Use of a Website to Increase Awareness about a Clinical Trial of Stem Cell Transplant for Sickle Cell Disease

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BACKGROUND

Sickle cell disease (SCD) is a genetic blood disorder that affects ~90,000 Americans and causes serious morbidity and early mortality. Hematopoietic stem cell transplantation (HSCT) is the only cure for SCD and has achieved very good results when using a human leukocyte antigen (HLA) identical sibling donor.1,2 Unfortunately >80% of patients with SCD do not have a suitable HLA-identical sibling.3-5 To overcome this barrier, HSCT can be performed using a haploidentical (half-match) donor. While a previous study of haploidentical transplant for SCD had some success, many patients on this study suffered graft rejection.6 We are currently testing the safety and effectiveness of haploidentical HSCT for SCD using a different conditioning regimen and stem cell product manipulation approach via a multicenter clinical trial (NCT01461837). Clinical studies for SCD have had difficulties due to poor recruitment.7 Limited access to information and resources about SCD HSCT clinical trials has been previously identified as a significant problem.8

OBJECTIVE

To increase patient and healthcare provider awareness about a clinical trial studying haploidentical T-cell depleted HSCT for high-risk SCD.

METHODS

A website was created featuring information about the clinical trial with the involvement of SCD patient advocacy group leaders. Institutional review board approval was obtained. The number of page views and unique visitors to the website were tracked over time.

RESULTS

Traffic to the created website has been steady over the past few months. Future plans include the addition of video and partnership with more patient advocates. Future work also will study potential participants’ opinions of the website as an education tool to learn about the clinical trial.

REFERENCES


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