The March of Dimes Global Network for Maternal and Infant Health: Harnessing the power of experts in lower-income countries to improve the health of women, mothers, newborns and babies

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This short report describes a model for international collaboration on perinatal health that is innovative, highly-productive and challenging. The model, funded by the U.S. March of Dimes Foundation and entitled the “March of Dimes Global Network for Maternal and Infant Health (GNMIH)”, allows developing country experts to more easily share their knowledge, experience, skills and materials in ways that can improve women’s, maternal, newborn and child health in lower-income countries. This report begins with a brief description of the March of Dimes and its Global Programs which oversees the GNMIH. It then discusses the structure of the GNMIH, with an emphasis on the benefits and challenges of working within the network, and concludes with a brief description of the activities of network members.

1 The March of Dimes Foundation

President Franklin Roosevelt established the March of Dimes Foundation in 1938 to find a cure for polio. In doing so, he created a partnership of volunteers and researchers that led to the development of the Salk and Sabine polio vaccines and the eradication of polio from the United States and, subsequently, most of the world.

With this success, the foundation in 1958 re-focused its mission by launching an adventurous program directed at birth defects by funding medical research and establishing birth defects treatment and evaluation centers throughout the U.S.\(^5\). As March of Dimes programs against birth defects developed after the 1960s, its mission expanded through the burgeoning fields of genetics and perinatology. In 2003, the March of Dimes launched a campaign to address the serious and growing problem of premature birth, the leading cause of death in newborns in the United States\(^1\). As with birth defects, babies who survive a preterm birth, even a late preterm birth at 34 – 36 weeks, often face lifelong disabilities such as cerebral palsy, mental retardation, vision and hearing loss\(^2\).

The current mission of the March of Dimes is, thus, to improve infant health by preventing birth defects, premature birth and infant mortality. Today as in the past, the March of Dimes mission is carried out through research, community services, education and advocacy. In doing so, the March of Dimes as noted by David Oshinsky “...became the gold standard for private charities, the largest voluntary health organization of all time. Its success in raising money, generating publicity, caring for patients, and sponsoring medical research would serve to redefine the role—and the methods—of private philanthropy in the United States.”\(^3\)

2 March of Dimes Global Programs

In 1998, the March of Dimes broadened its mission beyond the United States through the establishment of its office of Global Programs. Global Programs conducts its work through mission alliances—close working partnerships with technical partners in targeted countries—to improve perinatal health and prevent birth defects and preterm birth. Ideal partners are organizations that; (1) have an established presence in the target countries, including legal status and a local infrastructure; (2) share the March of Dimes mission to improve the health of babies; and, (3) demonstrate financial health and stability. The March of Dimes contributes to these partnerships through providing its technical expertise and rich resource of professional and public health education materials developed

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\(^2\) Birth defects as defined in this report are abnormalities of structure or function, including metabolism, which are present from birth. Serious birth defects are life threatening or have the potential to result in disability (physical, intellectual, visual or hearing impairment or epilepsy). Several thousand different birth defects have been identified to date. Some birth defects are clinically obvious at birth; others may only be diagnosed later in life. Spina bifida is one example of a structural defect that is obvious at birth. The bleeding disorder hemophilia is a functional defect usually not clinically obvious until infancy or childhood. The authors accept that the term ‘birth defect’ is not considered appropriate by some, but it has been used extensively in medical literature over time and is widely understood by the broad audience of this report.
through its years of international, national and community-based programs.

In all partnerships, the individual cultural differences of the partner organizations are acknowledged and respected. Building trust and cooperation requires open communication between partners and the developing of a program with shared goals and processes. The emphasis on close, collaborative partnerships has allowed partners to identify and, thus “own”, the strategies used to promote newborn health in their populations. This important sense of ownership is reflected in the fact that our mission partners have more than matched March of Dimes funding dollar-for-dollar in the past 11 years. More importantly, the projects conducted have emphasized product-intensive, measurable interventions that have been able to show success in the short term. This ability has made it possible to attract outside donors eager to partner on and support activities. Working accordingly, the March of Dimes in the past eleven years has helped implement effective, affordable and feasible programs in over 33 countries on four continents.

3 The March of Dimes Global Network for Maternal and Infant Health

In late 2007, March of Dimes Global Programs linked four of its key mission partners together 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. It did so because it recognized the need for an administrative structure that could promote greater collaboration and coherence in program and the science than was possible under the previous system of individual mission alliances. The four network partners were chosen on the basis of their history of demonstrated success in conducting rigorous, world-class public health interventions in their countries; their geographic balance; and their potential to expand their perinatal health interventions nationally and regionally. The four partners identified were Dr. Nanbert Zhong (Beijing, People’s Republic of China); Dr. Carmencita Padilla (Manila, Philippines), Dr. Khalid Yunis (Beirut, Lebanon) and Dr. Roberto Giugliani (Porto Alegre, Brazil).

The mission of the GNMIH has continued to be that of the March of Dimes Global Programs—to prevent mortality and disability from birth defects and preterm birth in developing countries. However, while structured in the manner of successful past mission alliances, the GNMIH represents an important step forward in the way Global Programs conducts its work. GNMIH 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 have been maintained. What has changed is the introduction of an initially simple but evolving structure to promote communication, collaboration, sharing of materials and best practices and, importantly, harmonization in project materials and approaches.

The core philosophy of the GNMIH 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. As with this report, publication of results in the peer-reviewed literature are co-authored by GNMIH partners as agreed upon. This approach of “south-to-south” collaboration—which has been much discussed by the global health community and widely recognized as needed—has never been implemented to the degree that the GNMIH offers. It is only through strategically managed networks like the GNMIH, however, where the locus of power and decision making reside as it should with the developing country partners, that their growth and core capacities can be developed and sustained. In this sense, the role of the March of Dimes and other industrialized country partners in the GNMIH is one of support, guidance and fundraising, rather than unilateral direction.

3.1 Benefits of working within the GNMIH structure

The GNMIH 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;
• providing a means to link international and national technical organizations to the expertise and experience of the network partners—and vice-versa;
• offering a model of a multinational, integrated, harmonized and, thus, cost-effective perinatal health program that is attractive to government and private donor organizations and philanthropists.

The GNMIH, in addition, coordinates its activities with other networks, including the EU funded project entitled “Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention (CAPABILITY)”, which is based on the GNMIH model but focuses on building capacity research and services in medical genetic.

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 are strong.

3.2 Challenges of working within the GNMIH structure

Traditionally, most national and international health networks have consisted of individual research and/or program entities working toward common programmatic goals and sometimes with one or more common protocols. What
is unique about the GNMIH is that it takes this traditional model one important step further by requesting of GNMIH members that they discuss, agree upon and implement, as a network, harmonized methodological approaches that include the adoption of common definitions, core metrics and research questionnaires.

While this approach has been recommended by many organizations over the years, the authors, in their many years of engagement in collaborative public health programs, have never seen the degree of research harmonization across countries that is currently in the process of being adopted by the GNMIH[5-8].

Experience in the first year of the GNMIH has shown why the many past recommendations for harmonization in research methods and approaches have generally not been implemented. While acknowledging in principle the benefits of research harmonization, GNMIH members have found in fact that it can be very difficult to overcome the usual institutional pressure “to do things as they always have been done”. However, GNMIH members are making great strides in developing a common set of disease and condition specific definitions, core metrics and even questionnaires that can be implemented network-wide. Our progress to date on this issue has already attracted the attention of potential outside donors interested in funding one or more network activities.

3.3 Current activities of the GNMIH

GNMIH programs currently encompass a broad variety of health research and program activities directed towards care and prevention of birth defects and preterm birth and the promotion of perinatal health more broadly. These include:

- establishment of surveillance systems, including the training of staff to use the data collected to assess national disease burden; evaluate interventions and generate reports for national and international policy makers;

- professional education and training of physicians, nurses, genetic counselors and other primary health care providers;

- community and public education;

- media education and outreach;

- preconception health;

- programs to engage young health professionals in volunteer public health activities and interaction with counterparts in other network countries.

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References


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