

PHSSCA is so grateful for your support this year... Thank you!

This year presented us with many inspiring ways to serve, educate, advocate and increase awareness for sickle cell disease.

Here's a small recap of some of our outstanding accomplishments and pictures from our biggest moments this year:

- -PHSSCA [in Mecklenburg county] served 548 clients with SCD.
- -PHSSCA partnered with Crisis Assistance Ministries to ensure <u>54</u> of our families' received emergency financial assistance for their rent and/or utilities.
- -<u>68</u> adult clients were enrolled to receive medical insurance assistance from DPH-Sickle Cell medical insurance program (NC TRACKS).
- -Facilitated Individual Education Plans (IEP/504P) for 122 clients, grade K-12.
- -Hosted <u>8</u> support group meetings catering to adults, Mothers & Teens.
- -Provided more than <u>2000</u> direct services, e.g. referrals, interventions, home visits, hospital/ER visits, phone contacts, transportation, etc.
- -100% of all babies born with **disease** in Mecklenburg--families received SCD education and genetic counseling, 13 born.
- -62% of babies born with Sickle Cell **Trait** in Mecklenburg received genetic counseling.

Transition to Independence, T21

During Spring Break, PHSSCA-Charlotte launched our first transition program, *Transition to Independence – T21*.

The 2-day program engaged students in lecture settings and kinesthetic activities to enhance their understanding of SCD & their body, alternate ways to manage stress, medication adherence, medical compliance, medical etiquette, personal responsibility and overall transition.

PHSSCA introduced <u>14</u> teens/young adults to the *adult* medical world/Sickle Cell Program starring Dr. Ify & Ms. Shirley Miller; M&F Bank hosted a session on financial literacy; a college tour and a painting-class designed to show teens other ways to reduce stress.







Outreach

PHSSCA participated in more than 150 outreach efforts to include: Advocacy Interventions, Education Sessions, Support Group Meetings, Hospital/ER visits and countless health/community fairs all to impact and raise awareness in Mecklenburg county and North Carolina.





Advocacy Day @ NC State Legislative Building





Education Series Program with The Adult Sickle Cell Program @ Levine Cancer Institute





Employee Community Fair

Sickle Cell Summer Enrichment Camp 2017

July 31 - August 4

Our Annual Sickle Cell Summer Camp was so much fun!

We celebrated our 34th year of hosting our camp which is offered free-of-charge to children in North Carolina with sickle cell disease, ages 6 through 15.

The camp fosters personal growth and lots of old-fashioned fun through a traditional summer camp experience which includes swimming, arts & crafts, fishing, field trips, motivational speakers and much more!



Group shot of our "Happy Campers", wonderful counselors and dedicated volunteer nurses!

<u>Sickle Cell Gala/Retirement</u> Farewell to Dr. Gladys Robinson

On Friday, September 8, 2017, Greensboro, NC, we held our annual Sickle Cell Gala and Retirement Party for Dr. Gladys A. Robinson, hosted by Celebrity Radio Host/The Steve Harvey Morning Show & National Sickle Cell Ambassador, Kier "Junior" Spates.

As the Executive Director for PHSSCA, Dr. Robinson served 34 years making a difference in the lives of those affected by sickle cell disease. Dr. Robinson, also serves as a NC State Senator and has done so for the past 7 years.

Thank you for your great service.

We appreciate you Dr. Robinson.



Left: Executive Director, Kathy M. Norcott; Middle: Celebrity Radio Host, Kier "Junior" Spates; Right: Senator, Dr. Gladys A. Robinson

PHSSCA 4th Annual Sickle Cell RunWalk

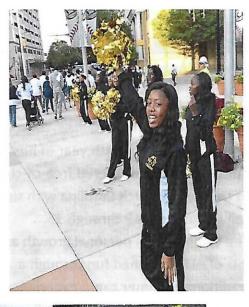
On Saturday, September 9, 2017, at 8:00 am, Piedmont Health Services and Sickle Cell Agency (PHSSCA) sponsored its 4th Annual 3K Sickle Cell Run | Walk in the heart of Uptown Charlotte on S. Mint Street, between Romare Bearden Park and BB&T Baseball Stadium.

The 3K Sickle Cell Run | Walk helps to help raise awareness for sickle cell disease and raises funds to support patients and their families, and our efforts. Over 500 people participated in the run this year.

It was a success... and thank you to our many sponsors and supporters.









Balloon Release

A Prayer Ceremony and Balloon Release was held to remember the 13 Sickle Cell Warriors that transitioned in 2017.

We continue to send prayers of love and strength to the families.

Forever Missed...

Forever Remembered.



Annual Christmas Celebration

On December 3, 2017, we hosted our annual Christmas Celebration at First Baptist Church West. We had lots of fun to include pictures with Santa, games, food, sweets and an awesome Fashion Show!





Model wearing a beautiful dress from Great Things Consignment.



Toys 4 Tots

PHSSCA partnered with
Toys 4 Tots to ensure
families had toys for
Christmas.
120 children received toys.
Marines, Thank You Much.





Meet & Greet - Doctors Talk About The Cure

On Wednesday, December 6, 2017, PHSSCA hosted a meet & greet, "Doctors Talk About The Cure for Sickle Cell Disease". Information on the The Cure was presented by several prominent doctors: Dr. Michael Kent (Carolina Medical Center), Dr. Sullivan (Duke University) and Dr. Krishnamurti (Emory University).

It was exciting to hear about the cure for sickle cell disease.

For more information:

Pediatrics Contacts:

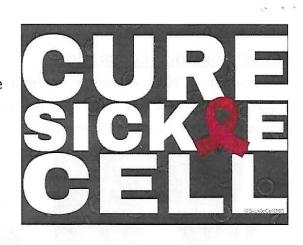
Children ages: 0 to 18 Carolinas HealthCare System

Kim Zahn - (704) 355-0425 Kim.Zahn@carolinashealthcare.org

Adults Contact

Adults ages: 18 and older

Carolinas HealthCare System LCI referral number (980) 442-2000





We have volunteer
opportunities.
Please call PHSSCA-Charlotte
office to get involved...
(704) 910-2002



www.facebook.com/phssca

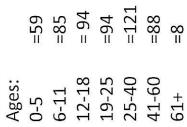


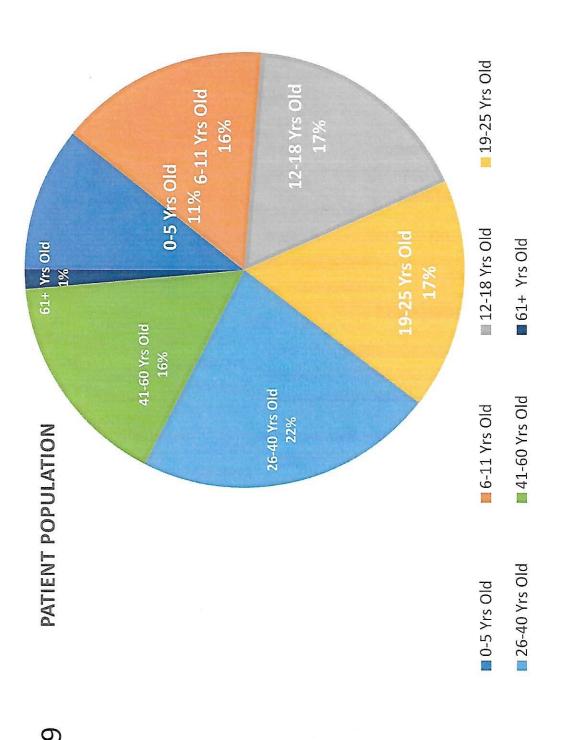
Will you please add PHSSCA to your donation list?

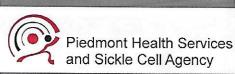
The donation you give will enable PHSSCA to continue providing essential services that improves the lives of many in our community. If you have any questions, please call (704) 910-2002 or visit our website www.piedmonthealthservices.org to make a financial donation.

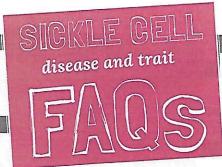
Active Clients: 549 Mecklenburg

Additional Breakdown











What is Sickle Cell Disease? Sickle Cell Disease is a group of inherited red blood cell disorders. It is the most common genetic disease in the U.S. Over 90,000 Americans have Sickle Cell Disease. Normal red blood cells are round like donuts, and they move through small blood tubes in the body to deliver oxygen. Sickle red blood cells become hard, sticky and shaped like crescents (or sickles, a tool used to cut wheat). When those hard and pointed red cells go through the small blood tube, they clog the flow and break apart. This can cause pain, damage and a low blood count (anemia).

What Makes the Red Cells Sickle? There is a substance in the red cell called hemoglobin that carries oxygen inside of the cell. One little genetic change in this substance causes the hemoglobin to form long rods in the red cell when it gives away oxygen. These rigid rods change the red cell into a sickle shape.

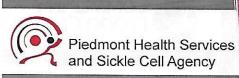
How Do You get Sickle Cell Anemia? The abnormal Sickle Cell hemoglobin is inherited from both parents who may have the disease, or simply be carriers for the trait. You cannot catch it from another person. You are born with the abnormal hemoglobin and it is present for life.

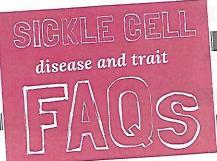
Does Sickle Cell Affect only African Americans? Sickle Cell occurs in many nationalities including African Americans, Arabs, Greeks, Italians, Latin Americans and Indians. All races should be screened for the Sickle Cell hemoglobin at birth. In the U.S., 1 out of every 10 African Americans have sickle cell trait and 1 out of every 500 African American newborns have the disease. In North Carolina, 1 out of every 360 African Americans currently have Sickle Cell Disease.

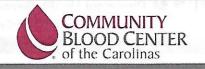
What is the Sickle Cell Trait? Sickle Cell trait is when a person carries one sickle hemoglobin gene and one normal hemoglobin gene (these are inherited from their parents). Normal hemoglobin is called type A. Sickle hemoglobin is called type S. When you have the trait, your hemoglobin gene is referred to as AS. (Someone with the disease would have an SS gene). Having the trait will NOT cause sickle cell disease and usually doesn't cause any major issues for the person carrying the trait. Other hemoglobin traits common in the U.S. are AC and AE traits.

How Can I Test for Sickle Cell? A simple blood test called the hemoglobin electrophoresis can be done by your doctor or local Sickle Cell foundation. This test will tell if you are a carrier of the trait or if you have the disease.

{continued...}







Are Newborns Tested for Sickle Cell? Most states now perform the sickle cell test when babies are born. Other types of traits may also be discovered including: Hemoglobin C trait, Hemoglobin E trait, and Hemoglobin Barts. If you are worried your child may have the trait or disease, be sure to ask your doctor about the test.

Are There Different Types of Sickle Cell Disease? There are three common types of Sickle Cell Disease in the United States:

- 1. Hemoglobin SS or sickle cell anemia
- 2. Hemoglobin SC disease
- 3. Hemoglobin sickle beta-thalassemia

Each of these can cause sickle pain episodes and complications, but some are more common than others. All of these may also have an increase in fetal hemoglobin which an protect the red cell from sickling and help prevent complications. The medication hydroxyurea also increase fetal hemoglobin.

Where Can I Get More Information? Visit the Piedmont Health Services and Sickle Cell Agency at www.piedmonthealthservices.org or by calling 336-274-1507 or 1-800-733-8297. For the Charlotte office, call 704-910-2002. Contact the Sickle Cell Disease Association of America at 1-800-421-8453.

How Can I Help? One way Sickle Cell patients receive treatment is through frequent blood transfusions. This will replace their sickled red cells with healthy cells and decrease the chance of pain crises. Because the majority of Sickle Cell patients are African American, the need for healthy African American blood donors is great. Due to the frequency of transfusions, Sickle Cell patients need very closely-matched blood in order to prevent transfusion rejection. This usually comes from African American blood donors.

Is Blood Donation Safe? Yes, blood donation is very safe. A mini-physical and health questionnaire ensure that you are healthy enough to donate blood each time you visit a donation center or mobile blood drive. Every donation uses sterile, single-use equipment. You are also able to prepare for donation by eating extra iron-rich foods and drinking plenty of water in the days before your donation.

Donate Blood or Host a Blood Drive To donate blood with the Community Blood Center of the Carolinas visit www.cbcc.us. When you donate with CBCC, your donation stays in this community, helping local patients. Also consider hosting a blood drive in your community, at work or at church. Call 704-972-4700 or 336-413-4995 to learn more.

Stroke, silent infarcts, Splenic function and CNS function Cardiac function , Leg ulcers ANN Psychological _ problems Hematology • Infections **Growth and** maturation -Kidney, Spleen & Liver Problems everywhere blood flows...

More Complications:

SCD can affect

-Fatigue/Irritability

-Organ Damage

-Pain

-Pulmonary Hypertension

-Jaundice

-Priapism

-Stroke

-Anemia

-Gall stones

-Pneumonia

-Breathing problems -Delayed Growth

PHSSCA Programs & Services

- Assessments
- Care Coordination
- Resource Development
- Link to Doctors | Providers | Resources
- Genetic counseling
- Education
- Testing
- Summer Enrichment Camp (Camp Care Free)
- Support Groups
- Support to Comprehensive Medical Centers

- · Support Clinic (Peds & Adults)
- Home Visits / Hospital & ER Visits -
- Patient Advocacy
- CDSA / CC4C Referrals
- 504/IEP School Meetings
- DPH Sickle Cell (formerly POMC) . Annual Sickle Ce
- Crisis Assistance Ministries
 Partner
- App, Financial Budget, Case plan An
- Assist Food Stamp / Medicaid App
- Transportation
- Counseling Referral

- T2I Transition to Independence
 P.U.S.H.
 (Parents Understand Sickle Cell Health) Support Group
- Teen Support Group
- Adult Support Group
- Annual Sickle Cell Run/Walk
- Annual Christmas PartyAnnual Book Bag/SchoolSupply/Winter Coat Event
- Blood Drives Partnership with CBCC
 - (Sickle Cell Heroes program)
- FILC

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Jan / Feb 2018

Bi-Monthly NewOsletter



PHS SC



Sickle Times

(704) 910-2002 - 740 WEST FIFTH STREET, SUITE 210, CHARLOTTE, NC 28202

(Located inside the Urban League Building)

Let's Talk About TRANSITION....

Transition is the transfer of care from pediatric to adult doctors, which can be challenging for adolescents with SCD. The need for "transition" programs is known; however, many SCD patients leave pediatric care without adequate preparation. As children with SCD become adults, care can become more difficult. Patients must find new doctors and face insurance issues. PHSSCA is helping to reduce barriers to adult care.

PHSSCA will help you address transitional needs with doctors, medical insurance, interventions and social services.



- Currently, the oldest person with SCD in Charlotte is <u>70</u> years old.*****
- 2. SCD is the most common genetic disorder in the US.
- 3. The CDC recommends flu vaccines because people with SCD are at high risks for infections.

MAKING THE TRANSITION EASIER:

PATIENTS

- *Learn about your type of SCD
- *Know your past medical history
- *Know what medicines you are on and why
- *Keep your appointments and arrive on time
- *Speak up and ask questions during clinic visits
- *Take medicines independently or with few reminders
- *Get plenty of rest, water, and exercise.
- *Eat a balanced diet and know your limits
- *Know when you need to come to the hospital and how to call for help
- *Learn about how insurance works
- *Think about your future and learn how to take care of yourself

FOR PARENTS

- *Encourage independence
- *Allow your child to speak for themselves and take an active role during clinic visits
- *Teach your child about the disease and the medications
- *Teach your child about past medical history
- *Help your child prepare questions for their health care team
- *Be a role model for good health habits related to diet, exercise, smoking, and alcohol use
- *Make sure that your child knows what type of health insurance you have and understands how insurance works
- *Help your child prepare for higher education, work, and living on their own



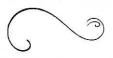
New Year ~ New Feels

New Breath ~ New Chances

Same dreams, fresh starts.

I dare you to believe in yourself.

You deserve all things beautiful, healthy & successful.



Outlook for 2018

- -Parents Understanding Sickle Cell Health [PUSH] will meet—Jan 18 & March 15
- -Q&A w/ Dr. Kent—Stem Cell Transplantation-March 6
- -Opiod Crisis-Guest Speaker, Dr. Ify & Dr. Wyatt-March 28
- -Transition 2 Independence (T2I) Date: Spring/Summer
- -Advocacy Day on Capital Hill, DC-April 18-19
- -Sickle Cell Camp—July 29-August 3
- -World Sickle Cell Day-June 19
- -PHSSCA Annual Sickle Cell Run/Walk—September 8
- -National SCDAA Convention, Baltimore, MD—October 9-13
- -Annual Christmas Celebration—December 2018

Do you have any suggestions for activities you would like to see happen this year?

Please email correspondence to acoleman@piedmonthealthservices.org

Above Abstract: Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness.

STUDENT CORNER

8 Pieces Of Advice For Graduating Seniors

1. You're Almost There!

You worked so hard to graduate so now is the time to relax, BUT with moderation! You have goals to reach so take a little time off, but also get ready to do the following...

2. Research Activities in College

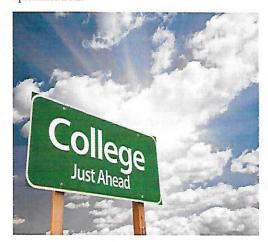
Look into the school you are about to go to and see what activities they have. Knowing what you want to be a part of on campus before you get there gives you a much-needed head start. If you wait until you start college you will be dealing with so many other things and forget to join a club, society, etc. when it is essential in college.

3. Volunteer

Both high school and college graduating seniors should volunteer for the sake of GAINING EXPERIENCE.

4. Consider Internships Early

What is an internship? It is a position of a student or trainee who works in a company, sometimes without pay, in order to gain work experience or satisfy requirements for a qualification.



5. Make a LinkedIn Account

PLEASE. PLEASE. PLEASE make a LinkedIn account and start making connections! Connections are the best thing to have when applying for a job. If you don't know what LinkedIn is, it is simply like a professional Facebook that showcases all your awards, your resume, skills, etc.

6. Start/Continue Looking For Jobs

I honestly prefer looking for jobs well in advance. When I was looking for summer jobs, I started as early as January, and I did the same when I was about to graduate. However, life gets the best of us so if you haven't started looking, START!

5. Speak Up – Tell Others About Your Goals

There is an expression: "A closed mouth doesn't get fed" which basically means that no one will know you recently graduated and are looking for job, internship, etc. unless you say something. Bring it up in conversation; you never know what connections people may have. You could unknowingly be chatting it up with a boss at a law firm, or be the wife to a journalist – so SPEAK UP! Don't be shy.



8. Stay Positive

When everyone graduates around the same time, there are thousands of applications sent to companies, right alongside yours. Stay positive and pray for the best since you are essentially competing with thousands of others. You most likely won't land the first dream job you apply for, but don't lose hope and don't stop applying!

https://www.society19.com/8-pieces-advice-graduating-seniors/

5 of the best websites to find a College Scholarship

- Fastweb.com
- Collegeboard.org
- Niche.com
- CollegeNET.com
- Scholarship Monkey

Did You Know?

For the 2016-17 academic year, here's how much it costs to attend college:

Public Two-Year College (in-district students): \$3,440

Public Four-Year College (in-state students): \$9,410

Public Four-Year College (out-of-state students): \$23,890

Private Four-Year College: \$32,410

List of Scholarships

Leslie Delk, Sr. Academic Scholarship

The Leslie Delk, Sr. Academic Scholarship administered by the *Taylor Delk Sickle Cell Foundation* will be awarded to individuals with sickle cell disease. Applicants must be graduating high school seniors attending a 4-year accredited college. One award for a total of \$5,000 per academic year, up to 4 years.

For additional information and/or applications please contact Tiffany Delk at (731) 694-8727 or via email <u>tiffanydelk@tdscf.org</u> to request an application.

The International Association of Sickle Cell Nurse and Physicians Assistants, Inc.

The Association offers \$500.00 scholarships to individuals diagnosed with Sickle Cell, who have either enrolled, or been accepted at a post-secondary institution.

Applicants will be evaluated based on individual GPA performance, level of financial need demonstrated, and level of participation in extracurricular activities and community service. Applications are available online, at the Association website.

http://www.iascnapa.org/docs/Scholarship.pdf



Call the office to get involved this year: (704) 910-2002

What Health Problems Does Sickle Cell Disease Cause?

Some of the most common complications of SCD include:

"Pain Episode" or "Crisis": Sickle cells don't move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection: People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis.

Hand-Foot Syndrome: Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet, usually seen in children.

Eye Disease: SCD can affect the blood vessels in the eye and lead to long term damage.

Acute Chest Syndrome (ACS): Blockage of the flow of blood to the lungs can cause acute chest syndrome. ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

Stroke: Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.



Piedmont Health Services and Sickle Cell Agency

Mecklenburg County Office

610 East 7th Street Suite 2-B Charlotte, NC 28202 Phone: (704) 910-2002 Fax: (704) 910-1611

Office Hours: Monday - Friday 8:30 am - 5:00 pm

Main Office

1102 E. Market St. Greensboro, NC 27401 Phone: (336) 274-1507 Fax: (336) 275-7984 Toll Free (800) 733-8297 www.PiedmontHealthServices.org



Mecklenburg County



Your Partner in Community Health

Our Mission:

Piedmont Health Services and Sickle Cell Agency (PHSSCA) provides outreach, education, screening and case management for people with high-risk health problems; focusing on sickle cell services, HIV/AIDS prevention and diabetes.



In Mecklenburg County, Piedmont Health Services and Sickle Cell Agency provides care coordination to over 700 patients and provides sickle cell education, genetic counseling and testing to the general public.



What You Should Know About Sickle Cell Disease

What Is Sickle Cell Disease?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

- Healthy red blood cells are round and they move through small blood vessels carrying oxygen to all parts of the body.
- In SCD, the red blood cells become hard and sticky and look like a Cshaped farm tool called a "sickle."
- Sickle cells die early, which causes a constant shortage of red blood cells.
 Sickle cells can get stuck in small
 - Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These blockages cause repeated episodes of severe pain, organ damage, serious infections or even stroke.

What Is Sickle Cell Trait?

Sickle cell trait (SCT) is not a disease, but having it means that a person has inherited the sickle cell gene from one of his or her parents. People with SCT usually do not have any of the symptoms of sickle cell disease (SCD) and live a normal life. However, if two people with Sickle Cell Trait have a child, there is a one-in-four chance that the child will be born with Sickle Cell Disease.

What Causes Sickle Cell Disease?

SCD is inherited in the same way that people get the color of their eyes, skin and hair.

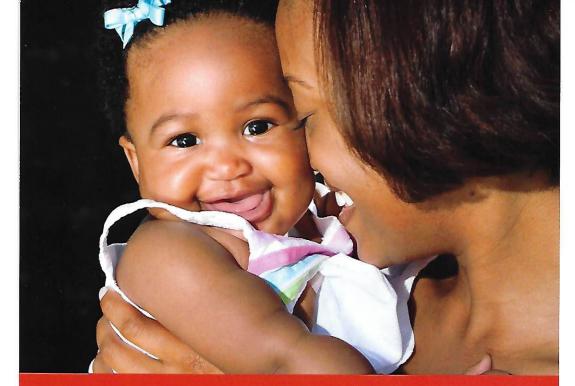
- A person with SCD is born with it.
 People cannot catch SCD from being
 - People cannot catch SCD from being around a person who has it.



Who Is Affected By Sickle Cell Disease?

SCD affects all races and ethnic groups. In North Carolina, SCD occurs in approximately 1 out of every 360 Black or African American births, and one out of every 10,800 Hispanic-American births. Other known ethnicities who are affected are those from Asia, Southeast Asia, the Middle East and Mediterranean countries such as Turkey, Greece, and Italy.





Do you have, or know someone, with sickle cell disease?

We can help...give us a call! 1 (800) 733-8297

See reverse for all of our services and locations!



www.PiedmontHealthServices.org www.facebook.com/phssca



Mission:

Piedmont Health Services and Sickle Cell Agency provides outreach, education, screening and case management for people with high-risk health problems, focusing on sickle cell services, HIV prevention and early childhood development.

Services:

Sickle Cell Screening, Genetic Counseling and Care Coordination

HIV Education and Outreach

Early Childhood Development Programs

1102 E. Market Street Greensboro, NC Phone: (336) 274-1507

401 Taylor Ave High Point, NC Phone: (336) 886-2437

1317 N. Cherry Street Winston Salem, NC Phone (336) 725-9181 610 East 7th Street, Suite 2B Charlotte, NC Phone: (704) 910-2002

Serving Alamance, Caswell, Forsyth, Guilford, Mecklenburg, Randolph and Rockingham Counties

www.PiedmontHealthServices.org

Toll Free (800) 733-8297