

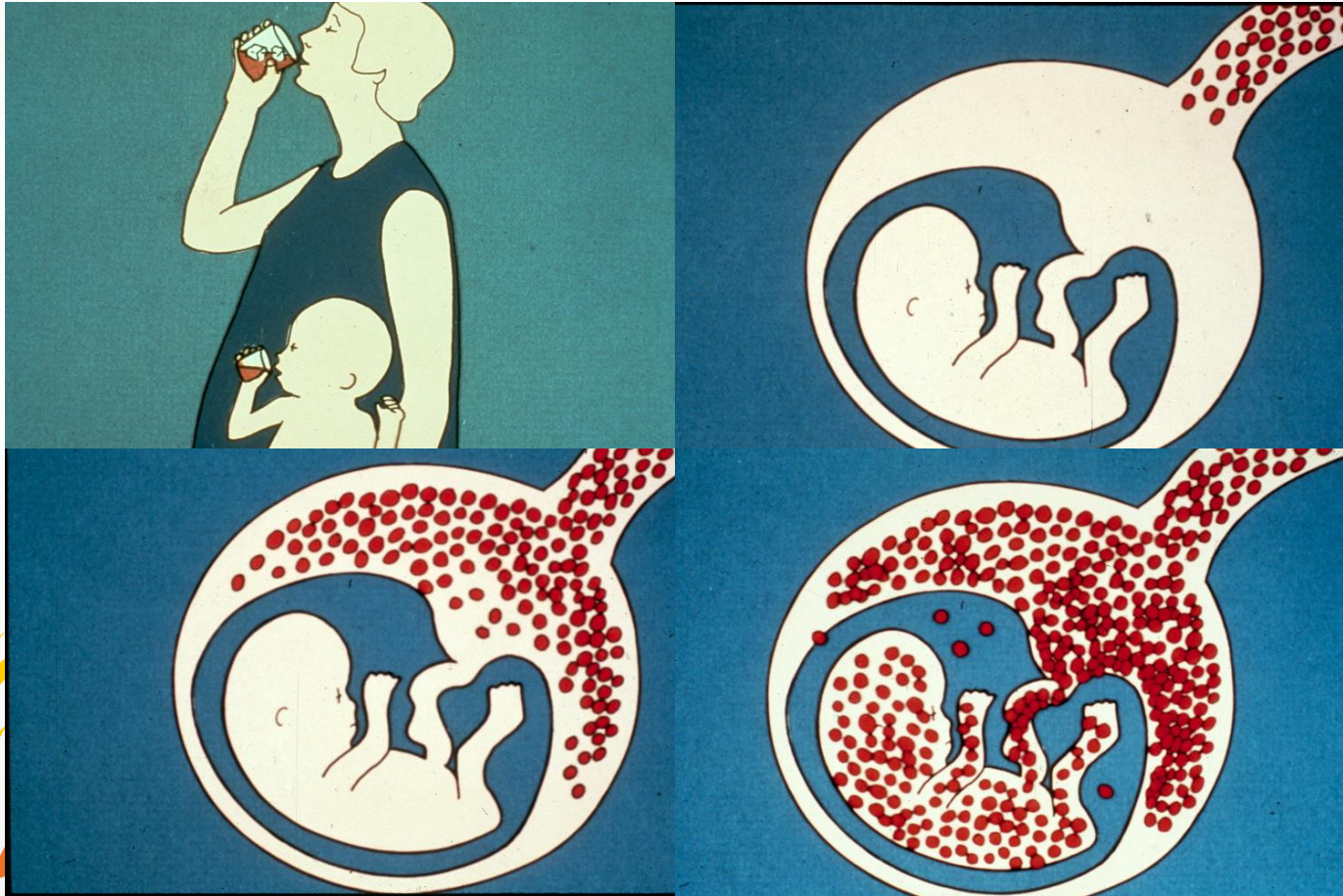
A History and a Future of FASD Prevention

Sterling K. Clarren MD

Disclosure Declarations

Sterling M. Clarren, MD, (Presenter)	Nothing to disclose
Kerry Mauger, (Planner)	Nothing to disclose
Karen Wolf-Branigin, (Manager)	Nothing to disclose
Leigh Ann Davis, (Manager)	Nothing to disclose

“Fetal alcohol syndrome” is more than anything a prevention term!



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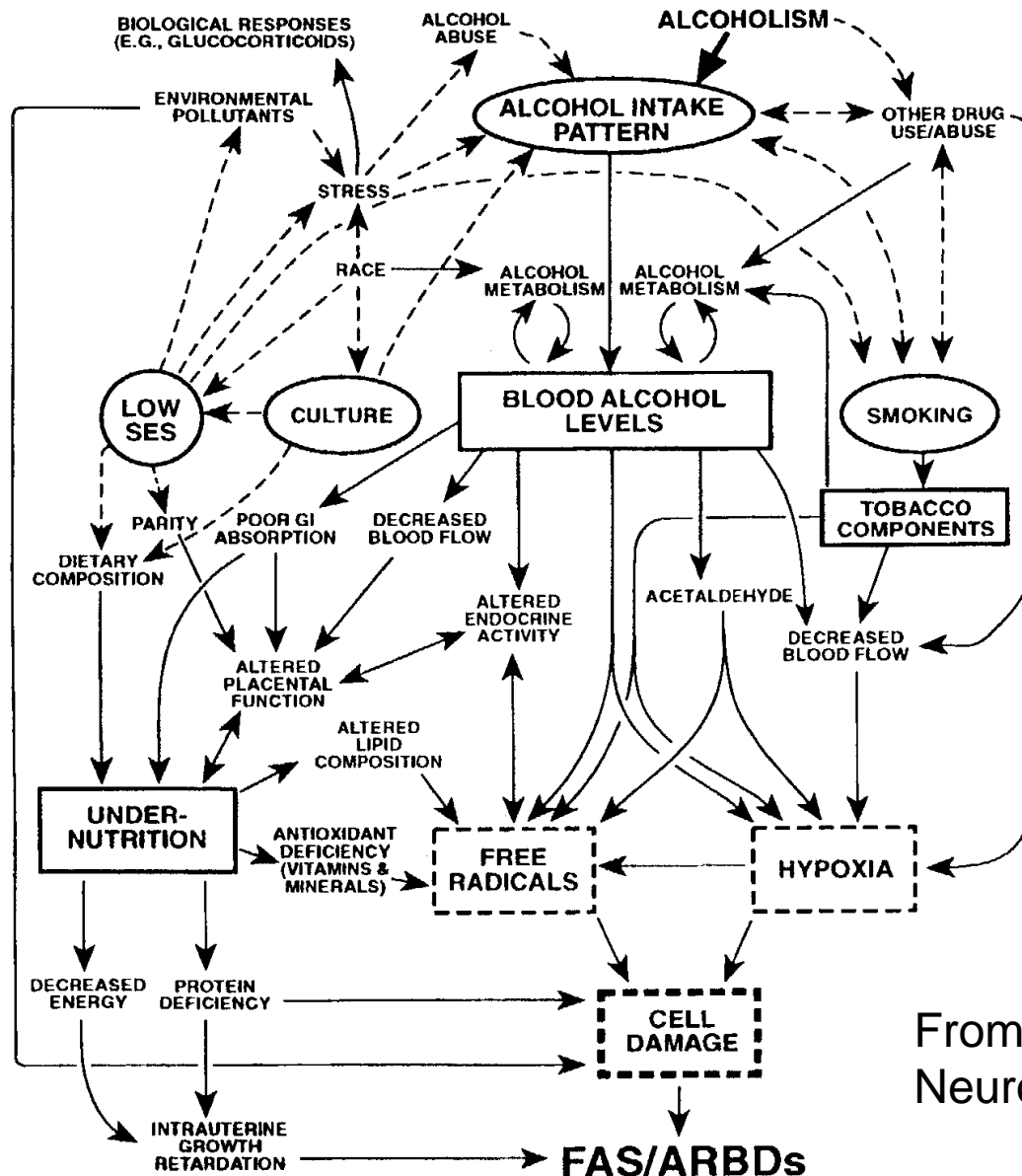
What Do We Know About FASD's

- Common:** Prevalence (FAS) is 1-3 to maybe 6/1000 in general populations
Prevalence (FAS) is 4-9/1000 in North American Native populations.
- Expensive:** Estimated cost 1 to 3 Million dollars per case lifetime
- Devastating:** Family disenfranchisement and dissolution
- Prevention:** Overall the use of alcohol has declined for women in their child bearing years over the last 2 decades
BUT no decline in the numbers of women who drink in a “high risk” fashion -5 to 6%

The Medical Model Approach

- Understand causation and the mechanisms of disease.
- Use a diagnostic process to recognize the specific condition.
- Initiate treatment(s) that resolve the problem.

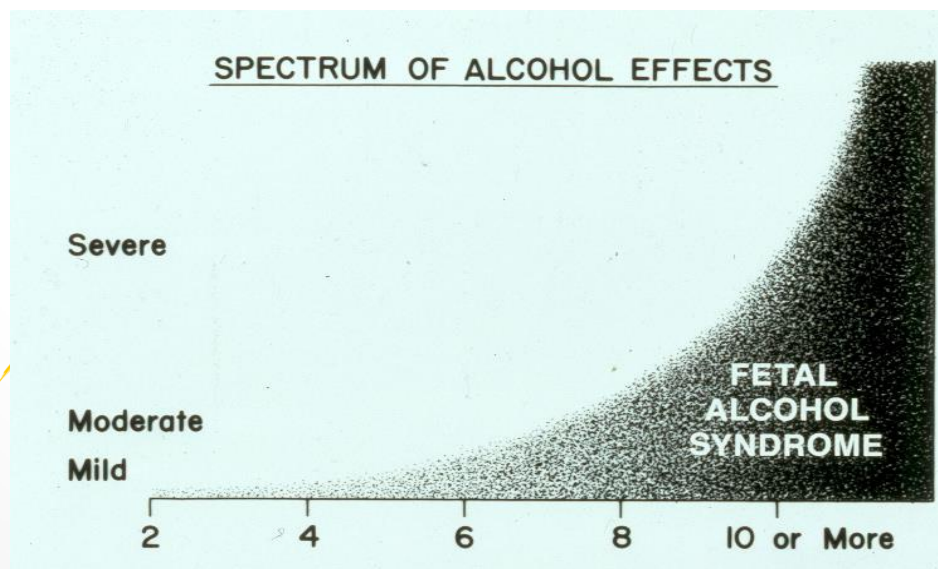
Some Mechanisms of Ethanol Teratogenesis



From E.L. Abel and J.H. Hannigan.
Neurotoxicol. Teratol. 17 (1995).

Much Has Been Learned About Alcohol Teratogenesis and Dose Response

- No amount is absolutely safe
- No amount is absolutely dangerous
- There is a relative risk
- BUT there is no evidence that “High Risk” drinking in women of child bearing age has diminished!



So the Approach of the Medical Model to FAS Prevention

- Has not yet yielded a simple avenue to reduced alcohol use – rather it has revealed a perverse situation for prevention with very early drinking and binge drinking as the most dangerous situations
- Has not yet yielded a simple approach to mechanism that would offer an antidote or corrective to the teratogenic process
- The field of Epigenetics still holds out promise, but the time line for this approach is completely unknown

An Alternative Approach is Social Intervention

1. Provision of information that might effect individual change
2. Direct interactions with women deemed to be at high risk for having children with FASD
3. Embedding FASD Prevention within a social determinants of health context
4. Incorporation of concepts for FASD prevention into other types intervention programs for women who might be also at high risk for having children with FASD.

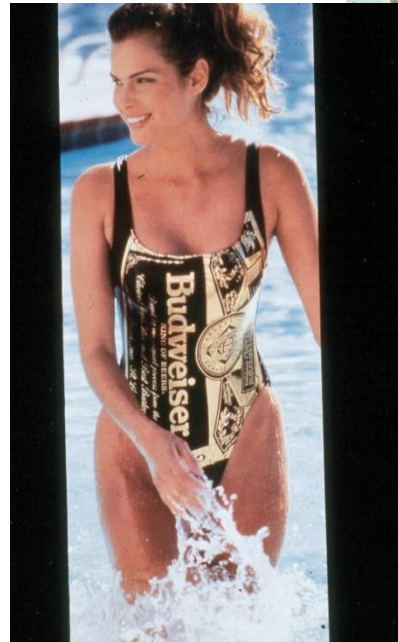
Provision of Information that Might Effect Individual Change

- Awareness campaigns directed at all women
- Awareness campaigns directed a specific subgroups by age, ethnic group, social profile, etc
- Awareness campaigns directed to professionals of any and all types
- Awareness campaigns directed towards mates, family or friends for directed action

For Example: In Canada Our Team Discovered

- Over 400 stop FASD campaigns used in Western and Northern Canada since 2000
- Only 4 were evaluated in any way
- None were evaluated for effectiveness
- The Social Marketing of FASD awareness/prevention campaigns is a field that needs to be developed and rigorously studied

Alcohol is sold with..... Glamour, romance, sex



It all leads to babies!


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The Field of FASD's Approach to the Media is Mostly More Modest:

THE WALL STREET JOURNAL. | HEALTH JOURNAL

HEALTH JOURNAL | JANUARY 24, 2012

Stricter Thinking on Alcohol During Pregnancy

YAHOO! LIFESTYLE
INDIA

Prenatal alcohol exposure can lead to abnormalities in offspring

By ANI | ANI - Tue 17 Jan, 2012 10:23 AM IST



No amount of alcohol during pregnancy is safe, study says

Newsmax  health

Total wellness for a better life

Health Wire

Alcohol With Pregnancy Unsafe In Any Amount

Wednesday, January 18, 2012 4:14

Medscape Today
NEWS

No Safe Level of Alcohol Use in Pregnancy

Megan Brooks

THE CLEVELAND LEADER
GREATER CLEVELAND'S PREMIER INDEPENDENT NEWS SOURCE

Moms Warned Drinking During 7th to 12th Weeks of Pregnancy Puts Babies at Highest Risk of Fetal Alcohol Syndrom

By Julie Kent. Published on 01/18/2012 - 11:20am

Public Health Warning as of Now

- “No alcohol = No risk”
- “Early exposure to alcohol may not be reversed by later abstinence”
- “If you want to drink don’t get pregnant, if you want to get pregnant don’t drink”
- BUT: apparently obstetricians and their patients don’t fully agree and various other messages circulate leading to confusion.

Robinson study, Australia, 2010

MEDIA = OK to drink in pregnancy

- **Study name:** Low-moderate prenatal alcohol exposure and risk to child behavioural development: a prospective cohort study

Published in: BJOG, International Journal of Obstetrics and Gynaecology

- **Focus:** Effects of alcohol during pregnancy on children's behavior

Sample size: 2,370 children

Evaluation period: Children age 2 through 14, evaluated every two or three years

Definition of “light drinking”: 2 to 6 drinks per week



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Robinson study, Australia, 2010

- Children of light drinkers actually had fewer behavioural and emotional problems than non- drinkers or heavy drinkers!
- Yeah, BUT, results possibly confounded by SES, better health of mothers and lack of other potential teratogens

Kelly study, England, 2011

MEDIA: OK to drink in pregnancy

- **Study name:** Light drinking during pregnancy: still no increased risk for socioemotional difficulties or cognitive deficits at 5 years of age?
Published in: Journal of Epidemiology and Community Health
- **Focus:** Effects of alcohol during pregnancy on children's behavioral, emotional, and intellectual development
Sample size: 11,513 children
Evaluation period: Children from birth to age 5, evaluated at regular intervals
Definition of “light drinking”: No more than two drinks per week

Kelly study, England, 2011

- No cognitive effects found in the light drinking group
- Better controlled for education and SES
- Yeah, BUT, Children only followed to age 5 at this point – too soon for many neurocognitive difficulties to be detected

Feldman study, California, 2012

MEDIA = not safe to drink in pregnancy

- **Study name:** Prenatal Alcohol Exposure Patterns and Alcohol-Related Birth Defects and Growth Deficiencies: A Prospective Study
Published in: Alcoholism: Clinical & Experimental Research
- **Focus:** Physical abnormalities in infants related to alcohol consumption during pregnancy
Sample size: 992 children
Evaluation period: Children evaluated shortly after birth
Definition of “light drinking”: Less than six drinks per week

Feldman study, California, 2012

- Finds that highest risk for FASD occurs with heavier drinking in last half of first trimester
- Yeah, BUT, this paper claims to support abstinence in pregnancy, but careful analysis of paper does not support this one way or the other

Kesmodel and Mortensen Study, Denmark, 2012

- Find that alcohol exposed children have same IQ scores and ADHD scores as controls
- Yeah, BUT, didn't measure other aspects of performance and really too young to detect problems in this general exposure group

Emily Oster Expecting Better: Why the Conventional Pregnancy Wisdom Is Wrong— and What You Really Need to Know. 2013

- It is fine to drink moderately in pregnancy
- “Imagine my surprise, then, after reading *Expecting Better* and following Oster media blitz this past week. It turns out Oster isn’t relying on interviews with medical professionals or public-health experts. She doesn’t reach her conclusions after tons of conferences or meetings with scientists. She’s combed through and “debunked” the pregnancy research—personally, as an economist. And that’s a problem. “

Review on line in Women in the World

So What are Women Being Told About Healthy Pregnancy?





STOP - There is
Danger for your baby –
everywhere!



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Does Pregnancy Counseling Really Look Like This?



Or more like this:

“Do you feel lucky?”



“Well, do ya?”

How Can We Initiate and Evaluate Programs for Success?

- Warning campaigns are too separated from the outcome of concern (FASD)
- Can we measure drinking patterns
- Should we be targeting specific groups
- If so, how does warning vary by age, ethnicity, region, drink norms, etc
- How much information should be directed at women per se vs family and professionals?
- Should we not engage women much more in helping us to develop appropriate messaging??
- THIS IS NOT A MATTER FOR OPINION- THIS IS RESEARCH THAT IS URGENTLY NEEDED!

Urgently Needed

- A Summit on Prevention with all needed experts and decision makers
- A commitment from government, outside funders and organizations like ours to start immediately on identifying programs, targeting opportunities, and initiating projects with evaluations.
- Rapid assessment and refinements in approach.
- In what kind of political climate could this happen?

But the Women at “High Risk” for Having Children with FASD Not Likely Swayed by Information Alone.

- Research finds that the mothers of children with FASD are patients too
- High levels of mental health and substance abuse problems
- Social isolation
- Likely to have FASD themselves



Speaking Directly to Women at Risk for Alcoholism and Births of Children with FASD

- Brief interventions have been advanced as a technique by the FAS Prevention program at the CDC.
- The technique has shown proximate reductions in alcohol use by women who are alcohol abusers, but not necessarily alcoholics.

The NAT Working with Women at High Risk

- Has found that the P-CAP model developed in Seattle, Washington has been embraced in Western Canada
- Approximately 40 sites funded through Health Canada for First Nations communities
- Approximately 20 sites in Manitoba, Alberta and British Columbia for general communities
- In addition PCAP has been replicated at “numerous sites” in the United States (funded by SAMHSA and HRSA’s Tribal Maternal, Infant, and Early Childhood Home Visiting program)

We Have Found

- Data describing the organizational form of any program, the selection criteria, the training for mentors, and any other aspect of program development.
- Limited data at this time that supports the value of these programs in reducing affected births.
- The program reports difficulty in accessing funding for the collection of this kind of information.

We Need

- Proof that these programs are as effective as we believe
- We urgently need a business plan presented to governments so that consideration of program expansion and support is at hand
- We need to monitor and support these programs to encourage quality improvement and prevent “clinical drift”

Embedding FASD Prevention Within the Social Determinants of Health

- The Sheway/Herway Models in British Columbia
- Provides a complete walk-in environment for life change and family care for women who have been marginalized in society
- The program show great promise, but again has not been studied itself as a business model for replication.

Incorporation of FASD Prevention into Any Intervention System

- Homelessness
- Violence against women
- Drunk driving programs
- Criminal justice in broad definition
- Mental Health
- Substance abuse
- Foster care/child advocacy

Incorporation of FASD Prevention Into Any Intervention System

- We have found that many programs informally state that they do consider FASD as an issue in their systems.
- We have found no published reports or studies that suggest that this has been evaluated.
- We have found little evidence of active FASD intervention when this diagnosis has been discerned.
- Pilot projects in this area are needed and are being encouraged at this time

SAMHSA has taken an important step

- SAMHSA is:
the Substance Abuse Mental Health Service Administration of the US Public Health Service
- They periodically issue:
Treatment Improvement Protocols (TIPs)

Incorporating FASD Thinking Into Larger Programs of Care

- SAMHSA is now published the first TIP on FASD!
- TIP 58: *Addressing Fetal Alcohol Spectrum Disorders*
- The goal is to alert and encourage those in the Mental Health and Substance Abuse programs to:
 - consider all female patients as potentially at risk for having future children with FASD
 - consider that all patients might have FASD as a component of their condition.
- The program is being operationalized in Alberta at this time
- I have received no feed back as yet on the actual use of the TIP in the United States

In Summary

- Prevention of FASD should be seen as a continuous priority by government
- Data is required that will stimulate governmental approaches and funding
- The lack of both leads to inaction
- We hope this meeting will set the stage for improved funding and commitment to this epidemic.

Questions??

Thank you.

The Arc's FASD Prevention Project

- For more information contact Kerry Mauger: mauger@thearc.org
- Check out our website for more information, resources, videos, etc., at: www.thearc.org/FASD-Prevention-Project
- Download our FASD Toolkit at: www.thearc.org/FASD-Prevention-Project/resources/toolkit