



# Prevalence of Fetal Alcohol Spectrum Disorders in an American Indian Reservation-based Sample

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# Disclosure

- ▶ Presenter has nothing to disclose

# Learning Objectives



- ▶ Estimate the prevalence of FASD among Southern California American Indians
- ▶ Compare and contrast with national estimates
- ▶ Recognize the possibility of cultural bias in prevalence estimates of FASD



# Why we wanted to do this study

- ▶ FASD status awareness required for ongoing project
  - ▶ Healthy Women
  - ▶ Healthy Native Nation (previous talk)
- ▶ The NIH-NIAAA Collaboration on FASD Prevalence (CoFASP) study



Source: Museum of Man, Kumeyaay, made by basketmaker Carmalita LaChappa

# Initial Steps

- ▶ Approved by UCSD and Southern California Tribal Health Clinic IRBs
- ▶ Local Native community members hired and trained
  - ▶ Recruitment including consent and assent
  - ▶ All scheduling and participant transportation
  - ▶ Surveys and interviews
  - ▶ Neurobehavioral exams
- ▶ Experts from San Diego County CoFASP sample study enlisted



# Methods



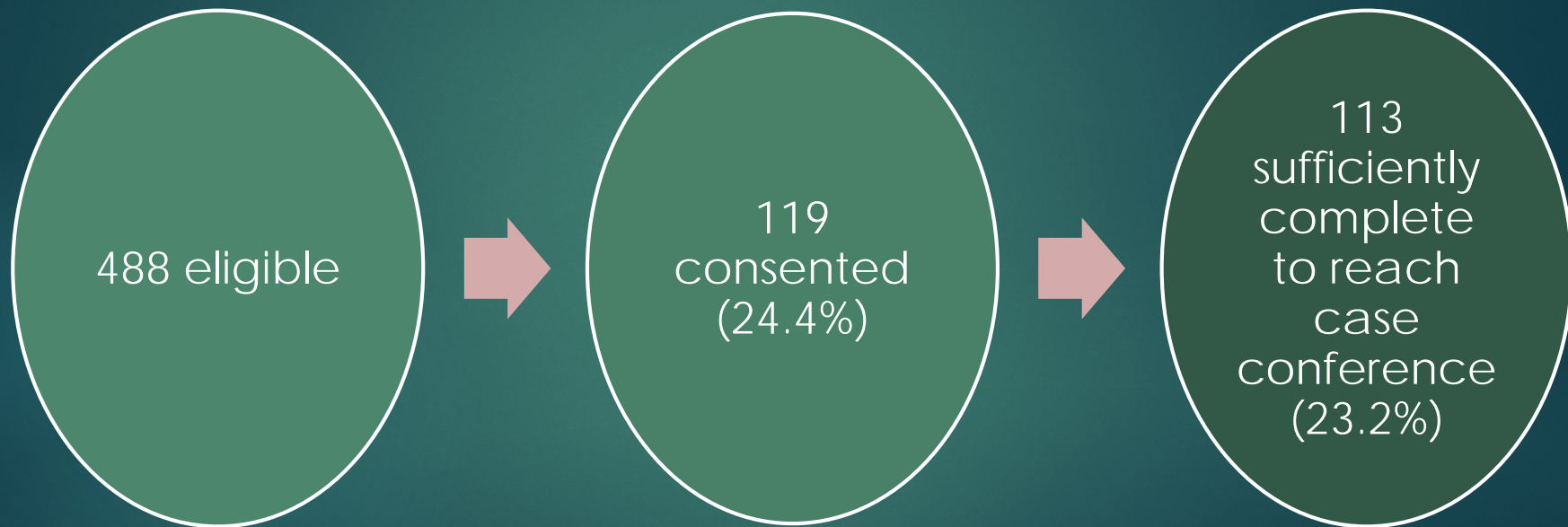
- ▶ Eligibility criteria
  - ▶ 5-7 year old community members and parent/guardian
  - ▶ Consent and assents obtained
- ▶ Recruitment
  - ▶ Letters to families with eligible children, flyers, newsletter blurb, and presentations at community events
- ▶ Logistics
  - ▶ Research sites
  - ▶ Transportation
    - ▶ Non-Native team members (ex. dysmorphologists) brought to reservation sites
    - ▶ Participants

# Methods



- ▶ Evaluations
  - ▶ Physical exam by developmental pediatrician
  - ▶ Neurobehavioral exam: DASII, NEPSY, VMI, Bracken
  - ▶ Child related Interviews: VABS, CBCL
  - ▶ Pregnancy and mother related interview including prenatal alcohol exposure
- ▶ Criteria for maternal alcohol consumption
  - ▶  $\geq 3$  drinks on  $\geq 2$  occasions during pregnancy
  - ▶  $\geq 6$  drinks per week on  $\geq 2$  weeks during pregnancy
- ▶ Diagnostic classification based on Institute of Medicine and Hoyme criteria

# Ready, Set, Go!





# Sample

	% or mean $\pm$ SD
Child Sex, Female	53.8
Child Age (months)	77.0 $\pm$ 10.8
Caregiver Age (years)	35.8 $\pm$ 10.1
Bio-Mom Interviews	82.6
Mothers consumed any alcohol in pregnancy	33.6
Mothers met CoFASP criteria for alcohol in pregnancy	25.2

# Results

	N	Crude Prevalence Estimate (% of Eligible Children)
ARND	14	2.90
PFAS	6	1.20
FAS	0	0
Total FASD	20	4.10

Total FASD prevalence was estimated at 4.1%

*Not different from non-Native San Diego or National samples*

# Limitations



- ▶ Less than a quarter of eligible children participated
  - ▶ Self-selected
- ▶ Small numbers: participants in total and cases in each category
- ▶ Single assessments as opposed to repeated
- ▶ Deficits may be caused by something other than prenatal alcohol exposure
- ▶ Not all validated measures had been validated among Native populations much less this Native population
- ▶ Unknown contribution of culture



# Strengths



- ▶ Community support
- ▶ Recruitment by trusted community members
- ▶ Study broadly publicized using culturally congruent methods
- ▶ Transportation and culturally expected food provided
- ▶ Active case-ascertainment
- ▶ Standardized protocol and measures allow comparison with other communities

# Local Relevance



- ▶ Identified need within the community for FASD related services, treatment, and support
- ▶ Identified families affected by FASD to facilitate Health Native Nation (HNN) goals
- ▶ Linked families and children to needed services
- ▶ Raised awareness of FASD, HNN, and currently available support
- ▶ Provided opportunities to decrease stigma
- ▶ Increased capacity of local clinic and community



# Conclusions



- ▶ The estimated minimum prevalence of FASD among a sample of reservation-based American Indians in Southern California was 4.1%
- ▶ The estimate was consistent with estimates from the national CoFASP study
- ▶ No cases of FAS were identified
- ▶ No cases had been previously identified
- ▶ May not be generalizable to all Native communities given the heterogeneity of Native communities



# Grateful for Support!



**Ready, Set, Go!** research was supported by the NIAAA Co-FASP grant #U01AA019879/05S2



Artist: Tiffany Wolfe

Questions?



# FAS

A classification of fetal alcohol syndrome requires all features specified in points A through D

A. A characteristic pattern of minor facial anomalies, including 2 or more of the following:

1. Short palpebral fissures ( $\leq 10$ th percentile)
2. Thin vermilion border of the upper lip (rank 4 or 5 on lip-philtrum guide)
3. Smooth philtrum (rank 4 or 5 on lip-philtrum guide)

B. Growth deficiency

1. Height, weight, or both at or below than the 10th percentile

C. Deficient brain growth

1. Head circumference at or below the 10th percentile

D. Neurobehavioral impairment

1. Point a, b, or both

a. with cognitive impairment

Evidence of global impairment (general conceptual ability  $\geq 1.5$  SD below the mean, or performance IQ or verbal IQ  $\geq 1.5$  SD below the mean) or

Cognitive deficit in at least 1 neurobehavioral domain of 1.5 or more SD below the mean (executive functioning, memory impairment, or visual-spatial impairment or 1.0 or more SD below the mean for specific learning impairment)

b. with behavioral impairment without cognitive impairment

Evidence of behavioral deficit in at least 1 domain 1.5 SD or more below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)

# pFAS

W/ PAE: A and D

W/o PAE: A and D, plus B or C

# ARND

Requires PAE

W/ cognitive impairment: D.a.  
but with cognitive deficits in at  
least 2 domains

W/o cognitive impairment: D.b.  
but with behavioral deficits in at  
least 2 domains





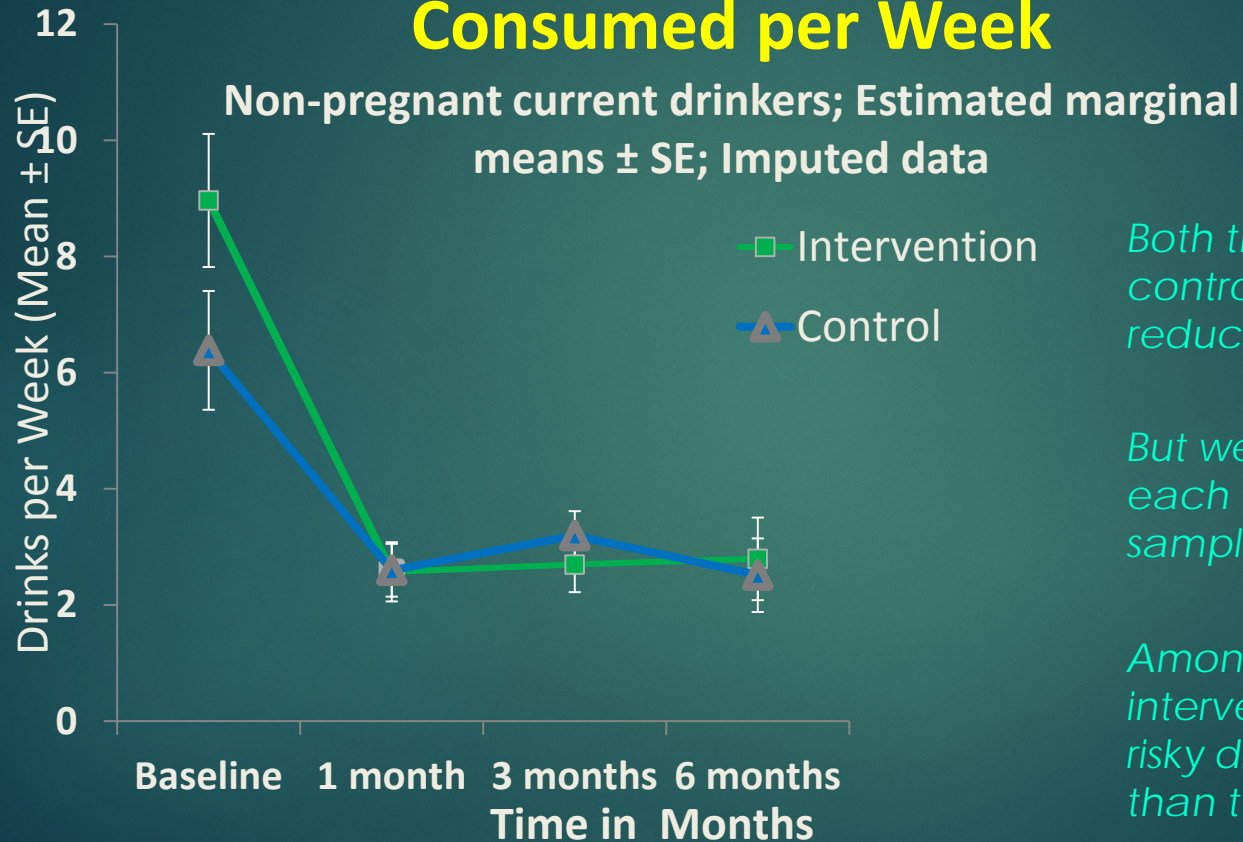
# California

- ▶ Largest number of Native Americans & most distinct tribes today
- ▶ ~1/3 of all Native Americans in U.S. pre-contact
- ▶ ~100 languages and >300 dialects pre-contact
- ▶ San Diego County has more tribes than any other county in the U.S.





# Average Number Drinks Consumed per Week



*Both the intervention and control groups significantly reduced risky drinking*

*But were not different from each other in the total sample*

*Among depressed, the intervention group decreased risky drinking to a greater extent than the control group*