

VANDERBILT School of Medicine

Developing an Educational Website for participants in the COALESCE Study

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Background

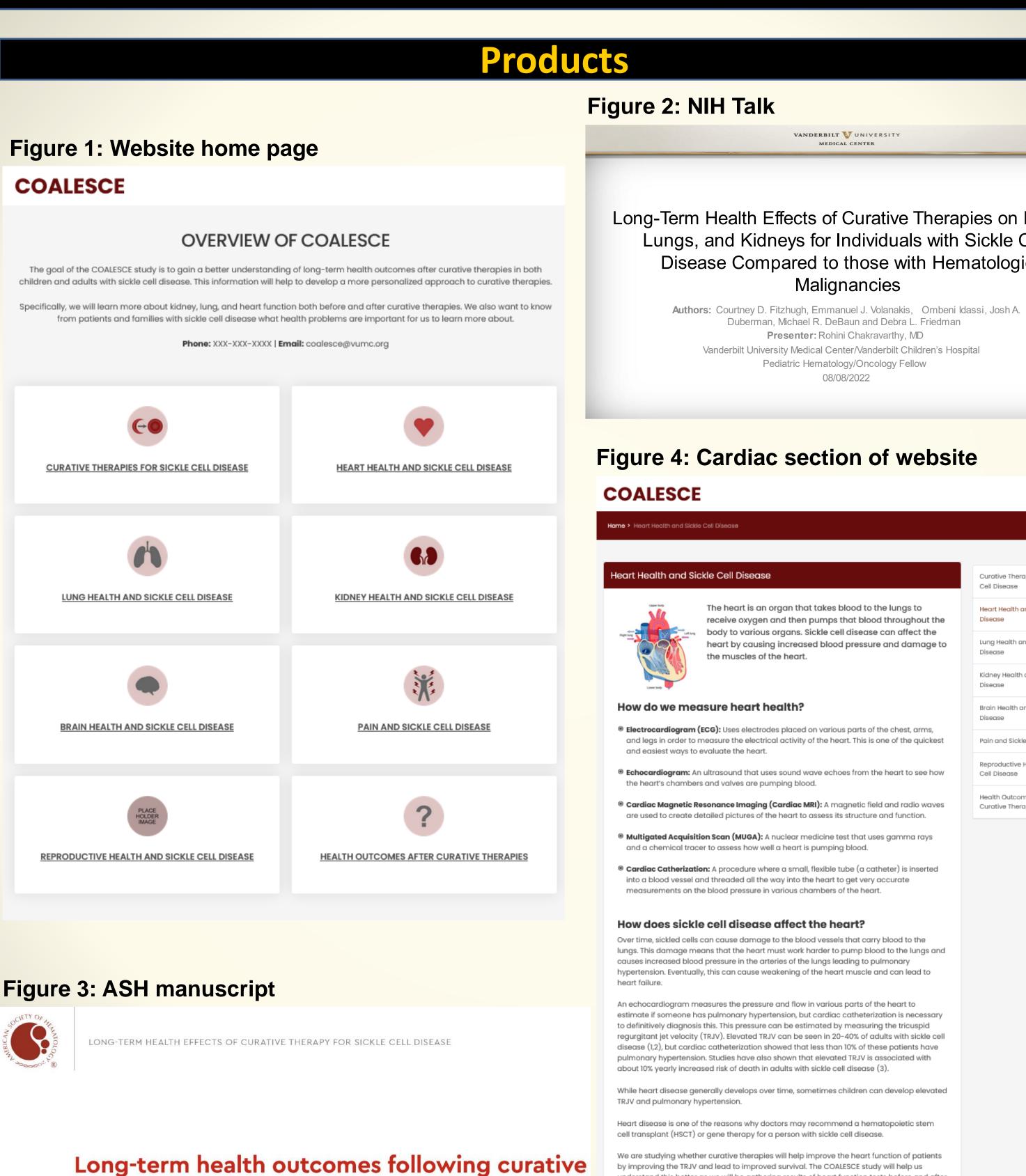
- Children and adults with sickle cell disease (SCD) can experience severe organ toxicities
- Allogeneic hematopoietic stem cell transplant (HSCT), gene therapy, and gene editing are being increasingly used as curative therapy options
- Paucity of data on the long-term health outcomes associated with curative therapies

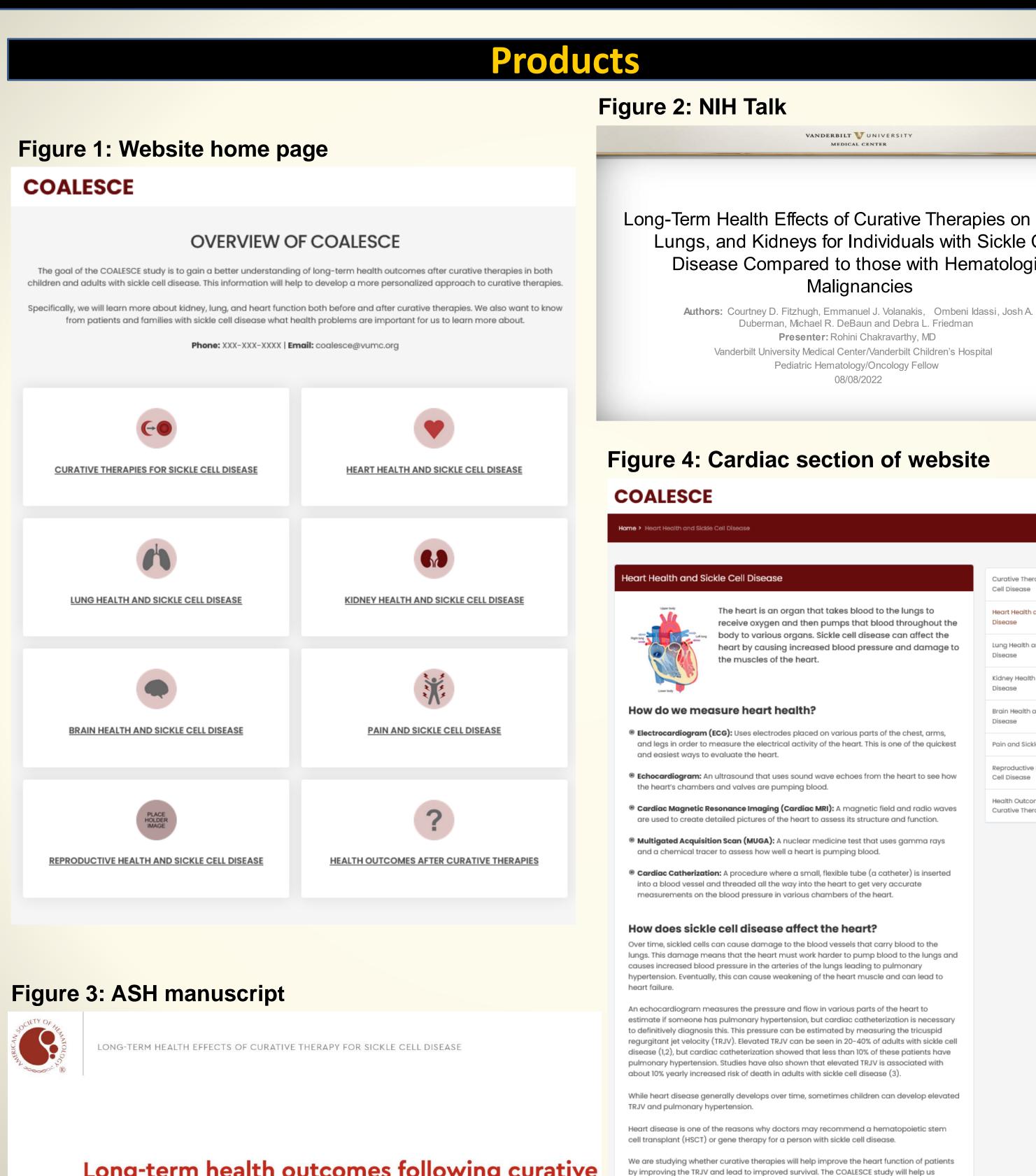
Objectives/Aims

- Develop an informational website for the participants of The Cooperative Assessment of Late Effects for Sickle Cell Disease **Curative Therapies (COALESCE) Study**
- COALESCE aims to understand more about long- term health outcomes following HSCT and gene therapy for SCD

Methods

- Website working group team developed
- Extensive literature search on current published data
- Information was summarized and published on the website
- Two study participants reviewed the website to assess design and utility of content







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therapies for sickle cell disease

in patients with sickle cell disease. N Engl J Med. Feb 26 2004;350(9):886-95. https://doi.org/10.1056/NEJMoa035477

curative therapy.

References

2. Sutton LL, Castro O, Cross DJ, Spencer JE, Lewis JF. Pulmonary hypertension in sickle cell disease. Am J Cardiol. Sep 15 1994;74(6):626-8. https://doi.org/10.1016 /0002-9149(94)90760-90

1. Gladwin MT, Sachdev V, Jison ML, et al. Pulmonary hypertension as a risk factor for death

understand this better as we will be gathering results of heart function tests before and after

3. Gladwin MT, Barst RJ, Gibbs JS, et al. Risk factors for death in 632 patients with sickle cell disease in the United States and United Kingdom. PLoS One. 2014;9(7):e99489. https://doi.org/10.1371/journal.pone.0099489



	Outcomes/Products
	Practicum products
Heart,	Educational website for COALESCE participants
Cell ic	 Oral presentation entitled "Long-Term Health Effects of Curative Therapies on Heart, Lungs, and Kidneys for Individuals with Sickle Cell disease Compared to those with Hematologic Malignancies"
Children's Hotpus at Vanderbit	 Manuscript entitled "Long-term Health Outcomes Following Curative Therapies for Sickle Cell Disease"
apies for Sickle >	Conclusions/Future Directions
and Sickle Cell >	 Website allows study participants to have a resource for reliable, evidence-based information on SCD
e Cell Disease > Health and Sickle	 Ability to engage community with COALESCE study and improve study recruitment and adherence
	 Similar webpage for providers and researchers
	 Future survey for participants regarding the utility of website content
	Acknowledgments
	 1U01HL156620 Clinical and genetic risk factors associated with adverse long-term health outcomes after curative therapies in individuals with sickle cell disease (COALESCE). National Heart, Lung, and Blood Institute.
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