

# SICKLE CELL and the Adeshigbin brothers

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QUEEN'S PARK BUREAU

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The eldest son suffered a stroke at age 5 that cost his sight and paralyzed his left side, leaving him in a wheelchair.

Another son has been in hospital so often he's a year behind in high school.

The third son is just 4 years old but knows to ask for codeine to ease the severe pain from the sickle cell disease he shares with his older brothers.

"It's like someone's hammering nails into your body," says middle brother Lanre Adeshigbin, 18, a track and field athlete despite frequent hospitalizations, the latest for two weeks in April when his agony was eased with morphine for a solid week.

Such is life for the Brampton family in which three of five children have the inherited disorder that blocks the hemoglobin in blood from carrying oxygen to fuel vital organs and tissues.

That weakens internal organs and immune systems, leaving them prone to infections that can quickly overwhelm the body. Strokes happen. Sudden death can occur. The lack of oxygen causes the debilitating pain. Even a chest cold can trigger a crisis, perhaps a collapsed lung. There is no cure, but prompt treatment can make a difference. The disease primarily affects people of African descent; experts estimate that as many as 67 black infants affected by sickle cell disease may be born annually in Canada.

Dr. Isaac Odame, a pediatric blood specialist at McMaster Health Centre in Hamilton, estimates that 20 to 25 babies with sickle cell are born in Ontario every year and says the hospital treatment they require is expensive.

Four of the five Adeshigbin children were born in their parents' native Nigeria, where there was no newborn screening for sickle cell.

The couple's fifth child, 4-year-old Isaiah, was born in Ontario, where there also is no screening.

The children's father is hoping that changes soon, so children harbouring the debilitating, lifelong disease can get early treatment with penicillin, preventing or minimizing problems like the stroke that slammed his son Abbey, now 20.

"It is extremely important to have screening," says John Adeshigbin, a Canada Post letter carrier recalling the many nights he and his wife Jumoke have spent sitting un



PETER POWER /TORONTO STAR

Four-year-old Isaiah Adeshigbin has sickle cell disease, an inherited blood disorder for which Ontario does not screen newborns despite the fact early detection and treatment can reduce mortality by 84 per cent. Three of the Adeshigbin family's five children have sickle cell. The eldest son, 20-year-old Abbey, suffered a stroke from the disease at age 5.

with their sick children or rushing them to hospital.

A camp for children with sickle cell has been named after Jumoke.

The Canadian Task Force on Preventative Health Care recently found that most deaths from sickle cell occur in children between ages 1 and 3, mainly because of infection.

Just knowing infants and children have sickle cell and giving them preventive doses of penicillin reduces deaths by 84 per cent, according to one study quoted by the task force in a recent report.

Every day, Lanre Adeshigbin, who had his spleen removed at age 3 because of the damage, takes penicillin, a blood pressure drug, folic acid to keep his blood count up and hydroxyurea pills to control his never-ending pain.

He keeps working hard at school, hoping to finish Grade 12 this year with good enough marks to earn a scholarship for teacher's college or a university program leading to law school.

"The teachers know so they help me catch back up," says Lanre, a member of the Brampton track club who specializes in short relays and long jump.

Of older brother Abbey, he says: "His is a whole different experience. I can't even relate to it. He just learned to live with it."

— **Rob Ferguson**