

Preventing FAS/FASD in Russian Children

Prevent FAS in Russia Research Group
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Phase I: Preventing FAS/ARND in Russian Children, NIH/Fogarty International Center, 2003-2007

Phase II: Development of Education Materials for Prevention of FAS in Russia, Centers for Disease Control and Prevention (CDC)/Association of University Centers on Disabilities (AUCD), 2005-2008

Phase III: Health of Children in Russia: Providing Education on FASD, AUCD/CDC, 2007-2008

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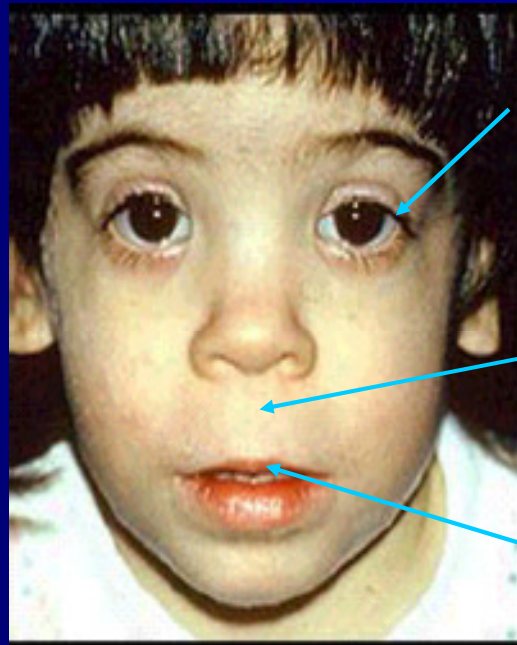
FASD terminology

- **Fetal Alcohol Syndrome (FAS)**
 - One of the diagnoses used to describe birth defects caused by alcohol use while pregnant
 - A medical diagnosis (760.71) in the International Classification of Diseases (ICD)
 - **The most common preventable cause of mental retardation in the world**

- **Fetal Alcohol Spectrum Disorders (FASD)**
 - Not a diagnosis
 - Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy
 - May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications
 - FAS
 - Alcohol-related neurodevelopmental disorders (ARND)
 - Alcohol-related birth defects (ARBD)

Fetal Alcohol Syndrome

- Specific pattern of facial features
- Pre- and/or postnatal growth deficiency
- Evidence of central nervous system dysfunction



Short palpebral fissure

Indistinct philtrum

Thin upper lip⁵

Child with FAS and mouse fetus with fetal alcohol exposure

Child with FAS



Small head

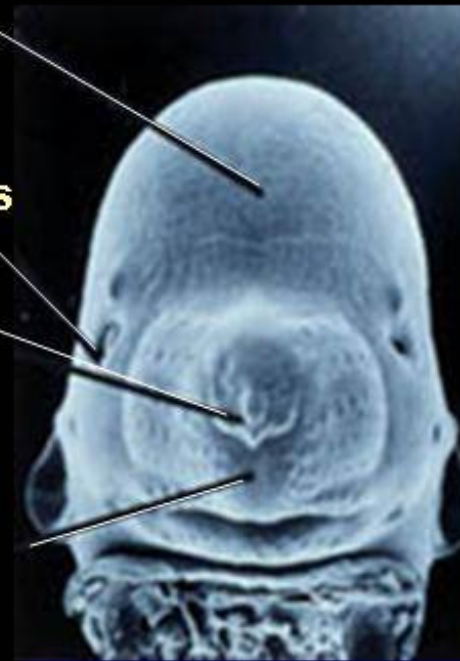
Short palpebral fissures

Small nose

Small midface

Long philtrum;
Thin upper lip

Mouse fetuses

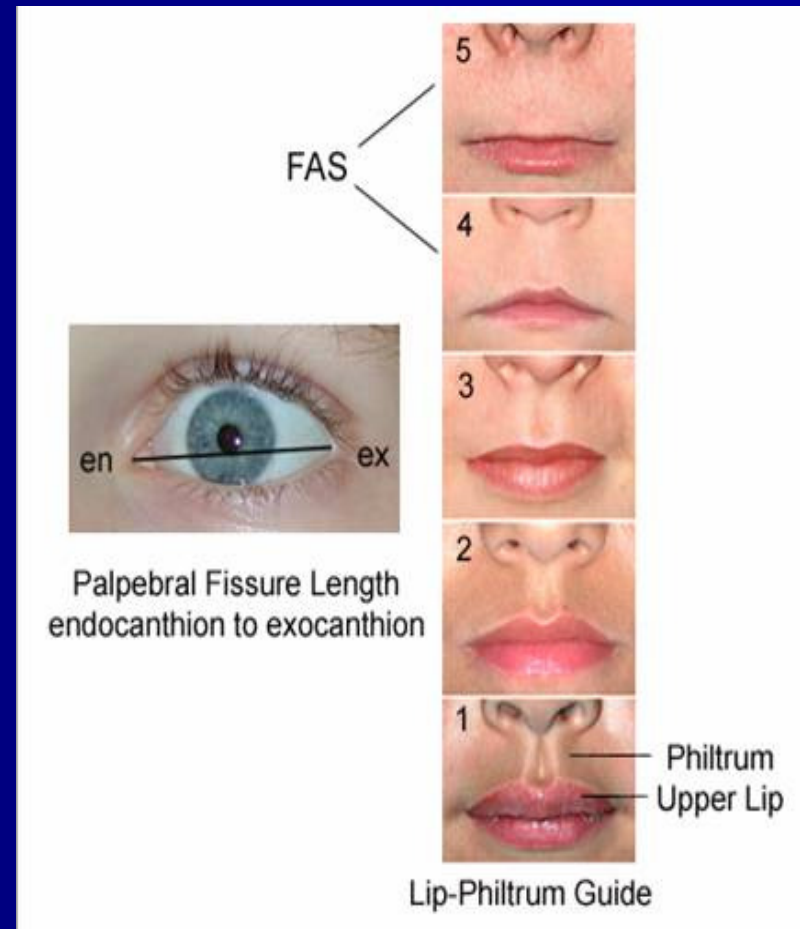


alcohol-exposed

normal

Diagnostic criteria FAS: facial features

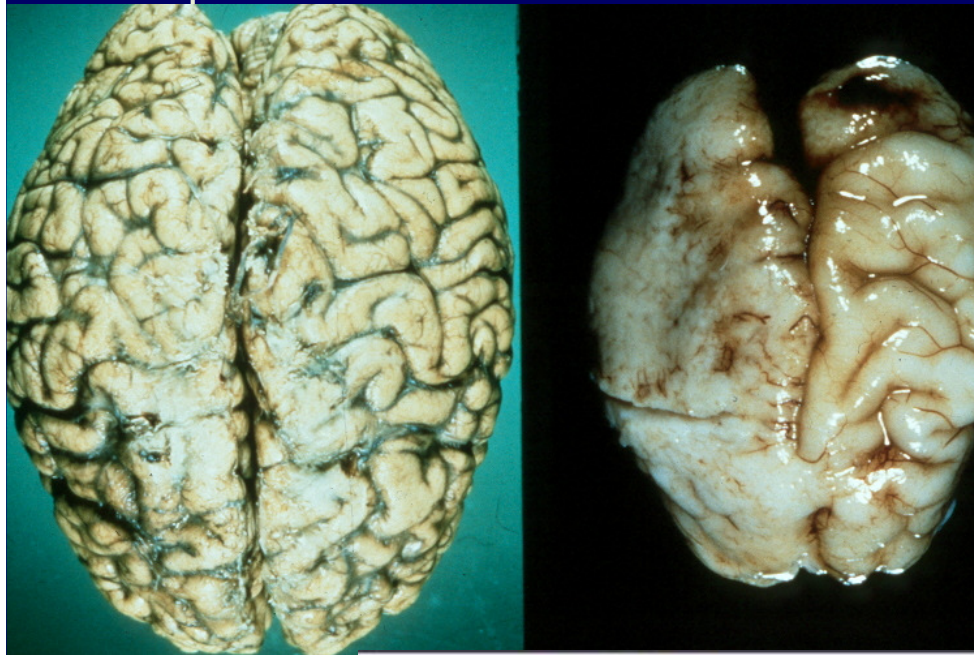
Source: Astley, S.J. 2004. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition*. Seattle: University of Washington Publication Services.



Growth Deficiency

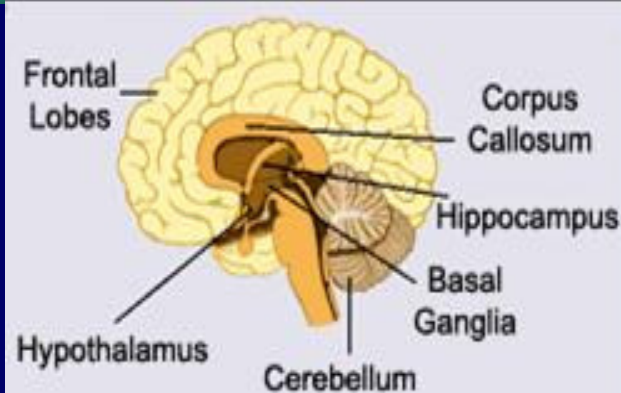


Brain Regions Affected



Normal brain of baby 6 weeks old
and brain of baby same age with FAS

Photo courtesy of Dr. Clarren



The Cerebral Cortex

The Hippocampus and Cerebellum

The Corpus Callosum

Primary CNS dysfunction



Growing up with FAS

Photo courtesy of Dr. Streissguth

- Decreased I.Q.
- Specific deficits in reading, spelling and math
- Fine and gross motor problems
- Executive functioning deficits
- Communication and social interactions problems
- Attention problems and/or hyperactivity
- Memory deficits

FAS Prevalence

- Fetal alcohol syndrome
 - 0.5 to 2/1000 live births in USA (May and Gossage, 2001)
 - Higher rates in some populations
 - 0.3/1,000 non-American Indian/Alaska Native, Alaska (2002)
 - 5.6/1,000 American Indian/Alaska Native
- Compare
 - Down syndrome.....1/800 births
 - Cleft lip+/-palate.....1/800 births
 - Spina bifida.....1/1000 births
- Incidence of FAS in subsequent births
 - 771 per 1,000 live births (Abel, 1988)

FAS Prevalence

- FAS – active case ascertainment at schools
 - 3.1/1,000 in Washington State (Clarren et al., 2001)
 - 3.7 to 7.4/1,000 in Italy (May et al., 2006)

Highest documented rate in South Africa

- 40.5 to 46.4 per 1000 children aged 5 to 9 (first grade population)/39.2 to 42.9 age-specific community rates for ages 6–7 (May et al., 2000)
- 65.2-74.2 per 1,000 children –second study in the same community (Viljoen et al., 2005)

FASD Prevalence



Combined FAS, ARND, ARBD
estimated

- 10/1,000 the birth population in USA (May & Gossage, 2001)
- 23 to 41/1,000 in Italy (May et al., 2006)

FASD Facts

- Alcohol is a teratogen

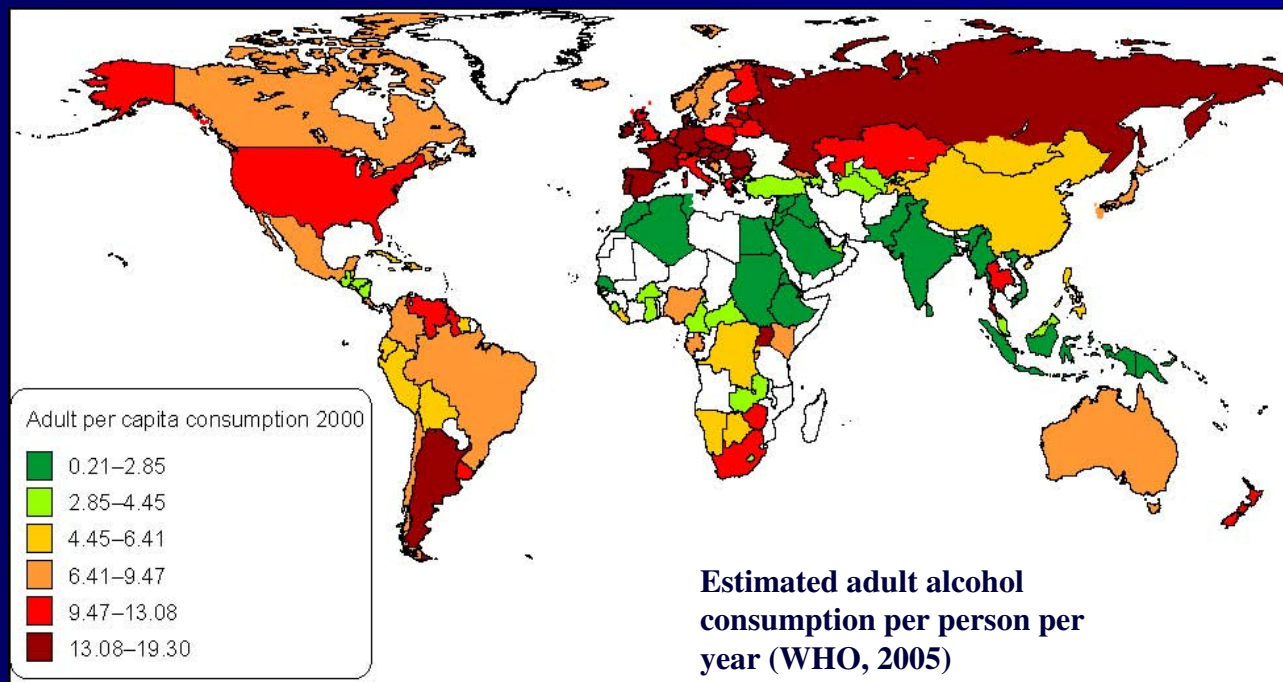
“Of all the substances of abuse including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—*Institute of Medicine Report to Congress, 1996*

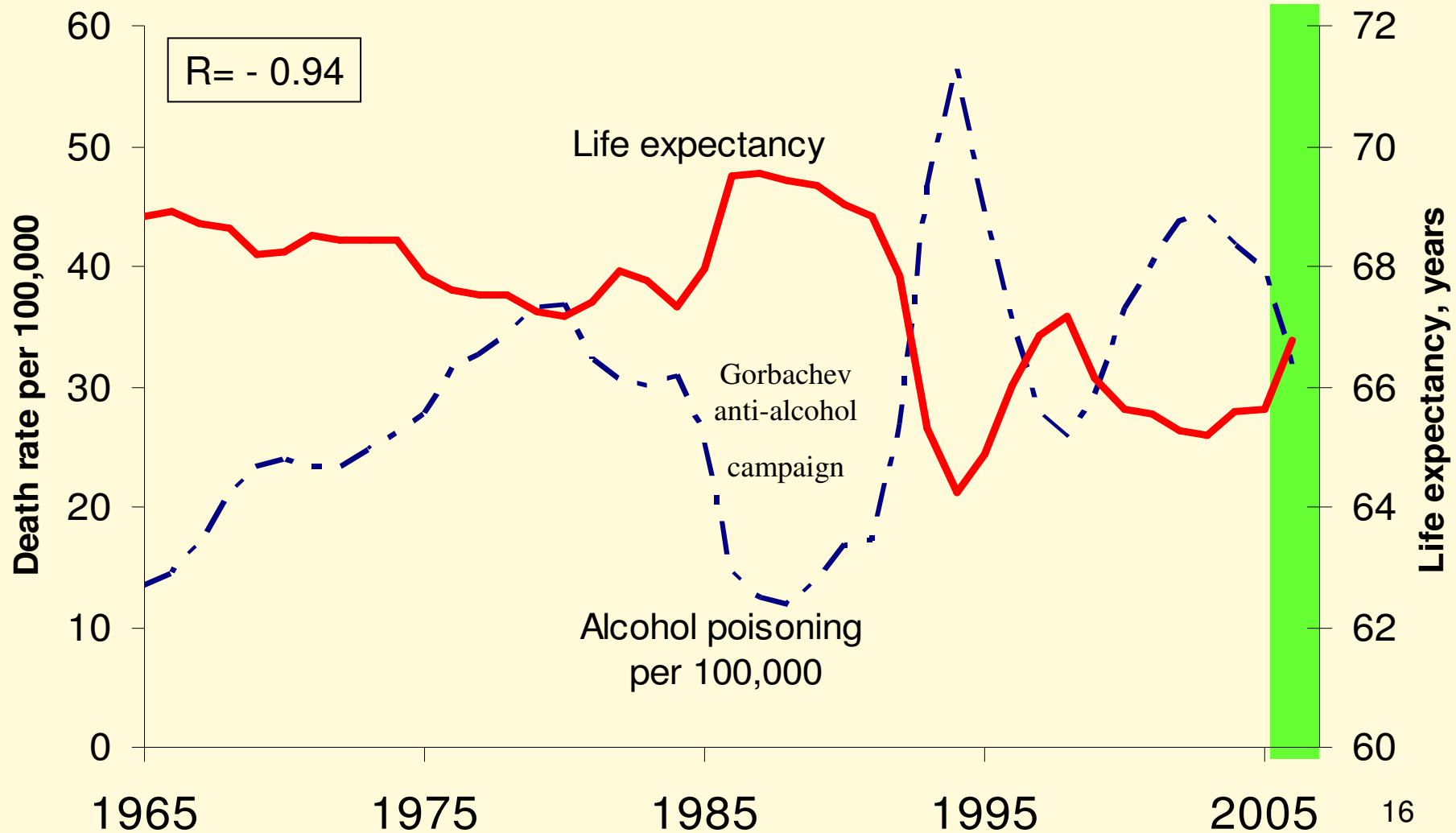
- Prenatal alcohol exposure is the leading preventable cause of birth defects, mental retardation, and neurodevelopmental disorders
- The cause is maternal alcohol use during pregnancy
 - No safe time to drink during pregnancy
 - No safe level of alcohol
 - Binge drinking is especially harmful
 - Lower level of prenatal alcohol exposure is adversely related to the child behavior (Sood et al., Pediatrics, 2002)

Alcohol consumption in Russia

- One of highest levels of alcohol consumption and burden of disease attributed to alcohol in world (WHO, 2005)
- Most hazardous patterns of consumption (Bobak et al., 1999)



Alcohol poisonings and life expectancy at birth in Russia (M+F), 1965-2006



Source : VM Shkolnikov

Increasing alcohol consumption

- 80% increase in alcohol consumption
 - from 5.38 liters of pure alcohol per person in 1990 to 9.7 liters in 2005
- Increasing consumption of other alcohol containing products
 - surrogates, perfume, cosmetics, household chemicals, and "samogon" (moonshine)
- Real consumption is higher
 - about 15 liters of pure alcohol per person per year



Chief Medical Officer of the Russian Federation, 2007

Changes in consumption

Marketing target women and youth

- Increasing production of
 - low alcohol-containing (9% and less) beverages (6 times) and
 - beer (3 times) between 1998 and 2006
- In 2006, sales of alcoholic beverages consisted of beer (75%), vodka and liquors (16%), wine (8%), and cognac (1%)
- Increasingly hazardous drinking in young people and women

Chief Medical Officer of the Russian Federation, 2007



Damskaya (Ladies') vodka:
*Producer believes that
vodka is not more harmful
than chocolate*

Alcohol consumption by women



In a convenience sample of 899 women in St. Petersburg in fall 1999 - spring 2000

- 95.9% reported consuming alcohol in the last 12 month
- 18.4% reported ≥ 5 drinks on at least one occasion in the last 30 days
- Most pregnant women reduced drinking, however 33% continued consuming alcohol (Kristjanson et al., 2007)



FAS/FASD in Russia



The actual rate of FAS in Russia is unknown

- In a sample of 2,352 (83% of total) children in orphanages for children with mental health problems in Moscow, 186 (7.9%) children with FAS were identified (International Consortium on Fetal Alcohol Spectrum Disorders, 2006)
- In screening evaluations for FASD in baby homes in Murmansk region 13% of children had high scores suggesting prenatal exposure to alcohol (FAS), 45% of children had intermediate phenotypic expression (FASD)

In over 50% of the cases there was no information regarding alcohol use in the medical records (Miller et al., 2006)



FAS prevalence

- FAS birth prevalence in a high risk maternity hospital in St. Petersburg
 - 2.7/1,000 live births in 2003
 - 1.2/1,000 in 2004
 - 3.6/1,000 in 2005
- Baby Homes in St. Petersburg
7.0% to 9.3% (70 to 93/1,000) in 2000 - 2004

(Palchik A.B. et al., 2006)



**The University of Oklahoma
Health Sciences Center**



**Профилактика ФАС в России
Prevent FAS in Russia Research Group**



**Санкт-Петербургский
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St. Petersburg State University**



Phase I



Objective

Assess knowledge, attitudes, drinking behaviors, and receptivity to prevention necessary for developing a FAS/ARND primary prevention program in Russia



Study sites



Phase I: study design

Sample

- Focus groups
 - 7 groups of women, partners, women with alcohol dependency substance abuse treatment physicians, OBGs, Pediatricians (N=51)

- Survey with 851 participants from St. Petersburg and the Nizhniy Novgorod region, fall 2004 - spring 2005
 - 648 women recruited at women's clinics:
 - 301 pregnant and 347 non-pregnant
 - 203 physicians recruited at continuing education courses:
 - 100 OBGs and 103 pediatricians

Results: alcohol consumption by women



Photo courtesy of Dr. Bertrand

- 95.6% nonpregnant women reported any alcohol use
- 62.2% reported consuming ≥ 4 drinks on at least one occasion (“How often do you have 4 or more drinks on one occasion?”)
 - including 31.5% binge once a month or more
- pregnant women reduced alcohol consumption significantly
 - however 20% reported continuing alcohol use
 - including 3% binge drinking (6% in SPB and 0% in the NNR)

Risk for alcohol-exposed pregnancies (AEP)

- **73% of non-pregnant women reported one or more unprotected sex in the last 6 months (might get pregnant)**
 - 92.3% of might get pregnant reported any alcohol use
 - 64.2% of might get pregnant reported consuming ≥ 4 drinks on at least one occasion (“How often do you have 4 or more drinks on one occasion?”)
 - Including 32.9% binge once a month or more
- **34.7% of non-pregnant women reported trying to get pregnant**
 - 88.3% of trying to get pregnant reported alcohol use
 - 55.7% of trying to get pregnant reported consuming ≥ 4 drinks on at least one occasion (“How often do you have 4 or more drinks on one occasion?”)
 - Including 20.9% binge once a month or more

Phase I: survey of physicians

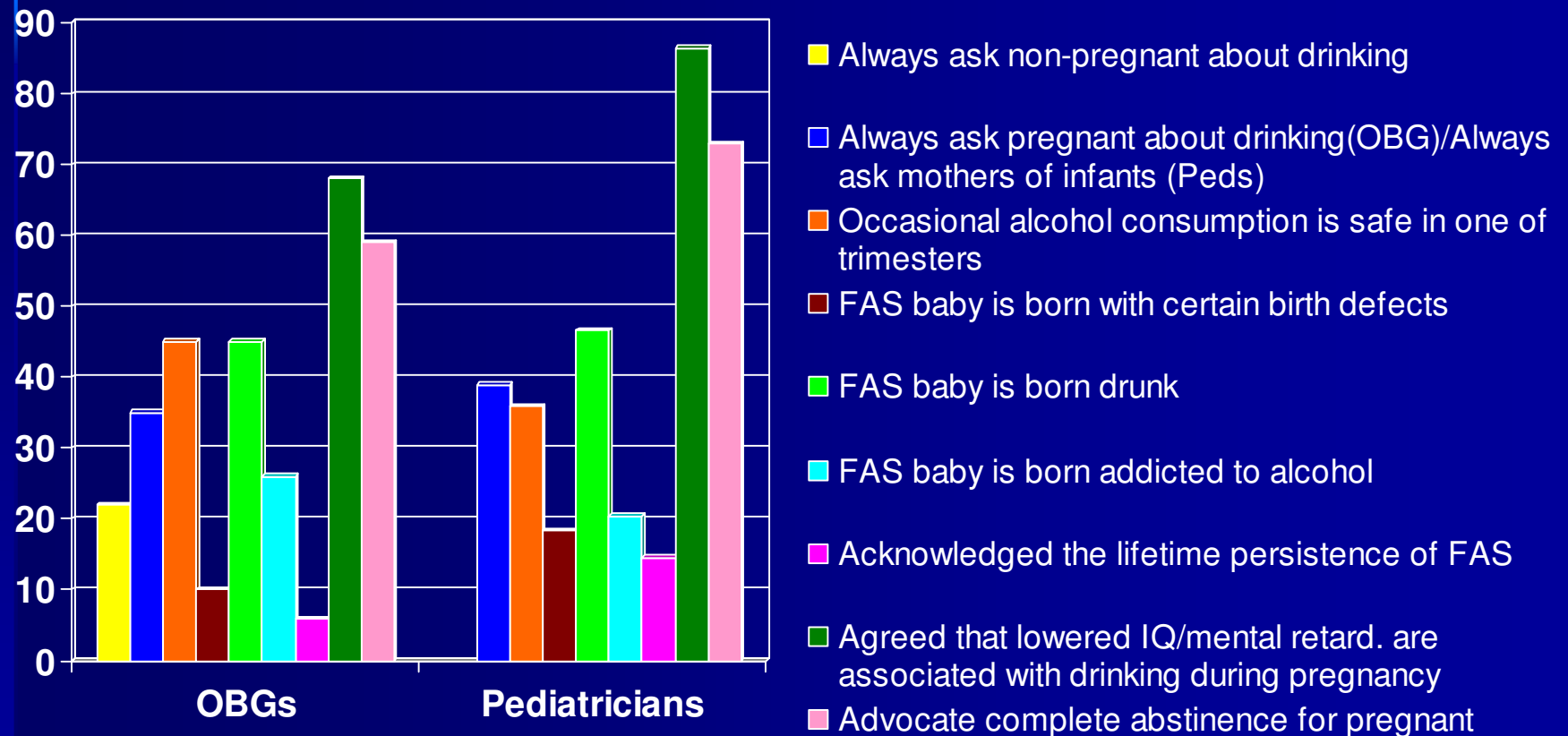




Photo courtesy of Dr. Bertrand

Phase I: conclusions

- Alarming high risk for AEP
- Decline in consumption after pregnancy recognition is promising for prevention efforts
- Interventions by OBGs may be influential for women to prevent AEP and FASD
- Training for physicians and education materials for women were not available

FASD Prevention

Good news
100% preventable



Prevent fetal alcohol exposure

Prevent pregnancy

Reduce risk drinking

(Project CHOICES, CDC 2004)

“If you plan to have a baby, do not drink; If you drink, do not have a baby!”

(FAS-Russia study participant , 2005)

Phase II: Developing education materials for prevention of FASD

Objectives

- Develop training materials for health professionals and information materials for women in Russia
- Evaluate materials in randomized trials in a pre-post test design to determine effectiveness of the training and print materials