



*March of Dimes
Birth Defects Foundation*

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News Release

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BIRTH DEFECTS: 8 MILLION ANNUALLY WORLDWIDE

Hidden Toll of Dying and Disabled Children;

A Comprehensive Global Analysis Identifies Trend and Interventions

WHITE PLAINS, N.Y., JANUARY 30, 2006 -- Every year an estimated 8 million children -- about 6 percent of total births worldwide -- are born with a serious birth defect of genetic or partially genetic origin, according to a new report from the March of Dimes.

Additionally, hundreds of thousands more are born with serious birth defects of post-conception origin due to maternal exposure to environmental agents, such as alcohol, rubella, and syphilis, says the **March of Dimes Global Report on Birth Defects: The Hidden Toll of Dying and Disabled Children.**

The report reveals that at least 3.3 million children less than 5 years of age die annually because of serious birth defects, defined as any serious abnormality of structure or function. An estimated 3.2 million of those who survive may be mentally and physically disabled for life.

Birth defects are a global problem, but their impact is particularly severe in middle- and low-income countries where more than 94 percent of births with serious defects and 95 percent of the deaths of these children occur, the report finds. Both high prevalence rates and larger numbers of births contribute to the differences between low- and middle-income countries and those with higher incomes.

“Our report identifies for the first time the severe, and previously hidden global toll of birth defects,” explains Dr. Jennifer L. Howse, president of the March of Dimes. “This is a serious, vastly unappreciated and under-funded public health problem.”

“The human toll of birth defects is even greater when one considers the impact of lifelong disability on children, their families, and society,” says Michael Katz, M.D., senior vice president for Research and Global Programs at the March of Dimes.

In addition to poverty and the many health problems that can accompany it, the report notes major demographic reasons for the higher rates of birth defects in poorer countries, including more women of advanced age having children and a greater frequency of consanguineous (blood relative) marriages. In countries along the world’s “malaria belt,” a greater proportion of the population carries one copy of a gene for an inherited disease that confers some protection against malaria -- specifically, sickle cell, thalassemia, and glucose-6-phosphate dehydrogenase deficiency (G6PD). When two carriers of these diseases have offspring, there is a 25 percent chance that each child will receive both copies of the gene and be affected.

The database prepared for the March of Dimes report details the prevalence rates and the numbers of affected births in 193 countries. The data collected include information on single-gene disorders, chromosomal disorders, and physical malformations.

The data do not allow for precise comparisons of birth defects prevalence among countries, according to its authors, Arnold Christianson, M.D., of the National Health Laboratory Service and University of the Witwatersrand, Johannesburg, South Africa; Bernadette Modell, M.D., Ph.D. of the Royal Free and University College Medical School, London, England; and Christopher P. Howson, Ph.D., vice president for Global Programs at the March of Dimes.

“Valid detailed comparisons among countries must await the collection of additional empirical data on birth prevalence,” says Prof. Modell.

The data, however, do permit broad comparison of specific birth defects across regions and among countries of different income level, Dr. Howson says. “Such comparisons show that the highest birth defects prevalence is found among the world’s poorest countries, whereas many of the lowest rates are found among the world’s wealthier countries.”

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

Five common birth defects of genetic or partially genetic origin combined accounted for about 26 percent of all such birth defects in 2001: congenital heart defects (1,040,865 births); neural tube defects (323,904 births); the hemoglobin disorders thalassemia and sickle cell disease (307,897 births); Down syndrome (217,293 births); and G6PD deficiency (177,032 births).

The database includes only birth defects due to genetic or partly genetic causes. Exact figures for birth defects due to post-conception damage from fetal alcohol syndrome, iodine deficiency disorder, congenital rubella syndrome, and congenital syphilis were not generated for this report.

“If these figures were available, one might expect the total to be higher, and we do expect them to increase as added information on infant mortality and disability is assembled,” Prof. Modell says.

What Can Be Done to Save Babies

The authors of the report say that it is a common misconception that attention to birth defects will draw funding from other priority public health efforts -- when, in fact, increased efforts to reduce birth defects in children contributes to the health of the entire population.

Their recommendations in this report are aimed both at addressing health disparities between richer and poorer nations and at reducing the toll of infant deaths, especially in low- and middle-income countries.

“Experience from high-income countries shows that overall mortality and disability from birth defects could be reduced by up to 70 percent if the recommendations in this report were broadly implemented,” says Prof. Christianson.

Among the interventions that would have immediate impact are folic acid supplementation to prevent neural tube defects; iodination of salt to prevent severe congenital hypothyroidism; and rubella immunization to prevent congenital rubella syndrome.

Recommendations in the report with both immediate and long-term impact include those that strengthen medical genetics services. “Building such services would allow nations to reduce the toll of death and disability from birth defects and to capitalize on the genetics revolution and rapid advances in molecular biology as they continue to unfold,” Dr. Howson says.

Step-By-Step Approach

The report recommends first steps for low-income countries with high rates of infant mortality that are consistent with the established maternal and child health programs. These include:

- Educate the community, health professionals and workers, policy makers, the media and other stakeholders about the toll taken by birth defects and opportunities for effective prevention, treatment and care.

- Ensure a healthy, balanced diet during a woman's reproductive years.

- Control infections in pregnant women.

- Train physicians, nurses, allied health professionals and workers in the recognition and care of children with birth defects.

- Establish national capacity for birth defects surveillance and monitoring.

Some middle-income countries have infant mortality rates that approximate those of the United States in the early 1960s, when it began its systematic effort to strengthen medical genetics services for the care of affected children and prevention of birth defects. For these countries, the next steps recommended include:

- Train health care professionals in medical genetics;

- Identify couples at higher risk of having children with genetic disorders;

- Establish newborn screening programs to identify babies born with devastating but treatable metabolic disorders such as phenylketonuria (PKU);

- Educate women and men of childbearing age about how they can work with health professionals to maximize the chances of having a healthy pregnancy and a healthy baby.

Improvement Is Possible, March of Dimes Says

Although poorer nations may lack resources for these recommended programs and their health services are already severely stretched, the March of Dimes report says major improvements can be made within existing health care systems, for example by training health care providers to use simple diagnostic and preventive tools that are available.

In the past, the toll of birth defects in these countries has been underestimated for a variety of reasons, the report authors say. These include poor, if any, health statistics; lack of birth defects surveillance or registries; reliance on hospital-based, rather than population-based, studies; and limited diagnostic capability. Even with the sophisticated facilities available in wealthier nations, only about 50 percent of birth defects can be diagnosed accurately, the report authors say.

Just one of those causes, fetal alcohol syndrome (mental and physical defects caused by drinking alcohol during pregnancy), is a “huge problem but there are countries that don’t recognize or monitor it,” Prof. Christianson says. “Around the world, fetal alcohol syndrome is one of the more common fetal environmental problems.”

Professor Modell has worked for many years to develop the database, using all information available and extrapolating, based on known experience in other countries, to fill in gaps. “This is a first cut,” she says. “With more study and more money, we will be able to answer many of the questions that this report has uncovered.”

Data provided for the first time in this report are considered an essential addition to the extensive worldwide effort to reduce infant and child mortality to meet one of the United Nations Millennium Development Goals for 2015. By the beginning of 2004, efforts to meet this goal fell far below U.N. projections. Data in the March of Dimes report make a strong argument for recognizing and addressing the significant contribution of birth defects to infant and childhood mortality if the U.N. goal is to be achieved.

The March of Dimes is a national voluntary health agency whose mission is to improve the health of babies by preventing birth defects, premature birth and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education, and advocacy to save babies and in 2003 launched a campaign to address the increasing rate of premature birth. For more information, visit the March of Dimes Web site at **marchofdimes.com** or its Spanish language Web site at **nacersano.org**.

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To order printed copies of the March of Dimes Global Report on Birth Defects:

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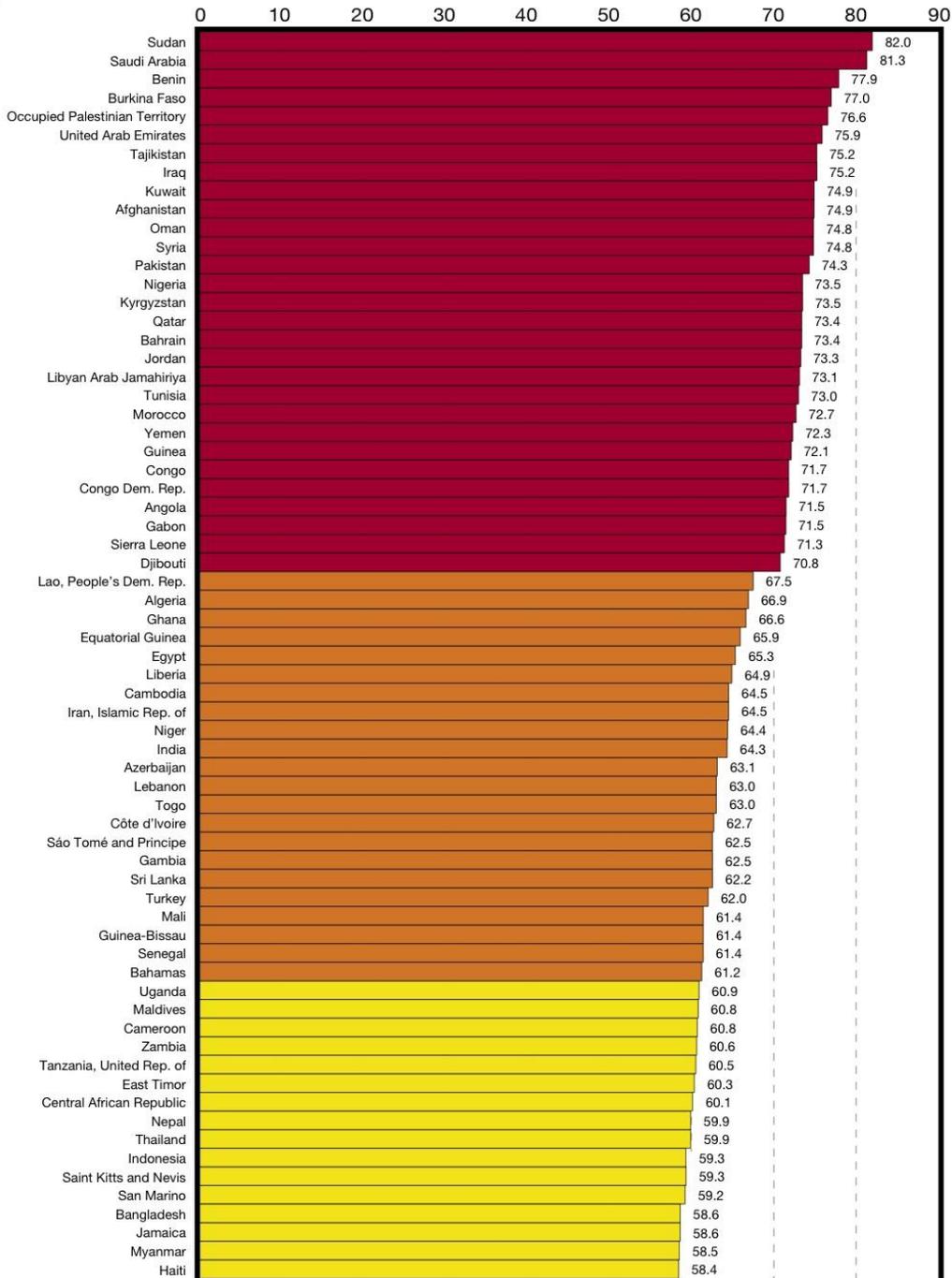
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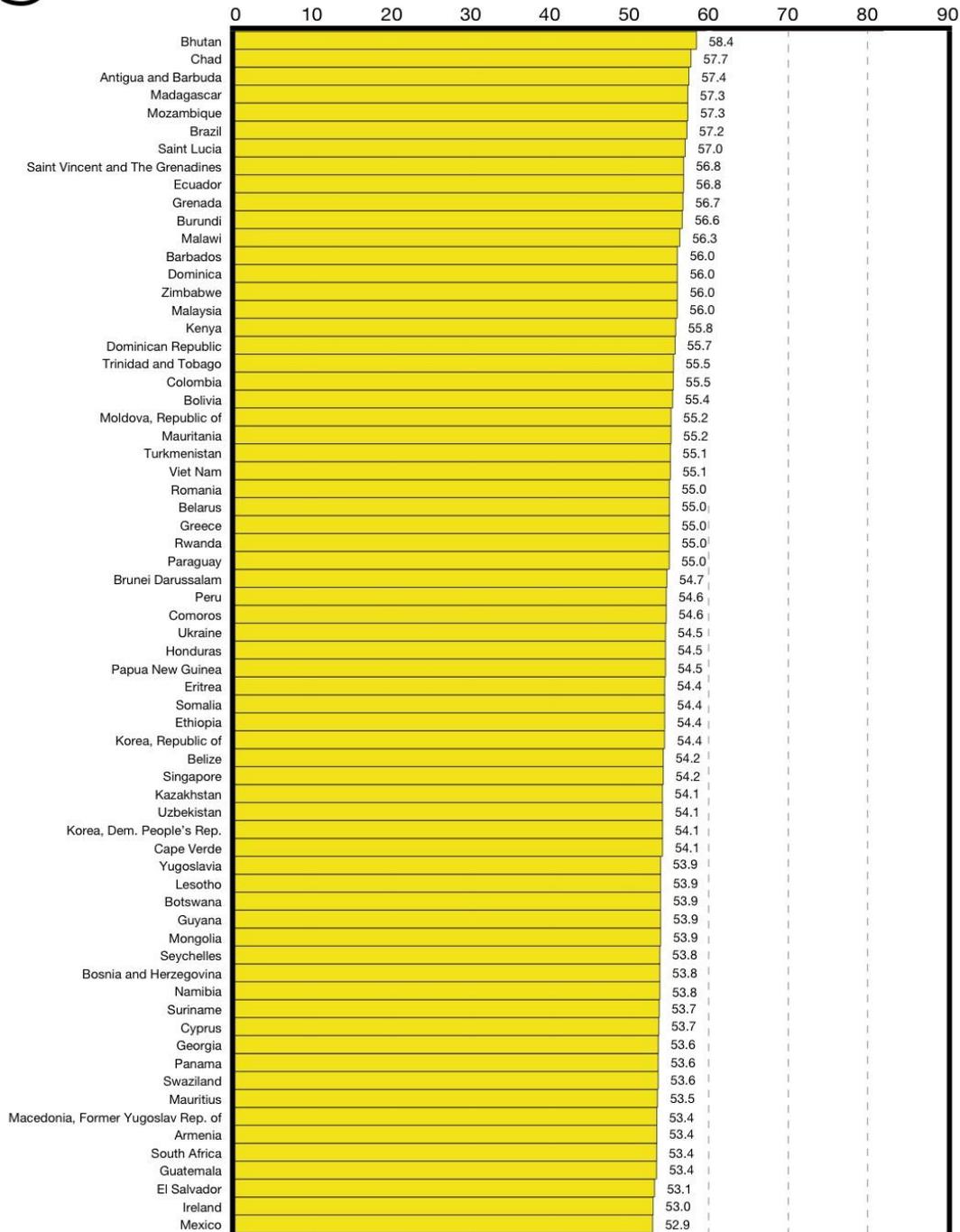
*** Birth Defects Prevalence per 1,000 Live Births.**



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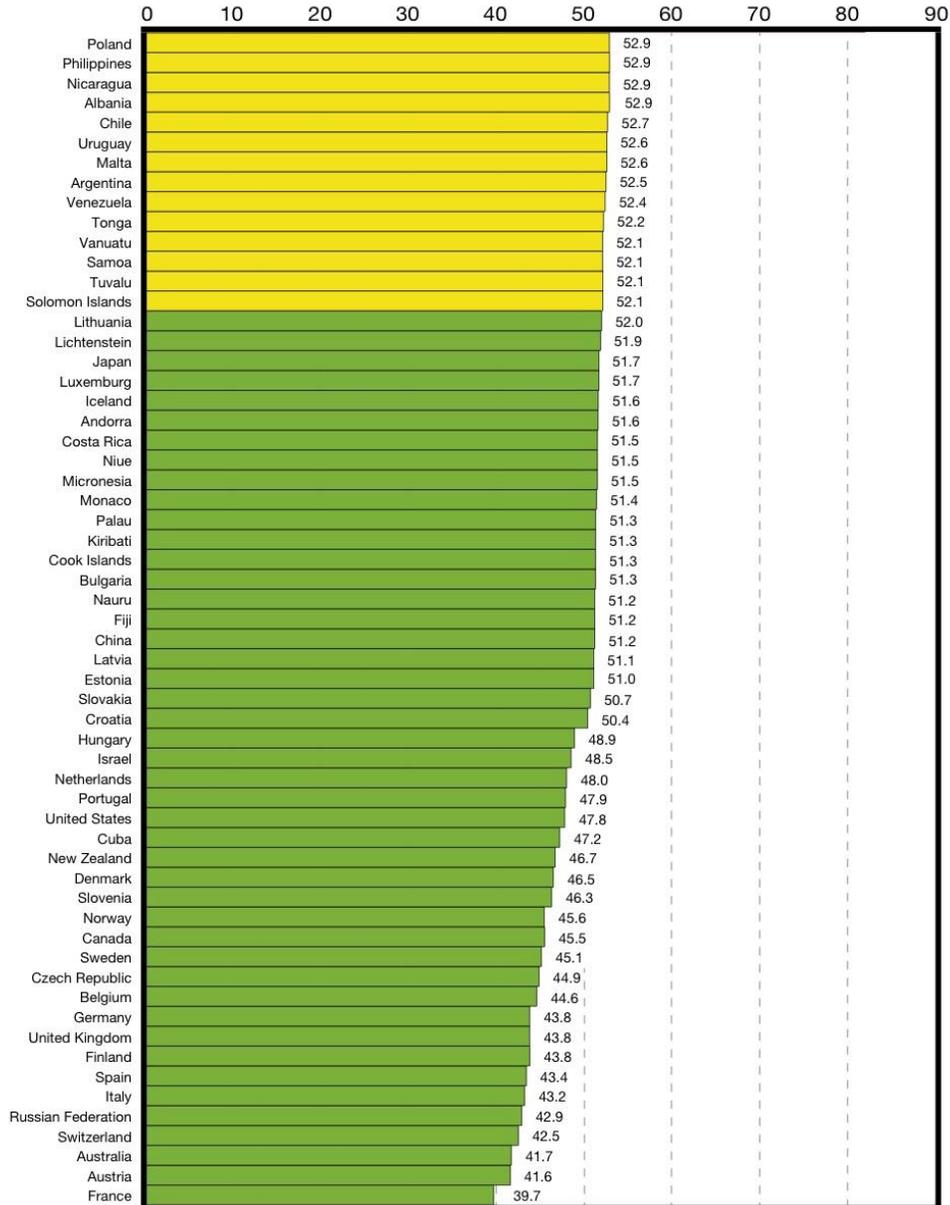
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*** Birth Defects Prevalence per 1,000 Live Births.**



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* Rankings are determined by prevalence rates, which have been calculated to the third decimal place, but are stated to the first decimal place, due to space limitations.