### Spina Bifida Score: 4 ★

**Spina Bifida - SCORE KEY**
- Excellent = 6 stars
- Good = 4-5 stars
- Improvements needed = 0-3 stars

### Hydrocephalus Score: 1 ★

**Hydrocephalus - SCORE KEY**
- Excellent = 5 stars
- Good = 3-4 stars
- Improvements needed = 0-2 stars

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<th>INDIA</th>
<th>Folate studies</th>
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<tbody>
<tr>
<td><strong>SPINA BIFIDA</strong></td>
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<td><strong>HYDROCEPHALUS</strong></td>
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### RECOMMENDATIONS

- **Spina Bifida**
  - Continue national surveillance of blood folate status among women of reproductive age
  - Continue surveillance and monitoring of spina bifida and hydrocephalus prevalence and mortality, over time and by population clusters (i.e. high-risk groups). Create prevention targets and benchmarks for trends, and report progress
  - Enhance surveillance efforts and conduct population- or large hospital-based studies, and publish prevalence and mortality rates for spina bifida and hydrocephalus at national levels
  - Undertake coverage and effectiveness studies for existing programs (voluntary fortification/supplementation), and explore opportunities for mandatory fortification policy of staple foods
  - Improve access to peripartum and neonatal care

- **Hydrocephalus**
  - Enhance surveillance efforts and conduct population-based studies, and publish prevalence and mortality rates for spina bifida and hydrocephalus at national levels
  - Create surveillance systems in multiple local and regional hospitals, and publish mortality rates for spina bifida and hydrocephalus
  - Improve global neurosurgical education and practice (e.g., training, residency, traveling fellowships, supportive partnerships, disease-specific development)
  - Take the next step to ratify the UN Convention and actively implement and enforce programmes and policies supporting the rights of persons with disabilities

### Additional Information:
India has prepared a 5-year national plan for surveillance, prevention, and control of birth defects. WHO-SEARO in collaboration with the U.S. Centers for Disease and Prevention conducted surveillance trainings for Indian medical colleges throughout the state, and most of these hospitals are already collecting and reporting birth defects surveillance data to the regional Newborn and Birth Defect surveillance system. In August 2014, the Ministry of Health and Family Welfare held a national review meeting of Rashtriya Bal Swasthya Karyakram with special reference to birth defects surveillance and called upon all states to identify one to two birthing hospitals per state to initiate birth defects surveillance. In August 2015, the ministry held a national consultation on wheat flour fortification and the development of "Operational Guidelines for Scaling Up Fortification of Wheat Flour with Iron, Folic Acid and B12: A Critical Intervention for Reducing Prevention of Iron Deficiency Anemia and Incidence of Neural Tube Defects." Haryana state is planning to conduct a pilot project in Ambala district to assess the feasibility, sustainability, and health impact of fortifying wheat flour with folic acid, vitamin B12, and iron using India’s existing open market and government systems. The Regional Director of WHO-SEARO also launched the “SEAR NBBD” mobile app for birth defects surveillance during the Regional Technical Advisory group meeting in December 2015 and it is being piloted in several hospitals.
**TECHNICAL NOTES**

**PUSH! Research Methodology**

The purpose of PUSH! Global Alliance Report Card Project is to provide a summary report of status of spina bifida and hydrocephalus at country-level, and by WHO-defined regions, with the best available and most current information by following indicators: a) availability of data (e.g., prevalence, mortality, folate studies); b) prevention; c) access to care; d) quality of life. Members of PUSH! Executive Committee and other expert advisors contributed in formulating credible, actionable indicators for exploration in each of the content areas. For each indicator, three levels of benchmarks were identified to help stratify progress into three scoring criteria (full star, half star, no star). Two independent searches per indicator per data source were conducted. Data sources included published studies retrieved through PubMed search engine, Food Fortification Initiative, WHO Global Database on the Implementation of Nutrition Action, and USAID, Millennium Development Goals Track, Neurology Atlas (WHO, 2004), and United Nations Convention on the Rights of Persons with Disabilities. PubMed searches for research studies on prevalence and mortality for spina bifida and hydrocephalus were conducted from 2000 onwards, and folate studies from 1990 onwards. The report cards deliver comprehensive information to Ministries of Health or other national level organizations on current status and need for spina bifida and hydrocephalus research, prevention, and policy in their countries.

**Scoring Criteria**

**Folate Studies Data**

1 Star = WHO data OR published population-based or large hospital-based data on RBC or serum folate levels (Publication Year: 1990 or upwards); 1/2 Star = Small studies on RBC or folate levels (Publication Year: 1990 or upwards); X = No studies on RBC or serum folate levels studies (Publication Year: 1990 or upwards)

**Prevalence Data**

1 Star = Published population-based or large hospital-based prevalence data on live births, still births, elective terminations (Publication Year 2000 or upwards) OR existing birth defects surveillance system; 1/2 Star = smaller hospital-based prevalence studies on live births, still births, elective terminations (Publication Year 2000 or upwards) OR small regional surveillance / official reporting; X = No published prevalence studies (Publication Year 2000 or upwards).

**Mortality Data**

1 Star = Published population-based or large hospital-based mortality data (Publication Year 2000 or upwards); 1/2 Star = Published smaller hospital-based mortality studies, small regional surveillance / official reporting (Publication Year 2000 or upwards); X = No published mortality studies (Publication Year 2000 or upwards).

**Prevention**

Spina Bifida: 1 Star = Mandatory folic acid fortification policy is implemented and is aligned with WHO standards; 1/2 Star = Voluntary folic acid fortification policy is implemented and is aligned with WHO standards; X = No mandatory or voluntary folic acid fortification policies.

Hydrocephalus: 1 Star = On track to, or has achieved MDG 4 AND MDG 5 targets; 1/2 Star = On track to, or achieved MDG 4 OR MDG 5 targets; X = MDG 4 and 5 targets not met or on track.

**Access to Care**

1 Star = Minimum of more than 1 neurosurgeon per 1,000,000 population; 1/2 Star = 0.2-1 neurosurgeons per 1,000,000 population; X = 0-0.2 neurosurgeons per 1,000,000 population.

**Quality of Life**

1 Star = Signed AND ratified the UN Convention on the Rights of Persons with Disabilities; 1/2 Star = Signed only the UN Convention on the Rights of Persons with Disabilities; X = Neither signed nor ratified the UN Convention on the Rights of Persons with Disabilities.
Recommendations for Indicators

The Global Report Cards reflect specific recommendations based on how individual countries scored and different recommendations were given depending on how countries scored in each area. Below is a complete list of the recommendations for each indicator. Please note: The recommendations provided for each individual country are for information purposes only and are not meant to be definitive or exclusive of other actions. PUSH! recognizes the specific circumstances of each individual country may vary.

Recommendations for FOLATE STUDIES (spina bifida)
- No star: Develop surveillance capacity to periodically monitor blood folate status in women of reproductive age
- Half star: Enhance surveillance to assess blood folate status among women of reproductive age at national levels
- Full star: Continue national surveillance of blood folate status among women of reproductive age

Recommendations for DATA for Prevalence & Mortality (Spina Bifida and Hydrocephalus)
- No star: Create surveillance systems in multiple local and regional hospitals, and publish prevalence and mortality rates for spina bifida and hydrocephalus
- Half star: Enhance surveillance efforts and conduct population- or large hospital-based studies, and publish prevalence and mortality rates for spina bifida and hydrocephalus at national levels
- Full star: Continue surveillance and monitoring of spina bifida and hydrocephalus prevalence and mortality, over time and by population clusters (i.e., high risk groups). Create prevention targets and benchmarks for trends, and report progress

Recommendations for PREVENTION (Spina Bifida)
- No star: Explore opportunities for mandatory fortification policies for staple foods, and implement or enhance supplementation programs in the interim to reach reproductive aged women
- Half star: Undertake coverage and effectiveness studies for existing programs (voluntary fortification / supplementation), and explore opportunities for mandatory fortification policy of staple foods
  - Full star: Periodically evaluate coverage and effectiveness in mandatory fortification, and implement required remedial measures to address gaps

Recommendations for PREVENTION (Hydrocephalus)
- No star: Improve access to peripartum and neonatal care
- Half star: Improve access to antenatal care
- Full star: Improve management of pre-term labor, including identification of women at risk

Recommendations for ACCESS TO CARE
- No star: Increase the number of neurosurgeons in country who can provide care to children and adults with spina bifida and hydrocephalus
- Half star: Improve global neurosurgical education and practice (e.g., training, residency, traveling fellowships, supportive partnerships, disease-specific development)
- Full star: Improve evidence-based treatment and post-surgical community-based support and follow-up, with quality control protocols

Recommendations for QUALITY OF LIFE
- No star: Take the first step to recognize the rights of persons with disabilities. Sign and ratify the UN Convention
- Half star: Take the next step to ratify the UN Convention and actively implement and enforce programs and policies supporting the rights of persons with disabilities
- Full star: Ensure that programs and policies supporting the rights of persons with disabilities are implemented and enforced

For additional inquiries please contact: push.global.alliance@gmail.com