Establishment of the Philippine Birth Defects Surveillance

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for the Birth Defects Surveillance Study Group

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ABSTRACT

Congenital anomalies have been in the top ten causes of infant mortality in the Philippines for the past 50 years. Since there is no systematic surveillance for congenital anomalies in our country, there are no specific programs directed toward better understanding of this group of patients. The Birth Defects Surveillance Project was conceived in 2008 to develop a system of reporting of newborns with birth defects at the hospital and community setting. The lead agencies for this project are the University of the Philippines Manila – National Institutes of Health and the Department of Health (DOH). This paper describes the establishment of the Philippine Birth Defects Surveillance.

Key Words: birth defects, congenital anomalies, congenital malformations, surveillance

Introduction

Birth defects are abnormalities affecting body structure or function including metabolism that is present from birth, which may be clinically obvious upon delivery or may be diagnosed only later in life. To date, more than 7,000 different birth defects of genetic or partially genetic origin have been identified, originating mostly before conception (preconception), or after conception but before birth (post-conception). More than half of these still have no known causes.[1]

Six (6) percent of total births worldwide (approximately 7.9 million children) are born with a serious birth defect annually. It can be lethal while those who survive may be disabled for life.[1] In the Philippines, the burden of birth defects is not well established because of the absence of any systematic surveillance. It is interesting to note that congenital malformations/anomalies remain in the top ten causes of infant mortality for decades now (Appendix 1).[2]

Data on birth defects is an important contribution to the current worldwide efforts of the United Nations (UN) Millennium Development Goal (MDG) of reducing child mortality. Investing in the care and prevention of birth defects will help reduce neonatal mortality and disability, consequently assisting in the realization of UN's MDG. Focus on the newborn, specifically on the effects of birth defects on its health, should be an integral component of any comprehensive women's maternal, newborn and child health program, as stressed in the Lancet Neonatal Survival Series.[1,3] However, many countries worldwide do not have any national policy on the prevention and care of children with birth defects. This is due in part to the lack of awareness among health policy makers and legislators on the immense toll of birth defects, including the true extent of death and disabilities.

Surveillance Efforts in other Countries

In the 1960s, it was discovered that rubella caused birth defects and that maternal use of thalidomide caused an epidemic of limb reduction defects. This breakthrough resulted in the establishment of birth defects surveillance programs in a number of countries. In 1967, the Metropolitan Atlanta Congenital Defects Program (MACDP) was started by the Centers for Disease Control and Prevention (CDC), Emory University and the Georgia Mental Health Institute. As the oldest population-based birth defects surveillance system in the United States, MACDP has been collecting, analyzing, and interpreting birth defects surveillance data and has monitored trends in birth defects rates. It serves as a case registry for descriptive risk factors and prognostic studies on birth defects, including studies of Agent Orange exposure among Vietnam War veterans, maternal use of multivitamins, diabetes,

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febrile illnesses, and survival of children with neural tube defects. It became a resource for the development of uniform methods and approaches to birth defect surveillance across the United States and in many other countries.[4-6] MACDP's purpose are: 1) to track the occurrence of birth defects; 2) to maintain data for use in epidemiologic studies (studies that look at health effects within the population); 3) to understand other health outcomes, such as mortality or death rates, associated with birth defects; 4) to provide data for education and health policy decisions leading to prevention of birth defects; 5) to serve as a model to help other programs develop and implement new tracking methods; 6) to collaborate with state and international birth defects programs in tracking prevention efforts; and 7) to provide a training ground for public health scientists in tracking and epidemiologic methods.[7]

In 1974, CDC and representatives from nine other surveillance programs, primarily from Europe, formed the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS). Surveillance programs monitored the prevalence of certain birth defects and the data obtained are used as basis for prevention, education, policy, and healthcare planning. The ICBDMS eventually became the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR). The Annual Reports generated by ICBDSR includes 40 registries from developed and developing countries that jointly monitor 40 birth defects. The activities include public health research and capacity building to reduce disease and promote healthy outcomes through primary prevention. ICBDSR monitors for teratogenicity of medications, manages an international database of people with orofacial clefts to promote outcome research, and has completed an international study of genetic polymorphisms of folate genes to promote international public health genetic research.[4,5,8]

Surveillance Efforts in the Philippines

In 1999, the Department of Health (DOH), in partnership with the Institute of Human Genetics-National Institutes of Health (IHG-NIH), University of the Philippines Manila conducted a pilot project of the Birth Defects Registry. This project involved examination of 191,576 newborns in 79 hospitals which revealed a total of 1,240 birth defect cases.[9] With neural tube defects in the top ten birth defects (6th in rank), initiatives were taken and awareness campaigns on the importance of folic acid as well as folic acid supplementation were carried out. This project had limitations: 1) it was not integrated into the programs of DOH; and 2) it was limited to hospital-born babies. Since there was no systematic surveillance for congenital anomalies, there were no organized programs for this group of patients.

To address these concerns, a national Birth Defects Surveillance (BDS) was proposed. The objectives of the surveillance are: (1) to implement a surveillance program for newborns with birth defects in different settings, such as government hospitals, private hospitals, and community health units; (2) to determine the incidence of birth defects in all participating sites; (3) to determine the rate of occurrence of different types of birth defects; (4) to provide morbidity and mortality statistics to assist in national policy and program planning; (5) to identify possible risk factors for commonly encountered birth defects; and (6) to make recommendations for adoption of the BDS on a nationwide scale.

This paper describes the establishment of the Philippine Birth Defects Surveillance Project.

Methods

Preparatory Stage

Prior to the implementation of the BDS, the following steps were done: 1) creation of the BDS core group; 2) systematic recruitment of hospitals and communities, and appointment of BDS coordinators; 3) finalization of the BDS form; 4) finalization of the manual of operations; 5) conduct of orientation workshops for clarification of definitions and flow of implementation; and 6) pilot testing of BDS form.

Creation of BDS Core Group. The BDS Core Group (Appendix 2) composed of clinical geneticists, neonatologists and representatives from the DOH sets the direction of the project and oversees the over-all implementation, monitoring and evaluation. Luzon, Visayas and Mindanao Regional Coordinators are in charge of the overall implementation in their health facilities and communities. Figure 1 shows the organizational structure of the Philippine BDS Project.

Systematic Recruitment of Hospitals and Communities. *The Sentinel Site Strategy*. Hospitals and communities were recruited by sentinel sites. A sentinel site is a group of hospitals and communities that are geographically linked. Every sentinel site has at least one tertiary government hospital, at least one tertiary private hospital, local government hospital/s (provincial, district and/or municipal/city hospital), and community-based health facilities (rural and urban). A tertiary hospital (private or government) provides clinical care and management on specialized and sub-specialized forms of treatment, surgical procedure and intensive care. A local government hospital is a hospital operated and funded by a local government unit (LGU). A community-based health facility is a basic unit that provides health services to a number of barangays.

The sentinel site strategy was introduced to cover livebirths in the health facilities and the home deliveries creating an efficient and systematic referral system among the health facilities and communities within a sentinel site.

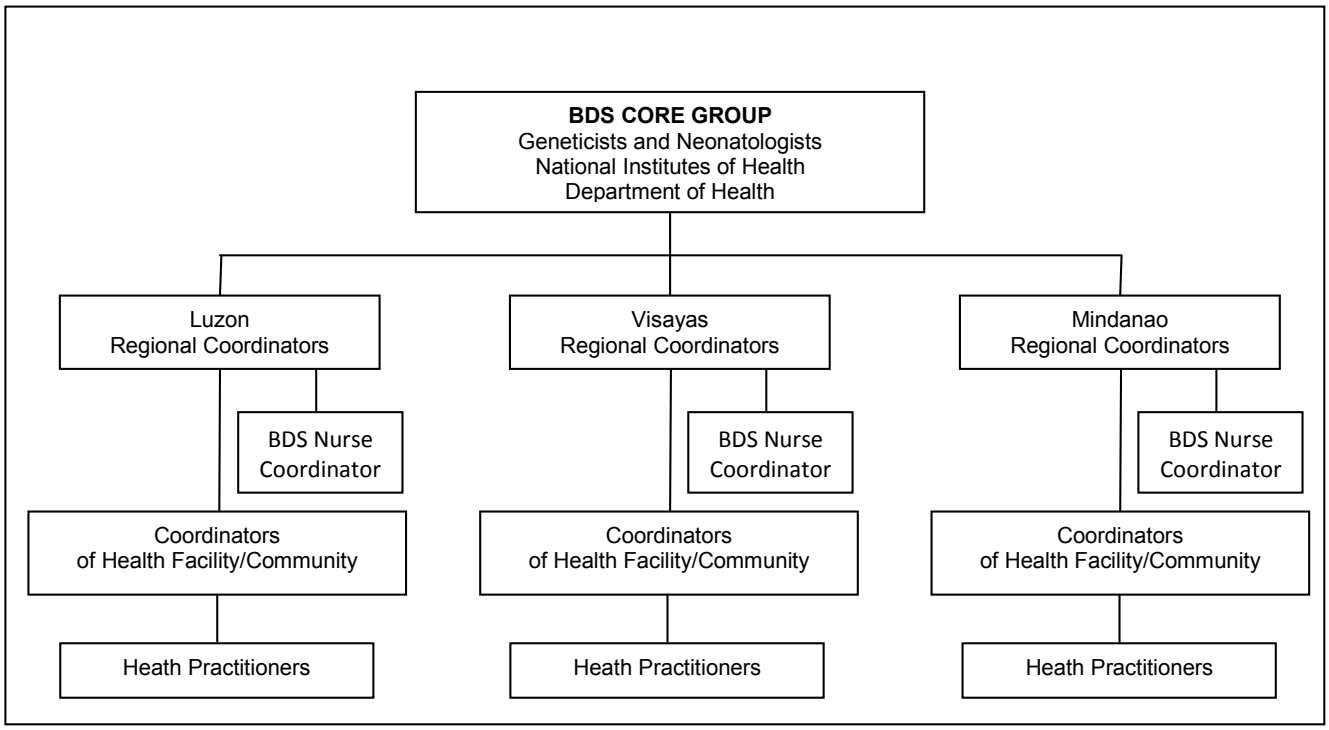

Figure 1. BDS Organizational Structure

During the first round of recruitment, a track record of excellent performance in a DOH program, i.e. the newborn screening program, was one of the criteria for selection. Formal commitment of the Pediatrics Department Chair/Chief of Hospitals/Medical Director or the Municipal/City Health Officer was a requirement for inclusion in the study group.

Every participating health facility or community has at least one (1) BDS Coordinator in charge of the implementation of BDS in their respective health facilities and communities. All BDS coordinators are members of the BDS Study Group (Appendix 2).

Finalization of the BDS Form. The BDS form was sent to the Global Network for Maternal and Infant Health (GNMIH) and the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) for comments. The final BDS form (Appendix 3) was pilot tested prior to implementation.

Finalization of the Manual of Operations. A BDS Manual of Operations contains the general information about the Philippine Birth Defects Surveillance Project, the project's flow of operations (Figure 2), guidelines on how to accomplish the form, and the role of national organizations and other key players in the execution of the project.

Conduct of Workshops/Meetings. Orientation and monitoring workshops were conducted at several phases of the project.

Implementation Proper

Inclusion/Exclusion Criteria. The BDS study group decided to include live births only in this registry. A separate registry will be done for stillbirths and fetal deaths. A livebirth is a newborn that breathes, or exhibits any sign of life (i.e., beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles) even for just a few seconds at the time of birth.[10] Babies born in participating health facilities (i.e. hospital, lying-in center, rural health unit/health center) were included. If the newborn with birth defect was home-delivered by a Traditional Birth Attendant (TBA) or Midwife, he/she must be referred by the Barangay Health Worker (BHW) to the nearest BDS Facility for proper reporting. BDS Forms must be accomplished within seven days from birth. Moreover, only major anomalies on physical examination were considered. Metabolic and/or inherited diseases and functional defects without obvious structural anomalies (e.g., PKU or congenital hypothyroidism), and poor pregnancy outcomes (e.g., low birth weight) were excluded.

Results

During Phase 1 (Year 1) of implementation, a total of 8 sentinel sites consisting of 32 health facilities and communities participated. Forty-one (41) facilities and communities were added in Phase 2. By the end of Phase 3 (Year 3) in August 2011 a total of 82 health facilities and communities from 18 sentinel sites are involved (Appendix

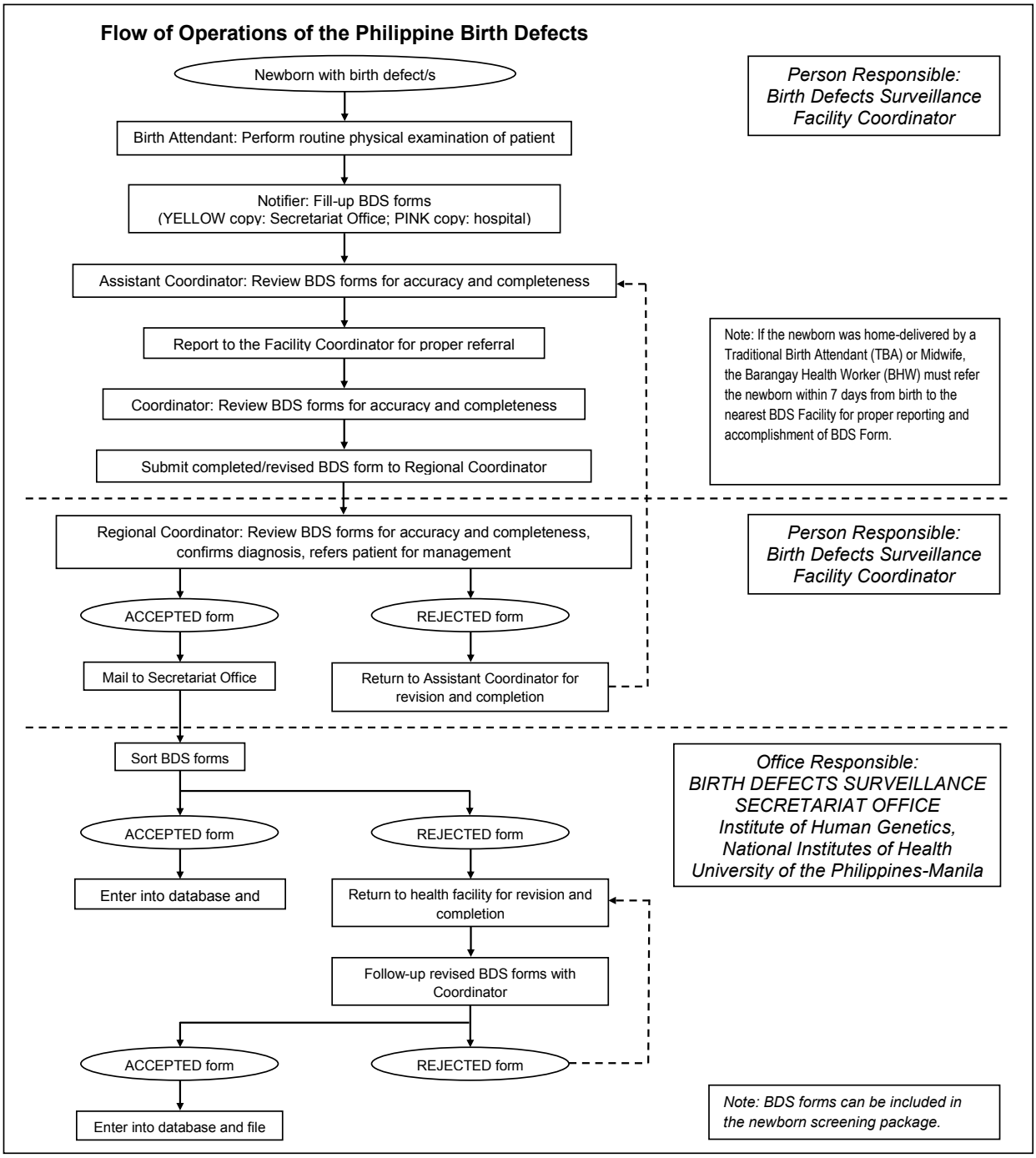

Figure 2. BDS Flow of Operations

1). Figure 3 shows the regional distribution of the sentinel sites.

Discussion

March of Dimes reports that experiences in developed countries have shown that up to 70% of birth defects can either be prevented or properly managed. Affected children can be offered care that could be life-saving or would reduce the severity of disability. Interventions include appropriate treatment particularly surgery, and prevention, especially before conception or in very early pregnancy. Salt fortification with iodine, for example, has led to a significant reduction in morbidity from iodine deficiency disorder.[1] Yi et al. reported that in the United States, the economic benefit of NTD prevention exceeded the cost of folic acid fortification, as demonstrated by a benefit-cost ratio of 4.3:1.[11]

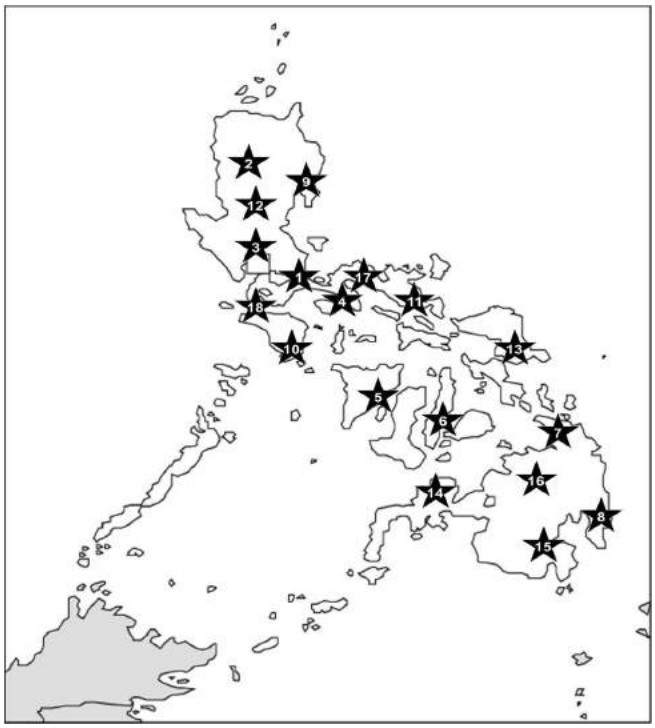

Figure 3. The Philippine Birth Defects Project sentinel sites. Each sentinel site has at least one (1) Tertiary Hospital Government, Tertiary Hospital Private, Local Government Hospitals (Provincial, District and Municipal/City Hospital), and Community Setting (rural and urban). Some sentinel sites in Mindanao, however, have secondary private hospitals included. **1**– National Capital Region (NCR); **2** – Ilocos Region; **3** – Central Luzon; **4**- Cavite, Laguna, Batangas, Rizal, Quezon (CaLaBaRZon); **5** – Western Visayas; **6** – Central Visayas; **7** – Northern Mindanao; **8** – Southern Mindanao; **9** – Cagayan Valley; **10** - Mindoro, Marinduque, Romblon, Palawan (MIMAROPA); **11** – Bicol Region; **12** - Cordillera Administrative Region (CAR); **13** – Eastern Visayas; **14** – Zamboanga Peninsula; **15** - South Cotabato, Cotabato, Sultan Kudarat, Saranggani, General Santos City (SocCSKSarGen); **16** – CARAGA; **17** – CaLaBaRZon; **18** – NCR

The March of Dimes, USA has involved the Philippines in the Global Network for Maternal and Infant Health (GNMIH), whose goal is to reduce mortality and disability from birth defects and preterm births in lower-income countries. Together with China and Lebanon, the Philippines embarked on birth defects surveillance projects to identify and help the affected patients.[12] In the Philippines, activities under GNMIH include a birth defects surveillance, prevention of birth defects campaigns, engaging the youth in GNMIH activities and preconception activities for the prevention of birth defects.

The burden of birth defects is not well-established in the Philippines. This is due to the lack of access of affected patients to specialists, constrained diagnostic capabilities, poor health-related statistics, and the absence of any systematic birth surveillance and registries. The causes of a substantial proportion of birth defects are also unknown, and risk factors as well as preventive strategies are not yet proven. Incidence rates and other important statistics about birth defects are not available.

If these information are made available, it would justify clinical services to affected children and families, improve programming and prevention strategies, and enhance community links. Data will also be instrumental in addressing urgent public health concerns on preconception and prenatal care (e.g. role of folic acid), genetic counseling (e.g. recurrence risk for syndromes with known Mendelian pattern of inheritance) and better understanding of risk factors (e.g. exposure to childhood infections like Rubella and Varicella). Therefore, an effective surveillance is needed to allow for the ready use of data for implementation of population-based planning for public health programs.

The inclusion of communities is a critical strategy since 60% of births are still delivered at home. For better implementation, the *telegenetics referral system* was introduced primarily to assist the health practitioners in the field to arrive at a correct diagnosis critical for proper management and proper genetic counseling. The geneticists in Manila (5), Cebu (1) and Davao (1) will respond to the queries from the field. Ten sites have been identified as pilot implementing areas: Batanes, Cagayan Valley, La Union, Baguio, Bicol, Iloilo, Tacloban Leyte, Zamboanga, Cagayan de Oro, and Surigao.

Conclusion and Recommendation

The Philippine Birth Defects Surveillance is important to the future of the patients with birth defects/congenital malformations/congenital anomalies. Prevention is the goal. For those born with the birth defects, the goal is early care and management for prevention of complications. Integration in the public health delivery system is the key to the success of the Birth Defects Surveillance. Extension of the BDS to communities is critical since more than 60% of births are born at home. It is strongly recommended that the DOH supports the maintenance of a national surveillance program for birth defects and the integration of genetic services in the public health delivery system.

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Appendix 1

Leading causes of infant deaths[10]

	1960*	1971*
Rank	**Causes**	**Causes**
1	Beri-beri	Pneumonia
2	Pneumonia	Ill defined diseases Peculiar to Early Infancy and Unqualified Immaturity
3	Ill defined diseases Peculiar to Early Infancy	Gastroenteritis and Colitis
4	Bronchitis	Bronchitis
5	Gastroenteritis and Colitis	Avitaminoses and other Deficiency States
6	Immaturity	Postnatal Asphyxia and Atelectasis
7	Postnatal Asphyxia	Tetanus
8	Tetanus	All Other Defined Disease of Early Infancy
9	Other Avitaminoses	***Congenital Malformation***s
10	***Congenital Malformations***	Other Infection of Newborn

**The Department of Health Statistics*

	1980*	1990*
Rank	**Causes**	**Causes**
1	Pneumonia	Pneumonia
2	Respiratory Conditions of Fetus and Newborn	Respiratory Conditions of Fetus and Newborn
3	Diarrheas	***Congenital Anomalies***
4	C***ongenital Anomalies***	Diarrheal Diseases
5	Avitaminoses and other Nutrional Deficiency	Septicemia
6	Birth Injury and Difficult Labor	Avitaminoses and other Deficiency States
7	Acute Bronchitis and Bronchiolitis	Birth Injury and Difficult Labor
8	Measles	Measles
9	Meningitis	Meningitis
10	Dysentery (All forms)	Acute Bronchitis and Bronchiolitis

**The Department of Health Statistics*

	2000*	2005*
Rank	**Causes**	**Causes**
1	Pneumonia	Bacterial Sepsis of Newborn
2	Bacterial sepsis of newborn	Respiratory Distress of Newborn
3	Disorders related to short gestation and Low birth weight not elsewhere classified	Pneumonia
4	Respiratory Distress of Newborn	Disorder related to short gestation and Low birth weight not elsewhere classified
5	Other Perinatal Conditions	Congenital Pneumonia
6	***Congenital malformations of the heart***	***Congenital malformations of the heart***
7	Congenital pneumonia	Neonatal aspiration syndromes
8	Diarrhea and gastroenteritis of presumed infectious origin	***Other Congenital Malformations***
9	***Other Congenital Malformation***	Intrauterine hypoxia and birth asphyxia
10	Neonatal Aspiration Syndrome	Diarrhea and gastroenteritis of presumed infectious origin

**The Department of Health Statistics*

Appendix 2
Birth Defects Surveillance Study Group

Philippine BDS Core Group
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National Secretariat
Grace Sheilla Alcaraz, Dr. Rommel Sales

Regional Birth Defects Nurses
Marian Cuenca, Anna Leah Millares, Ruben D. Sumaguio, Jr. and Edbert Jasper Jover

Participating Health Facilities and BDS Coordinators
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Sentinel 3 – Central Luzon – TG: James Gordon Memorial Hospital (Dr. Donna Bernal), TP: Angeles University Medical Center (Dr. Mel Guinto, Dr. Thang Ching Lee Chu), LGU: Bulacan Maternity Hospital (Dr. Arvin Escueta), C: Obando Rural Health Unit (Dr. Angela Pangan)

Sentinel 4 – CALABARZON – TG: De La Salle University Medical Center (Dr. Delia Caparas-Yu, Dr. Madeleine Sosa, Dr. Vicente Caluag), TP: Integrated Provincial Health Office, Quezon (Dr. Dennis Rivere, Mrs. Maricel Adofina, Ms. Jasmin Racelis), LGU: Sta. Rosa Community Hospital (Dr. Cristina Miranda, Ms. Myleen Gaca, Ms. Marciana Debuton), C: City Health Office, Lipa City (Dr. Ariel Lescano, Ms. Zenaida Verdera)

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Sentinel 6 – Central Visayas – TG: Cebu City Medical Center (Dr. Mary Jo Sucalit, Dr. Lee James Maratas), TP: Chong Hua Hospital (Dr. Jose Laddy Go, Dr. Teresa Fortunato, Dr. Erving Noel Merlin), LGU: Bayawan District Hospital (Dr. Sozelun Zerrudo, Ms. Helen Gaga-a), C: Tanjay Rural Health Unit II (Dr. Elizabeth Sedillo, Ms. Luz Casiano)

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Sentinel 13 – Eastern Visayas – TG: Eastern Visayas Regional Medical Center (Dr. Nenita Salinas, Dr. Gemma Ramos), TG: Southern Leyte Provincial Hospital (Mr. Gerry Buslon), TP: Bethany Hospital (Ms. Teresa Alacazaren), LGU: Biliran Provincial Hospital (Ms. Miraflor Arevalo), C: Almeria Rural Health Unit (Dr. Evelyn Garcia, Ms. Arlene Estrada)

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Sentinel 15 – SOCSARGEN – TG: Cotabato Regional Medical Center (Ms. Mary Jane Superales), TG: General Santos City Hospital (Dr. Arvin Alejandro), TP: General Santos Doctors Hospital (Dr. Sergio Demontano, Sr., Ms. Analee Gokatano) , TP: St. Elizabeth Hospital (Dr. Maria Helena Veneracion-Garcia, Dr. Julius Cada), TP: Socsargen County Hospital (Dr. Fe Rafael, Ms. Mylene Vigilancia), SP: Mindanao Medical Center (Dr. Felix Garces), SP: Howard Hubbard Memorial Hospital (Dr. Rosemarie Jesswani, Ms. Cecilia Elliot), SP: Diagan Memorial Hospital (Dr. Renato J. Diagan), LGU: South Cotabato Provincial Hospital (Dr. Conrado Brania, Jr, Ms. Lilien A. Gonio), C: Polomolok Rural Health Unit (Dr. Mary Grace Salazar, Ms. Yvonne Buenavista)

Sentinel 16 – CARAGA – TG: DOH Caraga Regional Hospital (Dr. Ma. Lourdes Cubillan, Ms. Maria Cristina Galito), LGU: Adella Serra Ty Memorial Hospital (Dr. Andres Dolar, Dr. Rogene Esparcia), C: Butuan City Health Office (Dr. Josephine Chua, Ms. Ivy C. Zoleta)

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Sentinel 18 – National Capital Region – TG: Dr. Jose Fabella Memorial Hospital (Dr. Melissa Juico), TP: Metropolitan Medical Center (Dr. Jamaica Dollete, Dr. Nancy Lao), LGU: Pasay City General Hospital (Dr. Aurora Libadia, Ms. Eva Suanino), C: Makati Health Department (Dr. Elizabeth Medina, Ms. Lorna Rimando)

Appendix 3

The Birth Defects Surveillance (BDS) Form

BIRTH DEFECTS SURVEILLANCE FORM

A project of the Philippine Birth Defects Surveillance Group

(For Secretariat's use only)

Serial No._____

HEALTH FACILITY/ COMMUNITY DATA

Name of The Health Facility/ Community:

Address:

NOTIFIER'S DATA

Birth Attendant [Surname *(in capital letters)*, Given Name, MI]

Designation: ☐MD ☐Nurse ☐Midwife ☐Others_____ | Signature:

Form accomplished by:

Contact number: | Date Accomplished (MM/DD/YY):

PARENT'S DATA

Mother's name *(optional)*: | Age: | Father's name *(optional)*: | Age:

Ethno-linguistic origin: | Ethno-linguistic origin:

Permanent Address: | Contact number:

NEWBORN'S DATA

Surname *(optional)*: | Given name (*optional)*: | Middle name *(optional)*:

Date of birth (MM/DD/YY): | Hospital Case No. | Gender _____ (1 male 2 female 3 ambiguous)

Plurality: ☐ Single ☐ Twin ☐ Triplet ☐ Other, specify:_____ | Gender of Co-twin _____ (1 male 2 female 3 ambiguous)

Co-Twin Malformation: ☐ Yes ☐No (If yes, please fill-up a separate form)

Pediatric aging *(Give exact weeks if known)*:_____ [1 *preterm(<37 weeks)* 2 *term (37-42 weeks)* 3 *postterm (>42 weeks)*]

Birth Length _____*(cm)* Birth weight _____ *(grams)* Head circumference _____ *(cm)*

Parental Consanguinity: ☐ Yes ☐No if yes, please specify relationship_____

Family history of malformation: ☐ Yes ☐No If yes, specify degree _____ (1 *sibling* 2 *parents* 3 *other relatives*)

If yes, specify kind of malformation:

Did baby die? ☐ Yes ☐No If yes, date of death: _____ Autopsy done? ☐ Yes ☐No

Results (attach if available):

MATERNAL HISTORY

Obstetric score: G___ P___ (F___ P___ A___ L___)

Maternal residence during first 12 weeks of pregnancy:

Maternal completed education:

Maternal occupation on the date of Last Menstrual Period:

Pre-natal check up done? ☐ Yes ☐No If yes, number of visits: _____ Where? _____

Prenatal ultrasound done? ☐ Yes ☐No If yes, trimester done/ results:

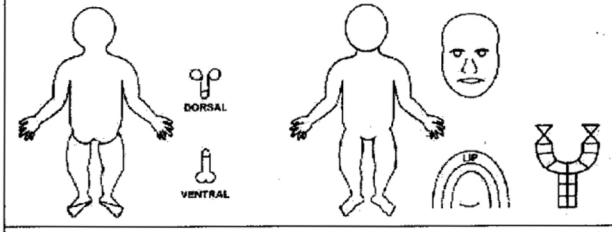
Did mother have/use the following on the first 3 months of pregnancy? If yes, specify at what week of gestation.

A. Any infection ☐ Yes ☐ No	B. Any pre-pregnancy/chronic illness ☐ Yes ☐ No
☐ Cough/colds	☐ Hypertension
☐ High fever	☐ Diabetes
☐ Rubella	☐ Obesity
☐ Varicella	Pre-pregnancy height and weight, if known:
☐ Others, specify:	☐ Epilepsy
	☐ Others, specify:
C. Any drugs/medications ☐ Yes ☐ No	**D. Any other substance/exposure ☐ Yes ☐ No**
☐ Insulin	☐ Alcohol
☐ Antihypertensives	No. of drinks per week:
☐ Anti-diabetes	☐ Smoking ☐ Active ☐ Passive
☐ Anticonvulsants	No. of sticks per day:
☐ Folic Acid	☐ Smoking (other members of the family)
☐ Vitamins	☐ Others, specify:
☐ Ferrous Sulfate	
☐ Others, specify:	

FINDINGS

STATE DIAGNOSIS/SYNDROME (IF KNOWN):

Describe abnormality. Indicate by marking in the appropriate diagram(s) the areas affected by the birth defect(s)/congenital malformation(s).



Illustrate birth defect(s)/malformation(s) if not shown on the left:

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