



# UAMS Department of Pediatrics

## Arkansas Newborn Screening

### Long-term Follow-up Cohort Study

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**The following speaker has no financial relationships with commercial interests to disclose.**

**There are no conflicts of interest or commercial support for this program.**

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# Purpose/Aim

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- Purpose: Tracking and monitoring the clinical care and public health outcomes for children diagnosed with a NBS condition through the Arkansas NBS Program and to follow them until 21 years of age.
- Primary Aim: Record demographics, characteristics of disease and treatment, utilization patterns, QI measures, and clinical outcomes



# Partnership/Funding

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- University of Arkansas for Medical Sciences (UAMS), Pediatric Genetics Section with the Arkansas Children's Hospital (ACH) and its Research Institute (ACHRI)
- Funding: Antenatal and Neonatal Guidelines, Education, and Learning System (ANGELS), a program at UAMS and in part by the UAMS, TRI, NCRR/NIH Grant 1 UL1 RR02988



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# NBS in Arkansas - Overview

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- ~ 38,000 births per year
- Prior to July 1, 2008, Arkansas screened for 7 conditions
- Since July 1, 2008, screen for 29 conditions on primary core panel (SCID & CCHD have not been added to the Arkansas NBS panel yet)
- ~ 70 diagnosed with a metabolic condition and another 70 with hearing loss, every year



# NBS in Arkansas (Continued)

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- Legislative mandate – Regulated by the Arkansas Department of Health (ADH)
- NBS – by State Public Health Laboratory
- 2<sup>nd</sup> Tier CAH and CF – by ACH Laboratory
- UAMS/ACH Pediatric Genetics: Consultant to ADH; NBS Coordinator position at UAMS/ACH serves as liaison between ADH and UAMS/ACH for coordination of follow-up on + NBSs



# Arkansas NBS LTFU Study

- IRB Approval: September 2011
- Database Implemented: January 2012
- Longitudinal, observational study
- Population: Four (4) Cohorts
  - ACH patients with NBS conditions meeting enrollment criteria
    - Study received waiver HIPAA and Consent forms for these subjects
  - Non-ACH patients with NBS conditions meeting enrollment criteria
    - Study will obtain consents for these subjects
  - Abstracting data from CF Registry on enrolled subjects
    - To date, this component has not been implemented
  - Obtaining health information from ADH
    - IRB approved the ADH component prior to implementation
    - Memorandum of Agreement established for the exchange of information between ADH and the Study; effective 1-2-12 through 12-31-13
    - Parental consent is required before health information can be shared with the Study



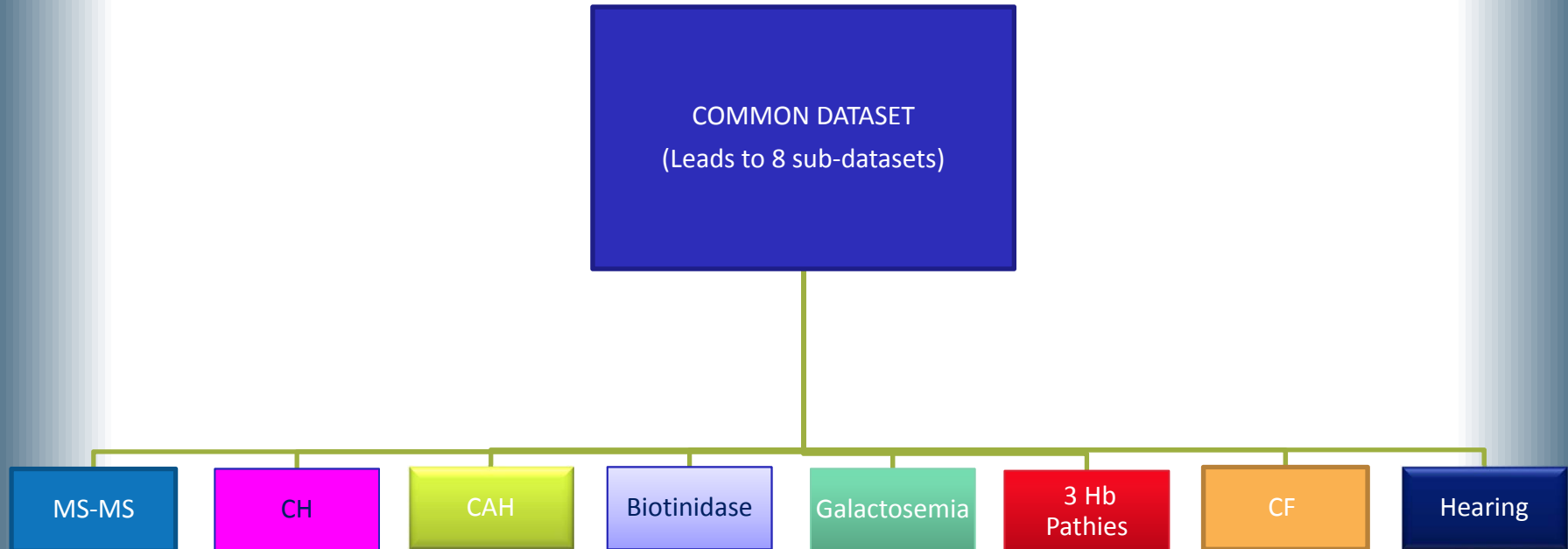
# Arkansas NBS LTFU Database

- Acknowledgement to NBSTRN: Utilized common data elements developed by NBSTRN as our starting point
- Collaborated with ACH clinical experts to develop 8 disease-specific data sets
- Utilized REDCap (Research Electronic Data Capture) hosted by UAMS Translational Research Institute (NCRR/NIH 1 UL1 RR02988)
- REDCap secure, web-based application designed to capture research studies
- Database created by abstracting and compiling information from the medical record.
- Data abstraction from the medical record for each visit to ACH Specialty Clinics

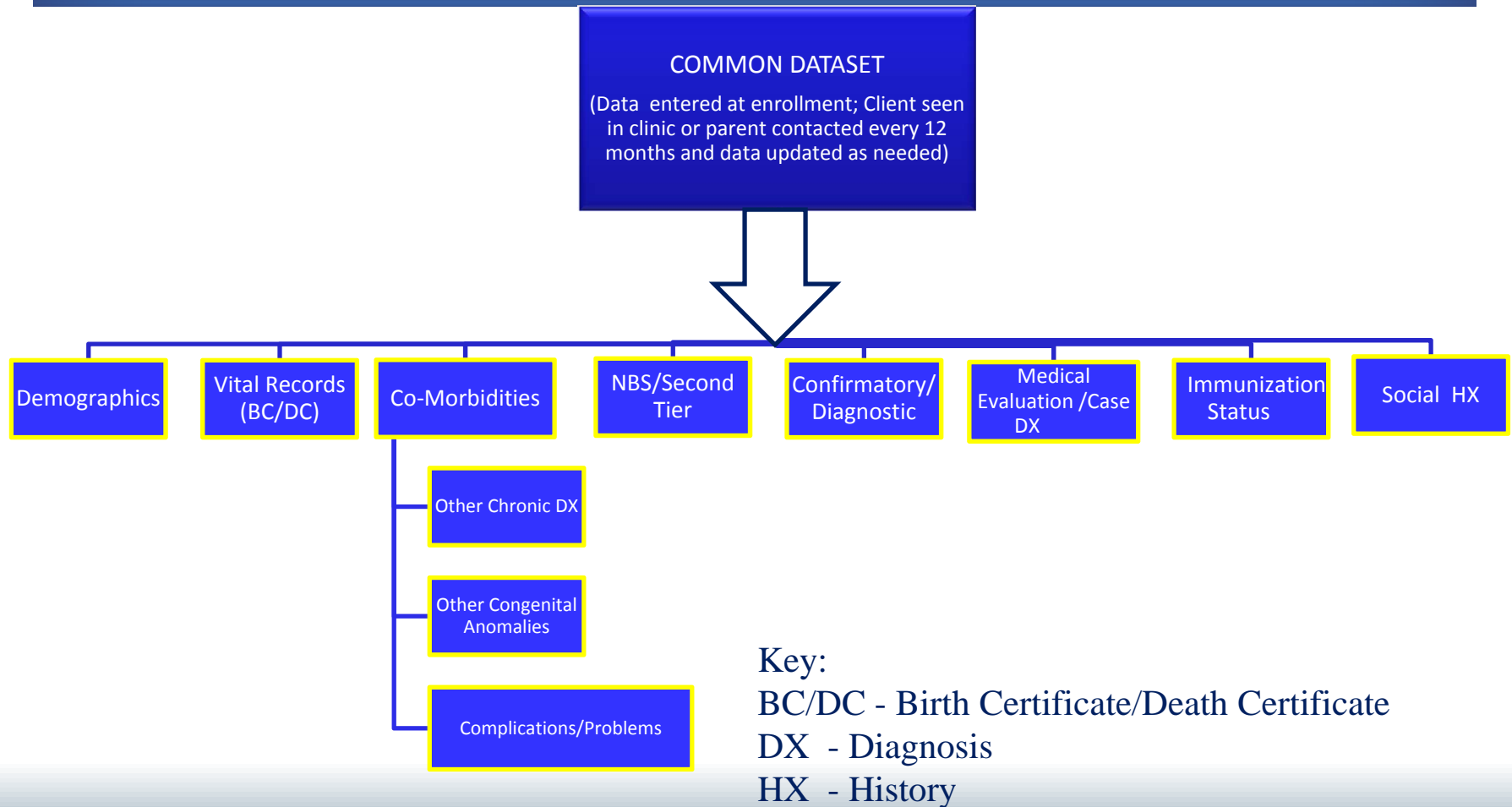




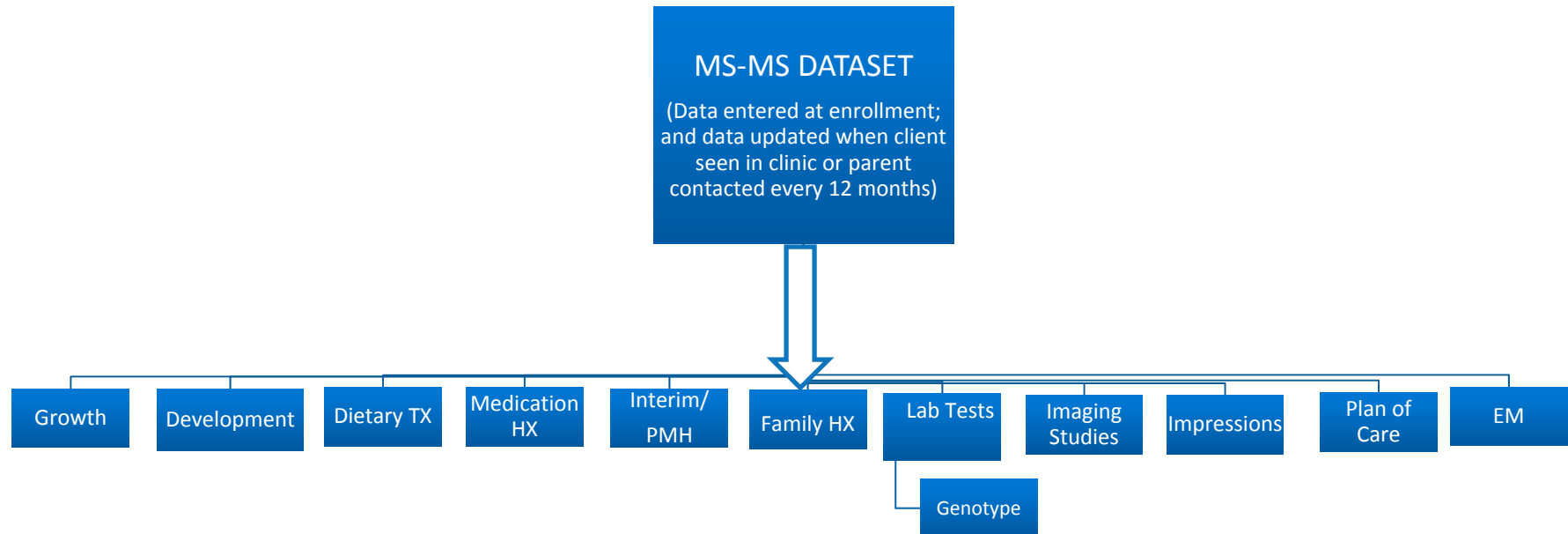
# Arkansas NBS LTFU Database – Organization



# Common Dataset



# MS-MS Dataset



## Key:

MS-MS - 20 Disorders (includes PKU) tested through Tandem Mass Spectrometry

TX – Treatment

HX - History

PMH - Past Medical History

EM - Emergency Management



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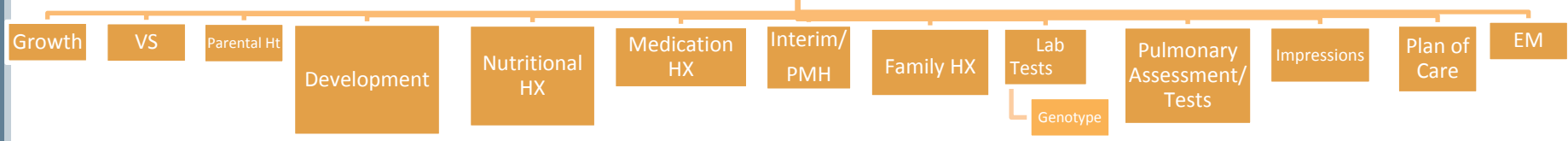
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# CYSTIC FIBROSIS

Cystic Fibrosis (CF)  
(Data entered at enrollment; and data updated when client seen in clinic or parent contacted every 12 months)



**Key:**

BMI/BSA - Basal Metabolic Index/Body surface area

VS - Vital Signs

Ht - Height

HX - History

PMH - Past Medical History

EM - Emergency Management



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# RESULTS

## Calendar Year 2012

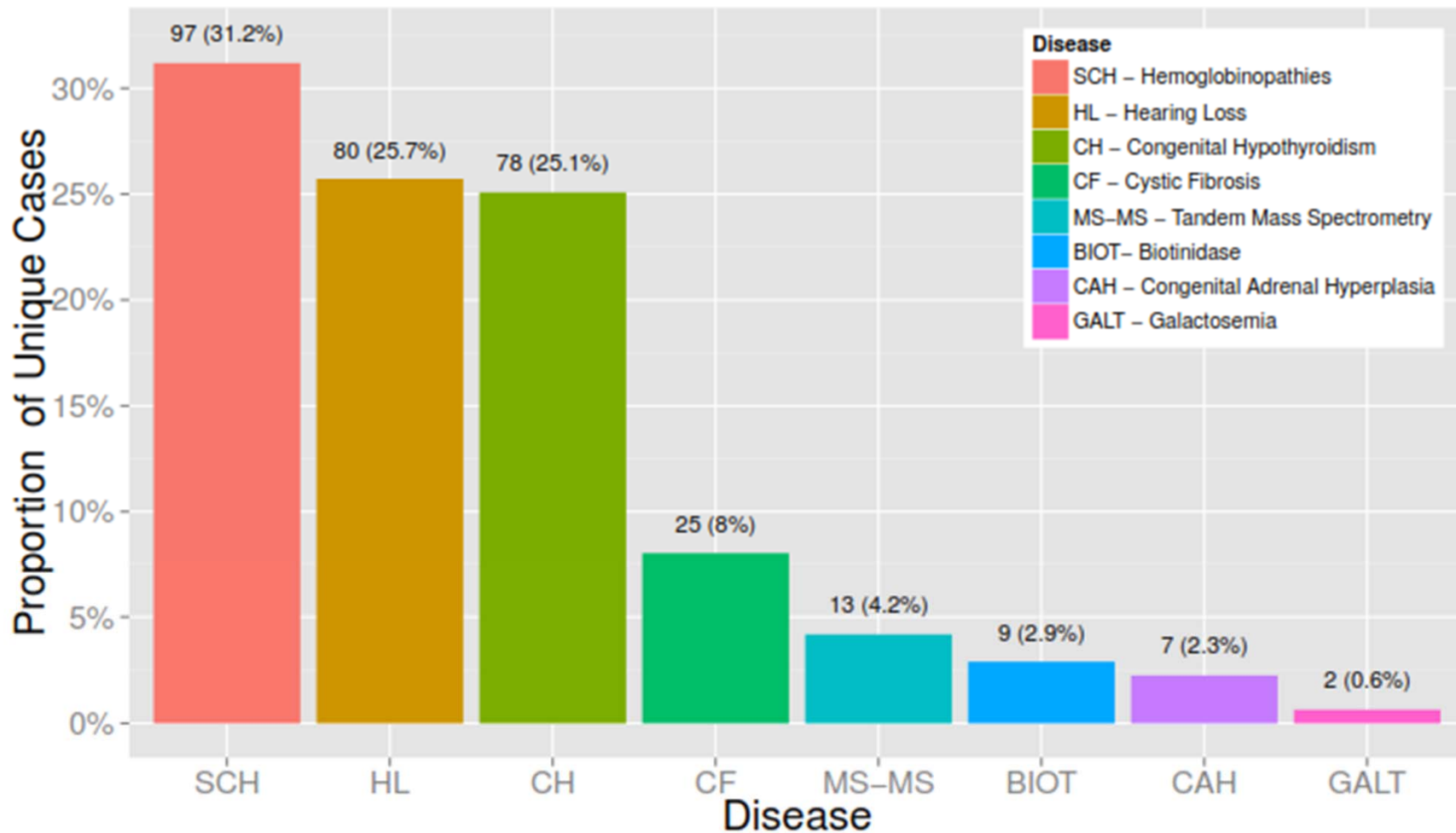
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### Descriptive Statistics for Unique Patients N=307

- Gender
  - Female 49% (151)
  - Male 51% (156)
- Race
  - African American 42% (128)
  - Caucasian 48% (146)
  - Hispanic 7% (23)
  - Other 3% (10)



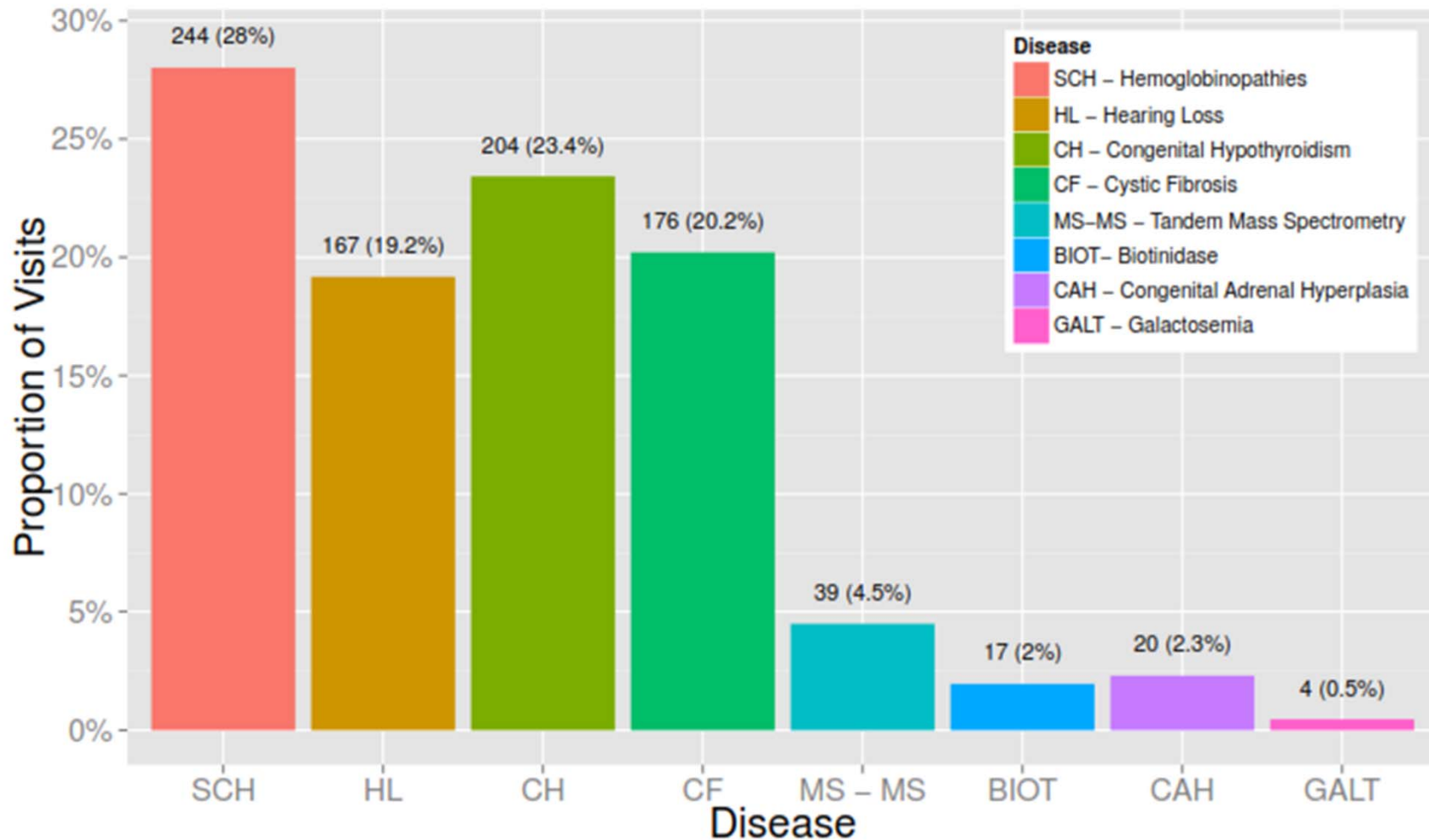
# Descriptive Statistics of NBS Conditions for Unique Cases (N=311\*)



\*Numbers above the bar represent the frequencies (percentages). Four children have 2 diseases; therefore we have 307 children in the database but 311 unique disease cases.



# Total Number of Records by Disease Sets (N=871\*)



\*Numbers above the bar represent the frequencies (percentages). There were a total of 871 clinic visits during Calendar Year 2012 consisting of 307 patients and 311 disease cases.



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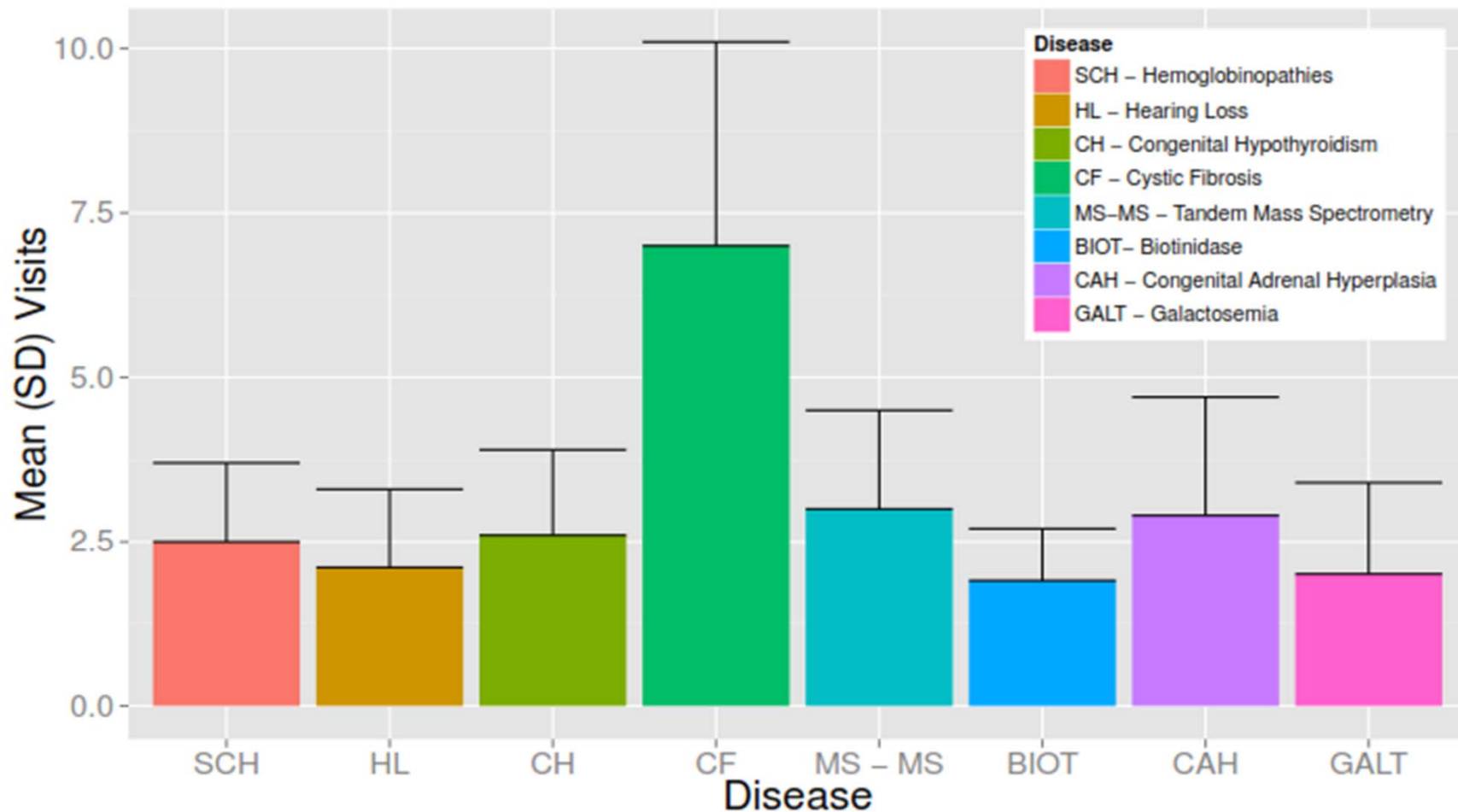


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# Average Number of Clinic Visits by Disease Set\*



\*Error bars represent one standard deviation.



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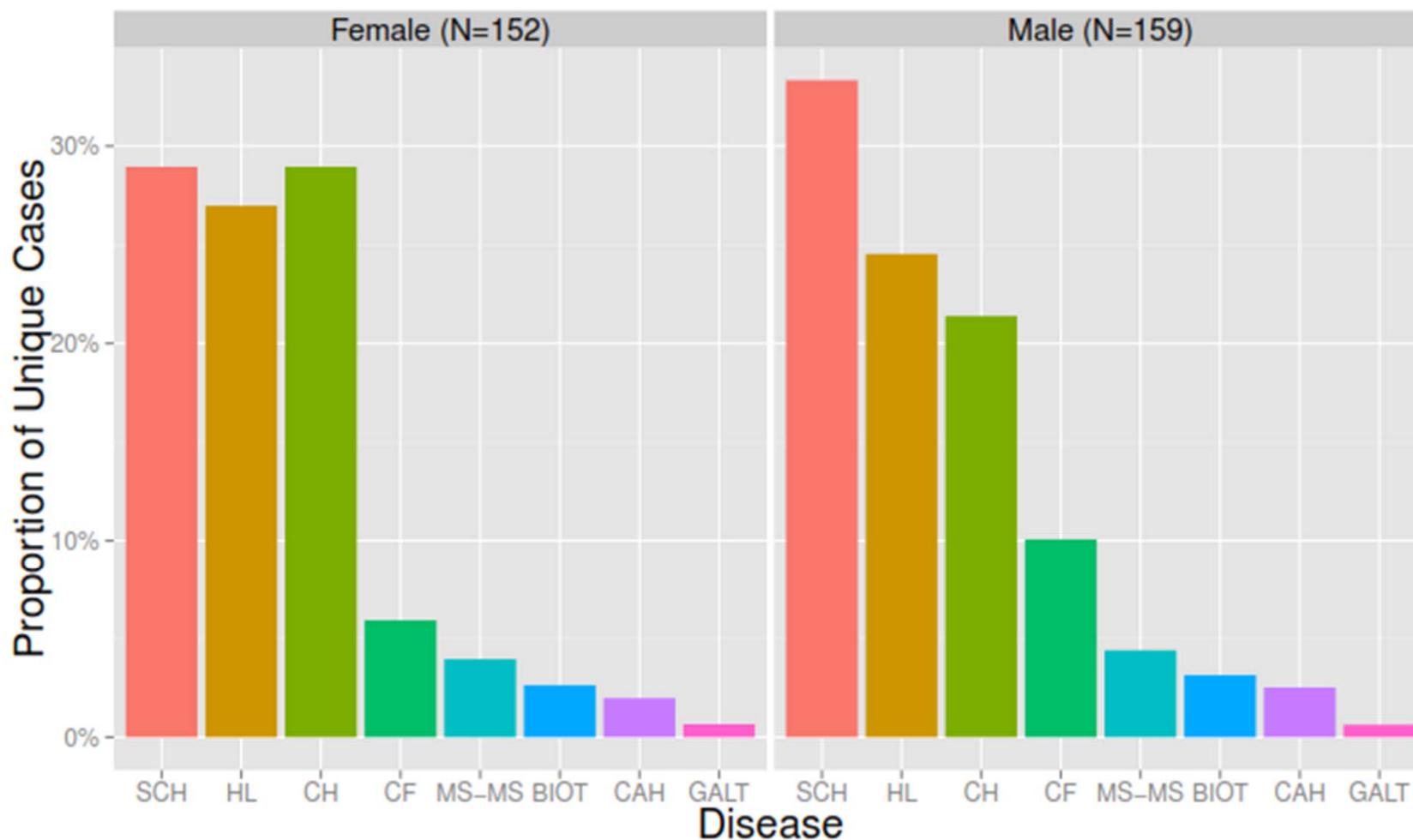
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# Gender Distribution by Disease (N=311)



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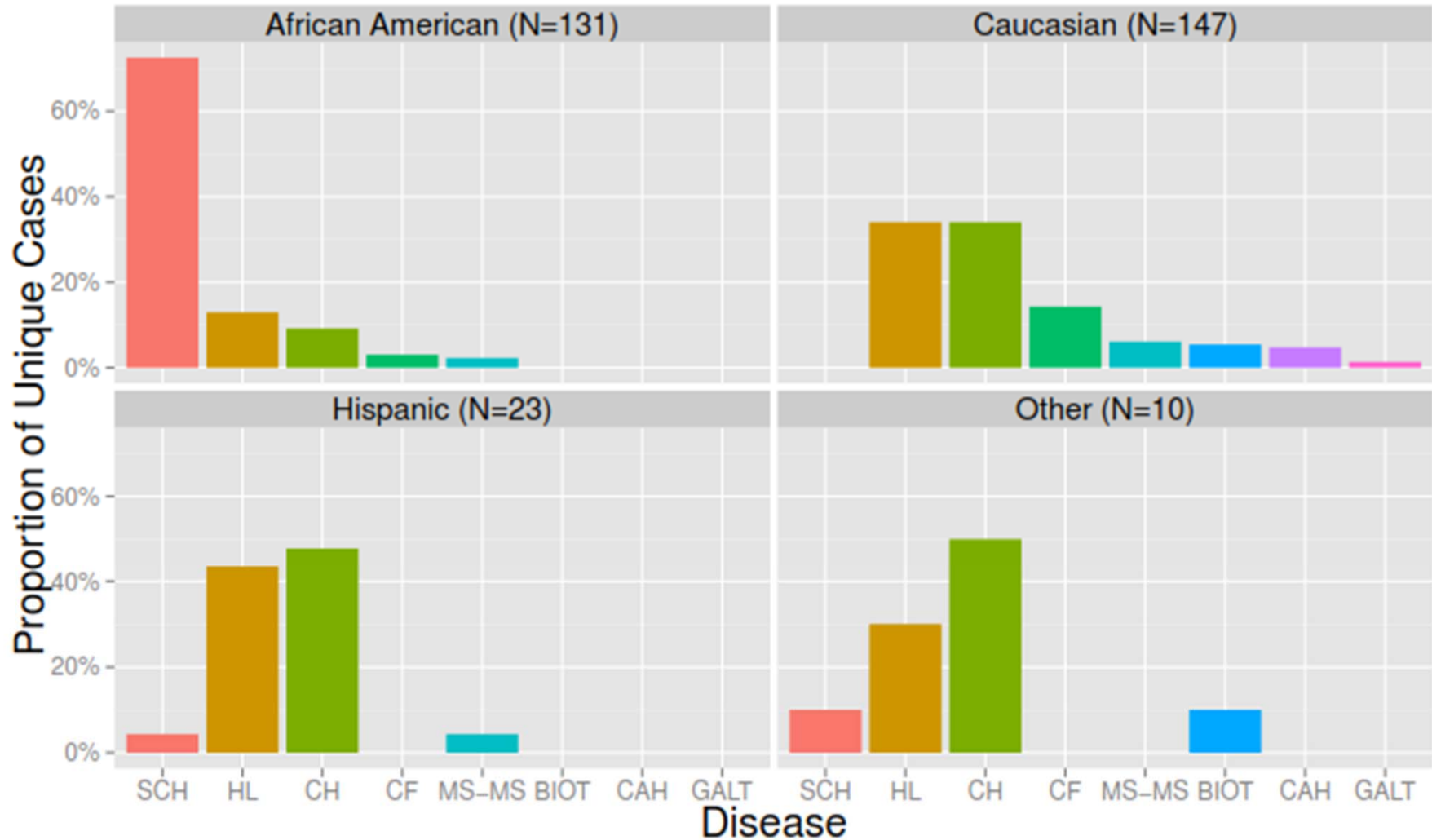


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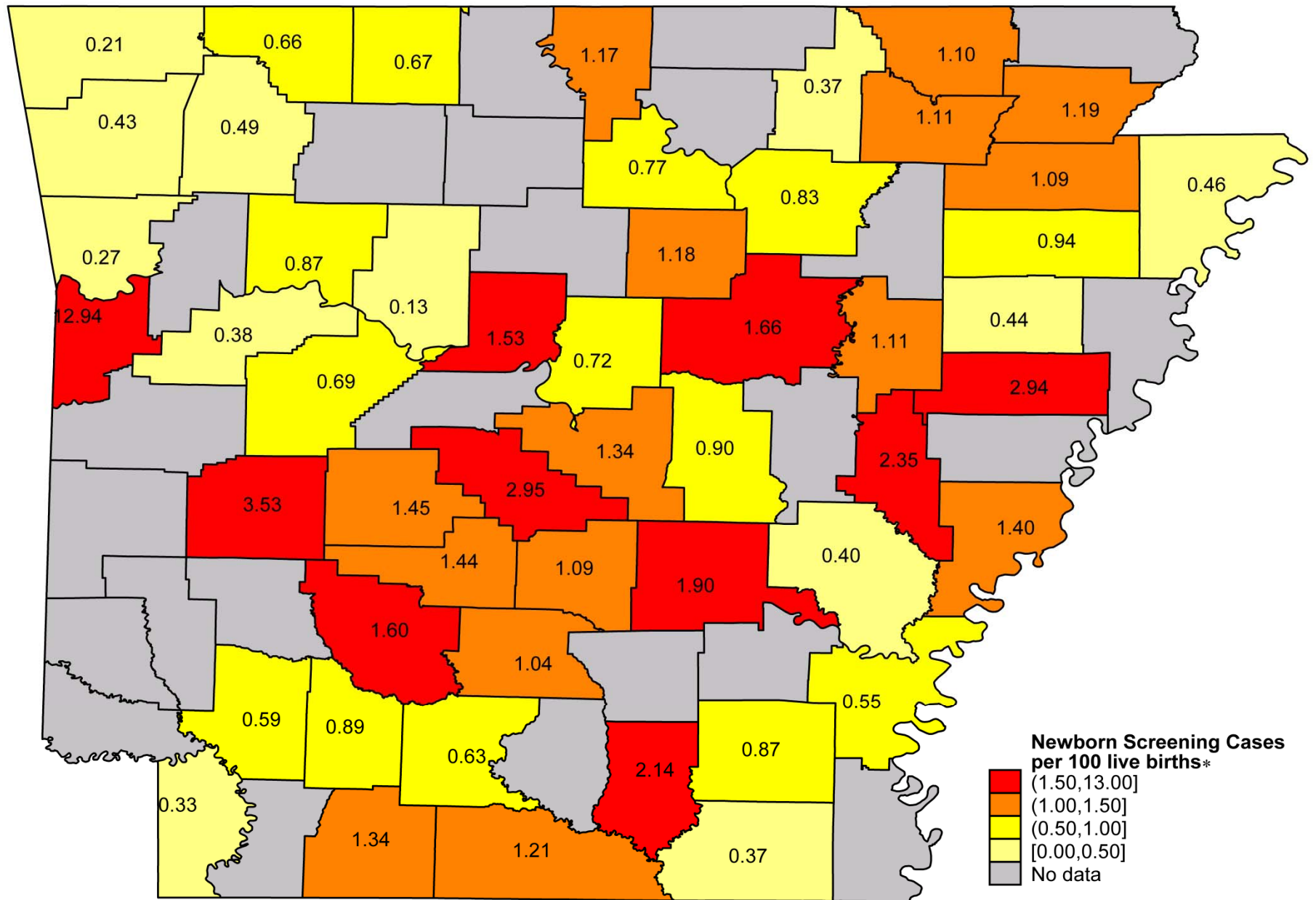
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# Race Distribution by Disease (N=311)



# Newborn Screening Cases by County



\*Bracket indicates range includes value; Parenthesis indicates range does not include value.

# CONCLUSION/IMPLICATIONS /NEXT STEPS

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- The Study will provide opportunity to monitor and track health outcomes over time; this could lead to improvements in health care
- Study staff reviewing and refining data entry forms over the next 12 months and plan to do annually.
- Data analysis will be conducted yearly



# Acknowledgement/Thank You Study Team

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- G. Bradley Schaefer, MD
- Tiffany Moore, BSN, RN
- Todd Nick, PhD
- Christopher Swearingen, PhD
- Maria Melguizo, MS
- Jerry Stalnaker, BA
- Chunqiao Luo, MS



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THANK YOU!

QUESTIONS



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