

The @MATES4Kids Movement: Reducing Preventable Mortality Associated with Congenital Adrenal Hyperplasia (CAH) by 30% by 2030

@MATES4KIDS

AFRICAN Region (AFR): Salwa Musa¹

Region of the AMERICAS (AMR): Raúl Calzada León², Jean-Pierre Chanoine³, Dina Matos⁴, Diane E.J. Stafford⁵, Paola Duran Ventura⁶

EUROPEAN Region (EUR): Hedi L. Claahsen⁷, Marika Mayrdorfer-Muhr⁸, Johanna Meschede⁹

EASTERN MEDITERRANEAN Region (EMR): Asma Deeb¹⁰, Mohsina Ibrahim¹¹, Jamal Raza¹²

WESTERN PACIFIC Region (WPR): Maria E. Craig¹³, Muhammad Yazid Jalaludin¹⁴

SOUTH EAST ASIAN Region (SEAR): Navoda Atapattu¹⁵, Sirisha Boddu¹⁶, Aman Pulungan¹⁷, Sumudu N. Seneviratne¹⁸

@MATES4Kids Secretariat: Kate Armstrong¹⁹, Carmen Auste²⁰

BACKGROUND: Children living with paediatric endocrine conditions in resource-poor countries experience inequitable rates of preventable mortality and morbidity. Reducing preventable mortality associated with CAH will help member states committed to delivering on the United Nations' Sustainable Development Goals 3.2.1, 3.2.2 and 3.4, and leverages additional synergies with SDGs 1, 10 and 17.

Clan Caring & Living As Neighbours (CLAN) www.clanchildhealth.org – has been improving health outcomes for children living with CAH in resource poor countries since 2004, through a rights-based, community development approach focusing collaborative action on five pillars: (1) Affordable access to medicines and equipment; (2) Education, research and advocacy; (3) Optimal medical management; (4) Family support groups; and (5) Reducing financial burdens on families. CLAN founded the @MATES4Kids movement in 2021, bringing together a broad range of individuals and organisations committed to practical actions to reduce preventable mortality from CAH.



@MATES4Kids' OBJECTIVES:

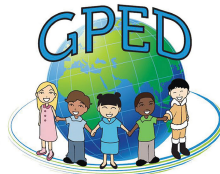
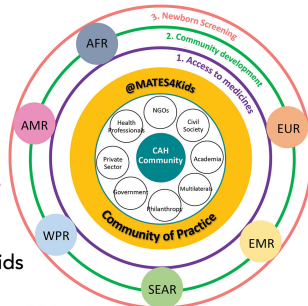
- (1) Improve access to essential medicines
- (2) Strengthen CAH Communities
- (3) Scale access to Newborn Screening.

METHODS: In 2022, @MATES4Kids elevated this issue to WHO in a briefing paper (see below), proposing a strategic approach to improving access to hydrocortisone and fludrocortisone tablets. An inaugural CAH@MATES4Kids Meeting co-chaired by CLAN and GPED (Global Pediatric Endocrinology and Diabetes) convened at IMPE (International Meeting of Pediatric Endocrinology) 2023, allowed interested stakeholders to share experiences, identify priorities and agree future strategies.

RESULTS: IMPE 2023 facilitated communication between global and regional paediatric endocrine societies and @MATES4Kids agreed an implementation plan for strategic action in the six WHO regions utilising the Knowledge To Action Framework.

Tools available in the @MATES4Kids Toolkit to aid identification of priorities, guide implementation, monitor progress and evaluate outcomes will be housed on the WHO's Knowledge Action Portal (KAP – image attached) and include: CLAN Snapshot Survey; CAH Health Needs Assessment; CAH Equity Scorecard; Child Health Equity Checklist Count (CHECC) Scorecard and @MATES4Kids Monitoring Indicators.

Champions for each WHO Region and a Community of Practice facilitate a Continuous Quality Improvement approach to critical action with an agreed timeline. Drug / monetary donations from Direct Relief, GPED, CARES Foundation, the international CAH Community and CLAN have already supported CAH Communities in Ukraine, Sri Lanka, Zimbabwe and Bolivia.



- SDG 17 - Partnerships for the Goals**
@MATES4Kids and the international CAH Community
- SDG 10.2 – Reduce inequality within and among countries**
Empower and promote social, economic and political inclusion
- SDG 3.8 - Universal Health Coverage**
Newborn screening, essential CAH medicines & healthcare
- SDG 3.4 - Reduce NCDs mortality**
Reduce mortality associated with CAH by 30% by 2030
- SDG 3.2.2** End neonatal mortality (0-27 days)
- SDG 3.2.1** End preventable deaths of children <5 years
- SDG 1 – End poverty**
Reduce out of pocket expenditures (OOPE) and catastrophic health spends associated with CAH

We all have a role to play...

What will it take to achieve equitable access to essential medicines & equipment for the global Congenital Adrenal Hyperplasia (CAH) Community?

A briefing paper for the World Health Organisation

Prepared by @MATES4Kids (Maximising Access To Essential Supplies for Kids) February 2022

World Health Organisation Knowledge Action Portal on NCDs

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@MATES4Kids – Maximising Access To Essential Supplies for Children living with NCDs

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Key Messages

- Listening to the CAH Community
- Frameworks informing the @MATES4Kids Community of Practice
- How is @MATES4Kids proposing to reduce the preventable mortality associated with CAH?

Learn more

DISCUSSION: Reducing preventable mortality associated with CAH will require innovative, sustained, multistakeholder and multidisciplinary efforts. All Paediatric endocrinologists have a role to play in advancing this agenda on the road to 2030. We welcome anyone with interest to reach out to info@clanchildhealth.org, or gpedinfo@gmail.com for more information.

1 Gaafar Ibn Auf Tertiary hospital & Al-Neelain University, Khartoum, Sudan. 2 National Institute for Pediatrics, Mexico City, Mexico. 3 British Columbia Children's Hospital and University of British Columbia, Vancouver, Canada. 4 CARES Foundation, New Jersey, USA. 5 Stanford University School of Medicine, Palo Alto, USA and GPED, Canada. 6 Fundacion Cardioinfantil-IC, Asociacion colegio Colombiano de endocrinologia pediátrica ACCEP, Bogota, Colombia. 7 Radboudumc Amalia Children's Hospital, Nijmegen, Netherlands. 8 CAH International, Hamburg, Germany and Netzwerk AGS- Österreich, Vienna, Austria. 9 CAH International. 10 Sheikh Shakhbout Medical City, Abu Dhabi, UAE. 11 National Institute of Child Health (NICH). 12 National Institute of Child Health (NICH), Karachi; Pakistan Pediatric Association, Society of Pediatric Endocrinology Pakistan (SPED) and South Asian Pediatric Association (SAPA), Pakistan. 13 Children's Hospital at Westmead and University of New South Wales, Sydney, Australia. 14 Faculty of Medicine, Universiti Malaya, Kuala Lumpur, Malaysia. 15 Lady Ridgeway Hospital, Colombo, Sri Lanka. 16 Rainbow Children's Hospital, Hyderabad, India. 17 Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia. 18 Centre for Complex Hormonal Disorders, Faculty of Medicine, University of Colombo, Colombo, Sri Lanka. 19 CLAN (Caring & Living As Neighbours), Sydney and Torrens University, Adelaide, Australia. 20 Cancer Warriors Foundation, Manila, Philippines.