Dear (insert name of official)

(insert name of individual or organisation) are reaching out to you to ask for your support for the draft resolution "Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification" which will be on the agenda of the Seventy-Sixth World Health Assembly (21-30 May 2023).

To celebrate and raise awareness of this important draft resolution a side event to the World Health Assembly is being organised together with a broad coalition of partners from civil society and sponsored by the government of Colombia and co-sponsored by Malaysia. The side event is scheduled to take place on the 23rd of May from 6pm to 8:30pm in Geneva.

We at the (insert name of organisation) support the adoption of the draft resolution and strongly believe that its essential for (insert name of your country) to be visible in its support of this initiative and have the interests of (insert name of country) represented at this event and during the World Health Assembly. We at (insert name of organisation) therefore highly recommend and request that as the representatives of (insert nationality (for example French) interests in the World Health Organization that the government of (insert country) join by co-sponsoring the side-event and join the (insert nationality) SBH community in advocating for the draft resolution.

The International Federation for Spina Bifida and Hydrocephalus (IF), of which (insert name of organisation) is a Member Association, has been a champion for fortification of staple foods with folic acid for decades. Ever since the connection between low levels of folate prior and during the early weeks of pregnancy and the development of neural tube defects was discovered over three decades ago. Research has systematically demonstrated that fortification is a safe public health policy that is significantly more effective than other options such as encouraging a healthy diet or supplements.

It is time that we, as a society, take the burden and responsibility for reducing the risk of neural tube defects in pregnancy away from women and the shame and stigma that this approach results in. The unrealistic expectation that all persons capable of becoming pregnant should take daily supplements for the entirety of their reproductive years or ensure that they are getting enough folate from their diet, a feat which is nearly impossible to achieve, has led to the perception that reducing the prevalence of neural tube defects is the personal responsibility of women. When in actuality research has systematically demonstrated that these policies are far from adequate and in particular fail to reach the most vulnerable in our communities.

The experiences of the 92 countries which have legislation for mandatory fortification with folic acid of at least one type of grain. Including the US which introduced legislation for mandatory fortification in 1998, an action which has since been thoroughly researched for efficacy and safety. Has categorically demonstrated that reducing the prevalence of neural tube defects, and by doing so optimising the chances of healthy pregnancies and reducing

the risk of miscarriages, stillbirths, and the need for terminations (of what was very often a wanted pregnancy which has then been given a terminal diagnosis of a neural tube defect incompatible with life such as an encephaly) is a task that can only be accomplished by taking strong action on the governmental level, together as a society, with a human rights approach to prevention policies.

Our priority is to advance the rights of persons with spina bifida and/or hydrocephalus. The UN Convention on the Rights of Persons with Disabilities states that <u>state parties must consult persons with disabilities</u> through their representative organisations for its implementation. Although this does not directly apply to the internal processes of the WHO. It has since become one of the fundamental basis and norm in protecting and advancing the rights of persons with disabilities, to involve them meaningfully in the policy making process for initiative relevant to them. The spina bifida community will be the most impacted by any initiative on folic acid. We, as the representative organisation of that community, implore the Member States of WHO to listen to the experiences and position of persons with spina bifida when considering their position on the issue.

We remain at your disposal for any questions and are happy to provide further information and resources to you on this subject. We hope to receive a reply from you soon so we may advance this important initiative together

With kind regards		