

WHO International Collaborative Research Project on the Global Prevalence of Fetal Alcohol Spectrum Disorders (FASD)

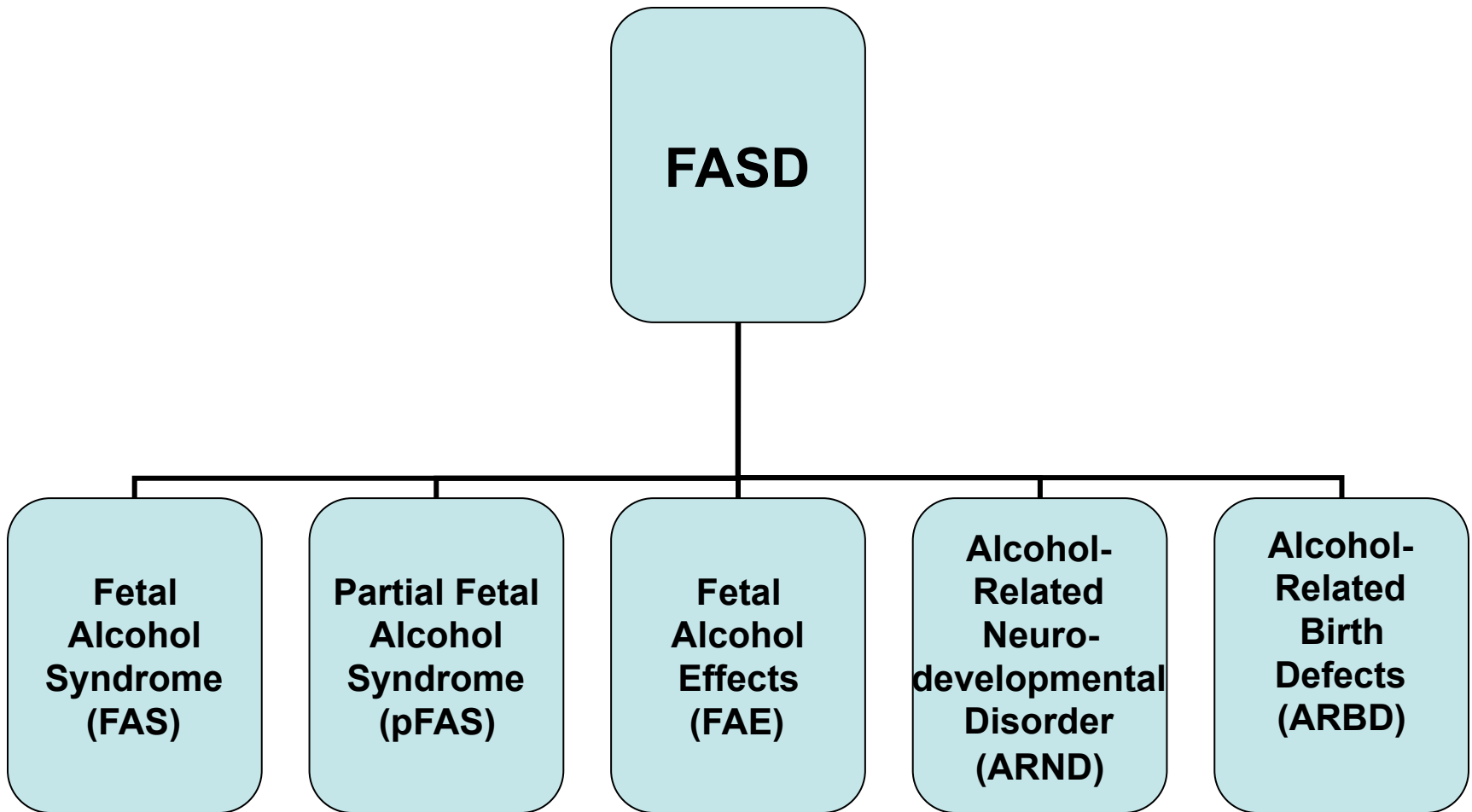
**Presented by
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**Training on FASD
Santiago, Chile
April 26-28, 2017**

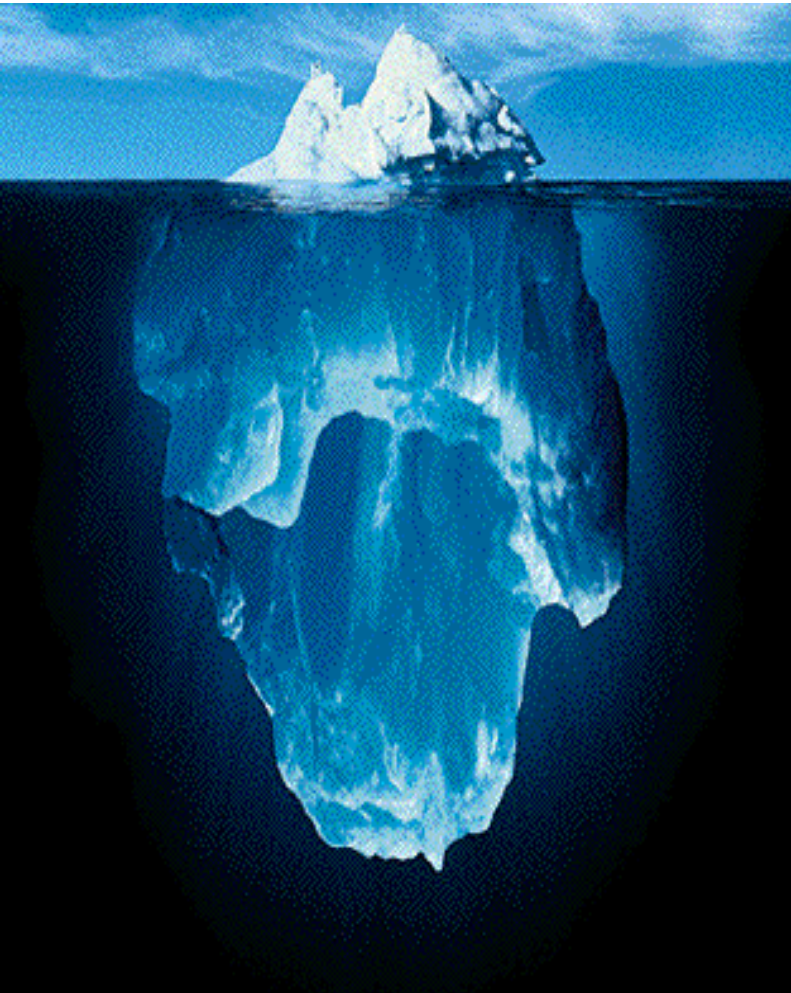


**Centre
for Addiction and
Mental Health
Centre de
toxicomanie et
de santé mentale**

Fetal Alcohol Spectrum Disorder (FASD)
is an umbrella term that covers several alcohol-
related diagnoses



What are Fetal Alcohol Spectrum Disorder (FASD)?



- Fetal alcohol syndrome (most severe)
- Partial FAS (some defects)
- Alcohol-related neurodevelopmental disorder
- Alcohol-related birth defects
- In the normal range, but never reach their potential (largest number of cases)

Why is a Prevalence Study Needed?

- **Data on incidence/prevalence of FASD are completely absent for the majority of the countries**
- **Existing data from only 25 countries are often imprecise and confusing (outdated and the studies have many methodological limitations)**
- **FASD is expensive! Lifetime cost > \$ 1M for selected cases, in terms of health care, special education, social services, and productivity losses (Than & Jonsson, 2009; Harwood & Napolitano, 1985; Weeks, 1989)**
- **To understand the severity and impact of FASD**
- **To plan policies and programs that will benefit people with FASD, and prevent additional children from being born with this conditions**
- **Urgent need to monitor and lower the rate of these conditions effectively in the world**

World Health Organization Global Prevalence Study on FASD

WHO Research Initiative on Alcohol, Health and Development with support of National Institute on Alcohol Abuse and Alcoholism (NIAAA)

- **Objective: To estimate the prevalence of FASD among children (7-9 years of age) using an active case ascertainment approach**
- **Participants: 7 selected countries in Europe (Belarus, Moldova, Ukraine, Poland); Africa (Namibia and Seychelles) as well as Canada**
- **CAMH, a Collaborating Centre of the WHO, will provide research support to all involved countries**

Global Prevalence Study on FASD



WHO Training in Namibia, Africa
April 2013

Participated countries: Ghana, Ethiopia, Kenya, Namibia, Rwanda, Seychelles, and Tanzania



WHO Training in Minsk, Belarus
November 2010

Countries that participated: Belarus, Kazakhstan, Moldova, Poland, Russia, Ukraine



WHO Training in Krakow, Poland October 2015
Participated countries: Belarus, Moldova, Ukraine, Namibia, Seychelles

Methodology: Data Collection

Sampling (3 sampling frames)

Children (7-9 years of age) ~2,500

Sampling frame 1: Regular schools, orphanages, and health care settings with existing regular health checkups

Sampling frame 2: Special educational institutions

- **Special schools for children with special needs**
- **Special educational programs for children with special needs in regular schools or elsewhere**

Sampling frame 3: Mental health institutions and social services

- **a) Disabled children in residential treatment and care;**
- **b) Disabled non-institutionalized children; and**
- **c) Non-disabled children who are in contact with these institutions.**

Data Collection

Phase I: Pre-screening

The pre-screening phase addresses two aspects of child development relevant to the diagnosis of FASD:

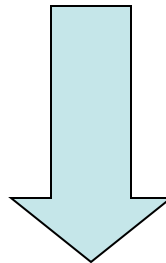
- a) growth deficit (weight, height, head circumference) and**
- b) behavioural and/or learning difficulties**

Data Collection (cont')

Phase I: Pre-screening

Children with a growth deficit or other suspected neurodevelopmental abnormalities:

- At or are below the 10th percentile on height/weight/OFC, and/or
- have other behavioural or learning abnormalities



Phase II

Data Collection (cont')

Phase II: Active case ascertainment

- **a) Dysmorphology assessment,**
- **b) Neuropsychological and behavioural assessment,**
- **c) Collection of data on prenatal risk exposure with a focus on alcohol consumption during pregnancy.**

CONTROL

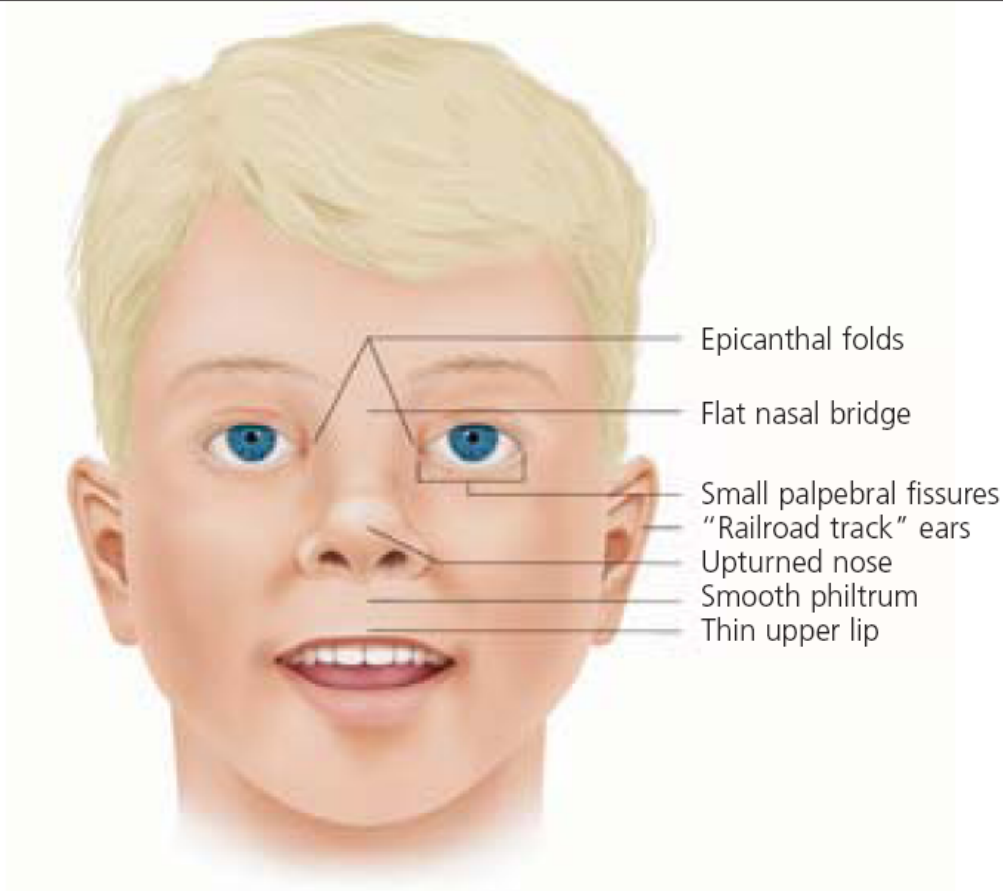
- **~200 children will be randomly selected and undergo an assessment in Phase II (i.e. dysmorphology, neuropsychological and behavioural assessment, as well as maternal interview) in order to obtain normative data on the measurements taken during ACA**

Data Collection (cont')

Phase II: Dysmorphology assessment

- **Dysmorphology can be assessed using 2 methods:**
- **i) direct examination of the face and other parts of the body of ALL children , and**
- **ii) photographic measurements of the face (to validate the clinical assessment of the dysmorphologist and to receive additional expert opinion on the specific case;**

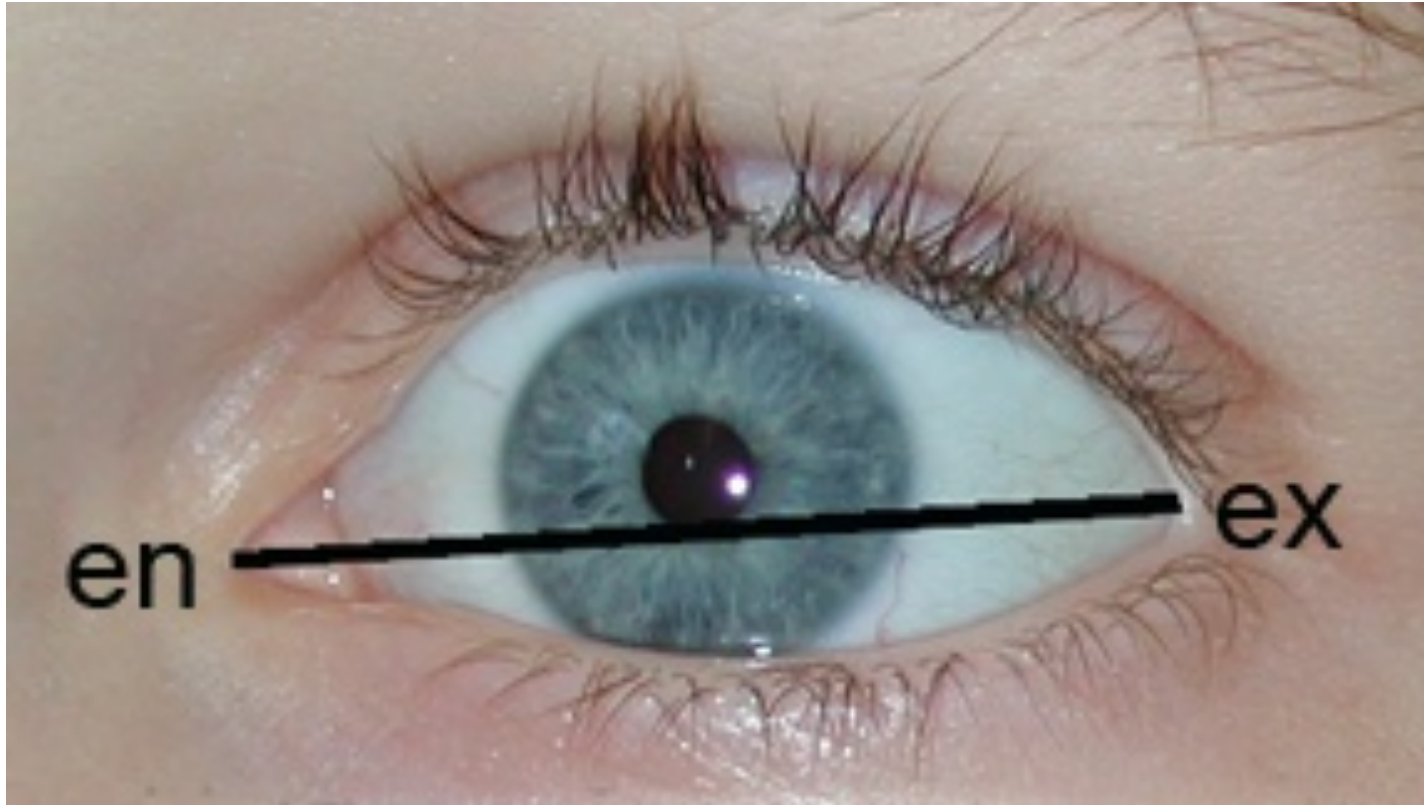
Specific Facial Phenotypic Features



Presence of 1 of the 3 specific phenotypic facial features:

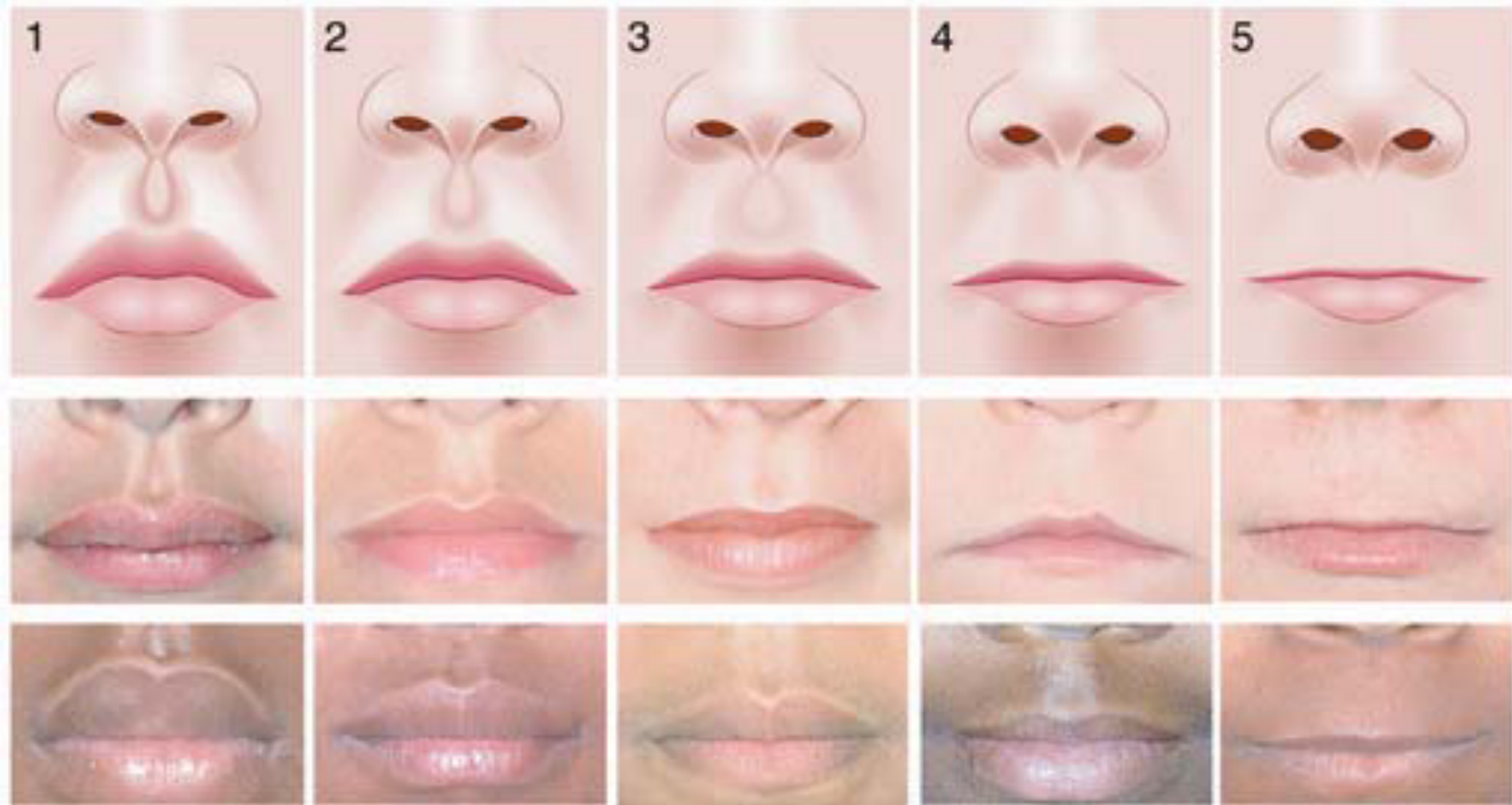
- 1) Short eye openings (palpebral fissures),**
- 2) Smooth or flattened philtrum (groove above the upper lip), and**
- 3) Thin upper lip**

What is the Palpebral Fissure?



The palpebral fissure is defined as the horizontal distance from the **endocanthion** (inside corner) to the **exocanthion** (outside corner)

Lip-Philtrum Guide



The smoothness of the philtrum and the thinness of the upper lip are assessed individually on a scale of 1 to 5 (1 = unaffected, 5 = most severe). Scores of 4 and 5, in addition to short palpebral fissures, correspond to fetal alcohol syndrome.

Row 2: Guide for white patients. Row 3: Guide for black patients.

Source: <http://www.aafp.org/aafp/20050715/279.html>

Other Characteristic Features



Underdeveloped upper part of the ear parallel to the ear crease below (“railroad track” appearance)



The curved 5th finger (clinodactyly) and the upper palmar crease that widens and ends between the 2nd & 3rd fingers (“hockey stick” crease)



Facial features in children with FAS from various ethnic background: A) child of Northern European decent; B) Native American child; C) Black child; D) Biracial (white, black) Source: <http://www.aafp.org/afp/20050715/279.html>

Data Collection (cont')

FAS Facial Photographic Analysis Software

FAS Facial Photographic Analysis Software (version 1.0) (FAS Diagnostic and Prevention Network, FAS, NDP, University of Washington, Seattle, Washington, 2003)

<http://depts.washington.edu/fasdpn/htmls/face-software.htm>

How to Take the Three Photographs (Front View) (Angle View) (Side View)



Standardized Photo Set

Data Collection (cont')

Phase II: Neuropsychological and behavioural measures

- Minimum test battery

I. Tests of general cognition:

The Wechsler Abbreviated Scales of Intelligence (WASI-II)

time: 30 min.

II. Measures of memory, attention, processing speed, and executive function:

- 1. *The Wechsler Intelligence Scale for Children IV (WISC-IV)*

time: 29 min

- 2. *A Developmental NEuroPSYchological Assessment (NEPSY-II)*

time: 28 min

III. Behavioural measures completed by parents or caregivers:

- *Child Behaviour Checklist (CBCL)* and, wherever possible,
- *The Vineland Adaptive Behaviour Scales II (VABS-II)*.

Data Collection (cont')

Phase II: Maternal alcohol history in pregnancy

- **Biological mothers of children with suspected FASD will be interviewed on demographics, living environment, pregnancy-related questions, and questions on prenatal alcohol exposure**
- **Consent forms will be solicited**
- **Alternatively, information on maternal alcohol use during pregnancy may also be obtained from health care providers, medical documentation or other appropriate sources of information.**

Screening Results

- **Independently collected data from the three groups**
 - **a) physical/dysmorphology;**
 - **b) neurodevelopmental;**
 - **c) maternal interviews**
- will be reviewed and discussed for every child during a case conference**
-
- **The diagnostic criteria for FAS, pFAS and ARND will follow the Canadian Diagnostic Guidelines (Chudley et al., 2005).**

After Screening

Parent/guardians will be informed of the results of their child's assessments

A needs assessment will be conducted for each child positively screened for FASD

Referrals will be made to local health services for further diagnostic evaluation, as well as to social services, educational programs and for special treatment and social support.

Communication of the Results of the Screening

To minimize potential social and psychological consequences of a positive screening result for the mother, child and/or parental and familial relationships

- This study will NOT be specifically linked to FASD**
- The aims of the study will be kept broad when they are explained to teachers and parents. Thus, the title of the study “Child Development Study” and its aim, as per the consent forms, is to ‘explore behavioural and developmental disorders linked to antenatal exposures including maternal nutrition, living environment, and alcohol’**
- The semi-structured interview of biological mothers will not be dominated by any one line of questioning. This will reduce the likelihood that attention will be drawn to the fact that they are being questioned about alcohol consumption during pregnancy specifically**

Communication of the Results of the Screening (cont'):

- The research team will NOT be responsible for disclosing FASD diagnosis to the parents/legal guardians, they will only provide the results of the screening as an independent assessment with respect to the child's strengths and weaknesses regarding the physical evaluation and the psychological assessment only
- *The attribution of the deficits and impairments demonstrated by the child to prenatal alcohol exposure or FASD will not be made in any regard*
- The child will be referred to available local health care services where a proper medical diagnosis can be further established. It will be a clinician's responsibility to complete the diagnostic assessment, establish the final diagnosis, communicate results to parents and families and provide appropriate medical interventions

Types of Services/Interventions that will be offered (for referral) for positively screened children and their families

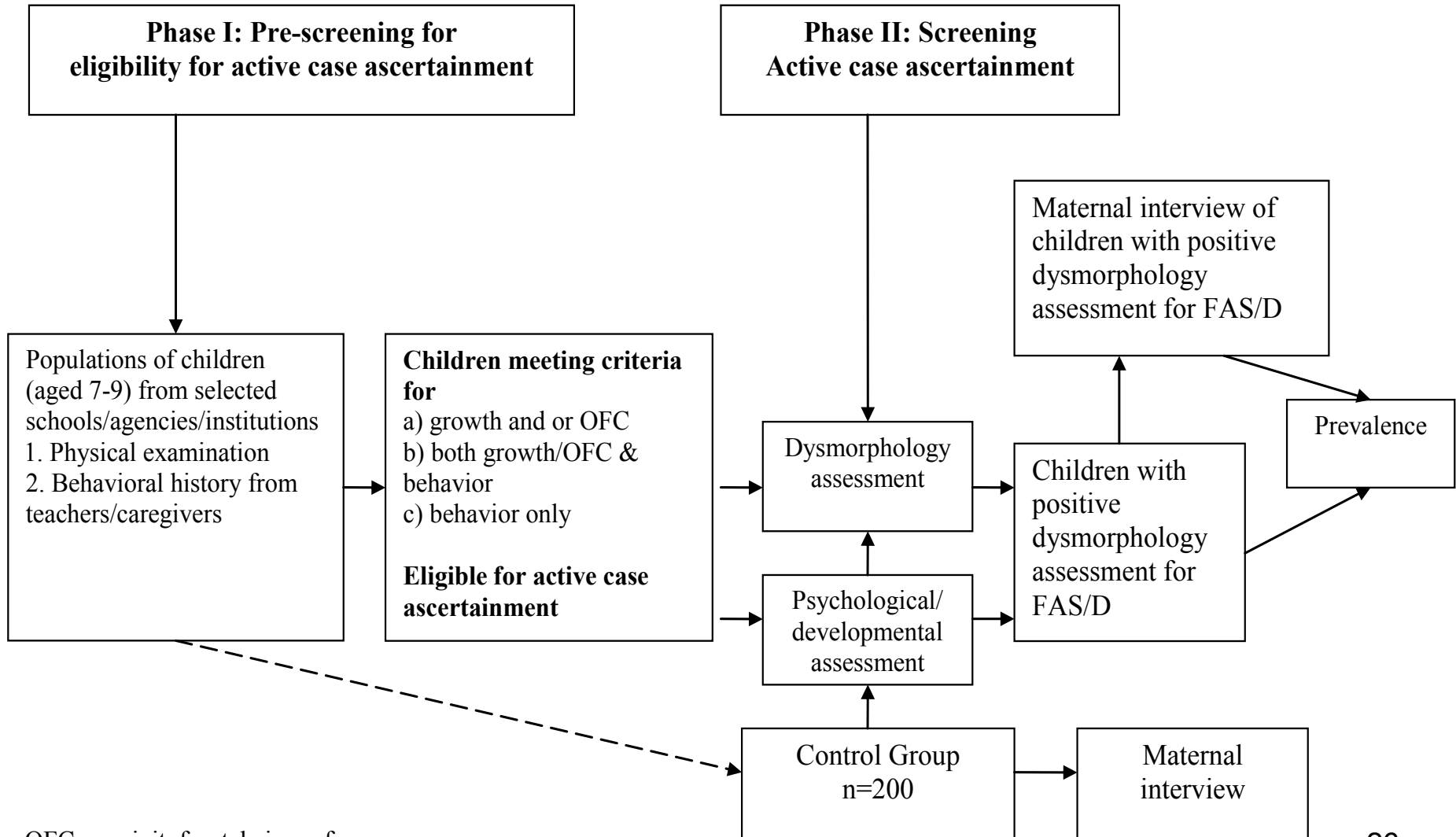
- - **Speech and Language Pathologists**
- - **Occupational Therapists**
- - **Mental Health Care Providers**
- - **Addiction Specialists/Treatment Providers (clinical and psychosocial services for mothers with Alcohol Use Disorders)**
- - **Psychiatrists/Psychologists**
- - **Family Therapists/Counselors**
- - **Physical Therapists**
- - **Educational programs for children with special needs**
- - **Social Workers**
- - **Support groups (e.g., for mothers with FASD-affected children)**

After Screening (cont')

Mothers with alcohol use disorders will be offered a referral to relevant health and social services with full respect for confidentiality and autonomy

Risk of having further alcohol-affected children will be decreased

Active Case Ascertainment



OFC - occipitofrontal circumference

Many people help with developing the methodology of this project

- **WHO (Dr. Vladimir Poznyak)**
- **CIFASD group (Drs. Ed Riley, Christina Chambers, Sarah Mattson and others)**
- **Dr. Phillip May's group (Wendy Kalberg)**
- **NIAAA (Drs. Margaret Murray, Ken Warren)**
- **Dr. Albert Chudley, Canada**
- **Dr. Jürgen Rehm (CAMH – WHO Collaborating Centre)**
- **AND MANY, MANY OTHERS!!!**

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