talking about heart disease and stroke, HIV Aids, Diabetes, and Maternity Mortality.”

“We need to make health care more accessible, more affordable, and more representative,” said Kelly, who serves on multiple health committees of the Congressional Black Caucus (CBC).

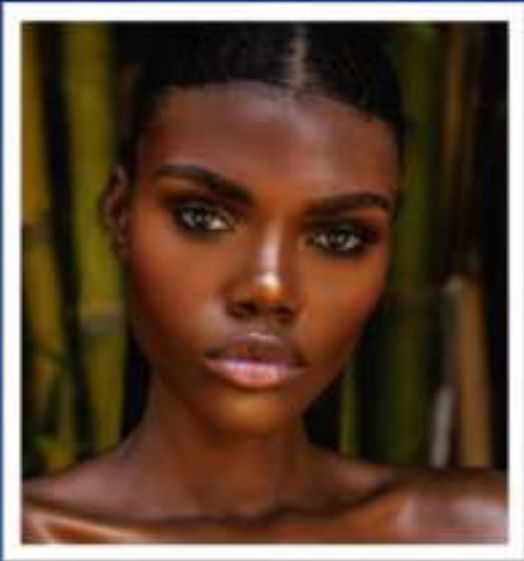
The CBC, together with the Congressional Hispanic and Asian-Pacific Caucuses, are looking to pass the Health Equity and Accountability Act (HEAA) which is based on the success of the Affordable Care Act.

But make no mistake, she warns. This is not an opportunity to pit one group against another. “We have a broken system that needs systemic reform. There is strength when we stand, shoulder to shoulder, together. There is more power when we all speak with one voice to create a better world for all.”

This is a collective victory, inspiring us to go further. Quoting Frederick Douglas, Kelly said: “Power concedes nothing without demand. Well, we are demanding.”

LONZIE LEE JONES

PATIENT ADVOCACY SYMPOSIUM



London Knight

Co-Hosts



Dexter Darden

Moderator



Kiarra Roseburgh

Enjoy this year’s forum, where we again borrow a format from the popular TV show “Family Feud.” Get inspired as our wonderful panelists share their stories.

Thanks go to our participants who represent our broad and diverse SCD community, and we thank our moderator and co-hosts for joining us to facilitate the discussion.



Vertex and CRISPR are proud to support the **Sickle Cell Disease Association of America's National Annual Convention**



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Honor Lectures

HONOR LECTURES - CHARLES F. WHITTEN, MD & CLARICE D. REID, MD

The Charles F. Whitten MD and Clarice D. Reid MD lectures are given annually at SCDAA's National Convention.

Their collective careers represent over a century of involvement in the research, education, clinical care, program and policy development, and advocacy of sickle cell disease.

Their combined legacies continue to provide inspiration to countless scientists and clinicians, as well as community and public health practitioners.

The Sickle Cell Disease Association of America, Inc. honors them by honoring others, in their name, who have made significant contributions to the sickle cell community.



Charles F. Whitten, MD, was the Co-founder and President Emeritus of the Sickle Cell Disease Association of America, Inc. His dedication and commitment to the Association and to those with sickle cell disease will be forever respected and cherished.

As a Pediatric Hematologist, Whitten was among the first to develop and insist on newborn screening for sickle cell disease, which is not performed worldwide. In 1974, he formed the Sickle Cell Detection and Information Center in Detroit, MI, the most comprehensive community program in the country. He also created color-coded "Whitten Dice" to educate couples about the genetic risks of having children with sickle cell disease.

It was 47-years ago when Dr. Clarice D. Reid, MD, began her impressive federal career at the Health Services and Mental Health Administration (HSMHA) in 1972, working with the newly established Sickle Cell Screening and Education Clinics.

As Deputy Director, she emphasized the importance of community programs in addressing national and local issues related to sickle cell disease and was instrumental in unifying the community service-oriented programs with the clinical and basic research programs at the National Institutes of Health (NIH).

The Director of the NHLBI/NIH recruited Dr. Reid on a detail from HSMHA to serve as Acting Chief of the Sickle Cell Disease branch. In 1976, she was appointed Chief of the Branch and the coordinator of the National Sickle Cell Disease Program.





2019 CHARLES F. WHITTEN, MD MEMORIAL LECTURE

“The Study of the Microbiome in Sickle Cell Disease Pain.”

Dr. Amanda Brandow is specifically interested in developing better ways to assess and treat pain in children with sickle cell disease. She is Associate Professor of Pediatrics at the Medical College of Wisconsin in its hematology/oncology/bone marrow

transplantation section. She focuses on understanding the pathophysiology of acute and chronic pain in children and adults living with sickle cell disease.

Dr. Brandow is an active advocate for comprehensive pain management for individuals living with sickle cell disease at the national level. She served on the US Department of Health and Human Services Pain Management Best Practices Inter-Agency Task Force and currently serves as Chair of the American Society of Hematology Evidence Based Sickle Cell Disease Management Guidelines for Acute and Chronic Pain.

“I went into medicine with the draw of not only being able to take care of patients, but the entire family, – from the delivery of a diagnosis right through treatment – which is really gratifying for me on a personal as well as professional level. “

Dr. Brandow is committed to and enjoys teaching medical students, residents, and fellows, helping them learn how to provide comprehensive and compassionate care to their patients.



Patients and science are at the center of everything we do.

At Sanofi Genzyme, we are inspired to push scientific boundaries to develop specialty treatments for people with sickle cell disease and other rare blood disorders, providing hope to patients and their families.



2019 CLARICE D. REID, MD, MD MEMORIAL LECTURE

“The Case for Compassionate Comprehensive Care for Children and Adults with Sickle Cell Disease”

Dr. Marie Olivieri Russell graduated top of her medical class in 1970 with the highest cumulative GPA and was the first student to serve as a full voting member of the Board of Trustees at Jefferson Medical College.

Without uttering the first word, her resume speaks volumes. Following a residency in Pediatrics and a fellowship in Pediatric

Hematology Oncology at Children’s Hospital of Philadelphia (CHOP), Dr. Russell co-founded the Comprehensive Sickle Cell Program with Dr. Elias Schwartz at CHOP in 1975. She served as the program’s director there for six years.

During her tenure at CHOP, she completed a landmark study defining the arteriographic changes in children with sickle cell disease who had strokes and demonstrated the effectiveness of chronic transfusion therapy.

Dr. Russell also helped establish the Sickle Cell Parents Group of CHOP, which remains a powerful advocacy group.

Before she retired, leaving CHOP and academic medicine, Dr. Russell transitioned into Primary Care, where she co-founded a pediatric practice affiliated with a large community hospital. Her practice grew to include six physicians, and later became part of CHOP’s Primary Care Network.

Over the years she held faculty appointments at the University of Pennsylvania, Hahnemann Medical College, and Drexel University, while continuing to teach students and residents care for sickle cell patients, and offer satellite outpatient oncology services.

Retired in 2005, Dr. Russell is spending more time with her family.



SCDAA LOCAL CHAPTERS

Visit SickleCellDisease.org for more about Member Organizations



ALABAMA

- North Alabama Sickle Cell Foundation – Huntsville
- SCDA-West Alabama Chapter – Northport
- Central Alabama Sickle Cell Foundation – Birmingham
- SCDAA- Mobile Chapter, Inc.
- Sickle Cell Foundation of The River Region- Montgomery
- Southeast Alabama Sickle Cell Association, Inc.- Tuskegee

CALIFORNIA

- Cayenne Wellness

COLORADO

- Colorado Sickle Cell Association, Inc. – Denver

CONNECTICUT

- Citizens for Quality Sickle Cell Care, Inc.-New Britain/Hartford
- SCDAA Southern Connecticut, Inc.- Bridgeport/New Haven

DELAWARE

- Tova Community Health

FLORIDA

- SCDAA of Escambia & Santa Rosa Counties – Pensacola
- SCDAA- Dade County Chapter, Inc. – Miami
- SCDAA-St. Petersburg Chapter
- Sickle Cell Association of Hillsborough County
- Sickle Cell Disease Association of Florida, Inc.- Tampa, FL
- Sickle Cell Disease Association of Tri-County, Inc. – Orlando

FLORIDA

- Sickle Cell Foundation, Inc.- Tallahassee

GEORGIA

- Sickle Cell Foundation of Georgia, Inc.- Atlanta

ILLINOIS

- Sickle Cell Disease Association of Illinois – Chicago

INDIANA

- Martin Center, Inc. – Indianapolis

LOUISIANA

- Northeast Louisiana Sickle Cell Anemia Foundation – Monroe
- Southwest Louisiana Sickle Cell Anemia, Inc.- Lake Charles

MARYLAND

- Maryland Sickle Cell Disease Association, Inc. (MSCDA)
- Sickle Cell Disease Association of America, Inc.

MASSACHUSETTS

- Greater Boston Sickle Cell Disease Association, Inc.

MICHIGAN

- SCDAA Michigan – Detroit

MISSOURI

- Sickle Cell Association of St. Louis

NEVADA

- Nevada Childhood Cancer Foundation- Las Vegas

NEW JERSEY

- The Sickle Cell Association of New Jersey, Inc. – Newark

NEW MEXICO

- The Sickle Cell Council of New Mexico – Albuquerque

NEW YORK

- Falling Angels Sickle Cell Foundation
- Queens Sickle Cell Advocacy Network – Queens Village
- Sickle Cell Thalassemia Patients Network (SCTPN)

NORTH CAROLINA

- Bridges Pointe Sickle Cell Foundation – Durham
- Community Health Interventions and Sickle Cell Agency, Inc. – Fayetteville
- Piedmont Health Services and Sickle Cell Agency – Greensboro

OHIO

- SCDAA-Ohio Sickle Cell & Health Association – Columbus

OREGON

- Sickle Cell Anemia Foundation of Oregon – Portland

PENNSYLVANIA

- Children’s Sickle Cell Foundation, Inc.- Pittsburgh
- SCDAA-Philadelphia/Delaware Valley Chapter
- The South Central PA Sickle Cell Council – Harrisburg

SOUTH CAROLINA

- James R. Clark Memorial Sickle Cell Foundation – Columbia

TENNESSEE

- Sickle Cell Foundation of Tennessee – Memphis

TEXAS

- Sickle Cell Association of Houston
- Sickle Cell Association of Texas Marc Thomas Foundation

VIRGINIA

- Sickle Association Inc.- Norfolk

Sickle Cell Disease Association of America Inc.

We wish you much success as you search for a cure and educate those in need of help with this disease at your

47th Annual National Convention

From the Officers of

The Most Worshipful Price Hall Grand Lodge of Colorado and Its Jurisdiction



Most Worshipful Grand Master Edward J.A. Moore

Sickle Cell Foundation – Mobile, Alabama

The Sickle Cell Certification program was designed to train and certify sickle cell educators and counselors to:

- Provide education and counseling to individuals diagnosed with sickle cell disease and other related hemoglobinopathies.
- Offer education about these disorders to health care professionals, paraprofessionals, as well as to individuals directly affected by sickle cell disease and other interested audiences.

These photos are from the Spring 2019 training. It is held twice a year, in the Spring and in the Fall.





Tova Community Health – Delaware

Out in About

Community Engagement & Outreach



Sickle Cell Disease Association of St. Petersburg - Florida



Mary Murph, President/Founder of the Sickle Cell Disease Association St. Petersburg Chapter receiving donation from Alpha Kappa Alpha Sorority, Inc. Zeta Upsilon Omega Chapter of St. Petersburg, Florida on September 14th



Sickle Cell Foundation of Georgia, Inc.- Atlanta



Camp New Hope 2019



Actor Karon Riley, Celebrity Spokesperson



Sickle Cell Foundation - Illinois



Annual walk for sickle cell In Chicago and & Alton, IL in partnership with A Precious Organization.



SCDAI in the Media spreading sickle cell awareness/ education



Advocating for Sickle Cell Disease with Illinois Local officials, mayors, state representatives



40 Campers and their families taking one last photo prior to loading onto the Bus for Sickle Cell Summer Camp in partnership with NorthStar Reach.



Men Living Well With Sickle Cell Event (program established by the Sickle Cell Association of Houston) in partnership with Cyclorion & BDO (BlackDoctors.org)



Martin Center Sickle Cell Initiative - Indiana



Gary Gibson, President and CEO of the Martin Center Sickle Cell Initiative (MCSCI), has successfully worked with the Indiana State Legislature since 2013, leading to a tripling of the state's budget for Sickle Cell services, and, most recently, the 2019 House Bill 1354, which expands care and services for Sickle Cell patients in Indiana.

Louisiana

Shine the Light on Sickle Cell



Southwest Louisiana Sickle Cell Anemia, Inc. in Lake Charles, La, observed World Sickle Cell Day with a Gospel Musical at New Sunlight Baptist Church.

Along with this Gospel Musical, Governor John Bel Edwards approved red lighting at the Governor's Mansion and the City of Lake Charles lighted the Board du Lac Boardwalk red in recognition of World Sickle Cell Day.





SCDAA – Michigan Chapter

2019 Sickle Cell Walkathon



The Sickle Strong Empowerment Circle 1st Annual Balloon Release



The Uriel Owens Sickle Cell Disease Association of the Midwest - Missouri

Provides assistance to patients throughout the Metro area and participates in multiple awareness events during the year. Events included participation in two local fashion shows benefiting SCD, attending Rare Disease Week in Washington DC, attending the State of Missouri Advocacy Day, speaking on local radio stations, presenting to local businesses and a local NAACP, having monthly support group meetings, having a holiday party for SCD patients and their families, multiple health fair attendance, and patient mentoring!





The Sickle Cell Association of New Jersey



SCANJ's CHW/ Community Outreach Coordinator (Ms. Darlene Young) at a Health Fair



SCANJ's CHW/ Community Outreach Coordinator (Ms. Darlene Young) facilitating a Chronic Disease Self Management Peer Leader Training



SCANJ's 24/7 Line Dance Marathon Fundraiser



SCANJ's CHW/ Executive Assistant (Mrs. Sakiyyah Burwell -Darden) doing a Sickle Sabbath Presentation at a local faith based organization



SCANJ's "Movie Night under the Stars" Event



SCANJ's Holiday Program with Kenta Claus (Santa's Brother from another mother)



SCANJ's Founder/ Executive Director at the Health Equity Form in Passaic County, New Jersey



SCANJ's Garden Stroll in support of the SCDA's Walk with the Stars



Queens Sickle Cell Advocacy Network – New York



2019 Annual Scholarship Banquet



2019 Walkathon

Houston's Sickle Cell Association - Texas

Sickle Cell Association of Houston's President & Board Member Testify On Bill They Helped Author

On April 3, 2019, Tonya Prince, President of the Sickle Cell Association of Houston, together with Board Member and Advocate, Phillip Okwo, testified before the Health Committee on the importance of the passage of HB2576 and HB3405. The two provided passionate accounts of living with sickle cell disease and its overall impact on our communities at large. They attested to the prevalence of sickle cell disease in Texas and the lack of supportive infrastructure that would best meet the needs of the population.



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THE LIVES OF PATIENTS
WITH SEVERE GENETIC
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INTEGRATED PRODUCT PLATFORMS
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We are developing integrated product platforms encompassing gene therapy, cancer immunotherapy and gene editing – providing us with the potential to deliver transformative therapies to patients with serious diseases.

Please visit us at www.bluebirdbio.com to learn more.

Awards

2019 CHAMPION - DR. LAKIEA BAILEY



Dr. Lakiea Bailey is a sickle cell disease advocate, educator, and research scientist. Diagnosed with sickle cell disease at age three, she has become a passionate advocate for those living with rare diseases and is committed to serving as a voice

of encouragement and empowerment within the sickle cell community. Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. During the course of her education, Dr. Bailey was named a Southern Regional Education Board (SREB) Doctoral Scholar; was the recipient of multiple honors and awards, including the Fisher Scientific Award for Overall Excellence in Biomedical Research; the Medical College of Georgia Alumni Association Award; the Georgia Regents University Leadership Award; and was inducted in the Alpha Upsilon Phi honor society.

She believes that through hard work, diligence, patience and faith, even the seemingly most impossible obstacles can be overcome.

2019 CHAIRMAN'S AWARD - DR. BIREE ANDEMARIAM



Dr. Biree Andemariam is a hematologist and founding director of the New England Sickle Cell Institute (NESCI) at the University of Connecticut Health Center. Established in 2009, NESCI now serves nearly 300 adults living with sickle cell disease. With a staff of twelve, including nurses, social workers, patient navigators, and research assistants, NESCI provides comprehensive care, acute pain management, specialized blood transfusions, and a destination for children in Connecticut who have aged out of pediatric SCD care.

Dr. Andemariam's research focuses on developing new pathways of care that improve SCD care quality as well as translational research on deciphering the interplay between red blood cell adhesion to the walls of the circulatory system and the development of pain. She holds an undergraduate degree in molecular biology from Princeton University and a medical degree from Tufts. She is also the Chief Medical Officer of the Sickle Cell Disease Association of America, Inc.

"Everyone living with Sickle Cell Disease should have access to appropriate medical care and everyone should get involved. There's a role for everyone in the community to help advocate for better care for people living with SCD," she said during a summit on access to care.

"What's most exciting is finally seeing new therapies emerging in clinical trials and I'm really excited for our patients, because, for once, they're going to feel that they have options."

2019 PIONEER - DR. MARIE O. RUSSELL



The title of her lecture, 'The Case for Compassionate Comprehensive Care for Children and Adults with Sickle Cell Disease,' is but a glimpse into why Dr. Marie Olivier Russell is being awarded as a Sickle Cell Disease Association of America Pioneer.

Dr. Russell's lifetime achievements, such as co-founding the Comprehensive Sickle Cell Program with Dr. Elias Schwartz at Children's Hospital Of Philadelphia (CHOP) in 1975; serving as its Program Director for six years; and completing a landmark study defining arteriographic changes in children with sickle cell disease who had strokes and demonstrated the effectiveness of chronic transfusion therapy, are but a few of her amazing and significant contributions to the Sickle Cell Disease community.

Establishing the Sickle Cell Parents Group of CHOP, a powerful advocacy voice, and creating a thriving Primary Care practice which grew and later became part of CHOP's Primary Care Network continue to add to the community's wealth of information, care, and advocacy.

In addition to all of her other accolades, the Pioneer Award is in recognition of the admiration and respect Dr. Russell engenders from her peers and others in the Sickle Cell Disease community.

IN PROUD SUPPORT



The New England Sickle Cell Institute at UConn Health is a proud sponsor of the Sickle Cell Disease Association of America.

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DJ BY NIGHT, SICKLE CELL ADVOCATE ALL THE TIME

By day, or as he likes to put it, in his spare time, Marcus Queen is a Data Scientist. He works for Nielsen where he specializes in measuring Digital Advertising. By night, he transforms into SUPAFLY TNT, a DJ getting crowds to move, glide, and sway across the Mid-Atlantic region.

There's one other thing this native Marylander does: he's a committed advocate for people directly and indirectly affected by Sickle Cell Disease.

It didn't happen overnight. Like so many others, Queen had heard the term, sickle cell, knew it was something *not* good, but never really thought much about it, until it hit close to home.

One of his cousin's three children, Raymond, died from sickle cell disease. He was 4 years old. "I was in high school at the time," says Queen. "I had no idea how to relate to that."

Sometime later, Raymond's sister Elizabeth, 22, also died from this horrific genetic disease. Their baby brother Roland, now 20, "lives with it every day."

From the outside looking in, Queen says he feels helpless, "knowing they're in pain and there is no escaping it." While there are pain management treatments that sometime help, there's so much more on top of the medical aspects of the disease. It affects one's mentality and quality of life, he notes.

"I didn't step up for my cousins back then," says Queen, who now has three kids of his own. They don't have the disease or the trait. But, he is looking to advocate for his cousins and others impacted by sickle cell disease across the country.

To that end, he gives kudos to the Sickle Cell Disease Association of America. "SCDAA is great. They help to raise money and they're getting other people involved." But kudos goes to Queen and his family who were the #1 fundraiser this year for SCDAA's Annual Walk with the Stars.

SUPAFLY TNT will be showing off his smooth sounds during SCDAA's Unity Gala, a night of good food and good fun, and with a *Caribbean* theme at SCDAA's 47th Annual National Convention.



One of the most anticipated events of the 4-day convention - giving participants an authentic Caribbean experience - the Unity Gala, more importantly, supports the life-saving work of SCDAA.



Sickle Cell Disease Association of America, Inc.

Presents

20th Unity Soiree

**FRIDAY, OCTOBER 11
7:00 PM – 10:30 PM**

**One of SCDAA's
most exciting
events during its 4
day convention!**

**Help support the
life-saving work of
SCDAA while
enjoying the
ultimate authentic
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CARIBBEAN EXPERIENCE

ENTERTAINMENT

By

DJ SUPAFLY TNT

djsupaflytnt@gmail.com

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We Believe



Klarra Roseburgh
SCDAA National Child Ambassador

WHAT WE BELIEVE DRIVES WHAT WE DO

At SCDAA, we believe there will come a day when children born with sickle cell disease will live pain-free lives. We believe every adult battling sickle cell disease will LIVE to see their children (and grandchildren) prosper.

We believe...and because we believe, WE DO...

WE FUND

Newborn Screening Programs to ensure children diagnosed with SCD get an early start at controlling the disease

WE TRAIN

Thousands of Community Health Workers across the nation to assist families, helping to manage their healthcare strategy and access to care

WE HELP

Community-based organizations build their capacity to serve more people living with SCD

At SCDAA, we believe...and because we believe,

WE DO...

And, YOU CAN TOO!

Ways to Give

TEXT TO GIVE

You can make a minimum donation of \$50.00 to SCDAA instantly through your mobile device by texting code "BREAK" to 52000.

BIRTHDAY DONATION

Use social media to support your friends and family by going to our Facebook page. You can set up a birthday fundraiser so all your friends can make a donation in your name. Visit www.facebook.com/sicklecelldisease.

TRIBUTE/MEMORIAL DONATION

As a family member or friend, you can share the story of a loved one affected by sickle cell disease with your family and friends using our online tools. Through your own fundraising site, individuals can share their memories and also make a donation to help support SCDAA's mission.

LEGACY DONATION

A planned gift is a contribution that requires planning and offers opportunities for you to support SCDAA now, and in the future. Remembering SCDAA in planning for the future gives you the opportunity to leave a legacy in support of our mission. Consider a bequest, charitable annuity or other option.

For more information, please contact Sonia Perkins, Director of Development & Strategic Initiatives, at Sperkins@sicklecelldisease.org, or call 410-528-1555 or (toll free) 800-421-8453.

SCDAA
7240 Parkway Drive, Suite 180
Hanover, MD 21076
www.sicklecelldisease.org



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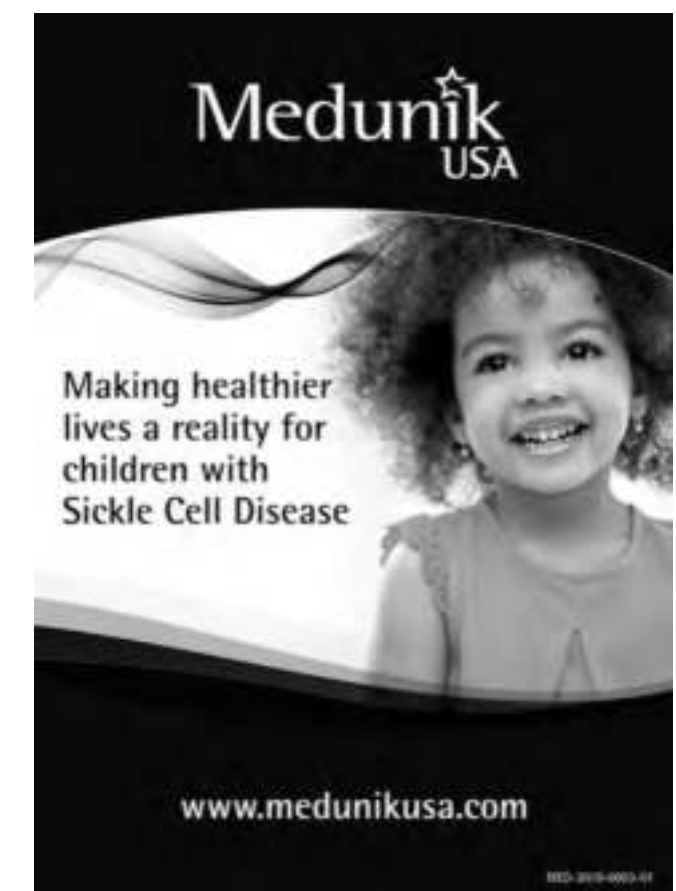
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Lewis Hsu, MD, PhD Convention Co-Chair

Committee Members

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Natasha Thomas
Sonia Perkins
Wanda Whitten-Shurney, MD
Kim Smith-Whitley, MD
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Lori E. Crosby, PsyD
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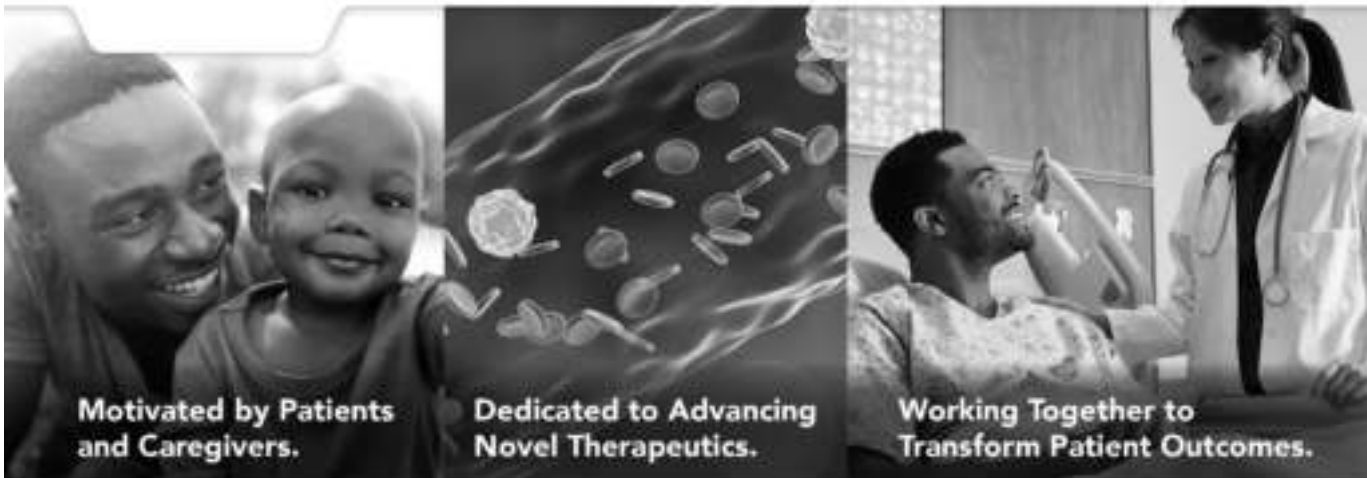
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Imara continues to advance IMR-687, a highly selective, potent small molecule PDE9 inhibitor that is being developed as an oral, once-a-day, potentially disease-modifying treatment for sickle cell disease (SCD) and beta thalassemia.

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Novartis proudly joins the Sickle Cell Disease Association of America as they celebrate their 47th Annual National Convention, Embracing Change Together.

Your dedication to helping patients with Sickle Cell is applauded.

At Novartis, our mission is to discover new ways to improve and extend people's lives. We use science-based innovation to address some of society's most challenging health care issues. We discover and develop breakthrough treatments and find new ways to deliver them to as many people as possible.

We are passionate about what we do and the impact we have on society, especially patients, including those living with Sickle Cell. We are Novartis, and we are reimagining medicine.





Sickle Cell Disease Association of America, Inc.

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410.528.1495 (fax)
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48TH ANNUAL NATIONAL CONVENTION

ORLANDO, FLORIDA

October 13 -17, 2020

ROSEN CENTRE

See you there!

SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2019 AND 2018

	<u>2019</u>	<u>2018</u>
<u>ASSETS</u>		
Current assets:		
Cash and equivalents	\$ 231,522	\$ 217,075
Accounts receivable	90,658	52,771
Grants receivable	177,568	174,452
Pledges receivable - current portion	55,274	49,653
Security deposits held	-	5,146
Investments	499,259	41,877
Prepaid expenses	4,205	1,530
Inventory	23,596	16,796
Total current assets	<u>1,082,082</u>	<u>559,300</u>
Other assets:		
Restricted cash and equivalents	214,832	213,144
Investments	-	456,517
Pledges receivable - non-current portion	73,876	65,819
Property and equipment, net	24,003	15,933
Security deposits held	4,574	4,574
Total other assets	<u>317,285</u>	<u>755,987</u>
Total assets	<u>\$ 1,399,367</u>	<u>\$ 1,315,287</u>
<u>LIABILITIES AND NET ASSETS</u>		
Current liabilities:		
Accounts payable and accrued expenses	\$ 294,356	\$ 350,386
Lines of credit	191,533	205,335
Refundable advances	98,321	9,542
Total current liabilities	<u>584,210</u>	<u>565,263</u>
Other liabilities:		
Refundable advances	35,493	97,849
Deferred rent	31,652	5,255
Total liabilities	<u>651,355</u>	<u>668,367</u>
Net assets:		
Without donor restrictions:		
Undesignated	689,921	560,456
With donor restrictions	58,091	86,464
Total net assets	<u>748,012</u>	<u>646,920</u>
Total liabilities and net assets	<u>\$ 1,399,367</u>	<u>\$ 1,315,287</u>

SEE NOTES TO THE FINANCIAL STATEMENTS

SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2019 (with 2018 totals for comparative purposes)

	2019			2018
	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	TOTAL	TOTAL
<u>OPERATING REVENUE AND SUPPORT</u>				
Federal grants	\$ 2,989,016	\$ -	\$ 2,989,016	\$ 2,856,887
Convention and special events	714,750		714,750	577,528
Contributions	464,257		464,257	754,635
Other grant income	25,000		25,000	9,616
Membership dues	15,775		15,775	22,000
Sales of educational materials	3,891		3,891	3,532
In-kind contributions	549		549	
Other revenue	19,956		19,956	2,914
Releases from purpose restrictions	28,373	(28,373)		
Total operating revenue and support	4,261,567	(28,373)	4,233,194	4,227,112
<u>OPERATING EXPENSES</u>				
Program services:				
HRSA	2,965,708		2,965,708	2,923,237
SCDAA	11,351		11,351	254,912
PCORI	-		-	43,112
Other programs	42,677		42,677	10,991
Total program services	3,019,736	-	3,019,736	3,232,252
Supporting services:				
General and administrative	880,176		880,176	684,519
Fundraising	313,742		313,742	67,467
Total supporting services	1,193,918	-	1,193,918	751,986
Total operating expenses	4,213,654	-	4,213,654	3,984,238
<u>NON-OPERATING REVENUES (EXPENSES)</u>				
Investment income (loss)	81,552		81,552	(23,234)
Change in net assets	129,465	(28,373)	101,092	219,640
Net assets, beginning of year	560,456	86,464	646,920	427,280
Net assets, end of year	\$ 689,921	\$ 58,091	\$ 748,012	\$ 646,920

SEE NOTES TO THE FINANCIAL STATEMENTS