What are we trying to prevent?
A GLOBAL VIEW ON REGISTRATION, PREVENTION AND CARE OF SPINA BIFIDA & HYDROCEPHALUS THROUGH IF PROGRAMMES

Lieven Bauwens, Secretary General
Casablanca, 11 May 2014
What we would like to cover:

- Setting the scene
  - What is IF?
  - What are Neural Tube Defects (NTDs)?
  - What is Hydrocephalus?
- Registration and prevention
- Care of NTDs and Hydrocephalus
  - Surgery
  - Lifelong care
  - User participation
What is IF?

- International Federation for Spina Bifida and Hydrocephalus
  - Global umbrella organisation
  - 51 national / regional members (organisations of people with SB/H or their parents) / 47 countries

- HQ in Brussels, liaison person in Kampala, Beijing and Buenos Aires
What is IF?

- **Mission**
  - The mission of IF is to decrease the incidence of Spina Bifida and Hydrocephalus by primary prevention and to improve the quality of life of those affected.

- **Domains**
  - Human Rights
  - Prevention
  - International Solidarity
  - Network Development
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

www.ifglobal.org
Activities

- An global network of knowledge
  - Parents, professionals and adults with SB/H, national and regional organizations
- Annual conferences
  - 2013: Turkey
  - 2014: Argentina
  - 2015: Italy
  - 2016: China (?)
- 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
What is Spina Bifida?

Birth defect that needs care and surgery at birth

Develops early in pregnancy

Can be prevented by folic acid

Spina Bifida (and related Hydrocephalus)
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 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!
What are neural tube defects (NTDs)?
What is Hydrocephalus?

CSF = Cerebrospinal fluid

Production of CSF
Circulation / function
Absorption of CSF

CSF = Cerebrospinal fluid
Situation without treatment
Situation without treatment
Negative Cycle

Institutionalization
Termination of pregnancy / life
Unmotivated professionals and parents
Situation in Africa
Positive Cycle

Hope

Quality care available – access to care

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

Positive outcomes → realistic image
IF projects in East-Africa

- Karthoum, Sudan
- Mbarara, Kampala, Gulu, Mbale, Uganda
- Kijabe, Kenya
- Dar es Salaam, Arusha, Moshi, Tanzania
- Lusaka, Zambia
- Blantyre, Malawi

Medical material, training, etc to many more countries (RDC, Ethiopia, Somalia …)
When you start looking for Spina Bifida...

- **Preconception care**
- **Preventative measures**
- **Access to health care (capacity)**
- **Inclusion in society, follow-up care**

**Undernutrition**

**Lifestyle**

**Environmental risks**

**Registration at birth**

**Registration later**

**MORTALITY**

- Diagnosis
- Scarce numbers
- Hospital based

**Co-morbidities**

**Reach?**

**Flour fortification**

**FA campaigns**

**FA recurrent**

**If at all**
Prevalence of NTDs, 2001

Rates per 1000 births: data from March of Dimes
Measuring… (EUROCAT)

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

[Graph showing prevalence trends from 2010 to 2012 with different lines representing different categories such as total prevalence, live births, fetal deaths, and TOPFA.]
Ignoring NTDs is not prevention

Other health outcomes:
- FA deficiency
- Low birth weight
- Pre-term birth
- Other birth defects
- …
- Recurrence?
Prevention of NTDs

- Large proportion of Spina Bifida can be prevented by taking Folic Acid (to 70%)
- (maybe) higher rate of prevention with other B-vitamins
- 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 + FA
- Improved maternal health

**Hydrocephalus**

- Improved maternal health
- Prevent neo-natal infections
- Combat malnutrition and prematurity
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 NTDs (eg: study prof. dr. Steegers, Rotterdam; fumonisin risk)
  - Families that include a person with a disability are at higher risk of poverty
    - Direct / Indirect costs
    - “Care-giver costs”
    - Loss of income

Care in LMIE
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

→ 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

Distances:
- Create a network of CBR projects and outreach clinics

Money:
- Doing less but better. Doing only what improves the quality of life.
- Need for (public) health insurance

Referrals:
- Fighting stereotypes through education
- Parent groups fighting for the rights of their kids
Access to care: low-cost 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:

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,

- 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 measuring tape**
Introduction of ETV (Dr Vloebergs)
Dr Warf in Uganda
ETV/CPC
Mbale, Uganda, since 2001
Doctors try new shunt-free treatment at Primary Children's Hospital

By Ed Yeates

March 10th, 2014 @ 7:08pm

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Continence management program with CIC and bowel wash-out
No expensive urodynamics. Parents train parents.
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
Spina Bifida teams in Europe and USA (pediatric, some adult) are under one roof.
Parental Hope!

Role models: UNCRPD, art. 25, access to health care
Parents take over
User participation in all aspects of care
Thank you!