



23andMe and Sickle Cell 101 Collaborate to Expand Sickle Cell Awareness Program

September 14, 2023

23andMe will offer its Health + Ancestry Service at no cost for up to 1,000 eligible participants who are 18 years or older and have African ancestry or ancestry from a region where sickle cell disease is common*

About one in 13 African Americans have the sickle cell trait. Many are unaware that they are carriers or what it means to be a carrier of the sickle cell trait

SOUTH SAN FRANCISCO, Calif., Sept. 14, 2023 (GLOBE NEWSWIRE) -- 23andMe Holding Co. (Nasdaq: ME) (23andMe), a leading human genetics and biopharmaceutical company, and the non-profit Sickle Cell 101, have joined forces to expand [awareness of people's sickle cell carrier status](#).

The collaboration will include DNA testing and access to 23andMe's Health + Ancestry Service for up to 1,000 eligible participants, and 23andMe will be providing monetary support to [Sickle Cell 101](#) to support this effort.

23andMe's Health + Ancestry Service includes a [Sickle Cell Anemia Carrier Status report**](#), allowing participants to discover their sickle cell carrier status. Although 23andMe's report includes extensive information about what it means to be a carrier of a sickle cell gene, this collaboration gives those with additional questions a trusted and reliable community partner like Sickle Cell 101 for answers. For instance, if a person has questions about the differences between having the sickle cell trait — being a carrier of one copy of the HbS variant — versus having sickle cell disease (inheriting two copies of the sickle cell gene), they can discuss this with a team of experts and certified sickle cell educators at Sickle Cell 101.

Sickle Cell 101 is a nonprofit organization that connects, educates, and empowers the sickle cell community through targeted digital engagement and data-driven initiatives. As the largest global digital patient organization that specializes in sickle cell disease and sickle cell trait education, the organization strives to advocate for improved funding for research and health equity for the global sickle cell community.

"This project builds on what we're already doing at 23andMe, but also what we're working on in the future," said Joyce Tung, PhD, Vice President of Research, 23andMe. "We have both research projects and an ongoing awareness campaign focused on sickle cell. Adding Sickle Cell 101's resources and expertise will allow us to expand that effort to more people. Beyond that, 23andMe is about empowering people through access to their genetic data so they can make more informed decisions about their health. This is exactly what this program and collaboration offers."

Roughly [one in 13 African Americans have the sickle cell trait](#), meaning they have one copy of the HbS variant. In other words, they are carriers of the sickle cell trait and can pass that variant on to their children. Historically, access to affordable and reliable genotype testing hasn't been readily available to individuals with African ancestry or ancestry from a region where sickle cell disease is common. All of these have resulted in most individuals being unaware of their sickle cell carrier status and understanding how that can impact their family planning decision making or their health in certain cases.

"At Sickle Cell 101, our holistic approach to advocacy includes prioritizing both sickle cell disease and sickle cell trait awareness," said Dr. Stephen Boateng, Vice President of Partnerships and Scientific Collaborations at Sickle Cell 101. "While our primary focus is deservingly on educating and advocating for improved funding, care, and treatment options for sickle cell disease, this collaboration with 23andMe reinforces our commitment to also addressing a historical healthcare disparity that has deprioritized access to testing and reliable information to the community most impacted by sickle cell."

Other forms of sickle cell disease are also caused by variants in the HBB gene. Instead of having two copies of the HbS variant, like people with sickle cell anemia, people with other sickle cell disease have one copy of the HbS variant and another variant elsewhere in the HBB gene. Examples of other types of sickle cell disease include hemoglobin SC disease and sickle beta thalassemia disease.

Building Awareness, Expanding Research

This project builds on [23andMe's ongoing awareness program](#) with the [Morehouse School of Medicine](#) and the [Sickle Cell Foundation](#) of Georgia. As part of that effort, the Sickle Cell Foundation of Georgia also created a dedicated webpage for program participants. Anyone who is participating in 23andMe's African American Genetics Project can access the site and [connect with genetic counselors at the Sickle Cell Foundation of Georgia](#).

From those efforts, we learned participants wanted to be able to ask questions about their status. Along with raising awareness about the importance of sickle cell carrier status testing and improving access to testing, this collaboration with Sickle Cell 101 will greatly expand online resources for people who may be sickle cell trait carriers or have sickle cell disease.

Beyond raising awareness, 23andMe is also committed to learning more about sickle cell through our research. Our scientists are working on sickle cell research, most recently collaborating with scientists at the [National Institutes of Health](#) and [Johns Hopkins University School of Medicine](#). The study's [initial findings](#) were presented at the American Society of Hematology's annual meeting in 2022 but have not yet been published. It is now the largest and most diverse genetic study of the sickle cell trait.

23andMe's Sickle Cell Anemia Carrier Status Report**

Authorized by the FDA, 23andMe's [Sickle Cell Anemia Carrier Status Report](#) looks at the HbS variant in the HBB gene linked to sickle cell anemia.

Sickle cell anemia is the most severe form of sickle cell disease. Three hundred million people worldwide and one in thirteen Black or African Americans in the United States have sickle cell trait, making them carriers for sickle cell anemia.

In addition to informing people if they have one copy of the HbS variant and are carriers for sickle cell anemia, 23andMe's report can also tell individuals if they have two copies of the tested variant and if they are at risk of developing symptoms. However the report does not describe one's overall risk of developing symptoms.

Because the HbS variant is more common in specific populations, the Sickle Cell Anemia report is most relevant for people of African descent, as well as people of Middle Eastern and South Asian descent, as well as people from the Caribbean, the Mediterranean, and parts of Central and South America.

***Eligibility:**

- You live in the United States
- You are at least 18 years old
- You have African ancestry; identify as Black, African American, or of African descent; or you have ancestry from a region where sickle cell disease is common**
- You are willing to provide a saliva sample for DNA testing
- You are willing to agree to 23andMe's [Terms of Service](#) and [Privacy Statement](#)
- Research consent is optional and not required for participation in the program

About 23andMe

23andMe is a genetics-led consumer healthcare and biopharmaceutical company empowering a healthier future. For more information, please visit www.23andme.com.

About Sickle Cell 101

Sickle Cell 101 (SC101) is a Silicon Valley-based non-profit organization that specializes in sickle cell education. Over the years SC101's global and world-renowned platforms have become reliable sources of information trusted by patients, caregivers, healthcare providers, and other stakeholders. SC101's educational resources encompass information for sickle cell disease (SCD) and sickle cell trait (SCT).

Forward-Looking Statements

This press release contains forward-looking statements within the meaning of Section 27A of the Securities Act of 1933, as amended, and Section 21E of the Securities Exchange Act of 1934, as amended, including, without limitation, statements regarding the future performance of 23andMe's businesses in consumer genetics and therapeutics and the growth and potential of its proprietary research platform. All statements, other than statements of historical fact, included or incorporated in this press release, including statements regarding 23andMe's products, strategy, financial position, funding for continued operations, cash reserves, projected costs, plans, potential future collaborations, product development and launches, the successful commercialization and market acceptance of new products and objectives of management, are forward-looking statements. The words "believes," "anticipates," "estimates," "plans," "expects," "intends," "may," "could," "should," "potential," "likely," "projects," "predicts," "continue," "will," "schedule," and "would" or, in each case, their negative or other variations or comparable terminology, are intended to identify forward-looking statements, although not all forward-looking statements contain these identifying words. These forward-looking statements are predictions based on 23andMe's current expectations and projections about future events and various assumptions. 23andMe cannot guarantee that it will actually achieve the plans, intentions, or expectations disclosed in its forward-looking statements and you should not place undue reliance on 23andMe's forward-looking statements. These forward-looking statements involve a number of risks, uncertainties (many of which are beyond the control of 23andMe), or other assumptions that may cause actual results or performance to differ materially from those expressed or implied by these forward-looking statements. The forward-looking statements contained herein are also subject generally to other risks and uncertainties that are described from time to time in the Company's filings with the Securities and Exchange Commission, including under Item 1A, "Risk Factors" in the Company's most recent Annual Report on Form 10-K, as filed with the Securities and Exchange Commission, and as revised and updated by our Quarterly Reports on Form 10-Q and Current Reports on Form 8-K. The statements made herein are made as of the date of this press release and, except as may be required by law, 23andMe undertakes no obligation to update them, whether as a result of new information, developments, or otherwise.

Important Test Information

***The 23andMe PGS test uses qualitative genotyping to detect select clinically relevant variants in the genomic DNA of adults for the purpose of reporting carrier status and reporting and interpreting genetic health risks. The relevance of each report may vary based on ethnicity. Our carrier status reports can be used to determine carrier status, but cannot determine if you have two copies of any genetic variant. These carrier reports are not intended to tell you anything about your risk for developing a disease in the future or anything about the health of your fetus, or your newborn child's risk of developing a particular disease later in life. For certain conditions, we provide a single report that includes information on both carrier status and genetic health risk. The Sickle Cell Anemia carrier status report is indicated for the detection of the HbS variant in the HBB gene. The report can tell you if you have two copies of the tested variant, and if you are at risk of developing symptoms of sickle cell anemia, but does not describe your overall risk of developing symptoms. This test is most relevant for people of African descent. It is also relevant for people of Middle Eastern and South Asian descent, as well as people from the Caribbean, the Mediterranean, and parts of Central and South America.*

Contacts:

23andMe: press@23andme.com
Sickle Cell 101: ask@sc101.org