

UTAH DEPARTMENT OF HEALTH


Pregnant Women Outreach and Services/Clinical Messaging

Utah Birth Defect Network

Amy Nance
 Program Manager
 Utah Department of Health

Utah Birth Defect Network (UBDN)


- Established in 1994
- Full registry in 1999
- 3 Components:
 - Surveillance
 - Research
 - Prevention



Surveillance

Goals: Timely, Accurate, Complete Data


- Children with Special Health Care Needs Bureau, Division of Family Health and Preparedness
- CDC and National Birth Defects Prevention Network
 - ✓ Standards and recommendations
- Data calls for CDC, NBDPN, ICBD, Birth Defects Research publication; multi state research projects; cluster studies




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UBDN Surveillance

- Track all major structural birth defects
- Statewide surveillance system
- Active/Passive surveillance
- Sources: Birth Defect Reporting Rule 398-5
 - Hospital Discharge data
 - Labs, clinics and birthing facilities
 - Birth and Fetal Death Certificates
 - Medical records abstraction






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Significance in Utah

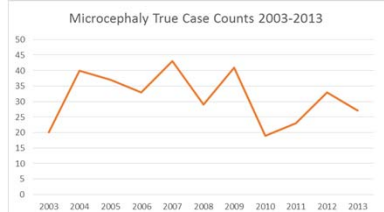
- Utah: 1,200 children are born with serious birth defects every year
 - the reportable birth defect rate for Utah is 22.8 cases per 1,000 live births.




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Significance in Utah

- Microcephaly specifically (2003-2013)
 - Utah: 345 born with microcephaly with prevalence rate 8.2 per 10,000






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UBDN Response to Zika

- Monitoring Zika virus in pregnant women and monitor fetal and infant outcomes following Zika virus infection during pregnancy – Pregnancy Registry and Birth Defect Registry
- Provide education to hospitals and providers
- Provide education to the public about Zika virus




Zika Pregnancy Registry

CDC / AMA webinar "Preparing for Zika Transmission in the U.S." presented by the AMA in partnership with the Centers for Disease Control and Prevention (CDC)



US Zika Pregnancy Registry


- Purpose of registry:
To monitor pregnancy and infant outcomes following Zika virus infection during pregnancy and to inform clinical guidance and public health response
- How it works:
The registry is a supplemental surveillance effort coordinated by CDC and dependent on voluntary collaboration of state, tribal, and local health departments



US Zika Pregnancy Registry


- Who is included?
Pregnant women with laboratory evidence of Zika virus infection and exposed infants born to these women; infants with laboratory evidence of congenital Zika virus and their mothers
- How can you support the registry?
Arrange for laboratory testing for Zika virus infection in pregnant women and infants who meet the clinical criteria for testing as outlined in the CDC guidelines

Spread the word about the US Zika Pregnancy Registry and assist with follow-up for pregnant women and infants who are part of the registry



Clinician Outreach


- Identifying clinicians in your area and providing education on:
 - Risks
 - Recognition
 - Diagnosis
 - Reporting
 - Clinical management
 - Outcomes
 - Prevention



Brain Abnormalities Associated with Congenital Zika Virus Infection

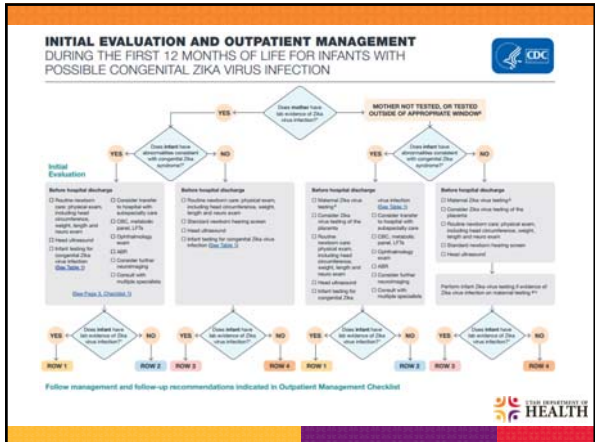
New guidance (version 1.1, 8/25/2016)

<ul style="list-style-type: none"> – Microcephaly – Intracranial calcifications – Hydrocephalus – Hydranencephaly – Pachygyria, lissencephaly – Agria – Brain atrophy and asymmetry – Enlargement of posterior fossa – Ventriculomegaly – Restricted middle cerebral artery flow 	<ul style="list-style-type: none"> – Abnormally formed or absent structures <ul style="list-style-type: none"> ○ Corpus callosum ○ Thalami ○ Cerebellar vermis ○ Brainstem
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'Rapid' Birth Defects Monitoring and Follow-Up

- Cases Reported through our UBDN system
- Positive and inconclusive Zika virus results
- Rapid ascertainment per UBDN protocol
 - Very similar to the pregnancy registry forms
 - Each case clinical reviewed by Pediatric Neurologist
- Follow-up completed at 2,6,and 12 months



'Rapid' Birth Defects Monitoring and Follow-Up

- Newborn Hearing Screening program
- Integrated Services Program



UDOH Resources/Contacts

Utah Birth Defect Network
Amy Nance
Program Manager
801-883-4661
aenance@utah.gov

Zika Testing Surveillance
Bureau of Epidemiology
801-538-6191

Zika & Pregnancy
MotherToBaby UT/PRL
801-328-2229

Julie Southwick
Health Educator
801-883-4647
jasouthwick@utah.gov

Amy Steele
Epidemiologist
amysteele@utah.gov