Democratizing Education for
Sickle Cell Disease Gene Therapy

Your mental health and gene therapy

Mental health includes emotional, psychological and social well-being.

Your mental and physical health are deeply connected. Mental health is important for your health and quality of life.

As a person living with sickle cell disease, you and your support systems make choices about your physical health, while thinking about the impact on your mental health and psychological well-being.

These are some questions and actions you may want to take as you think about taking part in a gene therapy clinical trial.

If you are considering a gene therapy clinical trial.

There are many unknowns about what to expect from gene therapy. Your thoughts, feelings, beliefs and attitudes can have a strong impact on your physical health. Because of this, it's important to care for your mental and physical health as you consider a gene therapy clinical trial.

Focus on your thoughts and feelings.

Discuss and assess your mental health with a mental health professional (like a psychologist, counselor or social worker), support system and/or trusted friend.

Write about how you feel about your disease and how it affects your life.

Reflect on why you might want to join this clinical trial. Discuss it with your healthcare provider(s) and your support system.

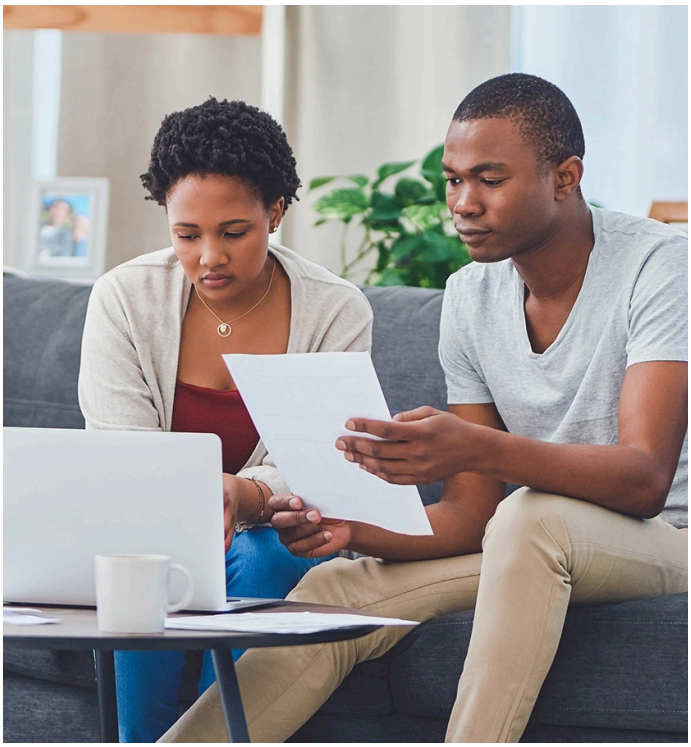
Reflect on what kind of support system you will need.

Your support system will play an important role throughout the process. Let them know about the possible risks and complications of the procedures in the trial.

Here are some questions that you might ask them:

- *How much mental, emotional, social and spiritual support will you provide me on this journey?*
- *How much can you support me with my healthcare activities (such as taking medicines and getting to appointments), everyday activities and/or financial support?*

A support system can be a group of people. One person may not have to provide all the help you may need. If you can put together a team to make up your support system, they can share the tasks.



Consider these other factors.

Risks of participation
Check out the sickle cell disease gene therapy FAQ

Cost
- What costs does the clinical trial cover?
- What costs are you responsible for paying?
- What costs will your support system be responsible for paying?

Hospital stay
- You may be hospitalized in a different city for an extended time.

Work–life factors
- You will need to take time away from your job and other daily responsibilities.

Manage expectations
- How will you feel if you are not eligible to participate in the clinical study?
- How will you feel if the gene therapy procedure does not work?

If you decide to participate in a gene therapy clinical trial

Think about your support system and your mental health.

- What kind of support will you need from others as you go through this process?
- How will you take care of your thoughts, feelings, beliefs and attitudes through this process?
- How do you care for your thoughts and feelings now?
- Are there other ways to help you mentally prepare for the unique challenges of participating in a gene therapy clinical trial?
- If possible, discuss your feelings with a mental health professional.

Think about how you will manage your emotions in the face of these challenges.

How will you feel:

- About complications or risks from the procedure?
- If the treatment does not work?
- A long-term hospital stay in a different city in order to be near your healthcare providers?

Focus on caring for your emotions.

You will experience many emotions as you go through this process. Don't be afraid to find help.

Choose someone in your life you can talk to about how you are feeling without fear of judgement.

If you have already participated in a gene therapy clinical trial

It is normal to have strong feelings after your procedure.

If the gene therapy works, you may have survivor's guilt. This means that you could feel guilty about no longer living with some of the symptoms of sickle cell disease while others still do. You may also feel guilty about being able to participate in a clinical trial when others cannot.

You may need to continue seeking medical care throughout your life for the effects of living with sickle cell disease. This may be because of previous impacts of the disease on your body.

You may still experience some symptoms of sickle cell disease.

Keep caring for your general health. You should keep seeking general health care after treatment.

You will need long-term follow-up appointments as part of the clinical trial.

You may struggle with your social identity.

If the gene therapy works, you may have a sense of loss of identity and community from no longer living with sickle cell disease.

It is important to continue seeking social and mental health support if you feel this struggle.

The Democratizing Education Project welcomes your feedback about the sickle cell disease gene therapy resources. Please email your comments or questions to DemocratizingEd@mail.nih.gov.