What do you prevent with fortification

Lieven Bauwens
Secretary General - International Federation for Spina Bifida and Hydrocephalus
Chair person – Child-Help Belgium and Child-Help International

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International Federation for Spina Bifida and Hydrocephalus
Our focus

Data

Preconception

Prevention

Right to life

Access to health care

Registry

Life-long follow-up

Right to Care

Registration at birth

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?
What is spina bifida?
What is hydrocephalus?
What is hydrocephalus?
Perception
Unfortunately
# People United for Spina Bifida and Hydrocephalus – PUSH


### Spina Bifida Score: 1.5 ★

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

### Hydrocephalus Score: 1.5 ★

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

<table>
<thead>
<tr>
<th>ETHIOPIA</th>
<th>Folate studies</th>
<th>Prevalence Data</th>
<th>Mortality Data</th>
<th>Prevention</th>
<th>Access to Care</th>
<th>Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SPINA BIFIDA</strong></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HYDROCEPHALUS</strong></td>
<td>N/A</td>
<td>X</td>
<td>X</td>
<td></td>
<td>No Data</td>
<td></td>
</tr>
</tbody>
</table>

### Recommendations

**SPINA BIFIDA**
- 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

**HYDROCEPHALUS**
- Increase the number of neurosurgeons in the 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

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Data
Lack of data

Rates per 1000 births: data from March of Dimes
Focus on surveillance

Data drives efforts in prevention
Data drives efforts in care provision

GUIDELINE:
OPTIMAL SERUM AND RED BLOOD CELL FOLATE CONCENTRATIONS IN WOMEN OF REPRODUCTIVE AGE FOR PREVENTION OF NEURAL TUBE DEFECTS
Ignoring NTDs is not prevention

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
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

Different strategies

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

<table>
<thead>
<tr>
<th>FOOD FOLATE</th>
<th>FOLIC ACID</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Found in liver, dark green vegetables, lentils, beans, oranges,</td>
<td>• Found in fortified foods and supplements</td>
</tr>
<tr>
<td>• Water-soluble</td>
<td>• Stable</td>
</tr>
</tbody>
</table>
| • 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

• 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

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).
What cereal would you fortify in Ethiopia?
Why are cereals a good vehicle?

- Staple food
  - Carbohydrate source
  - Daily consumed
  - High consumption levels

- Cereal processing industry
  - Well established world-wide
  - Large scale operations
Cereal processing
Industrially Milled Flour and Rice Fortification Legislation

- **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](http://www.FFInetwork.org)) November 2016
Role of SB associations

- 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
Blancaflor

HARINA LEUANGTE

con Vitazinc

Fuente de Vitaminas A, B6, B12, D y Zinc

La Original

LISHE BORA
It is the finest flour with enough nutrients for better health

Ingredients
Finger Millet
Maize
Rice
Groundnuts
Soya Beans
Wheat
Sorghum
Ufuta

Nutrients
Protein 15%
Fat 7.25%
Fibre 1.0%
Moisture 7.8%

Maelezo:
For more taste you can add some sugar, fresh milk or sour milk

International Federation for Spina Bifida and Hydrocephalus
Health economic evaluation

• QALYs = life years $\times$ quality of life
  – Quality of life: death = 0; perfect health = 1
  – Example: Intervention A versus B
Gapminder – child mortality
Gapminder – health costs
Economic impact

• 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

## Cost of (No) Folate Fortification

<table>
<thead>
<tr>
<th>Area</th>
<th>Lifetime cost €/NTD case</th>
<th>Population Million</th>
<th>Birth rate %</th>
<th>Newborn Thousand</th>
<th>NTD rate %</th>
<th>Economic cost Million €</th>
</tr>
</thead>
<tbody>
<tr>
<td>NL</td>
<td>243,000</td>
<td>17</td>
<td>1.07</td>
<td>182</td>
<td>0.09</td>
<td>40</td>
</tr>
<tr>
<td>D</td>
<td>243,000</td>
<td>82</td>
<td>0.82</td>
<td>672</td>
<td>0.10</td>
<td>163</td>
</tr>
<tr>
<td>EU</td>
<td>200,000</td>
<td>500</td>
<td>1.06</td>
<td>5,300</td>
<td>0.10</td>
<td>1,060</td>
</tr>
<tr>
<td>India</td>
<td>20,000</td>
<td>1,200</td>
<td>2.27</td>
<td>27,240</td>
<td>0.36</td>
<td>1,961</td>
</tr>
</tbody>
</table>

*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

- 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 (e.g., 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

A no-brainer to fortify?

- 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

• 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

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

⇒ Resulting in extremely high mortality
Access to care: cheap shunts
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:

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).

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

Introduction of ETV by Dr Warf in Uganda
ETV/CPC
Continence management program with CIC and bowel wash-out

Top medicine

Over 4000 children in continence management follow-up

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

• Spina 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
THANK YOU!

Lieven Bauwens
lieven.bauwens@ifglobal.org

www.ifglobal.org
www.pu-sh.org
www.child-help.be