I am delighted that we are celebrating 5 years of the sickle cell infusion center (SCIC). One of the main reasons that I opened the Center was because of the stories that I heard about how difficult it was to get good care in emergency rooms (EDs). What was remarkable about those stories was how similar they were and I could hear everyone’s frustrations. Although we have a great relationship with our colleagues in our emergency room it just seems that an ED is not the place to get care for vaso-occlusive pain crises. Most of our patients will agree that the SCIC provides a better environment to treat pain and that is reflected by our less than 10% admission rate from the Center. Almost all of the people go home after a visit to the clinic and are able to manage their pain at home and avoid a prolonged hospital stay.

The credit for the success of SCIC goes to the amazing staff that works tirelessly every day to help those in pain. From our original team of Mandy, Sherry, Dawn and Nicky to our current staff that includes Romaine, Candice, Terri, Cindy, Dzifa, Pius, Yvette and Dominique we have been incredibly lucky to have such a talented and caring team. I want to thank them all for the hard work they do. We also can’t forget the many volunteers who have given up their time to help out in the Center and who play such an important role in the care we provide. Finally, I must thank Dr. Myron Weisfeldt and Mr. Ron Peterson who have supported the Center from the beginning and were essential in getting the SCIC off the ground.

I hope that in the future we will study and find new therapies to treat vaso-occlusive crises but ideally our goal is to find a treatment that will make the SCIC obsolete; a cure for sickle cell disease.

By Dr. Sophie Lanzkron
Sickle cell Trait and Papillary Necrosis

It is well understood that people with sickle cell trait do not have sickle cell disease. In sickle cell disease, two abnormal genes code for the production of hemoglobin, whereas in the trait, there is a mix of at least one normal gene and a gene for Hemoglobin S. There are several kidney abnormalities that have been studied in sickle cell disorders but it depends whether the patient has sickle anemia disease or sickle cell trait. Papillary necrosis is one kidney disorder that is very common in people with sickle cell trait.

Usually, papillary necrosis is diagnosed when patients present with blood in their urine. The kidney is an area of the body that gets very little oxygen. While this is not a problem for most people. Those with a sickle disorder can have sickling in the kidney because of the low levels of oxygen. It is sickling in the kidney which ultimately causes papillary necrosis.

Clinical Presentation, Diagnosis and Treatment:

Patients with sickle cell trait may present with blood in their urine (hematuria), although sometimes there are only tiny, microscopic amounts of blood in the urine in routine urinalysis. This hematuria may be painless or may be associated with back or belly pain.

Initial workup for papillary necrosis starts with obtaining a CBC, Urinalysis and xrays of the kidneys. Often a dye study is needed to determine exactly where the bleeding is coming from. CT scan may also be used to help in the diagnosis. in diagnosing the sloughing of the papilla. Treatment is centered on stopping the bleeding. Hydration and making the urine less acidic are the mainstays of treatment. Typically, after several days of this treatment, bleeding stops. If bleeding does not stop, other medications and treatments are tried. A significant fall in blood counts may warrant blood transfusion.


By Pius Afriyie, PA-C
Wow, it doesn’t seem that long ago I was introduced to these lovely women that dedicate their
time to take care of the sickle cell patients like myself. I think this Infusion Center is the best that
has ever happened to the sickle cell world. It’s hard dealing with this terrible disease. Not having
to go to the ER and wait for hours is a big blessing. I just love this center for trying to make our
lives better. I love you all with all my heart and I thank you so, so much!! - D. W.

The SCIC makes a lot of difference. You don’t have to wait a long time in the emergency room.
I’m happy that this opened. You have good nurses and it’s good to have somewhere to come to
and be around people that have the same as you do. I like it. - P. B.

It means the world to me to have the Sickle Cell Infusion Center here. Not to wait long to be seen
and it helps to talk to your nurse who knows you and really cares. I thank God for everyone who is
on staff. They are very nice to me and they really care. - J. P

I am thankful for you all. If you weren’t here, I would have to deal with the emergency room. It
saves a lot of time. The center is comfortable so you can tell the staff more personal information.
Things run a lot smoother and quicker. You build friendships with everyone. I hope you go to 24
hours soon. The SCIC is the way to go, I love you all. - P. B.

The Sickle Cell Infusion Center has been a life changing center. It makes having sickle cell a
breeze. In short, it has meant the world to me, my life! - D. C

Coming from Pediatrics, I thought it would be scary to transition. It was actually a nice transition.
It beats going to the emergency room. The SCIC has done a lot for me. - A. L.

The truth is since the center opened, I haven’t had any crisis like I used to have. The Center has
been a big help in my life. - A. S.

I brag about the SCIC to my friends and family. When I speak of changes and progress, I say “we
changed” or “now we have”. I’m part of this! I can feel safe, secure, get treatment to feel better,
make good friends and head home swiftly. It’s all possible because of the SCIC and all the wonder-
ful staff. - D. G.
The SCIC is a place where you come to be treated. The doctors and nurses are there for you when you need them. I look at them like my family and champions of courage. They are good people that are strong-willed and mean more to me than just a regular doctor or nurse. They teach you and help you mentally, physically and emotionally. The SCIC helps me survive, live and enjoy my life. They don’t look at me different because of my disability. The Center gives me hope that one day I can wake up and say ‘yes there is a cure’. I have seen staff come and go like Mandy David. She was an awesome provider and was so sweet. When you walk into the Infusion Center, they want you to feel like you are at home and I always do. They only want the best in this Infusion Center. I’ve grown with you all. It helps you with your pain but also helps you to think positive for your health and yourself.  

– L. G.

I am truly blessed to have this team of miracle workers in my life. It is encouraging to know that there are professionals that know me, know what sickle cell anemia is and know how to treat it. Coming to a place where everyone is on the same page and works together for the common good of their patients is awesome! I’m so glad the clinic is here and I look forward to five more blessed and awesome years. Thank you.  

– B. H.

The Center helps me feel better, a lot better. I know when I come in the Center, I will be safe. I feel that I can always come and talk my problem away with some of the people that works here. I think we need more space and more workers with that space. This is what the Center has meant to me.  

– D. A.

Doctors with an understanding of sickle cell and correct treatment.  

– S. C.

The Center means a lot, I do like everybody here and it can be nice. When you are hurting, the only thing you need is some medication to make it through the day, so its cool.  

– D. L.

Even though I had ups and downs with the Infusion Center, I have had a great time dealing with the staff. They work with me, save me a lot of trouble with the ER and I leave happy every time. I know I’m not the best person to deal with when I’m ill but you all work with me and I thank each and every last one of you.  

– M. B.

The SCIC means everything. It takes all the thing away that we have to deal with in the emergency room. Its good to be able to call and talk to someone that understands what going on with me. If I’m sick, I can come here and don’t have to wait to be seen.  

– J. D.

The Center means everything to me. My quality of care received has not been better at any other health care facility. Because of this, my quality of life has never been better. The friendly, courteous and knowledgeable staff are a pleasure and a God send every time I come. I love you guys for everything you have done and will do for all the sickle cell patients.  

– A. S.
February is Black History Month…

Let’s highlight PIONEERS IN SICKLE CELL!

William Warrick Cardozo was an African-American physician and pediatrician. He is best remembered for his pioneering investigations into sickle cell anemia. Cardozo’s ground breaking paper, “Immunologic Studies of Sickle Cell anemia,” appeared in the Archives of Internal Medicine, October 1937. He began one of the first studies of sickle-cell anemia. He found that sickle-cell anemia is inherited. He also established that the disease strikes African Americans almost exclusively, does not cause death among all of the victims of the disease, and that not all persons whose blood contains the sickle cells actually suffer from anemia. These findings arose thirteen years before the nature and characterization of the hemoglobin abnormality that causes sickle-cell anemia was discovered and before the disease became a subject of considerable intensive research.

Dr. Yvette Francis-McBarnette, who is one of the early pioneers in Sickle Cell Disease research, dedicated a lifetime of work in improving and extending the lives of people with sickle cell disease at several hospitals and institutions around the country. Dr. Francis-McBarnette was the 2nd African American female to graduate from the Yale School of Medicine. In 1966 she started a comprehensive Sickle Cell Disease program at Jamaica Hospital in New York City and by 1970 was recognized as being one of the foremost experts in the field. She was able to use her notoriety to lobby for more assistance and funding for people with sickle cell disease. She was a director and founder of the Sickle Cell Center for Research, appointed as a medical consultant for New York State, and was selected by the United States Senate to serve on a congressional commission.

The late sickle cell disease pioneer Charles F. Whitten, M.D was a pediatric hematologist and co-founder of the Sickle Cell Disease Association of America (SCDAA). Whitten was among the first to develop and insist on newborn screening for sickle cell disease, which is now performed worldwide. In 1971, he formed the Sickle Cell Detection and Information Center in Detroit, the most comprehensive community program in the country. He created color-coded “Whitten Dice” to educate couples about the genetic risks of having children with sickle cell disease.
As cold temperature changes and infection are common “triggers” of a sickle cell crisis, it is important to remain warm and healthy during the winter season. Below are important tips to keep in mind:

**Bundle up:** dress in layers to decrease the amount of body heat loss and prevent wintry winds from coming in. Remember your coat, hat, gloves, long johns and sweaters. Consider staying indoors when extremely cold.

**Say no to germs:** cover all sneezes and coughs. Use face masks if necessary. Wash hands frequently for 15 seconds each time.

**Stay hydrated:** Don’t forget the indoor, dry heat during this season. Make sure you drink plenty of water!

**Are you vaccinated?** It is important to get the flu vaccine every year and the pneumococcal vaccine every 5 years.

**Antibiotics:** If you do become sick and have a fever, please see your primary care physician (PCP) immediately. Complete all antibiotic medications as prescribed by the doctor. Though you will start to feel better, the infection is not gone until you finish the antibiotics. If you are on Coumadin, please notify AC Clinic of any meds as some antibiotics can change your blood levels.
GUESS YOUR SICKLE TEAM PROVIDER:

Key:
Dominique, Nicky, Yvette, Romaine, Pius, Dr. Smith-Resar, Cyndi, Jordan, or Terri
Cynthia Washington
Registered Nurse

Nicklaine Paul
Lead
Registered Nurse

Dzifa Dordunoo
Registered Nurse

Dominique Lyles
Clinical Associate

Dawn Hatcher
BSW, Social Worker

Terri Blackwell
Clinical Associate

Cody Cichowitz
Research Assistant

Jordan Wilks
Research Assistant

Cedron Williams
Clinical Research Consultant

Sadie Molock
Sr. Medical Office

Romaine Bradshaw
Clinical Coordinator

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410-502-2814

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