USING PHG TOOLKIT FOR ASSESSING HEALTH NEEDS IN THREE DIFFERENT CONGENITAL DISORDERS IN BRAZIL

Autors:

1. *Lavinia Schuler-Faccini* [1] [2] [3]
2. *Maria Teresa Vieira Sanseverino* [2] [3]
3. *Ligia Azevedo* [2] [3]
4. *Corinna Alberg* [4]
5. *Luis Nacul* [4]

Affiliations:

1. *Genetics Department, Universidade Federal do Rio Grande do Sul, Brazil*
2. *INAGEMP - Instituto Nacional de Genética Médica Populacional*
3. *SIAT - Teratogen Information Service, Medical Genetics Service, Hospital de Clinicas de Porto Alegre*
4. *PHG Foundation*

Content:

In 2009, PHG Foundation began a programme to help low and middle income countries tackle the problem of congenital disorders through the development of a Toolkit to assist with Health Needs Assessment. In the present abstract we present our toolkit piloting experience in the following disorders in Brazil: Neural Tube Defects (NTDs), Sickle Cell Disease (SCD), and Fetal Alcohol Spectrum Disorder (FASD). NTDs are morphological birth defects with known strategies for primary prevention. SCD is a mendelian disorder prevalent due to high african ancestry. FASD is a teratogenic condition 100% preventable. They represent also situations where social unequalities play important role on prevalence and care of affected. The toolkit piloting results can be be summarized as follows: (1) For NTDs, Brazil has already an instrument for ascertainment of cases, based on the livebirth certificate, which should be improved. Flour folic acid fortification is mandatory but although it has helped in to decrease affected births, it is still under the optimum level (2) SCD has newborn screening covering most of the country, and a specific health program the SCD people is ongoing. However, the observed prevalence of SCD is higher than expected by initial estimatives, since in Brazil skin classification is not a good indicator of ethnic ancestry. In this way, SCD should be addressed as a general population health issue. (3) FASD has no prevalence indicators; and almost a lack of preventive and care programs. We conclude that the toolkit is an useful instrument to summarize and to produce country level data, allowing comparisons between different countries, and also to plan cost-effective interventions that could reduce significantly the burden of congenital disorders.

Dodał: schuler-faccini lavinia
Data dodania: 2011-06-24 00:49:45