Start Collecting Those Resources

January 30, 2015 By Cyntra Scott

As someone living with sickle cell, I learned long ago that no man is an island. We all need help from the many individuals and networks that surround us. But to get ourselves the most effective assistance it's key to know what's available and where to find what we need.

For this blog post, I am going to share some of the networks and potential resources available for the sickle cell community. I hope that this listing will provide you with a little bit of inspiration and interest to get involved, get connected, get motivated and become inspired.

This year, I am looking forward to expanding my network and increasing my knowledge pertaining to sickle cell disease and awareness throughout the year.

I'm also hoping that by sharing the resources I've listed below that you will also be able to do the same for yourself.

The following list of websites should help you get started. But, remember, there are more organizations out there, especially within each state, that offer information about sickle cell disease, so I encourage you to inquire and search on Google.

In addition, students with sickle cell disease should research the local and national SCD organizations to find out what scholarships and student assistance services are available.

Sickle Cell General Information
Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/sicklecell/index.html

National Institutes of Health
http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html

Johns Hopkins Medicine
http://www.hopkinsmedicine.org/Medicine/sickle

Center of Excellence in Sickle Cell Disease
http://www.bu.edu/sicklecell

The Mayo Clinic

http://www.mayoclinic.org/

Sickle Cell Information Center
http://scinfo.org

Global SCD Resources
www.globalsicklecelldisease.org
www.londonfocussicklecellafrica.org

Sickle Cell Disease Awareness and Support Groups
www.sicklecelldisease.org
The National Sickle Cell Disease organization has affiliated chapters throughout the United States and offers an Annual Scientific Convention that is exclusively about the many aspects of SCD.

www.ascaa.org
The American Sickle Cell Anemia Association provides a wide range of services to individuals and families with either sickle cell trait or variants of the disease.

www.wepsicklecell.org
The William E. Proudford Sickle Cell Fund, Inc. raises awareness about sickle cell disease and traits during September, National Sickle Cell Awareness Month and throughout the year. The organization also supports education about SCD, and state-of-the-art treatment and research to help those living with this devastating disease.

www.CandicesSickleCellFund.org
Candice’s Sickle Cell Fund, Inc. (CSCF, Inc.) is dedicated to improving services to those who suffer from sickle cell disease.

http://SickleCellCureFoundation.org
The Sickle Cell Cure Foundation is a nonprofit corporation that’s registered in Oklahoma and dedicated to curing sickle cell disease.

http://TheKISfoundation.org
The K.I.S. Foundation was launched by actress Kiki Shephard, the well-known host of Showtime At the Apollo. The foundation’s mission is to inform and educate the public and raise awareness about SCD through community outreach programs and educational scholarships.

www.InspiringMoreMinds.com
Inspiring More Minds is a nonprofit corporation founded by my sister, Bronwyn Scott, who, like me, suffers from sickle cell. Its ongoing mission is to raise money for an emergency fund to help people living with SCD negotiate financial hardships, further their education, or address any number of other positive achievements they’re seeking to pursue.

www.FacesofOurChildren.org

Faces of Our Children works with established educational institutions to develop and deliver educational programs and materials online and through the mass media at businesses and schools. Their mission includes effecting public policies and corporate and government funding to help improve the lives of families with members suffering with sickle cell disease.

www.sicklecellnewjersey.org
The Sickle Cell Association of New Jersey (SCANJ) is this state's member chapter of the Sickle Cell Disease Association of America. The group advocates on behalf of its membership to improve their quality of life, with improved health care and services for individuals, families, and communities affected by SCD and related conditions. SCANJ also supports the search for a cure of SCD that's available and affordable to everyone affected by the disease.

www.sicklecellwarriors.com
Sickle Cell Warriors is a non-profit group dedicated to education, empowerment and awareness about sickle cell disease. Part of its mission is to inspire those affected by sickle cell by providing resources, information and support about the disease.

www.inspire.com/groups/sickle-cell-anemia/
Inspire is a national organization that partners with patients to create online support communities based on medical condition. Inspire communities, such as the one created for people living with SCD, allow patients and caregivers to connect with others who share their health concerns via personal profiles, discussions and blogging.

Employment & SCD
Did you know that SCD is recognized by the American Disability Act? Often individuals with SCD have issues, problems and serious concerns with attaining and maintaining employment. Entrepreneurship can be an answer to gaining financial independence with SCD. Work at home job opportunities can also help individuals with SCD. When researching work-at-home positions, make sure of their legitimacy.

For more about the Americans with Disabilities Act, click here.

Research, Studies and Clinical Trials
National Institutes of Health
www.nih.gov
http://patientrecruitment.nhlbi.nih.gov/

Rare Patient Voice (potential paid survey opportunities)
www.rarepatientvoice.com/sign-up

www.clinicaltrials.gov (type in “sickle cell” and any other key words relevant to you)

Bone Marrow Transplant Organization
www.bethematch.org/Sickle-Cell

Facebook - search Sickle Cell
Sickle Cell Unite
Hope for SCD

Publications about Sickle Cell Disease
In The Blood: Sickle Cell Anemia and the Politics of Race
by Melbourne Tapper
Hope and Destiny
by Allan F. Platt P.A.-C, M.M. Sc.; James Eckman M.D.; and Lewis Hsu M.D.
“Sickle” A Personal Story of Pain, Purpose and Perseverance
by Dominique Friend
The Politics of Sickle Cell and Thalassaemia
by Elizabeth N. Anionwu and Karl Atkin
Uncertain Suffering: Racial Health Care Disparities and Sickle Cell Disease
by Carolyn Rouse

Be Well! Be Wonderful! Be You!
