

Cincinnati Sickle Cell Center Staff

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Cristina Tarango, MD

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Kelly Jump

Administrative Support Services

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Hemoglobinopathy Lab Manager

Lana Weckbach, PhD

Medical Director of Adult Services

George Atweh, MD

Farewell Director's Desk

Clinton H. Joiner, MD, PhD



As many of you may already know, I have left the Cincinnati Comprehensive Sickle Cell Center to move to Atlanta this summer, after 24 years at Cincinnati Children's Hospital Medical Center. It is hard to leave my friends and colleagues at Children's, and especially the many patients and families I have been privileged to serve for the past 16 years as Director of the Cincinnati Comprehensive Sickle Cell Center.

I am assuming the position of Director of Hematology at the Aflac Cancer and Blood Disorders Center at Emory University and Children's Healthcare of Atlanta. The Hematology program there is the largest in the country, with a very active Sickle Cell Center, so it is a real challenge and opportunity for growth. In addition, I grew up in Atlanta, so it is a homecoming for me.

The Cincinnati Comprehensive Sickle Cell Center will continue to meet all of your care needs. If I have been your child's primary hematologist, Lisa Ovesen will work with you to arrange for your child to see Dr. Karen Kalinyak, Dr. Charles Quinn, Dr. Theodosia Kalfa, or Dr. Punam Malik. Please contact Lisa Ovesen and let her know if you have a preference.

It has been my great pleasure to be associated with Cincinnati Children's Hospital Medical Center and the Cincinnati Comprehensive Sickle Cell Center. All of you will always occupy a special place in my heart.

Cincinnati Comprehensive Sickle Cell Center Welcomes New Director!

The Cincinnati Comprehensive Sickle Cell Center is proud to announce Dr. Punam Malik as the new Director. Dr. Malik has been an instrumental part of the Center since 2006, when she moved from Children's Hospital Los Angeles.

Many of you may have already met Dr. Malik or heard about her research in sickle cell disease. Known nationally and even internationally for her gene therapy research, she is the Program Leader of the Hematology and Gene Therapy Program at the Cancer and Blood Diseases Institute at Children's. She also leads the Translational Core Laboratory, which is a state-of-the-art research facility that works to translate laboratory discoveries into clinical trials.

Dr. Malik is also dedicated to patient care, especially children with sickle cell disease. She is a familiar face in the sickle cell clinic and is often on service as an attending physician for inpatient hematology.



September is Sickle Cell Awareness Month

There are several different ways you can participate in Sickle Cell Awareness Month:

- Recruit friends and families to sponsor you for the Cincinnati Walks for Kids Walk and set a personal goal for raising donations for the walk.
- Recruit your child's school, your place of employment, or your church to make donations or pledges in honor of your child with sickle cell disease.
- Call School Intervention to start the school year out right for your child and educate school staff about sickle cell disease.
- Talk to friends and family members about sickle cell disease.
- Get tested for sickle cell trait if you don't know if you have sickle cell trait.
- Talk to your child about what it means to have sickle cell disease and work on one self-management goal for the month.
- Ask your church to participate in Sickle Cell Sabbath on September 15 – 16th to raise awareness about sickle cell disease and sickle cell trait.
- Be creative to raise awareness about sickle cell disease and sickle cell trait.



Teens Taking the Opportunity to Volunteer Lisa R. Leace, LISW-S



Shayla D and Maleyia T (Friend of Shayla's), are pictured together as they wait patiently for more children to come by the booth and play "Find the Healthy Plate."



Pictured are members of the group that participated in Closing the Health Gap 2012; Jajuan C, Briana B, Theresa W, Shayla D, Maleyia T and Shawn R.

Several members of the Sickle Cell Peer Support group took the time to come out and volunteer during Closing the Health Gap Expo in April 2012. The event was held at the Cintas Center on Xavier University's campus. The teens were asked to commit to at least two hours of volunteer time during this event. They all went above and beyond commitment expectations.

Each teen worked at least five hours. The teens facilitated two games in the Children's Pavilion. One game required that the children make healthy food choices by fishing for the item that best represented their normal food choices. The teens then took the time to explain to the children why their food choices were either "good" or "bad" and discussed ways in which they could make more appropriate choices. The other game required the children to compare two plates prepared with food and identify the plate that appeared to be the healthier choice and explain why. The teens were patient and attentive as they worked with the children. The "Healthy Choice" games served as a great conversation piece between both the teens and the children that stopped by the booth. It also served as an avenue for the teens to educate the children while increasing their leadership and communication skills.

The Sickle Cell Peer Support group will resume in late summer 2012. Contact Lisa Leace at 513-636-9654 or lisa.leace@cchmc.org for more information.

A Research Study for Children and Adults who have Kidney Damage Caused by Sickle Cell Disease

What is the purpose of this study?

This is a research study to find out if a medication, called losartan, can help reduce or reverse sickle cell-related kidney disease.

Who will be included in this study?

Children at least 6 years old and adults who have a minor or major form of kidney damage caused by sickle cell anemia (SS disease) and sickle beta-zero thalassemia may be eligible to participate.

What is involved?

Participation in the study involves about eleven visits over a period of about six months. All study participants will receive losartan medication for a total of six months and will be required to maintain a medication diary for the duration of the study.

Other tests and procedures that will be performed include, but are not limited to:

- Health and medication history
- Physical exams, including height and weight, temperature, pulse, and blood pressure measurements
- Blood draws to check kidney function, blood cells, and blood levels
- Urine tests to check for protein levels
- EKG (electrocardiogram) and ECHO (ultrasound of the heart) to check heart function
- Walking tests to assess heart and lung function

A detailed list of tests and procedures will be provided to those interested in knowing more about this study.

What are the benefits?

Participants may receive a direct medical benefit by taking part in the study, including the possibility of reduced or reversed kidney damage. In addition, information from the study may benefit other patients with sickle cell disease in the future.

Will I get all the facts about the study?

Those interested in participating will be given a consent form that thoroughly explains all of the details of the study. The consent form covers all of the procedures, the potential risks and benefits, who to contact with questions or concerns and more. A member of the study staff will review the consent form with participants to ensure all questions are answered. Study procedures will not begin until the participant has signed this consent form.

What are the risks and discomforts of the study?

There are some potential side effects associated with taking losartan and minor discomforts associated with the study procedures. A complete list of risks and benefits will be provided in the consent form to those interested in learning more about the study.

What is the pay?

Participants may receive up to \$520 for time and travel.

Who should I contact for more information?

Clinical Research Nurse Coordinator
Sickle Cell Research Office
513-636-6770
Division of Hematology
Cincinnati Children's Hospital Medical Center
3333 Burnet Avenue
Cincinnati, OH 45229-3039
sicklecell@cchmc.org

Hot, Hot, Hot Weather Reminders

Tracy Mahaney, RN, BSN

Tis the season for hot weather and reviewing sickle cell "hot weather care". Following these guidelines will help ensure that you continue to have a healthy, happy summer and early fall:

1. Drink plenty of water - try to carry a water bottle with you.
2. Avoid temperature extremes; dress in layers, so that you may take off or add on. (ie: being out in the hot sun and then going into an air conditioned building can cause chills).
3. Swim only when sunny and the temperature is over 80 degrees. After swimming, dry off immediately and put on dry clothes.
4. If playing sports, rest often and stay hydrated. Talk to your Care Manager about sending a letter describing your sickle cell to your coach.
5. If traveling, be sure to pack for cold/hot weather as you should dress in layers to prevent chilling or over- heating. When traveling, carry a water bottle, plan for frequent restroom breaks, make sure you have enough of your medications, and speak to your Care Manager about getting a Travel Letter.

Care Manager Corner



Lisa Ovesen RN, BSN, CPN

What is a “medical home” and why is it important for my child?

You may have heard us talk about the need for your child to have a “medical home.” A comprehensive medical home requires both primary care and specialty care and its goal is to obtain the best care possible for your child. We often partner with other services, such as Ear, Nose and Throat or Pulmonary to care for your child. But one of the other services that is equally important but often overlooked, is “primary care”. Seeing the pediatrician is important because they monitor growth and development, give immunizations, and provide well-child checks. Keep in mind that not every issue is related to your child’s sickle cell disease and some things, like ear infections, colds/viruses, bug bites, and rashes are best dealt with by your child’s pediatrician. We recommend that you see your pediatrician at least once a year and follow up with your sickle cell team every 6 months. If you need help finding a pediatrician, please let us know and we can help you connect with physicians in your community.



Patricia Boyd, RN

My child is between the ages of 7-14. What educational opportunities are there for my child to learn about sickle cell disease?

We are starting a new Educational and Support Group meeting especially for this 7-14 year old age group and is open for families and friends. We hope to have the meetings three times a year. The next meeting is planned for October 2012. The purpose of the meeting is for the children and the adults to learn about sickle cell disease while networking and meeting other kids in Cincinnati who also have sickle cell disease. Watch for more details in early fall.



Tracy Mahaney, BSN, RN, CPN

Why is a “medical home” important for teens?

A “medical home” is a primary care focused provider that helps coordinate care with other doctors, home health care, lab, social work, psychology, physical therapy, any other health care team members the patient may need, and most importantly.....you (and your family)!

It is important for all of our patients to have a medical home, as this will be the provider who knows the patient best and coordinates care with all other providers for that patient. The medical home will assist in improving health care for children or adults with complex health needs (such as sickle cell disease), by working closely with all the team members who take part in the patient’s care. This is not a special, separate provider, but a team approach.

This is especially important for our adolescents, teenagers, and young adults, as this can be a more complicated age group with rapid growth, changes, and maturation. The medical home can be key in caring for this group, as it partners with families to plan visits, coordinate complex services, co-manage with specialists (such as Hematology/Sickle Cell doctors), connect with community services, offer efficient care, and assist with transition to adult care.

Be sure to ask your Care Manager about a medical home and how we can assist you.

Zoo Day - April 28, 2012



School is Out... But Not For Long! School Intervention Program

Leah Engelkamp, M.Ed



School may be out for the summer, but the start of the school year is quickly approaching. It is not too early to be thinking about what academic needs your child may have during the upcoming school year. Don't forget that the School Intervention Program is available to help.

What is School Intervention Program (SIP)?

The School Intervention Program, at Cincinnati Children's Hospital, strives to provide a successful school experience for patients with sickle cell disease. The primary role of the School Intervention Coordinators is to serve as liaisons between the family, the school, and the medical team. Leah Engelkamp and Dave Kathman are the School Intervention Coordinators dedicated to serve the sickle cell disease population. Dave works with patients grade 6 and below and Leah works with patients grade 7 and above.

What is the role of a School Intervention Coordinator?

- Educate teachers, school staff and classmates about sickle cell disease
- Provide staff with information and resources about the patients' diagnosis
- Participate in meetings with parents and the school to identify and obtain special education services including Individual Education Plans (IEP), or 504 Accommodation Plans
- Assist patients and their parents in navigating the school systems to access appropriate school services
- Provide support for parents to become advocates for their child
- Identify necessary classroom adaptations (i.e. bathroom privileges and water breaks)

What are some school-related issues that patients with sickle cell disease can experience?

- Poor academic performance
- Frequent absences
- Pain episodes at school
- Low self-esteem
- Lack of participation in physical education class

How can parents help?

Parents play a very important role in their child's education. Parents and School Intervention Coordinators attend school meetings together. Parents are responsible for communicating with the School Intervention Coordinator about their child's progress and educational needs.

Who qualifies for School Intervention Program services?

All patients of the Cincinnati Comprehensive Sickle Cell Center are eligible to receive help from the School Intervention Program. The School Intervention Program is a free service provided by the hospital with no charge to you or your insurance. Services are available for children in preschool through transition to adult care. If you are interested in the School Intervention Program, contact your social worker to initiate a referral.

For more information about the School Intervention Program, contact Leah Engelkamp or David Kathman at (513) 636-8604.

Have Fun Walking While Raising Funds for Sickle Cell Disease

Cincinnati Walks for Kids – October 20, 2012

Coney Island, 8 am – 1 pm



Registration is available online at

<http://giving.cincinnatichildrens.org/netcommunity/page.aspx?pid=1450> or for more information contact the Cincinnati Walks for Kids Team at walk@cchmc.org or phone 513-636-2941.

- Participate in a 1 mile or 3 mile walk. Or, participate as “virtual walker”!
- Recruit friends and families to sponsor you for the Cincinnati Walks for Kids Walk.
- Make the Cincinnati Walks for Kids Walk a great opportunity for a “family reunion”.
- Ask your friends to show support for sickle cell disease and walk with you.
- Create a personalized fundraising webpage to raise money for the walk.
- Have a contest to see who can raise the most funds.
- Use social networking, such as Facebook, to let your friends know about the upcoming walk and ask for their support.
- Wear team t-shirts to show team spirit and support for sickle cell disease.
- Be creative!

Don't miss this exciting, fun family event and the opportunity to network with other parents of children with sickle cell disease who, like you, want to make a difference right here in Cincinnati at the Comprehensive Sickle Cell Center. Free lunch is provided along with door prizes, face painting and other fun. Free t-shirts are given to all walkers who raise at least \$25.

Sickle Cell Sabbath

September 15-16, 2012



The Cincinnati Comprehensive Sickle Cell Center invites your congregation or faith-based organization to participate in this important educational program that aims to increase awareness about sickle cell disease and trait, and the need for minority blood donors. Free educational materials about sickle cell disease and sickle cell trait are available. Please ask your faith-based organization to contact Lisa Shook at 513-636-7541 or lisa.shook@cchmc.org by August 30th if they would like to participate.

Mark Your Calendar!

August 18, 2012

The Midwest Black Family Reunion will be held at Sawyer Point along the Ohio River. The Cincinnati Sickle Cell Center will be providing education and free sickle cell trait testing at the Health Fair during the event.

August 25, 2012

The 11th Annual Sickle Cell Disease Research and Education Day will be held at the Cintas Center from 11:00 am – 2:00 pm. For more information, please contact Heather or Adryan at 513-636-7817.

September 2012

Sickle Cell Awareness Month is observed each year in September. Take the opportunity to make a difference by increasing awareness about sickle cell disease and sickle cell trait in your community.

September 15-16, 2012

Sickle Cell Sabbath will be observed at faith-based organizations throughout the entire state of Ohio this weekend. This program is part of the Ohio Department of Health Sickle Cell Services Program. Churches and other faith-based organizations in southwestern Ohio, including Cincinnati, who would like to participate can contact Lisa Shook at 513-636-7541 or lisa.shook@cchmc.org for more information.

September 25-29, 2012

The Sickle Cell Disease Association of America (SCDAA) will hold their 40th annual convention “Renewing the Fight: One Community - One Cause - One Voice” in Baltimore, Maryland. For more information about conference registration, please check the SCDAA website at www.sicklecelldisease.org/index.cfm?page=annual-convention or call SCDAA at 1-800-421-8453.

October 20, 2012

Cincinnati Walks for Kids annual walk will be held at Coney Island. Patients, families, and supporters of Cincinnati Children’s will come together to participate in the sixth annual walk. This 1-mile or 3-mile walk offers fun for the whole family, including refreshments, music and more. Walker check-in begins at 8 am; opening ceremonies are at 10 am; and the event ends at 1 pm. There is no registration fee to participate but walkers are encouraged to raise \$25 to receive a free t-shirt.

Registration is available online at

<http://giving.cincinnatichildrens.org/netcommunity/page.aspx?pid=1450> or for more information contact the Cincinnati Walks for Kids Team at walk@cchmc.org or phone 513-636-2941.

Don't Forget SCD Research and Education Day is Moving To A New Location!

This year's Sickle Cell Disease Research and Education Day (August 25th) will be held at the Cintas Center this year!



For more information about studies currently enrolling sickle cell patients, please contact:

Hematology Research Office

513-636-6770

sicklecell@cchmc.org

Or visit: <http://www.cincinnatichildrens.org/svc/alpha/c/cancer-blood/blood-disease/sickle-cell/trials.htm>

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