



Brief Background on the *March of Dimes* Global Network for Maternal and Infant Health (GNWIH)

**CAPABILITY
MID-TERM EVALUATION MEETING
SOUTH AFRICA
25-30 March 2009**

Knowledge is of two kinds. We know a subject ourselves, or we know where we can find information upon it.

- Samuel Johnson (1709-1784)

The importance of surveillance data - how birth defects gained in international importance as a result of such data

The Situation in January 2000

Nationally, of 155 low- and middle-countries:

< 5 had national plans for strengthening primary care services for birth defects care and prevention

Only a few medical and nursing schools in these countries offered courses in diagnosis and prevention

Public awareness of the steps that couples and families could take to reduce their risk of having a baby with a birth defects was low

Internationally:

WHO had little sustained commitment to care and prevention

There was little interest on the part of other international and national organizations, NGOs and donor organizations in strengthening preventive or care services

Birth defects were thought to be rare and amenable only to high-tech, expensive interventions

The problem? There was a lack of data on the national and global toll of birth defects and, thus, also on the effectiveness of interventions conducted to date

In response, in January 2006 the March of Dimes published its *Global Report on Birth Defects: the Hidden Toll of Dying and Disabled Children*

The report provided estimates on the birth prevalence of and mortality from serious birth defects for 193 countries

The estimates were based on available surveillance data which for many regions were scarce

The report also provided recommendations on steps that governments, communities and families could take to reduce that risk by up to 70%

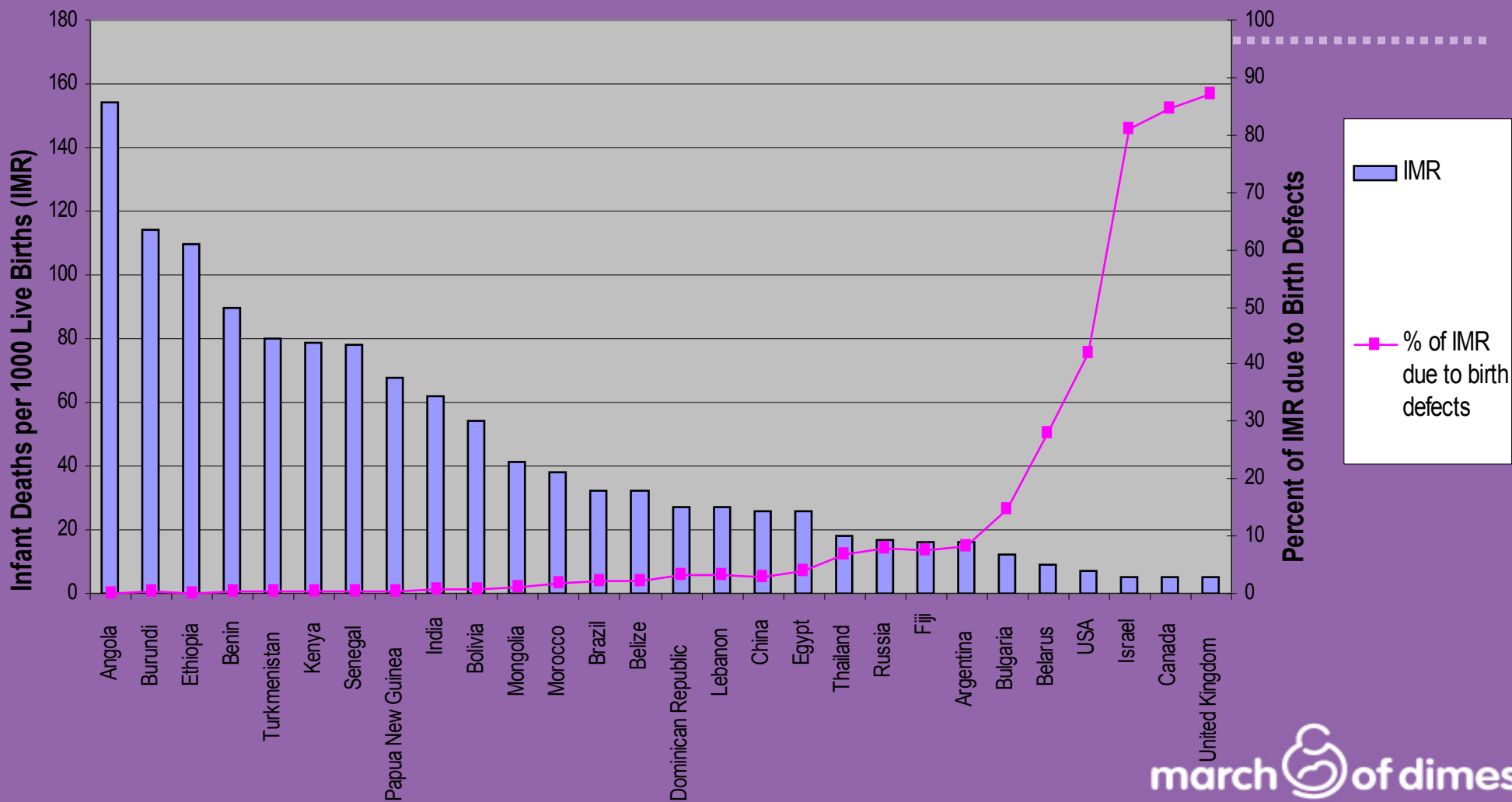


MARCH OF DIMES
GLOBAL REPORT ON BIRTH DEFECTS

THE
HIDDEN TOLL
OF DYING
AND
DISABLED
CHILDREN

The report showed that birth defects are not rare and that the greatest toll of death and disability is in middle- and low-income countries (like many of those in the Eastern Mediterranean Region)

Relationship between Infant Mortality Rate (IMR) and Percentage of Infant Deaths due to Birth Defects in the Absence of Known Preventive Services by Country - 2004



The Global Toll of Birth Defects

Every year:

An estimated 7.9 million children are born with a serious birth defect of genetic or partly genetic origin

Hundreds of thousands more are born with serious birth defects due to teratogens

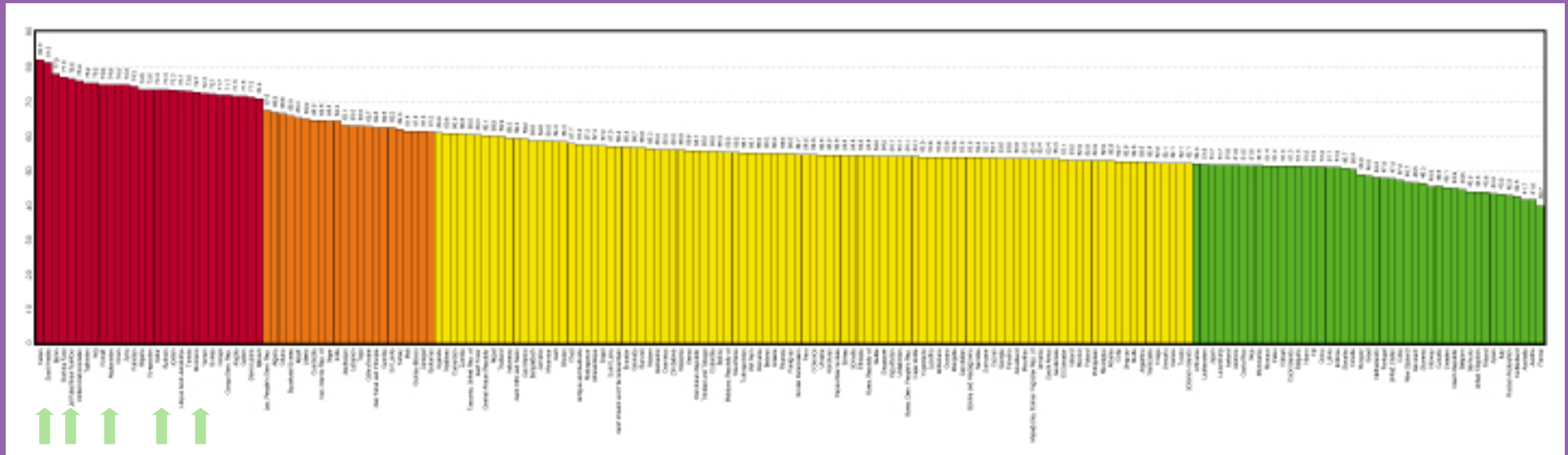
More than 3.3 million children die from birth defects in the first five years of life

An estimated 3.2 million of those who survive may be disabled for life

The Global Toll of Birth Defects

Birth defects are a global problem, but the highest rates are in low-income countries where more than 94% of the births with serious birth defects and 95% of the deaths of these children occur

Birth Defects Prevalence per 1,000 Live Births (in the absence of all known preventive strategies)



Worldwide, birth prevalence rates of all genetic birth defects combined range from a high of 82/1,000 live births in low-income regions to a low of 39.7/1,000 live births in high-income regions

The Power of Data: the Situation as of November 2008

Nationally:

A growing number of middle- and low-income countries have or are now drafting national plans for strengthening primary care services for care and prevention of birth defects (e.g. Oman)

An increasing number of medical and nursing schools are offering or asking for courses in diagnosis, prevention and treatment

There is an increasing professional and public demand across countries for care and preventive services

There is heightened interest by the media in publishing stories on birth defects

The Power of Data: the Situation as of November 2008

Internationally:

In May 2006, four months after publication of the March of Dimes Report, WHO convened a joint WHO-MOD meeting in Geneva to develop international guidelines for birth defects care and prevention

Shortly afterwards, the March of Dimes was asked to join the Global Partnership for Maternal, Newborn & Child Health

DALY estimates are now being generated separately for birth defects as part of the 2008 Global Burden of Disease Project

The Power of Data: the Situation as of November 2008

Internationally:

A chapter on birth defects has been included in this year's edition of the influential publication, *Disease Control Priorities in the Developing World*

There is increased interest on the part of donors in supporting research and intervention on birth defects

In particular, an increasing number of national surveillance systems designed to capture data on birth defects prevalence are being established

This is the good news!

The Not-So-Good News

Many perinatal/neonatal health surveillance systems are being set up or expanded without proper consultation or collaboration with other networks

As a result, disease definitions, diagnostic categories, questionnaires and methods of data capture and analysis differ markedly among surveillance systems, reducing the ability of investigators to evaluate their data accurately or to compare or pool their data across national or local systems

The Need for Data Networks

The Benefit of Data Networks

Networks:

improve site-to-site communication and allow partners to share best practices and lessons learned and build on each other's successes (thus reducing the need to re-invent the same wheel over and over again)

enhance consistency in data collection and study methods, thus providing greater opportunity to compare and pool data across network centers

promote the potential for complementary activities, thus providing for more cost-effective use of shared resources

offer the potential for an on-line repository of project materials (eg, questionnaires, curricula) for use by current and future network partners

All of these benefits, combined, can result in greater project visibility and, thus, an enhanced potential to attract national and international attention and funding

Remember: one size does not need fit all!

Examples of Current Networks

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WHO's Preterm Birth Surveillance Network

ELAMC (Latin America)

National China Birth Defects Network (NCBDN)

National Collaborative Perinatal Neonatal Network (NCPNN)

The March of Dimes Global Partnerships for Perinatal Health Network (GPPHN)

March of Dimes Global Network for Maternal and Infant Health

The Global Network for Maternal and Infant Health (GNMIH) is structured in the manner of successful past mission alliances, and represents an important step forward in the way Global Programs conducts its work. GNMIH provides a means for developing country experts to more easily share their knowledge, experience, skills and materials in ways that offer significant new benefits. What has changed with the GNMIH is the introduction of a 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 GMNIH 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 has been much discussed by global health policy makers and donor organizations and widely recognized as needed. However, it is only through strategically managed networks like GMNIH, where the locus of power and decision making resides as it should with developing country partners, that their development and core capacities can be effectively sustained.

Examples of current networks

WHO's Preterm Birth Surveillance Network

ELAMC (Latin America)

National China Birth Defects Network (NCBDN)

National Collaborative Perinatal Neonatal Network (NCPNN)

NIH Global Network for Women's and Children's Health Research

Objectives

Establish a global network of world-class academic partners to:

improve site-to-site communication, thus allowing partners to share best practices and lessons learned and build on each other's successes (thereby reducing the need to re-invent the same wheel over and over again)

enhance consistency in data collection and study methods, thus providing greater opportunity to compare and pool data across network centers

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The March of Dimes Global Network for Maternal and Infant Health (GNMIH)

- **Brazil** (Prof. Roberto Giugliani, MD, PhD, Hospital de Clinicas de Porto Alegre)
- **China** (Prof. Nanbert Zhong, MD, Department of Medical Genetics, Peking University)
- **Lebanon** (Prof. Khalid Yunis, American University of Beirut)
- **Philippines** (Prof. Carmencita Padilla, MD, MAHPS, Institute of Human Genetics, National Institutes of Health)

List of GNMIH projects by center

Brazil:

Develop and evaluate community information on primary prevention of birth defects and avoiding gestational risks

Implement newborn screening

Train professionals about prevention, screening, diagnosis and care of birth defects and genetic diseases

China:

Expand the birth defects surveillance system to include all MCH hospitals across China

Develop a questionnaire to be given to expectant mothers at high-risk of having a baby with a birth defect

Establish a primary prevention network for birth defects focusing on professional education in the Shangri-La region of western China

Conduct a cross-sectional study of preterm birth

Implement genetic studies on preterm birth and birth defects

List of GNMIH projects by center

Lebanon:

- Improve surveillance of the causes and risk factor of preterm birth
- Strengthen the surveillance system established by the NCPNN
- Train personnel at NCPNN health institutions on birth defects diagnosis and reporting
- Increase public awareness in Lebanon about preconception health and care

Philippines:

- Implement birth defects/PTB surveillance in different settings across the Philippines
- Use the data collected to establish a campaign to reduce deaths and complications from birth defects and preterm birth

Current partners

American Academy of Obstetrics and Gynecology (ACOG)

American Academy of Pediatrics (AAP)

Association of Women's Health, Obstetric and Neonatal Nurses
(AWHONN)

Centers for Disease Control and Prevention (CDC)

National Institutes of Health (NIH)

World Health Organization

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Initial Projects

Early projects focused on immediate needs, including the establishment of hospital- and population-based surveillance systems for the collection of high-quality data on the incidence, prevalence, mortality, disability and risk factors associated with increased risk of birth defects and preterm birth.

Another major focus has been on professional education and training of primary care providers, for example, in the identification, diagnosis and appropriate referral of babies born with a birth defect.

Current Focus

Recently, our developing country partners have expressed increasing interest in partnering on interventions for care and prevention of birth defects and preterm birth based at the community and family levels.

In part, this increasing interest reflects the success of our professional education partnerships to date and the growing recognition among Network members that education of community and family members (the health care consumer) is essential if families and individuals are to appropriately and effectively access the health care services in their communities.

- For example, delivering effective preconception health care—a serious unmet need in developing countries—requires an educated public.

GNMIH proposals in development

Develop a global network of volunteer youth leaders beginning with the GNMIH centers

Implement and evaluate preconception health interventions

Fragile X

The Need for Youth Leadership

As a result, March of Dimes and Network members have proposed the establishment of a Global Youth Leadership Network to develop the skills and abilities of students in their schools of medicine, nursing and the allied health professions, as well as recent graduates of these schools, to deliver community- and family-based health education in their localities. The Network would:

- Support the training and mobilization of students and young professionals to work on public health projects in their communities and countries;
- Link these students and young professionals actively and effectively to their counterparts in other Network countries and the United States; and
- Provide an opportunity for a youth representative from each participating country and the United States to present on the Global Youth Leadership Network and activities conducted at the *4th International Conference on the Prevention of Birth Defects and Disabilities in the Developing World* to be held on 4-7 October 2009 in New Delhi, India.

Global Youth Leadership Network

- Build leadership skills in a new generation of developing country youth;
- Develop a culture of volunteerism in countries where this is currently lacking by allowing youth leaders the opportunity to give back to their communities and make a difference locally;
- Offer a means for meaningful civic engagement, including advocating for local and national policies;
- Provide an opportunity for like-minded students and young professional leaders worldwide to network with each other and share experiences and best practices;
- Learn from existing models of youth volunteerism, including March of Dimes Team Youth and Zeta Phi Beta Sorority, Inc;
- Reduce professional isolation, broaden personal and professional horizons, and promote international friendships, dialogue and exchange.

International Conference Participation

Inviting the youth volunteers to attend the 4th International Conference in India would provide the means to:

Present a successful program as a model for engaging and sustaining youth and young professional volunteerism and for developing a new generation of health care leaders in the developing world; and

Encourage dialogue and the sharing of experiences and needs among the young professionals in attendance (e.g. from the Global Youth Leadership Network and India and other lower-income countries).

→ Conference organizers have agreed to establish a venue and time to hold the Global Youth Leadership Network meeting and will work with the March of Dimes and its partners to ensure the participation of a broad range of young professionals from across India and the region.

Project Overview

Goal: Establish a Global Youth Leadership Network to deliver effective community- and family-based health education and to provide a successful model for promoting youth and young professional volunteerism and developing a new generation of health care leaders in the developing world.

March of Dimes Global Programs will provide administrative oversight of Network. Funds requested for this purpose will support core administrative functions, such as the organization of annual meetings, scheduling of bi-monthly conference calls, ensuring effective programmatic linkages among the Network teams and US counterparts, and developing and maintaining the Network webpage. Funds requested will not be used for overhead or staff salaries.

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谢谢你

Muito
obrigado!

Muchas
gracias!

Thank You!