

**LONG ISLAND****New York newborn screening includes focus on genetic disorders affecting minorities**

Testing newborns in New York State for the genetic disorder, G6PD, which affects 10% of Black males in the United States, will begin in June. Credit: Getty Images/iStockphoto/Md Saiful Islam Khan

**By Keldy Ortiz**

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New York is expanding testing of newborns in 2022 to include screening for a range of potentially debilitating genetic conditions, with an emphasis on disorders common among certain ethnic and minority populations.

The expanded genetic testing, which already includes screening for 52 disorders, will begin in June after completing a regulatory process. It comes as a result of a package of legislation signed late last month by Gov. Kathy Hochul, and described by her office as addressing discrimination and racial justice.

The bill broadens newborn testing to include checks for glucose-6-phosphate dehydrogenase deficiency, a condition commonly known as G6PD. The disorder affects 10% of Black males in the United States and is also widely detected among those of Asian, Mediterranean and Middle Eastern ancestry, according to Johns Hopkins Medicine and other health experts.

Blacks and Asian Americans are among the fastest-growing ethnic groups on Long Island, according to data from the 2020 U.S. Census.

"I am proud to sign legislation that addresses this crisis head-on, addressing racism, expanding equity and improving access for all," Hochul said in a statement after signing the package of bills, which included legislation declaring racism a public health crisis.

The screenings already test for cystic fibrosis and sickle cell disease. Within the past two years, the Cystic Fibrosis Foundation has ramped up efforts to increase awareness of the affliction and "deepen its

understanding of this issue by listening to Black members of the CF community, other people of color with CF, and leading researchers who are focused on health disparities," the organization's website says.

A 2014 study by the Centers for Disease Control and Prevention found 73.1 sickle cell cases per 1,000 black newborns, compared with 3.0 per 1,000 white newborns, and 2.2 per 1,000 Asian or Pacific Islander newborns.

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As for G6PD, it can destroy red blood cells, leading to the onset of hemolytic anemia, said Dr. Marta Frigeni, a pediatrician and a medical geneticist, at Northwell Health. Hemolytic anemia is a condition that results in a dearth of red blood cells — crucial providers of oxygen to body tissue, according to Mount Sinai-New York.

When Mickel Smith and Shade Robinson's second child, Niko, was born in November at NYU Langone Hospital-Long Island in Mineola, doctors screened the child for the 52 disorders. The tests came back negative.

But when the newborn exhibited symptoms of G6PD, the doctors checked for the condition and the results came back positive.

Niko stayed in the hospital for the next week, his mother said, but is back home and doing well.

"It was pretty scary at first because we didn't know what was wrong with him," said Robinson, 21, who is of Barbadian descent.

Neither Robinson nor Smith, who is of Jamaican ancestry, have been checked for the disorder but they intend to, she said. They also plan to have their 1-year-old daughter, Amara, checked, she said.

Niko Smith, born in November with G6PD at NYU Langone Hospital-Long Island in Mineola, spent a week there being treated for the disorder. Credit: Shade Robinson

While there's no state-by-state data, the World Health Organization said 400 million people globally have the deficiency.

The deficiency is not widespread nationwide because its prevalence depends on the ethnic makeup of each state, said Dr. Robert Lee, president of the American Academy of Pediatrics' Chapter 2 region, which covers Long Island, Queens and Brooklyn.

"Since New York State has a big variety of ethnic backgrounds this is a very common condition," said Lee, who is a pediatrician at

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NYU Langone-Long Island.

On Long Island, the population of Asians and Black residents increased by 288,065, according to the 2020 U.S. Census. Residents who identify as minorities, including Hispanics, Blacks and Asians, comprise 40.2% of Long Island, according to the Census.

G6PD can be passed on to newborns through their mothers who carry the gene, according to Johns Hopkins, even without exhibiting symptoms.

Prospective parents can get tested for G6PD. A positive result shouldn't preclude people from having children, Lee said, or mean they will have a child with the genetic disorder, because "with any inherited condition, it's something they could be perfectly fine and healthy."

Because of the law, Lee said, pediatricians will have conversations with families earlier about signs of G6PD. A key indicator for the disorder is high amounts of jaundice — yellow discoloration of a newborns' skin and eyes caused by excess bilirubin — produced by the breakdown of red blood cells. On rare occasions, according to the Mayo Clinic's website, "an unusually high blood level of bilirubin can place a newborn at risk of brain damage, particularly in the presence of certain risk factors for severe jaundice."

Babylon resident Keely Harris, the founder of the [g6pd Deficiency Foundation](#), said her grandson, Brody, 8, tested positive for G6PD and developed kernicterus, a type of brain damage resulting from jaundice, days after his birth in Rhode Island.

"Our foundation was started to spare other newborns such life-threatening events by raising awareness of how undiagnosed G6PD deficiency can cause jaundice," reads a message on the Babylon nonprofit's website under the heading, "Brody's Story."

Adding G6PD deficiency to the newborn screening will "keep the baby healthy throughout its life," Harris said in an interview.

While newborns are currently checked for high bilirubin levels, Frigeni said the state adding G6PD deficiency as a condition on its screening list will mean more diagnoses.

"We're also going to change some of the guidelines when it comes to the treatment of high bilirubin in newborns and for the patients that have G6PD," Frigeni said. "We might start treating elevated bilirubin sooner than we would normally do for somebody who doesn't have the condition."

Sen. Gustavo Rivera (D-Bronx) sponsored the bill after connecting with Harris' foundation.

Rivera said in a statement that with ongoing disparities regarding access to health care, lawmakers "continue to implement measures that seek to build an equitable health care delivery system and address the needs of our ethnically diverse population."

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