



# Why You Need To Share Your Sickle Cell Story with ICER

A new report from the Institute for Clinical and Economic Review (ICER) says the new sickle cell disease treatments may not be cost effective. **The report is missing important information from the perspective of the patient and caregiver.** Help ICER get the report right by sharing your sickle cell story today!

**Here are the parts that ICER is missing**

## Managing Pain at Home .....

Acute pain crises and chronic pain have devastating effects; however, the report fails to capture the experience of pain when treated at home. Share your story about how many pain crises you manage at home without going to hospitals and how pain impacts your daily life.

## Unmeasured Cost of Sickle Cell .....

High out-of-pocket expenses for medical care? Lost wages due to missing work for sickle cell? ICER's economic analyses fail to include these costs that individuals and families face. Your story can help ICER understand the impact these unmeasured costs have.

## Effects of Fatigue .....

Exhaustion and tiredness can reduce the quality of life that patients and caregivers are able to live. Tell ICER how important it is for you to have new treatments that can reduce that worn down feeling.

## ..... Reduced Hospitalization

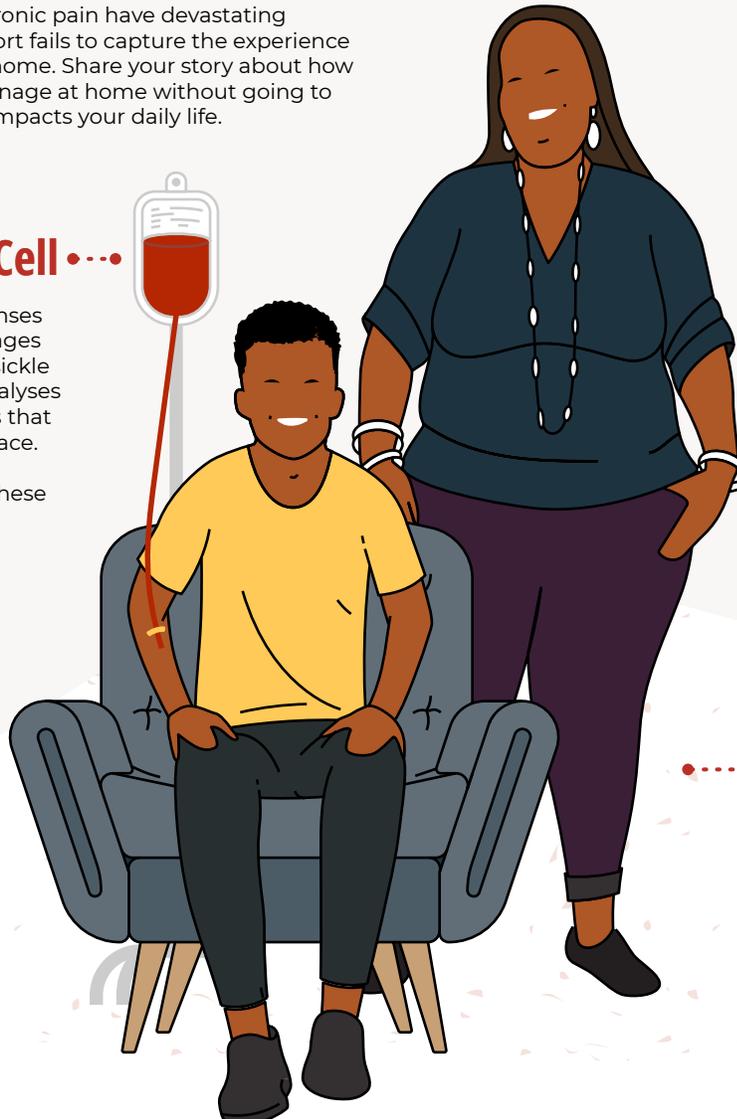
Hospital stays are stressful and costly. Anywhere from parking, eating out, to missed days from work or school, and the final bills. Share a story about how meaningful it is to avoid hospitalizations, even if it's by one hospital stay.

## ..... Battle Against Stigma

Lack of treatment options, discrimination, and stigma around the need for chronic pain management combine to make living with SCD extraordinarily difficult. Your story can help them understand how these new innovations in treatments are helping battle against the stigma of this disease.

## ..... Impact on Caregivers

Caregivers experience fatigue and financial impacts too. ICER's report lacks important outcomes related to caregiver burden and family productivity loss.



Submit your story today using Sick Cells' Public Comment Submission Form. Visit [www.sickcells.org/shareyourstory](http://www.sickcells.org/shareyourstory).

