What do you prevent with fortification

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Secretary General - International Federation for Spina Bifida and Hydrocephalus

Chair person – Child-Help Belgium and Child-Help International

Lusaka, Zambia, 15 May 2017

International Federation for Spina Bifida and Hydrocephalus

INTERNATIONAL FEDERATION for SPINA BIFIDA and HYDROCEPHALUS

Our focus

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Of course also:
Right to be with the mother
Right to an identity
….

Of course also:
Right to education
Right to work
Right to independent living
…

What is spina bifida?

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What is spina bifida?

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What is hydrocephalus?

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What is hydrocephalus?

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Perception

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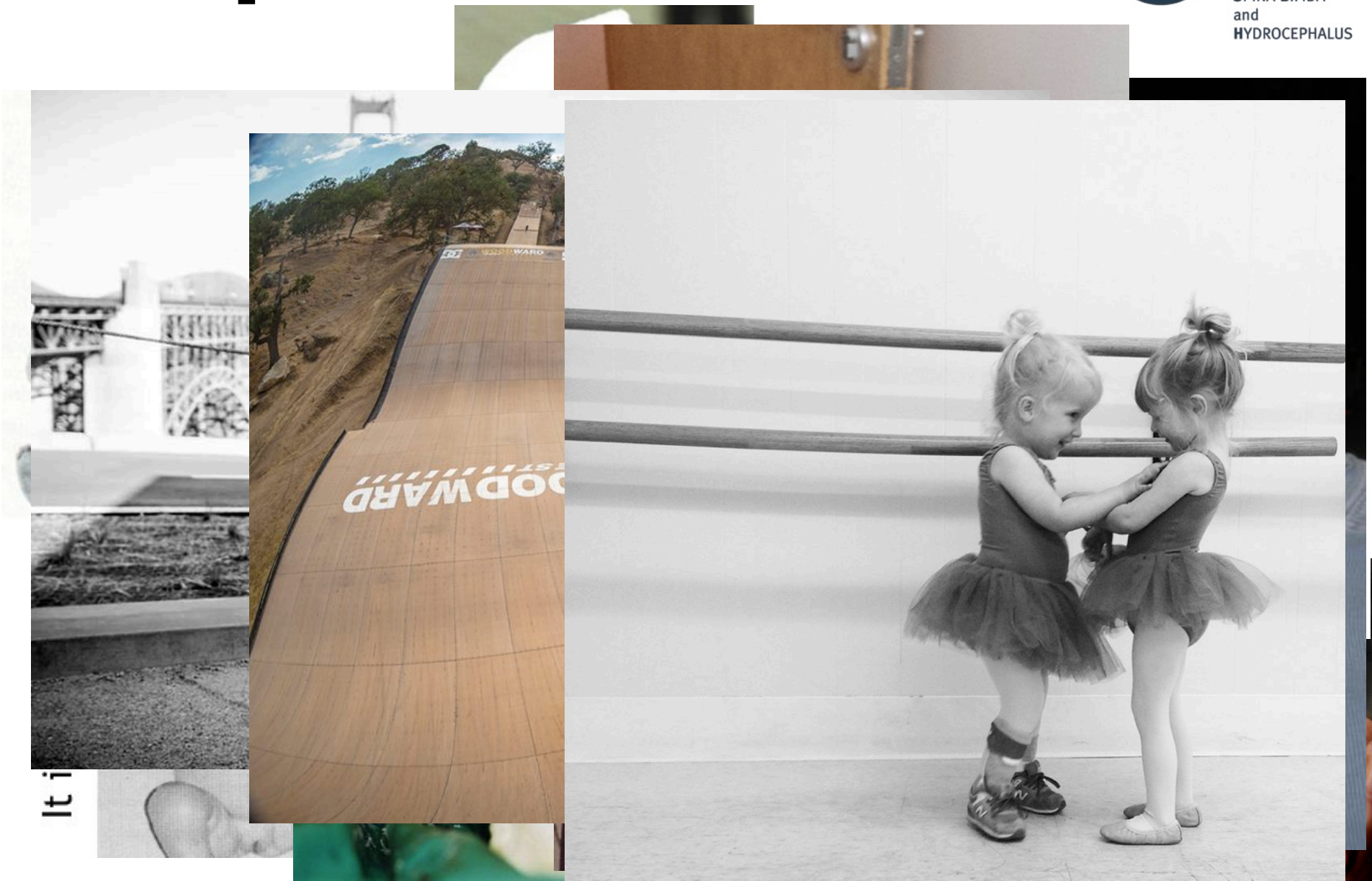

Unfortunately

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and

People United for Spina Bifida and Hydrocephalus – PUSH

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2016 PUSH! Global Alliance – Country Report Card: ETHIOPIA

Spina Bifida Score: 1.5 ★ **Hydrocephalus Score: 1.5** ★

Spina Bifida - SCORE KEY
Excellent = 6 stars
Good = 4-5 stars
Improvements needed = 0-3 stars

Hydrocephalus - SCORE KEY
Excellent = 5 stars
Good = 3-4 stars
Improvements needed = 0-2 stars

ETHIOPIA	Folate studies	Prevalence Data	Mortality Data	Prevention	Access to Care	Quality of Life
SPINA BIFIDA	X	X	X	★	No Data	★
HYDROCEPHALUS	N/A	X	X	★	No Data	★
RECOMMENDATIONS	Develop surveillance capacity to periodically monitor blood folate status in women of reproductive age	Create surveillance systems in multiple local and regional hospitals, and publish mortality rates for spina bifida and hydrocephalus	Create surveillance systems in multiple local and regional hospitals, and publish mortality rates for spina bifida and hydrocephalus	**Spina Bifida:** Undertake coverage and effectiveness studies for existing programs (voluntary fortification/ supplementation), and explore opportunities for mandatory fortification policy of staple foods **Hydrocephalus:** Improve access to antenatal care	Increase the number of neurosurgeons in country who can provide care to children and adults with spina bifida and hydrocephalus	Ensure that programmes and policies supporting the rights of persons with disabilities are implemented and enforced

http://www.pu-sh.org/ws-content/uploads/Report_Ethiopia.pdf

Data

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Lack of data

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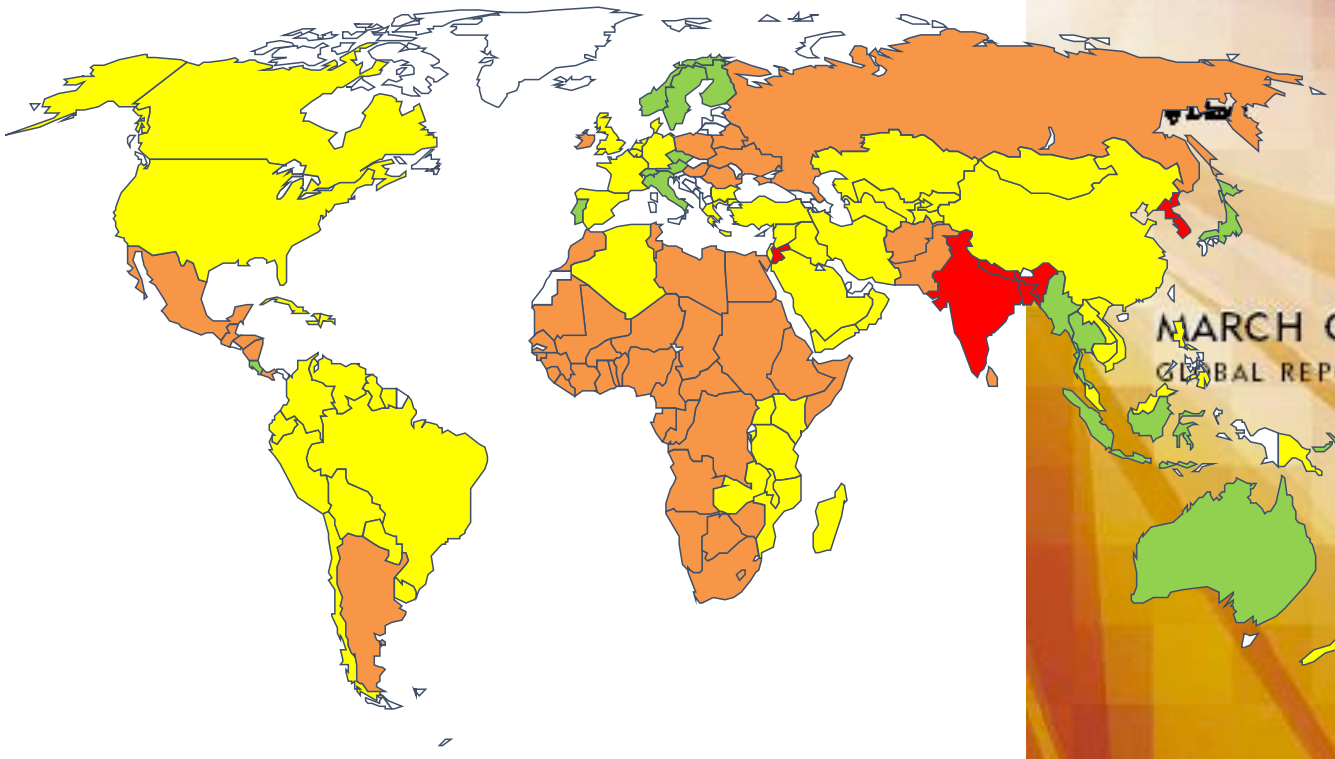
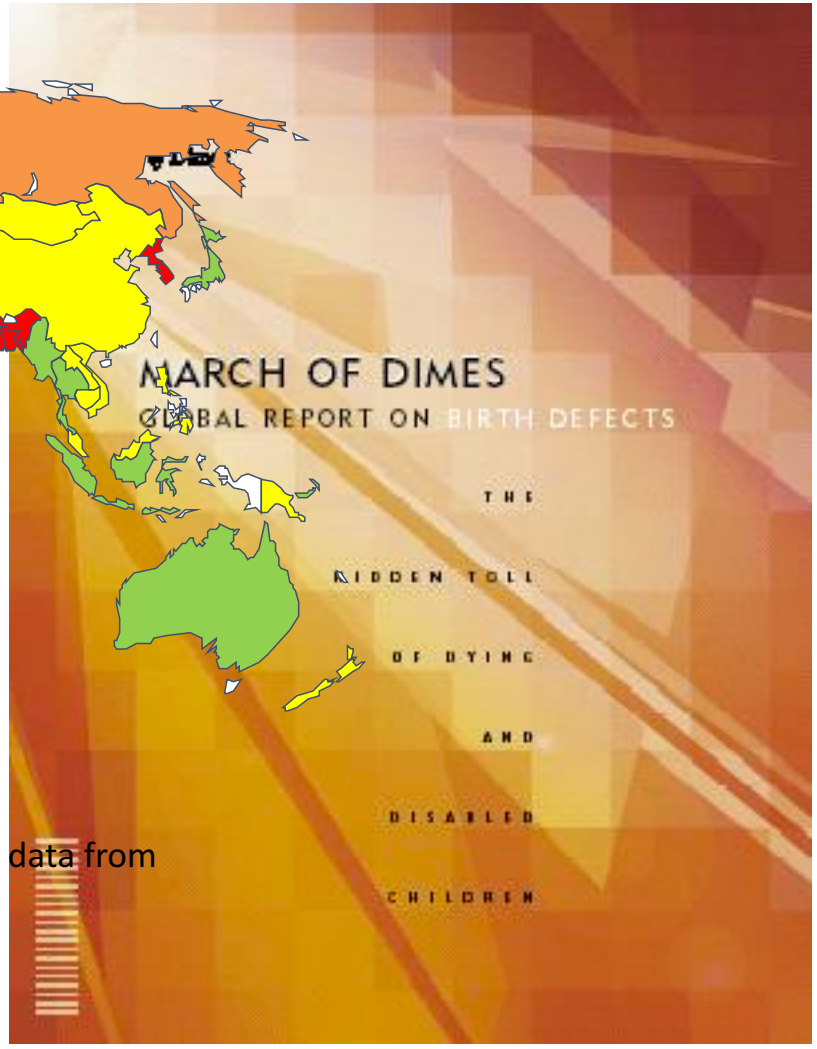


<=1.0 1.1-2.0

2.1-3.0 > 3.0

Rates per 1000 births: data from March of Dimes



Focus on surveillance

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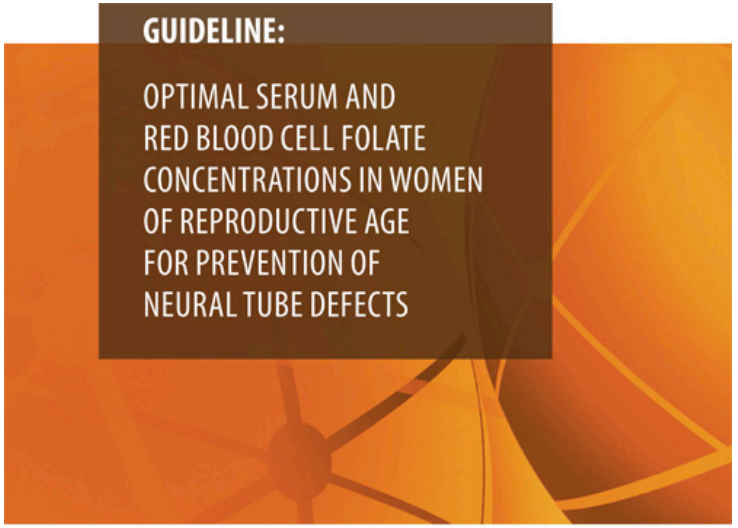
Data drives efforts in prevention
Data drives efforts in care provision

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION



World Health Organization

World Health Organization

Ignoring NTDs is not prevention

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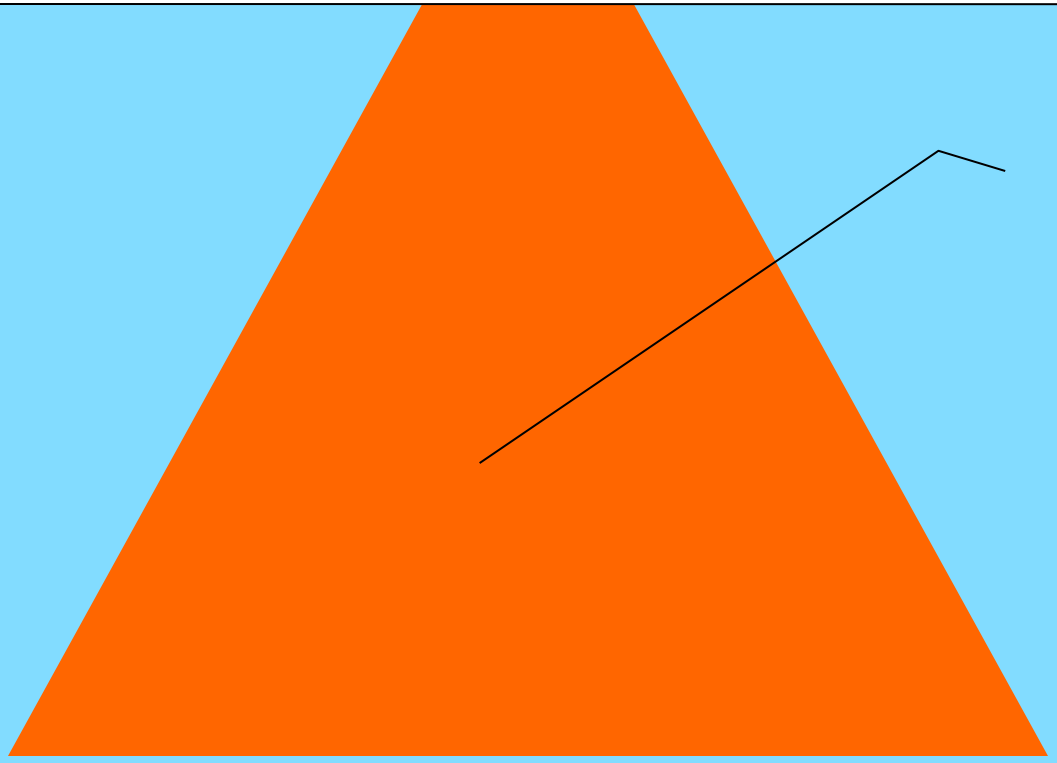

Other health outcomes:
Certainly: FA deficiency and related anemia
Probably: stroke
Possibly: Low birth weight, pre-term birth, cancer, other birth defects, …

Recurrence?

Overlaid data of Daly et al 1995 and Crider et al 2014

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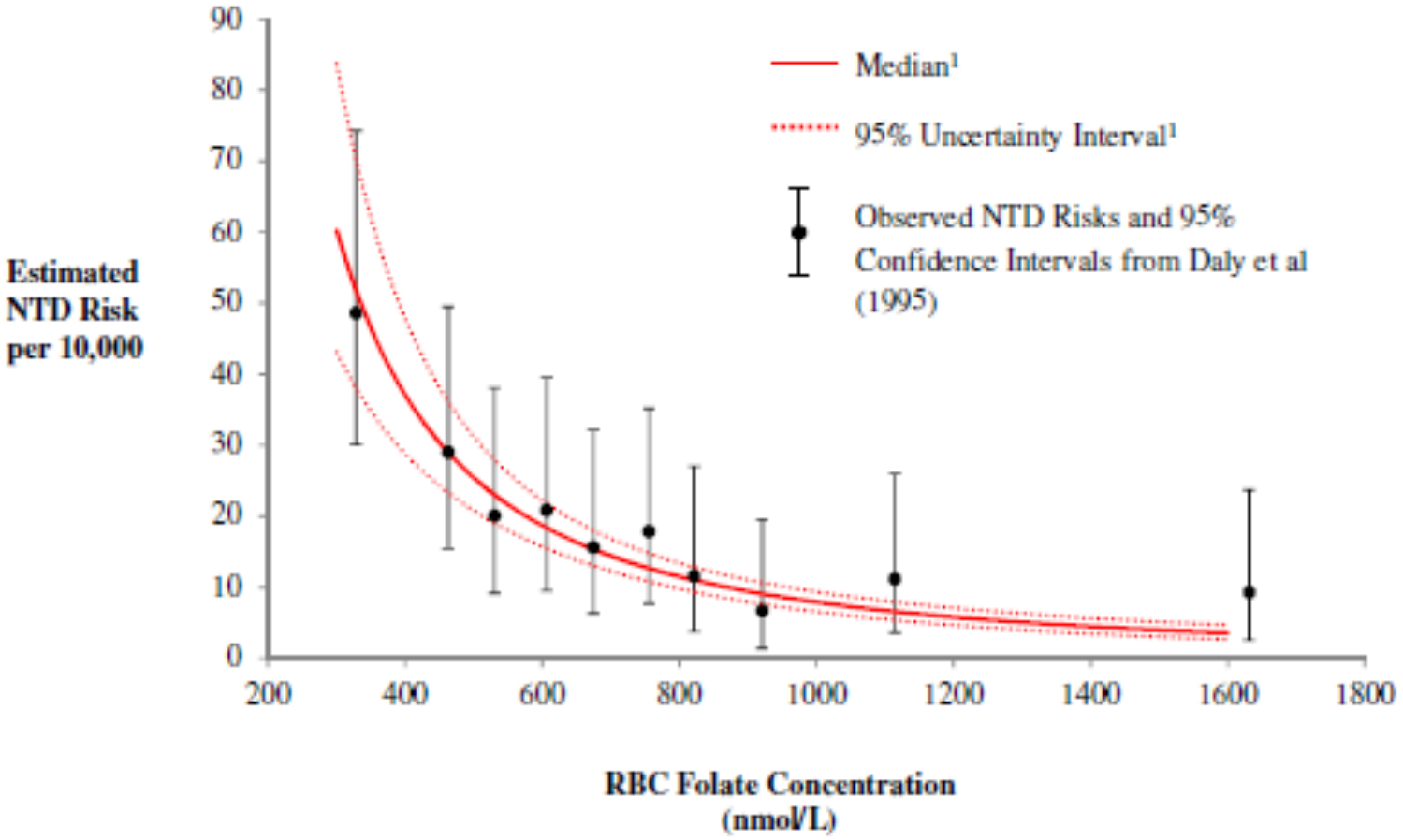

Prevention

- Prevention of NTDs by taking Folic Acid (to 70%)
- (maybe) higher rate of prevention with other B-vitamins
- Recommendation: daily intake of 0.4 mg of folic acid
  - at least two months prior to conception and the first months of pregnancy
- Parents at extra risk should take daily 4 mg

Prevention of NTDs

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Different strategies

- Supplementation
- Fortification
- Diet
- Oral contraceptive + Folic Acid
- Other

Folate

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FOOD FOLATE	FOLIC ACID
• Found in liver, dark green vegetables, lentils, beans, oranges,	• Found in fortified foods and supplements
• Water-soluable	• Stable
• Bioavailability ~50% in comparison to folic acid supplement taken on empty stomach	• Bioavailability 1. Supplements taken on empty stomach~100% 2. Folic acid taken with food ~85%

Potential Solution 1: Supplements

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- Limitations:
  - Cost and inconsistent use
  - Minority of women use folic acid supplements at the correct time for preventing NTDs (even when the pregnancy is a planned one) – important relation with socio-economic background
  - *Prior* to conception and during the first 12 weeks of pregnancy, women need 400 microgram folate or folic acid per day.

Potential Solution 2: Fortified flour

- Pro
  - Effective
  - Simple and inexpensive
  - Requires no change in dietary patterns or individual decision
  - Non-discriminating
- Contra
  - Controversial (myths)
  - Reach
  - Challenge of monitoring and enforcing of legislation

IF Supports Fortification

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Consultative status special category with Economic and Social Council of the United Nations
Participatory status, Council of Europe

IF POLICY STATEMENT ON PREVENTION OF NEURAL TUBE DEFECTS AND MANDATORY FOOD FORTIFICATION

Adopted by the IF Annual General Meeting on 28 June 2005 in Minneapolis

IF calls for action to:

1. Promote the health benefits of the vitamin folic acid.
2. Ratify a policy calling on all countries to fortify staple food with the vitamin folic acid to reduce the incidence of neural tube defects (NTDs).
3. Encourage further research into the prevention of neural tube defects (including spina bifida).

Food fortification vehicles

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OIL	MILK	CEREALS	SALT	SUGAR
				
Vitamin A,E	Vit A,D Ca	Fe, Zn Vit. B1, B2, B3, B6 Folic acid Vitamin A	Iodine	Vitamin A

What cereal would you fortify in Ethiopia?

Why are cereals a good vehicle?

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- Staple food
  - Carbohydrate source
  - Daily consumed
  - High consumption levels
- Cereal processing industry
  - Well established world-wide
  - Large scale operations

Cereal processing

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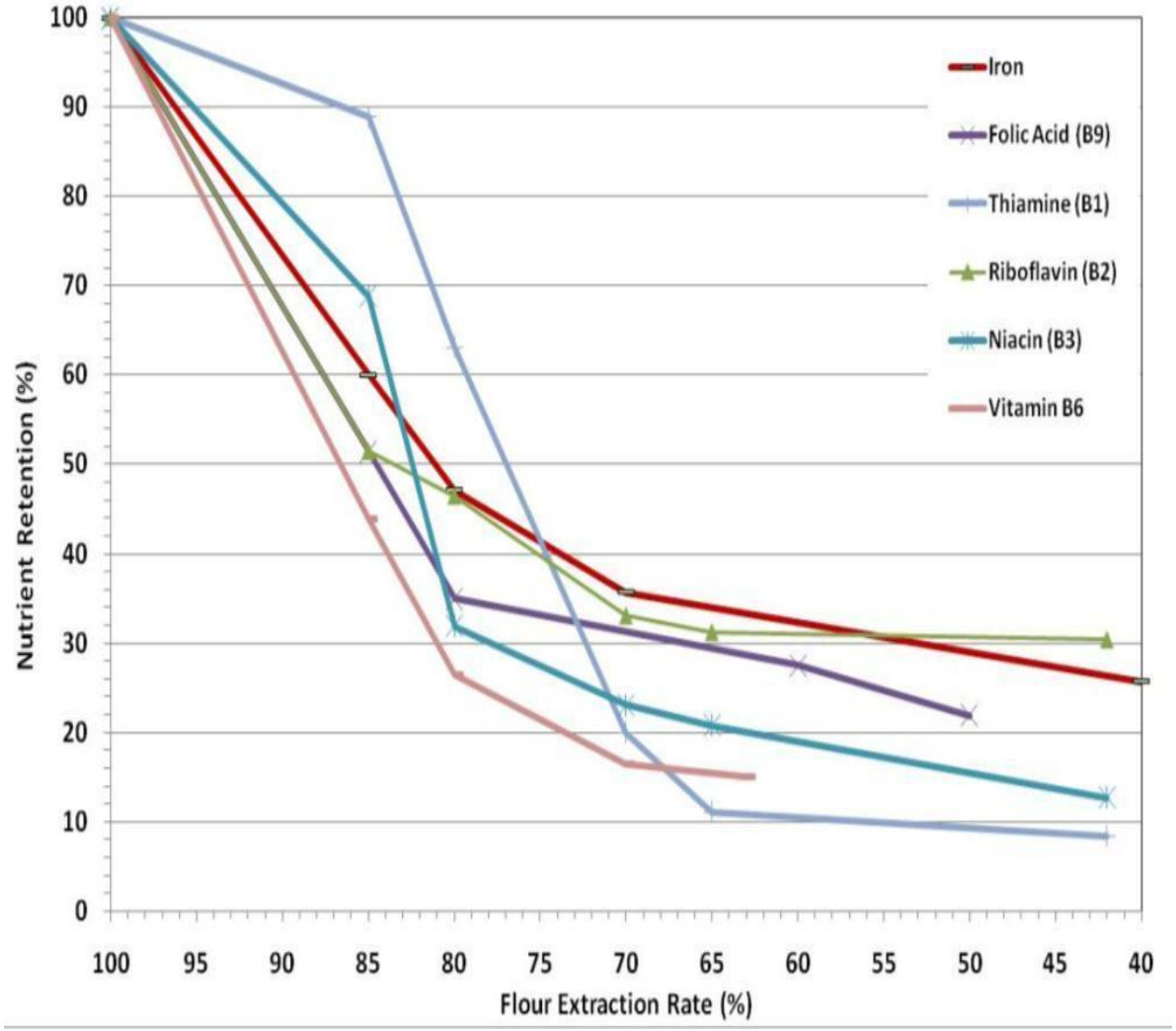

Industrially Milled Flour and Rice Fortification Legislation

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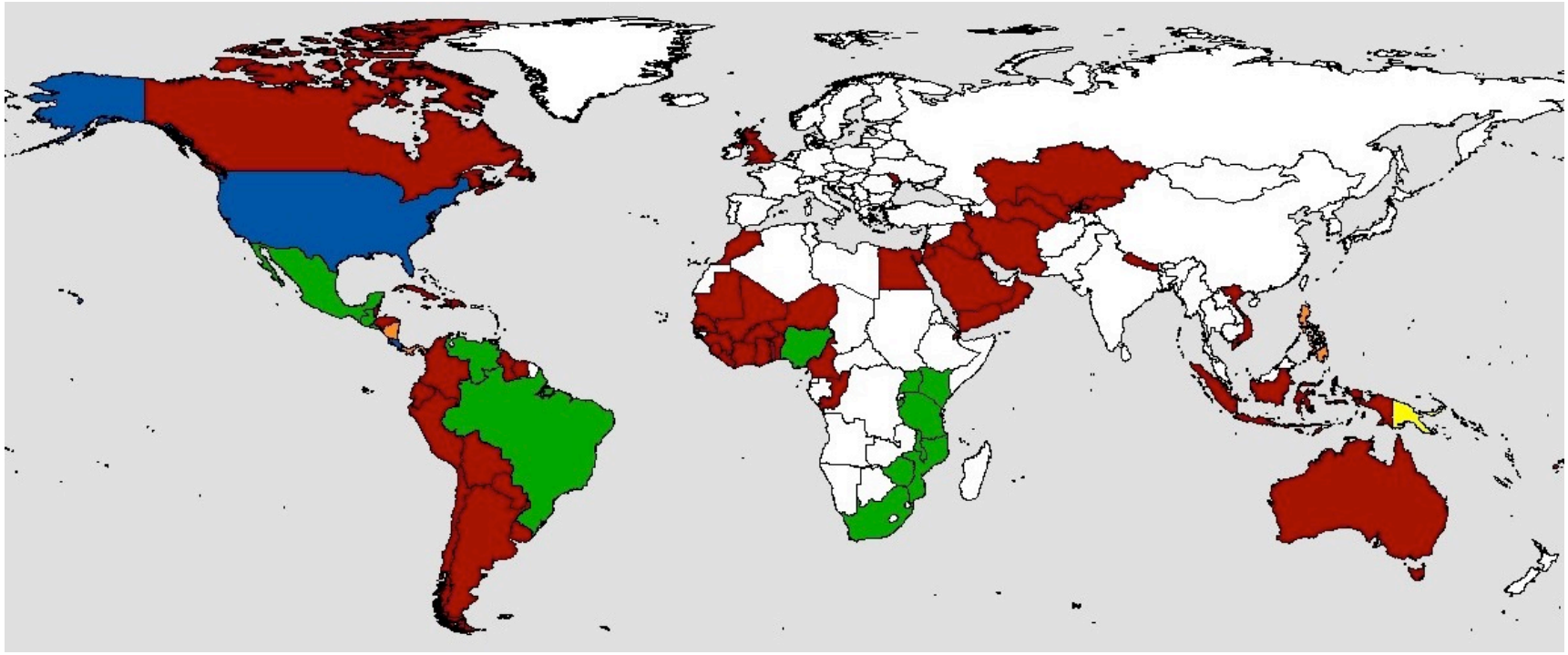

	Wheat flour – 66 countries
	Rice – 1 country (Papua New Guinea)
	Wheat flour and maize flour –14 countries
	Wheat flour and rice – 3 countries (Nicaragua, Panama, Philippines)
	Wheat flour, maize flour, and rice – 2 countries (Costa Rica and the United States)
	No grain fortification legislation

* Legislation has effect of mandating grain fortification with at least iron or folic acid.

Legislation status from the Food Fortification Initiative (www.FFInetwork.org) November 2016

Role of SB associations

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- Understanding the issue
  - NTD registration
  - Food and nutrition intake
- Understanding the local situation
- Build and be part of a National Fortification Alliance
- Advocacy
- Monitoring of the actions undertaken by government

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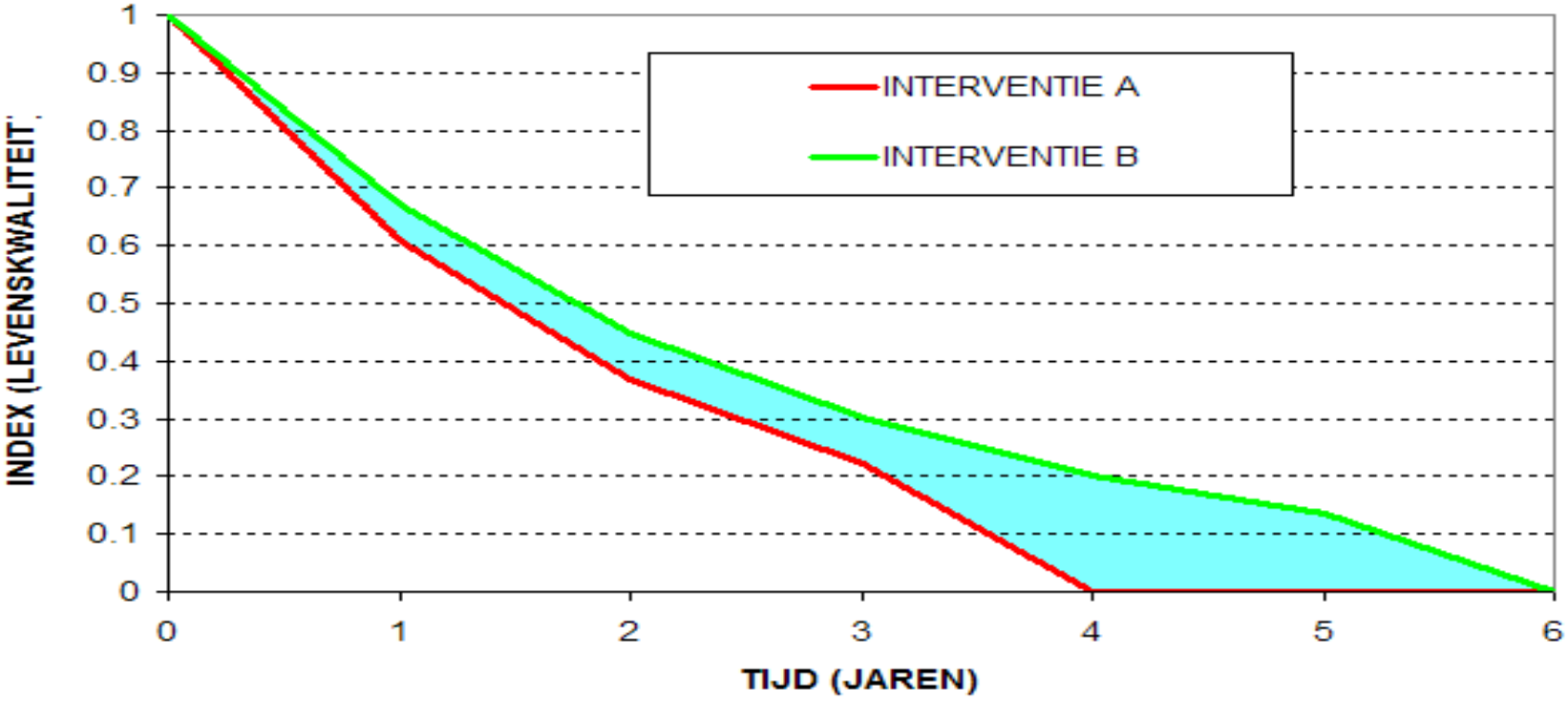
Health economic evaluation

- QALYs = life years X quality of life
  - –Quality of life: death = 0; perfect health= 1
  - –example: Intervention A versus B



Gapminder – child mortality

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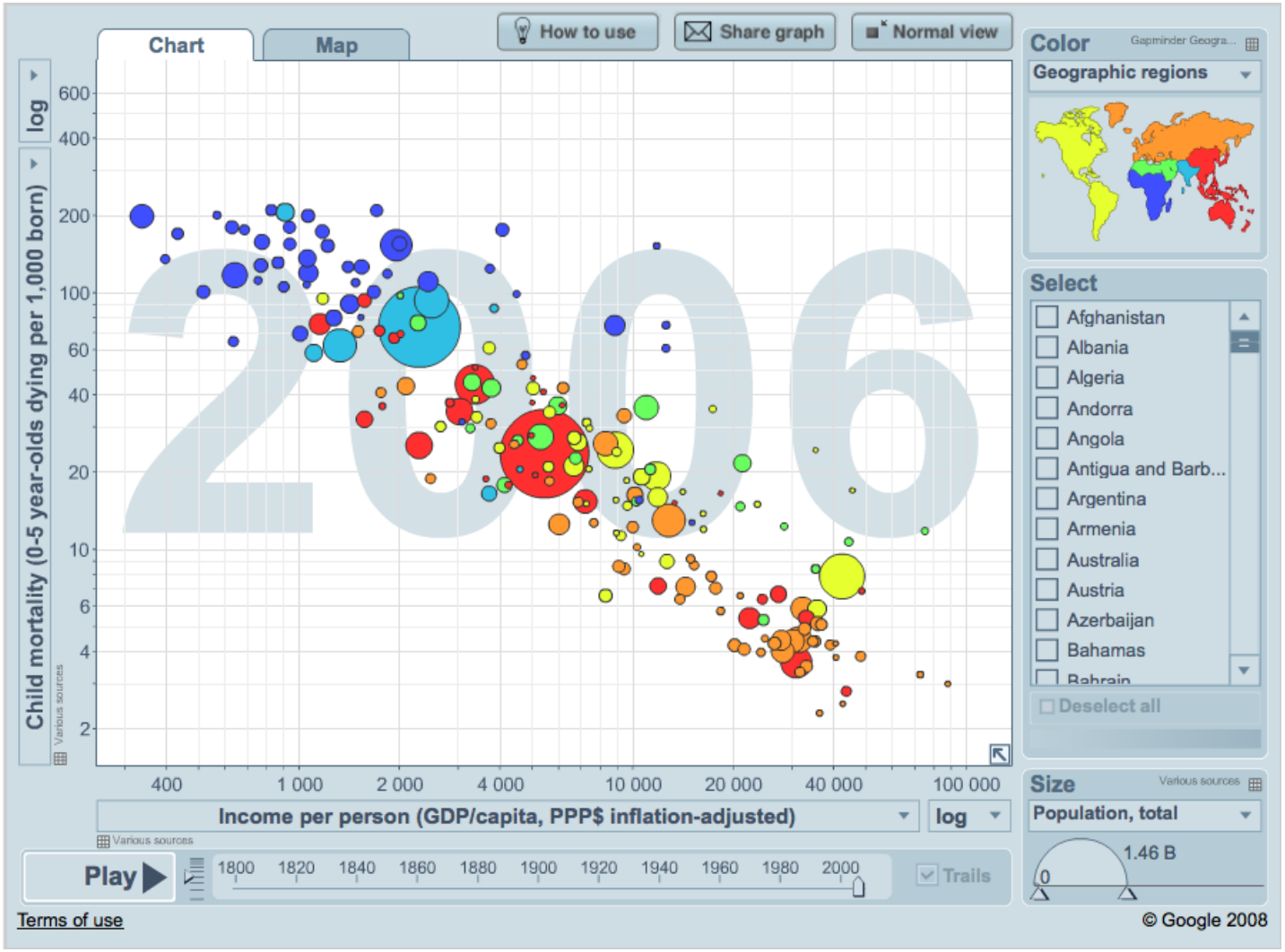

Gapminder – health costs

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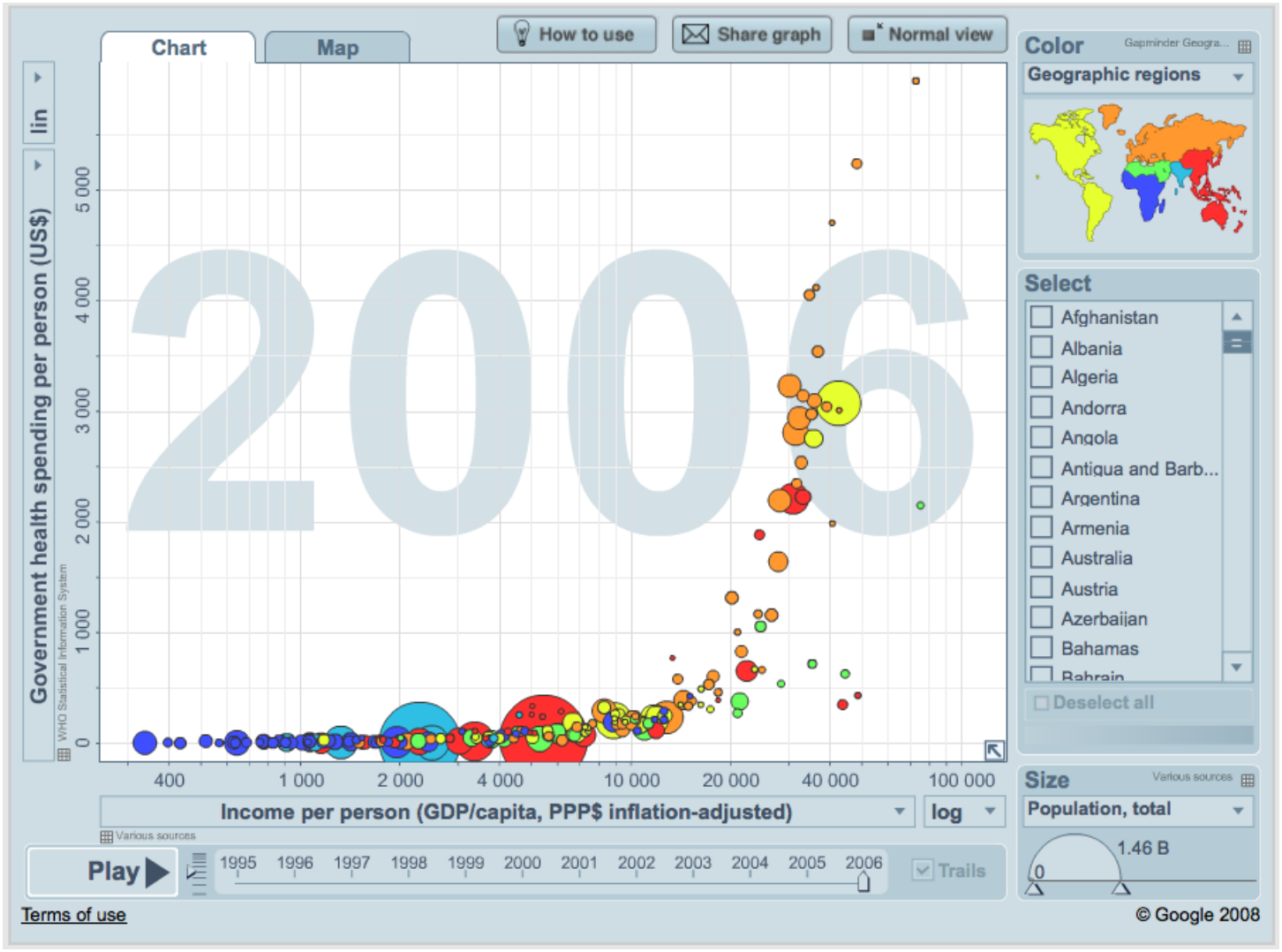

Economic impact

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- In the United States, folic acid fortification has been estimated to save $145 million per year in (direct medical) costs for the care of children born with spina bifida. [1]
- In Chili, fortification averts an average of $11.8 dollars for every dollar spent on fortification. [2]
- Study in the Netherlands: "Bulk food fortification with folic acid remains cost-effective as long as enrichment costs do not exceed 5.5 million €" [3]

[1]Gross, SD, et al, "Reevaluating the benefits of folic acid fortification in the United States; American Journal of Public Health 2005:95:1917-1922

[2] Llanos, Adolfo, et al. "Cost-effectiveness of a folic acid fortification program in Chile." Science Direct Health Policy 83 2007: 295-303

3 Eur J Public Health. 2008 Jun;18(3):270-4. Epub 2008 Jan 31.

Cost of (No) Folate Fortification

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Area	Life time cost €/NTD case	Population Million	Birth rate %	Newborn Thousand	NTD rate %	Economic cost Million €
NL	243,000	17	1.07	182	0.09	**40**
D	*243,000*	82	0.82	672	*0.10*	**163**
EU	*200,000*	500	1.06	5,300	0.10	**1,060**
India	*20,000*	1,200	2.27	27,240	0.36	**1,961**

Italic: estimated

Global wheat production: 628 million t/a

Estimated flour consumption: 400 million t/a

Estimated folate fortification cost: 80 million €/a

Poverty-disability-poverty

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- Renewed focus with World Report on Disability by WHO and World Bank
- WHO resolution on Birth Defects (May 2010)
- Important relation between poverty and disability
  - Families with lower socio-economic background are at higher risk of NTD (eg: study prof. dr. Steegers, Rotterdam)
  - Families with a person with a disability are at higher risk of poverty
    - Direct costs
    - Indirect costs
    - "care-taker costs"
    - Loss of income

World Report on Disability: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf
WHO resolution on Birth Defects: http://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_R17-en.pdf

A no-brainer to fortify?

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- Folic Acid works!
- Prevention is better than...
  - ..."cure"
  - ..."secondary prevention"
- FA supplementation – policy does not seem to work
- About half of pregnancies are unplanned
- Cost–benefit / Cost-efficiency
- Relationship poverty-disability
- Mandatory fortification does not discriminate

- Why wait?

Barriers to treatment

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- Lack of neurosurgical manpower / available care
- 1:4,000,000 - Kenya
- 1:8,000,000 – Uganda
- 1:18,000,000 – Tanzania
- Even less in Malawi, Congo, Rwanda, Burundi

- → Resulting in extremely high mortality

- Poverty and politics
- Lack of information / money
- Negative stereotypes on SB (referrals)
- Lack / cost of transport
- Poor infrastructure
- Regions of insecurity

Access to care: cheap shunts

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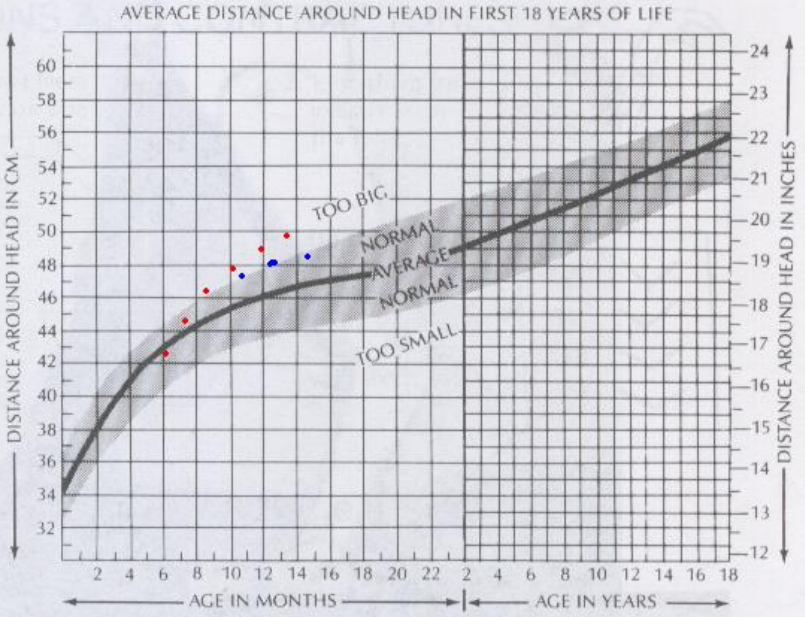
Record of the child's head size

On the chart put a dot where the up-and-down line of the child's age crosses the sideways line of her head size:

Measure around the widest part of the head.

If the dot is *below* the shaded area the head is smaller than normal. The child may be **microcephalic** (small-brained, see p. 278).

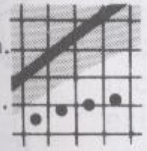
If the dot falls *above* the shaded area, the head is bigger than normal. The child may have **hydrocephalus** (see p. 169).



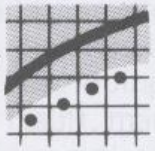
Note: Boys' heads average from ½ to 1 cm. larger than girls' heads. Also head size may vary somewhat with different races. If possible get local charts.

Use the chart for a continuing record. Every month put a new dot on the chart.* If the difference from normal increases, the problem is more likely to be serious. For example,

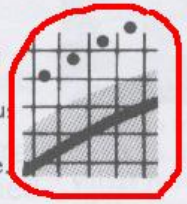
Brain not growing much. Probably microcephalic.



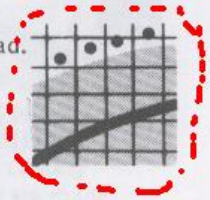
Brain growing well. Probably not serious.



Head too big; growing fast. Hydrocephalus or tumor. Getting worse.



Large head. Probably not a problem.



*Filling out this chart every month is especially important for children with spina bifida or suspected hydrocephalus (see p. 169). If you do not know how to use the chart, ask a local schoolteacher.

No MRI or scans, only endoscopy and a measure tape

Innovation

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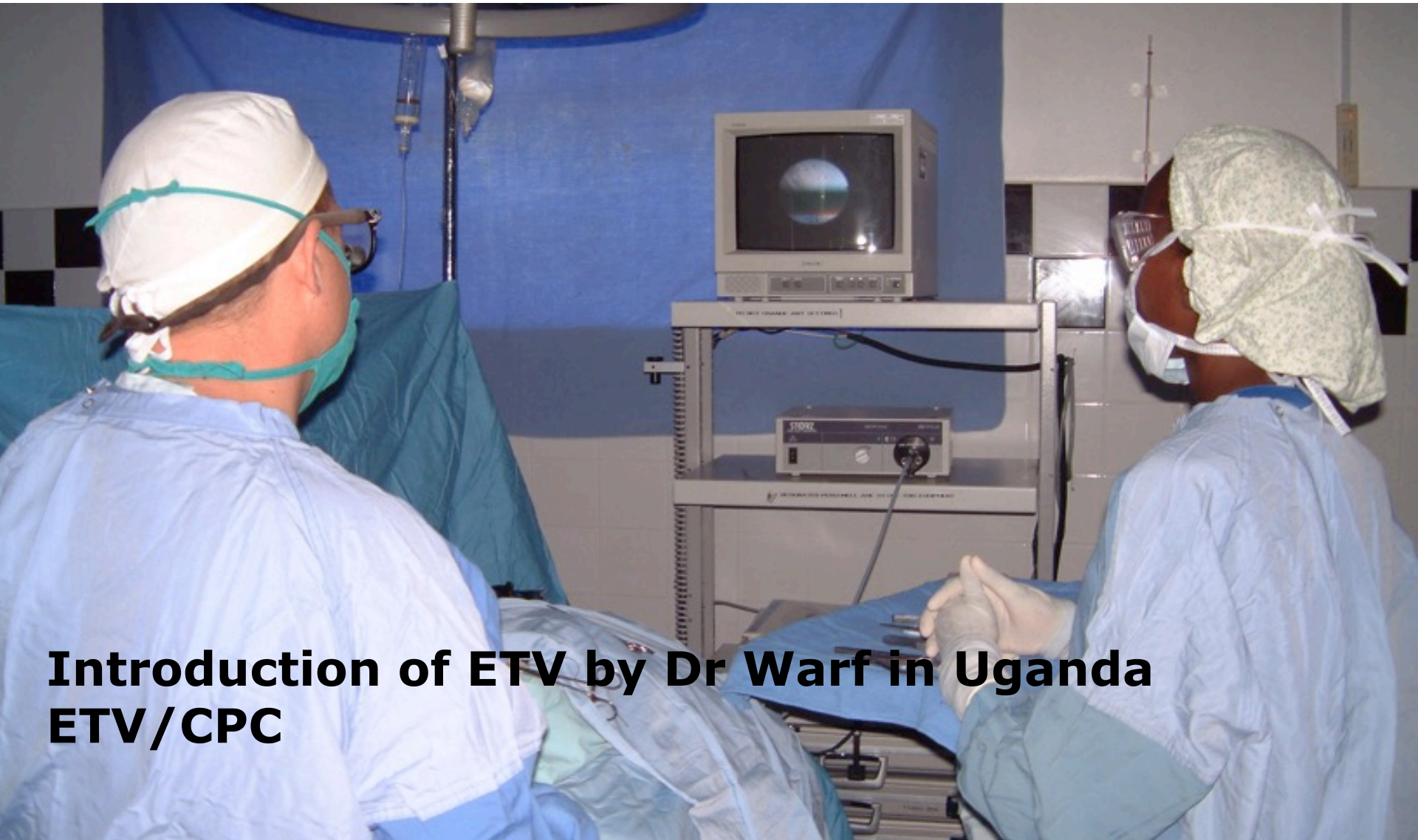

Introduction of ETV by Dr Warf in Uganda
ETV/CPC

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Continence management program with CIC and bowel wash-out

Top medicine

No expensive urodynamics. Parents train parents. <20USD per child, per year

SHIP

•**S**pina Bifida and
Hydrocephalus
Interdisciplinary
Programme

- Good cooperation with all stakeholders
- Improve communication through SHIP passport
- Shared protocols
- Controlled information in training-programs and training material
- User participation at all levels

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THANK YOU!