

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), Continece 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
-



Olga, psychologist & MD (NL)

Albert, 91y old (B)

Guro, politician (N)



Vicky, lawyer, 2 kids (Guatemala)

Jeffrey, conductor (UK)

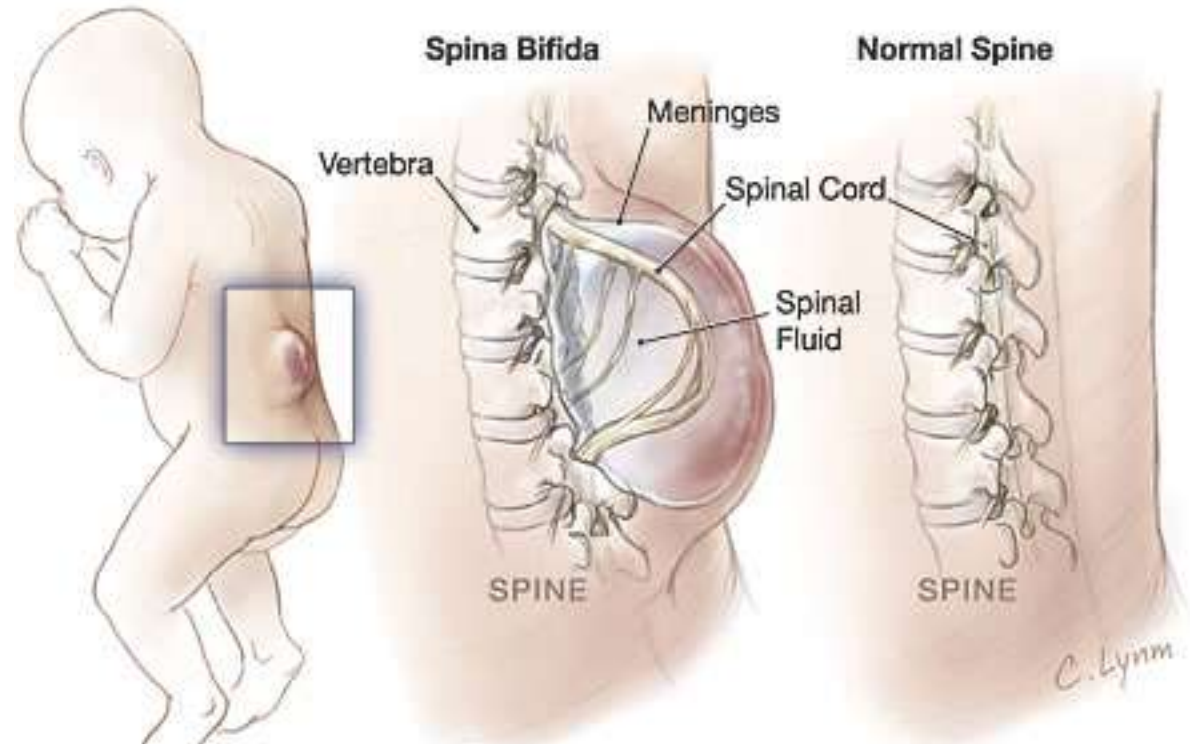
Francesca, Co-Worker, mother (K)

What 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



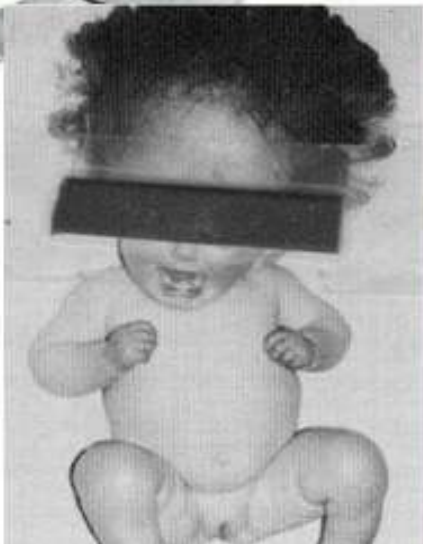
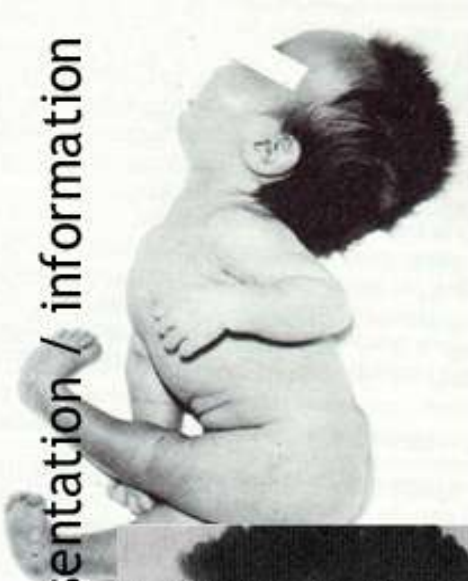
BUT: life is more than the medical deficit



- ▶ 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)?

It is all about presentation / information



What is Hydrocephalus?

Production of CSF

Circulation / function

Absorption of CSF

CSF = Cerebrospinal fluid

Situation without treatment



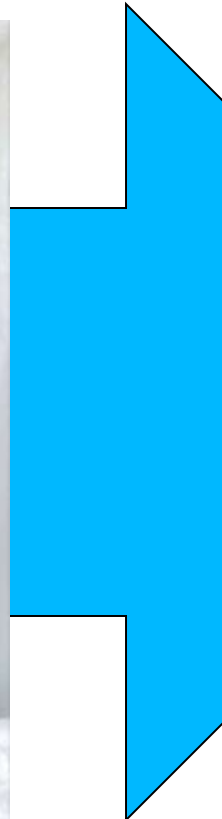
Situation without treatment



Negative Cycle



Situation in Africa



Positive Cycle

Hope

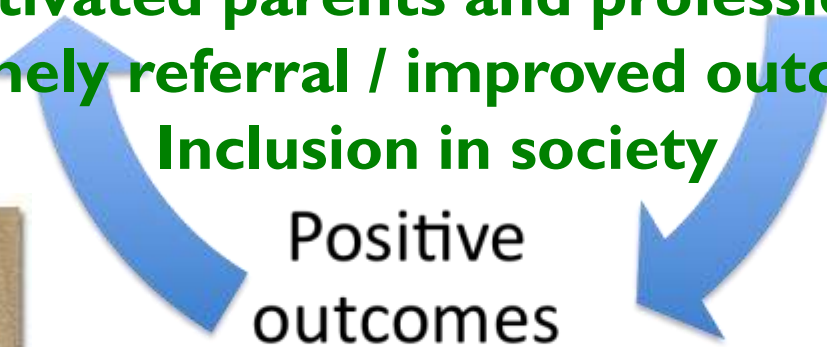


Quality care
available – access
to care



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

Positive
outcomes
→ realistic
image



IF projects in East-Africa



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SPINA BIFIDA
and
HYDROCEPHALUS



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 ...)

Rising
Above
Disability



www.avsi.org



When you start looking for Spina Bifida...



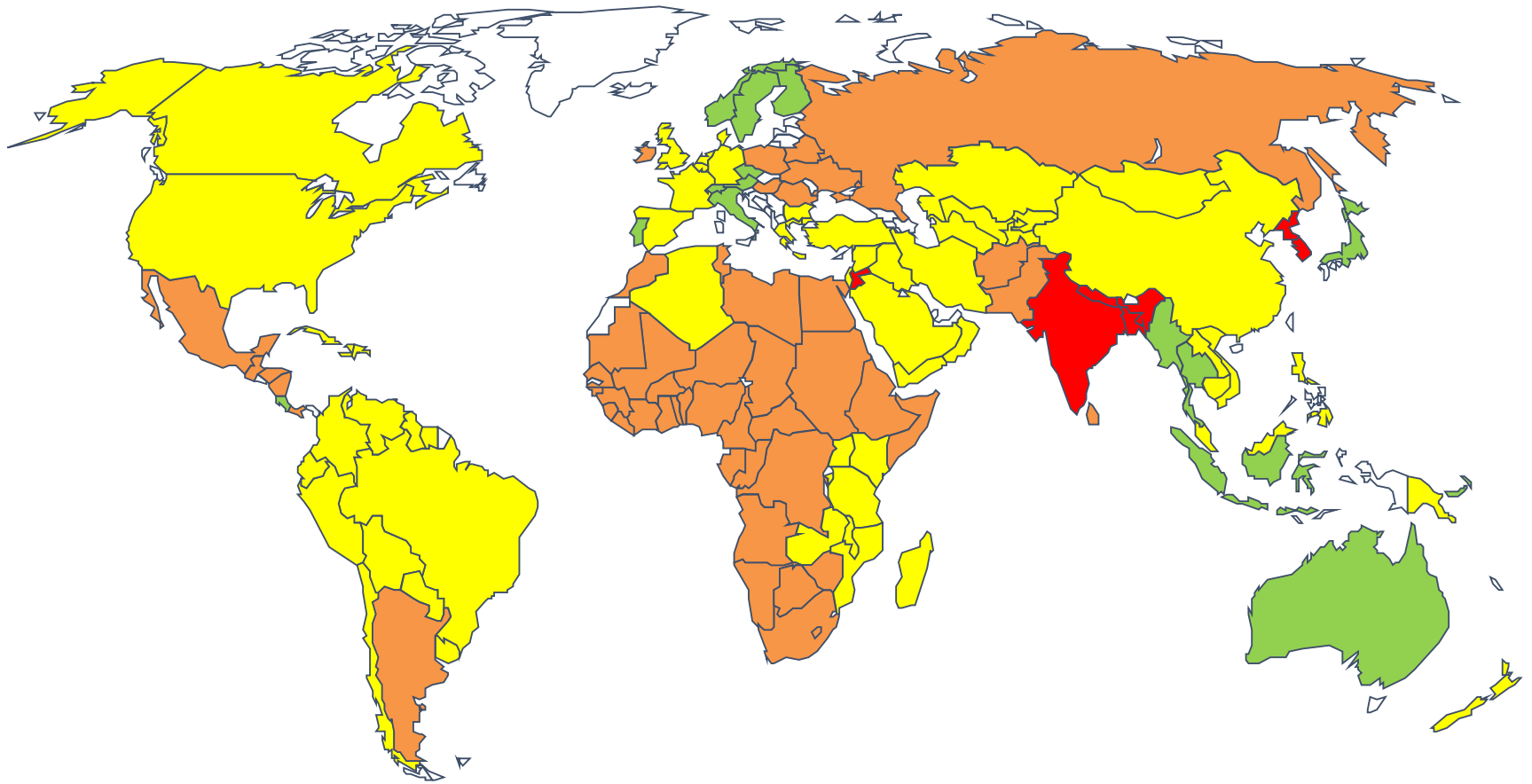
Registration at
If at all
Diagnose
Scarce numbers
Hospital based

Mortality

Registration at
If at all
Scarce numbers
Aged 2-9
Reach?

Flour fortification Reach?
FA campaigns
FA recurrent

Prevalence of NTDs, 2001

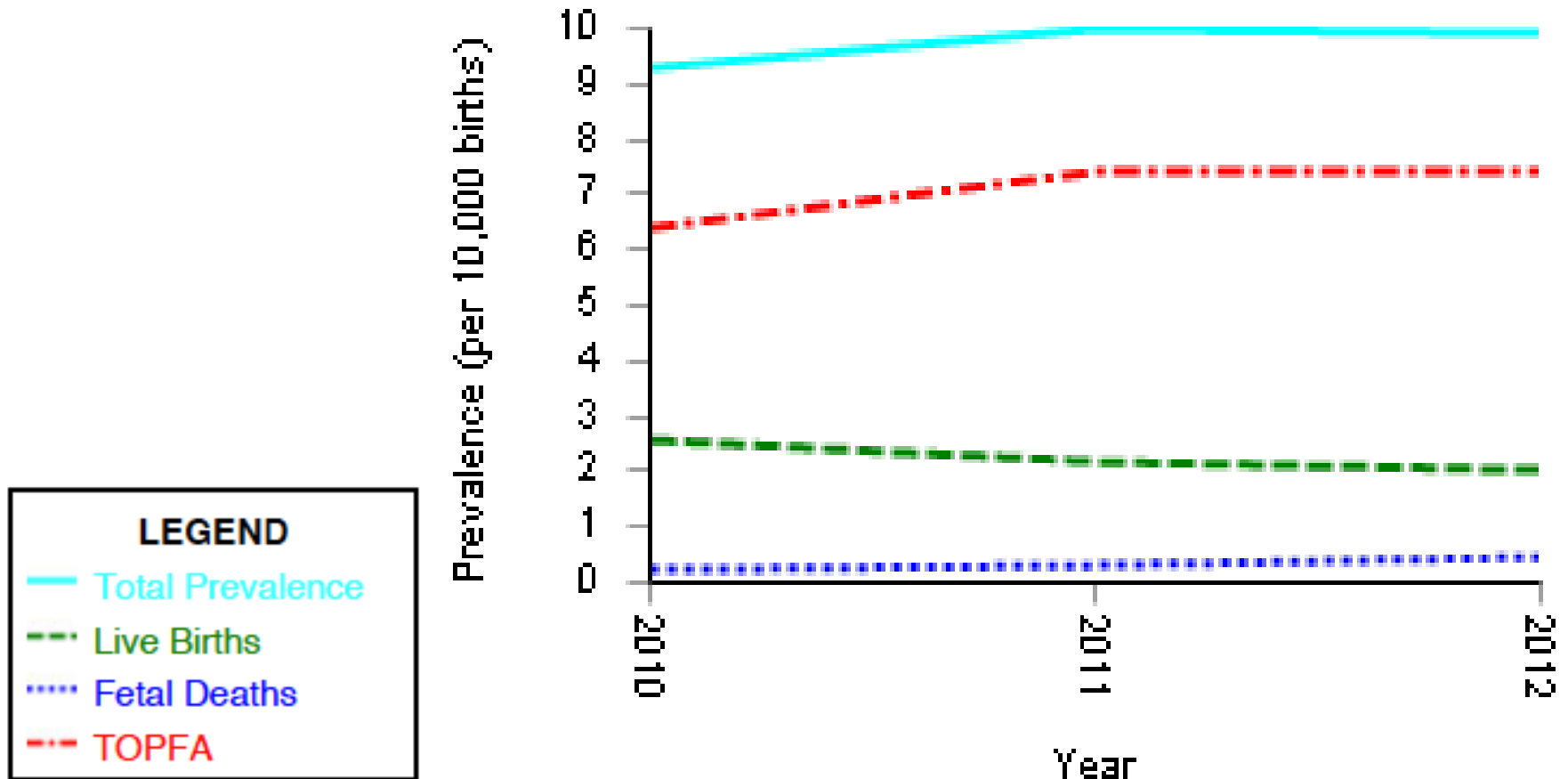


<=1.0 **1.1-2.0** **2.1-3.0** **> 3.0** Rates per 1000 births: data from March of Dimes

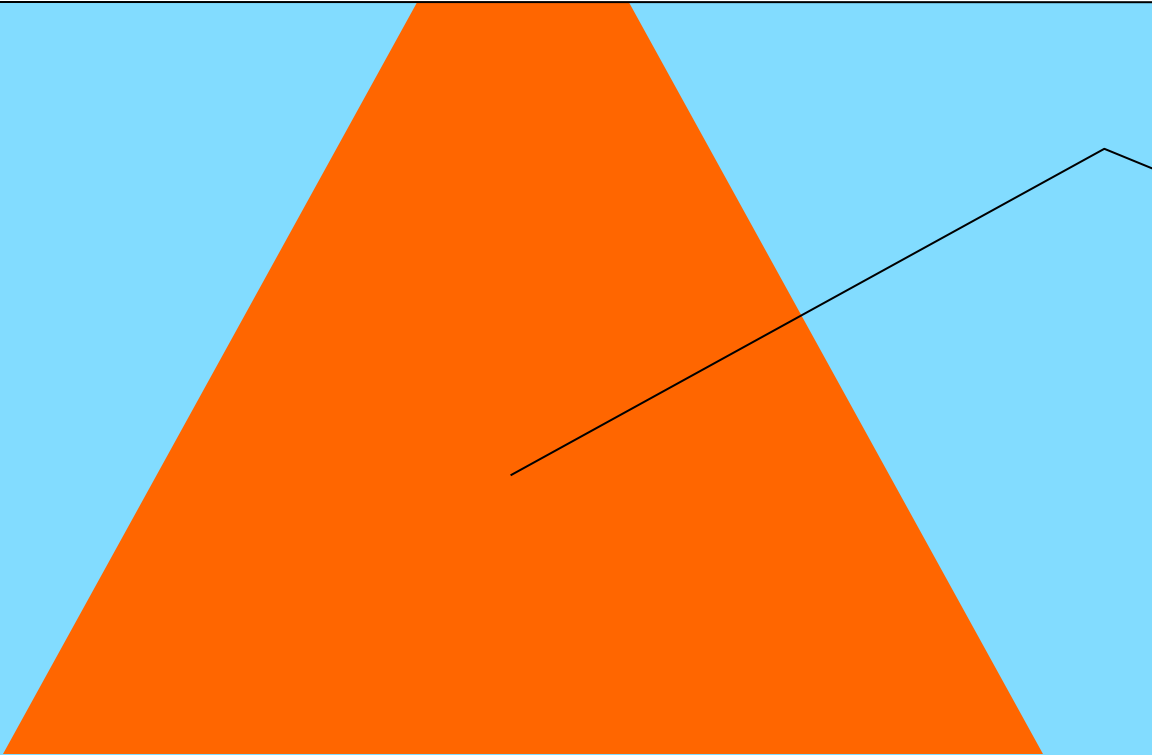
Measuring... (EUROCAT)

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

Neural Tube Defects



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

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

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:

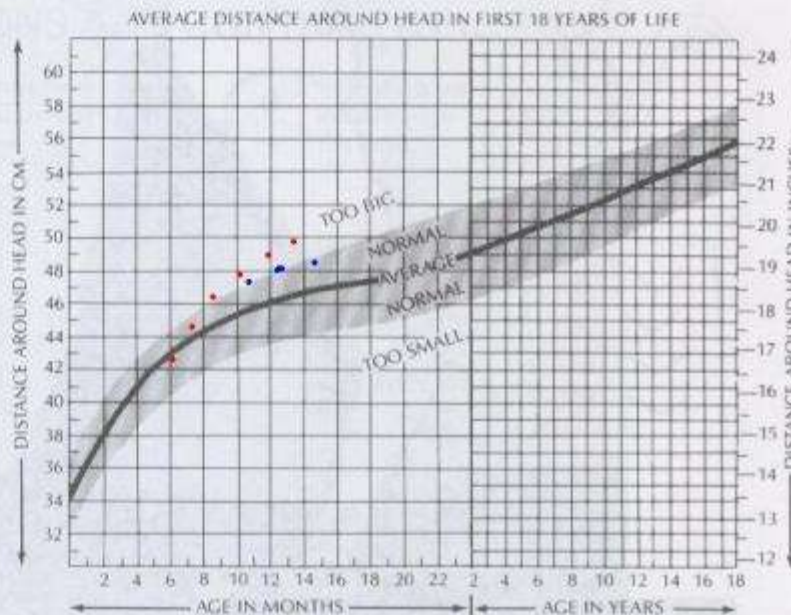


Measure around the widest part of the head.

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).



Note: Boys' heads average from 1/2 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.



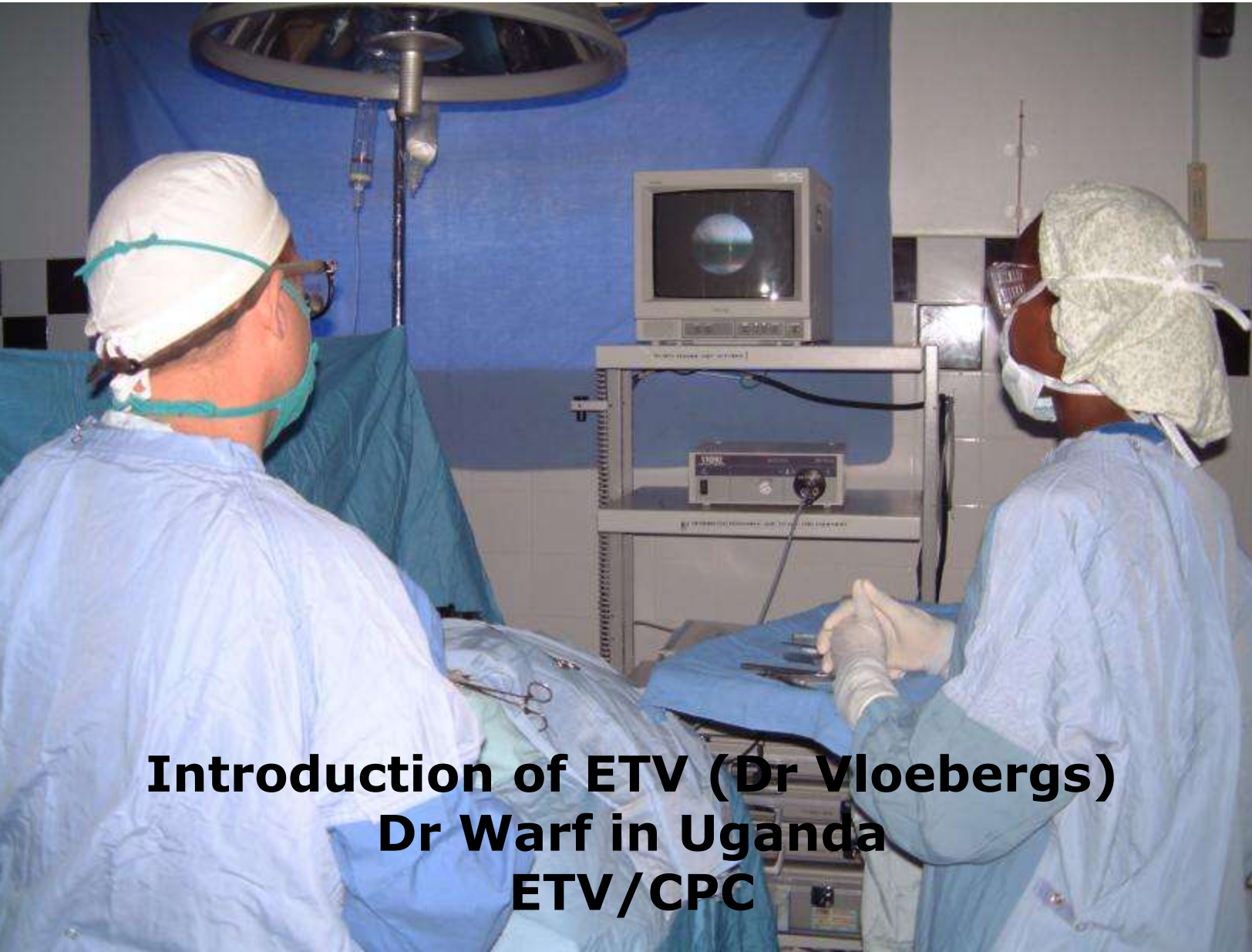
*Filling out this chart every month is especially important for children with spina bifida or suspected hydrocephalus (see p. 169). If you do not know how to use the chart, ask a local schoolteacher.

NO MRI or scans, only endoscopy and a measuring tape

Mbale, Uganda, since 2001



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**Introduction of ETV (Dr Vloebergs)
Dr Warf in Uganda
ETV/CPC**



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Doctors try new shunt-free treatment at Primary Children's Hospital

By Ed Yeates

March 10th, 2014 @ 7:08pm

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Ed Yeates

SALT LAKE CITY — Doctors at Primary Children's Hospital are using a

KSL news (Utah)
10 March 2014



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Continence management program
with CIC and bowel wash-out

No expensive urodynamics. Parents train parents.



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and
HYDROCEPHALUS



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





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**User participation in all
aspects of care**

Thank you!

