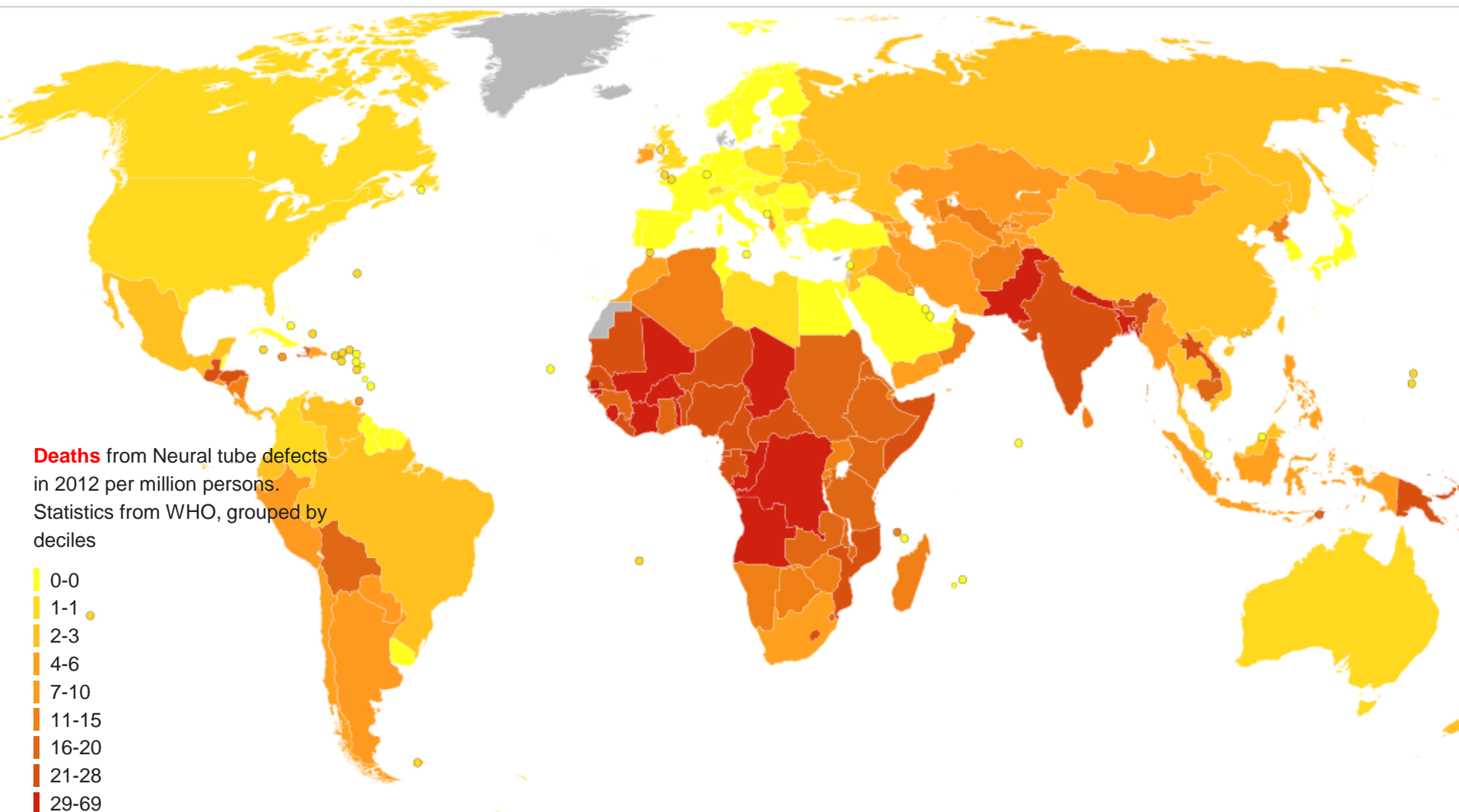


# Promoting prevention and early interventions

The case of Spina Bifida and Hydrocephalus

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

# The situation?



# Spina Bifida (NTDs)

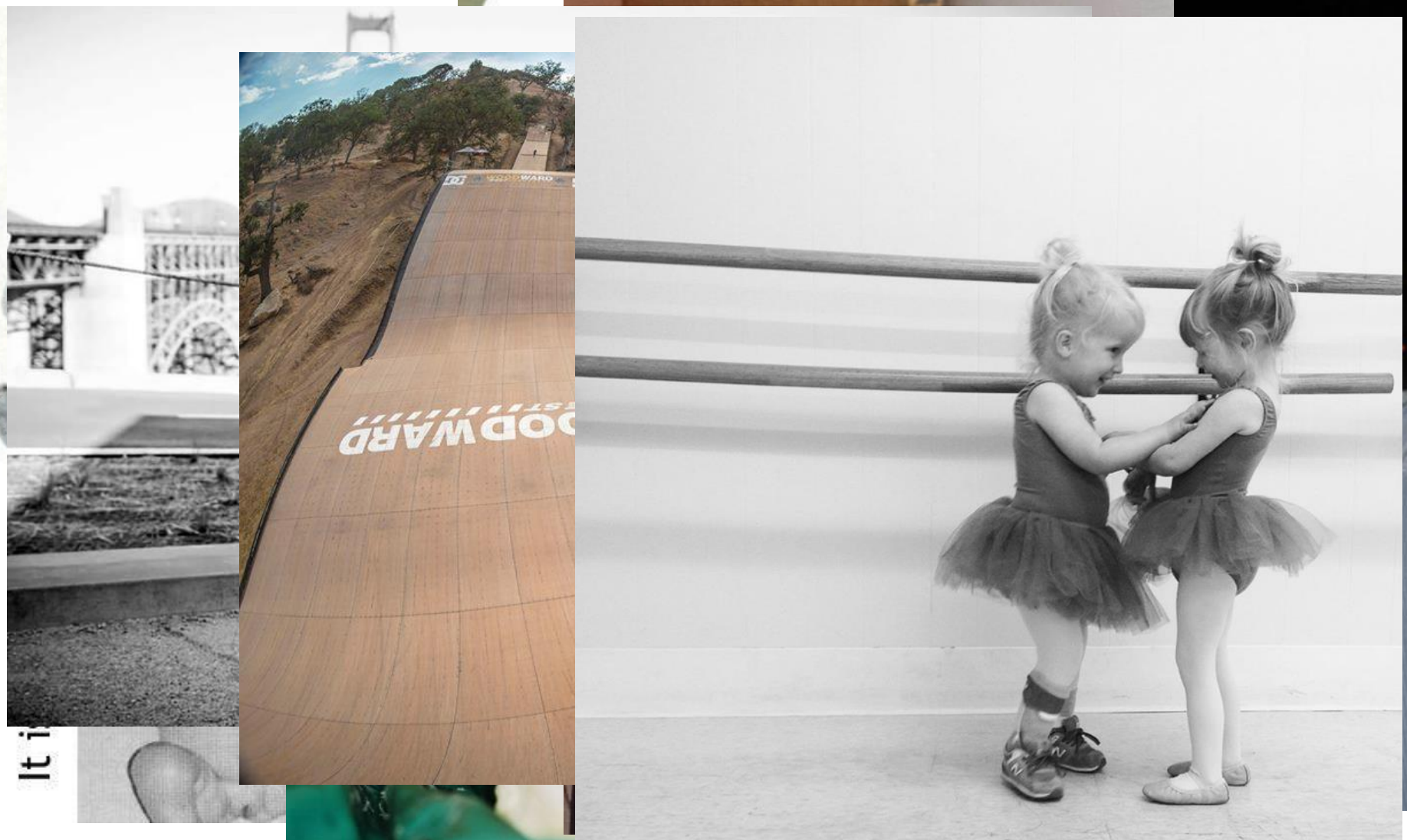


# Hydrocephalus





# Perception

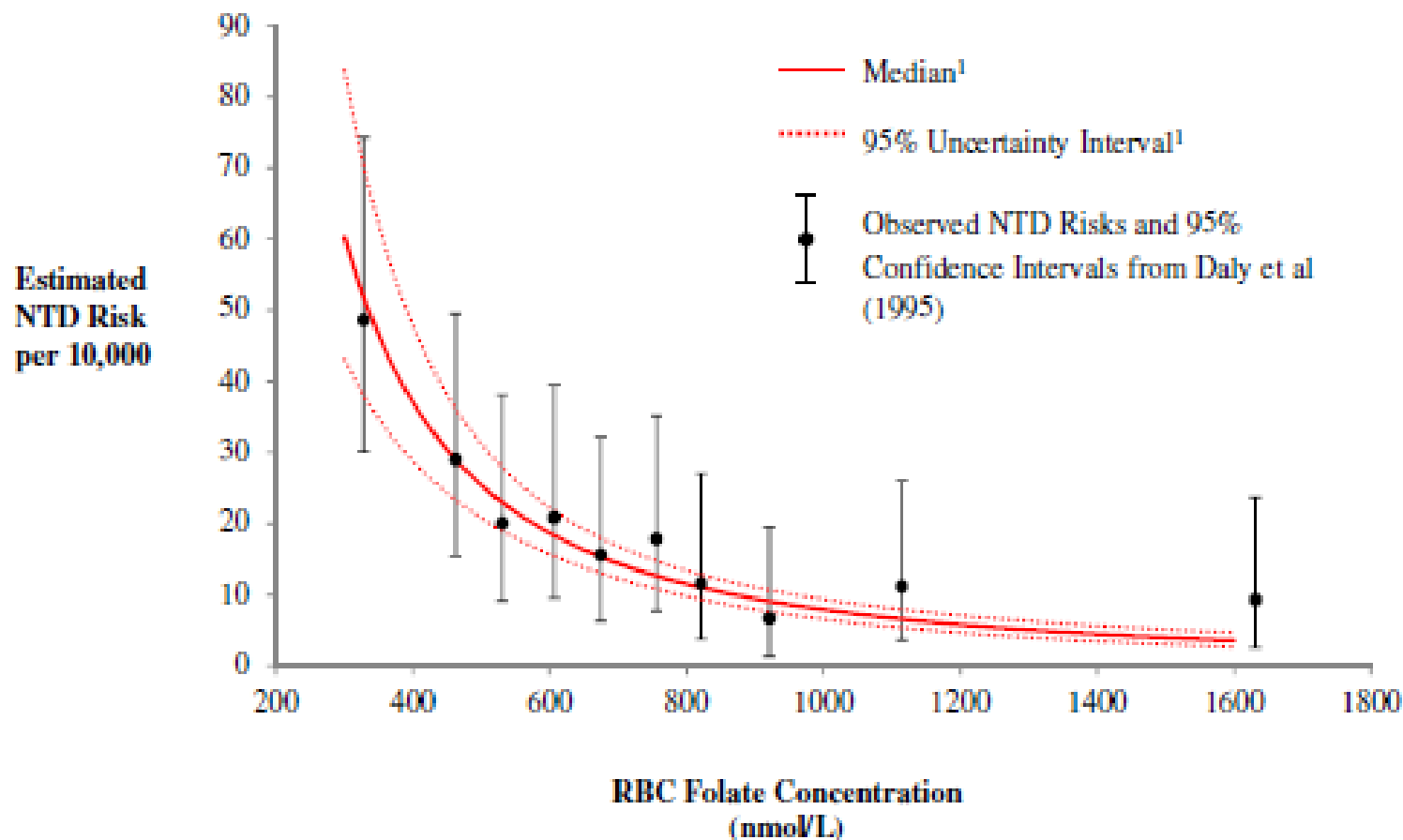


It i

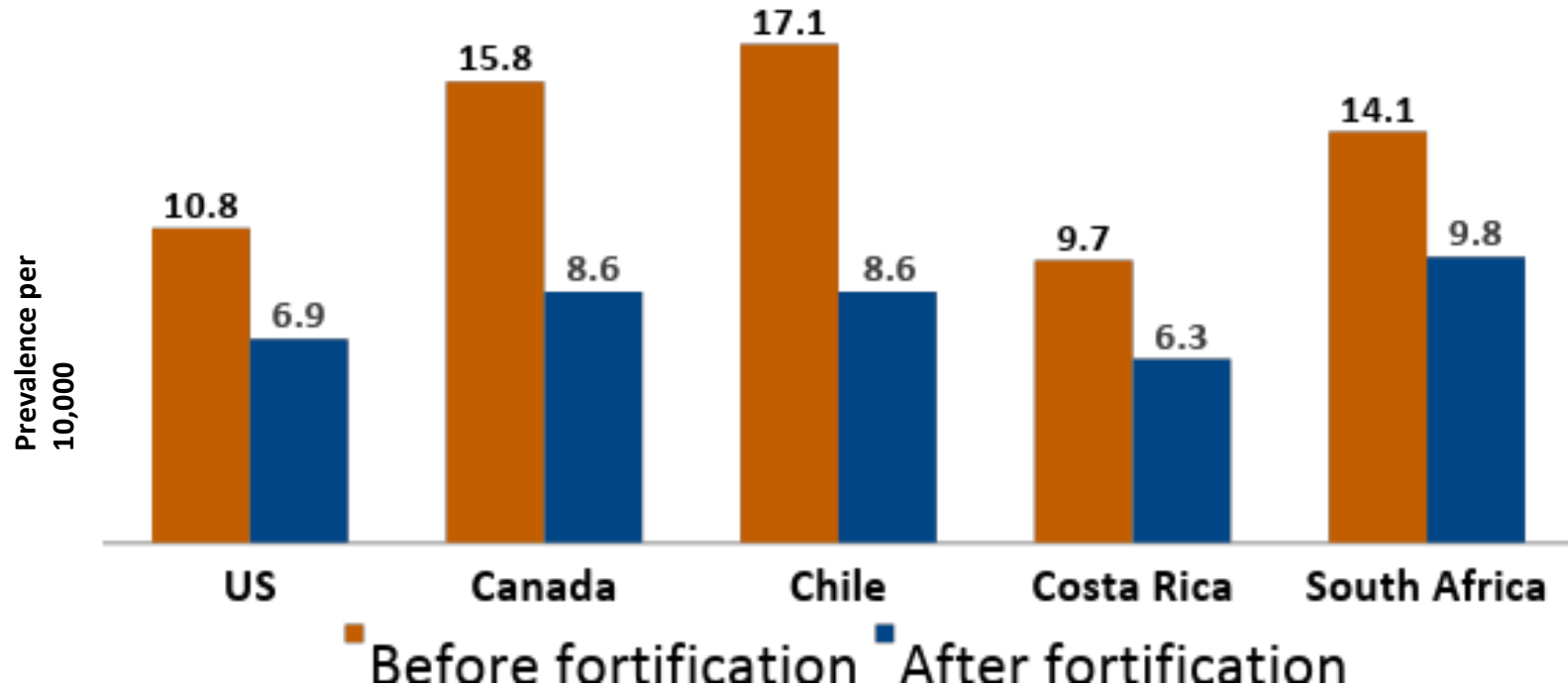
# Data



# Overlaid data of Daly et al 1995 and Crider et al 2014



# Folic acid fortification reduces prevalence of NTDs





# WHO Birth Defects resolution

[http://apps.who.int/gb/ebwha/pdf\\_files/WHA63/A63\\_R17-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_R17-en.pdf)

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.

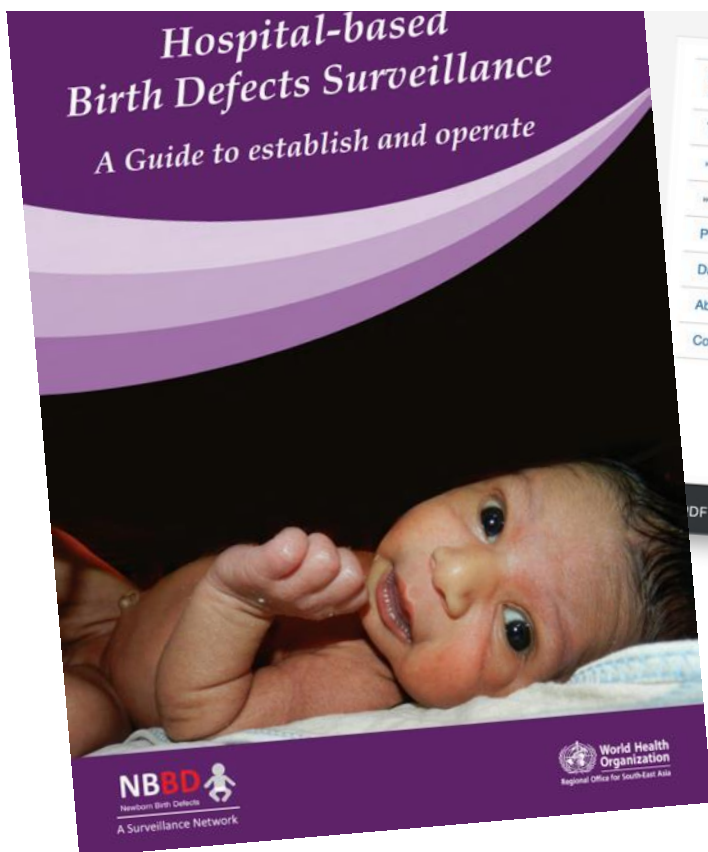
# WHO Searo: registration efforts



## Newborn and Birth Defects Database (NBBD)

World Health Organization - SEARO

Free



# CRPD, 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.



RARE  
DISEASES  
INTERNATIONAL

# Example from Ethiopia

RESEARCH ARTICLE

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

Birhane Alem Berihu<sup>1\*</sup>, Abadi Leul Welderufael<sup>2</sup>, Yibrah Berhe<sup>3</sup>, Tony Magana<sup>4</sup>, Afework Mulugeta<sup>5</sup>, Selemawit Asfaw<sup>2</sup>, kibrom Gebreselassie<sup>4</sup>

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Official Journal of  
the Japanese Society  
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www.elsevier.com/locate/braindev

Original article

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

Birhane Alem Berihu<sup>a,\*</sup>, Abadi Leul Welderufael<sup>b</sup>, Yibrah Berhe<sup>c</sup>, Tony Magana<sup>d</sup>, Afework Mulugeta<sup>e</sup>, Selemawit Asfaw<sup>c</sup>, Kibrom Gebreselassie<sup>d</sup>

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Original article

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

Abadi Leul Welderufael<sup>a</sup>, Birhane Alem Berihu<sup>b,\*</sup>, Yibrah Berhe<sup>c</sup>, Tony Magana<sup>d</sup>, Selemawit Asfaw<sup>c</sup>, kibrom Gebreselassie<sup>d</sup>, Ezra Belay<sup>f</sup>, Hayelom Kebede<sup>b</sup>, Afework Mulugeta<sup>c</sup>

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# Nothing about us, without us



## CRPD and Optional Protocol Signatures and Ratifications

■ Not Signed   ■ Signed Convention   ■ Signed Convention & Protocol   ■ Ratified Convention   ■ Ratified Convention & Protocol

As of 19 September 2017

