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For immediate release

Born Healthy – A UK-designed toolkit for tackling birth defects in low and middle income countries finds new home in Brazil

UK-based non-profit the PHG Foundation has handed over a pioneering toolkit to help tackle the problem of birth defects for people living in low and middle income countries.

Birth defects (or congenital disorders) are rapidly replacing infectious diseases as a leading cause of childhood death and disability around the world. Despite calls by the World Health Organization for member states to take action, birth defects remain a relatively neglected issue due to complexity and the lack of ready access to data, knowledge and tools to achieve real change.

The PHG Foundation has spent five years developing the toolkit which contains the best available data on birth defects for 192 countries and detailed expert guidance on what can be done – often with simple interventions – to improve prevention, diagnosis, treatment and care. The toolkit, aimed at health professionals and planners, guides users through the process of developing solutions which are relevant to their local needs and securing commitment to action from decision-makers. The toolkit encourages the involvement of local stakeholders in the planning process.

Now freely available online and with registered users in 146 countries, the toolkit has already played a significant role in changing government policy on newborn screening in Uruguay, and informing Brazil's rare diseases policy.

At a ceremony in Porto Alegre, southern Brazil on Saturday (5 April) attended by health leaders and policy makers, the PHG Foundation's Director, Dr Hilary Burton handed over the toolkit to a consortium including the Universidade Federal do Rio Grande do Sul, the Hospital de Clínicas de Porto Alegre and INaGeMP, the Brazilian National Institute for Medical and Population Genetics. As ongoing custodians they will ensure the toolkit is kept up to date and promote its uptake throughout Latin America and the rest of the world through their networks in the international health community.

Dr Hilary Burton said: *"We are delighted to be here in this very important year for Brazil, to pass on the PHG Foundation*

toolkit for birth defects into the safe hands of our Brazilian colleagues who have been such important supporters of this project from the outset. Having invested 5 years' work in developing the toolkit, the Foundation is confident that the team in Porto Alegre will ensure its legacy, catalysing changes in healthcare that will provide a healthier start and a brighter future for children all round the world".

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The PHG Foundation and toolkit

The PHG Foundation is a pioneering independent, not-for-profit health policy think tank with special focus on genomics and realising the benefits of society's investment in biomedical research. Established in Cambridge, UK in 1997 the PHG Foundation pioneered the field of public health genomics and today is a respected and trusted world leader in the translation and application of genomic technologies for health.

The toolkit is built on the health needs assessment approach which is standard practice in UK public health but is not routinely used in the developing world. It contains the best available data in an accessible format and expert guidance on what can be done to improve prevention, diagnosis, treatment and care in 17 topic areas, covering not just conditions with a genetic component (such as sickle cell disease and thalassaemias, Down's syndrome) but also those with environmental causes (for example neural tube defects such as spina bifida, congenital syphilis or rubella). It guides users through the process of deciding what services will be most beneficial and relevant to their local circumstances, taking into account contextual ethical, legal and social issues; and making the case for change with policy and decision makers.

The toolkit is freely available online at <http://www.toolkit.bornhealthy.org/>

Further information on the PHG Foundation or the toolkit may be found at <http://www.phgfoundation.org/>

Hospital de Clínicas de Porto Alegre, the Universidade Federal do Rio Grande do Sul and INaGeMP

The Universidade Federal do Rio Grande do Sul (UFRGS) is a century-old, nationally and internationally recognised educational institution based in Porto Alegre – the capital city of the State of Rio Grande do Sul in southern Brazil. The Hospital de Clínicas de Porto Alegre (HCPA) is the teaching hospital of UFRGS. It is a general and public hospital and operates within the SUS, Brazil's national public health system.

HCPA/UFRGS will host the Toolkit in partnership with INaGeMP, the Brazilian National Institute of Population Medical Genetics, whose main objectives combine research, clinical services and education with providing advice on preventive care strategies to SUS and the Brazilian Health Ministry.

Links to Brazilian press coverage (in Portuguese)

<http://www.sissaude.com.br/sis/inicial.php?case=2&idnot=21148>

<http://www.revistasupersul.com.br/sus-pode-ganhar-nova-tecnologia-capaz-de-reduzir-a-incidencia-de-doencas-geneticas/>

<http://www.felipevieira.com.br/Site/MostraConteudo/MostraConteudo.asp?cntId=59565>

http://zerohora.clicrbs.com.br/rs/geral/planeta-ciencia/noticia/2014/04/sus-pode-ganhar-aplicativo-para-reduzir-incidencia-de-doencas-geneticas-4463766.html?utm_source=Redes%20Sociais&utm_medium=Hootsuite&utm_campaign=Hootsuite