SolveSickle

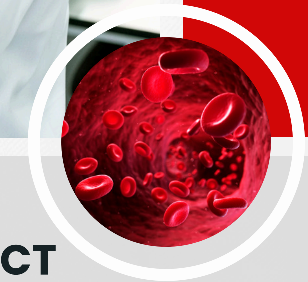
Newsletter

Thursday, May 7th, 2026/ Vol.1

GEORGIA RESEARCH ALLIANCE INNOVATION & ENTREPRENEURSHIP GRANT

The GRA Innovation Seed Grants support early-stage research projects in Georgia universities with strong commercial potential. They provide essential funding to help researchers move their discoveries toward market readiness, bridging academic research and the private sector.

To apply visit
Georgia Research Alliance



HB 334 SICKLE CELL DISEASE PROTECTION ACT

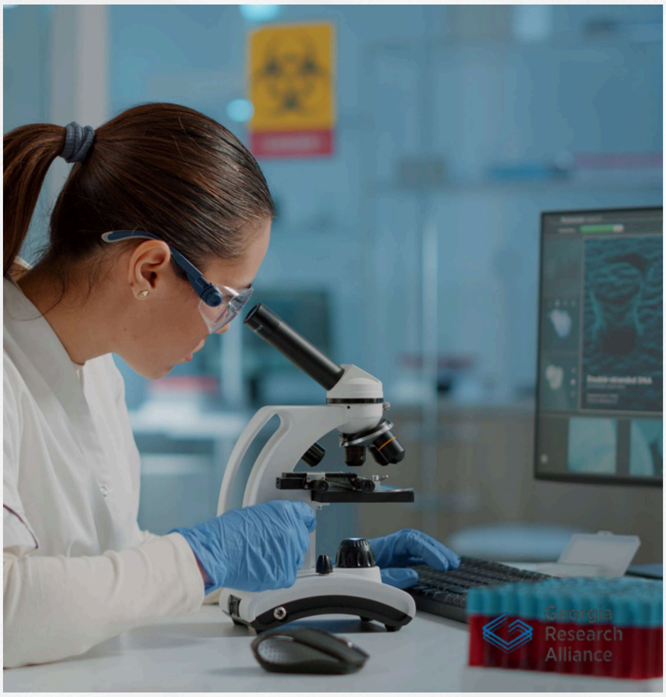
HHouse Bill 334 (HB 334), the Sickle Cell DiseaseProtection Act, has successfully passed the Georgia House of Representatives and Georgia Senate and now on the Governor's desk awaiting signature. This legislation represents a critical step forward in strengthening protections and improving care standards for individuals living with sickle cell disease across the state. HB 334 seeks to ensure greater accountability and consistency in care by requiring regular review and oversight of Medicaid services for individuals with sickle cell disease. It builds upon prior legislative efforts and reflects continued advocacy to address gaps in access, quality of care, and long-term health outcomes for our patient population. Within the framework of Georgia House Bill 334, we are sharing this information with all our stakeholders to empower our community to more effectively advocate for patients and contribute to shaping a coordinated strategy for sickle cell disease throughout the State.

Picured GA Rep. Omari Crawford and GA Rep Inga Willis

PHASE I TRIAL OF THE HDAC INHIBITOR PANOBINOSTAT IN SICKLE CELL DISEASE

PPanobinostat (LBH589) is a pan-histone deacetylase (HDAC) inhibitor being investigated in a Phase I, dose-escalation trial for adults with severe sickle cell disease (SCD) who are intolerant or refractory to hydroxyurea (HU)

If panobinostat proves safe and effective in PhaseI, it could advance to Phase II/III trials to assess clinical benefitin reducing vaso-occlusive events, hospitalizations, and organ damage in HU-unresponsive SCD patients.



GLOBIN RESEARCH NETWORK FOR DATA AND DISCOVERY

It is our pleasure to introduce our readers to GRNDaD, a multisite registry developed by internationally recognized physicians care providers.

Their goal is to collect longitudinal data on a cohort of people living with sickle cell disease to better understand how clinical characteristics predict outcomes. GRNDaD also collects patient reported outcomes including surveys on health-related quality of life and information on pain and fatigue. Another major goal of GRNDaD is to use the data collected for quality improvement and assess how sites are adhering to guideline recommendations. They will then use this information to develop appropriate interventions to improve adherence to recommendations whichwill lead to improved outcomes for this population.

If you have a clinic that takes care of people living with sickle cell disease and would like to inquire about joining as a GRNDaD site please email them at

GRNDaDSCD@gmail.com

ASH Hematology-Focused Fellowship Training Program (HFFTP)

The ASH HFFTP offers physicians specialized training in classical hematology focused on sickle cell disease, transfusion medicine, thrombosis, and health equity. Fully funded by ASH, the program has established 10 fellowship tracks across nine ACGME-accredited institutions to strengthen the hematology workforce, with a goal of training 50 new academic hematologists by 2030. Through mentorship, research, and targeted education, HFFTP supports the development of future leaders committed to advancing equitable, high-quality care for patients with blood disorders.