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Pucker Up and Take the Challenge for SCD Awareness!

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Have you heard about the ALS “Ice Bucket” Challenge? I’m pretty sure you have. After all, everyone from Cookie Monster and Bill Gates to Rihanna and Derek Jeter have taken the challenge. The donations made have raised over 100 million to date and has definitely raised awareness about ALS, or amyotrophic lateral sclerosis, a progressive disease that affects nerve cells in the brain and the spinal cord. Consequently, all types of challenges have been afoot.

I want to let you know about the “Bold Lips for Sickle Cell” Challenge. This campaign was started by Shamonica Wiggins. The challenge was created to raise money and awareness about sickle cell disease (SCD). SCD is the most commonly inherited blood disorder in the United States. It affects between 70,000 to 100,000 Americans, but awareness about the disease isn’t mainstream. As a result there are often lies, negative stereotyping and continued myths about sickle cell disease that can sometimes affect the treatment of SCD patients. Obviously, awareness is key to people understanding the illness!

Sadly, funding for SCD research and improved services has been an ongoing battle for the past 40 years. But, fortunately, the Sickle Cell Treatment Reauthorization Act (SCTRA) was introduced by Representatives Danny K. Davis and Michael C. Burgess this past July in the House of Representatives. The development of this bill was only the beginning step. For the bill to become law, it now needs to be introduced to the United States Senate and passed.

What is the Sickle Cell Treatment Reauthorization Act (SCTRA)? As described in legislative briefing materials by the Sickle Cell Disease Association of America (SCDAA), the Sickle Cell Treatment Act (an amendment in Public Law 108-357) "authorizes $10 million annually to support 40 demonstration projects and a National Coordination Center. To date only nine (9) of these centers have been effectively established and are severely underfunded. We request within the new reauthorization the fully authorized $10 million to fund twenty-five (25) treatment centers to be established for the purpose of supporting ongoing efforts to close gaps in medical service delivery, provider training, and transitional care. Particularly as patients continue to cope with a struggling national economy these gaps currently impede access to care for many Americans affected by SCD."

But if the current act isn’t reauthorized, it could become ineffective. The SCTRA would extend the time period by another four years for research, surveillance, prevention, and treatment of SCD. In addition, the bill also includes proposed modifications to improve the existing act. This legislation didn’t happen overnight. Many SCD advocates, including individuals from the SCDAA and numerous other organizations, worked arduously to campaign and push for this act to be initially passed (in 2003) and now want to see it reauthorized.

September is Sickle Cell Awareness Month
Here are five facts to raise your Sickle Cell I.Q.:
1. Sickle cell disease is hereditary and not contagious.
2. Sickle cell disease affects people from all types of nationalities, with people of African descent most highly affected.
3. Sickle Cell Disease can cause a host of complications which include: stroke, avascular necrosis, acute chest syndrome, jaundice, leg ulcers, spleen enlargement, swelling of hands and feet, infarctions, pulmonary embolisms, blood clots, high risk of infection, kidney failure, retinopathy, hearing loss, priapism, pulmonary hypertension and frequent episodes of severely excruciating pain.
4. Sickle cell disease currently can only be cured by a bone marrow transplant. But many with SCD are not medically eligible for the procedure.
5. Sickle cell disease patients with the most severe form of SCD may have a shorter life expectancy of 20 to 30 years.
And here are five ways YOU can raise awareness, eradicate stereotypes and help advocate for those with sickle cell disease:
1. Educate yourself. Google sickle cell and check out some of the various websites, big and small, dedicated to increased awareness of SCD, so you can help raise money for research and aid to individuals with SCD.
2. Educate others. Once you know about SCD and the painful effects that approximately 90,000 of us live with, tell your family and friends what you have learned.
3. Find a SCD awareness walk, or other sickle cell disease event in your area. Invite your family members to join you in participating
4. Donate to the SCD organization of your choice. There is likely to be a local SCD nonprofit organization in your area and the SCDAA is always in need of support. Check in with your workplace or place of worship to see if they’d be willing to donate to SCD research and awareness organizations.
5. Volunteer to mentor or tutor a child with SCD or support a family with either parents or children who have SCD.

Please click here to check out our (me and my sister’s) nonprofit organization, Inspiring More Minds, Inc. (IMM). IMM was created to inspire the minds and ease the lives of individuals with SCD through providing grants and scholarships for those living with sickle cell disease so they can pursue educational and entrepreneurial endeavors.

Today, my boyfriend and I were in the mall and we decided what better time than now to take the challenge! We went to a Sephora where I asked for a lip makeover, in the boldest of reds! After an excellent bold lip makeover--free of charge--I kissed my boyfriend on the cheek and we took our picture to post on the #BoldLipsforSickleCell Facebook page.
What was cool is that he left the lipstick mark on all day, even while we walked through the mall, and this solicited comments and questions providing us with the perfect opportunity to share about SCD.

Take the #BoldLipsforSickleCell Challenge! You can do this via Instagram, Twitter and Facebook.

I challenge you!

Be well! Be wonderful!
