**World Birth Defects Day (March 3)**

**2019-2023 Plan**

**Updated June 4, 2018**

*Document prepared by Pierpaolo Mastroiacovo and Salimah Walani with input from Boris Groisman, Eva Bermejo Sanchez, Marcia Feldkamp, Paul Romitti and Rachel Diana Schwarz (point of contact for CDC-NCBDDD Team)*

**The goal for the next five-years (2019-2023) is to harness the power of the World Birth Defects Day movement to move our collective efforts from simply raising awareness to mobilizing resources and commitment to improve birth defects surveillance, prevention and care**

**Abbreviations**

WBDD: World Birth Defects Day

WBDD-PO: Organization actively participating to the promotion of World Birth Defects Day

**THE WBDD VISION (2019-2023)**

The first WBDD was observed on 2015 with the aim to provide one global voice and a platform to all organizations and institutions engaged in birth defects related surveillance, research, prevention and care activities. For the first four years (2015-2018), the focus has been on raising awareness about the importance of birth defects. The success of WBDD is evident from the fact, that in 2018 a total of 130 organizations formally joined the WBDD efforts and millions were reached with birth defects awareness messages via social media. We believe that the WBDD movement, over the next five years needs to accelerate **coordinated efforts** to enable organizations and institutions to:

1. Disseminate health **knowledge** for reducing the occurrence of birth defects for which there are proven prevention strategies,
2. improve **quality of life** of all individuals and families affected by birth defects regardless of their race, social class or geography,
3. advance knowledge on **epidemiology** of birth defects by initiating new programs and strengthening the existing ones to better understand how birth defects impact communities,
4. secure financial and public support for **research** to find causes of birth defects and identify best practices for treatment and care of children with birth defects.

**APPROACHES FOR ACHIEVING THE WBDD VISION**

1. **Informing the population**

The WBDD efforts through its website, social media, print publications and on-ground activities should serve as an opportunity for disseminating the relevant information to the public about:

* ways to **prevent** some specific birth defects,
* the global **burden** of birth defects[[1]](#footnote-1),
* the standard **treatment and local resources** for care of those affected with the most common conditions,
* **programs** for improving the quality of life of affected children and their families,
* the critical importance of **research**.
1. **Increase efforts for gathering epidemiologic data**

There is a great need, worldwide, to have high quality data collection systems and more funds for birth defects research. This is, for example, the main lesson recently learned with the Zika virus epidemic. The WBDD should highlight the need for improving availability of data related to occurrence, mortality and morbidity of birth defects by promoting implementation of new initiatives in the field of epidemiology of birth defects and strengthening the existing efforts. Moreover, the WBDD movement should advocate for availability of funds for birth defects research because due to limited funding, even in countries where we have prevalence data, information on risk factors, quality and utilization of services and their impact is not known. Obviously the WBDD as such cannot enter in technical details, but it may be an opportunity for every WBDD-PO to contact its own Public Health Decision Makers and Research Funding Organizations and/or to bring them a particular feasible and cost-effective project.

1. **Use of WBDD website:** [**www.worldbirthdefectsday.org**](http://www.worldbirthdefectsday.org)

The WBDD website should be used as a hub for organizing the WBDD, to record the activities, to track the success, but the most important aim of the web should be to disseminated information about the birth defects. The WBDD website should provide links to selected information already available on the websites of some outstanding WBDD-POs. A specific committee should identify the best websites and the relevant fact-sheets to be included in the WBDD web. Every WBBD-PO should use the suggested fact-sheets to inform their own population.

1. **Leveraging partnerships**

WBDD was launched in 2015 by 12 organizations. The number of organizations joining the movement formally or informally has been increasing exponentially every year (130 in 2018). The vision is to engage a greater number of organizations on an ongoing basis to advocate for integrating activities related to birth defects epidemiology, prevention and care as part of global activities related to improving reproductive, maternal, newborn, child and adolescent health (RMNCAH) and bringing birth defects to the forefront of the UN’s Sustainable Development Goals agenda.

 The organizations participating in WBDD efforts are encouraged to use social media, their own organizational websites and other electronic and on-ground resources to increase visibility of the day, visibility of the WBDD movement and information on birth defects. To improve the effectiveness of their efforts, each organization should try to form a dedicated team/workgroup that meets regularly during the year or at least four months before March 3 each year to coordinate their organization’s engagement. Each organization should visit and register with [www.worldbirthdefectsday.org](http://www.worldbirthdefectsday.org) to not only seek information about the day but also to get recognized as a participating organization.

**KIND OF ORGANIZATIONS**

The WBDD needs the contribution of a wide variety of organizations from all parts of the world. Some examples of organizations are: maternal newborn and child health organizations, pediatric and maternal-child health hospitals, community health agencies, professional associations, foundations, donor agencies, Ministries of Health, not for profit organizations and civil society organizations such as parent groups are also encouraged to participate. The WBDD also needs cooperation from UN agencies such as, World Health Organization and UNICEF to ensure that birth defects are part of their campaigns.

**WBDD LEADERS AND PARTNERS**

*Leadership*

From 2014-2018, CDC, March of Dimes and ICBDSR have served as key organizations in the WBDD efforts.

Going forward, it is proposed that similar to the structure of professional associations, WBDD should have a Steering Committee and several workgroups[[2]](#footnote-2) [[3]](#footnote-3) [[4]](#footnote-4) as described below, with a 2-3 year terms:

1. **Steering Committee**: responsible for developing new ideas, encouraging new organizations to become WBDD-PO, making feasible and efficient plans for increasing participation and promotion of WBDD, including:
	* organizing an effort to seek WHO endorsement so that WBDD receives official recognition,
	* serve as the secretariat for dissemination of information via emails to all the WBDD\_POs and among the workgroups[[5]](#footnote-5)
2. **Workgroup for fundraising**: responsible for identifying potential funding opportunities and for reaching out to donors.
3. **Workgroup for scientific activities**
	* Responsible for compiling and producing evidence on mortality and morbidly of birth defects worldwide to help member organizations advocate for support of birth defects
	* Publish and disseminate commentaries, blogs and papers around WBDD
4. **Workgroup for marketing and promotion**
	* Generate fact-sheets and presentations to be posted in the WBDD website
	* Maintain, suggests and evaluates the contents of WBDD website
	* Develop social media toolkits
	* Help promote the day via Twitter, Facebook thunderclap, other social and traditional media platforms
5. **Workgroup for Partner Relations**
	* Recruit and maintain partnerships from all WHO regions

*Partnerships*

All WBDD-PO will be classified as “WBDD Partners” and are encouraged to achieve higher-level award based on the performance on WBDD. After each WBDD, based on the performance and activities (based on the submitted report), the Executive Committee will evaluate and recognize each PO for their efforts on [www.worldbirthdefectsday.org](http://www.worldbirthdefectsday.org) as follows:

1. **Platinum Partners**: WBDD-POs that fulfill three tasks:
* organize a significant local activity (examples, professional meeting, public health education meeting, a policy improvement activity with involving Public Health Decision Makers and/or Research Funding Organizations)
* have an informative website on birth defects and a page dedicated to WBDD (in English and/or in own country language),
* actively support the WBDD through own web, social media and Thunderclap.
1. **Gold Partners**: WBDD-POs that fulfill two tasks:
* have an informative website on birth defects and a page dedicated to WBDD (in English and/or in own country language),
* actively support the WBDD through their own web, social media and Thunderclap.
1. **Silver Partners:** WBDD-POs that fulfill only one task:
* actively support the WBDD through their own web, social media, and Thunderclap.

**IDEAS FOR MARKING THE FIFTH WBDD IN 2019**

1. A stakeholders meeting on or around March 3, 2019 in New York

Aim: To unify organization for prevention and care for all children with special needs.

Potential Stakeholders (preliminary list):

* 1. WHO and UN agencies
	2. Governmental agencies
	3. Not for Profit organization
	4. Professional societies, associations and groups
	5. Patient and parent advocacy organizations
	6. Selected WBDD charter and participating organizations
1. A publication on the link between birth defects and other global movements to improve maternal and child health
2. Perhaps organize a World Health Assembly 2019 side event
3. Reach at least 10 million on social media
4. Engage at least 200 WBDD-PO
1. We do not know the whole burden (occurrence, mortality, associated morbidity and/or disability, poor quality of life) of several birth defects. The WBDD website should provide the known specific information on the different conditions. [↑](#footnote-ref-1)
2. A person may be part of one or more committee [↑](#footnote-ref-2)
3. A committee may have more than one person belonging to the same organization [↑](#footnote-ref-3)
4. A committee should have at least two persons [↑](#footnote-ref-4)
5. ICBDSR will continue to serve as the WBDD secretariat to help convene the activities of the Steering Committee and the Workgroups until a new committed organization will take over. [↑](#footnote-ref-5)