Global Prevention of Neural Tube Defects

Accessible Version: https://youtu.be/OezK3hpF-cA
Prevention of Neural Tube Defects

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Division of Congenital and Developmental Disorders
National Center on Birth Defects and Developmental Disabilities
Neural Tube Defects (NTDs)

- Failure of the neural tube to close causes neural tube defects
- Neural tube forms very early in pregnancy, first days through day 28 of gestation
- Interventions to prevent must take place prior to neural tube closure, often before woman is aware of pregnancy
  - ~50% unplanned pregnancy rate in the U.S.

Spina Bifida, high lesion
Spina Bifida, sacral lesion
Anencephaly
Encephalocele

who.int/nutrition/publications/birthdefects_atlas/en/
With intervention, such as surgery or assistive medical equipment, people with spina bifida can live full and productive lives.

- Lifelong disability
  - Mean direct lifetime cost in US estimated to be ~$800,000

- Impacts the individual, family, and society
- Prevention would result in tremendous health and financial benefit

Folate (vitamin B9) is critical to basic processes in the body such as DNA replication and DNA, RNA, and protein methylation.

Folate is a general term used to describe the many different forms:
- Folic acid, dihydrofolate (DHF), tetrahydrofolate (THF), 5, 10-methylenetetrahydrofolate (5, 10-MTHF), and 5-methyltetrahydrofolate (5-MTHF).

Folic acid is a synthetic form of folate that, unlike natural food folate (generally 5-MTHF), is not easily degraded by heat or light.

Initially folic acid was used to treat megaloblastic anemia.
Randomized-controlled Trials Demonstrate Folic Acid Supplements Can Prevent Neural Tube Defects

1991: Among women with a previous NTD-affected pregnancy (n=1817)
- • 4,000 micrograms (µg)/day supplement containing only folic acid
- • 72% reduction in NTDs

1992: Among women without a history of NTD-affected pregnancies (n=4753)
- • 800 µg/day multivitamin supplement containing folic acid
Prevention of Neural Tube Defects
Evidence from a Community Trial: China (1993-1996)

- Intervention = 400 µg/day (folic acid only)
- Women enrolled during premarital examination
- Included 247,831 pregnancies
- 275 NTDs

Prevention of Neural Tube Defects
Evidence from a Community Trial: China (1993-1996)

- In the high-risk northern counties, NTD prevalence reduced by 85%
- In the moderate-risk southern counties, NTD prevalence reduced by 40%
- Showed that percent reduction in NTDs is dependent on baseline rates
- 400 µg/day folic acid alone could reduce risk but did not prevent all occurrences
  - NTDs can be caused by other conditions such as chromosomal anomalies

Prevention Recommendations in the United States

- In 1998, to reduce the risk of neural tube defects the Institute of Medicine recommended that women capable of becoming pregnant should take 400 micrograms of synthetic folic acid daily
  - From fortified foods or supplements or a combination of the two, in addition to consuming food with natural folate from a varied diet

- In 2017, U.S. Preventive Services Task Force
  - 400–800 µg/day of folic acid from supplements
  - Grade of A (highest level of confidence)
Challenges with Preventing Neural Tube Defects

- **Timing**
  - Women must consume folic acid supplements prior to conception and continue in early pregnancy
    - ~50% unplanned in US

- **Vehicle**
  - Difficult to achieve the equivalent of 400 µg folic acid through dietary food folate intake and requires behavioral change
    - 18 cups raw spinach
    - 31 spears of boiled asparagus
    - 7 1/2 cups canned kidney beans
  - Folic acid is the only form of folate that has been shown in clinical trials to prevent neural tube defects

- **Delivery**
  - Folic acid containing supplements are not widely consumed
  - Need to reach the highest risk women
Fortify Foods with Folic Acid
An Alternative Approach to Prevent Neural Tube Defects

- **Folic acid fortification of enriched cereal grain products**
  - Folic acid reduces the risk of NTDs
  - Folic acid is stable to heat and light (baking and storage)
  - Products already fortified with other micronutrients
  - Products consumed regularly, so no behavior change needed

- **1998**: Cereal grain products labeled as enriched were required to contain 140 micrograms (µg) folic acid for every 100 g product

[ods.od.nih.gov/factsheets/Folate-HealthProfessional/](ods.od.nih.gov/factsheets/Folate-HealthProfessional/)
[cdc.gov/ncbddd/folicacid/faqs/faqs-general-info.html](cdc.gov/ncbddd/folicacid/faqs/faqs-general-info.html)
Folic Acid Fortification and Neural Tube Defects (NTDs)


- 35% reduction in occurrence of NTDs post-fortification
  - Who is the intervention reaching?
  - How to reduce more?
  - How best to target further interventions?

* Anencephaly and spina bifida only, some programs without prenatal ascertainment

Williams J, Mai CT, Mulinare J, et. al. MMWR. 2015 Jan 16;64(1):1-5
Red Blood Cell (RBC) Folate Concentration As a Biomarker of Risk of Neural Tube Defects in Populations

- In 2015, WHO recommended optimal RBC folate concentration threshold in populations for NTD prevention in women of reproductive age
  - 906 nmol/L (400 ng/ml)

- As RBC folate concentrations increase, NTD risk decreases

- In 2015, WHO recommended optimal RBC folate concentration threshold in populations for NTD prevention in women of reproductive age
  - 906 nmol/L (400 ng/ml)

- Deficiency RBC folate concentration for prevention of anemia in the general population
  - 305 nmol/L

Crider KS, Devine O, Hao L, et. al. BMJ. 2014 Jul 29;349:g4554
who.int/nutrition/publications/guidelines/optimalserum_rbc_womenrep_tubedefects/en/
Using WHO-Recommended RBC Folate Concentration to Inform Folic Acid Interventions

1. Assess
   Measure RBC folate concentration distributions (microbiologic assay)

2. Identify
   Determine the need for intervention

3. Target
   Best approach to reach your high-risk populations

4. Implement
   Implement the intervention

5. Evaluate
   Reassess population RBC folate concentrations 6 to 12 months post-intervention

6. Adjust
   Adjust program/intervention based on data
Three Current Sources of Folic Acid in the US

- **Mandatory:** cereal grain products labeled as enriched (ECGP) must contain 140 µg folic acid for every 100 g of product

- **Voluntary:** ready to eat cereals (RTE) can have up to 400 µg folic acid per serving

- **Supplements (SUPP):** usually contain 400-800 µg folic acid
Using WHO Recommended RBC Folate Concentration in the US

- RBC folate concentrations in U.S. women age 12-49 years, NHANES (2007–2012)
- Majority of U.S. women at or above the optimal RBC folate concentration threshold
- 23% of U.S. women have suboptimal RBC folate concentrations

<table>
<thead>
<tr>
<th>Risk category</th>
<th>NTD prevalence</th>
<th>RBC folate concentration (NHANES assay)</th>
<th>Percentage of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>&gt;14 per 10,000</td>
<td>&lt;585 nmol</td>
<td>8%</td>
</tr>
<tr>
<td>Elevated</td>
<td>9–14 per 10,000</td>
<td>586–747 nmol</td>
<td>15%</td>
</tr>
<tr>
<td>Optimal</td>
<td>4–&lt;9 per 10,000</td>
<td>748–1216 nmol</td>
<td>46%</td>
</tr>
<tr>
<td>Limited additional benefit</td>
<td>Outside estimable range</td>
<td>≥1216 nmol</td>
<td>31%</td>
</tr>
</tbody>
</table>

Women with Suboptimal RBC Folate Concentrations Are More Likely to Have Only One Source of Folic Acid

48% of women of reproductive age have enriched cereal grain products (ECGP) as their only folic acid source.
The optimal RBC folate concentration threshold results in the ability to assess and monitor folic acid fortification programs.

- In the US, although most women are optimally protected (77%), some who consume only mandatory fortification products remain at increased risk.

Possible approaches that could be targeted to higher-risk populations:

- Fortify additional dietary staples (e.g., corn masa flour was added 2017).
- Encourage wider consumption of supplements containing folic acid.

In Guatemala, 47% of women of reproductive age had suboptimal RBC folate concentrations because folic acid fortification was not reaching the rural, low-income, and indigenous populations.


Birth Defects COUNT: What We Do

Birth Defects COUNT
Countries and Organizations United for Neural Tube Defects Prevention

Objective: Significantly reduce death and lifelong disability due to neural tube defects
Focus regions: South-East Asia and East Africa
Focus intervention: Fortification with folic acid
Fortifying Grains with Folic Acid to Prevent Neural Tube Defects: Successes and Opportunities

Scott J. Montgomery

Director, Food Fortification Initiative
What is Fortification?

Adding vitamins and minerals
during the milling process
to produce more nutritious foods

Photo from Mühlenchemie
Photo by David Snyder / CDC Foundation
Istockphoto
Our Niche: Wheat Flour, Maize Flour, and Rice
Our Focus: Industrially Milled Grains

Industrial mill

Village-type chakki mill
Oman Reaches National Coverage

Food Fortification Initiative

1.5 milligrams of folic acid per kilogram of wheat flour
2017: 81 Countries Require Folic Acid in Industrially Milled Wheat Flour, Maize Flour and/or Rice

Amount folic acid included varies by country
Globally an estimated 35,500 birth defects were prevented in 2015 — an average of 97 a day — where flour was fortified with folic acid.

Thousands More NTDs Could Be Prevented With Industrial Cereal Grain Fortification

160,800 annually

Greatest potential impact in:
- China
- India
- Russia
- Turkey

Fortification Led to A Drop in Neural Tube Defect Prevalence

NTD Prevalence Before and After Fortification, By Country

US: CDC Grand Rounds:. MMWR. 2010;59(31):980–4

US: 10.8 Before fortification 6.9 After fortification
Canada: 15.8 Before fortification 8.6 After fortification
Chile: 17.1 Before fortification 8.6 After fortification
Costa Rica: 9.7 Before fortification 6.3 After fortification
South Africa: 14.1 Before fortification 9.8 After fortification
Cameroon Results Show Folate Levels in Women Are Increasing

<table>
<thead>
<tr>
<th>Among Women in Urban Areas</th>
<th>2 years before fortification</th>
<th>1 year after fortification</th>
<th>Percent Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plasma folate* (nmol/L)</td>
<td>15</td>
<td>47</td>
<td>213%</td>
</tr>
<tr>
<td>Plasma B12 (pmol/L)</td>
<td>461</td>
<td>671</td>
<td>46%</td>
</tr>
<tr>
<td>Plasma zinc (μg/dL)</td>
<td>55</td>
<td>65</td>
<td>18%</td>
</tr>
<tr>
<td>Ferritin (μg/L)</td>
<td>37</td>
<td>47</td>
<td>27%</td>
</tr>
</tbody>
</table>

*Plasma/serum folate is a short-term measure and RBC folate concentration is a long-term measure of folate status and is the biomarker used for NTD risk. Correlation between plasma/serum folate concentration and RBC folate concentration is unknown.


Flickr Creative Commons
Fiji Study Demonstrates Folate and Other Nutrient Deficiencies Are Decreasing

Percent of Women Age 15–45 Deficient Before and After Flour Fortification, Fiji, N=869

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Percent Deficient Before, 2004</th>
<th>Percent Deficient After, 2010</th>
<th>Cut offs used for deficiency in women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum folate</td>
<td>8</td>
<td>1</td>
<td>Serum folate &lt;10 nmol/L</td>
</tr>
<tr>
<td>Iron</td>
<td>23</td>
<td>8</td>
<td>Serum ferritin &lt;15 mg/L</td>
</tr>
<tr>
<td>Zinc</td>
<td>39</td>
<td>0</td>
<td>Serum zinc &lt;10.1 mmol/L</td>
</tr>
</tbody>
</table>

In addition, anemia prevalence among this group dropped from 40% to 28%.

Anemia defined as hemoglobin <12g/dL

Only 16.1% of the women had taken nutrient supplements in the six months prior to the survey

National Food and Nutrition Centre 2010 ffinetwork.org/monitor/Documents/Fiji.pdf
apps.who.int/iris/bitstream/10665/161988/1/9789241549042_eng.pdf
Fortification With Folic Acid Prevents Spina Bifida

Annual Net Savings

<table>
<thead>
<tr>
<th>Country</th>
<th>Net Savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chile</td>
<td>USD 2.3 million</td>
</tr>
<tr>
<td>South Africa</td>
<td>USD 5.3 million</td>
</tr>
<tr>
<td>United States</td>
<td>USD 603 million</td>
</tr>
</tbody>
</table>

These are conservative estimates!

Return on Investment from Preventing Spina Bifida

1:12 Chile
1:30 South Africa
1:48 United States

<table>
<thead>
<tr>
<th></th>
<th>Wheat Flour</th>
<th>Maize Flour</th>
<th>Rice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available for human consumption</td>
<td>355</td>
<td>90</td>
<td>377</td>
</tr>
<tr>
<td>Industrially milled</td>
<td>250</td>
<td>26</td>
<td>171</td>
</tr>
<tr>
<td>Industrially milled and fortified</td>
<td>85</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>Percent industrially milled and fortified</td>
<td>34%</td>
<td>57%</td>
<td>0.7%</td>
</tr>
</tbody>
</table>

Food and Agriculture Organization of the United Nations (FAO) for 2013.
ffinetwork.org/about/stay_informed/publications/documents/FFI2016Review.pdf
Fortification Opportunities With The Most Potential Impact

- Industrial milling is available
- At least 75 grams of grain available per person per day
- Fortifying with folic acid is not mandatory for all commonly consumed grains
Summary

200,000 NTDs could be prevented annually through grain fortification

- Enduring value
- Minuscule costs
- Enormous benefits
Maize Fortification with Small- and Medium-scale Processors in Tanzania

Erin Smith, MPH
Country Director, Tanzania, Helen Keller International
Micronutrient Status Has Improved in Tanzania But Malnutrition Remains

Percent of Women and Children with Certain Health Characteristics of Micronutrient Malnutrition, Tanzania, TDHS 2015

- **ANEMIA**
  - Women 15-49 Years: 45%
  - Children < 5 Years: 58%

- **IRON DEFICIENCY**
  - Women 15-49 Years: 30%
  - Children < 5 Years: 35%

- **VITAMIN A DEFICIENCY**
  - Women 15-49 Years: 37%
  - Children < 5 Years: 33%

- 34% of children are stunted
- Under Five Mortality (U5MR): 81/1,000
- Infant Mortality: 51/1,000

NTD Prevalence in Tanzania Is Extremely High

- Review of NTD prevalence in neonates in the largest referral hospital in Tanzania in 2002
- NTD rate of 30.2 per 10,000 live births
  - 4,840 new cases per year
- High level of stigma against children born with NTDs or disability
  - Poor access to services results in a large number of cases are not seen by medical personnel

History of Fortification in Tanzania

- **National Food Fortification Standards and Regulations** requires large-scale industries to fortify
  - Law passed in March 2011

- **Industrial wheat and maize flour producers**
  - Add iron EDTA, zinc oxide, folate, Vitamin E, and vitamin B12

- **Vegetable oil producers to add**
  - Add Vitamin A

- **Salt producers**
  - Add potassium iodate

**EDTA:** ethylenediaminetetraacetate
Average diet contains 2x more maize than wheat AND maize less likely to be fortified than wheat flour

- Only 36% consume wheat but 59% of wheat flour is fortified
- Over 89% consume maize but only 3% of maize is fortified
Maize Production in Tanzania Is Fractured

- 96% of maize is produced by small- and medium-scale mills
- 6,892,480 MT each year

Number of Mills and Percentage of Maize Milled

- 2 Large-scale Mills (over 20 MT/day, most not sold directly to consumers)
- 5,000 Medium-scale Mills (10-20 MT/day)
- Estimated 10,000 Small-scale Mills (<1 MT/day)

MT: Metric tons
Many Challenges in Small- and Medium-scale Folic Acid Fortification

- **For millers, no motivation to fortify**
  - Small and medium millers not included in Fortification Law
  - Difficult to access to affordable technology and micronutrient mix
  - **Lack of consumer demand and awareness** = no market for product

- **Poor and rural residents don’t purchase maize flour**
  - Maize grown at home is often ground at small local mills
Community Intervention to Target Small- and Medium-scale Mills

- How could we work with 10,000 millers to fortify maize?
- What about millers’ compliance?
- Would it be cost effective?
- How could we reach the population who needed it most?
- How could we know we were having an impact?
Components of a Successful Fortification Program

- Enforcement
- Legislation
- Technology
- Advocacy
- Education
Baseline and endline assessments were conducted one year apart in January of 2016 and 2017 in three districts in Morogoro

- Population-representative sample: 400 Households (200 Urban/200 Rural) P:0.05

Study Objectives: Assess changes in

- Acceptability
- Purchasing and consumption patterns
- Household access
Changes in Acceptability of Fortified Products

Survey Results One Year After Community Intervention, Tanzania, 2016

- Knowledge of Fortification
- Could Identify Logo
- Could Name a Benefit
- Willing to Purchase
- Logo Influences Purchase

Baseline
Endline
Purchasing Habits Changed in Just One Year

Households Purchasing Maize vs. Home Production

Baseline Endline

- Purchased Maize, 82%
- Home Ground Maize, 17%
Household Consumption Changed in Just One Year

Fortified Samples From Households

Baseline (n=156)
- 98% Unfortified
- 3%*

Endline (n=161)
- 10% Unfortified
- 63% Adequately Fortified
- 27% Overfortified

*Does not add to 100% due to rounding
Increased Access for Poor Families

- 81% of poor households regularly purchasing packaged maize
- 94% of flour sampled in poor households fortified
- 72% of poor households accessing fortified flour
Legislative Steps Taken To Sustain Fortification

- By-law passed in Morogoro region in September 2017
- Adds sustainability to efforts
- Requires Small Scale Maize producers to add
  - Iron EDTA, zinc oxide, folate, Vitamin E, and vitamin B12

EDTA: ethylenediaminetetraacetate
Successful Fortification Leads to Healthier People

- Advocacy
- Legislation
- Education
- Enforcement

Improved Market Demand
- Improved Access to Product
- Higher Quality Production
- Safer Food Products
- Healthier Population
Birth Defects Surveillance and Prevention in South-East Asia: Lessons Learnt and Way Forward

Dr Neena Raina
Coordinator, Health through the Life Course
WHO-SEARO
Wheat Flour Fortification in India – A New Beginning

- India is estimated to hold 1/3 of the world's NTDs
- Many staple foods are not centrally milled (e.g., chakki mills)
- Food Safety and Standards Authority of India (FSSAI) set initial fortification standards for micronutrients too low
  - Folic acid level was below level to prevent NTDs
- In 2016, WHO-SEARO, CDC, FFI, and other partners led a successful effort to have FSSAI amend standards to align with global WHO standards
To understand the impact of fortification and to demonstrate reduction in the number of NTDs, we needed data.

WHO-SEARO and CDC collaborated to develop a reliable birth defects surveillance system.

- Regional Strategic Framework
- National strategies and plans

In 2014, launched SEAR-NBBD Database

- Define the magnitude and distribution of birth defects in SEAR
Progressive Increase In Reporting Hospitals

Number of Hospitals Reporting to SEAR-NBBD Hospital-based Birth Defects Surveillance and Database, 2014–2017, (146 online/108 offline)

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>13</td>
</tr>
<tr>
<td>2015</td>
<td>60</td>
</tr>
<tr>
<td>2016</td>
<td>109</td>
</tr>
<tr>
<td>2017</td>
<td>146</td>
</tr>
</tbody>
</table>

7 countries online
- Bangladesh
- Bhutan
- India
- Nepal
- Maldives
- Myanmar
- Thailand

3 countries offline
- Indonesia
- Sri Lanka
- Timor Leste

SEAR-NBBD Surveillance Data, July 2014–June 2017
Hospital-based Newborn and Birth Defects (NBBD) Surveillance & Database

- Standardized forms available online and through mobile app
- Training of data entry operators and other health professionals
- Verification and quality monitoring of data
  - Troubleshooting and periodic monitoring

SEAR-NBBD Surveillance data July 2014–June 2017

Legend
Number of hospitals
- Bangladeshi (10)
- Bhutan (2)
- DPRK (2)
- India (101)
- Indonesia (156)
- Malaysia (11)
- Myanmar (25)
- Nepal (28)
- Sri Lanka (33)
- Thailand (21)
- Timor-Leste (3)
- Hospital location

Reporting hospital
NBBD Is a Unique Surveillance System

1. Hospital-based surveillance
   - Fetus or baby delivered in the hospital
   - Birth defects identified at birth or until 7 days of life or until discharge
   - All live births and stillbirths born with a birth defect
   - Initial focus is on major structural birth defects but all BD included now
   - Monthly denominators are submitted

Form filled online by DR/DEO

1st Verifier checks for completeness, accuracy and timeliness (hospital)

Form submitted online

2nd Verifier re-checks each form
Hospital checklist also used

All forms verified/accepted online database
WHO/CC-WHO SEARO

SEAR-NBBD Surveillance Data, July 2014–June 2017
2. Quality assurance of surveillance at all levels
   - All birth defects forms once submitted online are verified for completeness, accuracy and timeliness
   - Feedback loop has been established to maintain data quality

3. Involvement of Ministry of Health (MoH) in every country
   - Government hospitals
   - Periodic follow-up easier due to MoH
   - Sustainable
Data are from the 146 hospitals in 7 countries that reported online to NBBD between 2014–2017 and does not reflect of the overall prevalence or proportion of birth defects in these countries. Data represent only the information collected on BD from participating hospitals from the NBBD network that often focusses on visible birth defects. However, with better training and more interest at the hospital level, all BDs started being reported hence the spike in 2015. Total babies with Birth defects (LBs and SBs) have been rounded off. SEAR-NBBD Surveillance Data, July 2014–June 2017.
Neural tube defects are classified into the Nervous System.
Distribution of Birth Defects by System
Nervous System Most Commonly Reported

67% of all birth defects are in Nervous System
Among stillbirths, 52% are in the Nervous System

Neural tube defects are classified into the Nervous System
SEAR-NBBD Surveillance Data, July 2014–June 2017
Distribution of Visible Birth Defects and NTDs

40% of the Visible BDs were NTDs
NTDs in SB > NTDs in LBs

Distribution of NTDs
Anencephaly > Stillbirths & Spina Bifida > Livebirths

SEAR-NBBD Surveillance Data, July 2014–June 2017
Distribution of Visible Birth Defects and NTDs

40% of the Visible BDs were NTDs
NTDs in SB > NTDs in LBs

<table>
<thead>
<tr>
<th>Visible Birth Defects</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrochisis</td>
<td>10.0</td>
</tr>
<tr>
<td>Exomphalos</td>
<td>10.0</td>
</tr>
<tr>
<td>Imperforate Anus</td>
<td>10.0</td>
</tr>
<tr>
<td>Hypospadias</td>
<td>10.0</td>
</tr>
<tr>
<td>Reduction limb defects</td>
<td>10.0</td>
</tr>
<tr>
<td>Talipes equinovarus</td>
<td>10.0</td>
</tr>
<tr>
<td>Cleft lip and palate</td>
<td>10.0</td>
</tr>
<tr>
<td>Neural Tube Defects</td>
<td>10.0</td>
</tr>
</tbody>
</table>

Anencephaly > Stillbirths & Spina Bifida > Livebirths

Distribution of NTDs

<table>
<thead>
<tr>
<th>NTD</th>
<th>Stillborn</th>
<th>Liveborn</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anencephaly</td>
<td>54.5</td>
<td>15.3</td>
</tr>
<tr>
<td>Craniorachischisis</td>
<td>3.1</td>
<td>69.4</td>
</tr>
<tr>
<td>Iniencephaly</td>
<td>2.0</td>
<td>14.1</td>
</tr>
<tr>
<td>Encephalocele</td>
<td>9.8</td>
<td>1.0</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>30.6</td>
<td>0.5</td>
</tr>
</tbody>
</table>

SEAR-NBBD Surveillance Data, July 2014–June 2017
Current Focus: Further Improving Data Quality and Evaluating Efforts

Completeness of form improved
Timeliness still challenging

BD description & ICD coding has improved considerably

SEAR-NBBD Surveillance Data, July 2014–June 2017
Stillbirth Pilot and Preivable Study, India, 2014–2017

- NTDs in stillbirths four times higher than livebirths in NBBD
- Stillbirth pilot had similar findings
  - Every third case of stillbirth had an NTD
- Lessons led to stillbirths surveillance expansion under NBBD

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2014
SB Pilot in India
--10 Hospitals
Chandigarh network

2015
Pilot expanded
-10 Hospitals added in Delhi network

2016
Trainings held to strengthen capacity

2017
India – 55 Hospitals
Bhutan – 3 Hospitals
Key Lessons Learnt from Implementing NBBD Surveillance and Database

- Stakeholder engagement is key
- Focal points with clearly defined roles for birth defects surveillance important for smooth operations
- Periodic refreshers and trainings needed for good data
- Focus on data quality and use by analysis and interpretation
- Hospital network can be leveraged
  - e.g., sharing guidelines and monitoring HCM during Zika outbreak
- Country-level MoH commitment is needed for sustainability

HCM: Head circumference measurements
MoH: Ministry of Health

Microcephaly picture source: CDC
Evidence for Action: Demonstration Project in Haryana, India

- **Aim** -- assess the feasibility, sustainability, and health impact of fortifying wheat flour with iron, folic acid, vitamin B12 using India’s existing open market and government systems.

**Phase 1**
- Birth Defect Surveillance
- Baseline household survey, Lab capacity and biomarker tests, Supply chain analysis, community needs assessment

**Phase 2**
- Birth defect Surveillance
- Fortification implementation

**Phase 3**
- Birth defect Surveillance
- Impact Evaluation
And the journey of NTD prevention continues...

Prevent Birth Defects
Improve Newborn Survival -
Ensure Quality of Life and Dignity

Thank You

Acknowledging collaboration

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Global Prevention of Neural Tube Defects