

SCDAA, 8 pharma companies team up to increase trial participation

New C.A.R.E.S initiative also aims for better awareness of SCD



by [Mary Chapman](#) | March 21, 2023



CLINICAL TRIALS



The [Sickle Cell Disease Association of America](#) (SCDAA) is collaborating with several pharmaceutical companies in a new initiative aimed at increasing awareness of the blood disorder and promoting clinical trial participation.

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Along with the SCDAA, the Sickle Cell Disease Collaboration of Advocates for Research, Education, and Science — officially the Sickle Cell Disease C.A.R.E.S. Consortium — includes eight pharmaceutical companies. They are [Agios](#), [Beam Therapeutics](#), [Editas Medicine](#), [Forma Therapeutics](#) (a Novo Nordisk company), [Hemanext](#), [Pfizer](#), [Sanofi](#), and [Vertex Pharmaceuticals](#).

“We have an opportunity and a responsibility to change the perception of clinical trials and increase the participation of sickle cell patients in clinical trials,” Regina Hartfield, SCDAA’s president and CEO, said in a [press release](#).

“Together, we will collectively leverage our resources to educate and encourage more trial participation while providing opportunities and therefore better options for the treatment of sickle cell disease,” Hartfield said.

The consortium already has launched an awareness campaign for the SCDAA’s [clinical trial finder](#), developed with [Forma](#) in 2021 to help connect patients, their families, and caregivers with [sickle cell disease](#) (SCD) studies. Using the tool, available on the organization’s website and as an app, participants can search for trials by keyword, location, study type, and phase.

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To call attention to the clinical trial finder, the awareness campaign will use personal narratives, infographics, videos, testimonials, and public relations and marketing strategies. It also will seek to counter myths associated with clinical research and prompt discussions about trial participation.

Clinical studies, which typically involve patients at varying disease stages and with different ranges of symptoms, depending on the treatment being tested, are at the heart of all medical advances. The goal of clinical trials is to determine whether a treatment candidate, device, or procedure is safe and effective. These trials also may evaluate new ways of using existing therapies, assess other aspects of care, or simply record disease progression over time.

Studies are ongoing to find more ways to treat SCD. Several new therapies are now in development and being tested in patients with the inherited disorder, which predominantly affects those of African lineage. Sickle cell disease also is more common among people from Central and South America and those of Middle Eastern, Asian, Indian, and Mediterranean descent.

Among other [symptoms](#), the disease can cause debilitating pain crises and put patients at an increased risk of infections. It can interfere with everyday living and render tasks more challenging to manage.

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