

Addressing Healthcare Disparity in Sickle Cell Disease: 2018 and 2019 Access-to-Care Summits



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2019 ATCS FACULTY



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2019 ATCS SPEAKERS

KEYNOTE SPEAKER: Admiral Brett Giroir

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2019 ACCESS-TO-CARE SUMMIT AGENDA

Tuesday, September	10, 2019 WELCOME RECERTION
Wedneedey Center	ber 11, 2010
8.00 - 8.10 am	WELCOME
8:10 - 8:30 am	KEYNOTE ADDRESS
	Admiral Brett Giroir
8:30 - 8:50 am	2018 ATCS ROAD MAP DELIVERABLES
	• Ken Bridges, MD
8:50 - 9:30 am	GBTS ACCESS TO EXCELLENT CARE FOR SCD PATIENTS (ACCEL) AWARDEES
	Center for Inherited Blood Disorders and Sickle Cell Disease Foundation
	James R. Clark Sickle Cell Foundation
	• Johns Hopkins
	 MAVEN Project (Medical Alumni Volunteer Expert Network)
	Sickle Cell Foundation of Georgia
9:30 - 10:00 am	BREAK
10:00 - 11:30 am	PLENARY SESSION
	Addressing the Deficit in SCD Provider Care
	Wally Smith, MD
	• Tyson Pillow, MD
	• Wanda Whitten-Shurney, MD
	Navigating the Emerging Complexity of Reimbursement for SCD Care
	• John Stancil
	• Edem Kojo Ablordeppey, PharmD
	The Power of Effective Advocacy: Advancing SCD Policy
	• Heidi L. Wagner
	 Senator Tim Scott of South Carolina (video message)
	Conor Sheehey
11:30 am - 12:30 pm	
12:30 - 2:00 pm	BREAKOUT SESSION 1
	Addressing the Dencit in Provider Care
	Navigating the Emerging Complexity of Treatment Coverage
2.00 - 2.15 pm	BREAK
2:15 - 3:45 pm	BREAKOUT SESSION 2
	• Addressing the Deficit in Provider Care
	Navigating the Emerging Complexity of Treatment Coverage
	• Power of Effective Advocacy: Advancing Policy
3:45 - 4:00 pm	BREAK
4:00 - 4:30 pm	2019 ATCS SUMMARY

TABLE OF CONTENTS

- **5** Introduction
- 6 2018 Access-to-Care Summit
- 8 2019 Access-to-Care Summit
- **11** Focus on Providers: Addressing the Deficit in SCD Provider Skills and Numbers
- **13** Focus on Payers: Navigating the Emerging Complexity of Treatment Coverage
- **17** Focus on Policy: Importance of Advocacy to Support SCD Policy
- **19** Last Words
- **21** References
- 22 Summit Attendees

"The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life, the sick, the needy and the handicapped."

- Hubert H. Humphrey

Sickle cell disease (SCD) is an archetype of healthcare disparity in the United States (US). Though its discovery during the 20th century represented an exciting breakthrough, progress along the road of clinical care for this disease has been slow and sputtering. It was first described in medical literature in 1910,¹ and in 1949, it became the first disorder proven to arise from a defect in protein structure, namely an aberration in the red cell oxygen transport molecule, hemoglobin.² Diseases caused by bacteria (eg, bubonic plague), parasites (eg, malaria), vitamin deficiency (eg, scurvy), and even the lack of a protein (eg, diabetes) were already known, but this groundbreaking discovery made SCD the first identified molecular disorder, namely a disease due to a protein that is present but abnormal. In 1956, the discovery that the sequence of amino acid building blocks for sickle hemoglobin has a single change from normal pointed to a mutation in the hemoglobin gene as the basis for the condition.³ Thus, SCD became the first genetic disorder for which the origin lies in the fabric of the human genome.

Current technology makes the description of genetic mutations in disease a common affair. Sixty years ago, however, only enormous and time-consuming effort by leading scientific minds could elucidate this fundamental issue in science and human biology, laying the groundwork for today's promise of genetic treatments. Unfortunately, this exciting scientific story contrasts sharply with the laggardly progress in the care, management, and survival of people with the disorder (Figure 1). Before the 1970s, most children with SCD in the US died before adolescence. Thanks to advances in treatment, the life expectancy for people with the disease is now 42 to 47 years; however, this is still decades shorter than that of the general population, and little improvement has occurred over the last 25 years.4,5

Figure 1. Increases in Life Expectancy in Patients With SCD, US, 1910-2000



National Heart, Lung, and Blood Institute, National Institutes of Health, Bethesda, MD.

SCD is a complex, chronic illness affecting approximately 100,000 Americans (Figure 2). The multifaceted disorder evolves over decades in character and manifestations. Except for the limited option of bone marrow transplantation, no cure exists.⁶ Moreover, of the 762 drugs approved by the US Food and Drug Administration (FDA) for orphan diseases between 1983 and 2018, only two were for SCD.^{7,8} Two additional drugs entered the treatment armamentarium in 2019, dampening but not eliminating the urgent need to expand treatment options.^{9,10} As with any lifelong chronic condition, a program of integrated, comprehensive care is vital to optimal management. The determinants of care access can be distilled to four key elements: programs, providers, policy, and payers, which were addressed by Access-to-Care Summits in 2018 and 2019 (Figure 3).

2018 ACCESS-TO-CARE SUMMIT

The 2018 Access-to-Care Summit, led by a steering committee of experts,¹¹ addressed the question of programs and discussed approaches for creating the structures that underpin healthcare delivery for people

with SCD. The Summit output was collated into a monograph outlining the elements and steps required to establish a comprehensive healthcare system.¹²

As outlined in Figure 4, pediatric treatment should bridge to an adult care program that includes an outpatient clinic and day hospital facilities for the management of sickle cell crisis pain and other acute issues. Leveraging available capacity within the existing medical center infrastructure, such as cancer or hemophilia treatment centers, can lower the cost of creating care programs for people with SCD.

Figure 5 highlights the elements required to build a comprehensive SCD care program. A sickle cell champion or advocate is the vital cog who initiates the process. Often the champion is a physician but can be another healthcare provider, patient, or patient advocate. The champion rallies support from other vital stakeholders, including patients and advocates, hospital staff and administration, and policy leaders. A supportive coalition is a critical component of an SCD care program.

Once the coalition is formed, a business plan is needed to move the project from theory to reality.

Figure 2. SCD in the US



The plan should be thorough, covering infrastructure costs, personnel recruiting and training, funding sources and cost offsets, and patient numbers and projections of services rendered. Data are essential to the business plan, and their acquisition requires extensive research that often involves input from external stakeholders, including billing and reimbursement data from third-party payers as well as data from pharmacy, laboratory, and imaging services. SCD programs are typically money-losing cost centers because some segments of the population are uninsured or underinsured, leading to



Figure 3. Core Elements of Care Access





Figure 5. Key Elements to Building a Comprehensive SCD Care Program



inadequate reimbursement levels. Financial projections for sickle cell centers often revolve around cost-saving models based on existing expenses, revenues, and resources. Therefore, prespecified metrics and milestones that demonstrate costsavings are vital to long-term program viability. The most important data metric, however, is improvement in the quality of patient care as assessed by parameters such as hospital admissions, adherence to medication regimens, and rational opioid analgesic management. Improved access to quality care should ultimately translate into longer, healthier lives for people with SCD.

A substantial number of people with SCD live in rural areas,¹³ which creates challenges to the delivery of specialized, expert care.¹⁴ Fortunately, evolving technology is being harnessed to address and mitigate the healthcare chasm between people in urban and rural regions of the country. Telemedicine¹⁵ and telementoring¹⁶ are new approaches that leverage technology to extend SCD management expertise from urban centers into rural regions (Figure 6).

2019 ACCESS-TO-CARE SUMMIT

Keynote Address

Admiral Brett Giroir, Assistant Secretary for Health, Department of Health and Human Services (DHHS), who began his career as a pediatrician caring for children with SCD, delivered the keynote address (Figure 7).

Admiral Giroir reinforced the promotion of highquality healthcare for people with SCD as a principle commitment of the Office of the Assistant Secretary for Health (OASH). The core elements of the effort are the:

- Provision of trusted data and information
- Convening of partners (federal, state, and local agencies, professional societies, nongovernmental organizations [NGOs], academia, civil society, commercial partners, patient advocates)
- Development of novel initiatives (gaining situational awareness, identifying gaps, building teams, setting a common agenda, and supporting infrastructure, ultimately with transition to Operational Divisions)
- Organization and leadership of national initiatives

Figure 6. Expanding the Reach of SCD Expert Care

Teleconsultation



Telemedicine

Hub & Spoke



Admiral Giroir's remit is broad, reflecting his leadership at several levels:

- Assistant Secretary for Health
- Senior Adviser, Immediate Office of the Secretary
- USPHS Commissioned Corps
- World Health Organization (WHO)

Enhancing SCD Awareness

Admiral Giroir was instrumental in securing a presidential message during National SCD Awareness Month in 2018. In addition, the awareness effort has tapped into the popularity of Twitter among young Figure 7. Brett P. Giroir, MD, Admiral, US Public Health Services, Assistant Secretary for Health, Senior Advisor, Immediate Office of the Secretary



people through the OASH, Office of Minority Health (#SickleCellStories). Furthermore, the newly formed SCD federal working group creates an enduring basis for cooperation and facilitation around initiatives in SCD by the DHHS (Figure 8).

Strategic Plan and Blueprint for Action

OASH leadership was integral to initiating the Strategic Plan and Blueprint for Action under the auspices of the National Academies of Sciences, Engineering, and Medicine. The National Academies will provide recommendations related to healthcare barriers for people with SCD, limitations or possible opportunities to develop disease-specific registries and/or surveillance systems, new research innovations, and the importance of patient advocacy and community engagement groups.

The National Academies have identified several important topics including the need for specific initiatives that will lead to substantially greater adherence to care and treatment guidelines. Another vital issue is the facilitation of seamless transition of care when patients exit a comprehensive, specialty pediatrics center and enter college and/or the adult internal medicine environment. The disturbing increase in mortality during late adolescence and early adulthood is partly attributable to healthcare disruptions related to the inadequate transition between pediatric and adult care.¹⁷ This spotlight by the National Academies should serve as a beacon for muchneeded attention and funding.

Improving Healthcare Infrastructure

Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (S. 2465). This act was signed into law on December 18, 2018 (Figure 9).¹⁸ The legislation reauthorizes an SCD prevention and treatment program and provides grants for research, surveillance, prevention, and treatment of heritable blood disorders. Efforts to acquire appropriations to implement the act are ongoing and vital to the future of healthcare in SCD. The Nixon-sponsored 1972 National Sickle Cell Anemia Control Act, the

Figure 9. Congressional Sponsors: The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (S. 2465)



Tim Scott Senator



Michael Burgess, MD Representative

Substance Abuse and Mental Health Services Administration	Office of Women's Health		
Centers for Disease Control and Prevention	Food and Drug Administration		
Agency for Healthcare Research and Quality	Health Resources and Services Administration		
Office of Minority Health	Centers for Medicare and Medicaid Services		

Figure 8. Federal Working Group

National Institutes of Health

distant antecedent to the current law, initiated the Comprehensive Sickle Cell Centers Program, the engine of the greatest medical advances to date in SCD.¹⁹ The 2018 act is a first step in recapturing that momentum.

Expansion of Data Collection by the Centers for Disease Control and Prevention (CDC). Another important recent initiative by the OASH is the expansion of the CDC's SCD data collection program, which collects health information about people with SCD to assess long-term trends in diagnosis, treatment, and healthcare access. Until now, Georgia and California have been the only state participants.²⁰ The CDC and OASH added \$1 million in additional funding in 2019 and will add another \$1 million in 2020. This supplemental support will allow the expansion of data collection to nine states covering up to 32% of people with SCD in the US.

Office of Minority Health of OASH. The Office of Minority Health of OASH has important new initiatives aimed at improving care for people living with SCD. A stakeholder engagement workshop will inform a possible SCD National Quality Improvement Effort. The workshop will solicit feedback from the SCD community on the Quality Improvement Effort proposed by the two medical professional societies most invested in SCD care and management, the American Society of Hematology (ASH) and the American Board of Pediatrics (ABP).

The Office of Minority Health will also pilot a new program of targeted outreach to primary care providers (PCPs), including providers at federally quality health centers (FQHCs) and student health clinics at historically black colleges and universities (HBCUs). This SCD Training and Mentoring Program for Primary Care Providers (STAMP) aims to tap into the potentially rich reserve of PCPs who, with appropriate training and support, could address the critical shortage of providers for people with SCD.²¹ In addition to these efforts, the Office of Minority Health will devote \$3 million (FY2020) for the development and implementation of an innovative care model for adolescents and young adults with SCD to improve longevity and quality of life.

Research

The National Institutes of Health (NIH), the arm of DHHS that focuses on research rather than patient

care, will devote approximately \$110 million to SCD-related research in FY2020. Patient care will benefit indirectly from NIH support of research that promotes innovative approaches to ensuring the delivery of evidence-based care. The NIH continues to fund basic and clinical research that catalyzes innovative therapies that enhance health outcomes and show promise for the eventual cure of SCD. Finally, the NIH is expanding its ken beyond the US to promote capacity building and research that enables SCD diagnosis, surveillance, and care delivery globally, especially in Africa.

Healthcare Coverage

Payment for healthcare is a challenging issue in the US. Medical care for a substantial proportion of patients with SCD relies on Medicaid programs.²² An important innovation in this arena is the Integrated Care for Kids (InCK) Model. This child-centered local service delivery and state payment model aims to reduce expenditures and improve the quality of care for children covered by Medicaid and Children's Health Insurance Program (CHIP), especially those with or at-risk of developing significant health needs. The goals of this new comprehensive care model for SCD are:

- Improved performance on priority measures of child health
- Reduction in avoidable inpatient stays and out-of-home placements
- Creation of sustainable Alternative Payment Models (APMs)

Global Outreach on SCD

Lastly. Admiral Giroir's Office has taken on the most daunting issue in SCD, namely the burden of care in sub-Saharan Africa. An estimated 300,000 to 400,000 children in this region are born each year with SCD, which equates to approximately 1,000 births per day (compared with about 1,000 per year in the US).²³ The 5-year mortality rate ranges between 50% and 80%.²⁴ Admiral Giroir hosted a roundtable on SCD attended by seven African delegations, professional societies, NGOs, and commercial corporations, as well as the WHO's chief scientist. A follow-up meeting, WHO-AFRO, was held in Brazzaville, Congo, in August 2019. The dialogue continued at a meeting during the UN General Assembly in New York in September 2019. Admiral Giroir's impact on SCD is truly global.

Following Admiral Giroir's keynote address, the Summit turned to the roles of providers, payers, and policymakers in access-to-care for people with SCD.

FOCUS ON PROVIDERS: ADDRESSING THE DEFICIT IN SCD PROVIDER SKILLS AND NUMBERS

In 2016, ASH presented its report card on the state of SCD, with access-to-care and training/professional education of providers scoring 3.7 and 3.2, respectively, on a 10-point scale (<u>Figure 10</u>).²⁵ The dire need to address these issues is pellucid.

Following overview presentations by Drs. Wally Smith, Tyson Pillow, and Wanda Whitten-Shurney, breakout session participants identified an exten-

Figure 10. Current State of Healthcare for SCD

sive set of providers who ideally should be part of a program of comprehensive care for people with SCD. Medical providers were divided into those who provide long-term care and those who provide intermittent or focused care to patients (Table 1).

Medical Providers: Long-Term Care

Although hematologists are core providers for people with SCD, the number of physicians within the subspecialty who care for patients with nonmalignant conditions is distressingly low.²⁶ The creation of hematology fellowship programs that focus on benign conditions would be welcome additions. Geography and other considerations deprive many hematology trainees of the opportunity to treat people with SCD. This lack of exposure could be



^aHealth insurance, availability of knowledgeable healthcare providers, provider experience, geography, economic status, coexisting conditions. ^bNot enough healthcare providers with SCD expertise, unpredictable and persistent pain, complications → management challenges. Primary care feels they have inadequate SCD background.

American Society of Hematology. 2016 Report Card. www.scdcoalition.org/pdfs/ASH%20Sickle%20Cell%20Disease%20Report%20Card.pdf.

Table 1. Providers in SCD Comprehensive Care Programs

Modical Providers							
Long-term care	Intermittent/focused care						
□ Hematologists	□ ED personnel ^c						
Nonhematologist SCD specialists ^a	□ Hospitalists						
□ Advanced practice providers ^b	□ Nurses						
Pain management specialists							
Nonmedical providers							
□ Social workers	Genetic counselors						
Therapists/mental health professionals	□ Pharmacists						
Patient navigators	Neurocognition specialists						
Community health workers	Vocational specialists						
alncluding PCPs.							

^bNPs, PAs, etc. ^cPhysicians, NPs, and nurses. addressed in part by the ASH SCD Initiative, which advocates fellowship exchange rotations to programs with robust training in sickle cell care.²⁷ A variant of this idea is a training program in rare blood disorders in which trainees would receive portions of their education at different specialty programs.

Engaging nonhematologists as care specialists for people with SCD is vital to addressing the current provider deficit. FQHCs could be a key support due to their focus on disease prevention and longterm management of chronic illness. Individualized one-on-one training by skilled sickle cell providers could greatly enhance both the knowledge and confidence of PCPs. In addition, treatment programs that share patient care with specialists would allow PCPs to handle many common issues of chronic illness, such as diabetes, while the specialists address SCD-related problems, such as iron overload or chronic pain.

Specialists in pain management are critical partners in the management of SCD given the central role of acute and chronic pain in the disorder. A working partnership between the patient, a sickle cell specialist, and a pain management specialist is essential. Although pain due to acute vaso-occlusion is a hallmark characteristic of SCD, consensus continues to grow around the importance of neuropathic and other pain mechanisms due to chronic organ and nerve injury.²⁸ Pain management regimens must be individualized by a team with comprehensive expertise in the care of patients with SCD.

Advanced practice providers (APPs), particularly nurse practitioners and physician assistants, play an increasingly large role in the management of patients with SCD. The scope of practice for APPs varies between states and locations and must be factored into any plan to provide comprehensive SCD care. Moreover, education is needed for physicians who may sometimes underestimate the role that APPs can play in the management of these complex patients. APPs provide treatment and oversight continuity, especially with the turnover of transient providers such as those in fellowship training.

Medical Providers: Intermittent/Focused Care

Because emergency department (ED) personnel are on the front line of emergency care, they are crucial to the management of people with SCD. Due to the stochastic pattern of acute sickle cell events and the variability in providers' on-call schedules, however, building personal familiarity and trust is difficult, and sustaining provider/patient relationships over time is rarely possible. Moreover, providers are often unfamiliar with the intricacies of the disorder and may have slanted perspectives based on a small subset of patients who frequent the ED.

A treatment algorithm can guide providers through management uncertainties, thus benefiting both providers and patients. Another suggestion is the creation of healthcare information exchanges in which ED physicians network in real time with ED SCD specialists, irrespective of provider location. Teleconsultation is another tool that can improve ED care of people with SCD by directly connecting the frontline personnel with experienced and knowledgeable providers.

The education of ED personnel is crucial to improving SCD care. Sensitivity training can help providers avoid scenarios that may be unintentionally confrontational or accusatory. SCD champions among ED personnel are vital as they can provide the leadership needed to address and resolve issues of bias and lack of understanding. Another suggestion is providing an area-wide training symposium aimed at ED personnel, PCPs, and APPs. Patients with SCD routinely report experiencing treatment delays in the ED. Most patients seek ED treatment only when they have no other resources available. Establishing a nursing rapid triage system to provide patients quickly with IV fluids and pain medications would greatly improve ED care and reduce tension for everyone.

Hospitalists are also key providers for patients with SCD because they assume the care and management of many patients moving from the ED into the hospital. As with ED providers, establishing enduring provider/patient relationships is challenging due to the division of coverage into shifts. However, in-hospital care often lasts for days rather than the hours typical of the ED, making consistent communication with the patient's long-term care team even more important. The hand-off of patients between hospitalists on different shifts must consider not only immediate issues such dose adjustments of parenteral analgesics but also longer-term issues such as adequate stabilization of underlying conditions that can cause early hospital readmission.²⁹ Improved working relations between SCD specialists and hospitalists can enhance the skills and comfort of the latter while apprising the former of evolving challenges to in-hospital patient management. Such interactions are ideally suited to individualized education. Departments of medicine and hospital administration can provide crucial support for education. The Society of Hospital Management might also weigh in to improve these relationships.

Nonmedical Providers

Nonmedical providers play crucial roles in comprehensive care for people with SCD. Indeed, social workers, mental health professionals, and therapists help patients navigate issues ranging from depression and low self-esteem to work- and school-related challenges. Medical and other bills are burdensome consequences of chronic illness that hamper optimal medical care. For instance, a prescribed medication will not help a patient if it is unaffordable. Additionally, missed appointments severely impede proper care. However, the lack of child care can make such events unavoidable. The deficit in social workers, mental health professionals, and therapists can be corrected only through commitment from hospital administrators who allocate institutional resources.

Patients with SCD face several challenges, including navigating a maze of providers, scheduling and keeping track of appointments, and managing a large array of medications and medical regimens. Patient navigators help patients with all of these aspects, thereby improving healthcare outcomes. In addition, patient navigator programs are associated with fewer missed appointments, which correlate with costly hospitalizations and readmissions.³⁰ Despite this critical role, these providers are often labeled as ancillary. Programs and efforts that maintain navigators as part of the healthcare team are essential.

Neurocognitive deficits are increasingly recognized as daunting issues for children and adults with SCD.^{31,32} Strokes and silent cerebral infarction can produce neurocognitive impairment, but these problems also occur in the absence of injury detectable by examination or imaging and correlate with the degree of anemia.^{33,34} Specialists in neurocognitive testing are essential members of the healthcare team whose work provides insight into this crucial type of injury. Neurocognitive testing is not universal in children and is uncommon in adults due to challenges in insurance coverage and reimbursement. Lobbying for increased coverage in this key area is vital to the future well-being of people with SCD.

Key Roles of Patients and Community-Based Organizations

Although the sessions focused on providers, the attendees strongly emphasized the important role of patients in their own care and in the enlightenment of healthcare providers. Patients who can advocate for themselves are more successful in obtaining the care they need. Community-based organizations can be a platform to promote self-advocacy by facilitating discussions among patients to share strategies and lessons learned.

Patients can help providers by consolidating their care at one institution, thereby facilitating communication among the various specialists. Figure 11 is an example of a patient information card, sometimes called a passport, which summaries information that is important to providers, particularly in the ED. Patients can facilitate the inevitable questions about medical history by asking their primary provider for this or similar information. Other information includes:

- Medications
- Hospitalizations
- Transfusion history
- Surgical history

- · ·

- Important diagnostic studies
- Medical appointments

Most importantly, patients can work with providers at every level to build trust.

Figure 11. Example of Key Information for a Patient Information Card

Patient Name/Address/Phone Number

Provider					
Facility/Hospital					
Type of sickle cell	SS	SC	S-beta thal 0	S-beta thal plus	other
Usual hemoglobin					
RBC allo-antibodies					
Allergies					

FOCUS ON PAYERS: NAVIGATING THE EMERGING COMPLEXITY OF TREATMENT COVERAGE

Access-to-Care Challenges

Health insurers have a limited understanding of the complexities of SCD because of its rarity and the paucity of new treatments. As new diagnostic tools and medications become available, however, it is anticipated that health plans will begin requiring prior approval for these new, innovative treatments. Therefore, the implementation of new health plan management tools could have the unfortunate collateral effect of restricting access to new treatments.

The Role of Key Stakeholders: Prescribing Physician, Manufacturer, Payer, Patient, and Community-Based Organizations

Payers welcome input from prescribing physicians and manufacturers when new therapies address underserved conditions like SCD (Figure 12). Payers commonly rely on treatment guidelines to inform decision making. Unfortunately, guidelines are not automatically updated following the FDA approval of new drugs. Months and even years can elapse between treatment approval and the incorporation of that treatment into clinical practice guidelines. During that gap, prescribing physicians and manufacturers can provide payers with current clinical data to support coverage determination for new, innovative treatments. Importantly, physicians should initiate dialogue with their local health plans (commercial, Medicare, Managed Medicaid, and State Medicaid) prior to the FDA approval of new therapies.

The Pharmacy and Therapeutics (P&T) Review Process (Figure 13)

Role of Prescribing Physicians

Physicians can share both knowledge and clinical perspectives with payers before or during the P&T review process. Educating payers is key, especially when there exists neither established

Clinical

Research

Manufacturer

treatment guidelines nor recommendations on the positioning of new options in the treatment hierarchy. Management of prior authorizations entails substantial costs in terms of time and money. More importantly, during this time, patient suffering is unaddressed. Payers should be made aware of the cost impact of managing prior authorizations to the prescriber's practice and the impact of treatment delay to patients. The key insight is that prescribers need to interface with the health plan's clinical staff/medical director for SCD coverage review and prior authorizations development.

- Role of Prescribing Physicians to Payers Prescribing physicians can provide key information to payers including:
 - Efficacy and outcomes information
 - National treatment guidelines
 - Clinical studies
 - Real-world experience
 - Place in therapy

For State Medicaid specifically, physicians can become involved early in the process, serving as a resource for the P&T committee. Physicians should contact their State Medicaid pharmacy director/ department concerning the issue.

Both regional and national payers often identify and proactively reach out to specialists in the treatment of specific conditions during their internal review. In other cases, prescribers may become aware of a specific payer policy and can reactively reach out to

Figure 12. Interactions Between Prescribing Physicians, Manufacturers, and Payers



Figure 13. The P&T Review Process

FDA

Approval

a regional or national payer concerning appropriate timing and mechanisms by which contributions can be made to decisions concerning coverage.

• Role of the Manufacturer in Creating Coverage (Figure 14)

- Present comprehensive disease state information and data to payers supporting access to new therapies and medically appropriate coverage criteria
- Display strong clinical trial data to encourage reimbursement by payers and have supplemental programs to ensure that medications are affordable for patients
- Support programs during preapproval that include education on the number of specialists and the location of key treatment centers
- Provide prescribing physicians with key payer

Figure 14. Role of the Manufacturer in Creating Coverage



Figure 15. Patient's Role Following FDA Drug Approval

Identify Resources Available Obtain Authorization and Understand Your Healthcare Benefits for SCD Patients Appeal a Denial Choose the Work With Your Appropriate **Government Programs Healthcare Provider Health Plan** Manufacturer **Programs** Advocacy Support What can patients do to successfully gain coverage?

contact information to facilitate the sharing of realworld clinical experience and relevant clinical data

- Educate prescribing physicians on the drugapproval process for local health plans
- Share website information whereby the prescribing physician and office staff can obtain coverage criteria information
- Provide payers with an Academy of Managed Care Pharmacy (AMCP) dossier and other pertinent clinical information, including FDA-approved package insert
- Submit real-world data and health economics and outcomes research information
- Respond to challenging payer coverage policies with payer education and integration of the HUB, specialty pharmacy partners, and field organization
- Patient's Role Following FDA Drug Approval (Figure 15)
 - Understand their healthcare benefits and choose a health plan that supports their medical needs, requires minimal out-of-pocket expenses, and maintains access to new therapies for SCD as well as access to appropriate medical professionals
 - Identify resources created for people with SCD including those provided by prescribing physicians, government entities, advocacy groups, and manufacturers
 - Secure coverage for new SCD medications through teamwork with the prescribing physician; working with physicians can help ensure that payers receive the information needed to make an informed coverage determination

Figure 16 summarizes the final takeaway from the breakout groups. After much discussion and sharing of ideas, the groups supported the following:

- Payer coverage criteria for new SCD therapies should support physician use of best medical judgment based on clinical data
- Coverage criteria should be based on both clinical trial data and the opportunity to improve patient quality of life
- Reducing barriers to SCD treatments and diagnostic tests can decrease the overall cost of healthcare because patients are complex, have multiple comorbidities, and require individualized treatment strategies

Key Role of Patients and Community-Based Organizations

Community-based organizations can play a vital role in supporting both patients and prescribing physicians by attending public payer panels such as State Medicaid P&T Committee meetings and discussing the work being done for and with patients living with SCD. Treatments should reflect benefits for people, not merely endpoints and statistics. The human face of suffering on the one hand and of hope on the other must be clear.

Attendees in the breakout groups reinforced the importance of improving dialogue related to ensuring coverage of new therapies for people with SCD. Payers, prescribing physicians, and advocates in the breakout groups identified specific ways to share information and positively influence coverage criteria. The process revolves around gathering clinical data and sharing medical experiences with local health plans and State Medicaid pharmacy directors.

FOCUS ON POLICY: IMPORTANCE OF ADVOCACY TO SUPPORT SCD POLICY

Figure 17. The First Amendment



Congress shall make no law respecting an establishment of religion, or prohibiting the free

exercise thereof; or abridging the freedom of speech, or of the press; or the right of people peaceably to assemble, and to petition the Government for a redress of grievances." [sic]

- US Constitution

Effective state- and federal-level advocacy is critical to the development of public policies that address the challenges and promote the objectives of patients, families, caregivers, physicians, and other stakeholders involved in managing the breadth of issues facing patients with SCD. These challenges include a lack of federal and state funding for the development and delivery of high-quality and coordinated healthcare services, insufficient numbers of specialists and other healthcare providers focused on treating patients with SCD, over-reliance on EDs to provide acute care services, lack of effective treatment options for patients, and barriers to timely patient access to new therapies and services in federal and state programs, such as Medicaid.

Despite the reauthorizations of the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention and Treatment Act in December 2018, minimal federal support has



Figure 16. Maximizing Medication Access for Patients With SCD

been invested in improving the lives of patients with SCD, particularly compared with that provided to diseases that affect fewer people, such as cystic fibrosis and hemophilia. To advance meaningful policy solutions at the federal and state levels, effective advocacy by patients, community-based organizations, healthcare providers, and other interested stakeholders is critical.

This session of the Access-to-Care Summit was designed to emphasize the importance of effective advocacy, demystify advocacy as appropriate only for professional advocates/lobbyists, and provide concrete suggestions and methods for success.

Plenary Session

During the plenary, five key principles for effective advocacy were outlined:

1. Do Your Homework

- Know who you're meeting and why (eg, constituent focus or issue focus)
- Know the facts about your issue(s)
- Does the person you're meeting with have a track record on the issue(s) you can leverage?
- 2. Tell the Truth and Get Personal (When Appropriate)
 - Your personal story has a tremendous impact
 - Always tell the truth; you want to be invited back!

3. Keep It Simple and Conversational

- Have an ask when possible or be clear that the meeting is informational only
- Staff members are busy, so being direct and concise is always appreciated

4. Accept Your Friends Where You Find Them

- Politics truly does make for strange bedfellows
- Check your personal politics at the door
- Build coalitions of champions and supporters; more voices are better than one

5. Be Patient and Flexible, but Persistent

- Follow up, follow up, follow up
- Send a thank you email and briefly reiterate your message and ask
- Continue to check in with those you meet
- Don't be shy; be persistent, but remember that staff members are juggling multiple issues so responses may be slow

Senator Tim Scott (R-SC) and his top health policy advisor both confirmed and emphasized the importance of direct and sustained engagement to their efforts to advance SCD policy.

Breakout Session

During the breakout session, participants discussed:

- 1. Principles
- 2. Preparation
- 3. Process
- 4. Practice

Principles

Advocacy is vital to the legislative process. Federal and state policymakers and legislators meet with advocates, constituents, and many others who educate them about issues and ask them to take action on legislation. Constituents are powerful advocates and are often the best source of information and perspective needed to educate government officials about issues on which they are voting. Because constituents live in the district/state of the legislators, constituents are some of the most effective advocates.

Preparation

Before conducting high-impact meetings, it is important to prepare your message using the following suggestions:

- Introduction
 - Introduce yourself
 - Describe the purpose of the meeting (eg, request that Congress or State legislature [through oversight and funding] ensure that patients living with SCD have access to high-quality services and therapies)
- Share your experience as an individual with SCD, caretaker, or healthcare provider
 - Speak about how SCD personally affects you and your family on a daily basis
- Facts about SCD:
 - SCD is a disabling inherited blood disorder that causes the production of abnormally shaped (sickled) red blood cells that stick together and block the flow of blood and oxygen
 - It affects approximately 100,000 patients in the US; the disease is concentrated in populations of African, Middle Eastern, and South Asian descent³⁵
 - SCD leads to severe medical problems, including anemia, jaundice, gallstones, strokes, restricted blood flow, damaged organ tissues, episodes

of considerable pain in the arms, legs, chest, and abdomen, and death $^{\rm 36}$

- The average life expectancy of individuals with SCD is shorter by approximately 30 years³⁷
- Share your experience accessing services and therapies
- Facts about access:
 - Individuals living with SCD often encounter barriers to obtaining quality care, including limitations in access to comprehensive care, suboptimal treatments, the high reliance on emergency care, and the limited number of specialists to manage and treat SCD
 - A significant percentage of patients are covered by Medicaid (~50%) and Medicare (~15%)³⁸
 - Fewer than 10% of Medicaid patients have access to a specialist $^{\scriptscriptstyle 38}$
 - About 20% of SCD patients receive most of their care in the ED setting³⁹
- State your objective—is the meeting objective to educate or make an ask? For example, advance/ support policy to ensure access to therapies and services
 - Congress/State legislature should ensure that patients living with SCD have access to highquality services and therapies
 - Congress has had a longstanding interest in addressing SCD: in 2004, Congress enacted the Sickle Cell Treatment Act (SCTA) to provide a new optional benefit for states under the Medicaid program, and last year, Congress passed the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018
 - Revolutionary treatments for SCD have the potential to change the course of the disease; however, breakthrough treatments for SCD will be meaningful only if those who are suffering have access
 - States often erect undue administrative hurdles that delay access to new medicines for months to years under Medicaid (some states routinely wait several months before reviewing or considering new and innovative treatments for coverage, some utilize prior authorization committees or drug utilization review boards to delay Medicaid coverage and access)
 - Through its oversight role and in collaboration with the Centers for Medicare and Medicaid Services, Congress/State legislatures should ensure that states provide immediate access to innovative breakthrough therapies
 - We also need Congress to prioritize SCD policy and pursue ways to increase access to comprehensive services and treatment for SCD

patients, including access to specialists and high-quality, coordinated care, through increased funding and education

Process: Congressional Advocacy Guide

Overview of Congress. The US Congress makes laws that affect our daily lives. It holds hearings to inform the legislative process (Figure 18), conducts investigations to oversee the executive branch, and serves as the voice of the people and the states in the federal government. Congress is divided into two institutions: the House of Representatives and the Senate.

House of Representatives. The House is the larger of Congress's two legislative bodies. Its membership is based on the population of each state, and the House sits for re-election every 2 years. By law, its current membership is set at 435 Representatives, plus nonvoting delegates from the District of Columbia and the US territories. The leader of the House is the Speaker. The House has a Democratic majority in the 116th Congress, with Nancy Pelosi (D-CA-12) serving as the current Speaker, and Kevin McCarthy (R-CA) serving as Minority Leader.

Senate. In the Senate, all states are represented equally. Regardless of size or population, each state has two senators who serve 6-year terms. The Senate shares full legislative power with the House. In addition, the Senate has exclusive authority to approve—or reject—presidential nominations to executive and judicial offices and to provide—or withhold—its advice and consent to treaties negotiated

Table 2. Policy and Advocacy Resources

- American Society of Hematology. Sickle Cell Disease.
 www.hematology.org/Patients/Anemia/Sickle-Cell.aspx
- □ Centers for Disease Control and Prevention. Sickle Cell Disease (SCD). www.cdc.gov/ncbddd/sicklecell/index.html
- National Heart, Lung, and Blood Institute. Sickle Cell Disease.
 www.nhlbi.nih.gov/health-topics/ sickle-cell-disease
- Centers for Medicare and Medicaid Services.
 <u>www.cms.gov/About-CMS/Agency-Information/</u>
 <u>OMH/research-and-data/information-products/</u>
 <u>data-highlights/Prevalence-of-Sickle-Cell-</u>
 <u>Disease-among-Medicaid-Beneficiaries-in-2012.</u>
 <u>html</u>

HOW DOES A BILL BECOME A LAW?



by the executive branch. The Senate also has the sole power to try impeachments. The Senate presently has a Republican majority, with Senator Mitch McConnell (R-KY) serving as the current Majority Leader of the Senate, and Senator Chuck Schumer (D-NY) serving as the current Minority Leader.

Legislative Staff. Legislative staff play an important role in Congress and serve as an extension to their boss (the Member). Most meetings with advocates are with legislative staff who focus on the technical aspects of legislation and advise their boss. Developing a relationship with legislative staff will lead to effective advocacy. Legislative staff includes chiefs of staff, legislative directors, legislative assistants and correspondents, communications directors, schedulers, and interns.

How to Contact Staff US House of Representatives switchboard: 202-225-2321

House email convention: jane.doe@mail.house.gov

US Senate switchboard: 202-224-2321

Senate email convention: jane_doe@senator last name.senate.gov

Practice. Practice. Practice.

Breakout participants practiced with two former seasoned Hill staff who provided real-life examples of the types of behaviors and experiences to expect. Participants were able to practice messaging as well as advocacy strategies and styles, then assess effectiveness. In all cases, the discussions were relevant and the experiences impactful. Participants came away with a greater understanding of the process, the need for and importance of advocacy at the state and federal levels, and tangible experience.

LAST WORDS

For people living with SCD, the road to equal healthcare access has been long, winding, and often uphill. At times, these sickle cell warriors have resembled Sisyphus, watching as the boulder rolled down the hill after each day of effort. There is, however, hope for the future. A plethora of new therapies are being developed by pharmaceutical companies large and small, new and old. Law- and policymakers are coming to see equitable healthcare in SCD as a litmus test of the American dream. Public debate over comprehensive healthcare coverage is turning slowly from whether it should happen to how it should happen. Recognition is dawning that chronic health problems are best approached with an eye to the horizon rather than the ground immediately afoot. There is hope. To quote Winston Churchill following an early victory in the fight against fascism:

"Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning."

REFERENCES

- 1. Herrick JB. Peculiar elongated and sickle-shaped red blood corpuscles in a case of severe anemia. *Arch Int Med.* 1910;5:517-521.
- Pauling L, Itano HA, Singer SJ, Wells IC. Sickle cell anemia, a molecular disorder. *Science*. 1949;110(2865):543-548.
- Ingram VM. A specific chemical difference between the globins of normal human and sickle-cell anaemia haemoglobin. *Nature*. 1956;178(4537):792-794.
- Platt OS, Brambilla DJ, Rosse WF, et al. Mortality in sickle cell disease. Life expectancy and risk factors for early death. N Engl J Med. 1994;330(23):1639-1644.
- Lanzkron S, Carroll CP, Haywood C Jr. Mortality rates and age at death from sickle cell disease: U.S., 1979-2005. *Public Health Rep.* 2013;128(2):110-116.
- Kassim AA, Sharma D. Hematopoietic stem cell transplantation for sickle cell disease: the changing landscape. *Hematol Oncol Stem Cell Ther.* 2017;10(4):259-266.
- US Food and Drug Administration. Hydroxyurea prescribing information. <u>www.accessdata.fda.gov/drugsatfda_docs/</u> <u>label/2012/016295s041s042lbl.pdf</u>. Accessed December 20, 2019.
- US Food and Drug Administration. L-glutamine prescribing information. <u>www.accessdata.fda.gov/drugsatfda_docs/</u> <u>label/2017/208587s000lbl.pdf</u>. Accessed December 20, 2019.
- 9. US Food and Drug Administration. Crizanlizumab-tmca prescribing information. <u>www.accessdata.fda.gov/drugsatfda_docs/</u><u>label/2019/761128s000lbl.pdf</u>. Accessed December 20, 2019.
- 10. US Food and Drug Administration. Voxelotor prescribing information. www.accessdata.fda.gov/drugsatfda_docs/label/2019/213137s000lbl. pdf. Accessed December 20, 2019.
- 11. Andemariam B, Eckman J, Campbell A, Smith-Whitley K, Strouse JJ, Desai P, Kanter J, Bridges K.
- Global Blood Therapeutics, Inc. Sickle Cell Disease. Access-to-Care Summit 2018. <u>www.gbt.com/file.cfm/89/docs/ATCS-2018-White-Paper.pdf.</u> Accessed February 5, 2020.
- US Census Bureau. The Black Population: 2010. <u>www.census.gov/</u> prod/cen2010/briefs/c2010br-06.pdf. Accessed January 15, 2020.
- Haque A, Telfair J. Socioeconomic distress and health status: the urban-rural dichotomy of services utilization for people with sickle cell disorder in North Carolina. J Rural Health. 2000;16(1):43-55.
- Woods K, Kutlar A, Grigsby RK, Adams L, Stachura ME. Primarycare delivery for sickle cell patients in rural Georgia using telemedicine. *Telemed J.* 1998;4(4):353-361.
- Stewart RW, Whiteman LN, Strouse JJ, Carroll CP, Lanzkron S. improving inpatient care for individuals with sickle cell disease using the Project ECHO model. South Med J. 2016;109(9):568-569.
- Hamideh D, Alvarez O. Sickle cell disease related mortality in the United States (1999-2009). *Pediatr Blood Cancer*. 2013;60(9):1482-1486.
- Syrop J. Bill addressing sickle cell disease/heritable blood disorders signed into law. December 29, 2018. <u>www.ajmc.com/</u><u>newsroom/bill-addressing-sickle-cell-diseaseheritable-blood-disorders-signed-into-law</u>. Accessed January 15, 2020.
- 19. Manley AF. Legislation and funding for sickle cell services, 1972-1982. Am J Pediatr Hematol Oncol. 1984;6(1):67-71.
- Paulukonis ST, Harris WT, Coates TD, et al. Population based surveillance in sickle cell disease: methods, findings and implications from the California registry and surveillance system in hemoglobinopathies project (RuSH). *Pediatr Blood Cancer*. 2014;61(12):2271-2276.
- 21. Lunyera J, Jonassaint C, Jonassaint J, Shah N. Attitudes of primary care physicians toward sickle cell disease care, guidelines, and comanaging hydroxyurea with a specialist. *J Prim Care Community Health.* 2017;8(1):37-40.

- 22. Dampier C, Kanter J, Howard R, et al. Access to care for Medicaid and commercially-insured United States patients with sickle cell disease. Presented at the American Society of Hematology, 59th Annual Meeting; December 9-12, 2017. Abstract 4660.
- Piel FB, Patil AP, Howes RE, et al. Global epidemiology of sickle haemoglobin in neonates: a contemporary geostatistical model-based map and population estimates. *Lancet.* 2013;381(9861):142-151.
- Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB, Williams TN. Sickle cell disease in Africa: a neglected cause of early childhood mortality. *Am J Prev Med*. 2011;41(6 Suppl 4):S398-405.
- 25. American Society of Hematology. State of sickle cell disease. 2016 report card. <u>www.scdcoalition.org/pdfs/ASH%20Sickle%20Cell%20</u> <u>Disease%20Report%20Card.pdf</u>. Accessed October 9, 2019.
- Marshall AL, Jenkins S, Mikhael J, Gitlin SD. Determinants of hematology-oncology trainees' post fellowship career pathways with a focus on nonmalignant hematology. *Blood Adv.* 2018;2(4):361-369.
- 27. ASH Sickle Cell Disease Initiative. <u>www.hematology.org/Advocacy/</u> <u>Sickle-Cell</u>. Accessed October 15, 2019.
- Ballas SK, Gupta K, Adams-Graves P. Sickle cell pain: a critical reappraisal. *Blood*. 2012;120(18):3647-3656.
- Carroll CP, Haywood C Jr, Lanzkron SM. Examination of the patient and hospitalization characteristics of 30-day SCD readmissions. *South Med J.* 2016;109(9):583-587.
- Cronin RM, Hankins JS, Byrd J, et al. Risk factors for hospitalizations and readmissions among individuals with sickle cell disease: results of a U.S. survey study. *Hematology*. 2019;24(1):189-198.
- 31. Wang W, Enos L, Gallagher D, et al; Cooperative Study of Sickle Cell Disease. Neuropsychologic performance in school-aged children with sickle cell disease: a report from the Cooperative Study of Sickle Cell Disease. J Pediatr. 2001;139(3):391-397.
- 32. Vichinsky EP, Neumayr LD, Gold JI, et al; Neuropsychological Dysfunction and Neuroimaging Adult Sickle Cell Anemia Study Group. Neuropsychological dysfunction and neuroimaging abnormalities in neurologically intact adults with sickle cell anemia. JAMA. 2010;303(18):1823-1831.
- Bernaudin F, Verlhac S, Fréard F, et al. Multicenter prospective study of children with sickle cell disease: radiographic and psychometric correlation. J Child Neurol. 2000;15(5):333-343.
- 34. Hijmans CT, Grootenhuis MA, Oosterlaan J, Heijboer H, Peters M, Fijnvandraat K. Neurocognitive deficits in children with sickle cell disease are associated with the severity of anemia. *Pediatr Blood Cancer.* 2011;57(2):297-302.
- Piel FB, Steinberg MH, Rees DC, et al. Sickle cell disease. N Engl J Med. 2017;376(16):1561-1573.
- Kato GJ, Steinberg MH, Gladwin MT. Intravascular hemolysis and the pathophysiology of sickle cell disease. J Clin Invest. 2017;127(3):750-760
- Siddiqi AE, Jordan LB, Parker CS. Sickle cell disease--the American saga. *Ethn Dis.* 2013;23(2):245-248.
- Dampier C, Kanter J, Howard R, et al. Access to care for Medicaid and commercially-insured United States patients with sickle cell disease. *Blood*. 2017;130(Suppl 1):4660.
- 39. November 2017 analysis of administrative claims data for 63,256 patients sourced from Symphony Healthcare Solutions.

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