



**Sickle Cell Neurodevelopmental
Clinic and Research Center
at Kennedy Krieger Institute**

2025 RESEARCH UPDATE





Sickle Cell Neurodevelopmental Clinic and Research Center at Kennedy Krieger Institute

DIRECTORS:



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Some of the photographs that appear in these pages are for illustrative purposes only, and any person shown in those photographs is a model.

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CLINICAL SERVICES

The **Kennedy Krieger Institute Sickle Cell Neurodevelopmental Clinic and Research Center** provides interdisciplinary care for children, teens and adults with sickle cell disease. Collectively, clinic specialists have expertise in neurology, developmental medicine, neuropsychology, education and behavioral psychology. Working together, they diagnose, discuss and provide treatment recommendations for various neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (ADHD), language delay and disorders, developmental delay, autism spectrum disorder, intellectual disabilities, stroke, headaches, seizures, selective mutism, learning disabilities, and other disorders. They also provide referrals to specialists with experience in treating patients with sickle cell disease in several other fields, including stroke neurology, psychiatry, rehabilitation and speech-language pathology.

Neurodevelopmental Medicine

Each of our patients is fully assessed by our neurodevelopmental physicians. The assessment includes a comprehensive review of the patient's medical condition and history, and a physical and neurological examination. The team also provides detailed recommendations, which can be shared with the patient's hematologist, if needed.

Neuropsychology

Our neuropsychologists review each patient's cognitive and academic challenges, collect a detailed medical and educational history, perform and interpret cognitive testing, and provide detailed recommendations, which can be shared with the patient's hematologist and school, if needed.

Behavioral Psychology

Our behavioral therapists review each patient's behavioral and mood conditions and collect a detailed behavioral history, including information about toileting, pill swallowing, sleep and mood. They also provide detailed psychology recommendations, which can be shared with the patient's hematologist, if needed.

Education

Our education specialist reviews educational challenges and makes school support recommendations based on the patient's and family's input and the clinical recommendations of the team. The recommendations can be shared with the patient's hematologist and school, if needed. Our education specialist is also available to attend school-based meetings to assist school teams in interpreting relevant healthcare information and designing responsive educational programming.



RESEARCH UPDATES

The Neuroimaging in Children With Sickle Cell Disease and Neurodevelopmental Disorders (SCD ADHD) Study

The **SCD ADHD study** explores changes over time in cognition, neurodevelopment, and brain structure and functioning in children 8 to 12 years old with sickle cell disease and ADHD and/or other neurodevelopmental disorders. Children undergo cognitive testing and have an MRI scan of the brain when they begin and conclude their participation in the study. A longitudinal history, examination and blood draw are done annually while in the study.

STATUS: Enrollment is complete, and the collection of longitudinal data is nearly finished.

NEXT STEPS: We are working on publishing additional papers on pica and enuresis, headaches, neuroimaging, and the overall results from the study. Stay tuned!

PUBLISHED FINDINGS

“Current developmental screening practices in young children with sickle cell disease” (PubMed)¹

“Imaging Blood–Brain Barrier Permeability Through MRI in Pediatric Sickle Cell Disease: A Feasibility Study” (PubMed)²

“Co-Occurrence of Neurodevelopmental Disorders in Pediatric Sickle Cell Disease” (PubMed)³

“Patients with Sickle Cell Disease and Autism Spectrum Disorder” (Advances in Neurodevelopmental Disorders)⁴

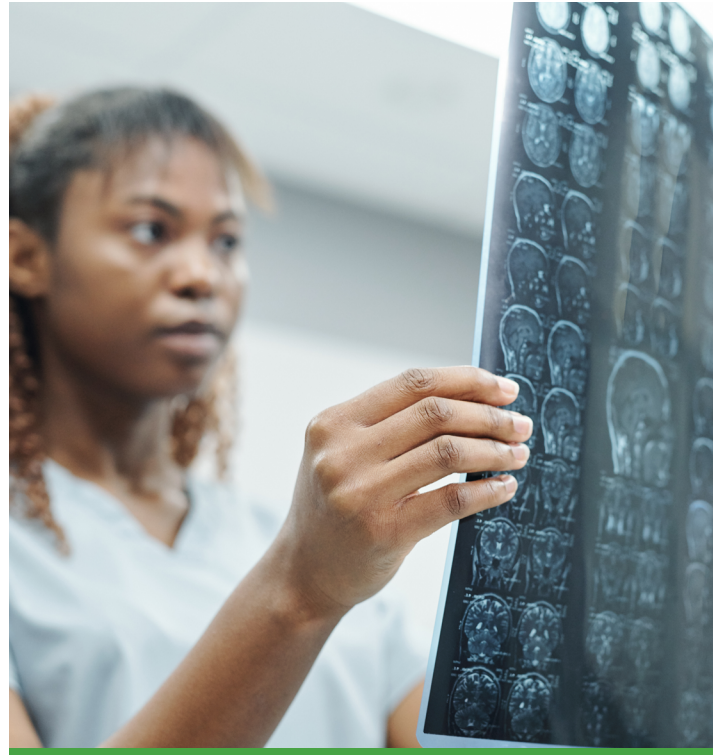


The Neuroimaging, Protein Biomarkers, and Neurodevelopment in Very Young Children With Sickle Cell Disease (SCD BABY) Study

The **SCD BABY study** explores the feasibility of obtaining MRI scans without sedation/anesthesia in children 6 years of age or younger with sickle cell disease. It also examines physical and cognitive symptoms associated with silent stroke in these young children. Children undergo cognitive testing at the beginning and conclusion of their participation in the study, with a longitudinal history, examination and blood draw done annually while they are in the study. Children begin behavioral training for MRI scans at 3 years old and undergo MRI brain scanning with associated neurocognitive testing once they pass the training.

STATUS: The study is actively recruiting new participants and continuing longitudinal follow-up with enrolled participants.

NEXT STEPS: The study is working on publishing **early results**⁵ regarding the feasibility of neuroimaging in young children and the rates of silent stroke in this age group.



The Pilot Study in Preparation for Validating MoCA for Screening for Mild Cognitive Impairment in Adults With Sickle Cell Disease (MoCA) Study

The **MoCA study** explores validating two cognitive screening tools, the Montreal Cognitive Assessment (MoCA) and the Rowland Universal Dementia Assessment Scale (RUDAS), in adults with sickle cell disease. Adults who have consented to participate in the study undergo screening with the MoCA and RUDAS, undergo formal neurocognitive testing virtually, and receive an MRI scan of the brain and a neurological examination.

STATUS: Study recruitment is currently on hold.

NEXT STEPS: The study is working on publishing **early results**⁶ regarding follow-up recommendations for patients with abnormal MoCA scores and obtaining additional funding.



The Hearing and Vestibular Issues in Sickle Cell Disease (HVI) Study

The **HVI study** explores hearing and balance issues in adults with sickle cell disease. In Phase 1 of the study, children and adults fill out a survey regarding hearing and balance issues. In Phase 2 of the study, adults undergo audiology and vestibular evaluation and MRI brain scanning.

STATUS: Study recruitment is currently on hold while we train new study personnel. Once recruitment resumes, we will recruit adults with and without sickle cell disease.

NEXT STEPS: The study is working on publishing **survey results**⁷ from Phase 1 and **retrospective study results**⁸ on hearing and vestibular functioning in children with sickle cell disease.



EDUCATION AND ADVOCACY

Sickle Cell Disease and the Brain: The Mind Matters

February 25, 2025 | Baltimore, Md.

Presented during the Kennedy Krieger Institute Behavioral Psychology Team Speaker Series.

SPEAKERS:



Dr. Alicia Cannon



Dr. Lisa Carey



Dr. Eboni Lance

Initiating Strategic Learning by Supporting Student Executive Function

March 12–15, 2025 | Baltimore, Md.

Presented to the Council for Exceptional Children.

SPEAKER:



Dr. Lisa Carey

Sickle Cell Disease

April 3, 2025 | Baltimore, Md.

Presented for a Johns Hopkins Bloomberg School of Public Health course, “The Intersection of Physical and Mental Health.”

SPEAKER:



Dr. Eboni Lance

Development and Implementation of an Interdisciplinary Special Education Eligibility Tool for Students With Chronic Health Conditions

May 1, 2025 | Virtual

Presented virtually to the Hospital Educator and Academic Liaison (HEAL) Association.

SPEAKERS:



Dr. Alicia Cannon



Dr. Lisa Carey



Mallory Legg, Esq.

Reducing the Barriers to Education for Children and Adolescents Treated for Cancer: An Exploration of the Hospital Education Liaison Program (HELP) as a Model to Support Patients, Their Families and Their Teachers Access, Participate and Achieve Their Educational Potential

May 12–16, 2025 | Dublin, Ireland

Presented to the HOPE Congress.

SPEAKER:



Dr. Lisa Carey

Let's Talk: Sickle Cell Disease and the Brain: The Mind Matters

May 20, 2025 | Philadelphia, Penn.

Presented as part of The Cooper Health System's series.

SPEAKERS:



Dr. Morgan Bifano



Dr. Alicia Cannon



Dr. Lisa Carey



Bridget Gibbons



Dr. Eboni Lance



Dr. Erika Wesonga

Mental Health and Chronic Illness: Let's Talk About It

June 21, 2025 | Baltimore, Md.

Presented as part of the 7th Annual Sickle Cell Disease Family Education Day Conference of the Maryland Sickle Cell Disease Association.

SPEAKER:



Dr. Eboni Lance

Sickle Cell Disease: A Consultant's Perspective

June 25, 2025 | Bethesda, Md.

Presented as part of the 11th Annual Meeting Event of the National Institutes of Health's NHLBI (National Heart, Lung, and Blood Institute) PRIDE (Programs to Increase Diversity Among Individuals Engaged in Health-Related Research).

SPEAKER:



Dr. Eboni Lance

The Educational and Behavioral Needs of Children With Sickle Cell Disease

June 26, 2025 | Virtual

Presented as part of the Cincinnati Children's Hospital Medical Center's "Expanding Your Career and Healthcare Opportunities" ECHO series.

SPEAKERS:



Dr. Morgan Bifano



Dr. Alicia Cannon



Dr. Lisa Carey



WORKS CITED AND RESOURCES

WORKS CITED

- ¹ **“Current developmental screening practices in young children with sickle cell disease”**
pubmed.ncbi.nlm.nih.gov/36454537/
- ² **“Imaging Blood-Brain Barrier Permeability Through MRI in Pediatric Sickle Cell Disease: A Feasibility Study”**
pubmed.ncbi.nlm.nih.gov/34676938/
- ³ **“Co-Occurrence of Neurodevelopmental Disorders in Pediatric Sickle Cell Disease”**
pubmed.ncbi.nlm.nih.gov/34397573/
- ⁴ **“Patients with Sickle Cell Disease and Autism Spectrum Disorder”**
link.springer.com/article/10.1007/s41252-021-00218-6
- ⁵ **“The Neuroimaging, Protein Biomarkers, and Neurodevelopment in Very Young Children With Sickle Cell Disease (SCD BABY) Study”**
– Early Results (Page 175)
childneurologysociety.org/wp-content/uploads/2022/09/ANA_v92_iS28_Rev.pdf
- ⁶ **“The Pilot Study in Preparation for Validating MoCA for Screening for Mild Cognitive Impairment in Adults With Sickle Cell Disease (MoCA) Study”**
– Early Results
ashpublications.org/blood/article/144/Supplement%201/3882/532299/Feasibility-of-Validating-a-Screening-Tool-for
- ⁷ **“The Hearing and Vestibular Issues in Sickle Cell Disease (HVI) Study”** – Survey Results
ashpublications.org/blood/article/138/Supplement%201/4183/477642/Sickle-Cell-Disease-and-Vestibular-Dysfunction?searchresult=1
- ⁸ **“The Hearing and Vestibular Issues in Sickle Cell Disease (HVI) Study”** – Retrospective Study Results (Page 86)
onlinelibrary.wiley.com/doi/epdf/10.1002/ana.26746

RESOURCES

Sickle Cell Neurodevelopmental Clinic and Research Center at Kennedy Krieger Institute

KennedyKrieger.org/SickleCell

KennedyKrieger.org/SCD-Resources

Instagram: Instagram.com/SCD_Brains

“Your Child’s Brain” Podcasts

Disability Services in College:
KennedyKrieger.org/College

Sickle Cell Disease:
KennedyKrieger.org/SCD-Brain

Maryland Sickle Cell Disease Association

MarylandSickleCellDisease.org

Events

Summer	Annual Educational Conference
Fall	Annual MSCDA Picnic

Sickle Cell Disease Association of America, Inc

SickleCellDisease.org

OUR TEAM

LEADERSHIP



Eboni I. Lance, MD, PhD
Neurodevelopmental Physician
Medical Director



Alicia Cannon, PhD, ABPP
Neuropsychologist
Neuropsychology Director

MEDICAL



Wilfreda Lindsey, MD, MS
Neurodevelopmental Physician

NEUROPSYCHOLOGY



Lisa Carey, EdD
Education Specialist



Sarah Fertig, MS
Psychology Associate



Erika Wesonga, PhD
Neuropsychologist

BEHAVIORAL PSYCHOLOGY

Pediatric Consultation Program



Keith Slifer, PhD
Pediatric Psychologist



Bridget Gibbons, MA
Psychology Associate

BEHAVIORAL PSYCHOLOGY

Child and Family Therapy Clinic



Morgan Bifano, PsyD
Licensed Psychologist



Front row, left to right: Alicia Cannon, Eboni Lance, Bridget Gibbons.
Back row, left to right: Morgan Bifano, Wilfreda Lindsey, Aliyah Allick,
Sarah Fertig, Lisa Carey.

ADMINISTRATIVE/RESEARCH

Angela Tanner

Clinic Coordinator

Aliyah Allick, BS, MHS

Research Coordinator

Phil Fanara, MA

Research Psychology Associate

Kim Novak

Care Center Scheduling Coordinator

Laurie Backus

Patient Access Intake Specialist