

## Gene therapy education materials for the sickle cell disease community

Understanding gene therapy for sickle cell disease



Sickle cell disease is the most common inherited blood disorder in the United States, affecting more than 100,000 people.

## **Overview**

Presently, there are only a handful of options to manage or treat sickle cell disease.

Now, researchers are developing new and emerging gene therapies to treat sickle cell disease.

To help navigate these new therapies, more than 50 scientists, physicians, patients and other experts worked together to develop content for the Democratizing Education for Sickle Cell Disease Gene Therapy Project, which is led by NHGRI in partnership with other organizations and individuals. This group met over the course of four workshops.



## **Patient education materials**

Together, the group developed educational materials that reflect the priorities and perspectives of individuals living with sickle cell disease and the gene therapy and biomedical research communities. These materials include helpful information and resources for people with sickle cell disease and their families to learn more about gene therapy.



Understanding the blood cell



**Understanding gene therapy approaches** 



Clinical trial process for sickle cell disease gene therapy



Your mental health and sickle cell disease gene therapy participation



Sickle cell disease gene therapy FAQ

The Democratizing Education Project welcomes your feedback about the sickle cell disease gene therapy resources. Please email your comments or questions to <a href="mailto:DemocratizingEd@mail.nih.gov">DemocratizingEd@mail.nih.gov</a>.