High Level Advocacy + On the Ground
The Case of Spina Bifida and Hydrocephalus.

Lieven Bauwens, Secretary General
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What I want to talk about

International Federation for Spina Bifida and Hydrocephalus

- Example 1: Prevention
- Example 2: Right to Health
Spina Bifida (NTDs)
Hydrocephalus
What is IF?

- International Federation for Spina Bifida and Hydrocephalus
  - Global umbrella organisation
  - 57 national / regional members (organisations of people with SB/H or their parents) / 51 countries (= General Assembly)
  - 9 member Board of Directors + SG ex officio
  - HQ in Brussels, staff in NL, UK, liaison persons in Kampala, Ho Chi Minh, Beijing and Buenos Aires

International Mandate

- UN and its agencies
- EU institutions
- International Development
Areas that we work in

Preconception
Prevention
Right to life

Access to health care

Life-long follow-up

Right to Health

DATA

International Federation for Spina Bifida and Hydrocephalus
Perception
Unfortunately
Institutionalization
Termination of pregnancy / life
Unmotivated professionals and parents

Negative Cycle

Loss of hope
No care available – no access to care

Negative outcomes
→ negative image
Positive Cycle

Hope

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

Quality care available – access to care

Positive outcomes → realistic image
We are not alone

A better life. For everyone.

PUSH! Alliance unites organisations as the global voice to accelerate spina bifida and hydrocephalus prevention, and to realise optimal care and better quality of life for those affected.

LEARN MORE

PUSH! Global Alliance

PUSH! Global Alliance is a platform for organisations to advance the greatest benefit to those affected by spina bifida and hydrocephalus.

Our mission To unite organisations as the global voice, to accelerate spina bifida and hydrocephalus prevention, and to realize optimal care and a better
### Example report card


<table>
<thead>
<tr>
<th>Spina Bifida Score: 1.5</th>
<th>Hydrocephalus Score: 1.5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spina Bifida - SCORE KEY</strong></td>
<td><strong>Hydrocephalus - SCORE KEY</strong></td>
</tr>
<tr>
<td>Excellent = 6 stars</td>
<td>Excellent = 5 stars</td>
</tr>
<tr>
<td>Good = 4-5 stars</td>
<td>Good = 3-4 stars</td>
</tr>
<tr>
<td>Improvements needed = 0-3 stars</td>
<td>Improvements needed = 0-2 stars</td>
</tr>
</tbody>
</table>

#### ETHIOPIA

<table>
<thead>
<tr>
<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>SPINA BIFIDA</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>No Data</td>
<td>★</td>
</tr>
<tr>
<td>HYDROCEPHALUS</td>
<td>N/A</td>
<td>X</td>
<td>X</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.
  - Increase the number of neurosurgeons in the country who can provide care to children and adults with spina bifida and hydrocephalus.

- **Hydrocephalus**
  - Undertake coverage and effectiveness studies for existing programs (voluntary fortification/supplementation), and explore opportunities for mandatory fortification policy of staple foods.
  - Improve access to antenatal care.
  - Ensure that programmes and policies supporting the rights of persons with disabilities are implemented and enforced.

#### Additional Information:

The International Federation for Spina Bifida and Anencephaly has donated shunts to 5 hospitals, has assisted with the availability of endoscopic third ventriculostomy, and is planning to start a spina bifida and hydrocephalus association in 2016.

The report cards, developed by PUSH! Global Alliance, provide country and regional snapshots of indicators for Spina Bifida and Hydrocephalus Surveillance, Prevention and Care. For more details on the PUSH! methodology, indicators, scoring criteria, and full recommendations, please see the technical notes on next two pages or visit [www.push.org](http://www.push.org).
Advocacy example 1:

PREVENTION
Prevention = Preconception

Access to health care

Life-long follow-up

Registration prenatally or at birth

Registry
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 the conception and the first months of pregnancy
- Parents at extra risk should take daily 4 mg
Overlaid data of Daly et al 1995 and Crider et al 2014
Data
Article 18 - Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including …

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.
Lack of data

Rates per 1000 births: data from March of Dimes
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?
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
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).
Consensus for Fortification
Grain Fortification Legislation

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

August 2015. Source: Food Fortification Initiative.
To request data, e-mail info@ffinetwork.org
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
5 CONDITIONS TO DESTROY THROUGH FOOD FORTIFICATION

SPINA BIFIDA
Each year 1,500 babies in the US are born with spina bifida, a birth defect causing paralysis or brain damage. Spina bifida can be prevented by boosting folic acid intake before and during pregnancy. More governments in countries across the globe are making folic acid flour fortification mandatory.

ANAEMIA
Anaemia, a condition where the number of red blood cells in the body is too low, is a major cause of maternal death. Iron, vitamin B12 and folic acid fight anaemia and its symptoms like exhaustion. Fortifying everyday foods (e.g., bread in Egypt) provides up to 40% of women’s daily iron needs.

GOITER
Enlarged thyroid gland due to low iodine in the diet. Iodine deficiency early in life can cause brain damage in young children. Adding iodine to salt can fight goiter and other iodine deficiencies. The World Bank reports that global salt iodization would cost just US$0.05 per child per year.

NIGHTBLINDNESS
An estimated 250,000–500,000 vitamin A deficient children become blind every year, half dying within 12 months of losing their sight. Large scale fortification programs add vitamin A to vegetable oil, maize and wheat flour.

RICKETS
Not enough vitamin D and calcium weakens bones in babies and children – a condition called rickets. In many countries, fortifying milk with vitamin D is mandatory.

Read more at www.gainhealth.org
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
Advocacy example 2:

RIGHT TO CARE
Prevention = Preconception

Access to health care

Life-long follow-up

Registration prenatally or at birth

Registry
Life long care

Survival
- Life-saving surgeries
- Shunts
- Counseling to new parents

Early years
- Early intervention and (re-)habilitation
- First mobility equipment
- Accessible childcare

School years
- Inclusive education and teaching assistance
- Accessibility of schools and other activities
- Interaction with peers

Transition
- New health needs
- Beginning of independent life
- Gaining life skills

Adulthood
- Work and social support
- Family life
- Sexual and reproductive health

Ageing
- Prolonging independent life
- Age-related health care needs
- Dignified retirement
CRPD Article 25 – Health (1/4)

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.
Resolution on Birth Defects
WHO WHA 63.17 (2010)

Urge member states...

(9) to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children and give priority to the child’s well-being and support and facilitate families in their child-care and childraising efforts;

(11) to support families who have children with birth defects and associated disabilities, and ensure that appropriate habilitation and support is provided to children with disabilities;
Barriers to treatment

• Lack of neurosurgical manpower / available care
• Poverty
• Corruption
• Lack of information / training
• Negative stereotypes on SB (referrals)
• Lack / cost of transport
• Poor infrastructure

→ Resulting in extremely high mortality or secondary disabilities

Regions of insecurity
Example 1: On the ground, access to health
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).

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,

*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
Introduction of ETV by Dr Warf in Uganda
ETV/CPC
Priority Assistive Products List
Example 2: high-level, OHCHR state review process

STATE submits report

COMMITTEE's list of issues

STATE submits answers

COMMITTEE's follow-up

STATE implements recommendations

COMMITTEE’S concluding observations

COMMITTEE’S SESSION
State presents the report and respond to the Committee’s questions
Where we can intervene

Civil society

STATE submits report

COMMITTEE list of issues

STATE submits answers

COMMITTEE's follow-up

STATE implements recommendations

COMMITTEE's concluding observations

Civil society

COMMITTEE'S SESSION

At national and international level, alone and with partners
Example: review of European Union (May 2015)

The state report (2014) gives a long overview on competences and actions of the European Union in the area of health

Health (art. 25) 29. Please explain how the European Union can prevent disability-based discrimination in health-care service provision and ensure the training of health-care professionals on the human rights of persons with disabilities, in the light of its shared competences with the European Union member States in the field of health care.

Committee’s list of issues to European Union

Responses by European Commission (my summary)
- Referral to competences of EU and member states
- EU Health programme supporting exchange of best practise
- Announcement of pilot project

European Union’s response to the Committee
Health (art. 25)
62. The Committee is concerned that discrimination on the grounds of disability is not explicitly prohibited in the field of health care. It notes the barriers faced by persons with disabilities in accessing health care in different member States.

63. The Committee recommends that the European Union explicitly prohibit discrimination on the grounds of disability in the field of health care and take measures to ensure access to quality health care for all persons with all types of disabilities. It also recommends that the European Union evaluate the impact of the European Parliament and the Council of the European Union Directive 2011/24/EU on patients’ rights in cross-border health care with regard to gaps in access for persons with disabilities, including accessible information, reasonable accommodation and training of professionals.
Individual Organizations of Persons with Disabilities (DPOs) join forces, develop a strategy and joint position.

They are supported by disability rights and development NGOs.

But then came SDGs…
All stakeholder groups join forces to coordinate and strengthen advocacy efforts towards their government. This includes the national disability community. For example, a message could be accessibility for children with disabilities, which would be coordinated with the national youth community, national education community, and national health community.

IDDC slides
All stakeholder groups advocate the same, coordinated messages to all government offices.

Stakeholders identify which government agency or ministry is responsible for overseeing and coordinating national implementation of the SDGs in order to ensure stakeholder participation.
Thank you!

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Pictures were taken from different sources to illustrate my presentation.

International Federation for Spina Bifida and Hydrocephalus, Pierre Mertens, Lieven Bauwens, Ernie Bufflo, Aaron Fotheringham, the Telegraph, Redefining Spina Bifida, Adriana Tontsh, dr. Ahuka Longombe, KSL news, the Food Fortification Initiative, Dieter Telemans (CCBRT), Donna Rose, Zero Project, OHCHR.