

MALACAÑANG
Manila

BY THE PRESIDENT OF THE PHILIPPINES

PROCLAMATION NO. 1989

DECLARING THE 4TH WEEK OF FEBRUARY OF EVERY YEAR AS THE
"NATIONAL RARE DISEASE WEEK"

WHEREAS, the Philippine Constitution provides that "the State shall protect and promote the right to health of the people, including the right of persons suffering from rare diseases to have access to timely health information and adequate medical care;

WHEREAS, Republic Act 8980, known as the Early Childhood and Development Act (ECCD), declares that it is the policy of the state to "promote the rights of children to survival, development and special protection with full recognition of the nature of childhood and its special needs";

WHEREAS, ECCD law aims to develop and establish a national system for early identification, screening, surveillance of early childhood disabilities, developmental problems and giftedness;

WHEREAS, the ECCD law is mandated to develop and implement various support mechanism that maximize the public and private resources for implementing ECCD programs, giving priority to the needy and high risk children from poor communities including the promotion of the right of children with special needs and advocate respect for cultural diversity;

WHEREAS, rare disorders are defined as rare diseases affecting no more than 1 in every 20,000 individuals in the country; and are recognized by the Department of Health upon recommendation of the National Institute of Health;

WHEREAS, 75% of rare diseases affect children, 30% of patients with rare disorders die before the age of 5 and 80% of rare disorders have identified genetic origin and thus, requires lifetime medical management;

WHEREAS, children affected with rare diseases despite of their special needs experience social isolation due to lack of network of support to aid them in their special medical needs resulting from lack of information about the nature of their illness;



WHEREAS, in 2009 Rare Disorders Day was celebrated in 30 countries in recognition of the significance of increasing public awareness about orphan disorders and educating the health sector and policy maker that caring for patients with rare disorders is a public affair or concern and responsibility;

WHEREAS, there is an urgent need to conduct a national information campaign in order to create awareness among health professionals about the nature and medical management of rare diseases; and instill awareness among the public about rare diseases to generate full support for the special needs of children affected by rare disease from both public and private sectors.

NOW, THEREFORE, I, GLORIA MACAPAGAL-ARROYO, President of the Republic of the Philippines, by virtue of the powers vested in me by law, do hereby declare the 4th week of February of every year as the "National Rare Disease Week". The Department of Health (DOH) and the Institute of Human Genetics (IHG) of the National Institute of Health (NIH), University of the Philippines Manila will serve as the national focal agencies for purposes of commemorating this event to the health sector and the public.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the seal of the Republic of the Philippines to be affixed.

Done in the City of Manila, this 8th day of February, in the year of Our Lord, Two Thousand and Ten.

Gloria M. Arroyo



By the President:

Eduardo R. Ermita

EDUARDO R. ERMITA
Executive Secretary



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