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Comparison of children diagnosed with cerebral palsy in a private cord blood bank to an epidemiological sample

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ABSTRACT

Background: Although cord blood (CB) stem cell research is being conducted for treatment of cerebral palsy (CP), little is known about children with CP and stored CB.
Aims: To compare demographic and clinical characteristics of children with CP and stored CB to children with CP identified in a population-based study.
Methods and Procedures: The Longitudinal Umbilical Stem cell monitoring and Treatment REsearch (LUSTRE®) Registry recruited children from the largest US private CB bank. Demographics, co-morbidities, and gross motor function (GMFCS level and walking ability) were collected and, where possible, compared with the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.
Outcomes and Results: 114 LUSTRE participants were compared to 451 ADDM participants. LUSTRE participants were more likely to be white, but sex distribution was similar. Co-morbidities (autism and epilepsy) and functional mobility were also similar.
Conclusions and Implications: The results of this analysis suggest that while children diagnosed with CP and with access to stored CB differ from a broader population sample in terms of demographics, they have similar clinical severity and comorbidity profiles. As such, LUSTRE may serve as a valuable source of data for the characterization of individuals with CP, including individuals who have or will receive CB infusions.

What this paper adds?

To date, little research has been done on families that choose to privately bank their children's cord blood (CB) and whose children are subsequently diagnosed with cerebral palsy (CP). This analysis was performed to help understand the extent to which the results of research within the private CB-storing population might be relevant to broader populations of children with CP. The study compared children with CP who were enrolled in the Longitudinal Umbilical Stem cell monitoring and Treatment REsearch (LUSTRE®) registry at the largest private, US cord blood bank to children with CP identified in the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. While the demographics of children with CP differed, these samples were similar when compared across several measures of functional mobility and for the prevalence of co-occurring medical conditions. Based on these results, LUSTRE may be useful for the characterization of children with CP, including individuals who have or will receive CB

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infusions.

1. Introduction

Umbilical cord blood (CB) contains a mixed cell population and is a rich source of hematopoietic stem cells (Gluckman et al., 1989). CB derived cellular therapy has been used for decades to treat pediatric and adult patients with hematologic malignancies and disorders (Butler & Menitove, 2011; Gluckman et al., 1989; Prasad & Kurtzberg, 2009). Based on evidence that CB cells may have the capacity to facilitate repair of damaged tissues outside of the blood and immune system, it is also in early phases of research as a treatment for a number of additional conditions, including cerebral palsy (CP) (Chez et al., 2018; Dawson et al., 2017; Kurtzberg, Durham, Laskowitz, Balber, & Bennett, 2016; Sun et al., 2015; Sun et al., 2016; Sun et al., 2017). The collection and private storage of umbilical cord blood, recently estimated at approximately 4 million units worldwide, has become an increasingly popular choice for parents of newborn children (Ballen, Verter, & Kurtzberg, 2015). However, little is known about the medical conditions that affect families that choose to privately store their newborns' CB.

The Longitudinal Umbilical cord blood Stem cell monitoring and Treatment REsearch (LUSTRE®) Registry identifies and follows families that have both stored their children's CB in the largest US CB bank and have children with conditions that are currently treated with, or under research for treatment with, CB. Over time, LUSTRE is designed to help better understand the clinical characteristics and disease severity of these children, describe the treatments they receive, compare the long-term clinical and quality of life outcomes associated with these treatments, and characterize the types of participants who are receiving stem cell therapy. CP, one of several neurological conditions currently being studied for potential treatment with CB, is a LUSTRE target condition.

Little research exists regarding the characterization of children diagnosed with CP who also have access to privately stored CB; nor is there published research on how this population compares to the broader CP population. This study was undertaken to describe the LUSTRE-CP cohort and to assess, in terms of demographics and disease severity, how children in LUSTRE with CP compared to a nationally representative sample of children with CP. We used data from the Autism and Developmental Disabilities Monitoring (ADDM) Network for this comparison group. ADDM is funded by the U.S. Center for Disease Control and Prevention (CDC) to estimate the number of children with autism spectrum disorder and other developmental disabilities living across the United States. The ADDM Network has routinely provided valuable insight into the epidemiology of various developmental disabilities, including CP (Christensen et al., 2014; Kirby et al., 2011; Yeargin-Allsopp et al., 2008). In order to determine how children with CP and stored CB compare to children with CP in the general public, we compared children in LUSTRE to children captured in the most recent assessment of CP conducted by ADDM in 2008.

2. Methods

2.1. Study design

LUSTRE is an observational disease registry open to all families who have stored CB in the largest, U.S.-based, private cord blood

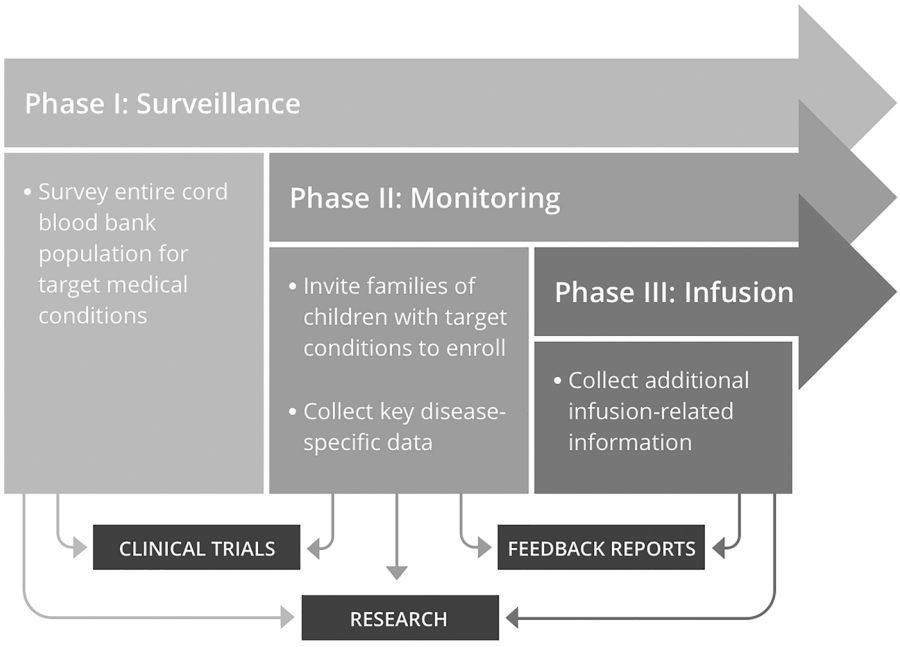

Fig. 1. LUSTRE Research Model.