



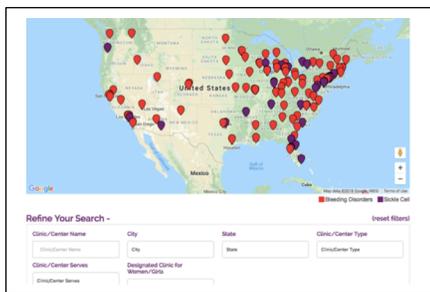
# FOUNDATION FOR Women & Girls with Blood Disorders

*Our Vision: All women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage.*

June 19, 2018

## NEW DIRECTORY OF SERVICES FOR WOMEN AND GIRLS WITH SICKLE CELL DISEASE

The Foundation for Women & Girls with Blood Disorders (FWGBD) is pleased to announce a service map directory that shares information about the availability and range of services specifically devoted to the care of women and girls with sickle cell disease, provided by hemophilia/thrombosis treatment centers (HTCs) and nationally recognized sickle cell centers across the country.



Sickle cell disease is a blood disorder where the hemoglobin in red blood cells forms into stiff rods, changing the shape of red blood cells from their usual disc shape into a curved, or sickle, shape. These sickle-shaped red blood cells are not as flexible as the normal disc-shaped cells and can burst as they move through the blood vessels.

The National Heart Lung and Blood Institute (NHLBI) estimates that SCD affects approximately 100,000 people in the US, mainly African Americans and a smaller percentage of Hispanic Americans. Roughly one in 13 African Americans carry the sickle cell trait.

Women with sickle cell disease face serious challenges, especially with regard to menstruation and pregnancy. For instance, women with SCD are recognized to have high-risk pregnancies mainly because of fetal risks but these women also face very serious maternal challenges, such as an increased risk of experiencing both medical complications (DVT, pulmonary embolism, sepsis) and pregnancy-related complications (preeclampsia, eclampsia, preterm labor, placental abruption). Additionally, the monthly event of menstruation is accompanied by an increased burden of pain. These challenges heighten the need for preconception counseling and for care by healthcare providers who understand and can apply the optimal treatment and management for women with SCD.

This Directory – the first of its kind – provides the following information about nationally-recognized sickle cell centers, federally-funded HTC serving sickle cell disease patients, or other specialty centers that offer maternal-fetal care for pregnant women with SCD:

- range of services
- hours of operation
- types of specialty and support services offered
- additional services and resources offered for pregnant women with SCD

“Earlier, appropriate and multidisciplinary care and management of females with SCD is crucial to achieving more positive outcomes during the reproductive life stages,” explains FWGBD Executive Director Kerry Funkhouser. “Identifying centers that have designated services for women and girls with SCD is a first step in helping them to find this type of care.”

Funkhouser explains that, in particular, pregnant women and their providers will benefit from the WG Sickle Cell Disease Directory because it enables them to locate services and resources to help with prenatal, intrapartum and postnatal management. Additionally, the Directory reinforces collaboration between ob/gyns and hematologists by highlighting where this takes place.

The Women & Girls Sickle Cell Disease Service Map Directory was made possible through an educational grant from Bioverativ and can be found on the Foundation for Women & Girls with Blood Disorders website: [fwgbd.org/clinics](http://fwgbd.org/clinics). To be listed in the current WGSCD Directory, please contact Melanie Croce-Galis, RN, MPH, at [mcrocegalis@fwgbd.org](mailto:mcrocegalis@fwgbd.org).

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### **About the Foundation for Women & Girls with Blood Disorders (FWGBD):**

Started by three internationally recognized physicians in women’s blood disorders – Drs. Andra James, obstetrics/gynecology, and Barbara Konkle and Roshni Kulkarni, hematology – FWGBD’s mission is to ensure that all women and girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage. It achieves this goal using a multi-faceted program of education activities that focus on educating healthcare providers across disciplines on a variety of blood disorders including von Willebrand Disease (VWD), rare factor deficiencies, hemoglobinopathies, thrombophilias, sickle cell disease (SCD) and sickle cell trait (SCT), immune thrombocytopenic purpura (ITP), and anemias.

#### *Sources:*

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