

Series Title: ELSIcon2022 ELSIconversations

Session Title: Access to Genetic Screening and Therapies: Case Study of Sickle Cell Disease

Date: February 15, 2023: 4-5pm ET

Presenters: Jeanne O'Brien, MD, MSc & Joshua C. Combs, MD, FACOG

Moderators: Liza Johnson, MD, MPH, MSB & Mildred Cho, PhD

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Biographies:

Panelist: Jeanne O'Brien, MD, MSc

Biography: <https://elsihub.org/directory/jeanne-e-obrien>

Panelist: Joshua C. Combs, MD, FACOG

Biography: <https://www.doximity.com/pub/joshua-combs-md>

Moderators: Liza Johnson, MD, MPH, MSB

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

Moderator: Mildred Cho, PhD

Biography: <https://elsihub.org/directory/mildred-k-cho>

Jeanne O'Brien, MD, MSc

Link to US Department of Health and Human Services Office of Minority Health:
<https://www.minorityhealth.hhs.gov/>

Link to APHL Hemoglobinopathies Project:
https://www.aphl.org/programs/newborn_screening/Pages/Hemoglobinopathies.aspx

Link to New York Times article by Gina Kolata (Dec 2021):
<https://www.nytimes.com/2021/12/28/health/sickle-cell-genetic-testing.html>

Link to New York Times article by Gina Kolata (May 2021):
<https://www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html>

Link to Brown (2021):
<https://www.thermofisher.com/us/en/home/global/forms/life-science/expanded-carrier-screening-resources.html>

Link to McQueen et al (2021): <https://doi.org/10.1007/s10815-021-02261-7>

Link to Ghioffi et al (2017): <https://doi.org/10.1007/s10897-017-0160-1>

Link to Attia et al (2020): <https://doi.org/10.1016/j.jpeds.2020.04.027>

Link to Wailoo (2017): <https://www.nejm.org/doi/full/10.1056/NEJMp1700101>

Link to Virtual Academy of Genetics:
https://ivf-worldwide.com/index.php?option=com_content&view=article&id=744&Itemid=463

Link to CDC SCD in Georgia, 2015:
https://www.cdc.gov/ncbddd/hemoglobinopathies/documents/2015-snapshot_sickle-cell-ga-508.pdf

Joshua C. Combs, MD, FACOG

Link to Salcedo et al (2021): <https://doi.org/10.1038/s41598-021-90405-1>

Link to Ballas (2009): <https://doi.org/10.1002/ajh.21443>

Link to Kauf et al (2009): <https://doi.org/10.1002/ajh.21408>

Link to Lubeck et al (2019):

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2755485>

Link to Lipton et al (2020): <https://doi.org/10.1093/humrep/dez203>

Audience Q&A

Link to Sickle Cell Disease Partnership:

<https://www.votervoice.net/SCDP/campaigns/97284/respond>

Link to ELSI Collection by Myers and Wakefield (2021):

<https://elsihub.org/collection/expanded-carrier-screening-ecs-clinical-and-ethical-considerations-genetic-counseling>

Link to ELSI Collection by Newson (2022):

<https://elsihub.org/collection/social-norms-selective-reproduction-implications-wide-offer-genetic-screening>