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

- 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

Infant Deaths per 1000 Live Births

- South Africa
- Ecuador
- Nicaragua
- Brazil
- Paraguay
- Philippines
- Mexico
- Egypt
- Colombia
- Kyrgyzstan
- Panama
- Kazakhstan
- Mauritius
- Argentina
- Russia
- Bahrain
- Ukraine
- Barbados
- Costa Rica
- Belarus
- Chile
- Kuwait
- Estonia
- U.S.A.
- U.K.
- Canada
- Spain
- Finland
- Sweden

% of IMR due to Congenital Anomalies

- IMR
- % of IMR due to CA
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
• 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
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
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
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!