

# THE VOICE



Novartis Pharmaceuticals Corporation  
East Hanover, New Jersey 07936-1080



Novartis Oncology

# THE VOICE



## Novartis proudly joins the Sickle Cell Disease Association of America and the 46th Annual National Convention

**Your dedication to helping patients with sickle cell disease 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 disease. We are Novartis, and we are reimagining medicine.



46<sup>TH</sup> ANNUAL NATIONAL CONVENTION EDITION

[www.sicklecelldisease.org](http://www.sicklecelldisease.org)

## CHAIRMAN'S GREETING



Welcome to the 46th Annual National Convention for Sickle Cell Disease! I would like to extend heartfelt greetings on behalf of the Board and the Sickle Cell Disease Stakeholder Community. I want to thank you for joining us for what has evolved to become the Sickle Cell Disease Community signature event. We are eager for you to participate in the various educational and resourceful events taking place this week. This year we are proud to focus on “Celebrating Diversity Within The Sickle Cell Community: Commitment, Innovation, Practice.” We are certain we have a tremendous program and we hope you find it to be inspiring and of course, enjoyable!

We continue to place special emphasis on the global advancement of treatments and research leading to a cure on behalf of those living with sickle cell disease. In fact, this was demonstrated this year with the support and sponsorship of our Sickle Cell Disease Association of America, Inc. (SCDAA) President’s visit to the Congo, Africa where the sharing of best practices and ideas took place.

I want to acknowledge our Convention Committee Program Chair Dr. Biree Andemariam who has worked diligently alongside SCDAA staff, community member organizations, sponsors, and volunteers to bring you a quality program that encompasses dynamic presenters from across the country. This year we also celebrate the continuation of the HRSA Grant which was awarded to SCDAA after a competitive selection process. Our submission highlighted SCDAA’s tremendous success in implementing the “Get Connected” platform, the first patient-powered registry and information database that secured close to 7,000 participants, the largest representation of the sickle cell community ever.

Additionally, the successful execution of the HRSA Grant will engage communities in 25 states to train Community Health Workers aimed at improving the quality of life for those affected by sickle cell disease by educating stakeholders on the latest developments in sickle cell, as well as other resources available in the community. You will have the opportunity to learn more about our progress during the program this week! I am also excited to mention that you will hear of the outstanding progress made legislatively related to the Sickle Cell Treatment Act that supports our overarching goals: Finding a universal cure, providing more comprehensive support for those living with sickle cell disease and producing better quality of life outcomes.

Whether it is clinical research, genetic counseling, or the management of sickle cell disease, you will have ample opportunities to participate in multiple captivating presentations. We extend our deepest thanks and gratitude to each of the magnificent presenters for joining us this year and for sharing their expertise and continued commitment to improving the quality of life for those affected by sickle cell disease.

Once again, on behalf of the Sickle Cell Disease Association of America (SCDAA), Inc., the Board of Directors, our sponsors, our staff and volunteers, I 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, PhD  
*Chairman, Board of Directors*

## CHIEF MEDICAL OFFICER'S GREETING



Welcome to the 46th Annual SCDAA Convention! It has been my distinct honor to chair the convention program again this year, and I could not have done so without the help of the full committee. Building upon the great momentum and widespread enthusiasm among over 600 participants last year, we have developed an even more impressive program that continues to provide something tangible and impactful for everyone. One of the unique aspects of our convention—and one of SCDAA’s strengths—is that each and every stakeholder in the battle against sickle cell disease is given a forum to be heard. This is particularly important as individuals living with sickle cell disease and those who care for them have long felt as if their voices weren’t loud enough, weren’t strong enough, or simply weren’t important enough. This year, you will find several innovative venues for information-sharing and open dialogue between individuals who all share a common goal—improving the care and quality of life for those affected by sickle cell disease. We continue to have robust attendance with participants from all sectors that include social workers, doctors, nurses, scientists, psychologists, researchers, industry representatives, advocates, and legislators. We firmly believe that the presence of individuals from all of these various interest groups will allow for enhanced communication, understanding and the propulsion forward toward better treatments and a universal cure.

I am invigorated by the continued medical advances in the treatment of sickle cell disease that we have all witnessed over the course of the last year—some disease-modifying, some curative, but all important. Clinical trials that are being conducted across the globe are inching closer to final results—results that will determine if the new treatments under study are as promising as the early results

have suggested. For those of you who have participated in a clinical trial, I thank you for being selfless in your action—and maybe even a little bit brave. Without your participation, new treatments will never make it onto the pharmacy shelves and into the hands of so many who desperately need them. For those of you who are considering participating in a clinical trial, you will find ample opportunity during convention to learn up-to-date information on available trials and how to get more information for either you or someone you know. We will highlight the advances in sickle cell disease care from many angles this year that include not only medical treatment, but also the psychosocial aspects of living with sickle cell disease. Our hope is that through education, cross-talk and even frank discussion, we can all leave at the end of convention feeling as though we have advanced our knowledge and realized our collective impact.

Finally, I personally want to hear from you, either during or after convention, and learn what you personally think SCDAA is doing well and what we might do differently to reach our common goals. Now, let’s join hands and hearts for the next few days. Let’s insure we each leave with more hope and fortitude than we came with and always remember that together, we are stronger.

Sincerely,

Biree Andemariam, MD  
*Chief Medical Officer*

## PRESIDENT'S GREETING



Welcome to SCDA A's 46th Annual Convention! I am honored to see many of you and greet those I haven't had the opportunity to meet as the new President and Chief Executive Officer of SCDA A.

Thank you for joining us in "Celebrating Diversity Within the Sickle Cell Community: Commitment, Innovation, Practice" with our Board of Directors, Community-based member organizations, staff and supporters.

I want to personally welcome you back to Charm City, home of SCDA A National Headquarters! It is the perfect backdrop for both work and play. The Hyatt Regency Baltimore 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 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, SCDA A 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. M. Dawn Nelson, Dr. Russell Ware and Dr. Julie Kanter, our keynote speakers this year. I am certain you will walk away inspired after listening to these amazing speakers.

I cannot express how proud I am of the work the SCDA A team has done this year and the efforts put in place to assure 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 SCDA A, thank you for joining us for what I anticipate will be the best convention yet. Furthermore, thank you for joining 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  
*President and Chief Executive Officer*

## PROGRAM AT A GLANCE

### WEDNESDAY OCT 10, 2018

7:00 PM REGISTRATION  
1:00 PM HRSA Grant Team Meeting  
5:30 PM SCDA A Member Training  
8:00 PM Board Meeting

### THURSDAY OCT 11, 2018

7:30 AM Registration  
7:30 AM Get Connected Kiosk  
9:00 AM Exhibitors Set-Up  
1:30 PM Exhibitors Open  
3:00 PM Poster Presentation Set-Up

7:30 AM Breakfast and Speed Networking  
8:00 AM SCDA A Business Session  
9:15 AM Opening Ceremony  
10:00 AM Break

#### PLENARY SESSION I

10:30 AM Community Based Organization Highlights  
12:00 PM Special Interest Lunch  
12:00 PM CBO Luncheon – Invitation Only

#### DEVELOPMENT & EDUCATIONAL CONCURRENT WORKSHOPS

1:15 PM Concurrent Workshops - Session I

- Beginner Track
- Patient & Family Track
- Nursing Track
- Physician/Provider Track
- Psychosocial Track
- CHW Training

3:15 PM Break

#### PLENARY SESSION II

3:30 PM Clinical Trial Update  
6:00 PM Poster Session (Judges Review)  
7:00 PM Chairman's Reception and Generation S "Rock the Block" Event

### FRIDAY OCT 12, 2018

7:30 AM Registration  
7:30 AM Get Connected Kiosk  
7:30 AM Breakfast and Speed Networking

#### PLENARY SESSION III

8:30 AM Real life Experience with Transplantation  
9:30 AM Charles F. Whitten, M.D. Memorial Lecture  
10:00 AM Diversity Panel  
11:30 AM CHW Training  
11:30 AM Healing the Healer Provider Session  
11:30 AM Patient Family Session  
12:15 PM Lunches – Require sign up  
1:30 PM Lonzie Lee Jones Patient Advocacy Symposium

3:00 PM Break

3:15 PM Simultaneous Session I  
6:00 PM Red Carpet Reception  
7:30 PM UNITY SOIREE

### SATURDAY OCT 13, 2018

8:30 AM Registration  
8:30 AM Get Connected Kiosk  
7:30 AM Exhibitors Open  
1:00 PM Exhibitors Breakdown

7:30 AM Breakfast and Speed Networking  
8:00 AM SCDA A Board Meeting  
8:30 AM Simultaneous Sessions II  
8:30 AM Patient Family Session III

#### PLENARY SESSION IV

10:00 AM Gene Therapy  
10:30 AM Clarice D. Reid, M.D. Lecture  
11:00 AM National Partner Updates  
12:30 PM Lunch on Your Own  
12:30 PM Youth and Young Adult Forum  
12:30 PM Patient Empowerment Luncheon (*Sign up Required*)  
1:00 PM Special Sessions  
3:00 PM SCDA A Closing Assembly & Adjournment



Prolong Pharmaceuticals is proud to be a partner with SCDA.



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Science matters. Because patients matter.

At Bioverativ, a Sanofi company, we are dedicated to transforming the lives of people with sickle cell disease and other rare blood disorders.

We believe that great science conquers the toughest medical obstacles, and we are inspired to push scientific boundaries to make a meaningful impact in the lives of people with rare blood disorders.



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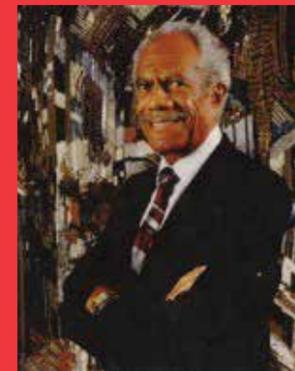
## HONOR LECTURES: CHARLES F. WHITTEN, MD & CLARICE D. REID, MD

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

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

Together, they have provided 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

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.



Clarice D. Reid

It was forty-three years ago when Dr. Clarice D. Reid 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.

## **CHARLES F. WHITTEN, MD 2018 MEMORIAL LECTURE**

*We've Fallen But We Must Get Up: Dizziness,  
Falling and Hearing Loss in Individuals Living  
with Sickle Cell Disease*



### **M. Dawn Nelson, PhD, CCC-A**

Associate Professor  
Central Michigan University

Dr. M. Dawn Nelson is an Associate Professor at Central Michigan University in the Department of Communication Sciences and Disorders, Doctor of Audiology (Au.D) Program. She received her Masters degree from the University of Maryland, her Ph.D. from Vanderbilt University, and completed a Post-Doctoral fellowship at the Johns Hopkins University Center for Hearing Sciences.

Her teaching, clinical, and research interests include assessment and management of vestibular (balance) disorders, auditory-evoked potentials, neuroanatomy, and auditory processing disorders. More recently, Dr. Nelson's research has explored imbalance, risk of falls, and hearing loss in individuals living with Sickle Cell Disease.

## **CLARICE D. REID, MD 2018 MEMORIAL LECTURE**

*Global Strategies for Sickle Cell Disease*



### **Russell Ware, MD, PhD**

Director, Global Health Center

Dr. Russell Ware obtained his MD and PhD degrees at Duke University, completed his Pediatric Hematology/Oncology fellowship at Duke, and served as Director of the Duke Pediatric Sickle Cell Program until 2004. He then moved to St. Jude Children's Research Hospital, serving as Chairman of Hematology before leading a sickle cell newborn screening program for the Republic of Angola. In July 2013, Dr. Ware joined Cincinnati, Ohio Children's Hospital Medical Center in Cincinnati Ohio as Director of Hematology and the Marjory Johnson Chair of Translational Hematology Research. He is also the Director of the Global Health Center.

Dr. Russell Ware is an internationally-recognized expert in the field of pediatric hematology with a special interest in sickle cell disease. He has had an NIH-funded laboratory since 1990, which has focused primarily on genetic modifiers of sickle cell disease and variable responses to hydroxyurea therapy. He has been the national Principal Investigator for several NIH-funded clinical trials using hydroxyurea for children with sickle cell disease, including the recently completed TWiTCH trial. He now leads efforts to introduce hydroxyurea safely and effectively into the Caribbean and sub-Saharan Africa. He recently completed a national sickle cell surveillance study in Uganda and Tanzania, as a prelude to further sickle cell screening. Dr. Ware is a distinguished researcher and author of more than 330 peer-reviewed scientific papers and textbook chapters. He has served on the Editorial Board of Blood and the Journal of Pediatrics, and is currently an Associate Editor for Pediatric Blood and Cancer. He serves on two Data Safety Monitoring Committees for clinical trials in sickle cell disease and was a member of the NHLBI Expert Panel that wrote the 2014 Evidence-Based Guidelines for sickle cell disease.

## SPECIAL LECTURE

### Gene Therapy for Sickle Cell Disease: Fact or Fiction?



### Julie Kanter, MD

Associate Professor  
Medical University  
of South Carolina

Dr. Julie Kanter is a lifespan hematologist specializing in sickle cell disease. She is an associate professor of Pediatrics at the Medical University of South Carolina and runs the first all-ages, Lifespan Comprehensive Sickle Cell Center. Dr. Kanter works closely with national partners including the American Society of Hematology and the National Institute of Health (NIH) to improve the lives of individuals living with sickle cell disease. In 2016, Dr. Kanter and her team was awarded one of eight of the NHLBI sickle cell disease implementation grants to form a sickle cell implementation center. Dr. Kanter is also very interested in expanding access to care for patients with sickle cell disease through the statewide program (SC)2. Dr. Kanter has authored and co-authored more than 50 articles, book chapters, and abstracts and hopes to train upcoming physicians and providers in sickle cell disease to expand the workforce for treating affected individuals.



In partnership with SCDAA

# GENERATION S

## A new story for a new generation

**Help rewrite the sickle cell disease (SCD) story by becoming a part of Generation S**

**Share your story and start the next chapter of SCD**

Novartis is teaming up with singer, actress, and advocate **Jordin Sparks** and the **Sickle Cell Disease Association of America, Inc.** to launch Generation S—and we want you to join the movement. From your earliest battle to your latest victory, and everything in between, **share your story** to help shape the SCD conversation and increase awareness for generations to come.

**Sign up to see the story develop**

You'll also receive educational resources, event invitations, and important program updates.

**Share your story and get a chance to meet Jordin Sparks**

Advocate Jordin Sparks has shared her story and she wants to hear yours, too—in person. Generation S members who share their stories by the end of November will have a chance to meet Jordin and work with a professional filmmaker on a mini-documentary. So go to **JoinGenS.com**, sign up, become a featured contributor, and get an opportunity to meet Jordin **to help write the next chapter in the story of SCD**.



**Go to [JoinGenS.com](http://JoinGenS.com) to sign up and share your story.**

Novartis is proud to partner with the  
Sickle Cell Disease Association of America, Inc.



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JAMES ECKMAN, MD  
**PIONEER AWARD**



MARSHA TREADWELL, PHD  
**PIONEER AWARD**

# 2017 PIONEERS & CHAMPIONS



DEXTER DARDEN  
**2017 CHAMPION**

Part of the SCDA Annual National Convention has always been devoted to the celebration of the community who actively participate in sickle cell advocacy and awareness. All honorees of the past and present have significantly impacted the progress being made in the fight against sickle cell disease. We honor those warriors for their dedication to filling the needs of the community.

## 2018 PIONEER



### **Kalpna Gupta, PhD**

Professor of Medicine, Dept. of Medicine and Co-leader, Molecular and Cellular Engineering Program at The Institute for Engineering in Medicine University of Minnesota Medical School

Dr. Kalpna Gupta has led pioneering work in initiating the understanding of the mechanisms of pain in sickle cell disease (SCD). These insights will help us treat both pain and the underlying disease process causing pain in the first place. Her laboratory has identified several new targets at the intersection of the sickle disease process and pain, including cannabinoid receptors, mast cells, and the nociceptin receptor, in addition to integrative approaches including diet modification, acupuncture and perception modulation to relieve pain. Dr. Gupta is also a recipient of the Excellence in Hemoglobinopathies Research Award from NHLBI to examine the potential of cannabinoids to treat pain and develop methods to quantify pain objectively.

She has organized several pain mechanism focused sessions at many national and international meetings to raise awareness of the need for mechanism-based targeting of pain in sickle cell disease. She continues to serve on several Federal and other organizations to advise on priorities to improve analgesic strategies to treat pain in SCD.

### **Russell Ware** 2018 PIONEER

See his bio on the Clarice D. Reid Lecture page.



# The 2018 Unity Soirée

*One of SCDAAs Most  
Exciting Events During  
The 4-Day Convention!*



It is our annual, culturally themed gala that is part of our Annual National Convention, now on its 46th year. This evening, you will move your feet to the sounds of the Joe Falero Band, one of D.C.'s finest Latin performing groups. Joe Falero and his powerhouse band will have you moving to the beat of your favorite Afro-Caribbean rhythms as they raise the roof with their performance of familiar hits and original tunes in styles that include Salsa, Bachata, Latin Jazz, and Merengue.

This evening's gala will not only give you an authentic Latin experience, but will also support the life-saving work of the Sickle Cell Disease Association of America, Inc. For 46 years, SCDAAs has worked diligently to advocate for and to enhance its memberships' ability to improve the quality of health, life, and services for individuals, families and communities affected by sickle cell conditions, all while promoting the search for a universal cure.

*Our convention is the largest four-day conference designed to address the multifactorial aspects of sickle cell disease.*



## 2018 CHAIRMAN'S AWARD



### Dennis Taylor

Vice President  
Corporate Services

Dennis joined Munich American Reassurance Company in July 2008 to provide leadership and direction to the company's Human Resources department.

Dennis' responsibilities include building strategic business partnerships, talent management, consulting and coaching, leadership and management development, compensation, benefits, recruitment, staffing and performance management. In addition to the Human Resources department, Dennis is responsible for Corporate Marketing and Communications, Facilities and Office Services. He is a member of the executive leadership team.

Prior to joining the company, Dennis held leadership roles in several industries: document management, information management, manufacturing and public utilities. Within each of these sectors he developed and put into place strategic changes to the human resources function, which increased productivity and efficiency, while enabling achievement of corporate objectives.

Dennis is a graduate of the University of California, Berkeley with a Bachelor of Science in Business Administration. He also holds a Masters of Business Administration from California State University, Hayward. He is certified as a Compensation Professional.

Dennis is a member of the Society for Human Resource Management, the National Black MBA Association, and a member of the board of directors for Sickle Cell Disease Association of America, Inc.



Ironwood is striving to support the sickle cell community through advancing increased awareness, understanding and empathy, and researching a potential treatment for sickle cell disease.



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## SPOTLIGHT

# HOWARD WOOLLEY: A CHAMPION FOR THE SICKLE CELL COMMUNITY



“Gail wanted to eradicate sickle cell disease and support patient care. She also wanted to inspire people with sickle cell to live the fullest and best life they can while managing their sickle cell disease. Those goals inspired Gail to write *Soar*.”

Howard Woolley became a sickle cell advocate and started raising public awareness about sickle cell disease, in conjunction with the 2017 release of the book *SOAR*, the memoir of Gail Campbell Woolley, his late wife. Howard is engaged in sickle cell anemia philanthropy with Johns Hopkins University department of medicine. He speaks at pharmaceutical company meetings and academic medical institutions about his experiences as a caretaker of a loved one with sickle cell, educating other caretakers and medics about increasing better care for those suffering from the disease. Howard also recently spoke at the Sickle Cell Disease Association of America, Inc.'s 5th Annual Walk With the Stars & Move-a-thon event in August 2018.

When Gail Campbell Woolley was seven, a pediatrician told her mother that she suffered from sickle cell anemia, a rare blood disease, and that she would be dead by age 35. While others may have responded to this horrifying news by descending into a fog of self-pity, Gail went in the opposite direction. She decided to live an eventful, exciting life that ultimately included—despite a troubled home life and the systemic racism and sexism of the late 20th century—academic success, an impressive career, a long and loving marriage, and the ability to leave her unmistakable stamp on every person she

met. By the time she finally succumbed to her disease at age 58 in 2015, she had ground that doctor's words into dust.

*Soar*, written in the last two years of her life, is Woolley's powerfully inspiring story, and its publication checks the last item off her extraordinary bucket list, which also included traveling to every continent except Antarctica. Written in an engaging, no-nonsense voice with a directness that reflects her many years in journalism, Woolley's remarkable story not only will move readers to root for this irrepressible, quietly heroic woman but also will push readers to reassess their own approach to life.

Howard, President/CEO of Howard Woolley Group LLC, is a leading expert in the field of regulatory risk management, public policy and government affairs. He lends his strategic business insights and technology policy expertise to high tech and telecommunications companies through his consulting business. He previously served as Senior Vice President for wireless public policy and strategic alliances for the Fortune 16 company, Verizon Communications.

Howard has received numerous write ups in the media, including a feature story in the *National Journal*. His article on corporate board governance of regulatory risk was published in the *National Association of*

Corporate Director's Directorship.com. Howard also serves on the board of Johns Hopkins Medicine; the telecommunications company, SOMOS Inc.; and the advisory board of his alma mater, the Newhouse School of Communications at Syracuse University. He has served on the board of the Executive Leadership Council. In 2013 he received the National Urban League's highest award for Outstanding Service on their Board of Trustees.

As part of Sickle Cell Awareness Month 2018 Howard was the keynote speaker at the Johns Hopkins Sickle Cell Infusion Center tenth anniversary and was interviewed about *Soar* at the William Proudford Sickle Cell Foundation where he and Gail (posthumously) received the Unsung Hero Award.

SCDAA thanks Howard for his commitment to sharing the touching story of his and his wife's story journey living with sickle cell disease. He is truly a champion for the sickle cell community, and his efforts are very much appreciated.

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You can also help by joining the Be The Match Registry® as a potential donor: [Join.BeTheMatch.org/SickleCell](http://Join.BeTheMatch.org/SickleCell)



PATRICIA BOATENG

LONZIE LEE JONES  
**PATIENT  
ADVOCACY  
SYMPOSIUM**



JEWEL DARBONE



CORY DAVIS



Co-Hosts: Dexter Darden + London Knight



Moderator: Kiarra Roseburgh



HOWARD FFRENCH



KC MORSE

You will enjoy this year's forum, where we again borrow a format from the popular TV show, "Hollywood Squares." You also will be inspired as our wonderful panelists share their stories.

We thank 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.



HERTZ NAZAIRE



KAY-DIENE ROBINSON



SHAMONICA WIGGINS



JIMMIE WILLIAMS

# Clinical Study Now Enrolling



## Do You Have Sickle Cell Disease?

**If YES**, you may be able to participate in a research study with a possible new treatment for Sickle Cell Disease.

### IF YOU:

- Are between 18 and 50 years old;
- Have Sickle Cell Anaemia;
- Have not been admitted to the hospital overnight for your Sickle Cell Anaemia more than 3 times in the last year;
- Do not require frequent transfusions;
- Are not pregnant.

**You may be able to participate in this study.**

#### Study IMR-SCD-102

A Phase 2a, Randomised, Double-Blind, Placebo-Controlled Study of IMR-687 in Adult Patients with Sickle Cell Anaemia (Homozygous HbSS or Sickle-β<sup>0</sup> Thalassemia)

Approval to conduct the study has been given by the Institutional Review Board of the hospital.

Participation in this research study is completely voluntary.

You may find it helpful to discuss the study with your usual Sickle Cell doctor.

Sponsored by



700 Technology Square, 2<sup>nd</sup> floor, Cambridge, MA 02139 US

# ABSTRACT REVIEWERS

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Director, Center for Child Health Policy and Advocacy  
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Department of Pediatrics  
Baylor College of Medicine  
Houston, TX

**Kim Smith-Whitley, MD**

Clinical Director, Division of Hematology  
Director of the Comprehensive  
Sickle Cell Center  
The Children's Hospital of Philadelphia  
Philadelphia, PA

**JJ Strouse, MD, PhD**

Associate Professor of Medicine Associate  
Professor in the Department of Pediatrics  
Duke University School of Medicine  
Durham, NC

**Marsha Treadwell, PhD**

Director, Network of Care for Sickle Cell Disease  
Children's Hospital Oakland  
Oakland, California

**Wanda Whitten-Shurney, MD**

CEO and Medical Director  
Sickle Cell Disease Association of America Michigan  
Chapter, Inc.  
Detroit, MI

**Teresa Works, MSW, LCSW**

Clinical Social Worker  
Ph.D. Candidate- Social Work  
New England Sickle Cell Institute  
UCONN Health  
Division Of Clinical Social Work  
Farmington, CT



## RESEARCHING SEVERE GENETIC AND RARE DISEASES WITH THE GOAL OF TRANSFORMING LIVES

bluebird bio is committed to individuals and families affected by severe genetic diseases and cancer, including severe sickle cell disease, transfusion-dependent  $\beta$ -thalassemia, also known as  $\beta$ -thalassemia major, cerebral adrenoleukodystrophy and multiple myeloma.

Thank you Sickle Cell Community for all that you do for those living with sickle cell disease.

Please visit us at [www.bluebirdbio.com](http://www.bluebirdbio.com) to learn more.

 @bluebirdbio  @bluebird\_bio  /bluebirdbio

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# Get CONNECTED



## What is Get Connected?

- High quality information about clinical care, research and health advocacy issues related to sickle cell disease and sickle cell trait.
- The storage of health information that enables patients to better navigate the health care system.
- Improved access to disease-specific health.
- A platform for research initiatives generated by the needs of our patient population.

## What are the benefits?

- Establishes a network to distribute information related to clinical care, research, health services, policies, and advocacy.
- Connects those afflicted with SCD to high quality resources for information on health care, behavioral health, clinical research, and other resources.
- Establishes registry for storage of medical information related to diagnosis and treatment.

## Who can use Get Connected?

- Children and adults with SCD and their families
- Sickle Cell Disease Association of America
- Health Care Providers
- Clinical researchers
- Advocacy organizations
- Children and adults with sickle cell trait

## Sickle Cell Disease Association of America, Inc.



World Kitchen is proud to sponsor SCDA's Annual Unity Soiree. We salute Sickle Cell Disease Association of America, Inc. and its 46 years of service in providing leadership, education, and patient support services and for its continued support in striving to improve quality access to care for individuals living with sickle cell disease.

## PLANNING COMMITTEE

**Biree Andemariam, MD Committee Chair**  
 Chief Medical Officer  
 Director, New England Sickle Cell Institute  
 Associate Professor of Medicine  
 Division of Hematology/Oncology  
 University of Connecticut Health Center  
 Farmington, CT

**Lewis Hsu, MD Committee Co-Chair**  
 Vice Chief Medical Officer  
 Director of the Sickle Cell Center  
 and Professor of Pediatrics  
 Pediatric Hematologist  
 University of Illinois at Chicago  
 Chicago, IL

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

**Wanda Whitten-Shurney, MD**  
 CEO & Medical Director  
 Sickle Cell Disease Association Michigan  
 Chapter, Inc., Detroit, MI

**Natasha Thomas**  
 Development and Special Events Coordinator  
 Sickle Cell Disease Association of America,  
 Inc., Baltimore, MD

**Carole Bernard, MS**  
 Director of Communications and Marketing  
 Sickle Cell Disease Association of America,  
 Inc., Baltimore, MD



**Global Blood Therapeutics (GBT) is committed to partnering with the community to change the future of sickle cell disease (SCD).**

We seek to understand the unique needs of people living with SCD.

We recognize the sickle cell community is medically underserved and are passionate about working closely with patients, their families and community organizations to drive change.

GBT is passionate about transforming SCD treatment.

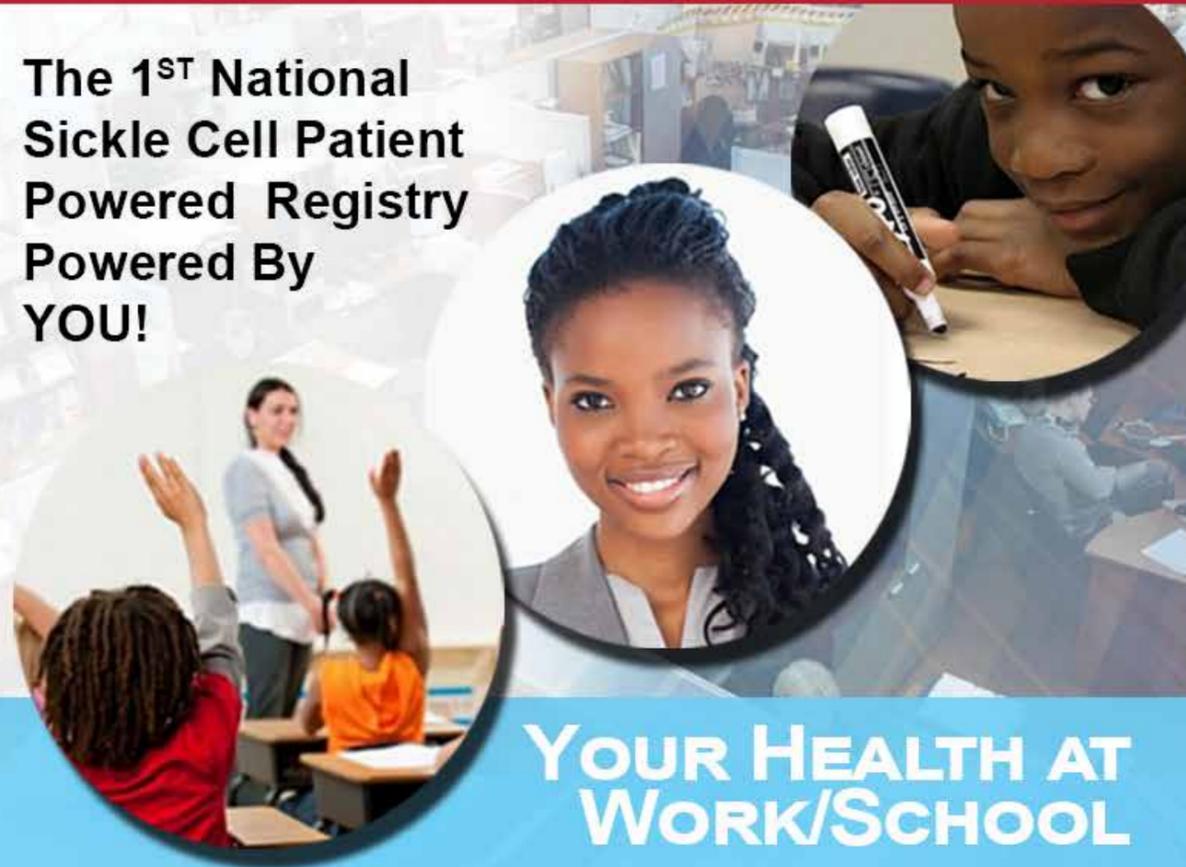
**Get**  
**CONNECTED**  
Patient Powered Registry



# YOUR HEALTH

## SELF CARE

The 1<sup>ST</sup> National  
Sickle Cell Patient  
Powered Registry  
Powered By  
YOU!



## YOUR HEALTH AT WORK/SCHOOL

**Six Facts to Share with teachers  
and/or staff to help you stay well.**

**Get Connected does not provide  
individual medical advice, diagnosis, or treatment.**

[WWW.GETCONNECTEDSCD.ORG](http://WWW.GETCONNECTEDSCD.ORG)

This resource is funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA)



## Pfizer Rare Disease

Rare diseases include some of the most serious of all illnesses and impacts millions of patients worldwide. At Pfizer Rare Disease we passionately dedicate our resources, expertise and global reach to bring innovative medicines to rare disease patients and their families.

Pfizer Rare Disease combines pioneering science and deep understanding of how diseases work with insights from strategic collaborations with academic researchers, patients, and other companies to deliver transformative treatments and solutions. We innovate every day leveraging our global footprint to accelerate the development and delivery of groundbreaking medicines and the hope of cures.

Visit [Pfizer.com/RareDisease](https://Pfizer.com/RareDisease) to learn more.





Sickle Cell Disease Association of America, Inc.

Statement of Activities

For the Year Ended December 31, 2017

|                                | <u>Unrestricted</u> | <u>Temporarily<br/>Restricted</u> | <u>Total</u>      |
|--------------------------------|---------------------|-----------------------------------|-------------------|
| Revenues:                      |                     |                                   |                   |
| Federal grant                  | \$ 1,625,944        | \$ -                              | \$ 1,625,944      |
| Convention and special events  | 535,761             | -                                 | 535,761           |
| Contributions                  | 321,780             | -                                 | 321,780           |
| Other grant income             | 135,088             | -                                 | 135,088           |
| Investment income              | 63,715              | -                                 | 63,715            |
| Other income                   | 6,436               | -                                 | 6,436             |
| Membership dues                | 23,980              | -                                 | 23,980            |
| Sales of educational materials | <u>7,677</u>        | <u>-</u>                          | <u>7,677</u>      |
| Total revenues                 | <u>2,720,381</u>    | <u>-</u>                          | <u>2,720,381</u>  |
| Expenses:                      |                     |                                   |                   |
| Program services:              |                     |                                   |                   |
| HRSA Grant                     | 1,625,157           | -                                 | 1,625,157         |
| SCDAA                          | 576,348             | -                                 | 576,348           |
| PCORI                          | <u>135,088</u>      | <u>-</u>                          | <u>135,088</u>    |
| Total program services         | <u>2,336,593</u>    | <u>-</u>                          | <u>2,336,593</u>  |
| Support services:              |                     |                                   |                   |
| Management and general         | 246,606             | -                                 | 246,606           |
| Fundraising                    | <u>152,933</u>      | <u>-</u>                          | <u>152,933</u>    |
| Total support services         | <u>399,539</u>      | <u>-</u>                          | <u>399,539</u>    |
| Total expenses                 | <u>2,736,132</u>    | <u>-</u>                          | <u>2,736,132</u>  |
| Change in net assets           | (15,751)            | -                                 | (15,751)          |
| Net assets, beginning of year  | <u>487,124</u>      | <u>32,464</u>                     | <u>519,588</u>    |
| Net assets, end of year        | <u>\$ 471,373</u>   | <u>\$ 32,464</u>                  | <u>\$ 503,837</u> |

See accompanying notes to the financial statements.

4.

Sickle Cell Disease Association of America, Inc.

Statement of Activities

For the Year Ended December 31, 2016

|  | <u>Unrestricted</u> | <u>Temporarily<br/>Restricted</u> | <u>Total</u>      |
|--|---------------------|-----------------------------------|-------------------|
| Revenues:                              |                     |                                   |                   |
| Federal grant                          | \$ 2,820,499        | \$ -                              | \$ 2,820,499      |
| Convention and special events          | 468,660             | -                                 | 468,660           |
| Contributions                          | 279,443             | 60,626                            | 340,069           |
| Other grant income                     | 34,208              | -                                 | 34,208            |
| Investment income                      | 29,731              | -                                 | 29,731            |
| Other income                           | 151,380             | -                                 | 151,380           |
| Membership dues                        | 20,066              | -                                 | 20,066            |
| Sales of educational materials         | 12,325              | -                                 | 12,325            |
| Net assets released from restrictions: |                     |                                   |                   |
| Satisfaction of donor restrictions     | <u>109,506</u>      | <u>(109,506)</u>                  | <u>-</u>          |
| Total revenues                         | <u>3,925,818</u>    | <u>(48,880)</u>                   | <u>3,876,938</u>  |
| Expenses:                              |                     |                                   |                   |
| Program services:                      |                     |                                   |                   |
| HRSA Grant                             | 2,820,499           | -                                 | 2,820,499         |
| SCDAA                                  | 601,043             | -                                 | 601,043           |
| PCORI                                  | <u>34,208</u>       | <u>-</u>                          | <u>34,208</u>     |
| Total program services                 | <u>3,455,750</u>    | <u>-</u>                          | <u>3,455,750</u>  |
| Support services:                      |                     |                                   |                   |
| Management and general                 | 312,972             | -                                 | 312,972           |
| Fundraising                            | <u>39,929</u>       | <u>-</u>                          | <u>39,929</u>     |
| Total support services                 | <u>352,901</u>      | <u>-</u>                          | <u>352,901</u>    |
| Total expenses                         | <u>3,808,651</u>    | <u>-</u>                          | <u>3,808,651</u>  |
| Change in net assets                   | 117,167             | (48,880)                          | 68,287            |
| Net assets, beginning of year          | <u>369,957</u>      | <u>81,344</u>                     | <u>451,301</u>    |
| Net assets, end of year                | <u>\$ 487,124</u>   | <u>\$ 32,464</u>                  | <u>\$ 519,588</u> |

See accompanying notes to the financial statements.

5.

**Sickle Cell Disease Association of America, Inc.**  
**Statements of Cash Flows**  
**For the Years Ended December 31, 2017 and 2016**

|  | 2017                     | 2016                     |
|--|--------------------------|--------------------------|
| Cash flows from operating activities:  |                          |                          |
| Change in net assets   | \$ <u>(15,751)</u>       | \$ <u>68,287</u>         |
| Adjustments to reconcile change in net assets<br>to net cash provided by (used in) operating activities: |                          |                          |
| Depreciation and amortization  | 1,668                    | 1,668                    |
| Unrealized gain on investments   | (64,088)                 | (15,625)                 |
| Realized loss on investments   | 473                      | 42                       |
| Decrease (increase) in assets:   |                          |                          |
| Accounts receivable  | 19,091                   | (36,273)                 |
| Grants receivable  | 165,356                  | (61,042)                 |
| Pledges receivable   | 70,158                   | (37,997)                 |
| Prepaid expenses   | (1,002)                  | 2,640                    |
| Inventory  | 3,268                    | (3,220)                  |
| Increase (decrease) in liabilities:  |                          |                          |
| Accounts payable and accrued expenses  | (165,396)                | 83,961                   |
| Refundable advances  | 16,756                   | (146,718)                |
| Deferred rent  | (4,987)                  | (3,714)                  |
| Total adjustments  | <u>41,297</u>            | <u>(216,278)</u>         |
| Net cash provided by (used in) operating activities  | <u>25,546</u>            | <u>(147,991)</u>         |
| Cash flows from investing activities:  |                          |                          |
| Proceeds from sales of investments   | 35,000                   | 60,717                   |
| Purchases of investments   | (35,100)                 | (15,537)                 |
| Net cash (used in) provided by investing activities  | <u>(100)</u>             | <u>45,180</u>            |
| Cash flows from financing activities:  |                          |                          |
| Proceeds from lines of credit  | 147,170                  | 191,480                  |
| Payments on lines of credit  | (167,229)                | (82,795)                 |
| Net cash (used in) provided by financing activities  | <u>(20,059)</u>          | <u>108,685</u>           |
| Net increase in cash   | 5,387                    | 5,874                    |
| Cash, beginning of year  | <u>225,842</u>           | <u>219,968</u>           |
| Cash, end of year  | \$ <u><u>231,229</u></u> | \$ <u><u>225,842</u></u> |
| Supplemental disclosures of cash flow information:   |                          |                          |
| Cash paid for interest expense   | \$ <u><u>13,967</u></u>  | \$ <u><u>8,094</u></u>   |

See accompanying notes to the financial statements.

6.

# SCDAA Board Members

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**David N. Braxton, PhD**  
Chairman of the Board  
Senior Vice President, Strategic Resourcing  
Sun Trust Bank, Inc.  
Atlanta, GA



**Jakela Parker**  
Board Treasurer  
Finance Director and Global  
Financial Controller  
DSM BioMedical, Inc.  
Exton, PA



**Ed Flowers**  
Vice Chair  
Senior Vice President & Chief People Office  
World Kitchen, LLC  
Rosemont, IL



**Genice T. Nelson, DNP, APRN**  
Board Secretary  
Nurse Practitioner Specialist  
Sickle Cell Disease Day Treatment Clinic  
UTSW Comprehensive  
Sickle Cell Disease Program  
Dallas, TX

# SCDAA Board Members

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**Biree Andemariam, MD**  
Chief Medical Officer  
Director, New England Sickle Cell Institute  
Associate Professor of Medicine  
Division of Hematology/Oncology  
University of Connecticut Health Center  
Farmington, CT



**Lise J. Hall, MBA**  
Associate Director of Consumer Marketing,  
Lung Cancer Franchise AstraZeneca  
Washington, DC



**Lewis Hsu, MD**  
Vice Chief Medical Officer  
Director of the Sickle Cell Center and  
Professor of Pediatrics  
Pediatric Hematologist  
University of Illinois at Chicago  
Chicago, IL



**Christopher Hollins, MBA**  
Executive Vice President  
Strategic Acquiring Partnerships  
WorldPay, Inc.  
Atlanta, GA

# SCDAA Board Members

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**Thomas L. Johnson, JD**  
CEO  
Family Matters of Greater Washington, DC  
Washington, DC



**Tanique Mitchell**  
Resource Center Supervisor  
Stradley Ronon Stevens and Young LLP,  
Law Firm  
Philadelphia, PA



**Bernie Lawrence-Watkins**  
Principal Attorney  
Lawrence Watkins & Associates  
Atlanta, GA



**Gwendolyn Poles, DO**  
Retired Physician, Honorary Medical Staff  
Member,  
Faculty/Medical Director,  
Internal Medical Residency Program,  
UPMC Pinnacle Health, Harrisburg, PA

# SCDAA Board Members

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**Crystal A. Riley, PharmD. MHA, MBA**  
Senior Manager /Healthcare Policy & Reimbursement  
Baxter International, Inc.  
Washington, DC



**Wanda Whitten-Shurney, MD**  
CEO & Medical Director  
Sickle Cell Disease Association Michigan Chapter, Inc.  
Detroit, MI



**Kim Smith-Whitley, MD**  
Clinical Director, Division of Hematology  
The Children's Hospital of Philadelphia  
Philadelphia, PA



**Kwaku Ohene-Frempong, MD**  
Board Member Emeritus

**Lennette Benjamin, MD**  
Board Member Emeritus