

Medicaid does not cover many costs of transplant for people with sickle cell disease

Survey shows more coverage needed for life-saving treatment



Some people with Medicaid insurance face delays or other problems getting blood and marrow transplant (BMT) for sickle cell disease.

Sickle cell disease can be disabling

Sickle cell disease (SCD) affects red blood cells. Starting in childhood, SCD causes episodes of severe pain, organ damage, and even strokes. SCD shortens people's lives. People of all races can inherit SCD, and rates are higher among people who are Black or African American.

Inadequate insurance stops people from getting treated

BMT can cure SCD, and it's important that people get treated. But researchers say that some Medicaid programs don't pay for parts of BMT.

Medicaid is state-run health insurance for people with low income or disabilities. Each state's program differs.

For example, many states cover only a certain type of BMT, using cells donated by a brother or sister who is also a close genetic match. However, many patients don't have a sibling who matches them. The only way to get BMT from another donor is to join a clinical trial. But some Medicaid programs will not cover clinical trials until 2022.

Also, people spend weeks or months in the hospital for BMT. Patients' caregivers may have to move closer to the transplant center. But most Medicaid programs don't cover lodging or out-of-state care, which most people who have Medicaid cannot afford. That's according to interviews with BMT coordinators in the 8 states where half of all Americans with SCD live: Florida, Georgia, Illinois, Michigan, New York, Pennsylvania, Texas and Virginia.

Researchers found that Medicaid pays hospitals less than private insurance, and involves more paperwork. This makes it hard for patients to get life-saving transplants.

In each state, people need to ask legislators for better Medicaid coverage of BMT for SCD.

Learn more about

- Financial help for BMT at BeTheMatch.org
- Becoming an advocate at BeTheMatch.org
- Medicaid in each state at BeTheMatch.org
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Source

Mupfudze TG, Preussler JM, Sees JA, et al. A Qualitative Analysis of State Medicaid Coverage Benefits for Allogeneic Hematopoietic Cell Transplantation (alloHCT) for Patients with Sickle Cell Disease (SCD). Transplantation and Cellular Therapy. 2021 Apr;27(4):345-351. Epub 2021 Jan 29. doi: 10.1016/j.jtct.2021.01.022.

About this research summary

This information is provided on behalf of the Consumer Advocacy Committee of the CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]). The CIBMTR is a research collaboration between the National Marrow Donor Program/Be The Match and the Medical College of Wisconsin.

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