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Understanding Long-Term Health Outcomes following Curative Therapy for Sickle Cell Disease: My experience working with the COALESCE Team



Introduction: Treatment options for patients with sickle cell disease (SCD) continue to rapidly expand and evolve, but there remains a paucity of data on the long-term health outcomes associated with curative therapies in children and adults with SCD. The primary objective of this practicum was to develop an informational website for the participants of The Cooperative Assessment of Late Effects for Sickle Cell Disease Curative Therapies (COALESCE) Study at Vanderbilt University Medical Center in Nashville, Tennessee, which aims to understand more about long term health outcomes following hematopoietic stem cell transplant (HSCT) and gene therapy for SCD.

Methods: The study group developed a website working group team to address the objective of this practicum. The team conducted an extensive literature search, and this information was summarized and re-written at a third-grade reading level and published on the website. Two study participants then reviewed the website to assess design and utility of content.

Results: The primary practicum product was an informational website that participants and the public could access. Topics on the website included: long term health outcomes of SCD and curative therapies on the heart, lung, kidney, pain, central nervous system, and reproductive system. Appropriate graphics were also created to aid readers in understanding written content. Secondary practicum products included a National Institute of Health oral presentation and an American Society of Hematology Educational Program manuscript entitled "Long Term Health Outcomes Following Curative Treatment for Sickle Cell Disease."

Conclusions: The website allows study participants to have a better understanding of SCD, its complications, and current known outcomes of curative therapies. Importantly, it will help communicate the significance of the COALESCE study to improve participant compliance and possibly even study recruitment. Next steps include developing a similar website for providers and researchers.