Title: Progression and Regression of Development in Children with Congenital Zika Syndrome

Authors: Anne Wheeler1, Danielle Toth1, Pollyanna Bezerra2, Lucélia Lima Nobrega2, Raine Costa Borba Firmino2, Claudia Marques da Silva2, Katherine C. Okoniewski,1 Liana Ventura², Don Bailey1, Camila Ventura2

1RTI International, 2Altino Ventura Foundation (FAV)

Introduction: There are currently nearly 4000 young children worldwide with Congenital Zika Syndrome (CZS), a severe condition resulting from prenatal exposure to the Zika virus. Clinical features that differentiate CZS from other congenital infections include severe microcephaly at birth, often with partially collapsed skull; thin cerebral cortices subcortical calcifications; macular scarring and focal pigmentedary retinal mottling; congenital contractures; and (5) marked early hypertonia and symptoms of extrapyramidal involvement.1 Given the systemic extent of these features, it is not surprising that nearly all children with CZS experience profound developmental delays.2 To what extent these children are making developmental progress as they are getting older and what variables may predict better or worse outcomes will be the focus of this presentation.

Method: As part of a 5-year longitudinal study of the consequences of CZS, 179 young children and their primary caregivers have participated in two completed assessments at the Altino Ventura Foundation (FAV) in Recife, Brazil. The children were assessed by trained data collectors using the Brazilian Bayley Scales of Infant and Toddler Development (BSID), and caregivers completed several measures to assess problem-solving, communication, and functional skill attainment. Medical records were also reviewed to identify co-occurring conditions.

Results: Nearly all of the children in this sample presented with profound developmental delays across all domains of functioning at the initial assessment, with average developmental functioning estimated to be in the 2-4 month range (average chronological age = 31.9 months). At the second assessment point, approximately 6 months later, the sample as a whole demonstrated a 1.4 point growth in cognitive skills, whereas language and motor skills remained virtually unchanged. Differential patterns emerge however, with examination of individual trajectories. A little over half the sample (56.9%) demonstrated progression in cognitive skills, with an average growth of nearly 5 points. Similarly 45% had improved skills in receptive language, 42% in expressive language, 45% in fine motor, and 42% in gross motor. Conversely 39% demonstrated regression in cognitive skills, 41% in receptive language, 47% in expressive language, 45% in fine motor, and 50% in gross motor. Preliminary results suggest seizures and other co-morbid conditions are associated with regression in skills. These findings, along with additional preliminary results from the third assessment (which are ongoing at the time of the writing of this abstract) will be presented.

Discussion: Whereas children with CZS are expected to have profound long-term developmental challenges, patterns are emerging to suggest around half of the children are making slow but steady developmental progress, whereas the other half are not gaining skills or are regressing. Understanding variables that can predict progression or regression of skills in children with CZS is critical to providing more targeted intervention strategies as well as making more precise predictions of prognosis and family needs.

References:
