MARCH OF DIMES FOUNDATION
GLOBAL PROGRAMS

Global Partnerships for Perinatal Health Network (GPPHN)
Building Global Networks of Experts in Lower-Income Countries to Improve the Health of Women, Mothers, Newborns and Babies

SUMMARY OF 17-18 DECEMBER 2007 MEETING
AND UPDATED PROPOSALS
26 June 2008

FIRST ANNUAL MEETING, WHITE PLAINS, NY
17-18 DECEMBER 2007

BACKGROUND TO THE GPPHN PROJECT

In September 2007, March of Dimes Global Programs established four coordinated mission alliances as a first step in developing a global network of experts working to improve the health of women, mothers and babies in lower-income countries. The goal of this three-year project is to reduce mortality and disability from birth defects and preterm birth in lower-income populations worldwide.

The Global Partnerships for Perinatal Health Network (GPPHN) is structured in the manner of successful past mission alliances, and it represents an important step forward in the way Global Programs conducts its work. GPPHN provides a means for developing country experts to share more easily their knowledge, experience, skills and materials in ways that offer significant new benefits. The strengths of the Global Programs mission alliance program will be maintained. What has changed is the introduction of an initially simple but evolving structure to promote communication, collaboration and the sharing of materials and best practices. Another important change is that network programs focus on the care and prevention of preterm birth as well as birth defects.

The core philosophy of GPPHN is *communication and collaboration* from the early stages of proposal development through the choice of program and evaluation methods to be used and the conduct and evaluation of Network projects. Publication of results in the peer-reviewed literature will be co-authored by the Network as appropriate. This approach of “south-to-south” collaboration–which has been much discussed by global health policy makers and donor organizations and widely recognized as needed–has never been implemented to the degree that GPPHN offers. However, it is only through strategically managed networks like GPPHN, where the locus of power and decision making resides as it should with developing country partners, that their development and core capacities can be effected and sustained. In this sense, the role of the March of Dimes and other industrialized country partners in the Network is one of support, guidance and fundraising, rather than unilateral direction.

The GPPHN offers a number of significant benefits. These include:

- providing a platform for developing and industrialized country experts to exchange knowledge and lessons learned;
- promoting a complementary portfolio of research and program activities across network centers;
- encouraging a consistent methodological approach to data collection, evaluation and analysis, thus enhancing the opportunity to pool and contrast project findings across centers;
- offering an infrastructure than can allow for the cost-effective introduction of new program and research activities; and
- providing a means to link international and national technical organizations to the expertise and experience of the network partners––and vice-versa.

Network partners were chosen for a history of demonstrated success in conducting March of Dimes mission-related public health interventions in their countries, geographic balance and their potential capacity over time to expand activities nationally and regionally. The four initial partners are Dr. Roberto Giugliani (Brazil), Dr. Khalid Yunis (Lebanon), Dr. Carmencita Padilla (Philippines) and Dr. Nanbert Zhong (People's Republic of China).

The project will be overseen by an International Advisory Counsel (IAC). The IAC will be tasked overseeing and advising program activities. The IAC–along with the Network PIs, sponsors and outside partner organizations–will meet annually.

The GPPHN, in addition, will coordinate with other networks, including the EU CAPABILITY project which follows the GPPHN model, but focuses on building capacity in medical genetic research and services. The CAPABILITY project has enrolled three centers: Johannesburg, South Africa, Cairo, Egypt and Buenos Aires, Argentina, the first two of which are Global Programs mission partners. Thus, the opportunities for synergy in program activities and future are strong.

Need

The global toll of birth defects and preterm birth

Every year 7.8 million children are born with a serious genetic birth defect. Hundreds of thousands more are born with serious birth defects due to teratogens, including fetal alcohol syndrome, maternal iodine deficiency syndrome, congenital syphilis and congenital rubella syndrome. Over 3.3 million children of these children die from their birth defect within the first five years of birth. The majority of children who survive are disabled for life. The impact of birth defects is particularly severe in low- and middle-income countries where more than 90 percent of births and 95 percent of deaths of children with serious birth defects occur.

Approximately 136 million births worldwide (6-12% of all births) are born preterm each year. Close to a third (27%) of infant deaths are due to prematurity and, like birth defects, a disproportion number of these deaths occur in lower-income countries. The birth prevalence of preterm birth in industrialized countries ranges from 125 per 1,000 live birth in the U.S. to 62 per 1,000 live births in France.

The Potential for Effective Intervention

Despite perceptions to the contrary, cost-effective approaches are available to markedly reduce the toll of birth defects in lower-income countries. Evidence suggests strongly that with widespread implementation of these interventions, up to 70 percent of death and disability from birth defects could be prevented or ameliorated. The majority of recommended interventions such as controlling maternal infections and other health conditions that are known to increase risk of birth defects and improving access perinatal health care services, including preconception services, are integral components of rational public health programs. Thus, such approaches will build on public health efforts by broadening the current scope of woman, maternal, newborn and child health services in primary health care and developing secondary and tertiary medical genetic services.

Much less is known about the causes and, thus, the potential to reduce the risk of preterm birth. However, a number of steps can be implemented right now that can improve understanding of the causes of preterm birth and improve birth outcomes in high-risk women. These same interventions can also serve to strengthen services for the care and prevention of birth defects. These include improving surveillance and analysis of data on birth prevalence and the strengthening the continuum of care across the female lifespan, with particular focus on perinatal health services.

MEETING SUMMARY

Introduction

The GPPHN held its first annual meeting on 17-18 December 2007 at the March of Dimes headquarters in White Plains, NY. The meeting was attended by the Principal Investigators of the four participating centers, members of the international council advising the project, March of Dimes staff and senior representatives of the following partner organizations: the World Health Organization, National Center on Birth Defects and Developmental Disabilities of the US Centers for Disease Control and Prevention; National Institute for Child Health & Human Development; American Academy of Pediatrics; and Association of Women's Health, Obstetric and Neonatal Nurses.

The goals of the meeting were to:

(1) Review the work plans submitted by the four GPPHN centers (Brazil, China, Lebanon and Philippines). Are the tasks warranted, feasible and measurable as described? What are the opportunities for program collaboration among centers?
(2) Discuss ways to enhance communication and the sharing of materials, knowledge and experience among GPPHN participants.
(3) Explore how the resources of the March of Dimes (professional curricula, information fact sheets and other Fulfillment Center holdings; IT; Perinatal Data Center; Pregnancy and Newborn Health Education Center) can be used to facilitate and strengthen the work of the Network.
(4) Discuss how GPPHN can effectively link to the EU CAPABILITY network, a network of three centers (South Africa, Egypt and Argentina) with similar structure and overlapping missions.
(5) Explore how other partner networks and organizations can use GPPHN to serve their respective missions and program interests.

(6) Identify other potential partner organizations.
(7) Discuss strategies for securing additional outside funding for Network/partner activities.

This meeting summary presents the key observations, conclusions and recommendations of the meeting. It also presents agreed-upon next steps. The summary follows the outline of the Meeting Agenda (Appendix A). The List of Participants is provided in Appendix B. The GPPHN proposals for the four participating centers are provided in Appendix C.

GPPHN WORKPLANS

Each of the four network sites prepared a written proposal (provided in the conference materials) and presented a project overview. This in-person meeting allowed participants to describe the depth and breadth of their activities as well as individual circumstances and challenges. Each of these case studies demonstrate the emphasis of the March of Dimes' Global Programs on short-term, product-intensive projects that integrate study and action. They also demonstrate the importance of supporting projects that are adapted to local needs, opportunities and conditions.

Brazil: Dr. Roberto Giugliani

Dr. Guigliani began with basic information about Brazil, its demography and characteristics of its health care system. Seventy percent of the population receives government-funded health services. National perinatal statistics are collected on a large proportion of the populations as well as statistics on birth defects. An existing hospital-based birth defects surveillance program has evaluated over 100,000 newborns.

He described the Medical Genetics Service at the Hospital de Clinicas de Porto Alegre. This center is a member of the WHO Collaborating Center for the Development of Medical Genetics Services in Latin America as well as the Estudio Colaborativo Latinoamericano de Malformacoes Congenitas (ECLAMC); as such, it attracts students from throughout Latin America. In addition, his hospital is the coordinating center for a resource network dedicated to metabolic diseases. The comprehensive services offered include prenatal screening and laboratory diagnosis (selective screening of high-risk patients), clinical care, research, professional and public education and training, and a genetic material bank. Current research activities are extensive and supported by a staff of over 80 persons.

Dr. Guigliani identified a number of infrastructure weakness that include: (1) lack of access to existing resources; (2) poor triage – those most in need are not routinely seen first; and (3) long waits by patients both for diagnosis and care. Most specifically, there is a significant lack of awareness among primary health providers and the public – both about prevention and diagnosis of birth defects and about the range and availability of specific resources.

To address these issues, Dr. Guigliani proposes to develop a pilot program to strengthen birth defects and disabilities at the primary health care level; improve linkages between primary health care centers and reference centers; and promote the use of existing programs for the care and prevention of birth defects. To achieve these goals, three separate educational curricula will be developed for training and evaluation within the primary care setting:

1. a curriculum to teach primary care providers about risk factors for birth defects during pregnancy (e.g. alcohol, smoking, drugs, nutrition, environmental agents). This curriculum will initially be given and evaluated within a single primary health care unit.
2. a training program on newborn screening to be taught to staff within two primary health care units; and
3. a training program on both acute and longer-term care of infants with birth defects to be given in two primary health care units.

The impact of these trainings will be evaluated through the comparison of provider knowledge surveys given to staff in primary care settings that have received the training versus those in centers that had not received the training. It is anticipated that this project will broaden the scope, visibility and use of existing services; identify barriers to access; and propose strategies to overcome barriers (including a "fast-track" to increase the timeliness with which patients are seen).

Recommendations from the general discussion included:

- It would be useful to assess clinical process outcomes in addition to knowledge – e.g. proportion of women screened; age they were screened; false positive rate, degree of misdiagnosis, etc.
- It would be helpful to have more detail on how health care providers will transmit the knowledge they acquire to the patients that they see.
- The proposal should include engagement of parent/patient groups as they can contribute both substantively and politically to the project.

China: Dr. Nanbert Zhong

Dr. Zhong began by providing a progress report on a current two-year collaboration between the Peking University Center for Medical Genetics–March of Dimes. Year 1 saw the establishment of a National Registry for Birth Defects in China (NRBDC) that has recruited over 30 hospitals across the country (representing about 30,000 births per year) to participate in on-going data collection. The database utilizes an on-line data collection process. Preliminary data on birth defects are now available. Current emphasis is on the collection of data on birth defects of genetic origin, but surveillance and registry of preterm births is being planned for the near future.

Dr. Zhong also provided updates on a series of planned genetic studies focusing on specific birth defects such as clubfoot, mental retardation, autism, progeria and Kalmann syndrome. With regard to outreach and education, the Peking University Center has begun both a training course on genetics and clinical applications as well as supported an international conference on care and prevention of birth defects in Tibet.

Dr. Zhong then discussed current proposed activities for the Network. He noted that as many as 1.2 million children are born with birth defects per year in China. The NRBDC in its first year identified 618 newborns with birth defects, representing 2.1% of births. The four most common birth defects were congenital heart defects (20%); limb defects excluding clubfoot (18%); ear defects (morphology) (18%); cleft lip/palate (10%). NTDs represented (6%) of the total. In response to these data, a three-year action plan is proposed that includes expansion of the surveillance system and development of a database for research and public reports; improving the quality of care; and strengthening health research and capacity building.

With respect to expansion of the surveillance system, data on preterm birth will begin to be collected in Year 1 through a process that includes development of a specific questionnaire and integration of this questionnaire within the existing National Registry. A one-month pilot study will be conducted, with a roll-out to a total of seven hospitals. A quality assurance process will also be implemented to audit for accuracy and completeness.

With respect to improving quality of care, Dr. Zhong proposes to follow mothers at high risk of birth defects in order to characterize high-risk populations, better understand risks of birth defects, improve monitoring of high-risk mothers during pregnancy and, if appropriate, implement risk-reduction measures. These activities will be carried out through a primary prevention network for birth defects that will be established in the Shangri-La region of south-western China. The network will emphasize professional education. Dr. Zhong described Shangri-La as a rural region with a large minority population, high levels of maternal mortality, poor birth outcomes, low levels of health education and limited access to health care services. The majority of births in the region occur outside of hospitals unlike most of the rest of China.

The proposed primary prevention network will build on the existing National Registry and utilize curricula developed by another March of Dimes mission alliance partner, ONE HEART, that is conducting similar work in Tibet focused on training primary health care workers in best practices in perinatal health. Tibet and the Shangri-La region are very similar in ethnic makeup and public health needs. The professional education curricula will include a focus on fetal alcohol syndrome as this is a significant public health problem in the region. Evaluation will include pre- and post-testing of those trained as well as assessment of changes in practice patterns and prevalence of fetal alcohol syndrome and other birth outcomes.

The final component of the proposed action plan is health research capacity building. The focus here will be on preterm birth with the goals of (1) assessing prevalence and risk through a cross-sectional epidemiological study; and (2) searching for causal genes and biomarkers through a case-control genetic association study that will collect peripheral blood from parents, cord blood from newborns and biopsy materials from the uterus.

Recommendations from the discussion included:

- It would be useful to have a preconception health component to the Shangri-La activity.
- It would be useful to draw from existing models for preterm birth on-line data collection systems. For example, WHO is in the process of an initial roll-out of a similar system in Latin America. Also, it would be useful for all of the Network sites to share the questionnaire and/or compare its content to existing questionnaires for consistency.
- It would be useful to connect to the CDC’s US-China collaboration with Peking University Health Science Center.
- A question was raised regarding the extent to which environmental toxins are a concern. It was decided that the target geographic areas for this study were not ones where this was a significant risk.
- A question was raised regarding the difficulty of gaining entré and acceptance in rural and/or isolated communities. Dr. Zhong has not found this to be a problem as the team includes those well-known in the community.
- There was discussion regarding the ONE HEART curriculum, its content and the non-profit organization that produced it. Information on these questions is available at (http://onehearttibet.org/).

Lebanon: Dr. Khalid Yunis

The presentation began with a geographic and demographic overview of Lebanon. The political impact of the war from 1978-1991 as well as the regional ethnic and economic diversity were described. There is a lack of a health care infrastructure, lack of resources for research, and an absence of an established national health statistical information system. Maternal care indicators and infant mortality rates were reported – these remain poor despite a high level of national expenditure on health.

Dr. Yunis described the National Collaborative Perinatal Neonatal Network (NCPNN) which is supported, in part, through a mission alliance with March of Dimes. This non-profit, multi-disciplinary collaboration is co-funded, in addition, by WHO and national sources (Lebanese National Council for Scientific Research among others). The objective is to improve perinatal and neonatal health in Lebanon by developing accurate, scientific systems for routine data collection, capable of identifying health problems and also inappropriate health practices. The current network consists of 19 hospitals (and growing) with a database on over 99,000 newborn infants and mothers. The scope of activities includes training, surveillance, data management, research and newborn screening. The methodology includes prospective data collection by trained staff using standardized questionnaires and web-based electronic submission of data. Preliminary data on birth defects, prematurity, low birthweight and mortality were presented.

The proposed workplan for the Network project contains three action components: improvement of surveillance, health research capacity building and a folic acid intervention. Improving surveillance requires the recruitment of additional hospitals across Lebanon in order to improve geographic coverage and increase the inclusion of hospitals serving populations most at-risk (rural and underserved, low SES, and those with Neonatal Intensive Care Units). At this time, these populations appear to be under-represented in NCPNN data. The surveillance system relies on an electronic data collection process that permits offline data entry at sites; export and upload of data to the main database and online services such as provision of reports, updates and discussion on matters of interest to NCPNN participants. The proposed expansion of surveillance will also build toward development of a regional network by (1) increasing the proportion of national births included in the NCPNN data set; (2) supporting assessments and monitoring of birth outcomes (birth defects, preterm birth, mortality); and (3) research on topics such as consanguinity and preterm labor. An updated version of the questionnaire has been developed. Also, investigators may choose to include additional sections on topics of interest.

Dr. Yunis explained that previous experience with hospitals currently in the NCPNN suggests that improving surveillance results in higher quality health care. It seems that the process of data collection itself calls attention to deficiencies in chart documentation, completion of basic procedures (such as blood cultures, birth temperature, discharge weight), and availability of specialist care. A secondary objective of expanding surveillance will, thus, be to more accurately assess the impact of joining the research network on the quality of health care at member institutions. A baseline assessment questionnaire at newly recruited hospitals and regular follow-up assessments will be used.

The second component of the proposed workplan relates to training personnel on birth defects diagnosis and reporting. This component is driven, in part, by the relatively low rate of birth defects reported in rural and underserved areas at this time. These findings are counter-intuitive particularly when one considers the degree of consanguinity and its impact on congenital malformations. Thus, it is suspected that these low rates are likely due to misdiagnosis and underreporting. Training materials (with detailed descriptions and color pictures) will be provided to physicians and nurses at member hospitals. An evaluation will conduct interviews with users after the training.

The third component is a folic acid intervention directed at health care providers. Pre- and post-survey data on knowledge and practice of health care providers will be collected following distribution of educational brochures and a health promotion campaign.

Recommendations from the discussion included:

- This presentation raised the need for a standard definition for pre-term birth and pre-term labor across the Network centers.
- The charts and maps depicting regional disparities that were shown in the presentation underscored to participants how such data can be very persuasive for policy makers.
- It was suggested that paper authorship might be a motivation for hospitals to join the NCPNN. However, Dr. Yunis reported that hospital accreditation deriving from improved quality of care has been a more effective motivator, particularly because of competition among hospitals in the Gulf (the most affluent region of Lebanon). If a link between participation in NCPNN and improved standards of care (and thus accreditation) can be shown, this will provide a strong rationale for hospitals to join NCPNN. Currently, NCPNN publishes both a public general report and a confidential individual hospital report that allows each participating hospital to benchmark itself against other participating hospitals. Thus, NCPNN is moving away from a model in which hospitals are paid to collect data and toward a model where NCPNN provides a data collection and reporting service that hospitals need and, thus, are willing to purchase.
- It was determined that while French is spoken throughout Lebanon, educational materials would need to be in Arabic as well, so that a greater range of health care providers such as nurses (especially in the newborn nursery) and assistants might have access.
- The need for folic acid fortification and the barriers to fortification in Lebanon were also discussed.

Philippines: Dr. Carmencita Padilla

Dr. Padilla provided a description of the geography and vital statistics of the Philippines. These vital statistics include data from a birth defects registry of almost 200,000 births. Of particular note is that over 60% of annual births occur at home and are delivered by a traditional birth attendant, midwife or family member.

In addition to their international work with the Asia-Pacific Society for Human Genetics (Dr. Padilla is President-Elect), the Institute for Human Genetics is a close collaborator of the Department of Health. The results and limitations of recent Department of Health (DOH)'s initiatives were described. At this time, despite findings from a DOH pilot, there is no folic acid fortification because of financial constraints. A recent newborn screening project created by law was rolled-out nation-wide and provides a strategic implementation model to follow. Dr. Padilla provided a detailed description of this project. One of the challenges facing that previous project and this current one is that there is no national infrastructure in support. Rather, implementation is conducted directly with local facilities.

The focus of the proposed GPPHN workplan for the Philippines is two-fold. The first is to promote and support birth defects registration in different health care settings: private tertiary hospitals, government tertiary hospitals, local government hospitals, and in both rural and urban community settings. The second is to reduce deaths due to complications of preterm birth in two settings: (1) at the hospital – where the aim is to increase awareness among mothers seeking care in the prenatal clinics and (2) at the community setting – where in addition to increasing awareness, a cohort of pregnant mothers will also be monitored for birth outcomes. The end goal is to increase public awareness of strategies to reduce deaths and complications from preterm births. The project will be implemented in "sentinel sites" or project areas.

The proposed activities include: (1) implementation of a birth defects registry at the different settings listed above, (2) training of personnel in support of the registry, and (3) creation of a birth defects database that would build on the existing one already in place at the Institute. Site selection criteria were reviewed. The methodology for consistent implementation of the Birth Defects Registry was described and a copy of the data collection instrument was provided. Fetal death is one item recorded. A flow chart of the operational process was provided as was a time frame.

The other component is a proposed campaign for reduction of deaths and disabilities from preterm births. Materials and methods will include print educational materials, an orientation to health workers about how best to distribute and supplement patient education materials and inclusion of information in existing mothers' classes. The project outputs are evaluation tools to assess baseline and follow up knowledge regarding signs of preterm labor, birth outcomes from the cohort to be followed and an awareness campaign conducted in parallel with a complementary DOH initiative entitled "Maternal-Newborn Health Policy and Strategy."

Recommendations from the discussion included:

- The need to double-checking of forms was discussed and use of potential electronic systems for this purpose.
- Pre-conception can be added here as well. The community setting will reach out to all women of reproductive age.
- One topic of interest is whether the home birth attendants will be able to identify birth defects. (Dr. Padilla indicated that the birth defects registry form is designed to be completed by any type of provider.)

EU CAPABILITY Project and Opportunities for Linkages to the PPHN:
Dr. Irma Nippert

Dr. Nippert provided an overview of the EU CAPABILITY network, a consortium of three patterned in a fashion similar to GPPHN, but with a different mandate. CAPABILITY stands for Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention (www.capabilitynet.eu). CAPABILITY's overall objective is to contribute to the efforts to establish and sustain a worldwide harmonization process for quality standards for the integration of genetic tests and genetic knowledge into practice and prevention. It is multi-disciplinary with expertise in epidemiology, ethics, genetics, and health care provision among other disciplines. The goal is collaborative engagement of various stake holders–including, researchers/scientists, laboratories, consumers' patient organizations, industry, policy makers, and health care providers. CAPABILITY's structure and activities emphasize working groups dedicated to systematic reviews, identification of knowledge gaps and data needed, and the drafting of model approaches. Each working group is tasked also with reaching out to the various stakeholders it represents.

The three-year model project is working toward successful, sustainable collaboration between European Union (EU) research centers and centers from developing countries. The three CAPABILITY demonstration projects are sited in South Africa, Egypt and Argentina. The efforts in each of these countries focus on outreach to rural isolated areas to improve local health workers' knowledge of genetics and implementation of genetics services.

Dr. Nippert described another EU-funded project entitled, EuroGentest (www.eurogentest.org). This project is directed to support for broader population based applications of genetic testing and movement into primary care and preventions. The model is a "network of networks" conducting evidence-based evaluation to support the transition from research to practice. There is also a coordination function to address what is currently a highly fragmented and often inadequate system for genetic testing and counseling across and within countries of the EU.

Recommendations from the discussion:

Dr. Nippert was asked if GPPHN could access EU funding in support of expansion of the Network. The EU funding system is complex (http://ec.europa.eu/grants/index_en.htm). Most funding requires an EU partner organization. One option for funding is via Specific Support Actions ("projects") – these funds support meetings and joint actions but not research and development (http://ec.europa.eu/research/biosociety/public_understanding/specific_support_actions_en.htm).

March of Dimes Resources

The next set of presentations by March of Dimes staff explored how existing resources might facilitate and strengthen the work of the Network.

Presentation	Key Points	Web-Site(s)
Goldman and Kauffman Information Technology for Network Communications	**How can GPPHN communicate its collective experience, standards and tools with Network members and also the world?** It was determined that e-mail is the best common platform. Key needs are for document sharing AND collaborative document development. Video-conferencing was also discussed as was the potential for online input and dialogue from experts with password access within and outside the Network. Site content will need to be managed and supported.	Examples: http://www.alzforum.org/ http://www.wiki.org/ www.socialtxt.net

Petrini Peristats	**How can public domain vital statistics and birth defects data be compiled, disseminated and used within the Network?** An overview of Peristats, the data center of the March of Dimes, was provided that reviewed goals, resources and formats of presented data. Features such as downloadable power-point slides were described. At this time, there are no international data in Peristats, but it provides a model and potential platform for gathering and reporting the data generated by Network members and other partners.	www.peristats.com
Biermann Education and Health Promotion	**How can GPPHN effectively access the public and professional education resources of the March of Dimes?** The March of Dimes raises public awareness through “mission marketing” of the problems of preterm birth and prevention of birth defects. Information is available for consumer retrieval on web-sites and is also “pushed-out” through newsletters. Methods for tailoring of materials for different international audiences was also discussed. Global Programs has a rich experience of doing this with its partners. March of Dimes resources for GPPHN include: **Pregnancy and Newborn Health Education Center** http://www.marchofdimes.com/pnhec/pnhec.asp also hard-copy catalogue and Spanish language telephone support Spanish language: www.nascersano.com **Prematurity Campaign** http://www.marchofdimes.com/prematurity/ **Preconception Health Promotion – MMWR article** http://www.cdc.gov/mmwR/preview/mmwrhtml/rr5506a1.htm http://www.marchofdimes.com/hbhb/ **Folic Acid** http://www.marchofdimes.com/pnhec/887.asp **Nursing Education** http://www.marchofdimes.com/nursing/index.bm2?cid=00000003 **Worksite Wellness** http://www.marchofdimes.com/hbhb/ Note: Please attribute these materials to their MOD source with a logo	

Plans for Developing a Preconception Health Package for the Network
Dr. Mary-Elizabeth Reeve

Dr. Reeve presented on opportunities for improving preconception health in middle- and low-income countries and discussed opportunities for collaborative activities within the GPPHN. She began by stressing that preconception health remains the weak link in the continuum of care. Preconception care links women and couples to maternal, newborn and child health (MNCH). Optimizing preconception health will improve maternal health and lead to better birth outcomes by reducing maternal mortality and morbidity, reducing the incidence of birth defects and low birth weight and improving overall neonatal, infant and child survival.

Dr. Reeve described recent March of Dimes Global Programs activities on preconception health, which include three symposia held in 2007 in the U.S., Brazil, and Italy. She mentioned two recent reports on preconception health–a 2007 report from the Health Council of the Netherlands and one from the CDC that will be available in early 2008.

The current four member countries of the GPPHN are middle income, although each also has sub-populations at particular disadvantage in country. Mary-Elizabeth noted that in middle income countries, preconception health care ranges from medical genetics clinics to public health measures such as fortification of foods with micronutrients important to birth defects prevention like folic acid, immunization campaigns (e.g. for MMR) and perinatal surveillance and monitoring. She noted that preconception health is currently not a priority in low-income countries.

Dr. Reeve suggested GPPHN members can contribute to improving preconception care by integrating preconception initiatives into their projects and advising other countries and colleagues about the importance of doing so in their populations. She presented four areas of potential collaboration: 1) create a generic preconception health curriculum that could be adapted by member countries for use in training health care providers; 2) create and disseminate key preconception health messages to patients, their families and community; 3) strengthen provision of medical genetics services; and 4) insure adequate perinatal health surveillance and monitoring. In 2008, Global Programs will put together a proposal for outside funding in support of preconception health projects in the GPPHN countries. Member countries will be asked to consult with one another in developing activities for the proposal. Global Programs will also assist with the development of an international network of health professionals interested in improving preconception health in both industrialized and developing regions.

Recommendations from the discussion included:

Dr. Zhong reported that preconception health had been provided in China as part of the mandatory premarital visit but that since the visit is no longer mandatory, far fewer couples are obtaining preconception health counseling. Dr. Nippert said that preconception health is important because it emphasizes health as a human right. Dr. Howson supported this notion and commented that this notion should be clearly articulated in proposals for outside funding.

Developmental Biology, Genetics and Teratology Branch, NICHD

Dr. Lorette C. Javois

Dr. Javois described her branch as focused on basic science with translational research (http://www.nichd.nih.gov/about/org/cdbpm/dbgt/index.cfm). Highlights of the various program areas (most especially developmental and clinical genetics and genomics) and funded projects were provided. The Birth Defects Initiative and Research Network was described.

Potential Resources for GPPHN:

NICHD funding at this time is likely to be tight. The R01 is one potential mechanism. These are open to foreign institutions and can also fund sub-contracts with US research institutions. For these sub-contracts, research must happen at the US-based institution and a case must be made for synergy that furthers activities at both institutions.

Centers for Disease Control (CDC)
Dr. Coleen A. Boyle

Dr. Boyle gave an overview of National Center on Birth Defects and Developmental Disabilities and provided examples of activities in each phase of their activity cycle: monitoring, research, and prevention. Monitoring activities are used to identify trends, those at risk, potential clusters and topics for further research. They also assist with evaluation. These *monitoring activities* range from local surveillance in Atlanta to collaboration with international initiatives (such as the International Centre of Birth Defects www.ICBD.org). *Research activities* focus on 9 cooperative agreements to bolster surveillance, conduct local studies, and collaborate on the National Birth Defects Prevention Study – a case-control study to evaluate risk factors -- (http://www.cdc.gov/ncbddd/protocol/NBDPS_Task_Protocol.pdf). *Prevention activities* center on promotion of the use folic acid as in the current US-China collaboration and also on the prevention of fetal alcohol syndrome. In the United States, prevalence rates for NTD-affected pregnancy among Hispanic women are highest. To reach this group, a Spanish language campaign has integrated mass media and interpersonal communication.

Potential Resources for GPPHN:

There are a number of folic acid education materials and intervention strategies as well as birth defects surveillance guidelines available on-line: http://www.cdc.gov/ncbddd/

Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)
Anne Santa-Donato, RNC, MSN

Ms. Santa-Donato explained the role, mission and advocacy priorities of AWHONN (http://www.awhonn.org/awhonn/). In particular, she cited the Late Preterm Infant Initative (www.awhonn.org/awhonn/content.do?name=02_PracticeResources/2C3_Focus_NearTermInfant.htm). This collaborative initiative is based on a conceptual framework that integrates physiologic functional status, the family role, nursing care practice and the care environment. Its goals are to first raise awareness and encourage research, develop guidelines and education resources, and move toward creating change in nursing practice.

Potential Resources for GPPHN:

There are two peer reviewed journals – JOGNN and Nursing in Women's Health (http://www.blackwellpublishing.com/journal.asp?ref=0884-2175&site=1 and http://www.blackwellpublishing.com/journal.asp?ref=1751-4851&site=1) that might provide opportunities for highlighting GPPHN work. Other resources include evidence-based clinical practice guidelines, nursing education programs and the fetal heart monitoring program. The annual convention has an increasing number of international presentations and scholarships and/or invited speaker opportunities are sometimes are available. The next conference is in Los Angeles from June 21 -25, 2008.

American Academy of Pediatrics (AAP) Section on Perinatal Pediatrics (SOPPe)
Dr. Deborah Campbell

Dr. Campbell described the history, membership, geographic reach and organizational structure of AAP and also of SOPPe (Note: the Office of International Affairs may be reached via Dr. William Keenan, MD keenanwj@slu.edu). There are a number of networking opportunities available for pediatricians via conferences and international partner societies as well as on-line groups and resources. The strategic plan and priorities for both AAP and SOPPe were reviewed and a guided tour of the web-site was provided.

Potential Resources for GPPHN:
A featured program of SOPPe is the Neonatal Resuscitation Program (http://www.aap.org/nrp/nrpmain.html). The program is being implemented globally through a partnership between WHO, NICHD, the Global Network for Women's and Children's Health and AAP. Another program – 2008 I-CATCH – was described. The I-CATCH is designed to give financial and technical support to pediatricians in developing/emerging countries to implement a community-based health initiative to improve access to child health care. The next submission cycle begins March 1, 2008 and financial support provided is a maximum of $6000 over a three-year period (http://www.aap.org/sections/ich/I-CATCH_page.htm).

World Health Organization
Dr. Mario Merialdi

Dr. Merialdi provided a useful case study of how data can be used to initiate policy discussion, gather public attention and in turn create new projects that lead to better data. He described the preterm birth estimates provided by WHO. This process drew from systematic literature review, facilities data and estimates. Data are presented at the regional/sub-regional level – it was not possible to present at a National Level. Despite that limitation, the data collection system appeared effective. Missing data were infrequent. No validity tests were conducted to Dr. Merialdi's knowledge. Hospital-based data are by definition limited. There is a need to tap into non-hospital based births.

The preterm birth genome project was also described. The goals are to conduct a genome-wide study of preterm birth. This will include the definition of and use of a common set of environmental risk factors as well as other studies of pregnancy outcomes. Genes with significant findings will be further researched.

Summary of Next Steps

Next Steps	Person(s) Responsible	Time Frame
AWONN Materials – might they be made available at free or reduced cost?	Santo Donato	February 2008
Clarify networking objectives in order to better determine appropriate web-based communications tool	Howson	June 2008
Connect Dr. Zhong to CDC-China Collaboration	Boyle	
Send Dr. Padilla preconception health resources	Reeves	May 2008
Serve as Clearinghouse for exchange of documents and materials	Howson	Ongoing
Identify Patient Group Collaborators	All GPPHN sites	June 2008
Disseminate existing WHO evaluation tools and related publications (Chile article of particular interest)	Merialdi	February 2008
Hold follow-on meeting to move toward harmonization of data collection	Merialdi/Howson	PREBIC meeting in April 2008

Topic Area Summary Chart

The purpose of this chart is to identify topic areas of relevance for future discussion and/or to support networking between sites on specific topics. It does not mean that these topics are not relevant to unchecked sites; it does mean that these topics are checked for countries that included them in their GPPHN workplan.

Topic Areas	Brazil	China	Lebanon	Phillipines
Primary care provider training on diagnosis of birth defects	X	X	X	X
Motivating provider participation in data collection (Birth Registry, Premature Birth):		X	X	X
Alcohol risk reduction	X	X		
Monitoring at-risk mothers (cohorts)		X		X
Rural health providers (home births)		X		X
Surveys to assess knowledge of birth defects*	X	X		
Pre-term birth surveillance			X	X
Regional and ethnic disparities		X	X	
On-line data collection and surveillance		X		X
Networking and partnership models**	X	X	X	X

*Brazil (Primary Care Patients); China (at-risk expectant mothers)
** added as a topic of interest by Dr. Nippert

APPENDIX A

Partnership for Perinatal Health Networks (PPHN)

First Annual Meeting
March of Dimes Foundation
White Plains, NY
17-18 December 2007

Monday, 17 December 2007

7:30 AM	Shuttle to March of Dimes from Crowne Plaza Hotel, White Plains	
8:00 AM – 8:45 AM	Breakfast	March of Dimes Cafeteria
9:00 AM – 9:20 AM	**Opening Session**	West Conference Room
	Welcome and Introductions Dr. Jennifer Howse, *President, March of Dimes* Dr. Michael Katz, *Senior Vice President for Research and Global Programs, March of Dimes*	
9:20 AM – 9:45 AM	**Background to the Partnership for Perinatal Health Network (PPHN) and Goals for the Meeting** Dr. Christopher Howson, *Vice President for Global Programs, March of Dimes*	
	Presentations of the PPHN Work Plans **(30 minute presentation, 30 minute discussion)**	West Conference Room
9:45 AM – 10:45 AM	Dr. Roberto Giugliani, *Medical Genetics Service, Hospital de Clinicas de Porto Alegre, Brazil*	
10:45 AM – 11:00 AM	**Break**	West Conference Room
	Presentations of the PPHN Work Plans (cont.)	West Conference Room
11:00 AM – 12:00 PM	Dr. Nanbert Zhong, *Director, Chairman and Professor Peking University Center of Medical Genetics, China*	
12:00 PM – 1:00 PM	**Lunch**	March of Dimes Cafeteria

Presentations of the PPHN Work Plans (cont.)

1:00 PM – 2:00 PM	Dr. Khalid Yunis, *Professor of Pediatrics, Director, Newborn Services, Director, National Collaborative Perinatal Neonatal Network, American University of Beirut, Lebanon*	
2:00 PM – 3:00 PM	Dr. Carmencita Padilla, *Director, Institute of Human Genetics National Institutes of Health, University of the Philippines*	
3:00 PM – 3:15 PM	**Break**	West Conference Room
3:15 PM – 3:45 PM	**Description of the EU CAPABILITY Project and Opportunities for Linkages to the PPHN** Dr. Irma Nippert, *Professor of Women's Health Research, University of Muenster*	
3:45 PM – 5:15 PM	**March of Dimes Resources (30 minutes each)** *How can these March of Dimes resources contribute to PPHN, and vice-versa?* **Internet/E-Business** Alan Kaufman, *Senior Vice President & Chief Information Officer* and Patricia Goldman, *Vice President & Chief Marketing Officer, Strategic Marketing & Communications, March of Dimes* **March of Dimes Perinatal Data Center** Dr. Joann Petrini, *Director, Perinatal Data Center* **Pregnancy & Newborn Health Education Center** Janis Biermann, *National Director, Pregnancy & Newborn Health Education Center*	West Conference Room
5:15 PM – 5:45 PM	**Tour of the Pregnancy & Newborn Health Education Center**	
5:45 PM	**Adjourn and transport to dinner**	
6:00 PM	**Dinner**	**Le Provencal Bistro** **436 Mamaroneck Avenue** **Mamaroneck, NY**

Tuesday, 18 December 2007

7:30 AM	Shuttle to March of Dimes from Crowne Plaza Hotel, White Plains	
8:00 AM – 8:45 AM	Breakfast	March of Dimes Cafeteria
9:00 AM – 9:30 PM	**Plans for Developing a Preconception Health Package for PPHN** Dr. Mary-Elizabeth Reeve, *Director for Global Perinatal Health Education Programs, March of Dimes*	West Conference Room
	Partner Comments (20 minutes each)	West Conference Room
9:30 AM – 9:50 AM	Dr. Lorette C. Javois, *Program Director,* *Developmental Biology, Genetics & Teratology Branch* *Center for Developmental Biology & Perinatal Medicine* *National Institute of Child Health & Human Development,* *National Institutes of Health (NIH)*	
9:50 AM – 10:10 AM	Dr. Coleen A. Boyle, *Associate Director for Science and Public Health, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)*	
10:10 AM – 10:30 AM	Anne Santa-Donato, RNC, MSN, *Associate Director, Childbearing and Newborn Programs* *Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)*	
10:30 AM – 10:50 AM	Dr. Deborah Campbell, *Professor of Clinical Pediatrics* *Albert Einstein College of Medicine* *Director, Division of Neonatology (representing AAP)*	
10:50 AM – 11:05 AM	**Break**	West Conference Room
11:05 AM – 12:20 PM	**General Discussion and Next Steps** • *What are the opportunities for collaboration among centers and partners?* • *What other potential partners should be brought into the PPHN?* • *What potential outside sources are available to fund the PPHN?*	West Conference Room
12:20 PM	**Adjourn (Lunch optional)**	
Late Addition	Dr. Mario Merialdi, *Coordinator, Maternal and Perinatal Health (WHO)*	

APPENDIX B

Participant List

Partnership for Perinatal Health Networks
First Annual Meeting
17-18 December 2007

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APPENDIX C

GPPHN PROPOSALS FOR 2008-2010

BRAZIL

Prof. Roberto Giugliani
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December 7, 2007

Statement of Need

Brazil, with a population of 184 million inhabitants, where 3,026.548 babies were born in 2004, has made progresses in reducing infant mortality in years. Infant deaths (from 0 to 364 days of age) dropped from 31.9/1,000 in 1997 to 22.6/1,000 in 2004.

Considering data available for 2004, around half (11,5/1,000, or 50.9 %) of this infant mortality occurs from 0 to 6 days of age. This proportion indicates that further improvements would require actions before term. This idea is reinforced by the perinatal mortality coefficient (22 weeks of pregnancy to 6 days after birth), which was 17.1/1,000 in 2004.

In Rio Grande do Sul, the Southernmost state of Brazil, where health demographics are more widely available and more reliable, 10.6 % of births are premature and 10.2 have low birth weight, and birth defects affect 1.8 % of livebirths. Taking this proportion for Brazil, this would mean over 50,000 babies with birth defects born each year with conditions which are in a large extent preventable by appropriate actions on the prenatal or even preconceptional period.

ACTION PLAN FOR 2008-2011

Proposed Activities, Objectives, Rationale, Methods, Evaluation and Timeline

Proposed Activities

1) DEVELOP A PILOT PROGRAM FOR THE INTRODUCTION OF PREVENTION OF BIRTH DEFECTS AND DISABILITIES ON PRIMARY HEALTH CARE PROGRAMS

Objective 1: Provide to the community information on primary prevention of birth defects and about how to avoid gestational risks (smoking, alcohol, drugs); also inform about prenatal diagnosis techniques and legal issues.

RATIONALE: Inappropriate information about environmental risks for preterm delivery and birth defects is a rule, and professionals involved on primary care are inadequately prepared to provide effective information.

METHODS: A training program about risks of environmental agents to pregnancy will be provided to health professionals of 2 primary health care units, and improvement on knowledge will be accessed; two other health care units, that will have no intervention, will have also be accessed;

EVALUATION: The health professionals involved on the training program will be evaluated before and after the training program about risks of environmental agents to pregnancy; in addition, a sample of women exposed to these professionals will be evaluated about their knowledge about these risk factors, before and after the training program; simultaneously, the professionals and a sample of women of two other health units, not exposed to the training program, will also be evaluated;

TIMELINE: The program prepared on Q3-Q4/2008, and implemented on the first primary health care unit in 2009. At the end of 2009 an interim evaluation will be performed, and an interim report will be prepared. According to the experience, an improved version of the program will be implemented on the second primary health care unit in 2010. During the same periods, primary health care which will not suffer any intervention will be also evaluated. On Q1-Q2 2011 the program will be fully evaluated and the final report and publications will be prepared.

Objective 2: Improve community education on neonatal screening tests, focusing on the increase of the proportion of screened newborns and on collection of the sample on the most appropriate period;

RATIONALE: Despite newborn screening for selected conditions (phenylketonuria, congenital hypothyroidism, haemoglobin disorders and cystic fibrosis) is provided free of charge as a public health program by the Brazilian government, the proportion of babies actually screened is still far from acceptable. Moreover, the period when the sample is collect is in many instances inappropriate, retarding onset of therapy, when needed, affecting the benefits of the program.

METHODS: A training program about newborn screening will be provided to health professionals of 2 primary health care units, and improvement on knowledge will be accessed; two other health care units, that will have no intervention, will have also be accessed;

EVALUATION: The health professionals involved on the training program will be evaluated before and after the training program about several aspects of newborn screening; in addition, ages at blood collection and percentage of inappropriate samples will be evaluated before and after the training program; simultaneously, the professionals and babies of two other health units, not exposed to the training program, will also be evaluated;

TIMELINE: The program prepared on Q3-Q4/2008, and implemented on the first primary health care unit in 2009. At the end of 2009 an interim evaluation will be performed, and an interim report will be prepared. According to the experience, an improved version of the program will be implemented on the second primary health care unit in 2010. During the same periods, primary health care which will not suffer any intervention will be also evaluated. On Q1-Q2 2011 the program will be fully evaluated and the final report and publications will be prepared.

Objective 3: Provide adequate training about prevention, screening, diagnosis and care of birth defects and genetic diseases to Primary Health Care professionals and Family doctors, who should be prepared to provide initial guidance (as appointments on a reference centre usually will take some time) and also to provide care for the most common conditions;

RATIONALE: Most primary care health professionals immediately refer a child with a birth defect to a specialized center; although this is a correct measure, there is a gap, some times of many months, between referral and effective admission of the baby at the reference center; so, primary health care professionals should be trained to provide initial guidance to the affected families.

METHODS: A training program about birth defects management will be provided to health professionals of 2 primary health care units, and improvement on knowledge will be accessed; two other health care units, that will have no intervention, will have also be accessed;

EVALUATION: The health professionals involved on the training program will be evaluated before and after the training program about general management of birth defects, with emphasis on the more common situations; simultaneously, the professionals and babies of two other health units, not exposed to the training program, will also be evaluated;

TIMELINE: The program prepared on Q3-Q4/2008, and implemented on the first primary health care unit in 2009. At this point, an interim evaluation will be performed, and an interim report will be prepared. According to the experience, an improved version of the program will be implemented on the second primary health care unit in 2010. During the same periods, primary health care which will not suffer any intervention will be also evaluated. On Q1-Q2 2011 the program will be fully evaluated and the final report and publications will be prepared.

2) DEVELOP A PILOT PROGRAM ON THE IDENTIFICATION OF PREGNANCIES AT RISK FOR PRETERM BIRTH

Objective 4: Evaluate tools appropriate for the Brazilian setting for the detection of pregnancies at higher risk of pre-term birth

RATIONALE: There are several situations already identified which predispose to preterm birth; its identification and assessment of prevalence the area would be important for the planning of preventive actions and for the provision of appropriate management;

METHODS: The project team will interview every pregnant woman, obtaining data about history of pre-term birth and/or previous low birth-weight child, and also birth spacing; uterine abnormalities will be searched for; we will also obtain information about parental birthweight and gestational age at delivery; tools to identify psychosocial stress will be applied; biological samples will be obtained from the pregnant woman to check for potential biomarkers on the future;

EVALUATION: The cases will be classified as low, intermediate or high risk for PTB; pregnancies will be followed, and the proportion of PTB on each group will be compared to validate or not the tools developed; potential biomarkers will be assessed, using specific protocols, according to the recommendations of PREBIC biomarkers group.

TIMELINE: The tools will be developed in Q3-Q4/2008, and the study will take place on 2009. At the end of 2009 an interim evaluation will be performed, and an interim report will be prepared. According to the experience, a revised protocol will be implemented in 2010. On Q1-Q2 2011 the program will be fully evaluated and the final report and publications will be prepared.

3) DEVELOP STRATEGIES TO BRIDGE THE GAP BETWEEN PRIMARY HEALTH CARE CENTERS AND REFERENCE CENTERS, IN ORDER TO IMPROVE THE CARE OF PATIENTS WITH BIRTH DEFECTS

Objective 5: Improve the access of selected patients and families to specialized genetic services, which would provide care for the more complex situations;

RATIONALE: Although there are several specialized reference centers in medical genetics, it is very difficult for the patients who need this assistance to reach these centers, due to barriers which should be investigated and eliminated.

METHODS: Identify, working together with public health authorities, the difficulties related to the access of the patients with birth defects to the specialized centers, and propose strategies to overcome these barriers;

EVALUATION: The number of referrals will be accessed, by measurement of the number of requests made by the primary health care center which are successfully admitted to the reference center, and the time from referral to admission;

TIMELINE: The problem will be accessed on Q3-Q4/2008, and measures to overcome the barriers will be implemented in 2009. At this point, an interim evaluation will be performed, and an interim report will be prepared. According to the experience, new measures will be implemented in 2010. During the same periods, referrals from primary health care units which will not suffer any intervention will be also evaluated. On Q1-Q2 2011 the program will be fully evaluated and the final report and publications will be prepared.

4) PROMOTE THE USE OF EXISTING PLATAFORMS FOR PREVENTION AND MANAGEMENT OF BIRTH DEFECTS

Objective 6: Expand and improve the use of existent programs, including the affiliation of a larger number of maternities to the ECLAMC program, the broadening of the scope of the teratogen information service to provide information on prenatal care, and increase the awareness about the metabolic information helpline.

RATIONALE: There are several successful programs related to the prevention of birth defects and disabilities in operation in Brazil, most of them working in small scale. The expansion of these programs may provide an improvement on reducing the burden of these conditions.

METHODS: Identify existing successful programs and practices in operation and, working together with the leaders of such programs, design and implement its expansion in order to magnify the coverage.

EVALUATION: The coverage of the selected programs and practices will be accessed before and after the implementation of the expansion strategies; other measurements, specific to each program, will also be performed.

TIMELINE: The survey of the existing programs will be accessed on Q3-Q4/2008, and measures to expand its coverage will be implemented in 2009. At this point, an interim evaluation will be performed, and an interim report will be prepared. According to the experience, new measures will be implemented in 2010. During the same periods, evaluations of the coverage (and other parameters) of these programs will be performed in areas where no intervention was held. On Q1-Q3 2011 the program will be fully evaluated and the final report and publications will be prepared.

BUDGET

Year 1

Description	MOD contribution	Local contribution
25 % time of 3 professionals involved on the program		24,000
Full time professional to manage the program on the primary health care units (objectives 1, 2 and 3)	12,000	
Part time professional to manage the program on the head primary health care units (objectives 4 and 5)	6,000	
Training materials	6,000	
Communication costs (fax, phone, internet access)	3,000	3,000
Transportation costs between project headquarters and primary health care centers	2,400	
Computers (2) and printer (1) to be used on the training program (primary health care center 1)	2,500	
Office supplies	1,500	
TOTAL	**31,000**	**33,000 $**
13 % institutional overhead	**4,030**	
GRAND TOTAL	**35,030**	

Year 2

Description	MOD contribution	Local contribution
25 % time of 3 professionals involved on the program		24,000
Full time professional to manage the program on the primary health care units (objectives 1, 2 and 3)	12,000	
Part time professional to manage the program on the head primary health care units (objectives 4 and 5)	6,000	
Training materials	6,000	6,000
Communication costs (fax, phone, internet access)	3,000	3,000
Transportation costs between project headquarters and primary health care centers	2,400	
Computers (2) and printer (1) to be used on the training program (primary health care center 2)	2,500	
Office supplies	1,500	
TOTAL	**31,000**	**33,000 $**
13 % institutional overhead	**4,030**	
GRAND TOTAL	**35,030**	

Year 3

Description	MOD contribution	Local contribution
25 % time of 3 professionals involved on the program		24,000
Full time professional to manage the program on the primary health care units (objectives 1, 2 and 3)	12,000	
Part time professional to manage the program on the head primary health care units (objectives 4 and 5)	6,000	
Training materials	6,000	
Communication costs (fax, phone, internet access)	3,000	3,000
Transportation costs between project headquarters and primary health care centers	2,400	
Expenses with data analysis, publications and media covarage	2,500	
Office supplies	1,500	
TOTAL	**31,000**	**33,000 $**
13 % institutional overhead	**4,030**	
GRAND TOTAL	**35,030**	

PEOPLE'S REPUBLIC OF CHINA

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December 2007

Statement of Need

Birth defects remain a major concern in China. Approximately 800,000-1,200,000 babies are born each year with a birth defect, representing 4-6 percent of total births. The four most important birth defects in China are neural tube defects (NTD), congenital heart diseases (CHD), mental retardation (MR), and cleft lip/cleft palate. The birth prevalence rates for these congenital abnormalities are 16, 8, 7 and 2 per 1,000 live births, respectively. These and other less common birth defects exact a harsh emotional toll on patients, their families and the communities they live in. They also exact a huge economic toll in China.

The current status of preterm birth in China appears also to be serious, given the highly observed rates in maternal health hospitals. But there is a clear need for better epidemiologic data on both the occurrence and distribution of preterm birth in the population. In this three-year action plan, we propose three main activities.

The following three projects will be designed to be focused and measurable to allow for a better determination of what works and what doesn't. The Ministry of Health is interested in expanding the activities and lessons learned to other at-risk populations in China and to developing a model for consideration by other countries in the region.

- First, we propose to expand our current surveillance of birth defects in high-risk populations and add preterm birth surveillance (PTBS) to the current NRBDC surveillance system. We will pilot test the preterm birth surveillance component in a limited number of hospitals to begin.

- Second, we would like to pilot test two programs in the rural populations of western China. In one, we would like to expand the NRBDC surveillance system to include rural hospitals and clinics where the majority of births occur. In the second, we would like to train rural primary health care workers in best practices in perinatal health based, in part, on the curricula that is currently being developed through the March of Dimes-One HEART mission alliance in Tibet. Both programs are important given the large proportion of the Chinese population living in rural areas and the high anecdotal rates of birth defects and preterm birth in these populations. As noted above, the China government would like to develop the program in the Shangri-La region of western China as a model for the entire country. Activities would include strengthening primary health care services through implementing surveillance of birth defects and PTBS in the rural network of hospitals and clinics in the region; implementing interventions recommended by the March of Dimes including training of primary care providers in the diagnosis and appropriate referral of babies with common birth defects and in the detection and control of maternal risks and other adverse conditions during pregnancy that are known to increase risk of birth defects and preterm birth.

- Third, we would like to conduct specific research activities in the Shangri-La region, including a cross-sectional study (CSS) of preterm birth and genetic studies on preterm birth and birth defects.

THREE-YEAR ACTION PLAN

Activities, Objectives, Rationale, Methods, Evaluation and Timeline

Background information

The interest of the Chinese government in this project reflects the high priority it has given to improving care and prevention of birth defects and preterm birth across all regions of mainland China and Tibet. In September 2007, the Ministry of National Population and Family Planning Commission (NPFPC), which is a special ministry in China directly under the Prime Minister and has a primary responsibility for strengthening care and prevention of birth defects in China, convened a meeting with NRBDC and March of Dimes in Beijing. Dr. Baige Zhao, the Vice-Minister of NPFPC, Dr. Christopher Howson, the Vice President for Global Programs of March of Dimes, and Dr. Nanbert Zhong, the Director of NRBDC, discussed the possibility of a joint project on the "Prevention and intervention of birth defects in western China." As a result of this meeting, the Vice Minister Zhao expressed the interest of NPFPC in working with the March of Dimes as an active partner in this three-year project. To underscore this commitment, the NPFPC will provide matching funds for the three years of the project, which may also bring in the hopes of attracting new partners to and funding for the Partnerships for Perinatal Health Network and to demonstrate at national and international levels the leadership of the NPFPC in promoting care and prevention of birth defects and preterm birth in China.

Proposed Activities

1. SURVEILLANCE & DATABASE – *Adding PTBS into the NRBDC System.*

Objective 1: Expand the birth defects surveillance system established as part of the NRBDC-March of Dimes project by collecting data on the prevalence of preterm birth in seven of the participating maternal and child hospitals (MCH). The hospitals will be chosen according to the criteria described below.

__Rationale__: The National Registry of Birth Defects in China (NRBDC) was co-funded by MOD and PUCMG in 2006. It is a hospital-based national surveillance network of birth defects, emphasizing on genetic-origin birth defects. It has aroused interests of hospitals across the country and more than 30 hospitals have been recruited into the NRBDC. A comprehensive review of the literature earlier indicated an almost complete lack of data on the occurrence of preterm birth in China. Thus, we propose to introduce preterm birth surveillance into the NRBDC system. Based on the current network, we propose to further develop the preterm birth surveillance/registry with seven MCHs, from which we can understand better about the current situation of preterm birth in China.

__Methods__: We will conduct a rigorous beta-testing of the new preterm birth surveillance (PTBS) component in seven of the current NRBDC hospitals.

- A questionnaire and methods of delivery and subsequent input of the data into the NRBDC system has been developed based on the current surveillance system.
- A one-month pilot study has been performed at Hai-Dian MCH in Beijing earlier this year. Hai-Dian MCH is the second largest MCH in Beijing city, with a birth rate of >1,000 per month. It is one of the current PUCMG cooperation hospitals, and is participating in the NRBDC. Performing a beta-test of preterm birth questionnaire will allow us to modify and improve it before we introduce it more broadly within the NRBDC.
- A systematical retrospective study on preterm and low birth weight has been conducted across 14 provinces. By investigating the data between 2005-2007 in those provinces, we obtained the following results:

	2005				2006				2007				3-Years			
Total Births (N)	44,665				51,289				82,227				178,181			
Preterm (%)	5.70				6.27				5.68				5.85			
Low Weight (%)	4.84				4.99				8.40				6.53			
Total (%)	10.54				11.26				14.07				12.38			
	23	Cn	Ci	P	27	Cn	Ci	P	45	Cn	Ci	P	48	Cn	Ci	P
Provinces from which data collected	Lao-Lin		4		Lao-Lin		4		Lao-Lin		7		Lao-Lin		7	
	He-Nan	2	1		He-Nan	2	1		He-Nan	2	2		He-Nan	2	2	
	Shan-Xi		1		Shan-Xi		1		Shan-Xi		1	1	Shan-Xi		1	1
	Beijing	1			Beijing	1			Beijing	6		1	Beijing	6		1
	Tian-Jing	7	3	1	Tian-Jing	7	3	1	Tian-Jing	7	3	1	Tian-Jing	7	3	1
	Guan-Dong	1			Guan-Dong	1			Guan-Dong	1			Guan-Dong	1		
	Zhe-Jian	1			Zhe-Jian	1			Jian-Xi		2		Zhe-Jian	1		
	Jian-Xi		1		Jian-Xi		3		Ji-Ling	1	3		Jian-Xi		3	
					Ji-Ling		1		Shan-Dong		1		Ji-Ling	1	3	
					Si-Chuan	1			Fu-Jian	1			Si-Chuan	1		
									He-Bei	2	1		Shan-Dong		1	
									Shang-Xi	1	1		Fu-Jian	1		
													He-Bei	2	1	
													Shang-Xi	1	1	
														23	22	3
													Cn+Ci+P=48			

- A database based on questionnaire will be developed. This database will be linked to the current NRBDC web-based database. The database will then be introduced to the seven selected MCH.

- There are an estimated 56 ethnic minorities, in addition to the majority Han group, in China. Therefore, the hospitals will be chosen on the basis of geographic site (one hospital northern China, southern China, south-eastern China, north-eastern China, south-western China, central China, and Tibet representing western China, respectively) as well as ethnic makeup of the population to ensure heterogeneity in the target populations, in addition to birthrate (a minimum of 500 births per month).

Evaluation: For the expanded PTBS system, we will take use of the rigid quality control methods in the ongoing NRBDC surveillance system as a reference. For instance, investigators or project coordinators will be sent to the seven hospitals at regular intervals to carry out an audit of the accuracy and completeness of case ascertainment and data collection. About 5 percent of preterm cases and their questionnaires will be randomly selected and inspected by the investigators or project coordinators and the data will be compared to the original clinical record.

Timeline: The database will be developed in Year 1. Incorporation of the preterm birth questionnaire into the NRBDC system in the seven participating MCH and evaluation of the accuracy and reliability of the data collection system will be conducted in Years 2 and 3.

Objective 2: Expand the current NRBDC surveillance system by developing a questionnaire to be given to expectant mothers at high-risk of having a baby with a birth defect.

Rationale: Populations at high-risk for having a child with a birth defects include those with the following characteristics: members of the family with a certain genetic disorder or birth defect; history of children with genetic disorders, mental retardation with unknown causes or birth defects; repeated abortion with unknown causes or stillborn births; pregnant woman older than 35 years; long contact history of high risk environmental factors. Collection of data related to this population will help us better understand risks of birth defects, improve monitoring of high-risk mothers during pregnancy, and take corresponding measures.

Methods: Format, use and inputting of the questionnaire, will be modeled on that currently used in the NRBDC system.

- The database will be based on the current birth defects surveillance system.
- The participating hospitals will be the same as the ones included in the previous system.
- We will set up the criteria for high risk of birth defects based on the characteristics described above.
- Training of the hospital personnel on how to recognize and collect information on this population will be conducted.
- We will also develop means to analyze and utilize the information gathered using the expertise and infrastructure of the NRBDC reference center.

Evaluation: The investigators or project coordinators will interview a 5 percent selection of high-risk pregnant women to ensure that they received the questionnaire in hospital. By the end of the three-year period, we will have gained information on the distribution and characteristics of targeted populations at high risk of having a baby with a birth defect. We should be able to determine by the end of Year 3 if this information has had any impact on the practice of care as reflected in changes in birth prevalence of birth defects in these populations at high risk.

Timeline: The construction of the database and training materials will be completed in Year 1. Implementation by participating hospitals will occur in Years 2 and 3.

2. QUALITY OF CARE – *Improving Perinatal Health Care in Rural Areas*

Objective 1: Establish a primary prevention network for birth defects in Shangri-La region

Rationale: The Shangri-La region spans the provinces of Sichuan, Yunnan and Tibet and is inhabited by a number of minority ethnic groups with different culture backgrounds and living styles. The Chinese government is strongly committed to developing the standard of living and improving health care and population health in this highly-rural region. According to preliminary surveys, the rate of deliveries in hospital throughout the region is extremely low. In addition, maternal, neonatal and infant mortality rates are higher than in other areas in China. Also, the availability of reproductive health services is relatively low. There is, thus, a huge need to develop and strengthen preconception, prenatal and postnatal health care services throughout the region. Doing so will require specialized effort. Most of the primary care providers in the region have a low educational level. Most of their knowledge about birth defects and preterm birth is not based on formal education and scientific knowledge, but rather comes from their hands-on, clinical experience. As a result, while motivated from what they see in clinical practice, they have little empirical understanding of how to prevent, diagnose and treat birth defects or provide effective perinatal services to mothers and babies. There is, thus, a critical need to provide training materials appropriate to these primary care providers. In addition, the Chinese government sees this project as a model that could be applied to strengthening maternal, newborn and child health services in other rural populations in China with a similar needs and medical infrastructure.

Methods: The goal of establishing a primary prevention network in the Shangri-La region will be met with the following approaches:

- As a first step, we propose to expand the NRBDC birth defects and preterm birth surveillance system in the region. The system will be hospital/clinic based and modeled on the NRBDC system that is currently being implemented in other regions of China.
- As a second step, we propose to train rural primary health care workers in best practices in perinatal health based, in part, on the curricula that is currently being developed through the March of Dimes-One HEART mission alliance in

Tibet. Training will include diagnosis and appropriate referral of babies with common birth defects and in the detection and control of maternal infections and other adverse conditions during pregnancy that are known to increase risk of birth defects and preterm birth. It was the consensus of participants at the two training workshops on prevention of birth defects that were held in Beijing and Lhasa in September of 2007 that such training is needed and feasible given the level of provider expertise in the region.

- Three counties from the three provinces involved in Shangri-La region will be chosen as pilot sites for the program. We will then extend the network to all other counties in the region. The three candidate counties are: Changdu in Tibet, Weixi in Yunnan and Xiangcheng in Sichuan.

Evaluation: Evaluation will be based on having a functioning and audited surveillance system for birth defects and preterm birth in place in the project region. Pre- and post-testing of primary health care workers trained with the March of Dimes-One HEART and other project curricula will be used to assess how effective the curricula and training methods are in these populations. We will also randomly collect the data in the rural area to compare and analyze practice patterns before and after the training process.

Timeline: The project will be piloted in three counties in three provinces in Year 1. The surveillance and training will be extended to the other counties in the region in Years 2 and 3.

Objective 2: Establish a professional education system as part of the primary prevention network for birth defects in the Shangri-La region. Particular attention will be paid to the prevention of fetal alcohol syndrome.

Rationale: The ethnic populations in Shangri-La region are minorities, mainly Tibetan. Among these minorities, consumption of alcohol is common in daily life. Recent data from a USAID-funded One HEART dietary survey in Lhasa Prefecture demonstrated an average daily consumption of 25 grams of alcohol during pregnancy. A recent field visit by Prof. Denis Viljoen of South Africa raised concern that FAS may be a significant public health problem in this same population. There is, thus, a need to train primary and other medical care providers care in the Shangri-La region in best practices in the care and prevention of birth defects. This project will help meet that need.

Methods: Two approaches will be pursued:

- We propose to educate primary healthcare workers in Shangri-La region about:
    - ❖ Basic knowledge of embryo development and the damage caused by teratogens like alcohol.
    - ❖ Relationship between maternal drinking and outcome of birth defects in the target population.
    - ❖ Diagnosis of fetal alcohol syndrome.
    - ❖ A training workshop for this specific education purpose—The Shangri-La Birth Defects Training Course— will be scheduled in the middle of June of 2008 in Lhasa city of Tibet.

- To develop a professional task force dealing with birth defects:
    - ❖ The task force team is composed of physicians, nurses, healthcare workers, and geneticists who are working in county hospitals, village clinics, and NPFPC institutions.
    - ❖ The team members are capable of recognizing a certain number of common birth defects, including cleft lip/cleft palate, NTD, congenital limb defects, clubfoot, fetal alcohol syndrome, preterm birth, and so on so forth.

Evaluation: To evaluate the outcome of education, the professional trainees will be tested immediately before, and after the completion of, the training course to evaluate their knowledge level. As the Shangri-La region will participate in the NRBDC birth defects and preterm birth surveillance system, comparison of the birth prevalence of FAS and other birth defects will be carried out annually.

Timeline: The activities will be carried out over the three years of the project.

3. **Health Research Capacity Building** – *Initialization of studies on birth defects and preterm birth*

Objective 1: Conduction of a cross-sectional study (CSS) on preterm birth.

Rationale: To obtain a preliminary data on the spontaneous preterm birth, a cross-sectional study (CSS) is proposed. It will be based on the surveillance system established in activity 1 (see above). The questionnaire we designed has already taken into account the requirements of the epidemiology study.

Methods: The CSS will be conducted in seven MCH for three months. For which, 10,500-21,000 newborns would be expected (estimation is based on that currently each MCH is having 500-1,000 births per month). Considering preterm birth accounts for 5-10% of pregnancies, a preterm birth cohort of minimal 525-1,050 to maximal 1,050-2,100 cases is anticipated. In addition to comparing risk factors between exposed and unexposed groups, the prevalence (P) will be assessed, as in a cohort study; and the prevalence odds [P/ (1-P)] will be compared, as in a case-control study.

Evaluation: Ultimately, effects of environmental risk factors to preterm birth will be evaluated.

Timeline: The study will be carried out in the third year.

Objective 2: Initialization of genetic studies on preterm birth and birth defects.

Rationale: Relevant genetic studies will be initialized in the third year, based on the system and information gained during the first two years. The questionnaire we designed has already taken into account the requirements of genetic studies.

Methods: During the CSS period (as described above), peripheral blood from parents and cord blood from newborns will be collected for the genetic studies. If available, biopsy materials will be collected from uterus. DNA, RNA, or protein will be extracted from the specimens collected. A case-control genetic association study on candidate genes participant in the preterm birth pathway will be conducted. Meanwhile, proteomic approaches will also be applied to search for biomarker(s).

Evaluation: Relevant papers will be published.

Timeline: The studies will be initialized in the third year. Allow more time for its accomplishment and paper publications.

BUDGET

Year 1 (7-1-08 to 6-30-09)

Description	MOD contribution	Local contribution
A database/software engineer		$15,000
A data analyst		$10,000
Two coordinators		$10,000
Two university research assistants	$6,000	
Workshop	$15,000	
Training materials and courses	$2,000	
A computer for data server	$2,000	
Media coverage	$2,000	
Transportation cost	$6,000	
Communication cost (fax, phone, internet access)	$1,000	
Office supplies	$1,000	
TOTAL	$35,000	$35,000

Year 2 (7-1-09 to 6-30-10)

Description	MOD contribution	Local contribution
Recruiting fees at recruited hospitals (data collection and entry fees)	$14,000	
Two coordinators		$10,000
Two university research assistants		$6,000
Workshop	$15,000	
Training materials and courses	$2,000	
Computers for data entry in recruited hospitals		$8,000
Database software & electronic submission maintenance		$5,000
Media coverage	$2,000	
Transportation cost		$6,000
Communication cost (fax, phone, internet access)	$1,000	
Office supplies	$1,000	
TOTAL	$35,000	$35,000

Year 3 (7-1-10 to 6-30-11)

Description	MOD contribution	Local contribution
Recruiting fees at recruited hospitals (data collection and entry fees, as well as blood sample collection fees)	$14,000	
Two coordinators		$10,000
Two university research assistants		$6,000
Workshop	$15,000	
Training materials and courses	$2,000	

Database software & electronic submission maintenance		$5,000
Research supplies		$8,000
Publications		
Media coverage	$2,000	
Transportation cost		$6,000
Communication cost (fax, phone, internet access)	$1,000	
Office supplies	$1,000	
TOTAL	$35,000	$35,000

LEBANON

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November 2007

STATEMENT OF NEED

Need brief paragraph outlining what is known about toll of mortality and disability from BDs and preterm birth in Lebanon. In other words, what is the public health goal(s) underlying NCPNN?

Health statistics and epidemiological research are prerequisites for developing national health programs and policies that address these needs. Similar to other developing countries, the Arab region suffers from a dangerous paucity of research and information gathering as described by the 2003 UNDP Arab Human Development report. The National Collaborative Perinatal Neonatal Network (NCPNN) is a growing team of physicians and health professionals from different medical centers in Lebanon whose objective is to improve maternal and neonatal health through quality research. Main activities of the network include 1) surveillance and maintenance of an integrated perinatal neonatal database 2) health care capacity building through training of personnel at member institutions 3) carrying several epidemiologic research projects 4) planning and implementing interventions in prevention and care.

ACTION PLAN FOR 2008-2010

Proposed Activities, Objectives, Rationale, Methods, Evaluation and Timeline

Proposed Activities

1. SURVEILLANCE OF PRETERM BIRTH

Objective: To improve the surveillance of the causes and risk factors of preterm birth.

Rationale: With an overall prevalence of 5-9%, preterm birth (PTB) is one of the leading causes of perinatal mortality. Preliminary data from the NCPNN database indicate a rate of 8.5% at 16 hospitals in Lebanon. The causes of PTB are multifactorial with potential complex gene-environment interactions. The genetic homogeneity of the Lebanese population, the practice of consanguinity and the socioeconomic disparities that exist between communities make it a rich setup for studying risk factors of PTB and for undergoing genetic investigations.

Methods:

A modified version of the NCPNN questionnaire is expected to be launched during the first year. It will include an additional section on risk factors of preterm birth and of preterm labor. Items that will be added include:

- The obstetric precursors of the PTB, i-e whether the PTB is spontaneous (due to spontaneous preterm labor with intact membranes OR due to preterm premature ruptures of membranes PPROM) or medically indicated (due to maternal or fetal complications)
- History of previous preterm birth, previous low birthweight
- Family history of previous preterm birth, previous low birthweight
- Parental birthweight and gestational age
- Psychosocial stress
- Uterine anomalies
- Birth spacing

Also, the NCPNN will be investigating the potential association between consanguineous marriage and preterm labor.

Timeline: Collection of the PTB data is expected to start during the first year.

2. DATABASE & SURVEILLANCE - *Expansion*

Objective 1: Strengthen the surveillance system established by the NCPNN by recruiting additional hospitals in all Lebanon to reach a national coverage of the Lebanese population.

Rationale: Currently the NCPNN includes 19 active hospitals and has the following geographical coverage:

Province	CAS* # of births†	NCPNN # of births†	% coverage by NCPNN
Beirut & Mount Lebanon	22,174	9,041	40.8 %
North Lebanon	22,412	4,264	19.0 %
South Lebanon	10,323	892	8.6 %
Nabatieh	11,520	--	--
Bekaa	6,361	764	12.0 %
Total	72,790	14,961	20.6 %

* Central Administration of Statistics – Lebanese Republic, National birth toll
† For the year 2006

As can be seen from the above table, the NCPNN captures over 40% of the population living in the capital Beirut and Mount Lebanon; coverage however needs to be increased in the other provinces. This expansion is fundamental as Lebanon suffers from apparent health inequities and striking regional differences with the burden of maternal, newborn and child mortality falling disproportionately in the Bekaa, Northern then Southern regions of the country.

Methods:

- On average, four new hospitals will be recruited per year. Enrollment will be mainly based on geography whereby priority will be given to hospitals in provinces other than Beirut, especially in rural underserved areas of the Bekaa, South and Nabatieh. Governmental hospitals will be specifically targeted as these serve large communities of low socioeconomic status. Having a Neonatal Intensive Care Unit is a prerequisite for membership.
  - Specific outcomes that will be surveyed include birth defects, preterm birth and mortality (early and late neonatal mortality, perinatal mortality and fetal death).
  - An electronic data submission system (EDS) is currently being developed to facilitate data transport from distant regions. During the first year of the project, the EDS will be launched. Also, as part of strengthening surveillance, the network's information system (electronic data submission system and other online services such as teleconferencing) will be progressively evolving.

Evaluation: By the end of the three years period, the number of member hospitals is expected to be close to 32 centers. With a yearly average of 870 deliveries per year per rural hospital, the overall coverage of the national birth toll is expected to increase by 10-15%. Geographical spread of the NCPNN hospitals will be assessed and the increase in underserved provinces will be observed. Changes in rates of birth defects, prematurity and mortality rates will be monitored as the sample becomes more representative of the Lebanese population.

Timeline: Hospitals will be continuously recruited over the three-year period.

Objective 2: To assess the impact of joining a research network such as the NCPNN on quality of care at member institutions.

Rationale: Many of the hospitals in the rural and/or underserved areas of Lebanon suffer from system deficiencies mainly related to poor or no documentation in medical charts. Certain basic procedures are not performed such as blood cultures, taking temperature at birth, taking the discharge weight and others. Many of these hospitals also have no neonatologist and/or pediatric cardiologist. Previous experience with the NCPNN has shown that being part of the network improves the above deficiencies, especially as filling the NCPNN questionnaire results in better documentation in medical charts.

Methods and Evaluation: An assessment questionnaire will be developed to track the documentation status, medical care and procedures and availability of personnel/staff at newly recruited hospitals. A baseline assessment of the hospital will be made at recruitment then steadily to monitor changes and detect improvements.

Timeline: A baseline assessment will be performed with each newly joint hospital. Evaluation will be done continuously in following years.

2. **HEALTH RESEARCH CAPACITY BUILDING** – *Training*

Objective: To train personnel at NCPNN health institutions on birth defects diagnosis and reporting.

Rationale: Data collected by the NCPNN during the past couple of years indicates a relatively low rate of birth defects in the rural and underserved areas, although these communities are expected to have poorer outcomes due to significantly higher rates of consanguinity, in addition to low socioeconomic status and its associated risks in addition. One suspected reason behind this observation is misdiagnosis and subsequent underreporting of birth defects at these centers, probably due to poor expertise, the unavailability of specialists, the lack of regional referral systems and the lack of equipments at these centers.

Methods: An explanatory manual on the birth defects reportable to the NCPNN will be developed and distributed to physicians and nurses at member hospitals. It will include color pictures showing the abnormalities, a description of the abnormalities, methods to diagnose them and other pertinent information. A training workshop will also be held to introduce the health care personnel to the birth defects manual.
Evaluation: Assessment of the use and benefit of this manual will be performed through interviews with users six months after the manual is made available. Change in rates of birth defects at these centers will also be monitored over time.

Timeline: The manual will be developed and distributed during the first year. The training workshop will be held around the same time. Evaluation of its impact will be done in years 2 & 3.

3. **INTERVENTION** –P*reconceptional Health Promotion*

Objective: To increase public awareness in Lebanon about preconceptional health and care

Rationale: International experience has shown that prenatal care alone is not sufficient to prevent the two major causes of mortality and morbidity: birth defects and prematurity. It is now recognized that several of the exposures and risks associated with poor neonatal outcomes can be identified and modified before conception. Some of the preventive measures are effective only if the intervention is implemented preconceptionally. Despite the evidence, knowledge and services related to preconceptional care remain limited, especially in developing countries like Lebanon.

The NCPNN, in collaboration with the Faculty of Health Sciences at the American University Hospital of Beirut and the University of California in Los Angeles (UCLA), has carried a multicenter survey on preconceptional folic acid intake in Lebanon. Data (soon to be published) shows that only 14% of Lebanese women took preconceptional folic acid in 2003-2004; which is partly explained by the fact that women usually seek medical help only once pregnancy is detected. This highlights the need to implement, on a national level, appropriate interventions to promote preconceptional care.

Methods: A lecture on preconceptional health and care will be given by the NCPNN team at schools in Lebanon. The target audience will be grade 11-12 students. The intervention will be implemented at a total of 48 schools in Lebanon, with an average of 8 schools (4 private and 4 public) in each of the six provinces. A one stage cluster sampling will be performed. The primary sampling unit will be the schools and the only stratification will be based on the type of school, whether private or public. Random sampling will be done proportionate to the size of the province. Only high schools with a minimum of 40 grade 12 students will be selected. The lecture will address preconceptional care in general and will focus on few topics relevant to the Lebanese population such as consanguinity, hubble-bubble smoking, folic acid and toxoplasmosis.

Evaluation: A pre-test will be administered to the students before the intervention to test their baseline knowledge about preconceptional care. The test will be repeated 2 months post-intervention to detect an improvement in their knowledge.

Timeline: The awareness campaign will be launched during year two and will be implemented over 2 years (this includes preparing the educational material, giving lectures at 48 schools in all Lebanon and doing the analysis comparing the pre- and post-intervention scores of participants).

BUDGET

Year 1

Description	**MOD contribution**	**NCPNN contribution**
Recruiting 4 hospitals (coordination, collection & transportation)	17,259 $	7,584 $
Training workshop		2,500 $
RA for developing BD manual (3 months)	2,466 $	
Printing costs for BD manual	1,120 $	
RA for developing hospitals assessment questionnaire (2 months)	1,644 $	
Data manager/analyst	9,864 $	
Communication costs (fax, phone…)		720 $
Partial maintenance of running NCPNN system		15,000 $
NCPNN bi-annual meeting		To be computed later
TOTAL	32,353 $	25,804 $
Total + 10% overhead	**35,589 $**	

Year 2

Description	**MOD contribution**	**NCPNN contribution**
Part-time IT consultant	6,000 $	6,000 $
Computer + printer	2,100 $	
Recruiting 4 hospitals (coordination, collection & transportation)	10,768 $	15,168 $
Preconceptional care intervention	13,837 $	12,000 $
Data manager/analyst		9,864 $
Communication costs (fax, phone…)		720 $
Partial maintenance of running NCPNN system		17,000 $
TOTAL	32,705 $	60,752 $
Total + 10% overhead	**35,975 $**	

Year 3

Description	**MOD contribution**	**NCPNN contribution**
Part-time IT consultant	6,000 $	6,000 $
Recruiting 4 hospitals (coordination, collection & transportation)	10,768 $	15,168 $
Preconceptional care intervention	6,256 $	9,000 $
Data manager/analyst	9,864 $	
Communication costs (fax, phone…)		720 $
Partial maintenance of running NCPNN system		19,000 $
TOTAL	32,888 $	49,888 $
Total + 10% overhead	**36,177 $**	

PHILIPPINES

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STATEMENT OF NEED

National Situation

The Philippine Health Vital Statistics shows that there are approximately 1.7 Million births annually. Currently, only 37.9% births are born in a health facility; 61.4 % are still born at home and are delivered either by a traditional birth attendant, midwife or a family member (Table 1). Of the 400 000 deaths each year, approximately 23 thousand (5.8%) die during the infancy period and almost 9 thousand or 4.4% during their fetal stage.

Table 1. Percent distribution of live births according to place of delivery

Region	Health Facility			Home	Other	Missing	Total
	Government Hospital	Government Health Center	Private Sector				
NCR	38.5	2.7	28.4	30.0	0	0.5	100
Cordillera Admin Region (CAR)	38.6	0	6.7	55.2	0	0	100
I-Ilocos	21.3	0.3	7.5	70.2	0.8	0.8	100
II-Cagayan Valley	19.2	0	6.5	73.9	0	0.4	100
III-Central Luzon	30.8	0.8	17.8	49.3	0	1.4	100
IV A – CALABARZON	22.6	3.2	20.0	58.5	0.8	0.2	100
IVB – MIMAROPA	13.0	0.6	21.1	83.0	0	1.3	100
V- Bicol	15.7	0.7	5.5	76.3	1.2	0.5	100
VI- Western Visayas	24.1	2.4	6.9	65.9	0	0.8	100
VII- Central Visayas	20.7	1.5	17.6	58.8	0.2	1.0	100
VIII–Eastern Visayas	14.7	0.7	5.3	79.3	0	0	100
IX – Zamboanga Peninsula	10.9	1.0	3.7	83.8	0.6	0	100
X – Northern Mindanao	18.5	0.3	10.1	70.2	0.8	0.6	100
XI – Davao	21.3	0.3	19.4	59.0	0	0	100
XII – SOCSARGEN	12.3	1.2	9.6	76.2	0.8	0	100
XIII – CARAGA	21.3	0.9	3.9	73.6	0	0.8	100

There is no reliable national data on the rate of prematurity. Instead, low birth weight, (LBW - less than 2.5 kg birth weight) with contributions from both prematurity and intrauterine growth restriction (IUGR) is estimated at 13% [National Demographic and Health Survey (NDHS 2003)] to as high as 20% [UNICEF 1998-2005]. Among women with a livebirth, 50% were not given information about danger signs of pregnancy (NDHS 2003).

Of the top ten causes of mortality among the general population, conditions originating in the perinatal period rank no. 10 cause of death among Filipinos. Congenital anomalies rank number 7 of the top ten causes of infant mortality.

Table2. Infant Mortality: Ten (10) Leading Causes Number & Rate/1000 Livebirths & Percentage Distribution Philippines, 2004 *

Cause	Number	Rate	Percent
1. Bacterial sepsis of newborn	3,402	2.0	15.1
2. Respiratory distress of newborn	2,500	1.5	11.1
3. Pneumonia	1,940	1.1	8.6
4. Disorders related to short gestation and low birth weight, not elsewhere classified	1,750	1.0	7.8
5. Congenital Pneumonia	1,501	0.9	6.7
6. Congenital malformation of the heart	1,451	0.8	6.4
7. Neonatal aspiration syndrome	1,256	0.7	5.6
8. Other congenital malformation	1,082	0.6	4.8
9. Intrauterine hypoxia and birth asphyxia	1,030	0.6	4.6
10. Diarrhea and gastro-enterities of presumed infectious origin	**914**	**0.5**	**4.1**

* The 2004 Philippine Health Statistics

The Philippine Birth Defects Registry

The first attempt on a formal birth defects registration was in 1999 - 2001 when the Department of Health-Essential National Health Research (DOH-ENHR) provided a small grant to pilot the Birth Defects Registry (BDR) in selected private and government hospitals. The birth defects forms were accomplished by pediatric residents/ pediatricians at the nurseries. This pilot project involved examination of 197 447 newborns in 79 hospitals with the following top ten congenital abnormalities:

1. multiple congenital anomalies
2. congenital malformations of the tongue, mouth, and pharynx (ankyloglossia)
3. cleft palate with cleft lip
4. Down Syndrome
5. congenital deformities of the feet (talipes equinovarus)
6. other congenital malformations of the face and neck (pre-auricular skin tag)
7. anencephaly
8. congenital malformations of the musculoskeletal system (diaphragmatic hernia, gastroschisis)
9. hypospadias
10. polydactyly and syndactyly

Active participation of these hospitals was sustained during the duration of the project through the regular monitoring conducted by a person designated by DOH. At the end of the pilot project, DOH monitoring was discontinued and the interest of the hospitals subsequently declined. The DOH reviewed the results and explored folic acid supplementation because of the presence of anencephaly in the top ten causes. There were discussions on strategies on folic acid supplementation but due to financial constraints, there were no national efforts to provide folic acid supplementation or fortification to the indigent patients. Mothers receiving antenatal care in the private sector eventually had an edge over mothers at the community setting.

The major problem in this pilot project was the failure to integrate the BDR into an existing DOH program after completion of the project. Also, it does not reflect the status among newborns that are home delivered, which account for the greater majority of the annual births.

The Institute of Human Genetics – National Institutes of Health continued the project in a limited scale. The registry is also hospital based (tertiary hospitals) with birth defects forms being accomplished by pediatric residents/pediatricians at the nursery. The top ten birth defects were:

1) congenital malformation of the heart, unspecified
2) multiple congenital malformations
3) Hirschprung's disease
4) congenital absence, atresia and stenosis of anus without fistula
5) unspecified cleft palate with bilateral cleft lip
6) congenital hydrocephalus, unspecified
7) ankyloglossia
8) Down syndrome, unspecified
9) cleft lip, unilateral
10) cleft hard palate with bilateral cleft lip

The major problem in this second registry is the participation of more hospitals in the tertiary setting. Again, it does not reflect the status among home delivered babies.

Proposal

The lead agency for the Philippine Project is the Institute of Human Genetics, National Institutes of Health, University of the Philippines Manila.

This proposal will focus on 2 areas:

1. Campaign for reduction of deaths/complications from preterm birth.

   The campaign at the hospital setting will be limited to increasing awareness among mothers seeking in the prenatal clinics.

   For the community setting, the strategies will include increasing awareness on the danger signs of pregnancy, risk factors for premature birth and monitoring the cohort of pregnant mothers for outcome.

2. Birth defects surveillance (BDS) in different settings
   a. Tertiary Hospital Private
   b. Tertiary Hospital Government
   c. Local Government Hospitals (Provincial, District and Municipal/City Hospital)
   d. Community Setting (Rural and City)

National data has shown that 62% of newborns are home delivered and thus, highlights the importance of a formal birth defects registration in the community setting. For the hospital delivered babies, 2 settings are taken into consideration i.e. private setting and the local government setting.

DOH has agreed to be a collaborating partner in this project. In line with the policy objective of the DOH to reduce maternal and neonatal mortality rates faster in order to meet the medium development goal (MDG) targets, the Maternal-Newborn Health Policy and Strategy (MNHPS) was created and expected to be implemented by 2008. It is envisioned that these 2 projects (c**ampaign for reduction of deaths/complications from preterm births and BDS**) will develop models that can eventually be integrated into the MNHPS and thus further enhance care for the high risk neonates.

A core group has been created to oversee the over-all implementation of the project (operations, administrative and financial matters, monitoring and evaluation). The members of the core group are:

Carmencita Padilla, MD (geneticist)	Institute of Human Genetics-NIH-UPM
Aster Lynn Sur, RN (nurse)	Institute of Human Genetics-NIH-UPM
Juanita Basilio (Chief, Division of Child Health Program)	Department of Health (DOH)
Yolanda Oliveros (Director, National Center for Disease Prevention and Control)	Department of Health (DOH)

Luzon Team

Eva de la Paz, MD (geneticist)	Institute of Human Genetics-NIH-UPM
Maria Asuncion Silvestre, MD (neonatologist)	Philippine General Hospital

Visayas Team

Edgar Posecion, MD (neonatologist)	West Visayas State University Medical Center
Barbra Cavan, MD (geneticist)	The Children's Genetic Center, Cebu

Mindanao Team

Conchita Abarquez, MD (geneticist)	Institute of Human Genetics-NIH-UPM
Cesar Jeffrey Masilungan, MD (neonatologist)	Zamboanga City Medical Center

ACTION PLAN FOR 2008-2010

Campaign for Reduction of Deaths/Complications from Preterm Births and Birth Defects Surveillance (BDS) Implementation

Objectives, Proposed Activities, Rationale, Methods, Evaluation and Timeline

MODULE 1.

CAMPAIGN FOR REDUCTION OF DEATHS/COMPLICATIONS FROM PRETERM BIRTHS

The **END GOAL** of this project is to increase public awareness on strategies to reduce deaths/complications from preterm births.

This campaign will be conducted in all BDS participating hospitals and communities. The campaign at the hospital setting will be limited to increasing awareness among mothers in the prenatal clinics. For the community setting, the strategies will include increasing awareness on the danger signs of pregnancy and monitoring the cohort of pregnant mothers for outcome.

In addition to the criteria set for BDS implementation at the community setting, additional preparations are necessary for implementation of this campaign. See Appendix B for additional requirements for community selection

Proposed Activities

AWARENESS CAMPAIGN FOR BETTER OUTCOME – Reduction of deaths/complications from preterm births

Objective: To promote awareness of strategies towards reduction of deaths/complications from preterm births

Rationale: Recognizing the lack of public awareness on the importance of prevention of preterm births, a panel of activities will be conducted that will increase understanding on preventive measures

Methodology: The following will be organized:

1) A committee will be organized to develop all reading/printed promotional materials that will be used during the prevention of prematurity campaign.
2) A pre-testing of informational materials will be conducted among selected mothers to determine the effectivity of the promotional materials prior to its reproduction.
3) Information materials will be distributed to all women of reproductive age in target areas (prenatal clinics and rural health units)
4) An orientation or seminar will be given to health workers on how to supplement the information about the informational materials distributed to the public, including but not limited to the need for maternal transfer to a health facility, the use of antenatal steroids when appropriate etc.
5) Promotion of prevention of prematurity and facility-based birth will be included in mothers' classes in both hospital and community settings.

Evaluation: An evaluation tool will be created to assess the baseline and follow up knowledge of the mothers in the reproduction age on the danger signs of pregnancy. Another parameter that can be used for evaluation will be the outcome of the pregnancies of the cohort of pregnant mothers.

Timeline: At the end of 3 years, the awareness campaign must be integrated with the DOH program Maternal-Newborn Health Policy and Strategy.

MODULE 2

BIRTH DEFECTS SURVEILLANCE

The **END GOALS** of the project are:

1. Implement Birth Defects Surveillance (BDS) in different settings namely:
    a. Tertiary Hospital Private
    b. Tertiary Hospital Government (DOH Retained Hospital)
    c. Local Government Hospitals (Provincial, District and Municipal/City Hospital)
    d. Community Setting (Rural and urban)
2. Establish a centralized database of birth defects for the country to include live- and stillbirths with birth defects.
3. Formulate policy recommendation for the nationwide implementation of BDS

There will be 4 phases in the implementation of the project namely:

1. Preparatory phase (Month 1-3 of Year 1) - Preparatory phase will include the following activities:
    a. Creation of the national BDS Core Group
    b. Hiring of BDS Staff
    c. Review/Revision of the current BDS forms
    d. Printing of the BDS Forms
    e. Pilot testing of the BDS forms
    f. Finalization of areas of health facilities for implementation
    g. Define flow of BDS operation from the field (health facilities) to the National BDS Office.
    h. Preparation of BDS Manual

2. Phase 1 (Year 1) will be the implementation in the first 8 sentinel sites at different settings: tertiary hospital private, tertiary hospital government, local government hospitals and community setting (a total of 32 facilities). The following are the activities:

    a. Conduct initial meetings with 1st batch target hospitals and communities
    b. Orientation of all stakeholders in all hospitals and communities about the significance of BDS and BDS operation in their respective hospitals
    c. Pilot testing of the BDS forms
    d. Actual operation of BDS
    e. Monitoring of the implementation
    f. Documentation and assessment of one year BDS implementation

3. Phase 2 (Year 2) will focus on expansion to another 8 sites (another 32 facilities). Activities will be similar to Phase 1.

4. Phase 3 (Year 3) will focus on expansion to another 16 sites throughout the country (another 64 facilities). Activities will be similar to Phase 1 and 2.

PROPOSED ACTIVITIES

1. SURVEILLANCE & DATABASE– *Implementation of BDS in the different settings*

Objective 1: Initiate BDS through recruitment of hospitals and communities

Rationale: To ensure successful implementation in this project, hospitals and health facilities with outstanding performance in the implementation of the bloodspot newborn screening program will be selected in 8 sentinel sites in year 1; another 8 sentinel sites in year 2; and another 16 sentinel sites in year 3. **Sentinel Sites** (Appendix A) are areas where the project will be implemented. Each sentinel site shall be composed of the following:

1. Tertiary Hospital Private
2. Tertiary Hospital Government (DOH Retained Hospital)
3. Local Government Hospitals (Provincial, District and Municipal/City Hospital)
4. Community setting (Rural and City)

Choices of Hospitals will be based on the following criteria:

1. Hospitals with proven good system and existing structures in the implementation Newborn Screening is the primary criteria in the selection of a BDS facility

2. In areas wherein there is no health facility that will qualify with the first criteria, a referral or endorsement will be obtained from DOH Regional Office as to the final selection of BDS health facility based on its performance in implementing other DOH health programs

3. Willingness and commitment of the Department Chair of Pediatrics/ Chief of Hospitals/Medical Director or its counterpart office.

4. Hospitals with reliable people that can initiate the BDS implementation

5. Geographical location

6. Administrative support/endorsement

7. Commitment to health care programs

Choices of the communities will be based on the following criteria:

1. Communities with proven good system and structures in the implementation of NBS.

2. In areas wherein there is no health facility that will qualify with the first criteria, a referral or endorsement will be obtained from DOH Regional Office as to the final selection of BDS health facility based on its performance in implementing other DOH health programs

3. Willingness and commitment of the Municipal/City Health officer and its health team

4. Proximity to one of the participating tertiary hospital (a relationship will be established between the tertiary hospital and the community to ensure that patients with birth defects identified at the community setting will have access to specialist care)

5. Support of the municipal mayor

Methodology:

a. Selection of Sentinel sites
b. Orientation of the health facility personnel to discuss the following:
    - significance of BDS
    - creation of a BDS team who will oversee the implementation and eventually the institutionalization of the BDS in the hospital/community
    - flow of BDS implementation
    - set indicators of success
    - the role of BDS team in the implementation
c. Implementation of BDS operations in participating hospitals and communities.

    The BDS operation will simultaneously be initiated in all participating hospitals. All accomplished BDS forms from participating institutions will be sent to the Institute of Human Genetics, National Institutes of Health, University of the Philippines Manila through a designated or official courier. All information will be encoded in the BDS database by a data encoder. A regular update of birth defects incidence among participating hospitals will be generated to provide updates to all BDS participating hospitals and communities. If the diagnosis is not straightforward the patient is referred to a geneticist for confirmation of findings/diagnosis. Pictures are taken and attached to the accomplished BDS forms.

    Because of the additional community preparation (see Appendix B), implementation will take place on the 3rd quarter of year 1.

d. Monitoring tools will be developed to include listing of babies born with birth defects in the participating hospitals (includes live- and stillbirths - examined by a physician, either an obstetrician or pediatrician, or by a midwife), completeness of data of BDS forms submitted to IHG, regular submission of accomplished forms. All BDS hospitals and communities implementing BDS will be monitored by field coordinators.

Evaluation: By the end of the 3 years, 32 sentinel sites (96 hospitals and 32 communities) will be recruited into the project. Annual evaluation will be done to identify problems encountered and improve the next year's operations.

Time Line: Hospitals and communities will be recruited in the 3 years.

2. CAPACITY BUILDING OF BDR IMPLEMENTORS – *Training*

*Objective:*To equip BDS implementers of participating hospitals/communities with knowledge and skills in BDS operations.

Rationale: One of the major keys to the success of the implementation of the BDS is the completeness and accuracy of diagnosis of patients identified with birth defects. Validity and reliability of the data gathered will be critical. Proper training of all personnel that will be involved in the accomplishment of BDS forms must undergo training.

Methodology: A BDS Manual will be developed during the preparatory phase of the project. The BDS Manual will contain pictures of the more commonly encountered birth defects. The BDS Manual will also provide steps for referral of patients that the health personnel (physician/nurse/midwife) cannot diagnose. Three geneticists are on call to review all problematic cases. The BDS Manual will be distributed to all potential health personnel who will be involved in the BDS implementation. In addition to the manuals, workshops will be conducted to further enhance the skills.

Evaluation: In addition to the pilot testing of the BDS manual during the preparatory phase to evaluate whether the manual will be useful at the hospital and community setting, interviews will be conducted 2 months after the formal BDS operations. Re-training will be done when necessary.

Timeline: The orientation and training module should be available in the 1st 3 months of implementation. Training of implementers will be conducted during the 1st quarter of the 1st, 2nd and 3rd years.

Evaluation: At the end of the project, the Manual of Operation in BDS is available for use by all implementers. All participating hospitals/ communities have undergone training.

Timeline: The manual is targeted to be finished by the first 3 months of the first year. All trainings will be conducted in one year.

3. CREATION OF BIRTH DEFECTS DATABASE

Objective: To establish a centralized database of birth defects in the country

Rationale: To establish the prevalence of the different types of birth defects common among Filipinos covered by the surveillance, the project will ensure that a centralized database will be created and established. The centralized database can be the basis of some policy recommendations to the DOH.

Methodology: All accomplished forms will be submitted to the Institute of Human Genetics which will house the database. A consolidated report will be generated regularly and will also be shared with all participating hospitals and communities.

Evaluation: A generated report will be the basis in establishing the prevalence rate of each birth defects covered by the surveillance.

Timeline: The database will be ready within the first 6 months of Year 1.

YEAR 1

Description	MOD Contribution	IHG Contribution	Total expenses
Recruitment of 24 hospitals (meetings and consultations)	$10,000.00	$10,000.00	$20,000.00
Training workshops and awareness activities		$5,000.00	$5,000.00
Development of BDR Manual of Operations	$2,500.00		$2,500.00
Printing of BDR forms		$2,000.00	$2,000.00
Development of advocacy and promotional materials (i.e posters and brochures)	$2,500.00	$2,500.00	$5,000.00
Meetings (for production of manual, promotional materials, etc.)		$1,000.00	$1,000.00
Maintenance of Database		$10,000.00	$10,000.00
Monitoring and Evaluation		$3,000.00	$3,000.00
Project Development Officers IV ((US$8000 per person)	$8,000.00		$32,000.00
University Research Assistants/Field (US$8000 per person)		$24,000.00	$24,000.00
Data encoders (12 months x 2 pax)		$6,000.00	$6000.00
Honorarium of writers for the manual (3 months)	$2,000.00		$2,000.00
Transportation costs		$6,000.00	$6,000.00
Communications costs (includes mailing)	$2,000.00	$8,000.00	$11,000.00
MOOE (office rental, project supplies, computers, etc)	$8,000.00	$8,000.00	$16,000.00
TOTAL COST	**$35,000.00**	**$95,500.00**	**$130,500.00**

YEAR 2

Description	MOD Contribution	IHG Contribution	Total expenses
Recruitment of additional 24 hospitals (meetings and consultations)	$10,000.00	$20,000.00	$30,000.00
Training workshops and awareness activities		$5,000.00	$5,000.00
Printing of BDR forms		$2,000.00	$2,000.00
Reproduction of advocacy and promotional materials (i.e posters and brochures)	$2,000.00	$2,000.00	$4,000.00
Maintenance of Database		$10,000.00	$10,000.00
Monitoring and Evaluation	$2,000.00	$4,000.00	$6 000.00
Project Development Officers IV (US$8000 per person)	$8,000.00		$8,000.00
University Research Assistants/Field (1US$8 000 per person)		$24,000.00	$24 000.00
Data encoders (12 months x 2 pax)		$6 000.00	$6 000.00
Transportation costs		$6,000.00	$6,000.00
Communications costs (includes mailing)	$2,000.00	$5,000.00	$7,000.00
MOOE (office rental and utility expense, project supplies, computers, etc)	$3,000.00	$6,000.00	$9 500.00
Expansion to other countries	$8,000.00	$3,000.00	$11,000.00

TOTAL COST	**$35,000.00**	**$93 000.00**	**$ 128 000.00**

YEAR 3

Description	**MOD Contribution**	**IHG Contribution**	**Total expenses**
Recruitment of 48 additional hospitals (meetings and consultations)	$10,000.00	$20,000.00	$30,000.00
Training workshops and awareness activities		$5,000.00	$5,000.00
Printing of BDR forms		$2,000.00	$2,000.00
Reproduction of advocacy and promotional materials (i.e posters and brochures)		$2,000.00	$2,000.00
Maintenance of Database		$10,000.00	$10,000.00
Monitoring	$ 3 000.00	$4,000.00	$8,000.00
Documentation and Evaluation	$2,000.00		$2,000.00
Project Development Officers IV (12 months x 1 pax)	$8,000.00		$8 000.00
University Research Assistants/Field (12 months x 3 pax)		$24 000.00	$24 000.00
Data encoders (12 months x 2 pax)		$6 000.00	$6 000.00
Transportation costs		$6,000.00	$6,000.00
Communications costs (includes	$2,000.00	$3,000.00	$5,000.00

mailing)			
MOOE (office rental and utility expense, project supplies, computers, etc)	2 000.00	$10,000.00	$10,000.00
Expansion to other countries	$8,000.00	$ 3 000.00	$7,000.00
TOTAL COST	**$35,000.00**	**$95 ,000.00**	**$130 000.00**

APPENDIX A

Sentinel Sites – are areas where the project will be implemented. Each sentinel shall be composed of the following:

1. Tertiary Hospital Private
2. Tertiary Hospital Government (DOH Retained Hospital)
3. Local Government Hospitals (Provincial, District and Municipal/City Hospital)
4. Community setting (Rural and City)

FINAL LIST OF PARTICIPATING HOPSITALS AND COMMUNITIES AND THEIR RESPECTIVE COORDINATORS AND REPRESENTATIVES (PHASE 1 – YEAR 1)

Sentinel 1 – NCR

Dr Rosalinda Yao	Chinese General Hospital [1]
Dr Resty Bautista	Philippine General Hospital [2]
Dr Nenita Decipulo	Doña Marta Lying-in [3]
Dr Dulce Macabudbud	Manila Health Department [4]
Dr Judy Gargantiel	Manila Health Department [4]

Sentinel 2 – Ilocos Region

Dr Hazel Rae Santos	Lorma Medical Center [1]
Dr Mary Grace De Vera	Ilocos Training Hospital [2]
Dr Mariel Mohammed	Ilocos Training Hospital [2]
Dr Macrima Iglesias	Bayambang District Hospital [3]
Dr Francis Galvez	San Fernando City Health Office [4]
Ms Emily Laroya	San Fernando City Health Office [4]

Sentinel 3 – Central Luzon

Dr Hans Christian Balgan	Angeles University Medical Center [1]
Dr Thang Ching Lee Chu	Angeles University Medical Center [1]
Dr Amor Espinosa	James Gordon Memorial Hospital [2]
Dr Donna Bernal	James Gordon Memorial Hospital [2]
Dr Arvin Escueta	Bulacan Maternity Hospital [3]
Dr Angela Pangan	Obando Rural Health Unit [4]

Sentinel 4 – CALABARZONE

Dr Delia Caparas-Yu	De La Salle University Medical Center [1]
Dr Madeleine Sosa	De La Salle University Medical Center [1]
Dr Vicente Caluag	De La Salle University Medical Center [1]
Dr Dennis Rivere	Integrated Provincial Health Office, Quezon [2]
Dr Velbe Del Moro	Integrated Provincial Health Office, Quezon [2]
Ms Jasmin Racelis	Integrated Provincial Health Office, Quezon [2]
Dr Cristina Miranda	Sta Rosa Community Hospital [3]
Ms Mayleen Gaca	Sta Rosa Community Hospital [3]
Ms Laura Esguerra	Sta Rosa Community Hospital [3]
Dr Ariel Lescano	City Health Office, Lipa City [4]
Ms Zenaida Vermera	City Health Office, Lipa City [4]

Sentinel 5 – Western Visayas

Dr Ma. Cristina Woo	St Paul's Hospital, Iloilo [1]
Ms Kathleen Ann Bacali	St Paul's Hospital, Iloilo [1]
Dr Cherry Tampus	Teresita Jalandoni Provincial Hospital [2]

Ms Riza Partillo	Teresita Jalandoni Provincial Hospital [2]
Dr Girlie Pinongan	Cadiz District Hospital [3]
Dr Josephine Pahamtang	Cadiz District Hospital [3]
Ms Dalia Segunla	Pontevedra Rural Health Unit [4]
Ms Ana Jurada	Pontevedra Rural Health Unit [4]
Sentinel 6 – Central Visayas	
Dr Jose Laddy Go (Absent)	Chong Hua Hospital [1]
Dr Mary Jol Sucalit	Cebu City Medical Center [2]
Dr James Maratas	Cebu City Medical Center [2]
Dr Sozelon Zerrudo	Bayawan Distric Hospital [3]
Dr Elizabeth Sedillo	Tanjay Rural Health Unit II [4]
Ms Luz Casiano	Tanjay Rural Health Unit II [4]
Sentinel 7 – Northern Mindanao	
Dr Dennis Absin	Madonna and Child Hospital [1]
Dr Pacita Kho (Absent)	Madonna and Child Hospital [1]
Dr Cynthia San Juan	Northern Mindanao Medical Center [2]
Dr Janipa Maunte	Northern Mindanao Medical Center [2]
Dr Mary Ann Alvisor	Bukidnon Provincial Hospital – Maramag [3]
Ms Magdalena Tupas	Bukidnon Provincial Hospital – Maramag [3]
Ms Alma Jean Orapa	Malaybalay City Health Office [4]
Dr Melirose Deticio	Malaybalay City Health Office [4]
Sentinel 8 – Southern Mindanao	
Dr Eleonor Du	Davao Doctors Hospital [1]
Dr Sheldon Paragas	Davao Doctors Hospital [1]
Dr Mike Manalaysay	Davao Medical Center [2]
Dr Joel Gallardo	Davao Medical Center [2]
Dr Maria Imelda Rosales	Davao del Sur Provincial Hospital [3]
Ms Carol Desabelle	Davao del Sur Provincial Hospital [3]
Dr Imelda Tan-Bendijo (Absent)	Panabo City Health Office [4]
Ms Mafel Mugas (Absent)	Panabo City Health Office [4]

[1] Tertiary Hospital Private
[2] Tertiary Hospital Government (DOH Retained Hospital)
[3] Local Government Hospitals (Provincial, District and Municipal/City Hospital)
[4] Community Setting (Rural and City)

APPENDIX B

Additional selection criteria for community setting

The implementation in the community setting for the campaign for reduction of deaths/complications from preterm births will involve additional requirements inasmuch this campaign will involve the follow up of a cohort of pregnant mothers.

The following steps have to done:

1. Consultation with key agencies (DILG, DOH) to finalize of choices of communities for the community implementation based on the following criteria:

   a. Willingness of the whole Municipal/ City Health Staff to adopt the project (MHO, PHN, Midwives etc). Full participation to the project would mean that the medical staff will be:
      a.1. willing to be oriented about the project
      a.2. willing to integrate the project in their current operation workflow
      a.3. willing to undergo training of about the project
      a.4. willing to be a part of the attaining the objectives on the project through a systematic and efficient operation (from orientation of medical and paramedical staff who will be involved in the implementation, documentation, operation, monitoring and evaluation)

   b. Willingness and support of the local government unit at all levels (Municipal/City and Barangay level)

   c. Willingness and support of the barangay health officials and barangay health committee

2. A listing of candidate communities will be generated. Correspondence shall be made to these communities as to their response or willingness to participate in the project.

3. Social Preparation

   Social preparation activities will include the following:
   a. Orientation of all stakeholders about the project. Target stakeholders will be composed of the following: local chief executives, municipal health staff (Municipal/City health office, public health nurses, midwives), barangay leaders, barangay health committee, barangay health workers and traditional birth attendants. If situation permits, a community assembly will be conducted for an orientation of the project.

      The orientation will discuss the following:
      - objectives and the significance of the project to the possible improvement of the health status of the community,
      - the benefit of their community experience to the possible duplication of their pilot implementation to other communities in future
      - flow of implementation of the project
      - roles and responsibilities of the community to the successful implementation of the project.

   b. Community planning for the implementation of the project. Planning will include the following: designation of person/s responsible for the projects, roles and responsibilities of persons designated, barangay health workers , barangay health committees, traditional birth attendants, rural midwife and the community in general