



REACHANOTHER
FOUNDATION

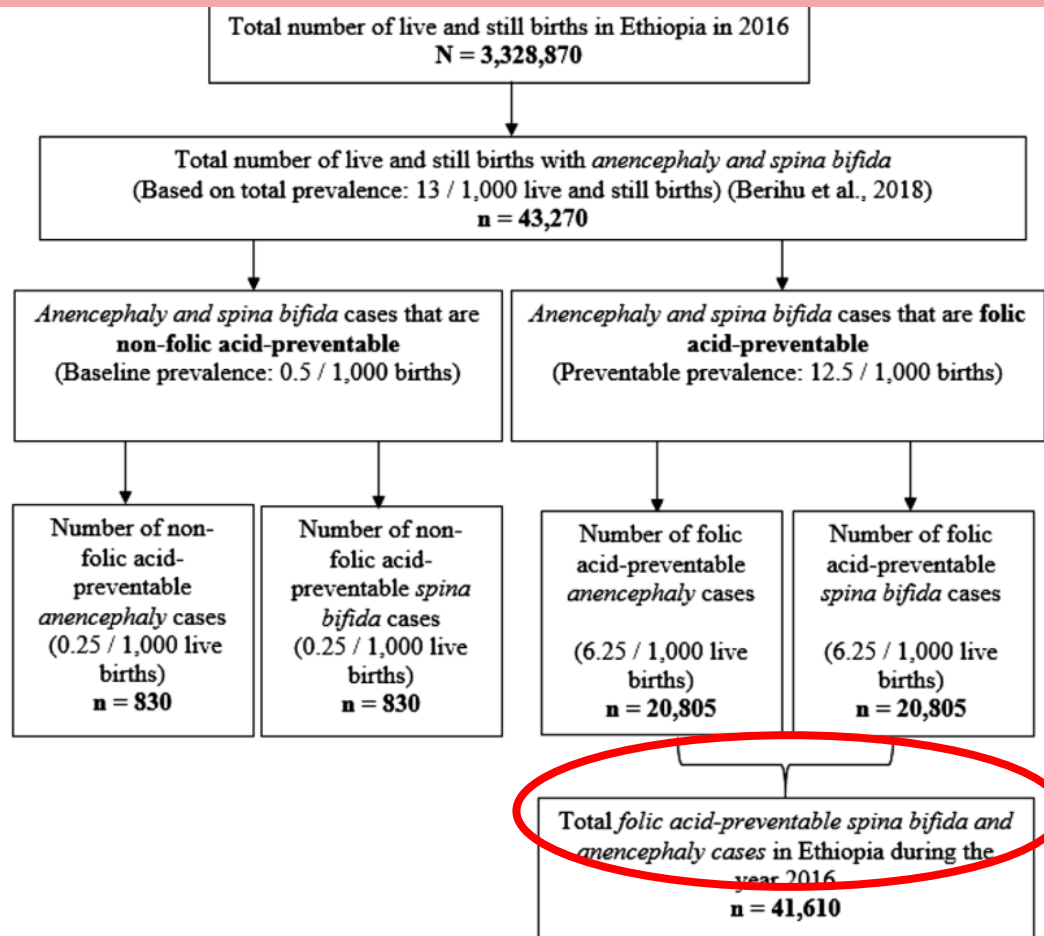
Neural Tube Defect Prevention, Treatment, and
Aftercare in **Ethiopia**

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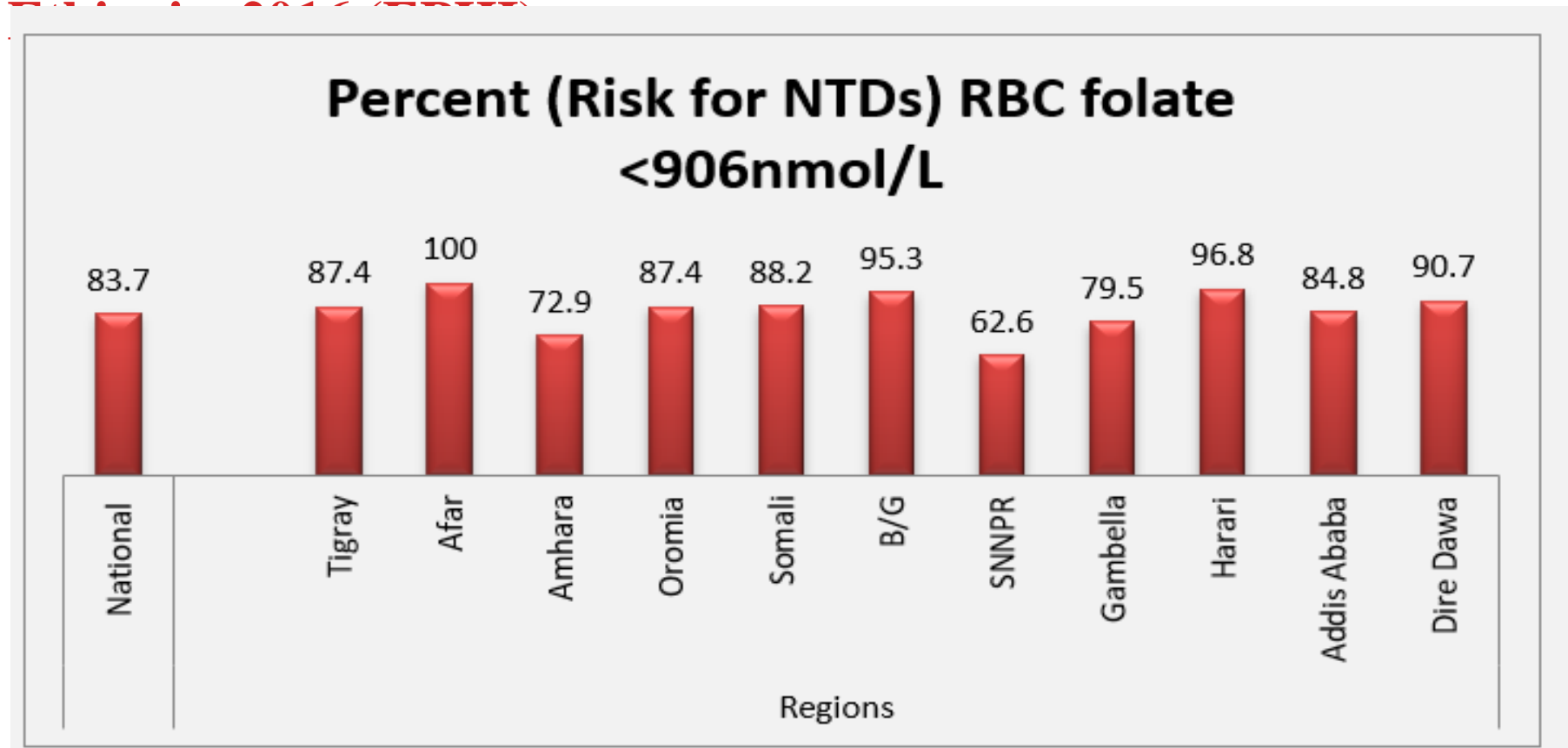
Background

- Worldwide, more than **325,000 babies** are born annually with neural tube birth defects
- More than **41,000 pregnancies affected** with NTDs in Ethiopia yearly with proportional high prevalence compared to global average
- Women in Ethiopia can access folic acid either with diets naturally or should take tablet daily
- Adding folic acid into a staple food items has been **an easy process** practiced in 59 countries but still at infancy in Ethiopia
- Ethiopia approved food fortification strategy. Wheat fortification with folic acid underway but double fortification of salt with iodine and folic acid is under study

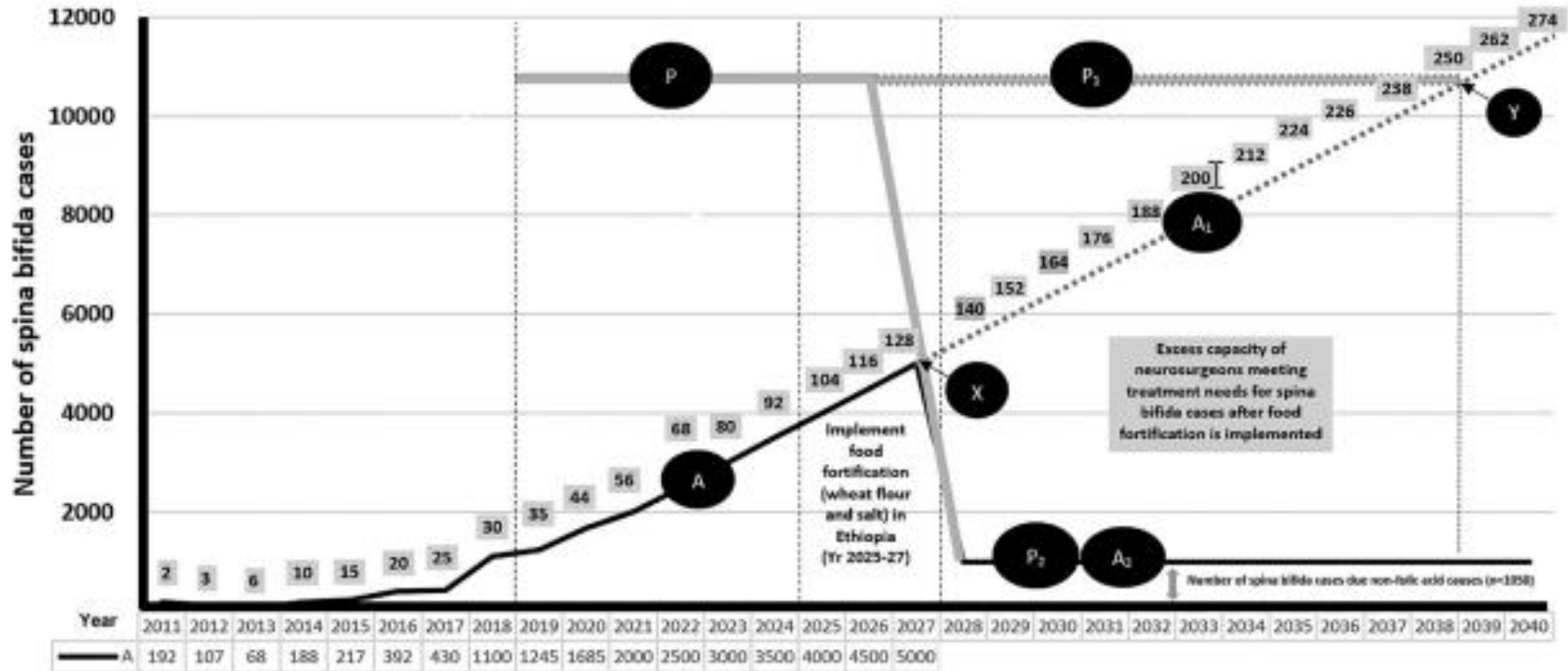
Based on *Hospital based study* Preventing Stillbirths and Under-5 Mortality due to NTDs in Ethiopia



Prevalence of folate *insufficiency* (RBC folate <906 nmol/L) among non-pregnant women in every province of Ethiopia



Preventable NTDs Impact on



ETHIOPIA CHAMPS DATA - 2022

ALARMINGLY HIGH PREVALENCE OF NTDS IN ETHIOPIA



BILL & MELINDA
GATES foundation

10% of all deaths are due to NTDs

20% of stillbirths are due to NTDs

15 of 25 NTD cases have craniorachischisis

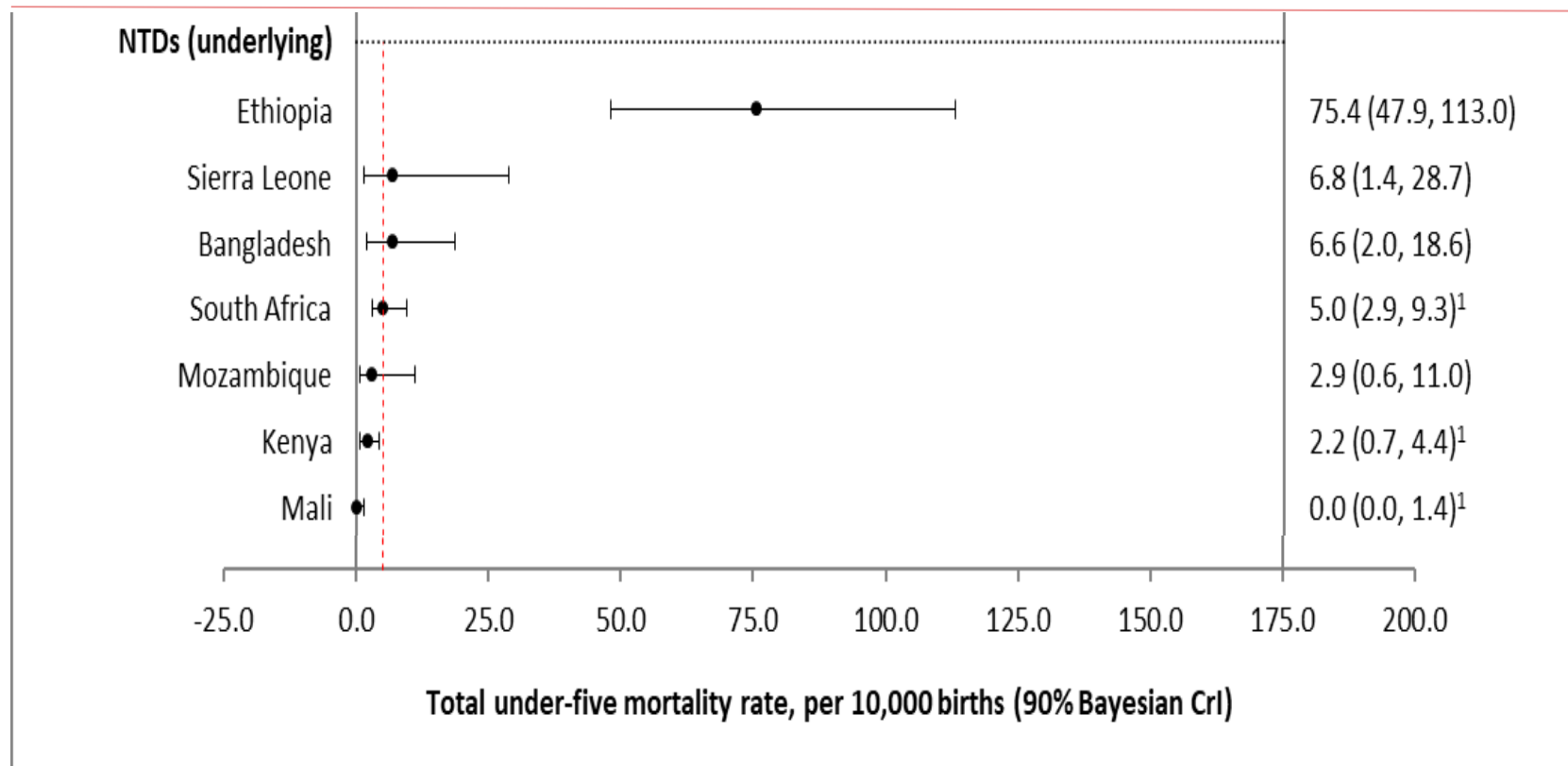
Prevalence in Ethiopia CHAMPS:

7.5 per 1,000 births (90% CI: 4.8, 11.3)

(VERY HIGH compared to other CHAMPS sites)



Under 5 mortality in CHAMPS countries



DHIS2 Routine Report, Ministry of Health, Ethiopia

- **Among Nationally identified and reported congenital malformations >10% are associated with NTDs**
- **The number increases every year with increased facility based delivery**
- **2023 alone, 10,335 cases of Spina Bifida been reported through the administrative report**

Efforts Made So far



History

- In 2009, there were only **three neurosurgeons** in Ethiopia, and a **large caseload** of spina bifida and hydrocephalus
- ReachAnother Foundation (RAF) was founded by brothers Marinus Koning, MD, and Jan Koning, MD
- They aimed to **support the neurosurgical care capacity** in Ethiopia

Surgical Capacity Building

- Expansion of neurosurgery centers from one to eight
- Training of neurosurgeons from 3 to 100
- Expansion of Neurosurgery training program from AAU to SPHMMC and Ayder hospital
- Four thematic areas
 - **Surgery ,**
 - **Aftercare service**
 - **Evidence generation**
 - **Prevention**

Creating a Conducive Policy Environment

- HSTP II endorsed and still neonatal mortality reduction is a top priority
- National nutrition strategic plan finalized and approved
 - Fortification is also listed among the interventions
- National food fortification plan is approved
- National Birth defect advisory team established
- National Spina Bifida technical working group
- Reporting system is in place for all congenital malformations
- Celebration of SB and Birth defect days

Program areas:

1. **Prevention:** Advocating for food fortification and implementing folic acid supplementation through the High-Risk Prevention Project.
2. **Treatment:** Conducting neurosurgeries, training neurosurgical physicians and nurses, and providing critical equipment.
3. **Aftercare:** Building multidisciplinary teams for patient-centered care, focusing on self-catheterization training and SBH col¹³ses.
4. **Data Collection and Evidence Generation:** Utilizing the RAF SBH database for decision-making, supporting data analysis, and research projects to improve patient outcomes.

Centers of Excellence in Pediatric Neurosurgery

Centers are designed to provide a “one-stop” service for spina bifida and hydrocephalus care



8 Centers
across 6 cities
in Ethiopia

Each center has
a goal to provide
spina bifida and
hydrocephalus
surgery for 1,000
babies per year

Recent initiatives



Aftercare improvement program

Establishment of eight pediatrics physiotherapy units across 8 COE hospitals

The country first Pediatrics Neurosurgery center

64 bedded
comprehensive center
at Zewditu



Ongoing efforts



Spina Bifida and Hydrocephalus Team Training Curriculum for Pediatric Neurosurgery

Implemented 7 times across s,3 universities. 140 professionals trained

RAF Spina Bifida and Hydrocephalus Parent Handbook

4,000 copies have been printed and distributed



Ongoing efforts



Multidisciplinary care and follow up

Twice a week in 8 hospitals
with a multispeciality follow
up

Evidence based aftercare services

Regular phone call
follow up and
experience of care
along with CIC
trainings for parents



Ongoing efforts



ETV/CPC services

Procured and distributed 8 ETV machines and Neurosurgeons are trained

Expanding Pediatrics Neurosurgery

8 Operating microscope on procurement and distributions



Ongoing efforts



**Electronic database
for spina bifida and
hydrocephalus
surgery and care**

Launched in each Center of
Excellence





Focus on Prevention

- Folic acid fortification of staple foods is an effective means of **spina bifida prevention**
- The Ethiopian Government introduced policy to **mandate folic acid fortification** of wheat flour

High risk prevention

- Educating mothers on Folic acid supplementation
- Supplementation of 4mg [high dose] folic acid
- Evidence generation and policy formulation
- Working with Rotary international to reach more mothers



KEY CHALLENGES

- Generating Scientific evidences
- Creating more Champions advocate for children affected by Spina Bifida
- Unavailability of standardized protocols [Treatment, rehabilitation and social inclusions] for LMICs situation
- Funding for researchers and parent support

KEY CHALLENGES

- Multidisciplinary care concept is not well developed
- Access to education and other services is limited
- Access to healthcare

Thank you



Learn more
about RAF here:

