

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

Products

Figure 1: Website home page

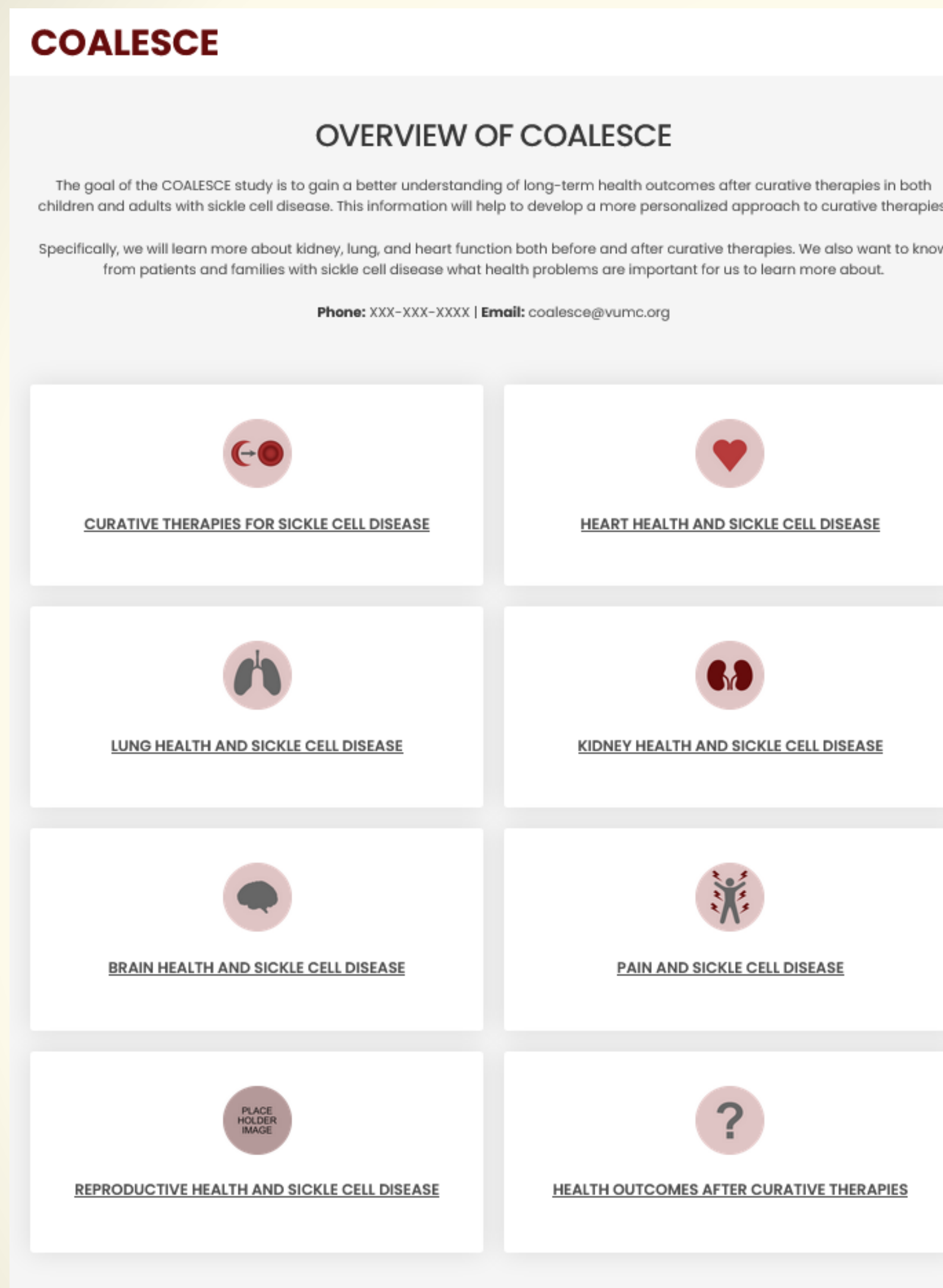


Figure 3: ASH manuscript



Figure 2: NIH Talk

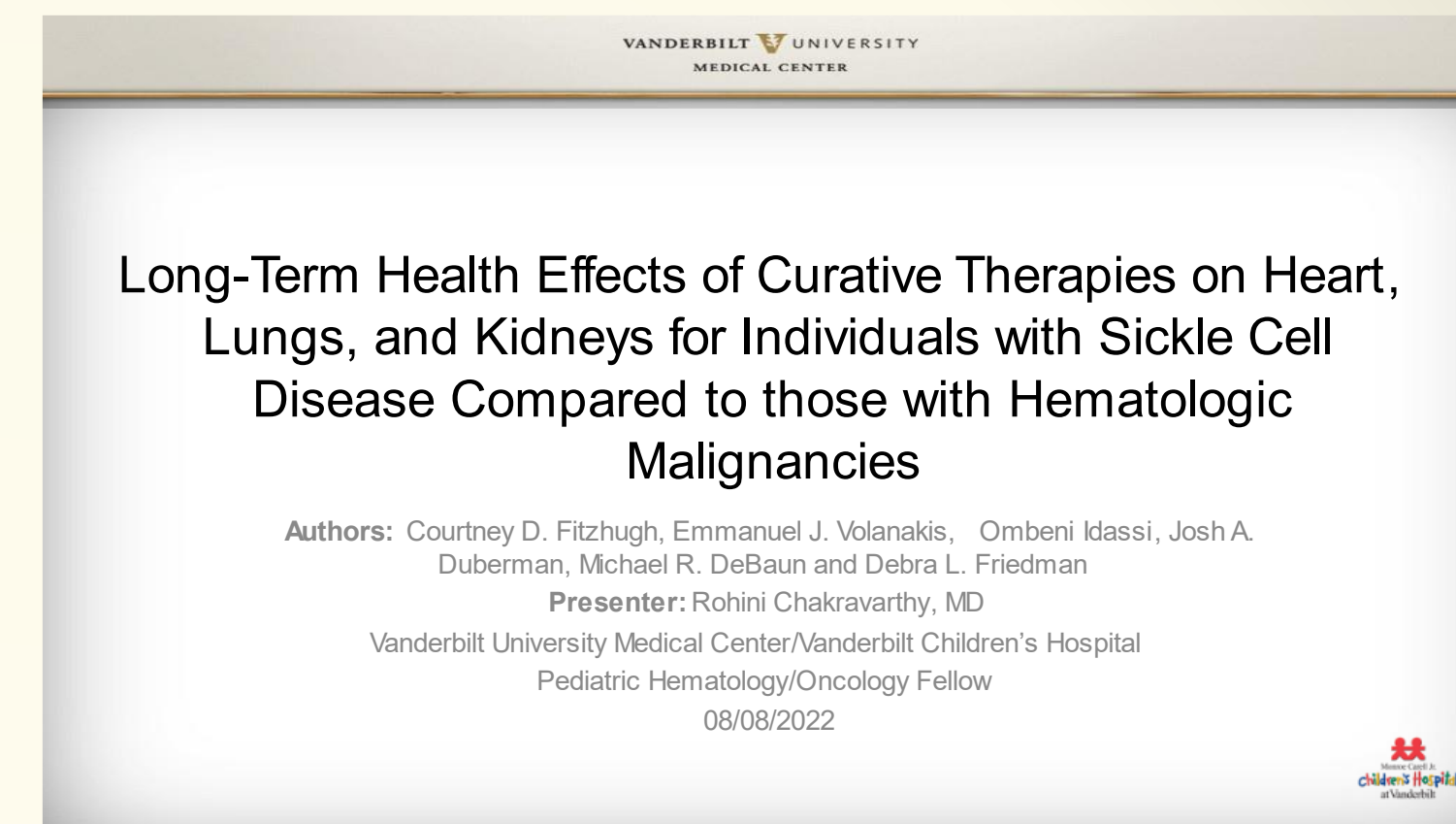
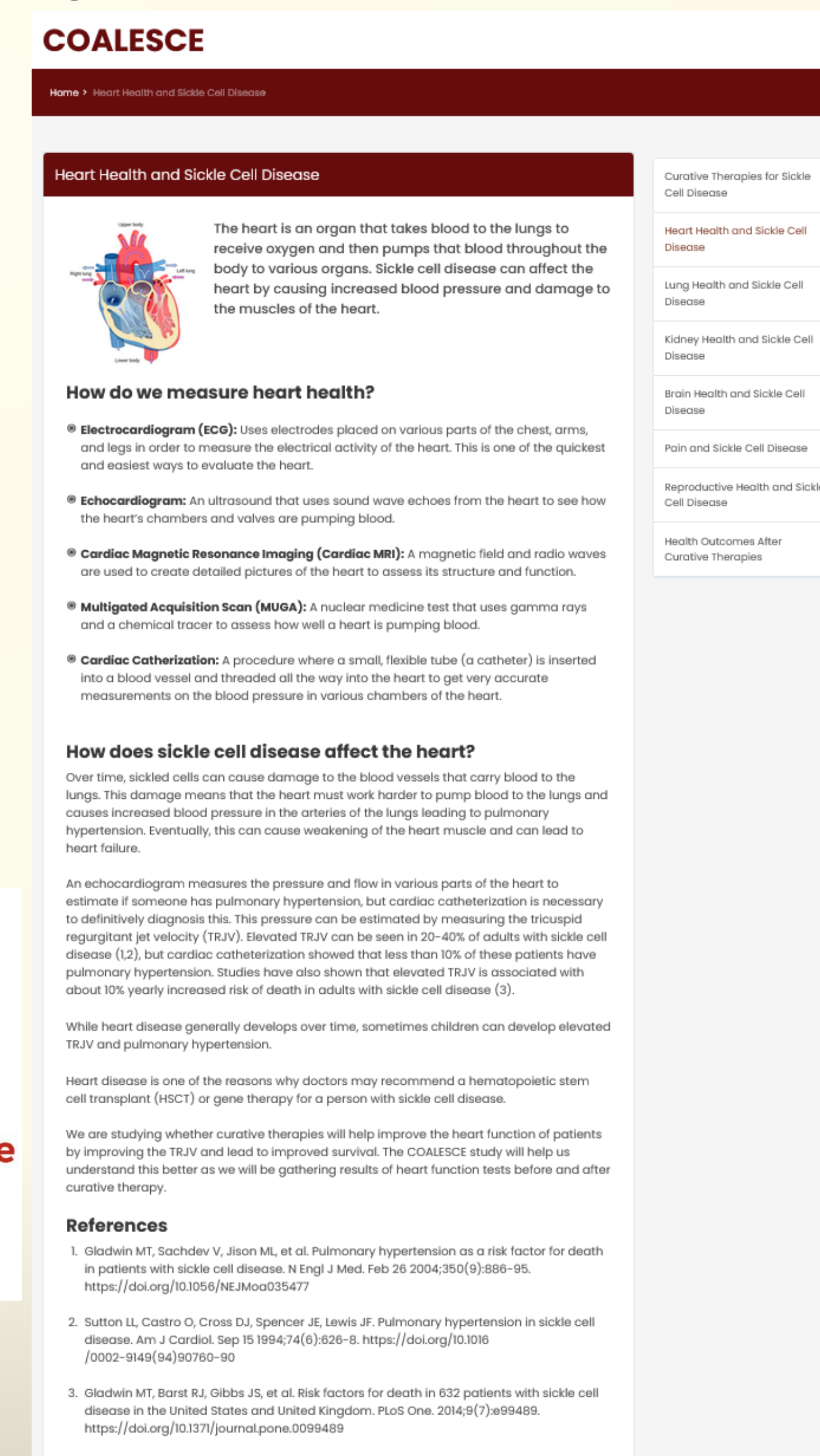


Figure 4: Cardiac section of website



Outcomes/Products

- Practicum products
 - Educational website for COALESCE participants
 - 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"
 - Manuscript entitled "Long-term Health Outcomes Following Curative Therapies for Sickle Cell Disease"

Conclusions/Future Directions

- Website allows study participants to have a resource for reliable, evidence-based information on SCD
- 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

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