

# AMCHP 2017

March 4-7, 2017 | Kansas City, MO

ENGAGEMENT WITH INTENTION: Inclusivity, Diversity & Non-Traditional Partnerships

## Zika and Enhancement of Birth Defects Surveillance: Tennessee Experience

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## Tennessee Birth Defects System (TNBDS)

Integrated surveillance, case management, and linkage to services

- CDC US Zika Pregnancy Registry
- CDC Enhanced Microcephaly and Zika associated Birth Defects Surveillance
- Tennessee birth defects registry
  - TCA 68-5-506



## Starting Point: Tennessee Birth Defects Registry

Established June 2000 (TCA 68-5-506)

- Annual report of birth defects prevalence and trends
- Determine possible association of environmental hazards and other potential causes of birth defects
- Evaluate current birth defect prevention initiatives
- Provide families of children with birth defects information on public services available

### Limitations:

- Unfunded
- 18-24 month lag
- Based on hospital discharge data set
- Very limited capacity for linking datasets, following outcomes, connection to care, or prevention efforts

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## Rapid Evolution

### Case Identification:

- Zika testing in pregnancy (January 2016)
- Provider report to RedCap web interface (microcephaly 2/16 evolving to neurologic birth defects 1/17)
- Eventual integration with birth file as secondary means of neurologic birth defect identification

### Linkage:

- RedCap/vital records data fields to Neometrics case management system
- Data verification and completion by epidemiologist, linkage systems, nurse, administrative systems
- Generation of follow up protocols (clinical, early intervention, family peer navigator)
- Outcomes monitoring through nurse, follow up in EIS system for 3 years/up to age 5

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# Enabling Factors

## Funding

- ELC M2: Epidemiologist
- Microcephaly/birth defects (CDC-DD16-1605): nurse consultant, admin/data support, IT and case management build out
- ELC Supplement: hospital reporting support, increased screening and referral capacity of provider network, educational and communications campaign, informatics

## MCH :

- “Surge capacity” of informatics, newborn screening, CYSHC
- People, systems and infrastructure



# Partnerships

- Informatics
- Education/Early Intervention Systems
- LEND
- Perinatal and genetics centers
- TNAAP
- Family Voices
- Hospital Association

