

Update on the Study of the Prevalence of FAS in Italy

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Epidemiology of FAS in Italy

- Pilot project funded by NIAAA 2003 -2005 via CIFASD and subcontract from San Diego State University: \$75,600.
- **Major funding for all Italian operations provided by the Italian Government.**
- Supported by officials of the City of Rome and the Lazio province.

FASER in Italy

- April, 2001, NIAAA, at the initiation of Italian colleagues, asked us to consider epidemiology studies in Italy.
- November, 2002, six Italian clinicians were trained in South Africa by FASER.
- June, 2003, NIAAA officials and FASER personnel visit Rome to plan and negotiate the study.

Italy (cont.)

- April, 2004, two weeks of dysmorphology clinics were held in 33 schools in the Lazio region, 1 to 2 hours from Rome.
- Funded by the Italian government and NIAAA.
- Because the drinking and eating pattern is different in Europe, we are learning more about relative risk.
- This is the 1st study of its kind in any European country.

Collaborators

- Mauro Ceccanti, M.D., Co-PI.
- Daniela Fiorentino, M.A., Program Mgr.
- Giovanna Coriale, M.A., Psychologist.
- Support by CIFASD Dysmorphology Core.
- Three maternal interviewers.
- Medical students (2).
- Medical colleagues (4).

Insights into Italian Perceptions about Drinking

- Bonati and Fellin (1991) were careful to distinguish between ***drinking with meals*** and ***drinking between meals***.
- Between meal drinkers are the Italian definition of “alcohol abusers” (<1% of those in the study).
- Birth weight was affected only by abuse.
- ***Drinking during meals and the diet are believed to be protective.***

Further Insights: Prenatal Drinking

- Primatesta et al., (1993) in Milan found binge drinking (no definition cited) during pregnancy in 1.4% of their sample.
- Yet, **2%** had 23 or more drinks (277g) per wk., and, **7%** had 11.5 to 23 drinks per wk.
- Therefore, very substantial risk for FASD (by US standards) for at least **9%**.
- ***During pregnancy, 29% of women continued to drink daily.***

Italian Study Population: Wave I

- 68 schools in two school districts in this part of the Lazio Region, province of Rome.
- District covers 15 towns one to two hours southeast of the City of Rome.
- 25 schools (jurisdictions) picked randomly.
- 1086 children in 1st grade classes.
- 543 (50%) were provided consent to participate.

I. Dysmorphology Sampling Data

- 233 children examined in dysmorphology screening.
- 62 of 233 (**26.6%**) were provided a preliminary diagnosis of deferred for further testing.
- 19 of 72 randomly-selected controls (**26.4%**) were found to have some signs of growth deficiency or other concerns, so they were not kept in the control group at this stage, but they could be returned to control status if all other findings are normal.

Final Dysmorphology Sample

253 total picked for full screen.

(227 seen by clinical team in two weeks while training and traveling to 33 schools, and 6 followed up by Luigi Tranni, M.D.)

233 effectively seen.

Of the 20 not accounted for: 17 of the random controls already selected for growth; 2 were absent multiple times; and 1 was a no consent.



II. Psychological Testing

- Total for psychological testing = 147
- Reason for testing:
 - dx = preliminary deferral for some symptoms.
 - 52 were randomly-selected controls from the same schools and same grade.

Psychological Testing

- 140 evaluated; 7 parents would not consent to testing.
- Tests administered:
 - ***Ravens Colored Matrices.***
 - Italian TROG judged not suitable because of small Italian samples which are not validated and published.
 - ***Rustioni's Evaluation of Language Comprehension*** (Italian norms standardized on 2,622 children)

III. Maternal Interviews

- 517 administered by three very persistent and successful interviewers.
- Form is an Italian language and culture-based questionnaire with: demographics; reproductive, social, and dietary history; and timeline follow-back with Q,F,T measures of drinking.
- Similar methods and protocols proven effective in South Africa and the Plains.

Maternal Interviews: Quality

- Interviews completed with mothers of:
 - Preliminary FAS children -- **(93.3%)**.
 - Deferred Children -- **(91.1%)**.
 - Controls – **(95.9%)**.

IV. Parental Feedback

- Individual meetings scheduled with all parents of children tested at the school.
- Not all came.
- All were provided with a report of growth, teacher's report on behavior and performance, and the psychological evaluation.
- No mention of alcohol-related issues mentioned, as diagnoses not finalized yet.

V. Final Case Conferences

- Final diagnoses will be made for children in formal case conferences to be held in Albuquerque, NM: January 24 – 28, 2005.
- Case conferences include data and professional representation of:
 - Dysmorphology.
 - Psychological evaluation.
 - Maternal interviews.

Future Directions – Second Wave of Data Collection

- Screening in another 25 randomly-selected schools started in December, 2004: permission sought & preliminary growth assessment.
- Dysmorphology exams: March 1 – 16, 2005.
- Working on a higher consent rate and a larger sample.

Positively No Data Released Until...

- Agreement has been made with all parties that no data will be released until after the composite data from both waves are finalized and a strategy is developed.
- Approximate date is April, 2006.
- This is a very sensitive issue regardless of final results.

Future Research: Beyond the Pilot

- There should be some gold standard cases of FAS and Partial FAS identified by this project.
- Also some ARBD and ARND cases will be identified.
- 75 to 100 random, age-stratified controls will have been identified.

Future Research: Beyond the Pilot

- We are going to propose to the consortium that a third year of funding be granted.
- The third year would be for intensive testing of children with FASD and matched controls with the CIFASD neuropsychological battery.
- Cases and data would then be added to the consortium data bank.