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.
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 patients, 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
Welcome to SCDDAA’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 SCDDAA.

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 SCDDAA 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 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, SCDDAA has organized an outstanding agenda with the hope it will quench your educational thirst. I cannot express how proud I am of the work the SCDDAA 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 SCDDAA, 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

I want 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. Dowia 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 SCDDAA 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 SCDDAA, 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 EXHIBITORS TEAM MEETING
5:30 PM SCDDAA MEMBER TRAINING
8:00 PM BOARD MEETING

**THURSDAY OCT 11, 2018**
7:30 AM Registration
7:30 AM Get Connected Kissk
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 SCDDAA 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
  - CBO Training
3:15 PM Break

PLENARY SESSION II
3:30 PM Clinical Trial Update
4:00 PM Poster Session (Judges Review)
5:00 PM Chairperson’s Reception and Generation S

“Rock the Block” Event

**FRIDAY OCT 12, 2018**
7:30 AM Registration
7:30 AM Get Connected Kissk
7:30 AM Breakfast and Speed Networking

PLENARY SESSION III
8:30 AM Real Life Experience with Transplantation
9:30 AM Charles E. Whitman, 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
12:30 PM Lunches – Require sign up
1:30 PM Lonnie Lee Jones Patient Advocacy Symposium
3:00 PM Break

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 SCDDAA Closing Assembly & Adjournment

**SATURDAY OCT 13, 2018**
8:30 AM Registration
8:30 AM Get Connected Kissk
7:30 AM Exhibitors Open
1:00 PM Exhibitors Breakdown
7:30 AM Breakfast and Speed Networking
8:00 AM SCDDAA Board Meeting
8:30 AM Simultaneous Sessions II
8:30 AM Patient Family Session III

PLENARY SESSION V
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 SCDDAA Closing Assembly & Adjournment
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 SCDAAs 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 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 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.
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 on 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.

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.
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 (SC2). 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.

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 to sign up and share your story.
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.

Part of the SCDAA 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.

Russell Ware
2018 PIONEER
See his bio on the Clarice D. Reid Lecture page.
The 2018 Unity Soirée

One of SCDAA’s 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, SCDAA has worked diligently to advocate for and to enhance its membership’s 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.
Be The Match offers free programs and resources to support patients with sickle cell disease before, during and after transplant.

**AT EVERY STEP, WE’RE HERE TO HELP:**

**VISIT:**  
BeTheMatch.org/sicklecell

**CALL:**  
1 (888) 999-6743

**EMAIL:**  
patientinfo@nmdp.org

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

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.

**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 medicals 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—a highly successful 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 journey living with sickle cell disease. He is truly a champion for the sickle cell community, and his efforts are very much appreciated.
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.

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-β0 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.
ABSTRACT REVIEWERS

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

Nina Anderson, RN, DNP
Executive Director & Founder
Tova Community Health, Inc.
Wilmington, DE

Samir Ballas, MD
Emeritus Professor of Medicine and Pediatrics
Cardeza Foundation
Philadelphia, PA

Shawn Bediako, PhD
Associate Professor, Department of Psychology
Affiliate Associate Professor, Department of African Studies
University of Maryland, Baltimore County
Baltimore, MD

Andrew Campbell, MD
Director, Comprehensive Sickle Cell Program
Children's National Medical Center
Associate Professor of Pediatrics
George Washington University School of Medicine and Health Sciences
Division of Hematology
Washington, DC

Jean Leclerc Raphael, MD, MPH
Associate Professor of Pediatrics
Director, Center for Child Health Policy and Advocacy
Associate Vice Chair for Community Health
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

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 β-thalassemia, also known as β-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 to learn more.
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.
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 to learn more.
Sickle Cell Disease Association of America, Inc.
Statement of Activities
For the Year Ended December 31, 2017

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<th>Revenues:</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
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| Expenses:                              |              |                        |        |
| Program services:                      |              |                        |        |
| HRSA Grant                             | 1,625,157    | -                      | 1,625,157 |
| SCDAA                                  | 576,348      | -                      | 576,348 |
| PCORI                                  | 135,088      | -                      | 135,088 |
| Total program services                 | 2,336,593    | -                      | 2,336,593 |
| Support services:                      |              |                        |        |
| Management and general                 | 246,606      | -                      | 246,606 |
| Fundraising                            | 152,933      | -                      | 152,933 |
| Total support services                 | 399,539      | -                      | 399,539 |
| Total expenses                         | 2,736,132    | -                      | 2,736,132 |
| Change in net assets                   | (15,751)     | -                      | (15,751) |
| Net assets, beginning of year          | 487,124      | 32,464                 | 519,588 |
| Net assets, end of year                | $ 471,373    | $ 32,464               | $ 503,837 |

See accompanying notes to the financial statements.
Sickle Cell Disease Association of America, Inc.

Statement of Activities

For the Year Ended December 31, 2016

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
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</tr>
<tr>
<td>Net assets released from restrictions:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction of donor restrictions</td>
<td>109,506</td>
<td>(109,506)</td>
<td></td>
</tr>
<tr>
<td><strong>Total revenues</strong></td>
<td>3,925,818</td>
<td>(48,880)</td>
<td>3,876,938</td>
</tr>
</tbody>
</table>

|                                |              |                        |         |
| **Expenses:**                  |              |                        |         |
| Program services:              |              |                        |         |
| HRSA Grant                     | 2,820,499    |                        | 2,820,499 |
| SCDA                          | 601,043      |                        | 601,043  |
| PCORI                          | 34,208       |                        | 34,208   |
| **Total program services**     | 3,455,750    |                        | 3,455,750 |

|                                |              |                        |         |
| Support services:              |              |                        |         |
| Management and general         | 312,972      |                        | 312,972  |
| Fundraising                    | 39,929       |                        | 39,929   |
| **Total support services**     | 352,901      |                        | 352,901  |
| **Total expenses**             | 3,808,651    |                        | 3,808,651 |

|                                |              |                        |         |
| Change in net assets           | 117,167      | (48,880)               | 68,287   |
| Net assets, beginning of year  | 369,957      | 81,344                 | 451,301  |
| **Net assets, end of year**    | $487,124     | $32,464                | $519,588 |

See accompanying notes to the financial statements.

Halt Buzas & Powell, LTD

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

<table>
<thead>
<tr>
<th>Cash flows from operating activities:</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depreciation and amortization</td>
<td>1,668</td>
<td>1,668</td>
</tr>
<tr>
<td>Unrealized gain on investments</td>
<td>(64,088)</td>
<td>(15,625)</td>
</tr>
<tr>
<td>Realized loss on investments</td>
<td>473</td>
<td>42</td>
</tr>
<tr>
<td>Decrease (increase) in assets:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>19,091</td>
<td>(36,273)</td>
</tr>
<tr>
<td>Grants receivable</td>
<td>165,356</td>
<td>(61,042)</td>
</tr>
<tr>
<td>Pledges receivable</td>
<td>70,158</td>
<td>(37,997)</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>(1,002)</td>
<td>2,640</td>
</tr>
<tr>
<td>Inventory</td>
<td>3,268</td>
<td>(3,220)</td>
</tr>
<tr>
<td>Increase (decrease) in liabilities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>(165,396)</td>
<td>83,961</td>
</tr>
<tr>
<td>refundable advances</td>
<td>16,756</td>
<td>(146,718)</td>
</tr>
<tr>
<td>Deferred rent</td>
<td>(4,987)</td>
<td>(3,714)</td>
</tr>
<tr>
<td>Total adjustments</td>
<td>41,297</td>
<td>(216,278)</td>
</tr>
<tr>
<td>Net cash provided by (used in) operating activities</td>
<td>25,546</td>
<td>(147,991)</td>
</tr>
</tbody>
</table>

Cash flows from investing activities:

| Proceeds from sales of investments | 35,000| 60,717 |
| Purchase of investments           | (35,100) | (15,537) |

Net cash (used in) provided by investing activities

| (100) | 45,180 |

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

| (20,059) | 108,685 |

Net increase in cash

| 5,387 | 5,874 |

Cash, beginning of year

| 225,842 | 219,968 |

Cash, end of year

| $ 231,229 | $ 225,842 |

Supplemental disclosures of cash flow information:

| Cash paid for interest expense    | $ 13,967 | $ 8,094 |

See accompanying notes to the financial statements.
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Senior Vice President & Chief People Office
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Nurse Practitioner Specialist
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UTSW Comprehensive Sickle Cell Disease Program
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Director of the Sickle Cell Center and
Professor of Pediatrics
Pediatric Hematologist
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Lawrence Watkins & Associates
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UPMC Pinnacle Health, Harrisburg, PA
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