

March of Dimes Global Programs



First Capability Workshop

Trolleholm, Sweden

8 May 2007

What My Presentation Will Cover



- **Description of the March of Dimes**
- **Description of its Global Programs**
 - **Initial activities**
 - **Current priorities**
 - **Network project**





Be sincere, be brief, be seated.

- Franklin Delano Roosevelt

March of Dimes Statement of Mission



The mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth and infant mortality



March of Dimes Strategies



- **Research**
- **Education**
- **Community interventions**
- **Advocacy**



March of Dimes Organizational Structure

- **Grassroots organization founded in 1938**
- **Activities supported by 2 million+ volunteers and 1400 staff**
- **52 Chapters (in 50 states and Puerto Rico)**
- **National Office - White Plains, NY**
 - **Pregnancy and Newborn Health Education Center**
(www.marchofdimes.com)
 - **Perinatal Data Center (“Peristats”)**
- **Office of Governmental Affairs - Washington, D.C.**
- **Global Programs (established in December 1998)**



March of Dimes - History of Success 1

- **1950 - Fellowship awarded to James Watson to investigate the structure of DNA**
- **1955 - Salk inactivated polio vaccine found to be safe, potent and effective; licensed for use in the U.S.**
- **1961 - Development of PKU screening by Robert Guthrie**
- **1962 - Sabin live polio vaccine licensed for use in the U.S.**
- **1969 - Founding of the first master's degree program in genetic counseling**
- **1970 - Establishment of a network of genetic services centers across the U.S.**



March of Dimes - History of Success 2

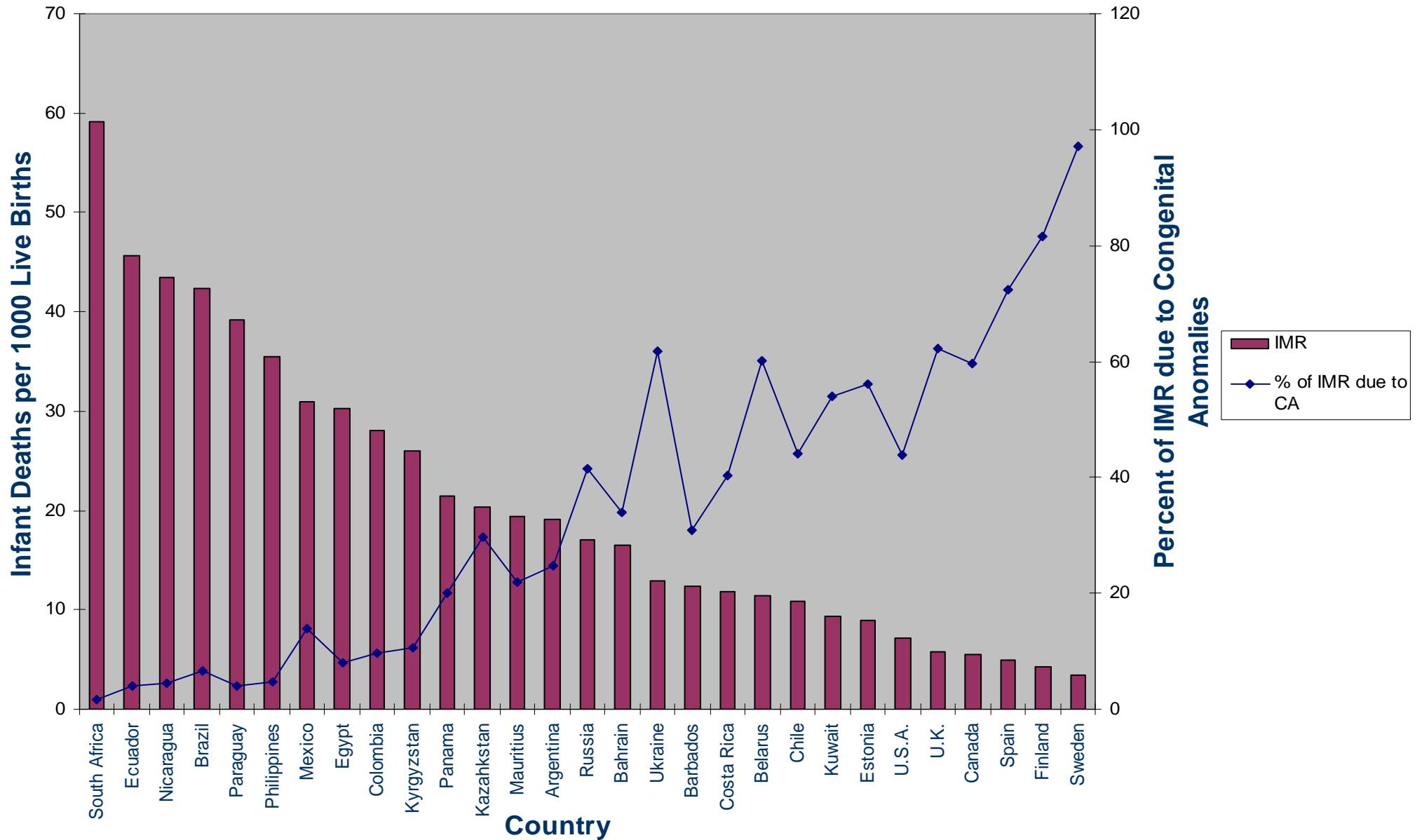
- **1973-87 - Nine international workshops on human gene mapping laying the foundation for the Human Genome Project**
- **1976 - Publication of “Towards Improving the Outcome of Pregnancy” and regionalization of perinatal care in the U.S.**
- **1985 - Development of surfactant therapy**
- **1998- U.S. Birth Defects Prevention Act passed**
- **1998 - Folic Acid Campaign to lower NTD rates begins**
- **2003 - National Prematurity Campaign launched**






March of Dimes Global Programs

Relationship between Infant Mortality Rate (IMR) and Percentage of Infant Deaths due to Congenital Anomalies (CA) by Country





**A man with his mouth open will wait
a long time before a roast duck flies
in.**

- Chinese proverb

Global Programs



- **Established in 1998**
- **Guiding Principles**
 - **Cost-sharing**
 - **Focus**
 - **Synergy**
 - **Flexibility**

Program Emphasis



- **Established in 1998**
- **Program budget ~ \$300,000 per year**
- **Programs in 23 countries on four continents**
- **Key is small grants emphasizing:**
 - **Product-intensive partnerships**
 - **Short-term projects**
 - **A focus on projects with a high probability of success**
 - **Robust science and evaluation**

Initial Activities



- **Increase awareness of the human and economic toll of birth defects and preterm birth worldwide**
- **Establish partnerships to reduce mortality and disability from birth defects and preterm birth**
- **Improve the training of health care providers in perinatal health, including medical genetics**
- **Expand public education and the capacity for community action**

Initial Activities



- **Support expansion of folic acid fortification of foods worldwide**
- **Promote the incorporation of rubella vaccine into current global measles control efforts**

Program Activities

Perinatal Health Education

- Latin America
- Russia and Eastern Europe
- India
- Central Asia
- South-east Europe

Genetics Education

- SAIDA partnership in South Africa
- Partnership in China, Tibet, Egypt
- *Genetics & Your Practice* dissemination (South Africa, Italy, Tunisia and North Africa)
- European Genetics Foundation

Birth Defects/Perinatal Health Surveillance

- Partnerships in Lebanon, China, Tibet

Folic Acid Fortification

- Folic acid fortification in the Americas

Rubella Immunization


- WHO/PAHO/UNICEF/CDC/MOD Partnership for R. Immunization

World Birth Defects Report

- Recommendations to reduce mortality and disability from birth defects worldwide by up to 70% (English and Spanish)



Global Programs 2007 -



**When one tugs at a single thing in nature, he
finds it attached to the rest of the world.**

- John Muir

Current Priorities

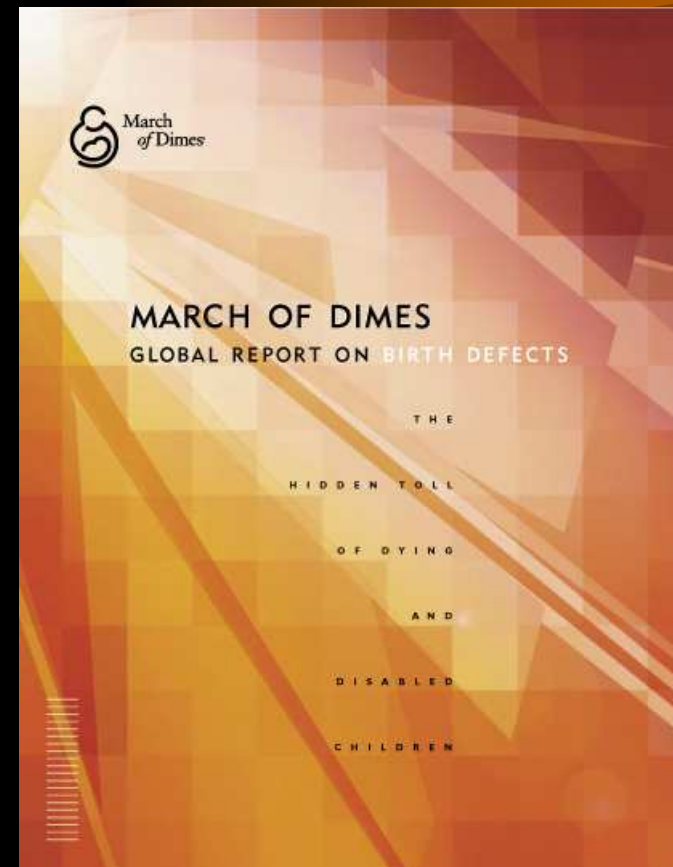


- **Expand our mission alliances – the village band**
- **Improve extent and quality of data collection**
 - Data on birth prevalence, mortality, disability and economic costs are essential to getting the attention of policy makers, government and funders
- **Emphasize monitoring and evaluation in all activities**
 - Quality assurance
 - Economic analyses – cost-benefit of intervention
 - Nothing breeds success like success

Current Priorities

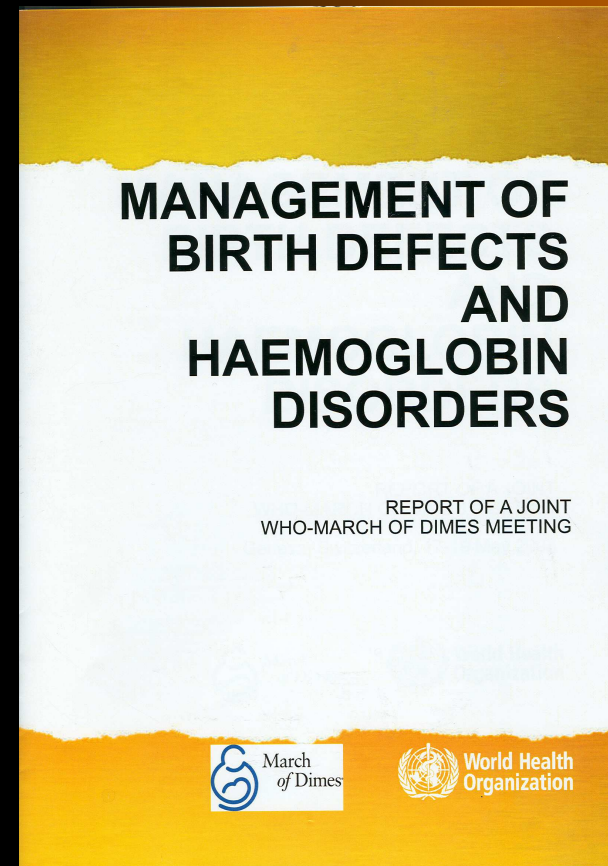
- Publish new editions of the **Global Report on Birth Defects** (update mortality statistics, document the global toll of disability, economic costs etc.)

<http://www.marchofdimes.com/globalprograms>



Current Priorities

- **Help convince international health agencies that care and prevention of birth defects should be a global public health priority**



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- **What we know about the global toll of preterm birth**

Importance of Linking Interventions for Preterm Birth and Birth Defects



Similar target populations

Similar systems for detection and monitoring

Synergies in program and capacity building

Professional education

Patient and public awareness

Parent and other lay support groups

Research (fundamental, etiologic and applied)

Current Priorities



- **Establish a global network dedicated to prevention of birth defects and preterm birth and to the care of those affected**
 - **Strengthening care, prevention and research requires broad-based involvement of all stakeholders and “peer-to-peer” networking of partners**

The Networks Project



***Building Capacity to Prevent Birth Defects
and Preterm Birth in Developing Countries***

Project Goal



Demonstrate that the toll of mortality and disability from birth defects and preterm birth in developing countries can be reduced through simple, low-tech interventions

Strategy



Establish networks of excellence in target countries that have the technical capacity to:
assess the toll of birth defects and preterm birth in their populations, and
conduct and evaluate rigorous, needs-based pilot projects to reduce this toll

Selection Criteria

Network sites must demonstrate the following

technical and political capabilities:

**ability to assess the toll of birth defects and preterm birth
in their target populations**

**capacity to develop, conduct and evaluate rigorous, needs-
based pilot projects to reduce this toll**

**ability to engage academic centers, professional
organizations, lay support groups and other stakeholders in
the public sector**

ability to secure government sign-off on all activities

Project Description



Three-year project conducted in two phases

Project Description



Phase 1 (Months 1-12)

Objectives:

Establish organizational structure

International Steering Committee

National Task Forces

Assess population health needs

Conduct population needs assessments

Develop pilot projects to address these needs

The projects may be regional, national or local in focus

Project Description

Phase 2 (Months 13-36)

Objectives:

Implement pilot projects (Months 13-14)

Evaluate pilot projects

Mid-term evaluation in Month 24; adjust projects as needed

Final evaluation in Month 35

Promote inter-network communication

Support partner-to-partner consultation

convene national partners to share best practices, successes and other knowledge and experiences gained

Ensure network sustainability

Actively seek and recruit new partners

Work with partners in Year 3 to identify next steps and funding possibilities for these

Project Hallmarks



Evidence-based decision making

Consistency in study methods

Building upon existing capacity and political will

Empowering the public as a change agent

Flexibility and adaptability to local needs and conditions

Site-to-site interaction

Possible Target Sites



MOD-funded sites

India

China

South Africa

Lebanon

Egypt

Tunisia

Additional sites

Oman, Czech Republic, Hong Kong

Project Benefits

The project will:

- encourage intersectoral communication and collaboration within national networks**
- develop national platforms that can readily incorporate future projects, including intervention and research**
- create an international network of partners that emphasizes peer-to-peer (“south-to-south”) consultation on program development and evaluation**
- provide robust, visible opportunities for high-quality professionals to work, publish and present at international symposia**
- develop national capacity in the prevention of birth defects and preterm birth that can be exported to other countries in the region**

March of Dimes Global Programs

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Thank you!