



University of Arizona  
Department of Pediatrics  
Division of Genetics & Developmental Pediatrics



## Overview

- ▶ We partner with the following organizations
  - ▶ Arizona Department of Health Services (ADHS)
  - ▶ Arizona Department of Education (ADE)
  - ▶ Arizona University Center on Disabilities (AzUCD)
  - ▶ Arizona Leadership Education in Neurodevelopmental Disabilities and Related Disorders (AZLEND)
  - ▶ Arizona Clinics and Hospitals
- ▶ We have 3 active surveillance projects that are all funded by the Centers for Disease Control and Prevention (CDC)

## Fetal Alcohol Syndrome (FASSNET-II)

- ▶ FASSNET-II conducts surveillance for all of Arizona
- ▶ Funded from 1997 to 2002 and 2009 to 2014
  - ▶ No new funding is anticipated
- ▶ One of 3 sites participating
  - ▶ Surveillance includes individuals who were AZ residents in 2010 and were born between 1/1/2001 – 12/31/2003
- ▶ Research Highlights
  - ▶ Methods and Prevalence paper focusing on operations (submitted). Arizona Estimated prevalence 0.25 per 1,000
  - ▶ Comparative paper looking at documentation of diagnostic features by community physicians and specialty physicians (pending data)

## Autism and Intellectual Disabilities (ADDM)

- ▶ ADDM conducts surveillance for a portion of Maricopa County, including 5 school districts
- ▶ Funded from 2000 to 2014
  - ▶ Additional funding for 4 years is anticipated
- ▶ We are one of 3 sites to produce estimates for each of the six published study years.
  - ▶ Participating sites ranged from 11 to 14 sites in each of the study years
  - ▶ Surveillance includes AZ residents who turn 8 during each study year
- ▶ Research Highlights
  - ▶ Produced ASD prevalence estimates in even years 2000 – 2010, (2012)
  - ▶ Prevalence has increased in the AZ study area from 6.5 per 1,000 in 2000 to 15.7 per 1,000 in 2010

<http://www.cdc.gov/ncbddd/autism/addm.html>

## Muscular Dystrophy (MD STARnet)

- ▶ MD STARnet conducts surveillance for all of Arizona
- ▶ Funded from 2002 to 2014
- ▶ DBMD longitudinal surveillance (2002 – 2011)
  - ▶ Arizona residents born on or after 1/1/1982
- ▶ Expansion into 9 MDs Cross-sectional (2011 – 2014)
  - ▶ Arizona residents with a visit at any source during 2005 - 2010
- ▶ Research Highlights
  - ▶ 15 manuscripts, 28 conference presentations
  - ▶ 13 manuscripts planned or submitted during 2014
  - ▶ Prevalence for DMD 1.12 per 10,000 and BMD 0.26 per 10,000

<http://www.cdc.gov/ncbddd/muscular dystrophy/research.html>

## Other Types of Research

- ▶ Spina Bifida Neuropsychological testing pilot
  - ▶ NP testing for children aged 3-6 as baseline for longitudinal study
  - ▶ Data are in cleaning stage
- ▶ DBMD Parent and adult male self report questionnaires
  - ▶ Interview, needs assessment, health care transitions
- ▶ Autism and iPads in the home
  - ▶ Brief interviews with parents on their personal experience with iPad
- ▶ Developmental Screening Technical Assistance Program
  - ▶ Assisting community physicians with incorporating developmental screening with PEDS and M-CHAT into current practice