Promoting prevention and early interventions

The case of Spina Bifida and Hydrocephalus

Lieven Bauwens, Secretary-General
International Federation for Spina Bifida and Hydrocephalus
The situation?

Deaths from Neural tube defects in 2012 per million persons. Statistics from WHO, grouped by deciles:
- 0-0
- 1-1
- 2-3
- 4-6
- 7-10
- 11-15
- 16-20
- 21-28
- 29-69
Spina Bifida (NTDs)
Hydrocephalus
Perception
Data
Overlaid data of Daly et al 1995 and Crider et al 2014
Folic acid fortification reduces prevalence of NTDs

Prevalence per 10,000

Before fortification | After fortification
---|---
US | 10.8 | 6.9
Canada | 15.8 | 8.6
Chile | 17.1 | 8.6
Costa Rica | 9.7 | 6.3
South Africa | 14.1 | 9.8

Blencowe et al. 2010
CDC 2010
Cortes et al. 2012
Sayed et al. 2008
De Wals et al. 2007
Rosenthal et al. 2014
Calls on Member States to strengthen surveillance systems, prevent birth defects wherever possible, implement screening programs, and provide ongoing support and care to children with birth defects and their families.
WHO Searo: registration efforts

Newborn and Birth Defects Database (NBBD)
World Health Organization - SEARO
Free

Hospital-based Birth Defects Surveillance
A Guide to establish and operate
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.
Example from Ethiopia

High burden of neural tube defects in Tigray, Northern Ethiopia: Hospital-based study

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Maternal risk factors associated with neural tube defects in Tigray regional state of Ethiopia

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Nutritional status among women whose pregnancy outcome was afflicted with neural tube defects in Tigray region of Ethiopia

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