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**Follow-up to the Fourth World Conference on Women and
to the twenty-third special session of the General Assembly
entitled “Women 2000: gender equality, development and
peace for the twenty-first century”**

Statement submitted by Caring & Living as Neighbours, Incorporated (CLAN), a non-governmental organization in consultative status with the Economic and Social Council*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

* The present statement is issued without formal editing.



Statement

Caring & Living as Neighbours (CLAN) supports the sixty-seventh session on the Commission on the Status on Women (CSW) and its mission to improve gender equity as outlined in the Beijing Declaration and Platform for Action (BPfA) in 1995. Caring & Living as Neighbours would like to acknowledge the Wallumedegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. Caring & Living as Neighbours also acknowledges the Lenape people, on which the United Nations is headquartered in New York City, and we pay our respects to Elders past, present, and emerging.

Caring & Living as Neighbours is an Australian non-governmental organization (NGO) founded in 2004 with the mission to maximize the quality of life for children living with Non-Communicable Diseases and other chronic health conditions in poor resource settings. Caring & Living as Neighbours operates under a rights-based strategic framework for action that promotes a community development approach to redressing inequities through multisectoral collaborative efforts focused on five pillars considered essential to achieving the highest possible quality of life. The five pillars focus action on:

1. Access to essential medicines and equipment
2. Education, research and advocacy
3. Optimisation of medical management
4. Encouragement of family support groups
5. Actions to reduce financial burdens and promote financial independence.

The World Health Organization (WHO) acknowledges health innovations as new or improved solutions with the transformative ability to accelerate positive health impacts. Innovation is particularly essential for organisations that focus on non-communicable diseases, particularly for communities living in disadvantaged circumstances, as it offers the hope of new life-saving medications, treatments, and awareness to improve life outcomes for those most affected.

Caring & Living as Neighbours is proud to serve as Secretariat for MATES4Kids. MATES4Kids is an international movement committed to collaborative action aimed at identifying, implementing and monitoring practical solutions and innovations to improve access to essential medicines for children living with chronic health conditions. Newborn screening is one such innovative public health solution.

Newborn screening continues to be a public health innovation long after its introduction in the 1960s. Quick, affordable and simple heel-prick blood tests from newborn babies are now combined with other low-cost initiatives (such as hearing and pulse oximetry screening tests on newborns) undertaken in all high-income countries of the world, and have the potential to diagnose conditions requiring urgent (yet affordable) treatment to prevent profound developmental delay, disability and even death. Phenylketonuria, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia and Cystic Fibrosis are amongst the many congenital conditions that can now be diagnosed and treated early in order to redress preventable childhood mortality and morbidity.

It is unacceptable that newborn screening is not uniformly available to all. Children born with these same non-communicable diseases in low- and middle-income countries are at increased risk of preventable morbidity and mortality. Non-communicable diseases cause 24.8% of disability-affected life years and 14.6%

of deaths among children and adolescents. In addition, the Centres for Disease Control and Prevention states that non-communicable diseases account for 41 million deaths each year with about 85% occurring in middle- and low-income countries. With vulnerability of age and socioeconomic factors combined, these children face disadvantaged abilities to live with their conditions.

Of all children living with chronic conditions, girls are at increased risks from preventable morbidity and mortality associated with non-communicable diseases. In low- and middle-income countries, women have less access to care, and when they do, they often receive less aggressive treatments due to a lack of gender-specific guidelines on non-communicable diseases, therefore increasing their risk of complications and denial of their basic human rights to life and health.

Newborn screening overcomes gender inequities (universal newborn screening programs do not discriminate against girl babies) and has the potential to cut through the social and cultural determinants of health. When available equally to every newborn child, newborn screening can overcome gender inequities, but it must be scaled and made available to all – and most particularly to those living in the most vulnerable circumstances. Newborn screening meets World Health Organization screening criteria, and is low-cost, effective, acceptable, available, and safe. The technology is already developed and has only to be scaled appropriately to cover more disadvantaged populations.

Universal Health Coverage will be key to scaling newborn screening to all children around the world. Cost benefit analyses have clearly demonstrated the value of newborn screening, and administration that choose to cover the costs of the essential medicines and equipment required to implement newborn screening would reap the benefits in terms of reduced developmental delay and disability. With affordable access, families in vulnerable situations would be less likely to be forced into making decisions about how to spend limited resources. Optimal treatment of childhood non-communicable diseases during the “golden years” would give children the opportunity to enjoy their rights to life and health and reach their full potential.

Caring & Living as Neighbours and the MATES4Kids movement is committed to redressing inequities for children living with chronic health conditions in partnership with our national and regional communities, the Commission on the Status of Women, UN-Women, the World Health Organisation, and other relevant United Nations entities. The international community has a tremendous role to play in ensuring children living with non-communicable diseases in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbours in wealthier countries. Caring & Living as Neighbours emphasizes the crucial point that all children have a right to health and life and no child or family should ever face the threat of disability or death due to preventable causes. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-seventh session of the Commission on the Status of Women’s priority theme of “innovation and technological change, and education in the digital age for achieving gender equality and the empowerment of all women and girls.” In this context, Caring & Living as Neighbours would like to especially underscore the vital role newborn screening technology has to play in providing equal, accessible treatment for women and girls.

Caring & Living as Neighbours calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to acknowledge the vital role newborn screening plays in providing early awareness and treatment for women and girls suffering from noncommunicable diseases. It is essential to increase the span of newborn screening globally; the technology already exists and has been proven reliable and cost effective. If it were to be scaled globally as a matter of

urgency, there would be significantly improved health outcomes for those affected by congenital noncommunicable diseases.

Caring & Living as Neighbours calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to recognize the vast potential of newborn screening, Universal Health Coverage, and technological change and innovation in redressing inequities and protecting the rights of children living with non-communicable conditions in resource poor settings. Innovations such as newborn screening and universal health coverage do not discriminate against women and girls and should be made available to all.

Caring & Living as Neighbours reaffirms its commitment to eliminate gender inequality in accordance with the Commission on the Status of Women and Beijing Declaration and Platform for Action. We believe women serve as vital agents of change and recognise the indispensable need for women's empowerment in order to accelerate the UN Sustainable Development Goals and champion the values of UN-Women.
