



CONSTITUENCY STATEMENT ON THE RARE DISEASE RESOLUTION

AGENDA ITEM 6: UHC

ORGANIZER: THE INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY [SIOP]

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Non-State Actors participating in the Statement

- SIOP (The International Society of Paediatric Oncology) - organizer
- CCI (Childhood Cancer International)
- IAHPC (International Association for Hospice and Palliative Care)
- IPA (International Pediatric Association)
- ISN (International Society of Nephrology)

Additional supporters:

- IAPB (International Agency for the Prevention of Blindness)

STATEMENT

We welcome the initiative of Member States on a World Health Assembly Resolution on Rare Diseases, stress its importance for the millions of children with life-altering rare conditions such as paediatric cancers or rare kidney disease, and call for its adoption and subsequent implementation as both ambitious and pragmatic by pursuing global health equity and synergizing with relevant programmes across the WHO agenda.

The Resolution is set to foster an integrated effort which should span the patient pathway and promote equitable and sustainable access to care, including diagnostics, treatments, follow-up surveillance and palliative care, while integrating socioeconomic and psychosocial support to address the lifelong impact on paediatric patients and families.

These actions should build on and coordinate with programmes of relevance to severe rare diseases in children including:

- WHO Global Initiative for Childhood Cancer (GICC) which aims for increased survival and reduced suffering by 2030.
- Global Accelerator for Paediatric Formulations Network (GAP-f) which works on paediatric formulation development for vulnerable populations.
- WHO initiatives promoting access to clinical trials and research, including in relation to the WHO Resolution on Clinical Trials, since pooling of specialist expertise is essential in rare diseases and the unique challenges in the paediatric population.

Coordinated approaches can foster multiplier effects. For example, childhood cancer diagnosis and treatment have been recognized as a WHO ‘Best Buy’, pointing to the cost-effectiveness and potential of such investment to strengthen overall health systems. The increasing inclusion of childhood cancer under Universal Health Coverage (UHC) demonstrates that bold strides in health equity are possible in rare diseases.

By coordinating with the GICC and other relevant initiatives, a global action plan on rare diseases is set to accelerate life-enhancing progress and foster efficiency, sustainability, and the potential to harness the transformative power of UHC.

We commend the Resolution on Rare Diseases as a unique initiative in global health poised to complement, reinforce, and accelerate a coordinated and inclusive approach to ensure life-saving progress for children with rare diseases worldwide.

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