The Broadsheet

health equity essentials

TIMELY FEATURES ON HEALTHY FOODS FOR THE FALL, THE SIGNIFICANCE OF MEN'S WELLNESS & HOW SICKLE CELL DISEASE IMPACTS OUR WORLD

FALL EDITION SEPTEMBER 2017

ALL THINGS HEALTH EQUITY
This last month has been quite the whirlwind for our world:

Last week, Hurricane Maria devastated Puerto Rico and the US Virgin Islands (USVI). Now, more than ever, not only do the people of Puerto Rico and USVI need basic supplies, like food and water, but they also need basic healthcare and medical equipment, like dialysis machines for kidney wellness and access to prescriptions for treating chronic conditions.

Professional athletes are standing in solidarity with teammates who stand for equality and justice.

Furthermore, this last month has also been a whirlwind for health policy and health equity:

My colleagues in the Senate abandoned—for now—their myopic mission to dismantle our nation’s healthcare system.

As the federal fiscal year comes to a close on September 30, 2017, the House of Representatives has yet to decide on the state of funding for critical health programs and supports. Funding for the Children’s Health Insurance Program (CHIP), for Community Health Centers, and support for Disproportionate Share Hospitals (DSH) has yet to be addressed as deadlines near—even within the next 24 hours.
As uncertainty looms about the future of our healthcare system, securing the foundations of health for our nation is even more imperative. I am evermore encouraged by the work that so many of you are doing through your practices, research, teaching, advocacy, and even your questions about how to transform our healthcare system more equitable and efficient. Many of you shared your work with me last week during the Congressional Black Caucus Annual Legislative Conference Health Braintrust Future of Health 2020 Town Hall and Expo (see pictures below). For you all, keep up the stellar work! As Chair of the Health Braintrust, know that I stand with you.

Thank you,

[Signature]

the Health Braintrust in review
Future of Health 2020 Panelists: (l to r) Dr. Christy Gamble, Dr. Kevin Sneed, Dr. Ray Bignall, Dr. Loren Robinson, Dr. Doris Browne, Dr. Ian Smith, & Dr. David Mahoney

Providers, healthcare advocates, academicians, and faithful Health Braintrust followers listen during the Future of Health 2020 Panel
"Black Love is Essential to Mental Health."
Health Braintrust attendees agree.

Dr. Britt Weinstock, Staff Director of the Senate HELP Committee, (r) receives the Chairwoman's Staff Leadership Award, and a hug from Audra Wilson, Deputy Director of IL-02.
Prostate cancer is the leading cause of cancer among men, and the second leading cause of cancer deaths. Prostate cancer can be cured if detected and treated early, but becomes incurable if not treated early.

However, there has been long standing controversy about early detection screening because not all prostate cancers are life-threatening. Previously, there had not been any scientific way to determine which cancer is or is not life threatening. There is even concern that some men are treated for non-lethal prostate cancer and suffer the side effects of treatment unnecessarily.

Now, there are biomarker tests available to help determine which prostate cancers are life threatening and should be treated immediately.

All men should know their prostate health through early detection screening. This should begin at age 40 for Black men, who are diagnosed with prostate cancer at a rate 60 percent higher, and at an earlier age than all other men.

Men should let their health care providers know that they want to know their prostate health. All wellness efforts around prostate health should include a strong educational component which presents the benefits and risks of early detection screening, and for the different prostate cancer treatments.

Mr. Thomas A. Farrington (pictured above, 5th from the right) knows a thing or two about the challenges of prostate cancer.
In 2003, he founded the Prostate Health Education Network (PHEN) following his treatment for prostate cancer. Mr. Farrington was diagnosed just three months after his father died from prostate cancer, and after losing both grandfathers to the disease in earlier years. Even with this history, Mr. Farrington realized that he had no knowledge about prostate cancer when he was diagnosed. This prompted him to do extensive research about prostate cancer and to write a book to increase awareness. Battling The Killer Within was published just one year after Mr. Farrington was treated in 2001.

The mission of PHEN is to eliminate the African-American prostate cancer disparity. As part of its national initiatives, PHEN has been holding Prostate Health Educational Symposiums in 20+ cities throughout the year. On September 21st and 22nd PHEN hosted its 13th Annual African-American Prostate Cancer Disparity Summit in Washington, D.C. The second day of the summit was part of the Congressional Black Caucus Annual Legislative Conference.

Increased funding for prostate cancer research, education and awareness efforts needs to be a priority. There is a great need for additional resources allocated specifically to address eliminating the prostate cancer racial disparity. Senate Resolution 529 was passed by the 112th Congress, “recognizing that the occurrence of prostate cancer in African-American men has reached epidemic proportions and urging federal agencies to address that health crisis by supporting education, awareness outreach, and research specifically focused on how prostate cancer affects African-American men.”

September is Prostate Cancer Awareness Month!
To learn more about prostate health, click here to visit the PHEN website.
September is “Fruits and Veggies- More Matters Month”. Health officials recommend that children and adults fill their meal plates with half fruits and vegetables. Daily, I endeavor to eat some of my favorite fruits—bananas for potassium and digestive wellness; grapes for protein, fiber, and vitamin C. For dinner, I like a mixed greens salad with beets. (I love beets!) Each of these foods enables me to feel most energized while I am fighting for health equity in Congress.

Yet, for many, access to fresh over processed foods is a major challenge. Low fruit and vegetable consumption is not completely a matter of individual will. Socially determining factors, including cost, geography, and even know-how on how to eat certain fruits and vegetables keep many of our family members and neighbors from acquiring their optimal level of nutrition. Consequently, diabetes, cancers, and heart disease are very common conditions. Obesity plagues our communities, and hunger is a consistent feeling for too many children.

We each have the responsibility to battle hunger, obesity, and all expressions of food insecurity. As Chair of the Health Braintrust, I am committed to upholding, at the forefront of this battle against food insecurity, a call to action for quality, healthy options and unbarred access to affordable, nutritious foods.
sickle cell disease & the world

FEATURING: THE AMERICAN SOCIETY OF HEMATOLOGY
What is sickle cell disease?
Sickle cell disease (SCD) is an inherited, lifelong blood disorder. Individuals with the disease produce abnormal hemoglobin which causes their red blood cells to become rigid and sickle-shaped. The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, the sickle-shaped red blood cells get stuck and block blood and oxygen flow to the body. This can cause pain, infections, and other serious problems. SCD complications include stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, other disabilities, and in some cases, premature death.

Worldwide, SCD affects millions of people, specifically individuals whose ancestors descended from sub-Saharan Africa, South America, the Caribbean, Central America, Saudi Arabia, India, and the Mediterranean (Turkey, Greece, and Italy). While the exact number of people living with SCD in the U.S. is unknown, the Centers for Disease Control and Prevention (CDC) estimate that:

- SCD affects approximately 100,000 Americans.
- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,300 Hispanic-American births.
- About 1 in 13 Black or African-American babies are born with sickle cell trait (SCT).

Sickle cell trait (SCT) is not a disease. Having SCT simply means that a person carries a single gene for sickle cell disease (SCD) and can pass this gene along to their children. People with SCT usually do not have any of the symptoms of SCD and live a normal life.

State of SCD Care and Research
Although the molecular basis of SCD was established many decades ago, it has been challenging to translate this knowledge into the development of novel targeted therapies. New approaches in managing this disease have improved diagnosis and supportive care over the last few decades, but many patients still have severe complications to overcome. SCD patients encounter major issues accessing high quality care. Because SCD is a complex illness that affects multiple organ systems, few physicians specialize in SCD or can assume primary responsibility for a patient’s care. Coordinated treatment continued across multiple settings is essential for patients to receive adequate care.

Medicaid/Medicare and Sickle Cell Disease
Many sickle cell disease patients are covered by Medicaid into adulthood; many adults with sickle cell disease are also covered by Medicare due to disability. There were more than 246,596 emergency room visits with principal diagnosis of sickle cell disease in 2014. Sickle cell disease was the 5th most common discharge diagnosis for hospital “super users” for Medicaid patients under age 64 despite a relatively small population.

September is Sickle Cell Awareness Month!
Steps Needed to Bridge the Gap in Care and Research - Sickle Cell Disease Legislative and Advocacy Asks
There is a critical need to improve outcomes for patients suffering with this disease. With exciting and promising new SCD research to be announced at the December 2017 American Society of Hematology’s (ASH) Annual Meeting, there is the opportunity to expand access to care and treatment options for individuals with SCD. Now is the time to make the investment to ensure that patients have access to state-of-the-art clinical care. ASH encourages you to: (1) spread the word about the need to improve the state of SCD; (2) encourage your Member of Congress to join the Congressional Sickle Cell Disease Caucus; and (3) advocate for Comprehensive SCD Legislation and enhanced Federal programs.

American Society of Hematology’s Multifaceted Sickle Cell Disease Initiative
ASH represents over 17,000 members committed to the study and treatment of blood and blood-related diseases and disorders. The organization is committed to addressing the burden of SCD and is undertaking a multi-faceted initiative to improve outcomes for individuals with the disease, both in the United States and globally. ASH has engaged a broad group of experts and stakeholders to review the state of SCD and identify the greatest opportunities for improvement. ASH continues to invest in and explore the important actions needed to make a significant difference in SCD access to care, research, and global issues.

In 2016, ASH founded the Sickle Cell Disease Coalition (SCDC) to help amplify the voice of the SCD stakeholder community, promote awareness and improve outcomes for individuals with SCD. The SCDC’s growing membership of nearly 50 groups includes public health, research, and provider organizations; patient groups; federal agencies, industry representatives, and foundations.

The SCDC continues to provide members with a platform to communicate with an international network of key stakeholders interested in SCD and engage in joint action. The Society has also committed to developing and implementing up-to-date guidelines describing the management of acute and chronic complications of SCD, and educating hematologists and other healthcare providers in all settings to recognize and properly respond to SCD complications in their everyday practices. ASH is exploring the development of a consortium of African countries to institute a population-based registry study for newborn screening and early intervention. And, through ASH’s research priorities in SCD and sickle cell trait, the Society continues to encourage the study of unaddressed research questions that could greatly impact the field. Furthermore, ASH continues to work with Congress and federal agencies to enhance and expand federal sickle cell disease programs.

Congresswoman Kelly with (l to r) ASH Leaders Drs. Susan B. Shurin, Roy L. Silverstein, Alexis Thompson, Kenneth Anderson, Robert A. Brodsky
You Can Never Feel My Pain: Prodigy, Sickle Cell, and Implicit Bias in the ED

by Italo Brown MD MPH

On every shift at my Bronx, NY hospital, I encounter patients just like Prodigy: sick, conscious of their condition and its vast effects, yet resilient in a way that only the initiated would understand. And despite the blend of literature and clinical gestalt circulating within the emergency medicine community, management of sickle cell patients remains an ongoing debate. Sure -- the definitive end-points of management are clear: sick patients get admitted, and not-so-sick patients get treated, observed, and ultimately discharged. However, the gray area in sickle cell patient care is pain management. Philosophies differ on which medication is appropriate, and what doses should be given. However, a deeper and potentially more harmful conversation remains largely unexplored -- implicit bias.

In June, the hip-hop community lost one of its icons, Albert Johnson. As one half of the infamous Mobb Deep, Prodigy is best known for his smooth monotone delivery over the snare-and-siren laden street anthem, “Shook Ones”.

However, a lesser known track entitled, “You Can Never Feel My Pain”, is Prodigy’s magnum opus. In this song, the Queensbridge lyricist offers insight into his lifelong struggles with sickle cell disease.
It is a known fact that sickle cell disease affects persons of color predominantly. Also, the data suggests that opioids (for pain control) are more likely to be withheld from persons of color in the emergency department.

Here are three quick points that will hopefully help open this dialogue:

1. **Sickle Cell Pain is Real Pain.**

   The disease is characterized by small vessel occlusions leading to respiratory compromise, splenic autoinfarction, susceptibility to bacterial infections, and a constant onslaught of pain crises that often require hospitalization. These crises are commonly described as sharp, never ending 10/10 debilitating pain. Frankly, the large majority of patients and providers alike have not experienced this degree of pain in a single occurrence, let alone in scattered episodes over the course of a lifetime. As such, it is imperative for providers to lead with compassion. Allow each patient to describe their pain, comparing it to prior episodes, and completely characterizing its immediate impact on ability to function or perform daily activities.

2. **Acknowledge the bias.**

   Sickle cell patients have a genetic predisposition to chronic pain. As such, they come to the ER at a high frequency. During an active crisis, sickle cell patients often require narcotics at doses much greater than those typically prescribed to achieve adequate pain relief. This has created subconscious bias among emergency department personnel, where the increased utilization of services, and the increased tolerance to analgesics is quickly associated with drug seeking behavior or malingering. The damage in doing this is evident -- patients may remain in pain for hours, because of underdosing or under-assessing the patient. Providers must exercise the same critical eye in checking their own biases

3. **Treat the patient. Each time.**

   Each patient is different, and their thresholds for pain vary. Some patients will require higher doses of analgesics or more frequent redosing than others. Providers must be sensitive to this. Providers must also resist the urge to use prior management trends to dictate their real-time treatment strategy. The best approach is to fully evaluate each patient, establish a relative pain scale, and frequently reassess them to gauge improvement.

In the final verse of the song, Prodigy offers a chilling end: “I can only hold it but for so long. Put me to sleep. Do I sound insane? If I do, then this here was written for you”. We hear you Prodigy -- we hear all of you.
The health outlook and health care systems in the US Virgin Islands (USVI) has been strained for quite some time. Before two consecutive category-5 hurricanes, Irma and Maria, hit the USVI and Puerto Rico, the people of the Virgin Islands were already living under a system of healthcare similar to what is commonly called “Trumpcare”. That is, the Medicaid program in the territory is block granted and federal support is capped at an amount that has no relationship to local needs. The territories receive an arbitrarily low rate of federal matching funds (FMAP), which help to offset costs for critical health services. This FMAP assigned to USVI and the American territories is limited to 55 percent, which is more than twenty percentage points below what it would be if the FMAP were based on per capita income, as it is everywhere else throughout the United States.

The Virgin Islands are also excluded from the Disproportionate Share Hospital (DSH) program eligibility. Hospitals that serve a disproportionately high number of Medicaid, Medicare, and uninsured patients receive DSH payments to make up for the revenue lost from uncompensated care. But, based on federal restrictions, the USVI and the territories cannot reap the benefits of this program. Consequently, many Virgin Islanders go without adequate care and providers are persistently uncompensated, all elements which have an ongoing, deleterious impact on the local government, hospitals and health systems, and people in the most need of medical attention.

FEATURE: CONGRESSWOMAN STACEY PLASKETT (D-VI)
The recent ravishes of Hurricanes Irma and Maria further exacerbates these health systems strains on USVI and Puerto Rico. Since these hurricanes rocked the shores of the islands, both hospitals on the Virgin Islands-- Schneider Regional Medical Center (St. Thomas) and Juan F. Luis Hospital and Medical Center (St. Croix)-- have been partially destroyed. Consequently, they may have to be knocked down and entirely restructured to be suitable to receive patient admissions. Patients who were already receiving care from either hospital have had to be moved to U.S. military mobile hospital units, and to facilities on the mainland. The islands' Department of Health facilities were also compromised. Over six hundred people remain displaced in shelters. Hunger and dehydration difficulties persist as food and water distribution is ongoing.

Friends of the Health Braintrust may be actively involved in the USVI recovery effort by visiting the American Red Cross website, and may stay in the know by visiting the Facebook page of the Virgin Islands Territorial Emergency Management Agency (VITEMA), as well as local news outlets like the Virgin Islands Consortium.
Want to learn more about what you've read? Want to see something in future editions of the Broadsheet? Let us know! Contact us at TheBroadsheet@mail.house.gov