

To:  
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New York, New York 10017  
U.S.A.

Subject: Including congenital anomalies in all actions

Brussels, March 2018

With great interest we learned about the UNICEF report “Every Child ALIVE”, which has just been published. We wholeheartedly agree that there is an urgent need to end newborn deaths, in particular those that can be prevented.

Among the newborns that die every day before one month of age are also children with congenital anomalies and disabilities, for instance children with Spina Bifida and Hydrocephalus. If they don't receive proper surgery soon after birth, and if infections are not treated, their chances of long-term survival are radically reduced.

With an increasing feeling of frustration, we notice once more that the report does not mention this extremely vulnerable group, and only focuses on still-births and preterm birth. Although preterm birth is in itself a risk factor for the development of Hydrocephalus in newborns, we regret the plain omission of about 1 million newborns per year born with Spina Bifida and Hydrocephalus, of the millions more born with other disabilities, a majority of which will die because of violation of their basic human rights.

Poverty is not the only cause and injustice with regard to newborn mortality. Even when healthcare is available, newborns with Spina Bifida and Hydrocephalus may go without treatment and be left to die immediately after birth, due to prejudice, stigma and superstition with regard to children born with disabilities.

While this is another contributing factor with regard to premature deaths, this insidious threat to the lives of newborn and blatant violation of their human rights, which can happen in both low-income and high-income countries, is not mentioned in the report. Non-treatment due to congenital anomalies or disability should be prevented through awareness raising and human rights training in line with the UN Convention on the Rights of Persons with Disabilities. Doctors, nurses and midwives should not only be trained and skilled at their profession, they also need to ensure that no newborn is left behind due to a congenital anomalies or disability.

Although both the UN convention and the Sustainable Development Goals call for universal registration of children (with disabilities) at birth, we see gross underrepresentation of children born with disabilities in official statistics, in particular in developing countries. They are never registered, do not receive any treatment, and disappear without a legal trace.

When the World Health Assembly adopted the Birth Defects Resolution WHA63.17 in 2010, it recognized the importance of birth defects (WHO has since used the term “congenital anomalies”) as a

cause of stillbirths and neonatal mortality, and it expressed that it was deeply concerned about birth defects still not being recognized as priorities in public health. While we fully agree that improving access to maternal and newborn health services as well as improving their quality are necessary steps to bring down rates of newborn mortality, we emphasize the urgency to protect the rights of newborns with birth defects and disabilities, to safeguard their lives and offer them the opportunity to thrive, equal to others.

We call upon UNICEF to include birth defects in all its actions, especially communications related to the “Every Child ALIVE” report. We need to reach governments, funders, and wider society, to ensure that congenital anomalies get noticed. It needs to be widely acknowledged that newborns with birth defects are among the 2.6 million babies that die before turning one month old.

Without addressing congenital anomalies, the SDG target of reducing neonatal mortality to 12 per 1000 live births and under-five mortality to 25 per 1000 live births will be almost impossible to achieve by 2030.

Sincerely,



Dr. Margo Whiteford, President, and Lieven Bauwens, Secretary General, on behalf of the board of directors of the **International Federation for Spina Bifida and Hydrocephalus**



Dr. Salimah Walani, Vice President of Global Programs  
**March of Dimes**



Dr. Benjamin Warf  
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Sara Struwe, President and CEO  
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Scott Montgomery, director  
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Dr. Paige Terrien Church, Director, Neonatal Follow Up Clinic  
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