



# ELSI FRIDAY FORUM

## Ethical Challenges in Novel Gene Therapies for Sickle Cell Disease

**Date and time:** Friday, June 11, 9am PT / 12pm ET

**Speakers:** Liza-Marie Johnson and Melissa Creary

**Moderator:** Pilar Ossorio

### Biography

Liza-Marie Johnson, MD, MPH

Biography: <https://elsihub.org/directory/liza-marie-johnson>

Melissa Creary, PhD, MPH

Biography: <https://elsihub.org/directory/melissa-creary>

Moderator: Pilar Ossorio, JD, PhD

Biography: <https://secure.law.wisc.edu/profiles/pnossorio@wisc.edu>

### Liza-Marie Johnson, MD, MPH

For more information on SCDGENE, a CERA working group, see:

<https://elsihub.org/news/novel-gene-therapies-pediatric-and-young-adults-sickle-cell-disease-engaging-patient-and>

Link to Piel et al (2013): [https://doi.org/10.1016/S0140-6736\(12\)61229-X](https://doi.org/10.1016/S0140-6736(12)61229-X)

Link to “These Sisters With Sickle Cell Has Devastating, and Preventable, Strokes”:

<https://www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html>

For more information on Sickle Cell Disease Coalition, see:

<http://www.scdcoalition.org/report.html>

Link to the Power-Hays and McGann (2020):

<https://www.nejm.org/doi/full/10.1056/NEJMp2022125>



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**Melissa Creary, PhD, MPH**

Link to “On That Edge of Fear’: One Woman’s Struggle with Sickle Cell Pain”:

<https://www.nytimes.com/2021/05/30/us/sickle-cell-black-women.html>

Link to “How a Genetic Trait in Black People Can Give the Police Cover”:

<https://www.nytimes.com/2021/05/15/us/african-americans-sickle-cell-police.html>

Link to “These Sisters With Sickle Cell Has Devastating, and Preventable, Strokes”:

<https://www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html>

Link to “In A 1st, Doctors in U.S. Use CRISPR Tool To Treat Patient With Genetic Disorder”:

<https://www.npr.org/sections/health-shots/2019/07/29/744826505/sickle-cell-patient-reveals-why-she-is-volunteering-for-landmark-gene-editing-st>

Link to “Researchers Halt Trials of Promising Sickle Cell Treatment”:

<https://www.nytimes.com/2021/02/22/health/sickle-cell-gene-therapy-bluebird.html>

Link to Wailoo and Pemberton (2006):

<https://jhupbooks.press.jhu.edu/title/troubled-dream-genetic-medicine>

Link to “Prioritizing Sickle Cell Patients: A Chance to Mend Broken Ties”:

<https://innovativegenomics.org/blog/prioritizing-sickle-cell-patients-chance-mend-broken-ties/>

Link to Cure Sickle Cell: <https://curesickle.org/>

Creary, Melissa. “Bounded Justice and the Limits of Health Equity.” *The Journal of Law, Medicine & Ethics*, 49 (2021): 241-256.

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<https://elsihub.org/news/novel-gene-therapies-pediatric-and-young-adults-sickle-cell-disease-engaging-patient-and>

Link to “Gene Therapy: Erasing Sickle-Cell Disease”: <https://www.nature.com/articles/549s28a>