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NDSC REBUKES MISINFORMATION ON DOWN SYNDROME AND CALLS ON INFLUENTIAL GLOBAL ORGANIZATIONS TO CORRECT INACCURATE LANGUAGE

March 16, 2022, Atlanta, GA – The National Down Syndrome Congress issues the following statement regarding the listing of Down syndrome among birth defects by prominent health organizations, including the World Health Organization, the Centers for Disease Control and Prevention, and March of Dimes.

On February 28, 2022, in preparation for World Birth Defects Day on March 3, the World Health Organization (WHO) wrongly listed Down syndrome on their website among the "most common severe birth defects." This statement and others like it by national and global leaders mislead the public by suggesting two untrue statements about Down syndrome – that Down syndrome is a birth defect and that it can be prevented through prenatal care.

The National Down Syndrome Congress (NDSC) is a non-profit organization dedicated to an improved world for individuals with Down syndrome. We are proud to be the leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome.

Essential to the NDSC's work is the dispelling of harmful myths such as those perpetuated by this public communication by WHO. Although WHO has retracted the original social media post, the organization has not issued a correction to the statement on their website (https://www.who.int/news-room/fact-sheets/detail/birth-defects).

This fact sheet and accompanying social media promotion help identify a larger problem about the misrepresentation of Down syndrome as a birth defect by other world leaders, including the Centers for Disease Control and Prevention (CDC)

(https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html) and March of Dimes (https://www.marchofdimes.org/complications/down-syndrome.aspx).

These misstatements by organizations with global influence are not without consequences; they have the power to perpetuate already widespread misunderstanding about people with Down syndrome.

Down syndrome is not a disease, illness, or birth defect. It is a genetic condition. Its causes are unknown and cannot be prevented, as these organizations in national and global positions of authority suggest, by prenatal or newborn care. Individuals with Down syndrome benefit from loving and supportive homes, early intervention, therapies, medical care, high-quality education, positive public attitudes, and welcoming communities.

Our purpose at the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information. We believe that accurate information is essential to creating a safe and welcoming world for people of all abilities and

backgrounds. We firmly stand against language that conflates genetic variation with compromised or inadequate maternal care.

In their corrected Facebook post on March 3, WHO commits verbally to "providing continued support for all those affected by Down syndrome, including appropriate healthcare, access to specialized services and respectful treatment."

Similarly, March of Dimes identifies as an organization "fighting for the smallest among us and advocating for their health." Parents of children with Down syndrome are among the more than 300 million Americans—and countless others globally—who rely on the CDC for accurate health information.

We at the NDSC urge these national and global leaders in healthcare to continue in this commitment by correcting these misstatements on their websites and ensuring that their online resources reflect accurate information about populations like those living with Down syndrome.

About the National Down Syndrome Congress

Founded in 1973, the National Down Syndrome Congress is the country's oldest organization for people with Down syndrome, their families, and the professionals who work with them. A 501(c)(3) non-profit advocacy organization, the NDSC provides support and information about issues related to Down syndrome throughout the lifespan, as well as on matters of public policy relating to disability rights. The National Down Syndrome Congress is committed to creating a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome. For more information about the NDSC, please visit our website at www.ndsccenter.org.