Wednesday Afternoon Session

- Addressing Institutional Bias and Racism
  - Contextualizing Race, Racism, and Bias in Sickle Cell Disease
    - Dr. Melissa Creary
  - Recognizing and Addressing Implicit Bias
    - Dr. Lori Crosby

- Q & A

- Personal Experiences Panel Discussion
  - Sage Hurd and Charles Carrington

American Society *of* Hematology
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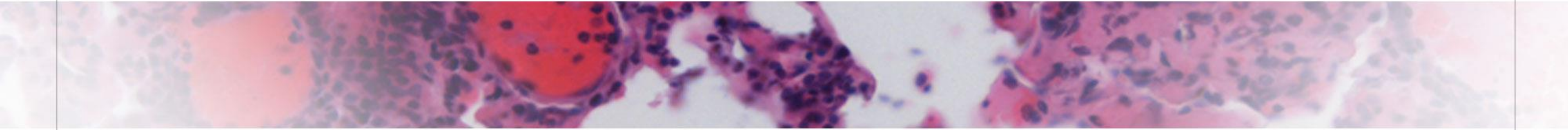


Contextualizing Race, Racism, and Bias in Sickle Cell Disease

Melissa S. Creary, PhD, MPH
University of Michigan, School of Public Health,
Health Management and Policy

Disclosures for Melissa Creary, PhD, MPH

In compliance with ACCME policy, ASH requires disclosures to the session audience:

- **Consultancy**: American Thrombosis and Hemostasis Network, Sage BioNetworks
- **Research Funding**: Robert Wood Johnson Foundation

Discussion of off-label drug use: N/A

Learning Objectives

- Contextualize race, racism, and bias in cases of sickle cell disease (SCD)

- Better understand the needs for and processes toward equity for SCD

- Reflect on questions towards individual and collective action

Shared Understandings

Bias

- Implicit bias → a form of bias that occurs automatically and unintentionally, that nevertheless affects judgments, decisions, and behaviors

- Institutional bias → involves discriminatory practices that occur at the institutional level of analysis, operating on mechanisms that go beyond individual-level prejudice and discrimination

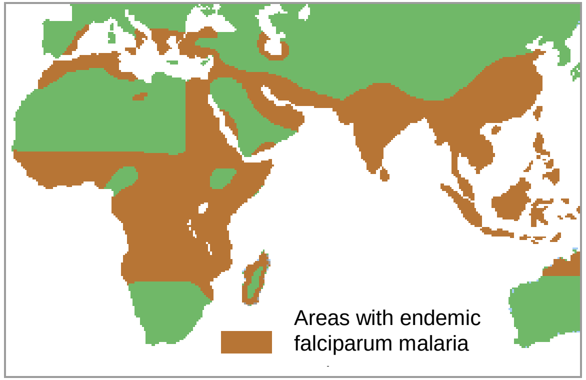
Health Disparities

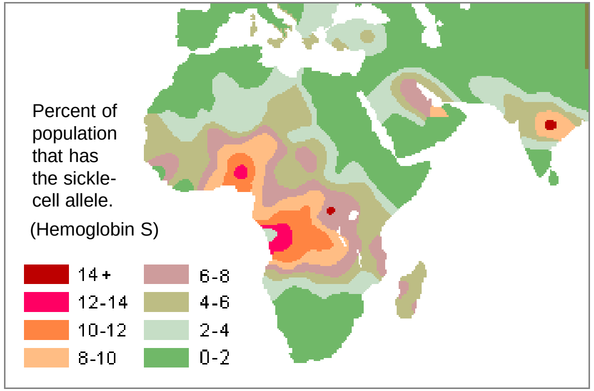
Health disparities are systematic, plausibly avoidable health differences adversely affecting socially **disadvantaged** groups

- Racial or ethnic group
- Religion
- Socioeconomic status
- Gender
- Age
- Mental health
- Culture
- Cognitive, sensory, or physical disability
- Sexual orientation or gender identity
- Geographic location
- Other characteristics historically linked to discrimination or exclusion

SCD as a Racialized Disease

- Etiology historically associated with Black race
- Hemoglobin S correlates with the geographic distribution of malaria, not with race
- Notions of invisibility—
  - Hispanics
  - Northwestern Indians
  - Mediterranean Whites
  - Saudi Arabians





Lundy Braun. *"Race, Ethnicity, and Health: can genetics explain disparities,"* Perspectives in Biology and Medicine. Volume 45(2), Spring 2002, 159–74.

Discussing Disparity and SCD

Health disparities are systematic, plausibly avoidable health differences adversely affecting socially **disadvantaged** groups

Sickle cell disease (SCD) is both useful and problematic to discuss as a health disparity…

- Useful: serves as a prime example how people are differentially invested in and treated
- Problematic: biological basis for disparity

SCD is a biologically-based disease that is not race limited yet is associated with differential investment and treatment which likely reveals racism as a root cause for disparity

Public Health Definitions of Racism

Camara Phyllis Jones, MD, PhD

A system of structuring opportunity and assigning value based on the social interpretation of how one looks (which is what we call “race”) that:

- Unfairly disadvantages some individuals and communities
- Unfairly advantages other individuals and communities
- Saps the strength of the whole society through the waste of human resources

Public Health Definitions of Racism

David R. Williams, PhD

An organized social system in which the dominant racial group, based on an ideology of inferiority, categorizes and ranks people into social groups called "races" and uses its power to devalue, disempower, and differentially allocate valued societal resources and opportunities to groups defined as inferior

- Functions on multiple levels
- Adaptive and innovative
- Driver of multiple upstream societal factors that perpetuate racial health inequities

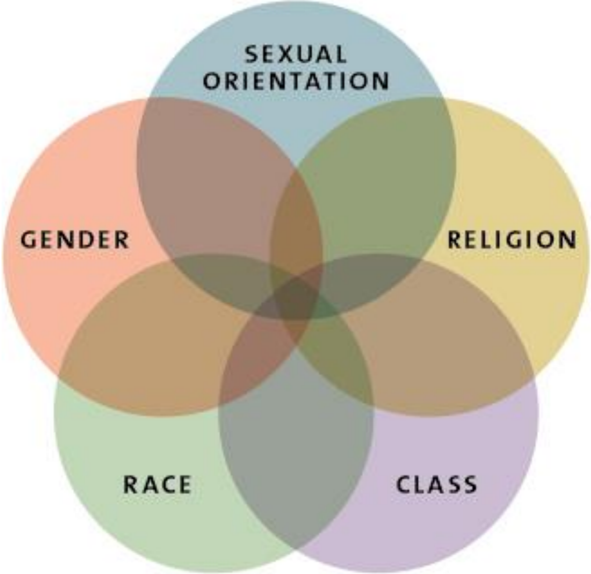
Health Equity: Some Definitions

Disparities in health and its determinants are the metric for assessing health equity

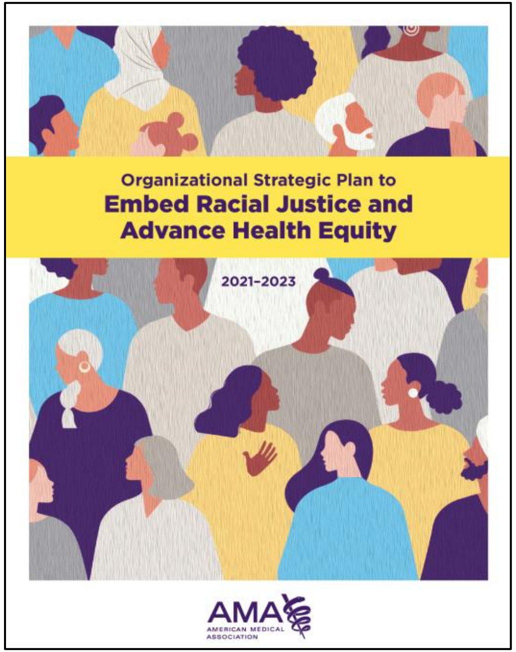
- Health equity is social justice in health
- Equity in health care means equal utilization, distribution according to need, equal access, and equal health outcomes
- Horizontal Equity: Equality of opportunity–equals are treated the same
- Vertical Equity: Equality of outcome–people are treated differently according to their initial endowments, resources, privileges, or rights

Intersectionality

- An analytical framework for understanding how aspects of a person's social and political identities combine to create different modes of discrimination and privilege
- What's needed: the ongoing examination of the overlapping systems of oppression and discrimination that communities face based on race, gender, ethnicity, ability, etc.
- The modes of exclusion are intersectional, not additive



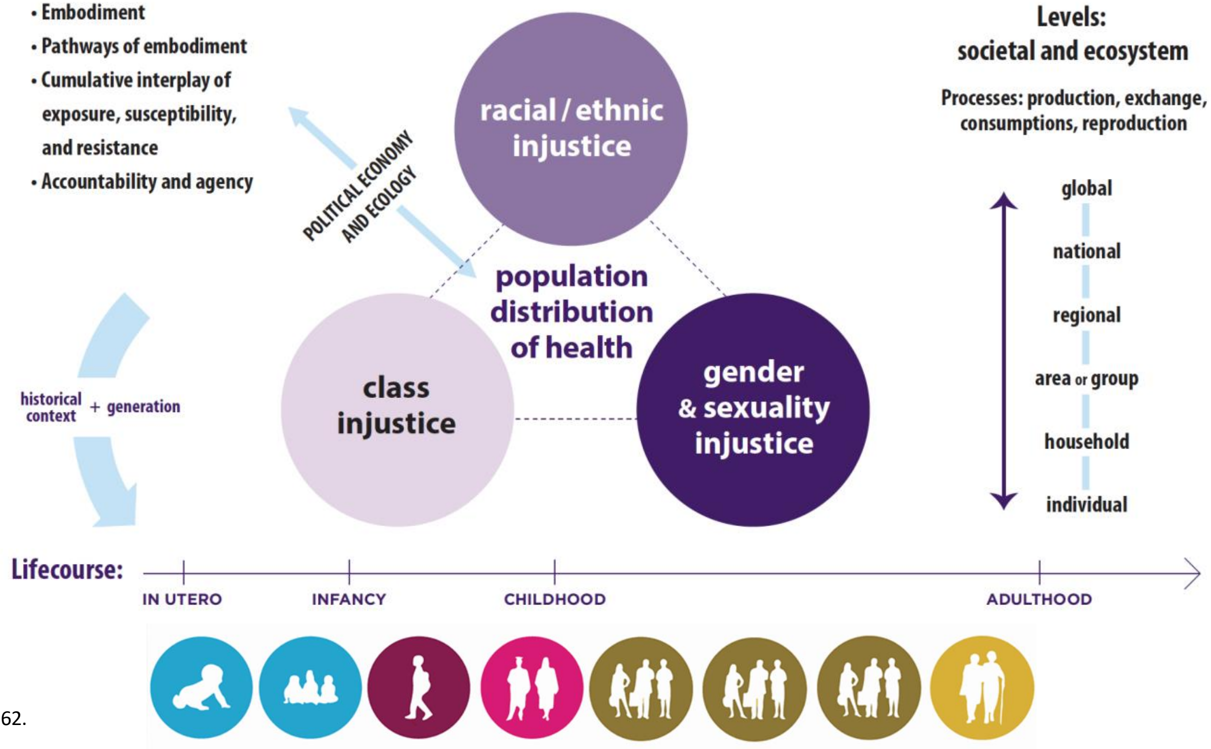
Ecosocial Theory: Levels, Pathways, and Power (Mechanisms of Racism)



Organizational Strategic Plan to
Embed Racial Justice and Advance Health Equity

2021–2023

AMA
AMERICAN MEDICAL ASSOCIATION



- Embodiment
- Pathways of embodiment
- Cumulative interplay of exposure, susceptibility, and resistance
- Accountability and agency

POLITICAL ECONOMY AND ECOLOGY

racial / ethnic injustice

population distribution of health

class injustice

gender & sexuality injustice

historical context + generation

Levels:
societal and ecosystem

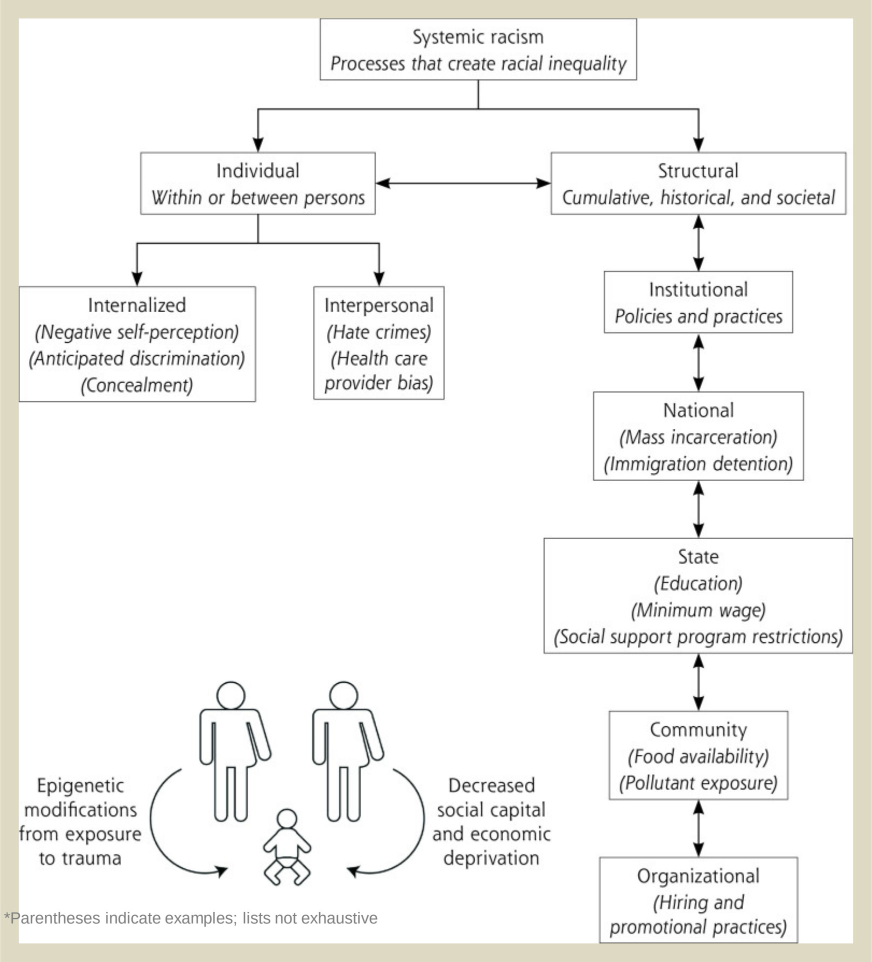
Processes: production, exchange, consumptions, reproduction

global
national
regional
area or group
household
individual

Lifecourse: IN UTERO — INFANCY — CHILDHOOD — ADULTHOOD

Adapted from: Krieger N. *Ann Rev Public Health*. 2020;41(1):37-62.

Elements of Systematic Racism



Systemic racism
Processes that create racial inequality

Individual
Within or between persons

Structural
Cumulative, historical, and societal

Internalized
(Negative self-perception)
(Anticipated discrimination)
(Concealment)

Interpersonal
(Hate crimes)
(Health care provider bias)

Institutional
Policies and practices

National
(Mass incarceration)
(Immigration detention)

State
(Education)
(Minimum wage)
(Social support program restrictions)

Community
(Food availability)
(Pollutant exposure)

Organizational
(Hiring and promotional practices)

Epigenetic modifications from exposure to trauma

Decreased social capital and economic deprivation

*Parentheses indicate examples; lists not exhaustive

Lett E et al. *Ann Fam Med*. 2022;20(2):157-163.

What is Antiracism? What does it mean to be Antiracist?

- Antiracism: A commitment to dismantling racism, which has dimensions that are institutional and social as well as attitudinal and behavioral
- Antiracist Organization: An organization that “acknowledges the destructive power of racism in society, which it attempts to ameliorate, and maintains a critical stance toward its own organizational racism
- Antiracist: One who is expressing the idea that racial groups are equals and none needs developing, and is supporting policy that reduces racial inequity
- Antiracism praxis: A framework to eradicate the disadvantage and oppression caused by racism, which also acts to neutralize racism’s shadow side—white privilege

Ford C et al. *Racism: Science & Tools for the Public Health Professional*. Washington DC, Apha Press, 2019.
Kendi IX. *How to be an Antiracist*. New York, NY, One World, 2019.

Sickle Cell Disease: A Question of Equity

	SCD	Cystic Fibrosis
US prevalence	80,000	30,000
Federal Support (in millions $)	90	128
CF foundation revenue **2003**		$152,231,000
SCDAA revenue **2003**	$498,577	
Total NIH/private support (millions $)	90.4	280.2
Total support /per person affected with disease $	1,130	9,340

Smith LA et al. *Pediatrics.* 2006;117(5):1763-1770.

JAMA Network | Open

Original Investigation | Health Policy

Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity

Faheem Farooq, MD; Peter J. Mogayzel, MD, PhD; Sophie Lanzkron, MD; Carlton Haywood, PhD; John J. Strouse, MD, PhD

Question: Are differences in disease specific funding between sickle cell disease and cystic fibrosis associated with variations in drug development and research publications?

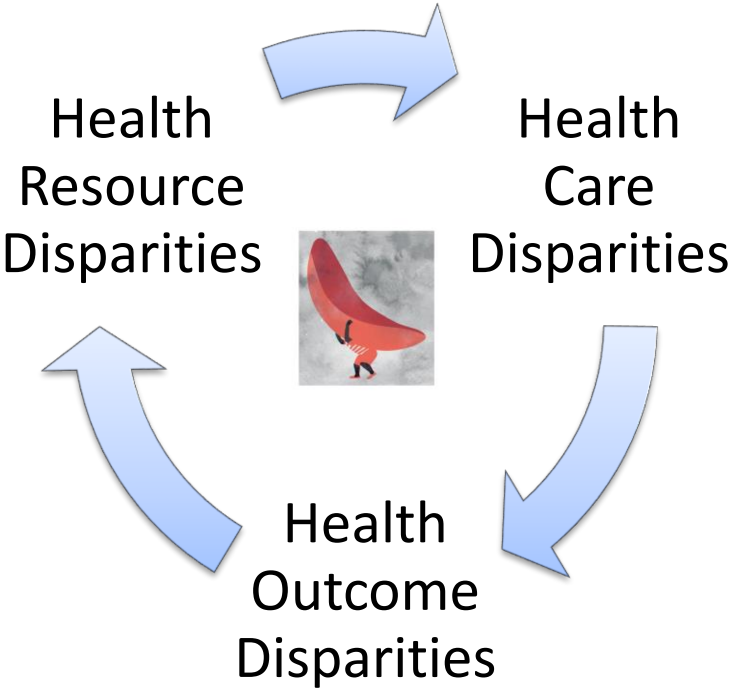
Findings: This cross-sectional study of research funding and outputs for cystic fibrosis and sickle cell disease found that both federal funding and foundation expenditures were greater for cystic fibrosis compared with sickle cell disease. Significantly more research articles and drug approvals were found for cystic fibrosis compared with sickle cell disease, but the total numbers of clinical trials were similar.

Meaning: The findings show that disparities in funding exist between sickle cell disease and cystic fibrosis, and that these disparities may be associated with decreased research productivity and novel drug development for sickle cell disease

Farooq F et al. *JAMA Netw Open*. 2020;3(3):e201737.

Public Health Challenges

The public health burden, lack of understanding, and lack of resources is significant



Health Resource Disparities

Health Care Disparities

Health Outcome Disparities

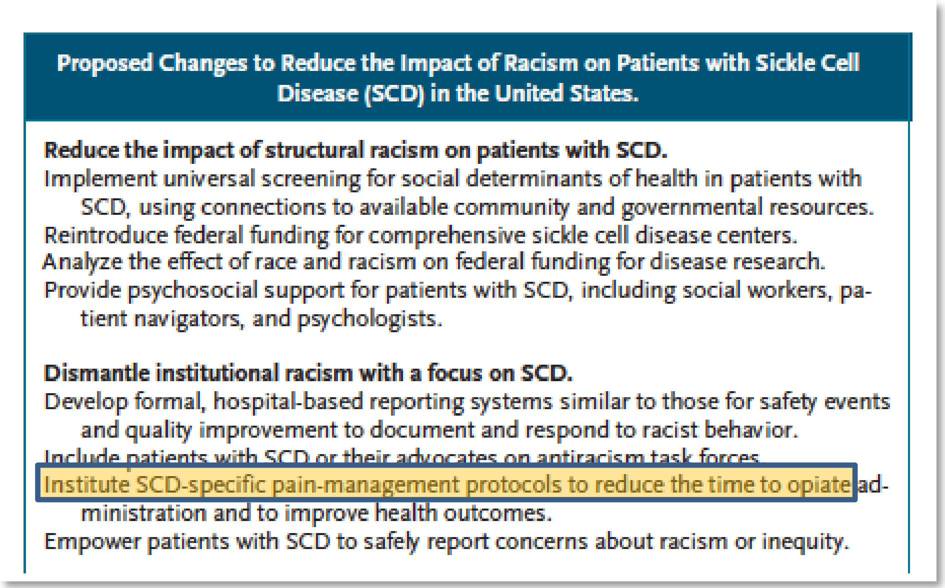
Bounded Justice: A Cautionary Tale

Bounded justice suggests that it is impossible to attend to fairness, entitlement, and equity when the basic social and physical infrastructures underlying them have been eroded by racism and other historically entrenched -isms

Creary MS. *J Law Med Ethics.* 2021;49(2):241–256.

Interrogate Inclusion

Inclusion: The co-creation and continual nurturing of a culture in which all people experience respect, belonging, access to opportunity, and influence through the integration of many cultural backgrounds, ideas, perspectives, and approaches to the work



Proposed Changes to Reduce the Impact of Racism on Patients with Sickle Cell Disease (SCD) in the United States.

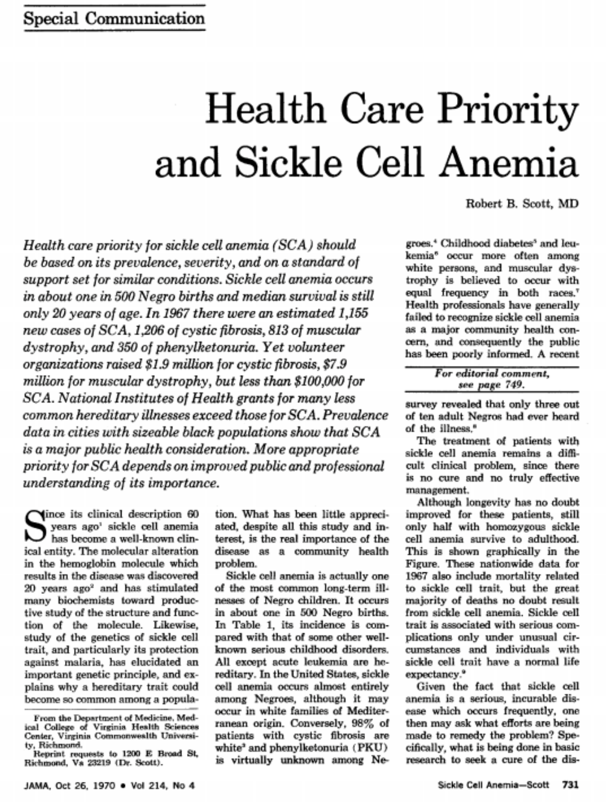
Reduce the impact of structural racism on patients with SCD.
Implement universal screening for social determinants of health in patients with SCD, using connections to available community and governmental resources.
Reintroduce federal funding for comprehensive sickle cell disease centers.
Analyze the effect of race and racism on federal funding for disease research.
Provide psychosocial support for patients with SCD, including social workers, patient navigators, and psychologists.

Dismantle institutional racism with a focus on SCD.
Develop formal, hospital-based reporting systems similar to those for safety events and quality improvement to document and respond to racist behavior.
Include patients with SCD or their advocates on antiracism task forces.
Institute SCD-specific pain-management protocols to reduce the time to opiate administration and to improve health outcomes.
Empower patients with SCD to safely report concerns about racism or inequity.

Artist: Kimberly Winkle

Power-Hays A, McGann PT. *N Engl J Med.* 2020;383(20):1902-1903.

Sickle Cell Disease and the Constant Quest for Equity



Special Communication

Health Care Priority and Sickle Cell Anemia

Robert B. Scott, MD

Health care priority for sickle cell anemia (SCA) should be based on its prevalence, severity, and on a standard of support set for similar conditions. Sickle cell anemia occurs in about one in 500 Negro births and median survival is still only 20 years of age. In 1967 there were an estimated 1,155 new cases of SCA, 1,206 of cystic fibrosis, 813 of muscular dystrophy, and 350 of phenylketonuria. Yet volunteer organizations raised $1.9 million for cystic fibrosis, $7.9 million for muscular dystrophy, but less than $100,000 for SCA. National Institutes of Health grants for many less common hereditary illnesses exceed those for SCA. Prevalence data in cities with sizeable black populations show that SCA is a major public health consideration. More appropriate priority for SCA depends on improved public and professional understanding of its importance.

Since its clinical description 60 years ago[1] sickle cell anemia has become a well-known clinical entity. The molecular alteration in the hemoglobin molecule which results in the disease was discovered 20 years ago[2] and has stimulated many biochemists toward productive study of the structure and function of the molecule. Likewise, study of the genetics of sickle cell trait, and particularly its protection against malaria, has elucidated an important genetic principle, and explains why a hereditary trait could become so common among a population. What has been little appreciated, despite all this study and interest, is the real importance of the disease as a community health problem.

Sickle cell anemia is actually one of the most common long-term illnesses of Negro children. It occurs in about one in 500 Negro births. In Table 1, its incidence is compared with that of some other well-known serious childhood disorders. All except acute leukemia are hereditary. In the United States, sickle cell anemia occurs almost entirely among Negroes, although it may occur in white families of Mediterranean origin. Conversely, 98% of patients with cystic fibrosis are white[3] and phenylketonuria (PKU) is virtually unknown among Negroes.[4] Childhood diabetes[5] and leukemia[6] occur more often among white persons, and muscular dystrophy is believed to occur with equal frequency in both races.[7] Health professionals have generally failed to recognize sickle cell anemia as a major community health concern, and consequently the public has been poorly informed. A recent survey revealed that only three out of ten adult Negros had ever heard of the illness.[8]

For editorial comment, see page 749.

The treatment of patients with sickle cell anemia remains a difficult clinical problem, since there is no cure and no truly effective management.

Although longevity has no doubt improved for these patients, still only half with homozygous sickle cell anemia survive to adulthood. This is shown graphically in the Figure. These nationwide data for 1967 also include mortality related to sickle cell trait, but the great majority of deaths no doubt result from sickle cell anemia. Sickle cell trait is associated with serious complications only under unusual circumstances and individuals with sickle cell trait have a normal life expectancy.[9]

Given the fact that sickle cell anemia is a serious, incurable disease which occurs frequently, one then may ask what efforts are being made to remedy the problem? Specifically, what is being done in basic research to seek a cure of the dis-

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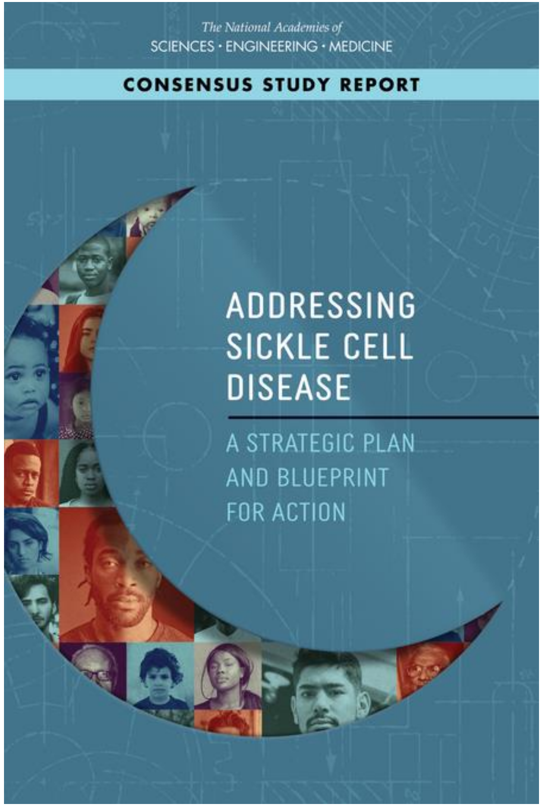
From the Department of Medicine, Medical College of Virginia Health Sciences Center, Virginia Commonwealth University, Richmond.

Reprint requests to 1200 E Broad St, Richmond, Va 23219 (Dr. Scott).



The National Academies of
SCIENCES · ENGINEERING · MEDICINE

CONSENSUS STUDY REPORT

ADDRESSING SICKLE CELL DISEASE

A STRATEGIC PLAN AND BLUEPRINT FOR ACTION

Scott RB. *JAMA*. 1970;214(4):731-734.

Quest for Equity: The Way Forward

- At *every* step, engage those whom have been historically disadvantaged in the bleeding disorder community
  - How can your healthcare system earn the trust of these populations?
- Though the quest should be scientific, it is also undergirded by the values of the healthcare system and the individuals in power within that system
- Do not ask **IF** racism, sexism, homophobia, or classism is operating here, but ask **<u>HOW</u>** is it operating here
- Turn a reflexive and critical appraisal inward

Some Questions to Ask…Individually

- How does racism manifest in my work context?
  - What is being done to address these issues?
  - Who is leading/providing guidance?
  - What’s my role? How might I effect change?

- How do my core beliefs and values manifest in my commitment to public health? How might these beliefs and values differ from others I work with?

- What skills do I offer to antiracism work? What skills do I want to build?

Ford C et al. *Racism: Science & Tools for the Public Health Professional*. Washington DC, Apha Press, 2019.

Some Questions to Ask…Collectively

- What is our strategy for understanding and addressing racism (head on) in our department?
- How are the public health aspirations of individuals and communities of color being prioritized?
- Who is at the decision-making table? Who is missing? Have we deeply investigated what brought them to the table?
- Who are we accountable to? What are we doing to be accountable?

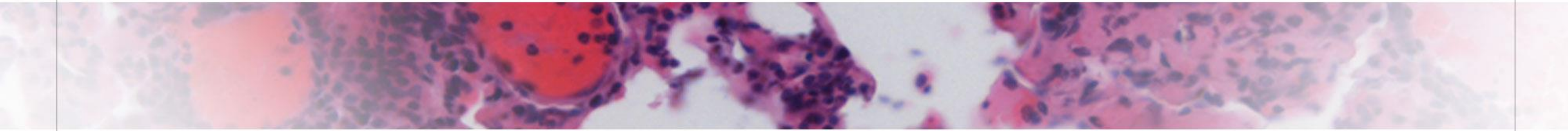
Ford C et al. *Racism: Science & Tools for the Public Health Professional*. Washington DC, Apha Press, 2019.

Some Questions to Ask…Collectively

- How are we equipping staff to work across differences from a starting point of understanding their own power and position? How might we recognize that there will be different starting points for different people?
- What mechanisms do we have in place to make our work transparent and open to feedback?
- How are we valuing and resourcing community relationships?
- What mechanisms do we have in place to ensure these relationships can be sustained?

Ford C et al. *Racism: Science & Tools for the Public Health Professional*. Washington DC, Apha Press, 2019.

American Society *of* Hematology
Helping hematologists conquer blood diseases worldwide



Recognizing and Addressing Implicit Bias

Lori E. Crosby, PsyD
University of Cincinnati and Cincinnati Children's Hospital Medical Center

Acknowledgement: Some slides developed by faculty and students at the Medical College of Wisconsin

Disclosures for Lori E. Crosby, PsyD

In compliance with ACCME policy, ASH requires disclosures to the session audience:

- **Consultancy**: Forma Therapeutics
- **Research Funding**: Health Resources and Services Administration; National Center for Advancing Translational Sciences, National Institutes of Health; Patient-Centered Outcomes Research Institute

Discussion of off-label drug use: N/A

Acknowledgements

- Wally Smith, MD, Virginia Commonwealth University
- Emily McTate, PhD, LP, Mayo Clinic
- Elizabeth Muenks, PhD, University of Kansas Medical Center

Learning Objectives

- Give examples of racial stress and trauma and how this may impact individuals living with sickle cell disease
- Describe how implicit bias may impact the care of individuals living with SCD
- Identify strategies informed by social justice and cultural humility to promote health equity in SCD

S.T.O.P

STOP

Stop

Stop whatever you are doing and come into the present moment.

Take a deep breath.

Breathe in deeply a few times. Feel the breath enter your nose, fill your belly and then leave your body.

Observe

Observe the moment you are in, the thoughts you are experiencing, your emotions and how your body feels.

Proceed

Continue on with whatever you were doing, yet stay present by keeping this sense of conscious awareness active in the background.

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Case Study: Meet Adriana

- 19-year-old female with HBSS SCD
- Lived with several relatives throughout her childhood
- Has had several jobs since high school–currently working at a retail store
- History of marijuana use as a teenager
- Prescribed hydroxyurea but team is concerned she may not always be taking it (no recent prescription)
- Reports severe stomach pain during clinic visit and asks for pain medication but no visible signs that she is in pain–laughs and jokes
- Providing vague answers to the team members' questions

HBSS, homozygous for abnormal hemoglobin S gene

What are some things providers/teams might say/think about Adriana?

SCD and the “Difficult Patient” Conundrum

- Convergence of SCD’s unique political, historical, cultural, medical, and psychological restrictions → blaming patients
- Often classified as “difficult”

Bergman EJ, Diamond NJ. *Am J Bioeth*. 2013;13(4):3-10.

SCD and the "Difficult Patient" Conundrum (cont'd)

- Traditional designation as the "difficult" patient warrants reevaluation
  - Barriers to care unique to SCD
  - Need to redefine orthodox notions of the "difficult" patient

Bergman EJ, Diamond NJ. *Am J Bioeth*. 2013;13(4):3-10.

SCD: Two Major Overlapping Determinants

- Chronic Health Condition
  - Chronic Non-Cancer Pain (CNCP)
    - ➢ Common
    - ➢ Significant burden to adult patients
    - ➢ Known to lower quality of life[1,2]
    - ➢ May be poorly managed
      - Anxiety and distress related to subsequent treatment
      - Negative long-term psychological effects
- Racial and ethnic minoritized population

1. Kowal J et al. *Pain.* 2012;153(8):1735-1741.
2. Ferrell BR. *Nurs Clin North Am*. 1995;30(4):609-624.

Racism as a Public Health Crisis: Inequities and Health Disparities

Inequities

- Differences in outcomes across access, pay, housing, etc.
- Avoidable, unfair, and unjust
- Result of social, economic, and environmental conditions

Disparities

- Differences in incidence and prevalence of health conditions/status between groups
  - Overall health status
  - Prevalence of chronic conditions
  - Premature death
- Adversely affect groups with characteristics linked to discrimination, exclusion, and systematic experience of obstacles

Health Equity Institute at San Francisco State University,
Health policy Institute of Ohio

Defining Racism

- How do you define **race**?
  - Race is "generally understood as *a social construct*. Although *biologically meaningless* when applied to humans–physical differences such as skin color have no natural association with group differences in ability or behavior–race nevertheless has tremendous significance in structuring social reality."
- What is **racism**?
  - "An ideology of racial domination" in which the presumed biological or cultural superiority of one or more racial groups is used to justify or prescribe the inferior treatment or social position(s) of other racial groups through the process of racialization
  - Interpersonal: racial prejudice or discrimination; Institutional: laws, policies, and practices

Racial Stress and Trauma

- Racial Stress
  - Emerges from direct and/or vicarious discriminatory racial encounters
- Racial Trauma
  - PTSD like symptoms that emerge because of exposure and re-exposure to racial stressors

How might this show up?

- How might you see the impact of racial trauma, structural racism, and implicit bias in clinical care?
  - Mistrust/hesitance in trusting the medical system
  - Emotional dysregulation
  - Defensive language
- Remember variation!
  - Different ACEs
  - Different protective factors
  - Different lived experiences

ACE, adverse childhood experiences

Let’s Revisit Adriana

- 19-year-old female with HBSS
- Lived with several relatives throughout her childhood
- Has had several jobs since high school–currently working at a retail store
- History of marijuana use as a teenager
- Prescribed hydroxyurea but team is concerned she may not always be taking it (no recent prescription)
- Reports severe stomach pain during clinic visit and asks for pain medication but no visible signs that she is in pain–laughs and jokes
- Providing vague answers to the team members’ questions

How might racism be impacting this individual patient's presentation?

Start the presentation to see live content. For screen share software, share the entire screen. Get help at **pollev.com/app**

How can we use our understanding of racism and structural inequities to reframe how we think about this patient?

How might racism affect staff/providers in providing care to patients?

Implicit Bias

- Occurs at the individual level
- “Ingrained habits of thought that lead to errors in how we perceive, reason, remember, and make decisions”

http://www.ihi.org/communities/blogs/how-to-reduce-implicit-bias

Microagressions

- Microassaults (eg, purposeful actions of discrimination such as name-calling)
- Microinsults (eg, subtle communications that demean a person’s cultural identity)
- Microinvalidations (eg, subtle communications that negate a person’s cultural reality, such as displaying colorblind attitudes or telling a person of color that you don’t see color)

Sue & colleagues (original source)
Current source: https://ct.counseling.org/2016/12/practicing-cultural-humility/

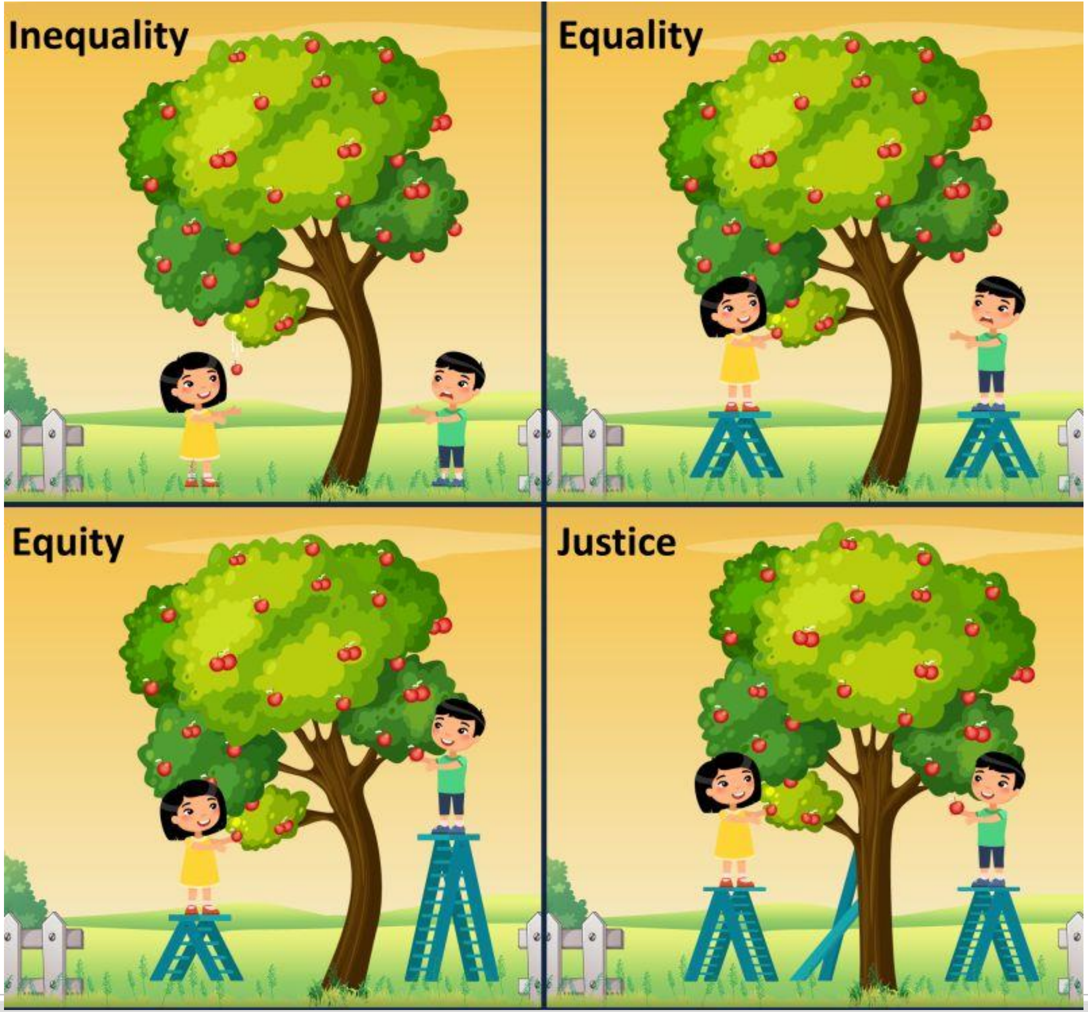
Self-awareness and Humility

- Examine your own values, beliefs, and traditions
- Explore ways in which health, illness, and healing are understood by different people
- Set aside your own bias in order to deliver effective care to diverse populations

Your Role

- Care for your patient/family
- Appreciate racial stress and trauma in clinical work with families
- Engage in difficult dialogues
- Focus on patient and family centered care
  - Build trust by listening
  - Provide culturally tailored care

- Is NOT to:
  - Have all the answers
  - Fix their experience of racism
  - Justify the behavior
  - Change the family's narrative


Inequality
Equality
Equity
Justice

Start the Conversation…

- It’s OK to be nervous or to feel uncertain
  - The most important thing is to open the door to the conversation, listen, validate, and acknowledge your patient’s experience

- Offer the invitation
  - It’s OK if they decline

Clinician Actionable Strategies (OPCU)

OBSERVE

Objective description of what you are seeing in the room

Non-verbal communication?

Effect?

Behaviors?

PAUSE

CONSIDER

- What are the considerations that you have in the context of this patient’s various identities, experiences, and intersectionality
- What are you bringing into the room?

UNPACK

- With the integration of your observations and considerations, what might you be curious about?
- What else is here?

Clinician Actionable Strategies (OPCU)

OBSERVE

Refusal to answer some questions

PAUSE

CONSIDER

- I wonder why she might not be answering questions
- Judgment received in the past?
- Fear of information being used against her?

UNPACK

- I am getting frustrated as I am trying to help and I need to change my approach
- How can I validate and acknowledge that I am considering?

How can you use this framework to describe Adriana to your team?

- Our thinking matters but words matter too
- Bias rounds
  - Anything else we need to consider
  - Same treatment approach for friends and family

Unpacking With Medical Team

Team Says

- Adriana is “non-compliant”
- She is not taking this seriously, making her high-risk
- Her history of substance use is problematic

Underlying Message

- “Noncompliant” places blame while non-adherence considers complex contributors
- Internal attribution error
- Drug-seeker is dehumanizing

Medical Provider Says…

- There may be concerns with non-adherence
- She belongs to a group that is economically and socially marginalized
- Adriana has had a difficult life and her coping has been effective for her in the past

Let’s Discuss

How would you describe Adriana in your note?

Communication

Documentation that is sensitive to bias

Providing context

Language that focuses on advancing health equity

Intersectionality

"Intersectionality is simply about how certain aspects of who you are will increase your access to the good things or your exposure to the bad things in life."

-Kimberly Crenshaw

Intersectionality

How do you see intersectionality affecting individuals with SCD?

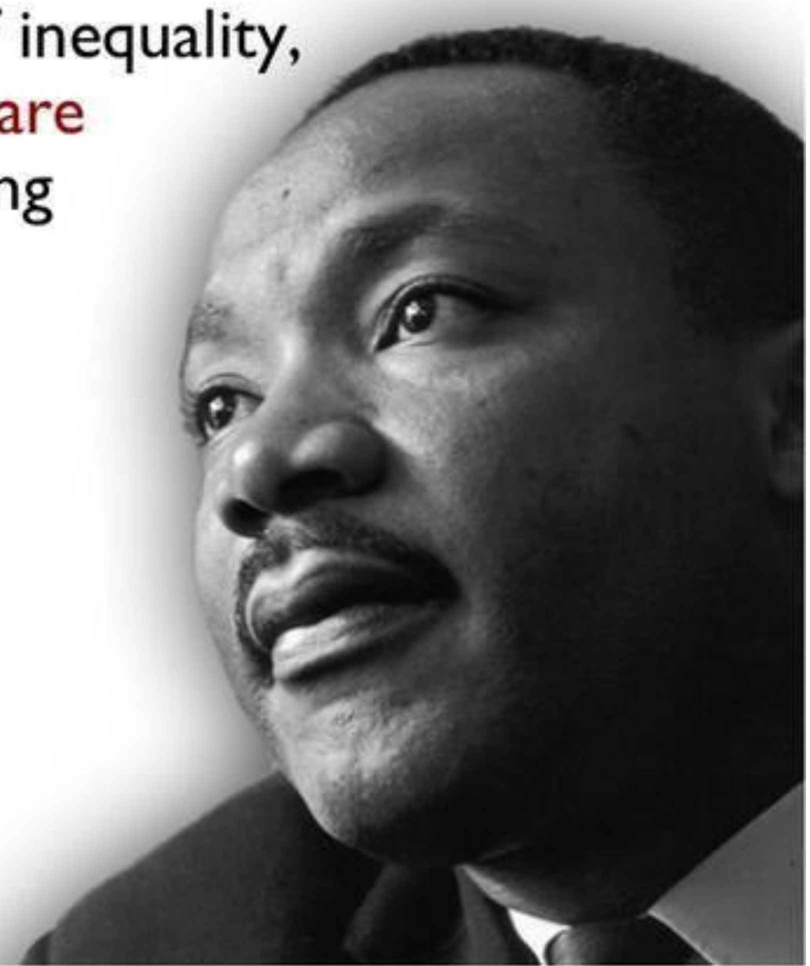
Provider Strategies

- Be authentic
- Foundation of curiosity and partnership
- Give patients the benefit of the doubt
- Strive to provide the best care possible

Conclusions

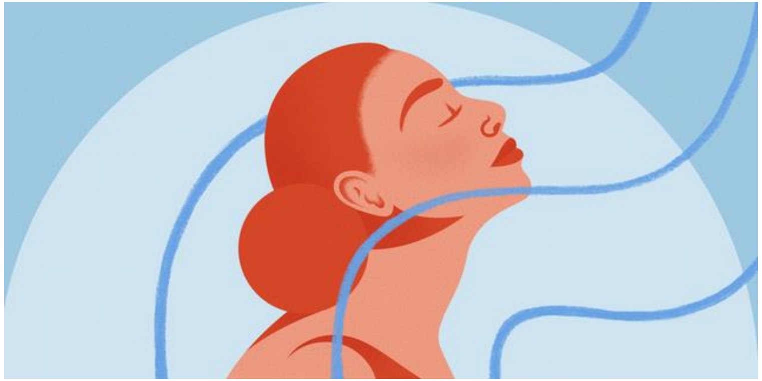
- SCD patients are often seen as difficult rather than disadvantaged
- SCD is impacted by implicit bias
  - Care provided
  - Health outcomes
- Inequities such as systematic racism, bias, and other determinants (socioeconomic disadvantage) are the major drivers of health disparities
- Inequities can be addressed via self-reflection and cultural humility
- Clinician-focused actionable strategies (OPCU) based on cultural humility and social justice can facilitate equitable health care for individuals living with SCD

Of all the forms of inequality,
injustice in healthcare
is the most shocking
and inhumane.



Dr. Martin Luther King, Jr.
March 25, 1966

Stand Up and Breathe…….



hold 4 seconds…

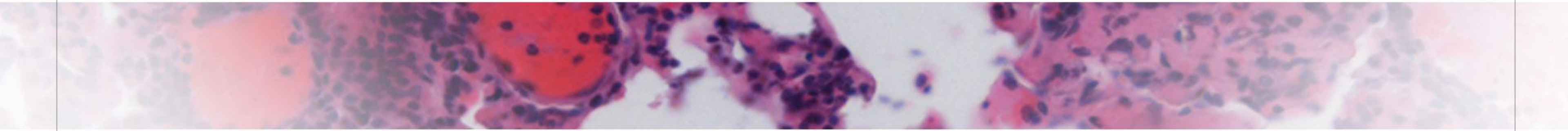
Inhale
4 seconds…
(nose)

Exhale
4 seconds…
(mouth)

Start

hold 4 seconds…

American Society *of* Hematology
Helping hematologists conquer blood diseases worldwide



Panel Discussion

Personal Experiences

TIME FOR A BREAK

Year 1 return to Kennedy; Year 2 teams move to break-out rooms