



**STATEMENT**

**BY**

**H.E. MR. COLLEN V. KELAPILE  
PRESIDENT OF THE UNITED NATIONS ECONOMIC AND SOCIAL  
COUNCIL (ECOSOC)**

**AT**

**AN EVENT ON**

**"RAISING AWARENESS OF SPINAL MUSCULAR ATROPHY (SMA)  
FOR SUCCESSFUL APPLICATION OF EXISTING  
SOLUTIONS AND BEYOND"**

**28 OCTOBER 2021  
13:15-14:15 HOURS  
VIRTUAL FORMAT**

*Please check against delivery.*

**Excellencies  
Distinguished Guests,  
Ladies and Gentlemen,**

1. I am honoured to speak at this event intended at **“Raising Awareness of Spinal Muscular Atrophy (SMA) for Successful Application of Existing Solutions and Beyond.”**
2. As the theme suggest, there is a need for us as the international community to step up and take immediate action on the plight and suffering of the people living with the SMA disease. We cannot continue to stand idle and turn a blind eye to their suffering and predicament.
3. The SMA situation is especially worrisome and devastating on children, as it is the number one genetic cause of infant mortality. **One** in **6,000** to **one** in **10,000 children** are born with the disease.
4. Like other neurological conditions, SMA causes great burden to individuals, families, communities, and Governments due to crippling disabilities, financial hardships, productivity losses and mortality. These combined further put pressure on limited resources and worsens poverty situations and overall progress to achieving agenda 2030 and its sustainable Development Goals.

## **Excellencies, Distinguished guests,**

5. The Secretary-General's report on progress on SDGs suggest that globally, **74 per cent** of all deaths in **2019** were caused by **non-communicable diseases**.
6. Furthermore, the COVID-19 pandemic has underscored the need for further attention to interventions in non-communicable diseases, as people, including children, with underlying non-communicable diseases are at higher risk of severe illness and death from COVID-19.
7. Disruptions in the health services as a result of COVID-19 has in fact affected people with non-communicable diseases the most. While COVID-19 pandemic is an emergency and requires us to act now, we cannot undermine efforts to deal with other non-communicable disease such as SMA.
8. This therefore teaches us that to **Ensure healthy lives and promote well-being for all at all ages**, we need policy makers and health experts to work in solidarity, so that resources and attention is spread almost equally among all types of diseases, so that no one is left behind.
9. Having said that, there is a lot of work that needs to be done to mitigate the impact and burden of SMA on our societies. This can be done among other things through prevention, early detection and timely treatment.

10. The best treatment for SMA, like many genetic diseases, is only in its initial stages. We have seen through the COVID-19 pandemic how much science can achieve when scientists join hands and sufficient resources are mobilized. We should direct more resources and efforts to research to find ways to combat and cure this terrible disease.
11. Education on the disease is also important. We need to invest in appropriate dissemination of knowledge, technology and know-how. We also need global solidarity and cooperation as well as multistakeholder partnerships, to make research and inventions accessible and available to all in order to attain the highest level of health and wellbeing for everyone.
12. However, we cannot forget that the lack of access to universal health care and the high treatment gap in middle- and low-income countries continue to reveal profound health inequities, particularly for those living in poverty, rural or remote areas, and other vulnerable populations. It is therefore essential that we reaffirm the right of everyone to the enjoyment of the highest attainable standards of physical and mental health, without distinction of any kind. This calls for accelerating efforts to strengthen health systems and to achieve universal health coverage and access to safe, effective, quality, affordable and essential medicines, diagnostics, vaccines and other health technologies for all.

**Excellencies,  
Ladies and Gentlemen,**

13. As you will recall, the High-Level Political Forum on Sustainable Development (HLPF) under the auspices of the Economic and Social Council (ECOSOC) in July this year reviewed **SDG 3 on Good Health and Well-being**. It reiterated the importance of strengthened people-centered and gender-responsive health and social protection systems with a focus on combatting inequality and empowering women and groups disproportionately affected by the pandemic.
  
14. Important events such as this are intended to galvanize our determination to mobilize investment in science and research on diseases such as SMA and to share knowledge and treatments. They should remind us that we are all equal and have the right to live happy and productive lives wherever we are and whoever we are.
  
15. In conclusion, I thank Ukraine, Lithuania, Honduras and Georgia, the organizers of this event for their significant contribution to global advocacy campaign to raise awareness of SMA with a view to promote its early detection and treatment.

**I thank you for your kind attention.**