Title: Early Development and Behavioral Profiles in Infants with Congenital Zika Syndrome: Pilot data from Brazil

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Introduction: The recent Zika outbreak and the link to microcephaly and other birth defects in infants exposed in utero have garnered widespread international attention.¹ Although Zika no longer meets the World Health Organization (WHO) definition of a Public Health Emergency of International Concern (PHEIC), the WHO reports that nearly 4000 infants worldwide have been affected². Based on the severity of birth defects, the extent of impairment in these infants is expected to be profound; however, virtually nothing is known regarding the developmental and behavioral sequela of CZS. This pilot study collected parent-reported patterns of development, sleep, and behavior in infants with CZS in Recife, Brazil to develop some baseline information regarding the impact of CZS on the child and family.

Method: Participants were 44 caregivers of infants with confirmed CZS who are being followed for clinical services at the Altino Ventura Foundation (FAV) in Recife, Brazil. With assistance from clinicians at FAV, caregivers completed Brazilian Portuguese versions of the Ages and Stages Questionnaire (ASQ), the Brief Infant Sleep Questionnaire (BISQ) and the Infant Behavior Questionnaire (IBQ). All infants were between 13-22 months of age at the time of the assessment.

Results: Only 1 infant was displaying age appropriate developmental skills at the time of the assessment. Most (~75%) had mastered some communication and gross motor skills at around a 6-8-month level. Communication skills were a relative strength on average for the sample, while problem-solving and fine motor skills were relative weaknesses. Sleep was noted to be a problem for around 18% of the sample, although over half of the infants still required being held or rocked in order to fall asleep. With regard to temperament, infants with CZS were reported to have higher levels of negative affect, perceptual sensitivity, and difficulties with regulation, and lower approach and vocal reactivity than comparison samples from the literature.

Discussion: CZS will have lifelong consequences for affected children and their families. Understanding the developmental and behavioral trajectories of affected infants will help in identifying appropriate family supports to improve quality of life. Our pilot data suggests that at around 18 months of age nearly all infants have severe to profound developmental delays and potentially significant behavior challenges. Planned longitudinal research to identify variables associated with better or worse outcomes will be discussed.

References/Citations:

- Roos RP. Zika virus—a public health emergency of international concern. JAMA Neurol. 2016. doi:10.1001/jamaneurol.2016.3677

1. RTI International, Research Triangle Park, NC
2. Altino Ventura Foundation, Recife, Brazil