



The Perspective of African American Teens with Sickle Cell in Massachusetts



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Table of contents

01

Definition &
Examples

02

Quality of Care

03

Mistreatment

04

School &
Extracurriculars

05

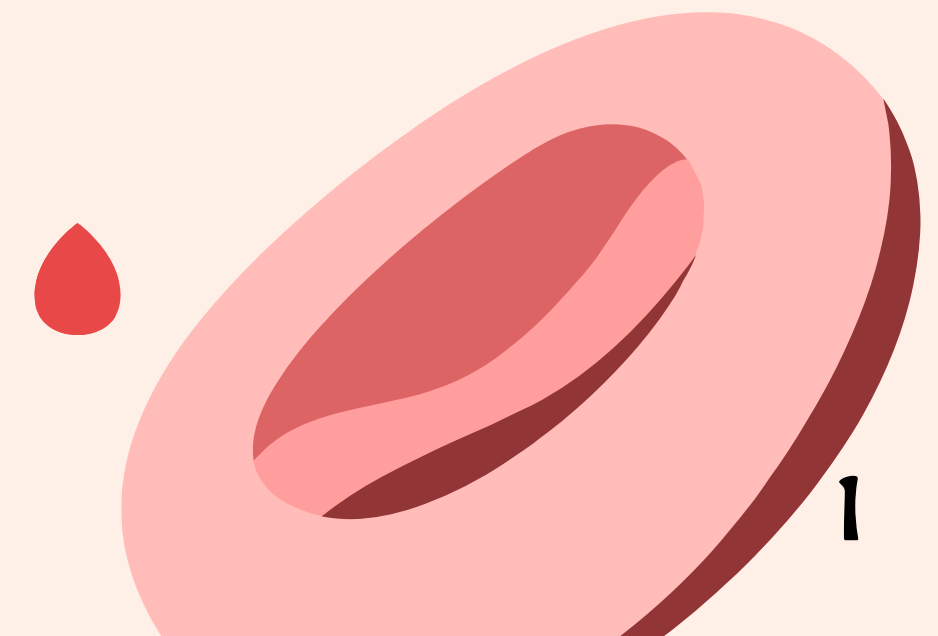
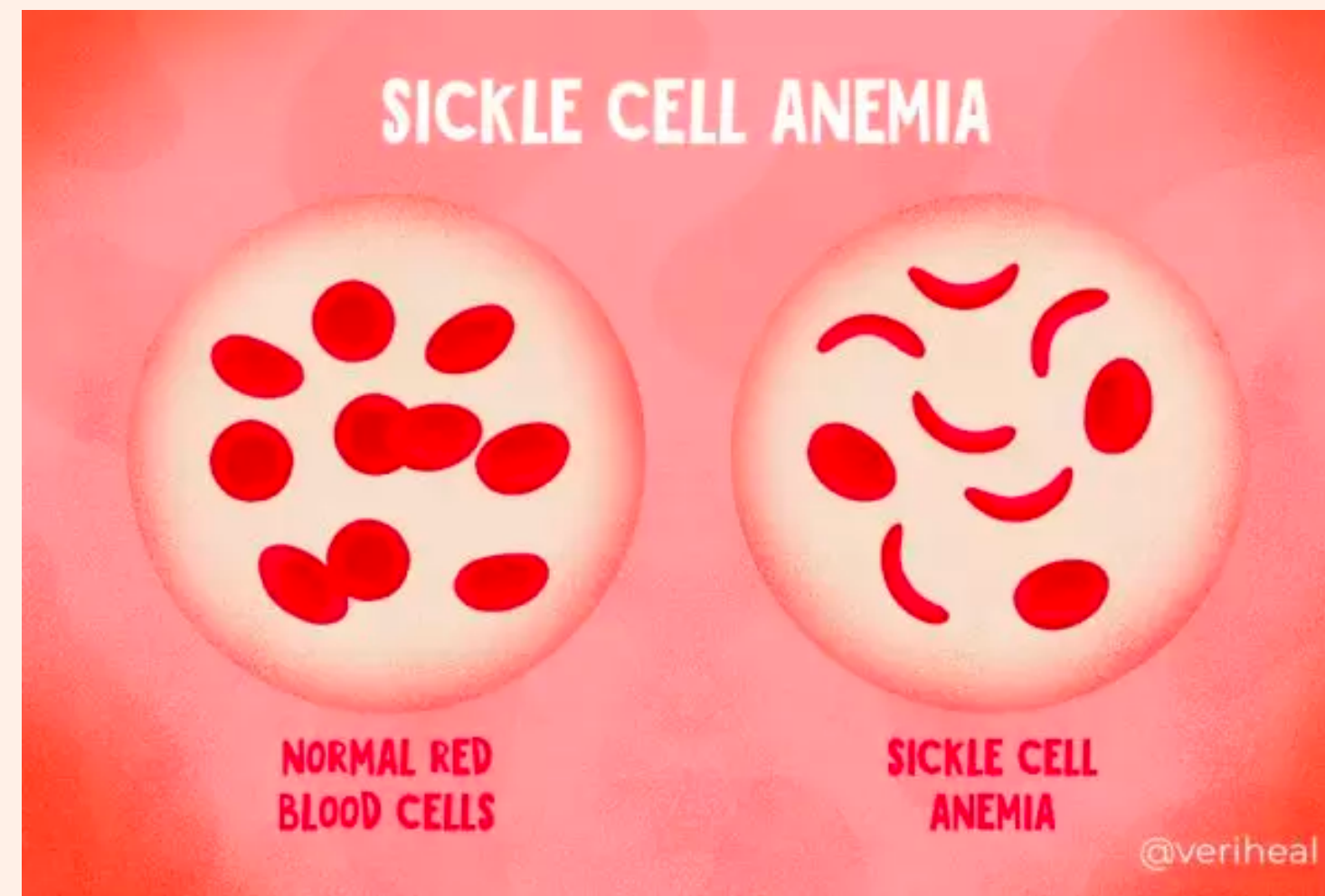
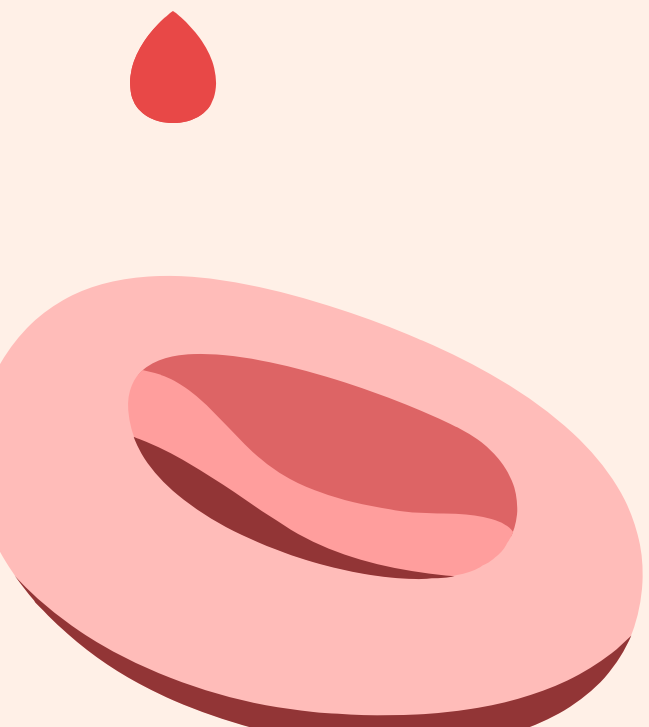
Raising
Awareness

06

Questions

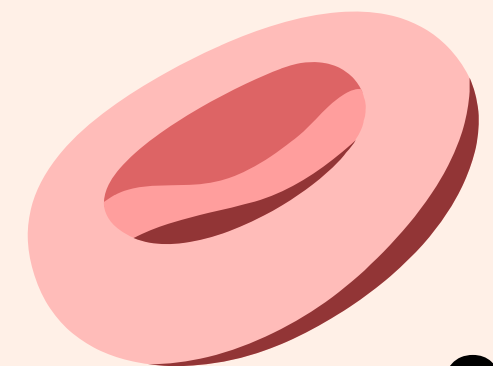
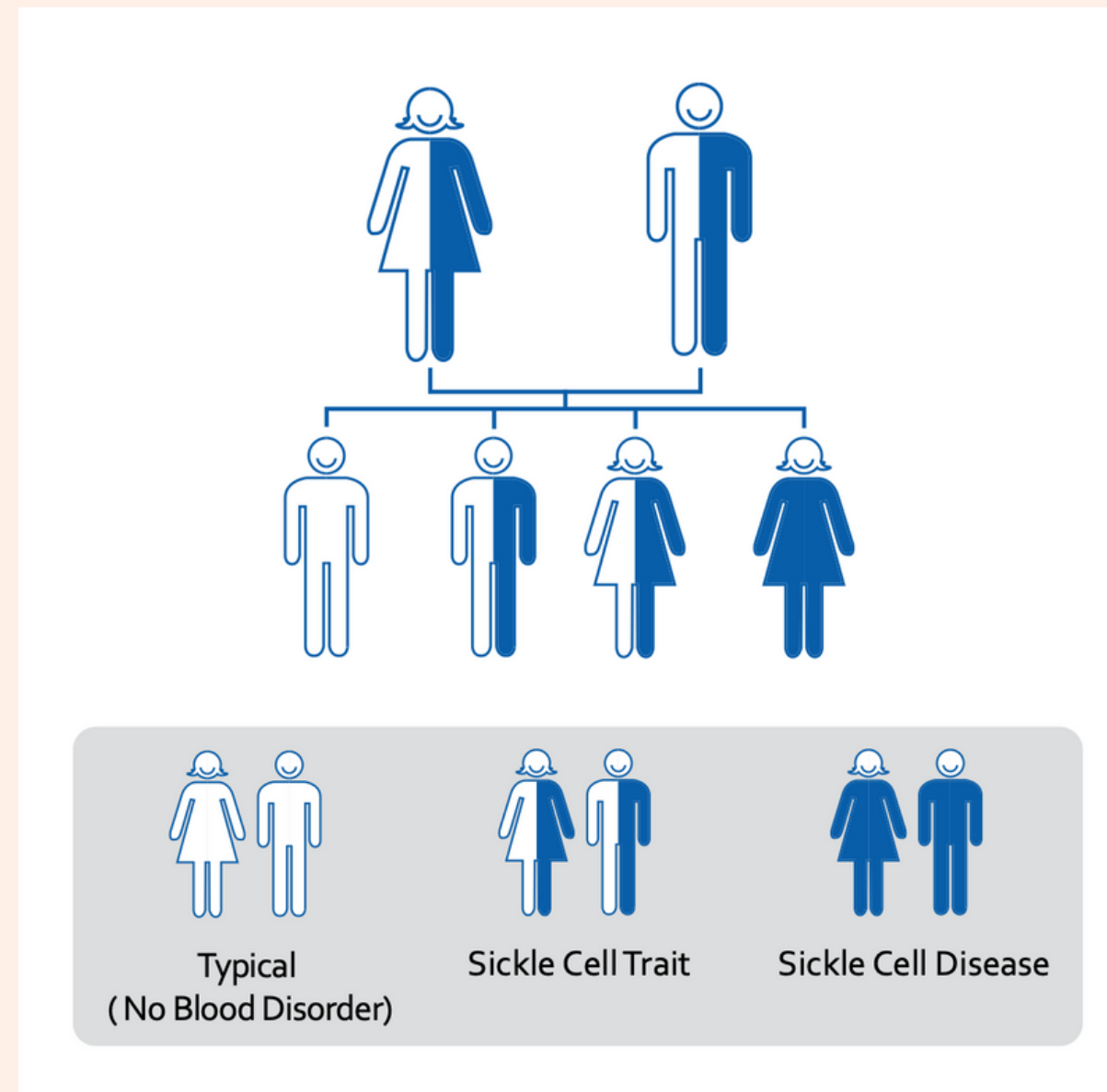
What is Sickle Cell?

Sickle Cell is a group of disorders that causes red blood cells to become misshapen and break down.



Gene Tree

If both parents are carriers of the sickle cell gene, they have a 25% chance of any of their children having the sickle cell disease



Symptoms of Sickle Cell



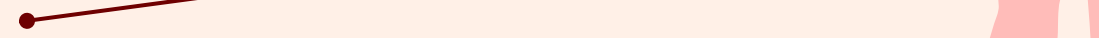
Fevers



Vision Problems

Retinal detachment and vision loss from blocked or bleeding blood vessels caused by sickled cells

Anemia



Frequent infections

Flu, Meningitis, and Pneumonia

When blood produce a lower-than-normal amount of healthy red blood cells

Swollen Hands & Feet

Swelling is caused by sickle-shaped red blood cells blocking blood circulation in the hands and feet.



Chronic Pain

Pain that lasts most days for 6 months or more.



What is a Health Disparity?

A health disparity is when a certain group of people are more susceptible to a disease or disorder than the rest of the population

Don't receive the care they deserve because of biases they can't control such as,

Race, Gender, Age, Ethnicity, or Religion

Why Is It a Health Disparity

- African American teenagers are not likely to receive the help that they need.
- They fear that they will be turned away or will not be treated well, due to the color of their skin.

Testimony



“A lot of times the ER waits are dangerously long and then even when you do get someone in the ER again, they're not familiar with sickle cell, so they don't know how to work with you or then you're blatantly just mistreated because you're thought of as being a drug seeker and this is a disease that we have no control over, that we don't ask for.”

-Massachusetts Sickle Cell Patient



Disparity Data

Figure A

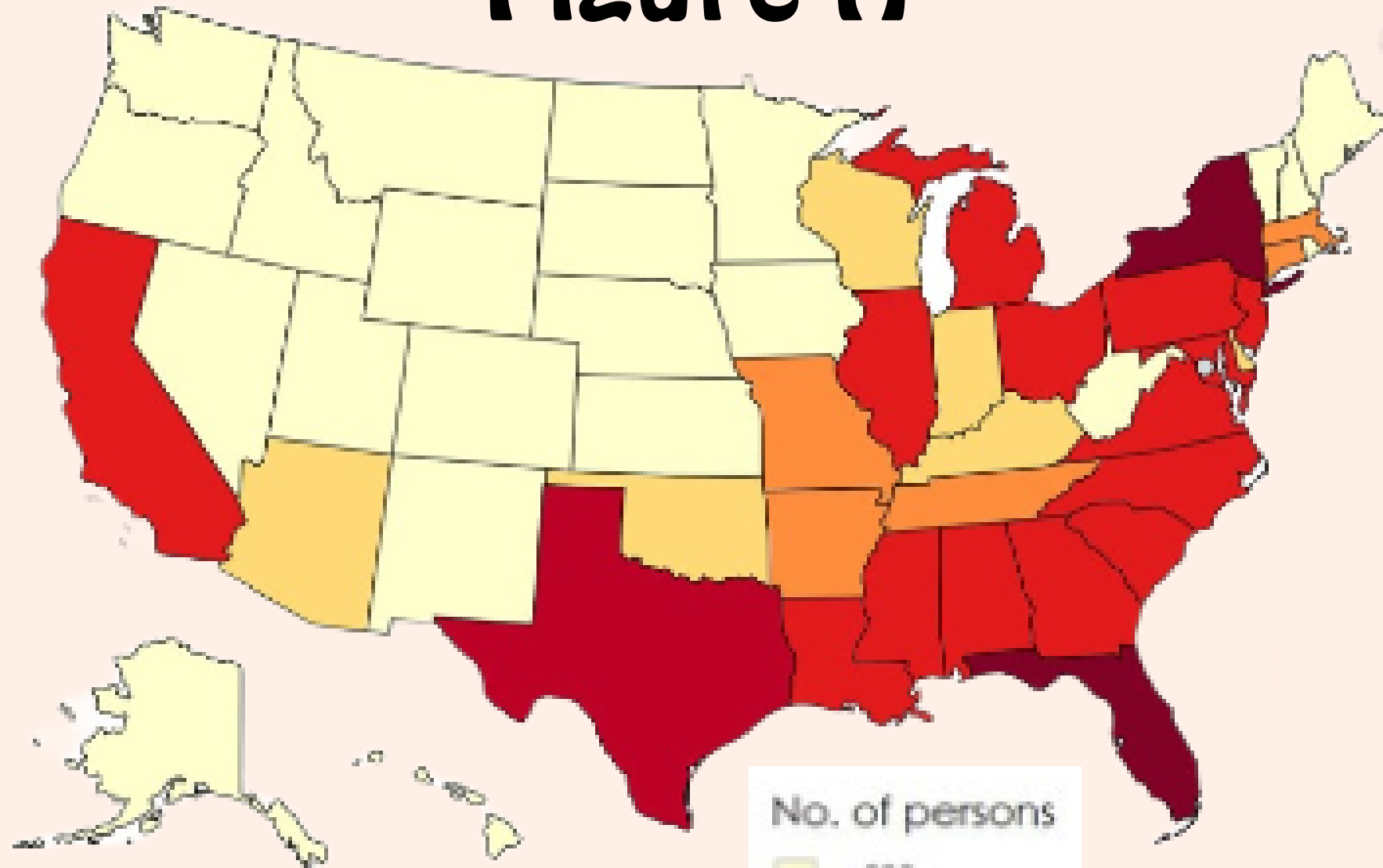
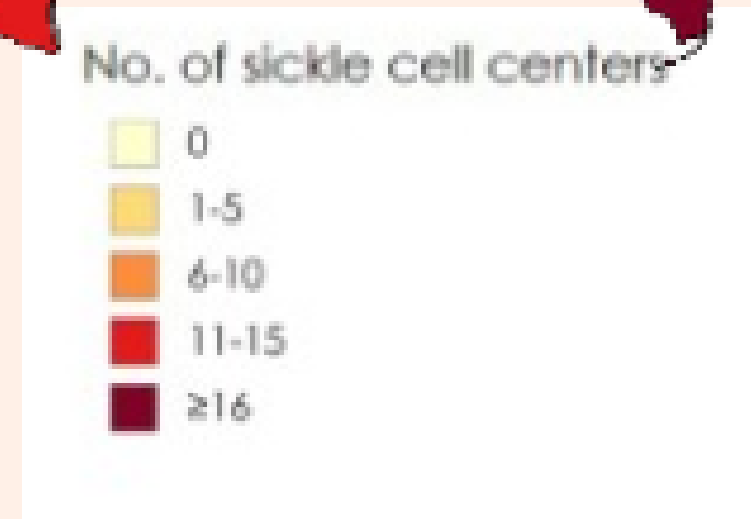
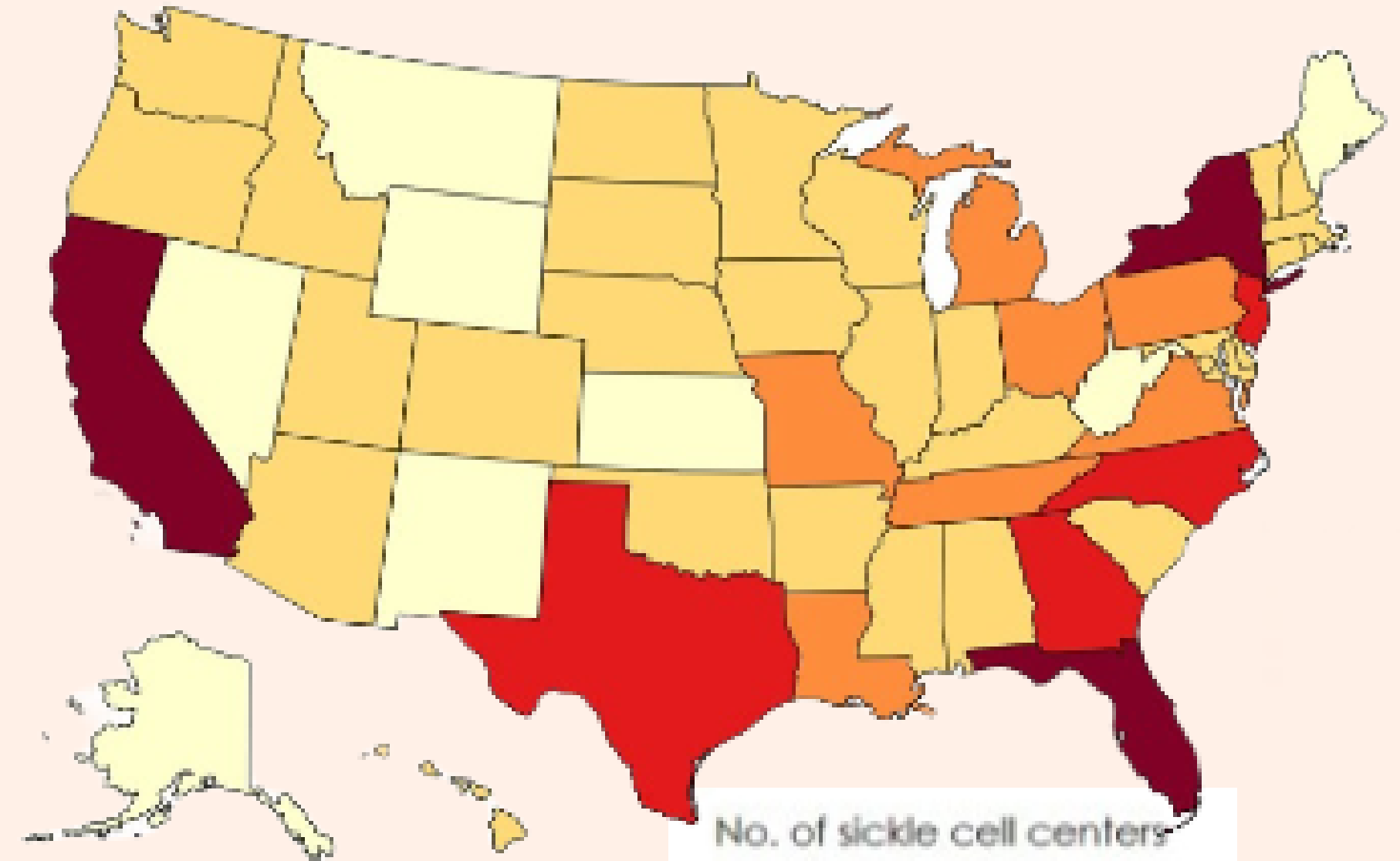
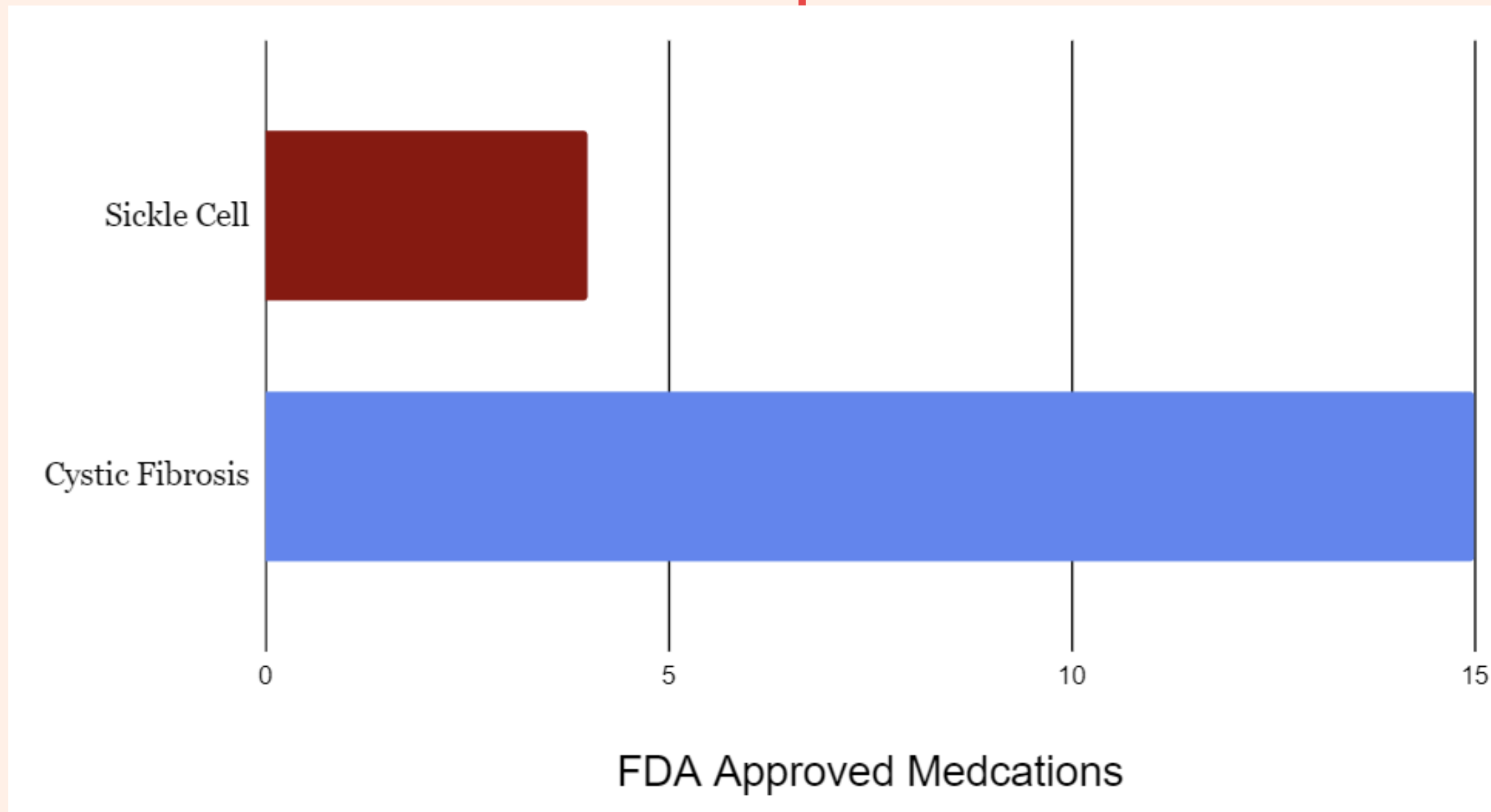


Figure B



Treatment Comparisons

" It gets **seven to eleven times the research funding per patient** which results in different rates in the development of medicine"



Quality of Care

Adolescents with Sickle Cell experience the worse quality of care due to poor communication.



Teens with Sickle cell experience healthcare providers not giving them as strong of medications because of their skin color.



The NEW ENGLAND
JOURNAL of MEDICINE

Mistreatment



[Video Link](#)

Mistreatments

Two sisters with Sickle Cell were never given the screening test for stroke when diagnosed with sickle cell. This screening could have prevented both of the sisters strokes.



Kyra(Left and Kami(Right)

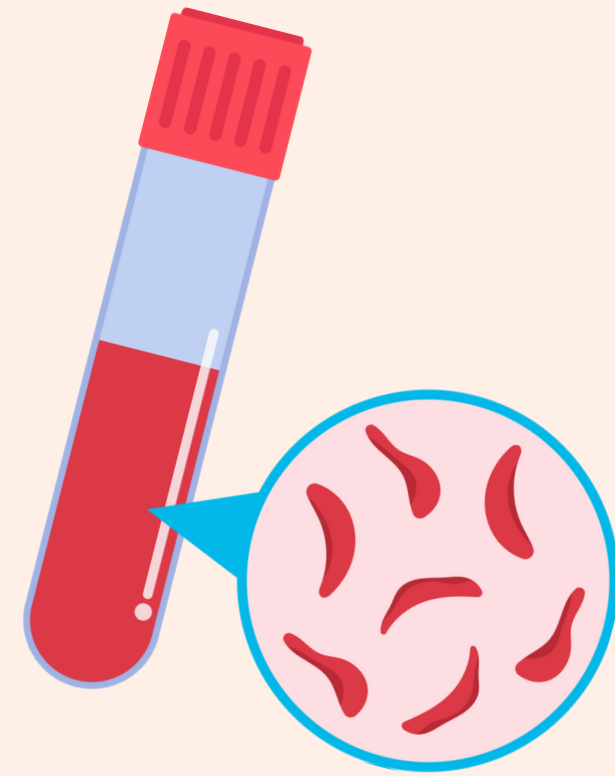




Raise Your Hand If...

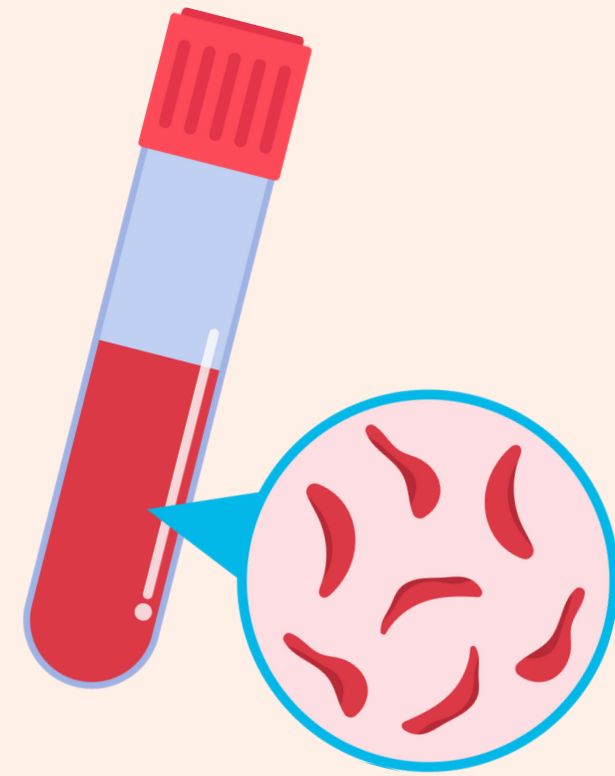
Education & Clubs

- Chronic fatigue or pain can make it appear that students aren't motivated to learn



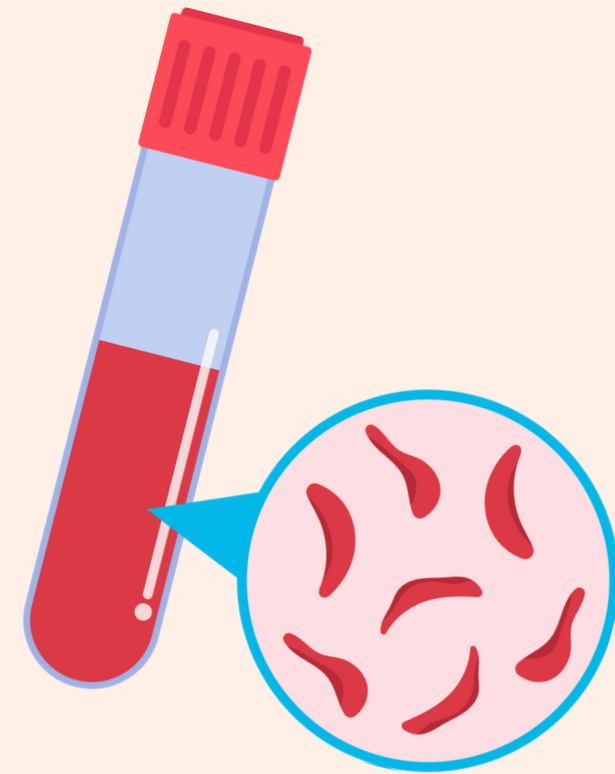
Education & Clubs

- **Chronic fatigue or pain can make it appear that students aren't motivated to learn**
- **Students with SCD may miss instructions, assignments, and testing**



Education & Clubs

- **Chronic fatigue or pain can make it appear that students aren't motivated to learn**
- **Students with SCD may miss instructions, assignments, and testing**
- **As well as miss class time or be absent for doctor visits or hospital stays**

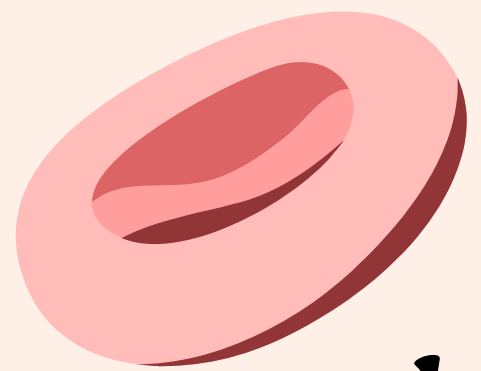


Raising Awareness

Massachusetts General Hospital

Comprehensive Sickle Cell Disease Treatment Center

"Our approach is to **create a true medical home** where patients and their families can **feel seen and heard**. We understand the **complexities of sickle cell disease** and our comprehensive team has the experience to care for you and your family."





Raising Awareness



One organization in Massachusetts helps people struggling with Sickle Cell as well as raise awareness.





**MASSACHUSETTS SICKLE CELL
ASSOCIATION**

**RED
RIBBON
GALA**


They host annual Red Ribbon Galas as well as scholarships awards for people with SCD in Mass





Conclusion

"I just think not only
for me but for everyone with sickle cell,
things really need to change"
-Massachusetts Sickle Cell Patient



Citations

- Adams, RJ, and K Ohene-Frempong. "Tips for Supporting Students with Sickle Cell Disease." CDC.Gov, 2001, www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf.
- CDC. "Sickle Cell Disease Research." Centers for Disease Control and Prevention, 23 June 2023, www.cdc.gov/ncbddd/hemoglobinopathies/index.html.
- Dave, Jatin, et al. "Sickle Cell Legislative Report - Mass.Gov." Mass.Gov, 18 Apr. 2023, www.mass.gov/doc/2023-sickle-cell-disease-report-for-legislators/download.
- Davison, Gail, et al. "Children's and Adolescents' Experiences of Healthcare Professionals: Scoping Review Protocol." Systematic Reviews, 7 Mar. 2020, www.ncbi.nlm.nih.gov/pmc/articles/PMC7060982/.
- "Greater Boston Sickle Cell Disease Association." oneSCDvoice, 2023, www.onescdvoice.com/place/greater-boston-sickle-cell-disease-association/.
- Kanter, Julie, et al. "Perceptions of US Adolescents and Adults with Sickle Cell Disease on Their Quality of Care." JAMA Network Open, 1 May 2020, www.ncbi.nlm.nih.gov/pmc/articles/PMC7260622/.
- Kolata, Gina, and Ilana Panich-linsman. "These Sisters with Sickle Cell Had Devastating, and Preventable, Strokes." The New York Times, 23 May 2021, www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html.
- Lee, LaTasha, et al. "Reducing Health Care Disparities in Sickle Cell Disease: A Review." Public Health Reports (Washington, D.C.: 1974), 2019, www.ncbi.nlm.nih.gov/pmc/articles/PMC6832089/.
- Lee, LaTasha, et al. "Reducing Health Care Disparities in Sickle Cell Disease: A Review." Public Health Reports (Washington, D.C.: 1974), 2019, www.ncbi.nlm.nih.gov/pmc/articles/PMC6832089/figure/fig1-0033354919881438/.
- Massachusetts Sickle Cell Association, 2023, sicklecellhope.org/.
- Mayo Clinic. "Sickle Cell Anemia." Mayo Clinic, 9 Mar. 2022, www.mayoclinic.org/diseases-conditions/sickle-cell-anemia/symptoms-causes/syc-20355876.
- NIH. "Sickle Cell Disease | Sickle Cell Anemia." MedlinePlus, 25 Nov. 2020, medlineplus.gov/sicklecelldisease.html.

Citations(Cont.)

Power-Hays, Alexandra, and Patrick McGann. "Racism and Sickle Cell Disease ." The New England Journal of Medicine, 12 Nov. 2020, www.nejm.org/doi/full/10.1056/NEJMp2022125.

"Sickle Cell Disease Factsheet (for Schools) (for Parents) - Nemours Kidshealth." Edited by Mary L. Gavin, KidsHealth, Aug. 2018, kidshealth.org/en/parents/sickle-cell-factsheet.html#:~:text=Students%20with%20sickle%20cell%20disease%20may%20miss%20class%20time%20or,aren't%20motivated%20to%20learn.

"Sickle Cell Disease Treatment Center." Massachusetts General Hospital, 2023, www.massgeneral.org/medicine/sickle-cell-disease.

Photos Used

"Sickle Cell Disease Treating the Symptoms of Sickle Cell Disease with Medical Cannabis." Veriheal, 27 June 2023, www.veriheal.com/conditions/sickle-cell-disease/.

"Red Ribbon Gala 2023." Cox Center Tulsa, 30 Jan. 2023, coxcentertulsa.com/events/red-ribbon-gala/.

Kolata, Gina, and Ilana Panich-linsman. "These Sisters with Sickle Cell Had Devastating, and Preventable, Strokes." The New York Times, 23 May 2021, www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html.

Video

"Sickle Cell Disease Is Painful, Debilitating and Sometimes Fatal. Why Doesn't It Get More Attention?" YouTube, YouTube, 21 Feb. 2023, <https://www.youtube.com/watch?v=hGHsImaYJA8&t=234s>. Accessed 25 July 2023.

The background features several light pink, 3D-style rings of varying sizes and orientations, scattered across the white space. Interspersed among these rings are small, solid red teardrop shapes. The overall aesthetic is clean and modern.

Questions?