

# Prevention of NTDs: some thoughts

## IF'S VIEW ON REGISTRATION AND PREVENTION

Lieven Bauwens, Secretary General

Ede, 8 October 2014

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# What we would like to cover

- ▶ What is IF?
  - ▶ Spina Bifida and Hydrocephalus
    - ▶ Care
    - ▶ Registration
    - ▶ Prevention
      - ▶ Supplementation
      - ▶ Fortification
-

# What is IF?

## ► Mission

The mission of IF is to reduce the incidence of Spina Bifida and Hydrocephalus by primary prevention, and to improve the quality of life of people with SBH and their families through human rights education, political advocacy, research and community building.

## ► Strategic Objectives

- Right to Health
  - Prevention
  - Global Community
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# What is IF?

- ▶ International Federation for Spina Bifida and Hydrocephalus
    - ▶ Global umbrella organisation, started in 1979
    - ▶ 52 national / regional members (organisations of people with SB/H or their parents) / 49 countries
  - ▶ HQ in Brussels, liaison person in Kampala, Beijing and Buenos Aires
-

# What is IF?

- ▶ IF represents people with Spina Bifida and Hydrocephalus
    - ▶ One of 7 “Key EU networks” of people with disabilities for the European Commission
    - ▶ Consultative status at the UN (ECOSOC)
    - ▶ Participatory status at the Council of Europe
    - ▶ Actively seeking partnerships with FFI, WHO, CDC, Unicef, OHCHR, EUROCAT and others
    - ▶ Pending membership of International Disability Alliance (IDA)
    - ▶ Fortification-project (training, advocacy) with Akzo, HKI and FFI – [www.smarterfutures.net](http://www.smarterfutures.net)
    - ▶ [www.ifglobal.org](http://www.ifglobal.org)
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# Activities

- ▶ An global network of knowledge
    - ▶ Parents, professionals and adults with SB/H, national and regional organizations
    - ▶ Annual conferences
      - ▶ 2013: Izmir, Turkey
      - ▶ 2014: Buenos Aires, Argentina
      - ▶ 2015: Italy
    - ▶ WWW: website, monthly newsflashes, social media
    - ▶ Workshops
      - ▶ 2013: Monitoring and Surveillance (J'burg), Continence mgmt (Kampala/Kijabe), Fundraising (Izmir), QA/QC (Cairo), Cost-Benefit fortification (Dar es Salaam)
      - ▶ 2014: QA/QC workshop (Casablanca, Douala), Advocacy (Bratislava, Tallinn, Brussels), Multidisciplinary Care (Cape Town)
    - ▶ Stimulating research
    - ▶ Facilitate Networking and Cooperation
-

# Global Expert Panel / Network

Services and  
Care  
Dr Benjamin Warf

Human Rights  
David Morrissey

Public Health  
Dr Klaus Krämer

Chaired By Dr Margo Whiteford

Genetics  
Dr Richard Finnell

Social Inclusion  
Dr Amy McPherson

Causes  
Dr Anne Molloy





Olga, psychologist & MD (NL)

Albert, 91y old (B)

Guro, politician (N)



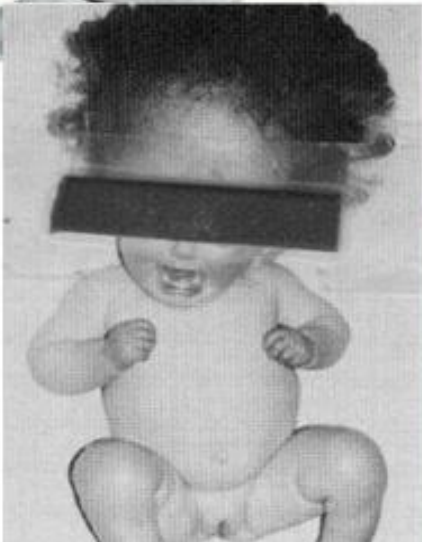
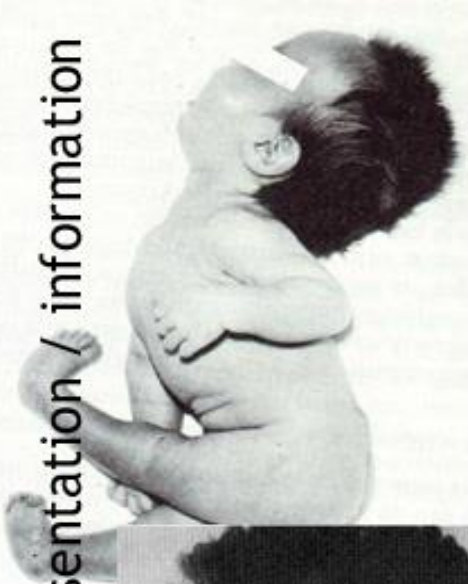
Vicky, lawyer, 2 kids (Guatemala)

Jeffrey, conductor (UK)

Francesca, Co-Worker, mother (K)

# What are neural tube defects (NTDs)?

It is all about presentation / information





# Small defect, a lot of damage

Dr Liptak: “the most complex congenital malformation compatible with life”

- ▶ Nerves interrupted
- ▶ Paralysis below the lesion
- ▶ Incontinence for stool and urine
- ▶ Mobility problems
- ▶ Loss of sensation and risk of pressure wounds
- ▶ Hydrocephalus / secondary malformations (eg. Chiari)
- ▶ Resulting in a lot of medical needs



# BUT: life is more than the medical deficit

- ▶ Concentrate on the abilities and not only at the disabilities
  - ▶ Medical interventions should be limited to absolute minimum.
  - ▶ Less can be more! Conservative is not always a bad word.
    - ▶ ETV/CPC versus shunting
    - ▶ CIC versus urological surgical interventions
    - ▶ Prevention of pressure wounds
    - ▶ Qualitative technical aids
    - ▶ Training (self control and independence)
- 
- ▶ AND: primary prevention!

# Situation without treatment

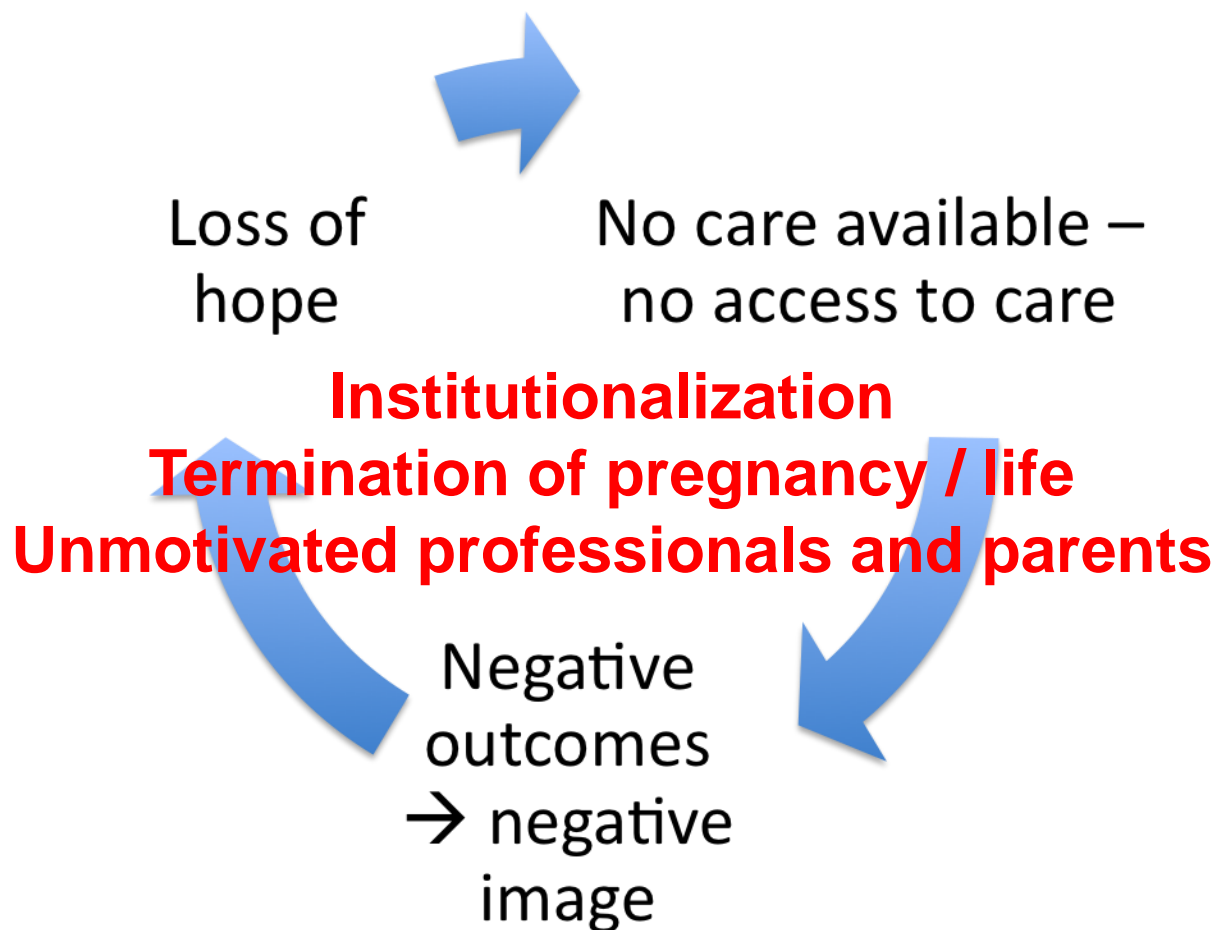




# Situation without treatment

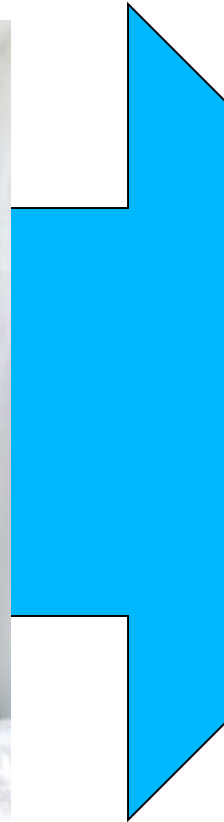


# Negative Cycle





# We try to change this...





# Positive Cycle

Hope

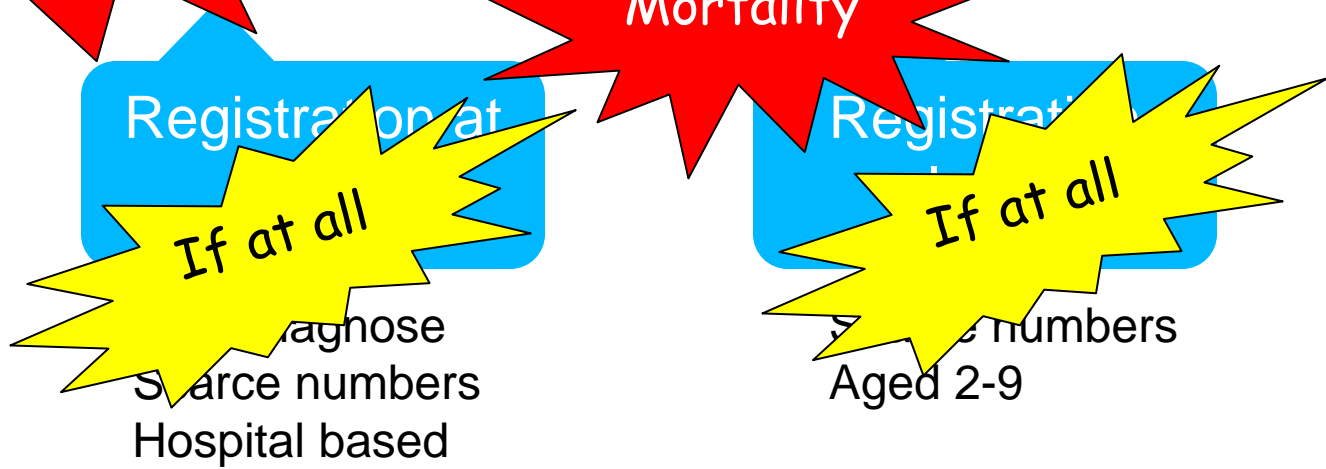
Quality care  
available – access  
to care

**Motivated parents and professionals**  
**Timely referral / improved outcome**  
**Inclusion in society**

Positive  
outcomes  
→ realistic  
image



# When you start looking for Spina Bifida...



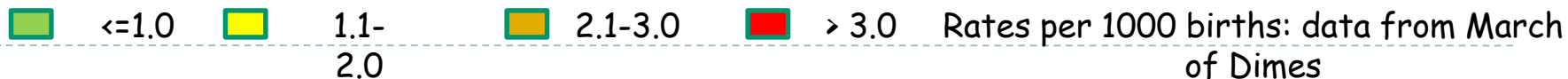
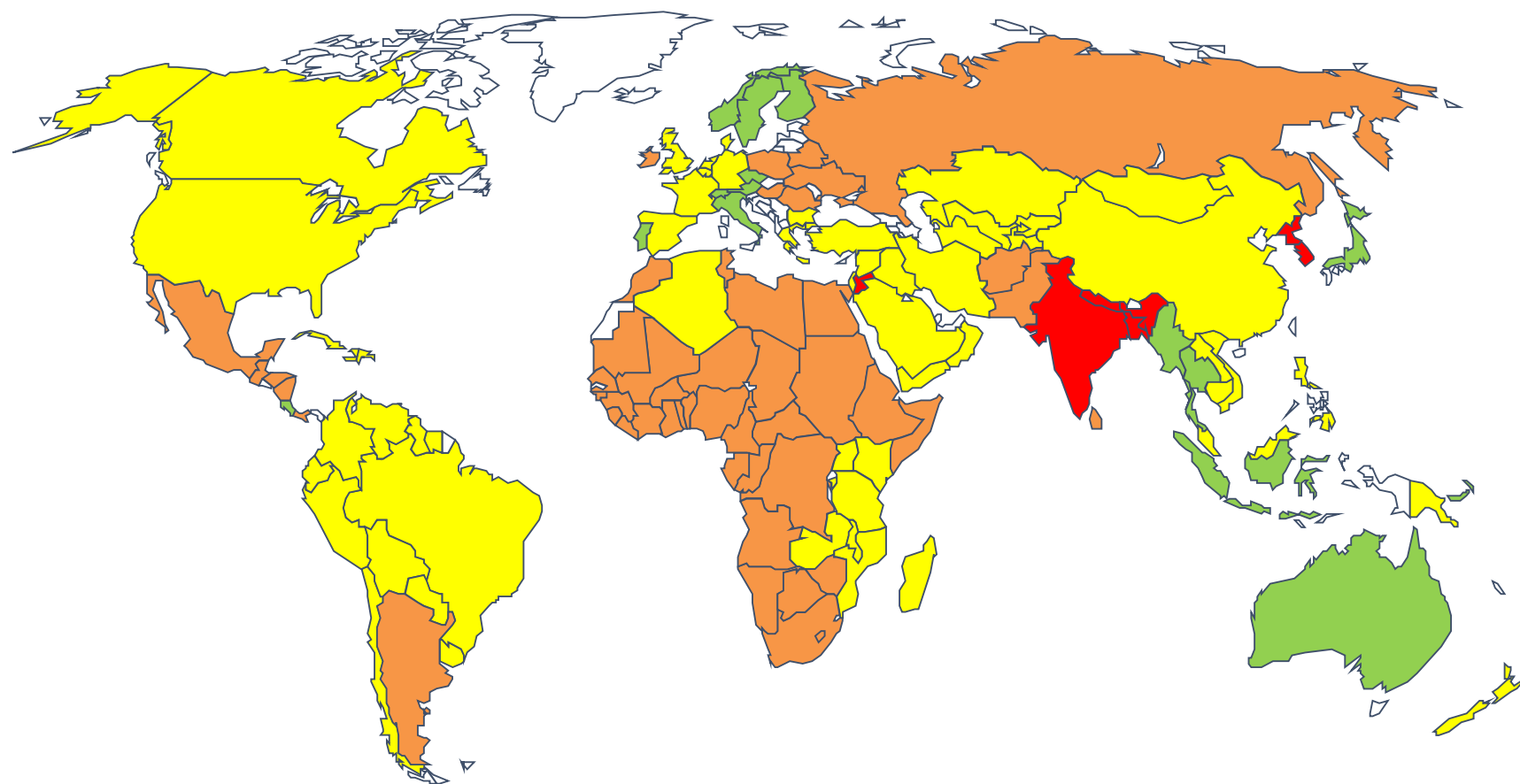
Flour fortification  
FA campaigns  
FA recurrent

Reach?

Reach?

Reach?

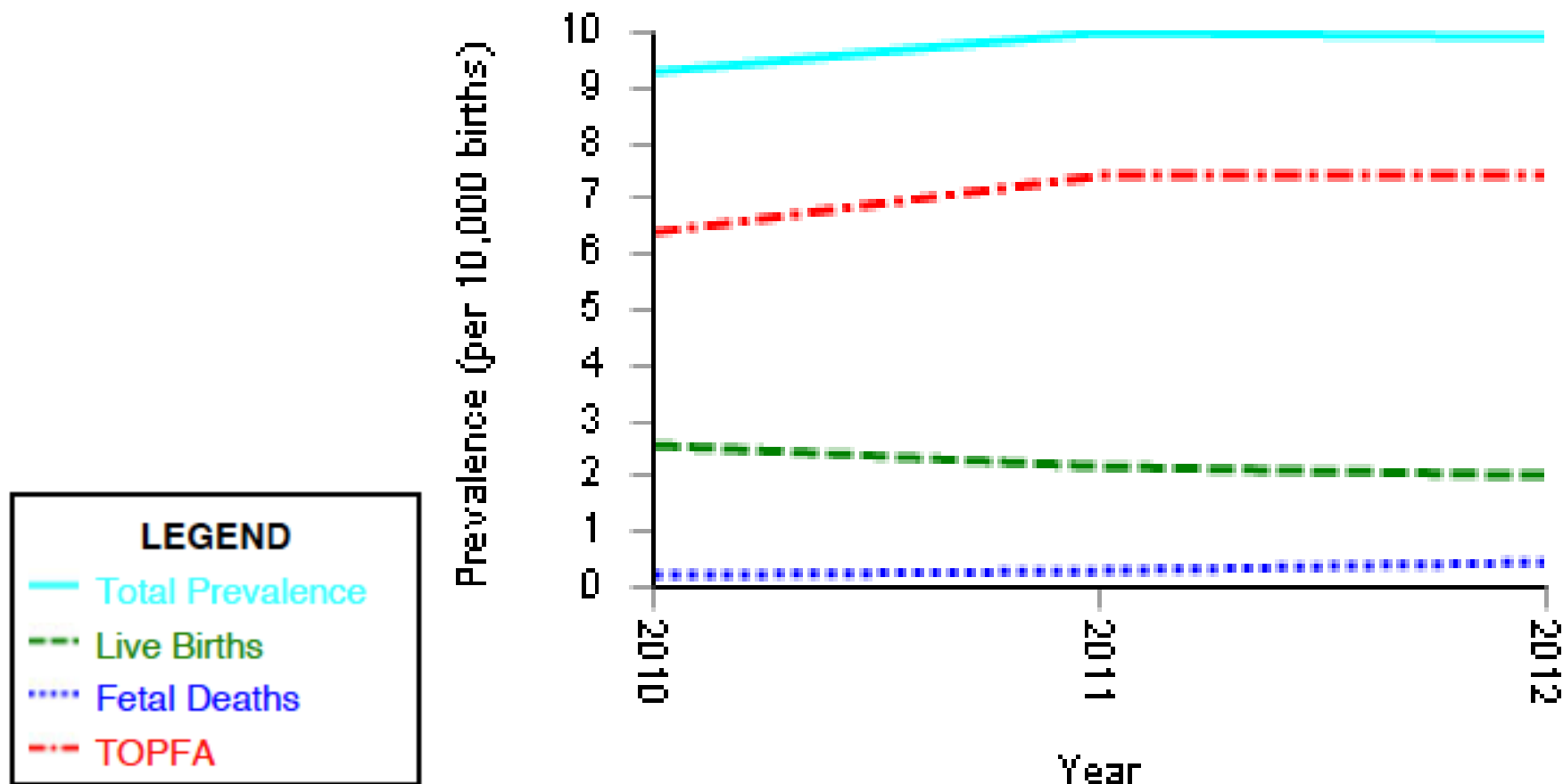
# Prevalence of NTDs, 2001



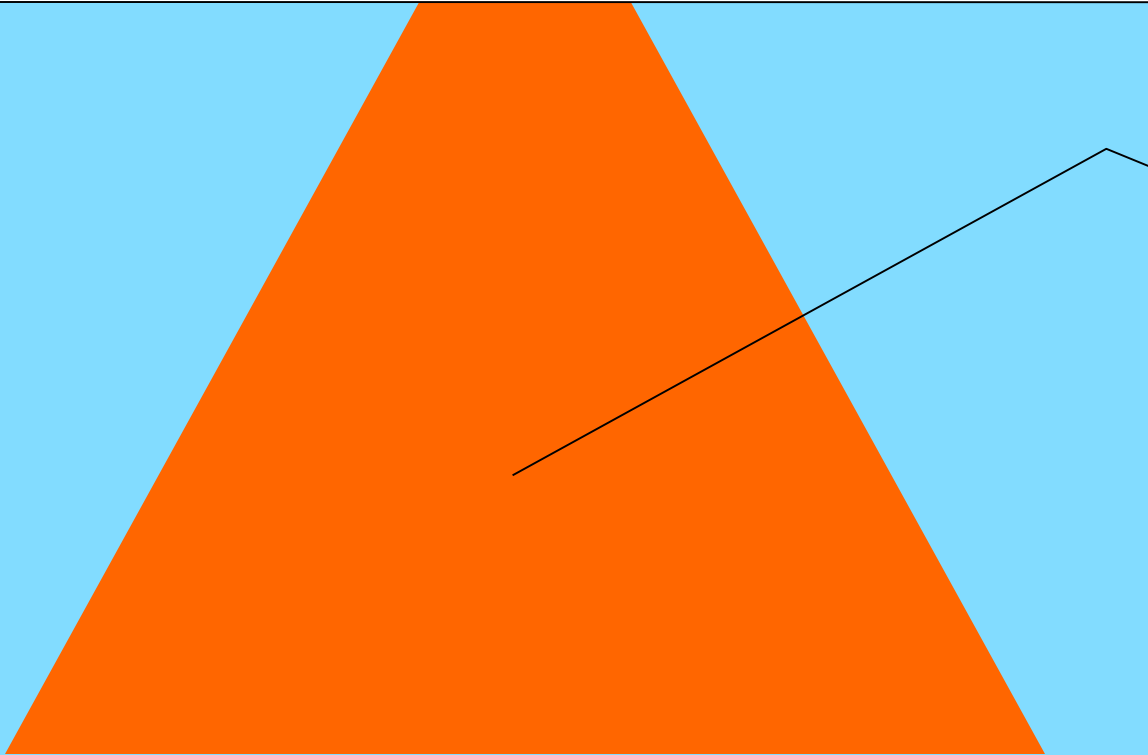
# Measuring... (EUROCAT)

**Prevalence per 10,000 births of Neural Tube Defects,  
for All Full Member Countries, from 2010 - 2012**

## Neural Tube Defects



# Ignoring NTDs is not prevention



Other health  
outcomes:  
FA deficiency  
Low birth weight  
Pre-term birth  
Other birth defects

...

Recurrence?

# Prevention

- ▶ Large proportion of Spina Bifida can be prevented by taking Folic Acid (to 70%)
- ▶ (maybe) higher rate of prevention with other B-vitamins
- ▶ Additional daily intake of 0.4 mg of folic acid
  - ▶ at least two months prior to the conception and the first months of pregnancy
- ▶ Parents at extra risk should take daily 4 mg



# Prevention of NTDs

## Spina Bifida

FA Strategies:  
Supplementation,  
Fortification, Diet, Oral  
contraceptive + Folic Acid,  
...

Improved maternal Health

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## Hydrocephalus

Improved maternal health  
Prevent neo-natal infections  
Combat malnutrition and  
prematurity

# Potential Solution 1: Supplements

## Limitations:

Cost and inconsistent use

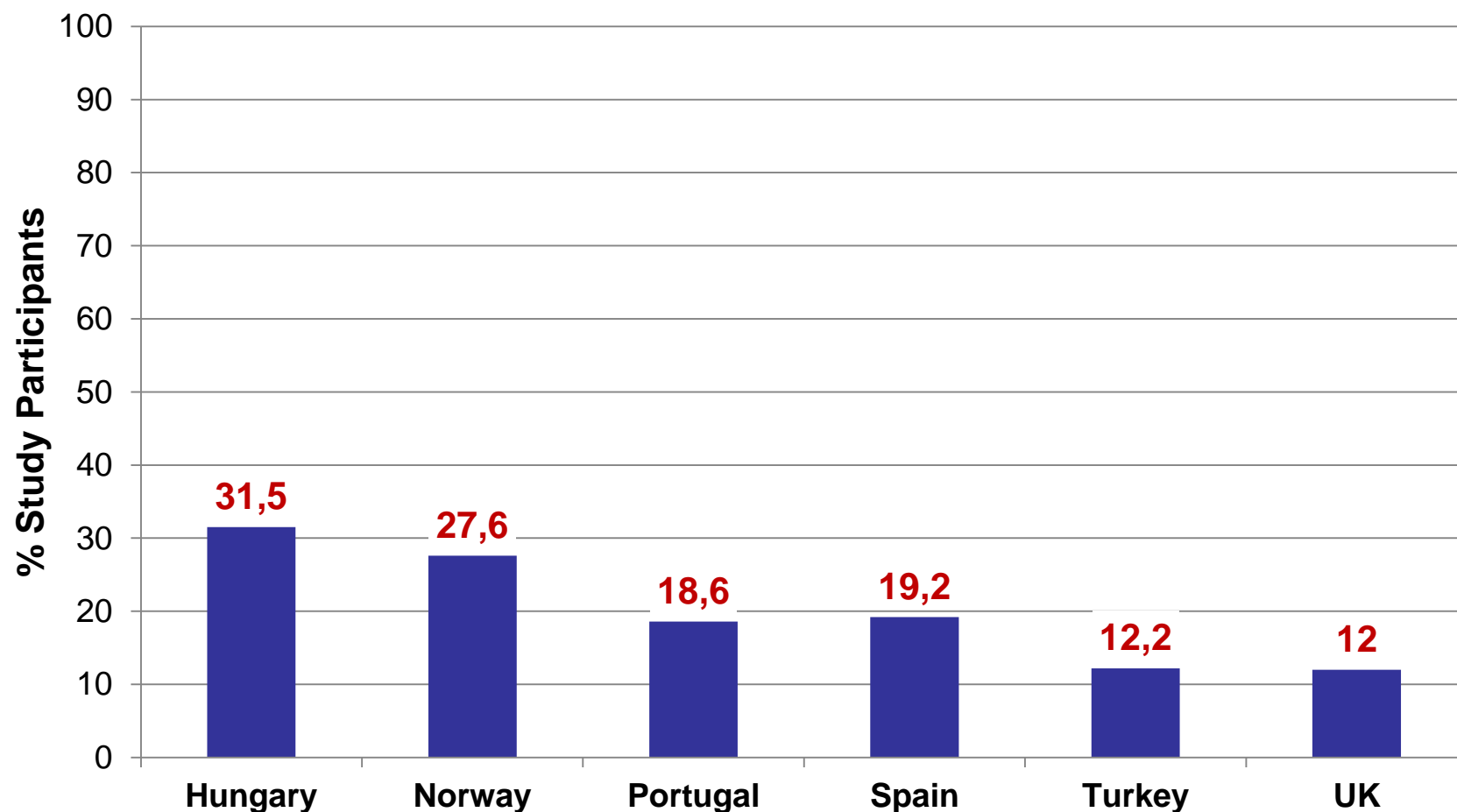
Minority of women use folic acid supplements at the correct time for preventing NTDs (even when the pregnancy is a planned one) – important relation with socio-economic background

*Prior* to conception and during the first 12 weeks of pregnancy, women need 400 microgram folate or folic acid per day.





# Preconceptional Folic Acid Use

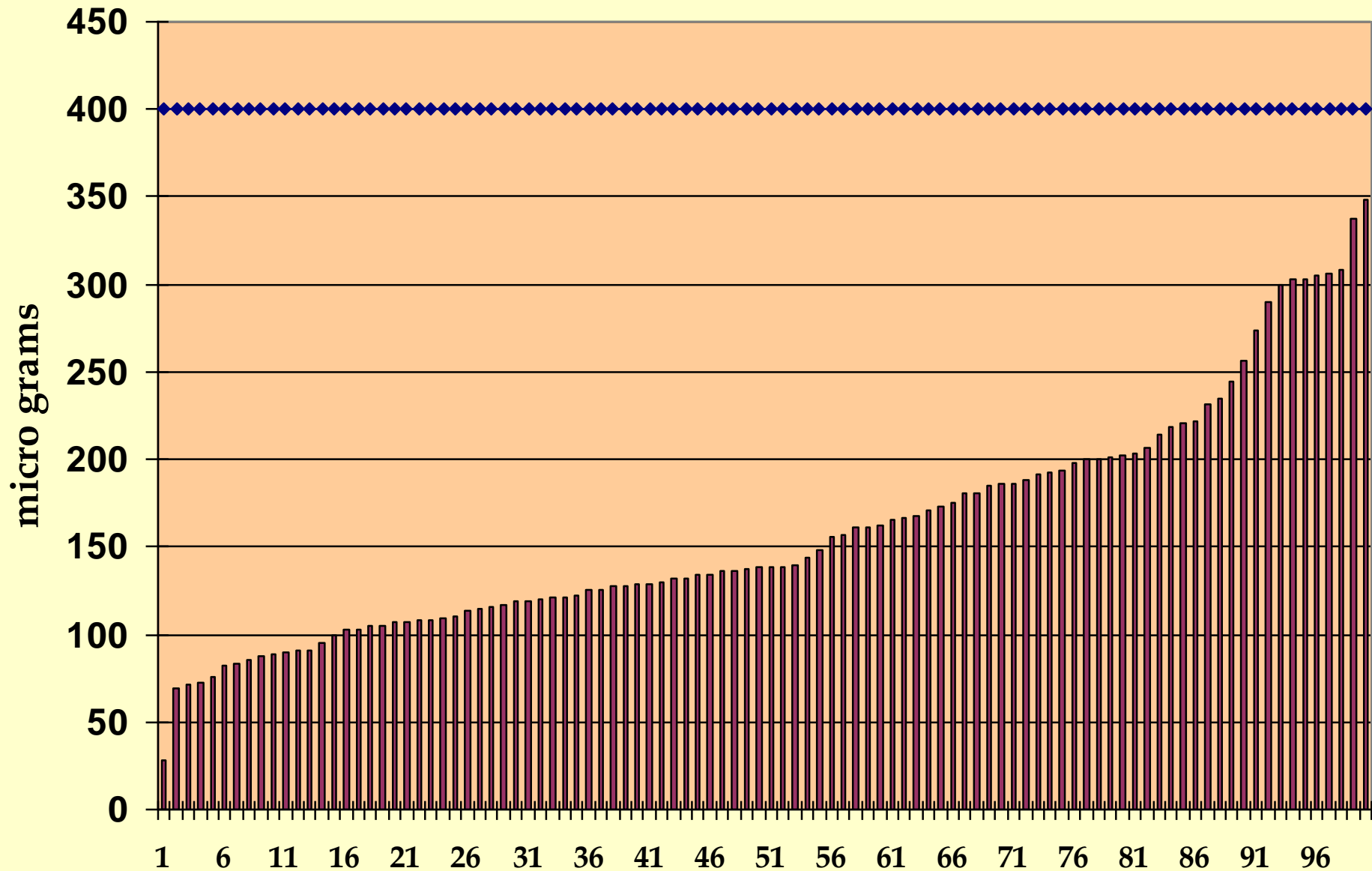


1. Paulik E et al. Eur J Obstet Gynecol Reprod Biol. 2009 Jul; 145(1) 49-52.
2. Nilson R et al. Am J Clin Nutr 2006; 84 : 1134-1141.
3. Pinto, E et al. Public Health Nutr. 2009 Jul; 12(7):922-931.
4. Navarrete-Muñoz EM. Med Clin (Barc). 2010 Nov 13;135(14):637-43.
5. Baykan Z et al. Arch Gynecol Obstet (2011) 283:1249-1253.
6. Brough L. J Hum Nutr Diet. 2009 Apr; 22(2): 100-107.

BUT:

## Daily Intake of Folic Acid

N= 100



# 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



# What is Flour Fortification?

Fortification adds vitamins and minerals to flour during the milling process so that the foods made with wheat flour are more nutritious.

Flour = wheat and maize flour (rice is very different)

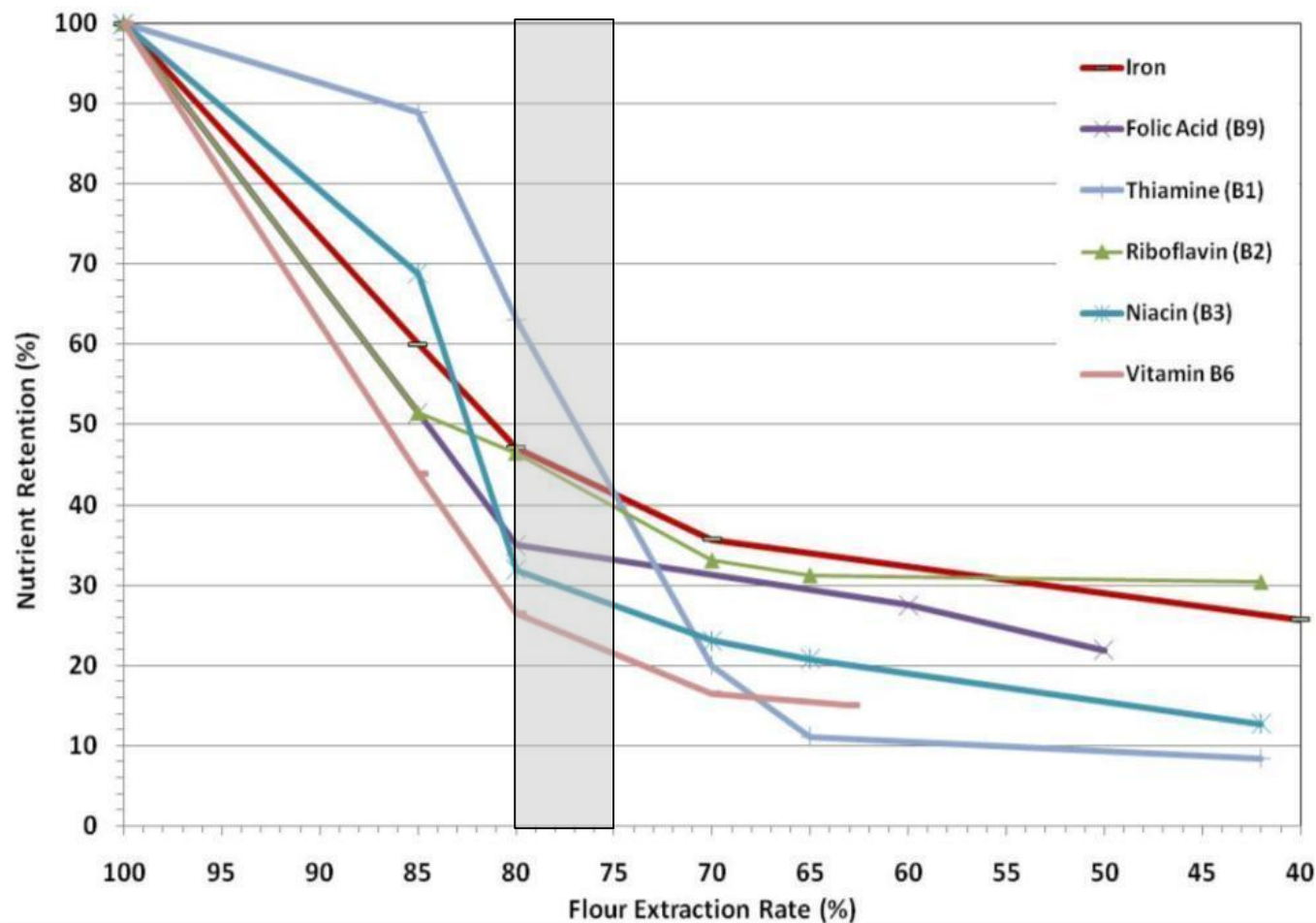
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# Essential Nutrients are Lost During the Wheat Milling Process



INTERNATIONAL  
FEDERATION  
for  
SPINA BIFIDA  
and  
HYDROCEPHALUS

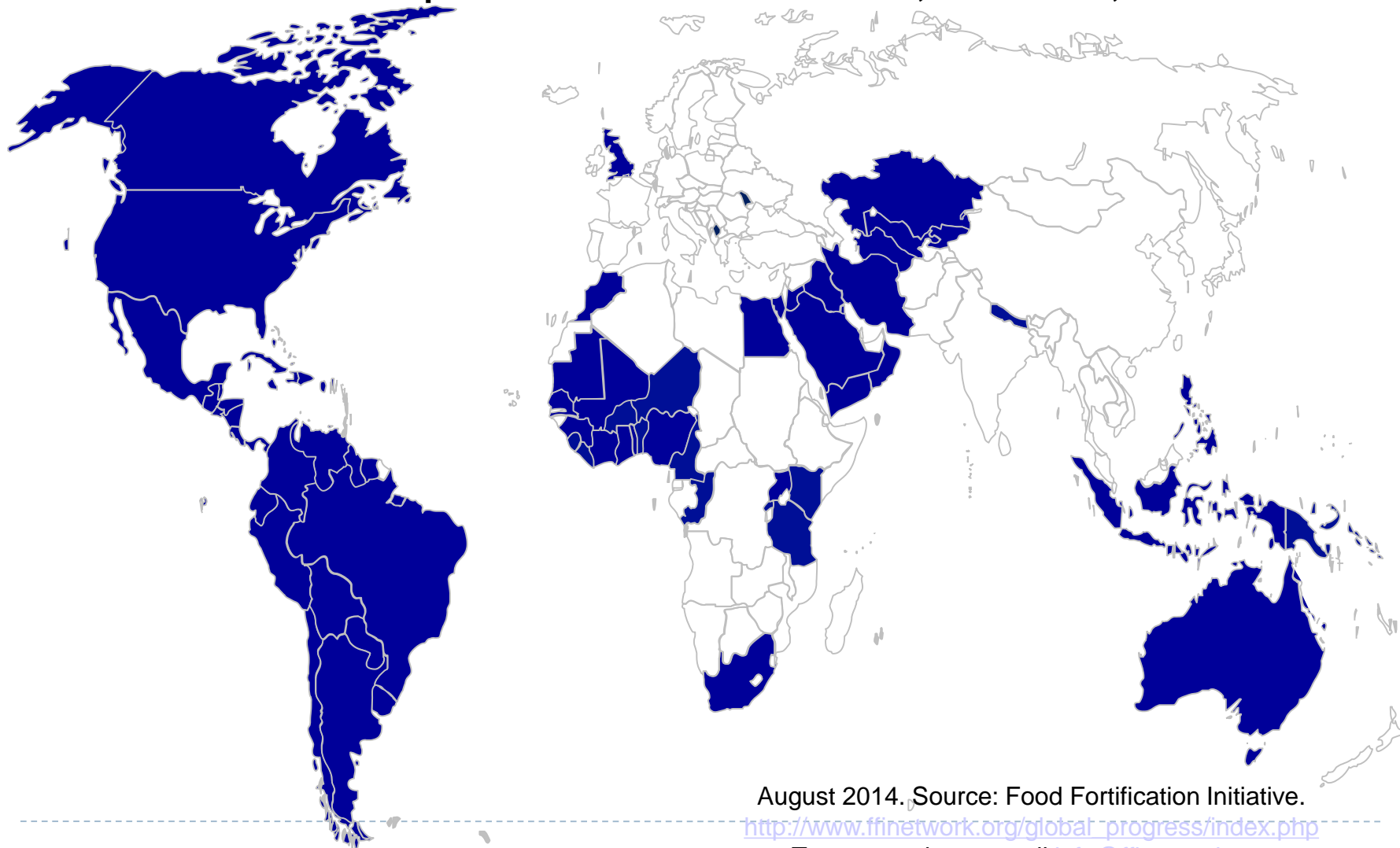


Adapted from "Wheat in Human Nutrition" by W.R. Aykroyd and  
Joyce Doughty

Food and Agriculture Organization of the United Nations, Rome

# Grain Fortification Legislation

**81 countries require fortification of wheat flour, maize flour, and/or rice**



August 2014. Source: Food Fortification Initiative.

[http://www.ffinetwork.org/global\\_progress/index.php](http://www.ffinetwork.org/global_progress/index.php)

To request data, e-mail [info@ffinetwork.org](mailto:info@ffinetwork.org)



# IF Supports Fortification



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).

# Consensus for Fortification





# Resolution on Birth Defects

## WHO WHA 63.17



*To support Member States in developing national plans for implementation of effective interventions to prevent and manage birth defects* within their national maternal, newborn and child health plan, strengthening health systems and primary care, *including* improved coverage of vaccination against diseases such as measles and rubella, of addressing tobacco and alcohol use among pregnant women and women trying to conceive, and *food fortification strategies, for the prevention of birth defects*, and promoting equitable access to such services

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# Conclusions

1. Prevention is a crucial part of the IF mission
  2. Prevention is a difficult public health issue
  3. Each prevention strategy has its challenges
  4. IF networks and cooperates with others to reach mission
  5. Europe is not fortifying
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# Thank you!

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