



**HIGH-LEVEL POLITICAL FORUM
ON SUSTAINABLE DEVELOPMENT**

United Nations High Level Political Forum 2022

*Building back better from the COVID-19
Pandemic while advancing the full
implementation of the 2030 Agenda for
Sustainable Development*



Caring & Living As Neighbours

**OFFICIAL
EVENT
REPORT**

6 July 2022

CARING AND LIVING AS NEIGHBOURS (CLAN)

Presenter: Emma Santini - Project support officer for Mates4Kids

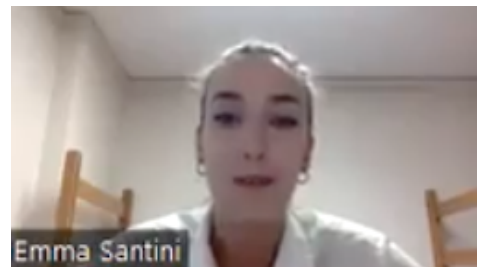
Key Message

Mission: Maximize the quality of life for children and their families who are living with chronic health conditions in resource poor settings of the world

Framework for action: Use a rights-based approach where family and children are put at the center

Five pillars:

- Affordable access to medication and medical equipment
- Education, Research and Advocacy
- Optimization of medical management
- Encouragement of family support networks
- Reducing financial burdens on families that result in poverty, helping people to become financially independent so that they can provide the necessary health care for their children longer term



Connect further with CLAN at
Twitter: @clanchildhealth
Instagram: @clanchildhealth
Website: clanchildhealth.org



Caring & Living As Neighbours

MATES 4 KIDS

Presenter: Dr. Kate Armstrong - President of CLAN and Co-Chair for Mates4Kids

Key Message

Maximizing Access to Essential Supplies 4 children living with CAH (Mates4Kids)

- A coalition of like-minded organizations and individuals committed to collaborative action aimed at identifying, implementing and monitoring practical solutions to improve access to essential medicines for the global CAH community



Seeking to reduce the preventable mortality currently associated with CAH by 30% by 2030

Timeline:

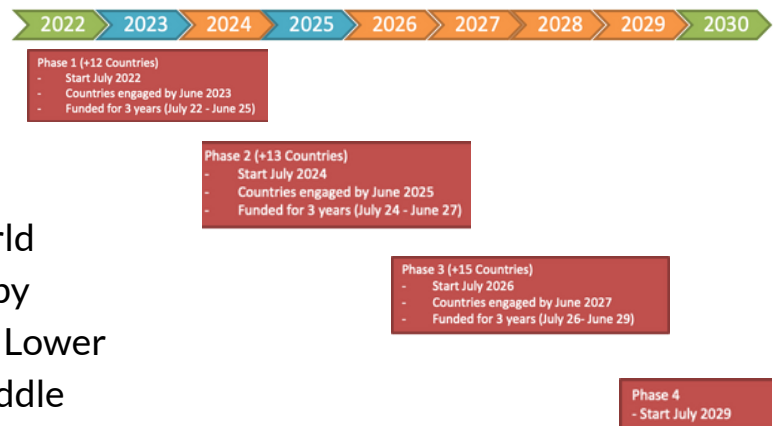
2022 – UN HLPF

2023 – 2nd UN HLM UHC

2025 – 4th UN HLM NCDs

- World Health Organization and the World Bank categorize countries by region and by income level - 132 countries identified as Lower income/Lower Middle Income/ Upper Middle Income.

- To achieve 30% reduction of preventable mortality – need to make a difference in at least 40 countries



Connect further with Mates4kids at
Twitter: @mates4kids
Website: clanchildhealth.org/mates4kids.html



ESSENTIAL MEDICINES FOR CAH PATIENTS IN PAKISTAN- CHALLENGES WITH AND WITHOUT COVID-19

Presenter: Professor Jamal Raza - Executive Director, Sindh Institute of Child Health & Neonatology

Key Message

Challenges of CAH children in developing countries: essential CAH medicines are not available.

- Essential Medicine list by Drug Regulatory Authority of Pakistan
- Fludrocortisone and hydrocortisone are on the list of essential medicines, but the medicine is still not available

Local production is the solution

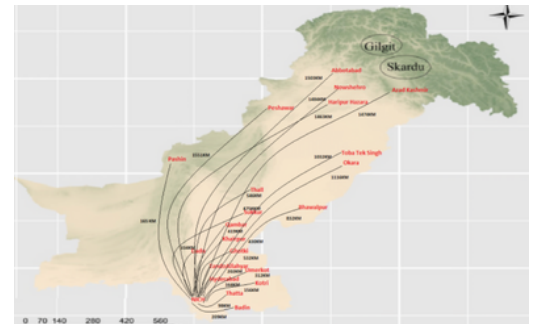
- With the help of Dr. Latif Shaikh, Tabros Pharma agreed to produce fludrocortisone and hydrocortisone locally at an affordable price

Door Step Delivery Project

- Six month project from March-August 2020
- In person visit cost for medication – 12-15 USD/visit
- Courier charges for each patient – 1-3 USD/shipment

Expanding Borders

Working with Muzzamil Barry, we were able to send bulk shipments of fludrocortisone and hydrocortisone, approximately 1150 units of medication, for 1270 USD exported to Zimbabwe



Connect further with Professor Jamal Raza at

Twitter: @Jamalraza13

Website: sichn.com.pk

CLAN AFRICA AND PARTNERSHIPS AMIDST COVID-19

Presenters: Dr. Andrew Twineamatsiko – Community Development Officer for CLAN Africa

Trudy Nyankambangwe - Founder of Child and Youth Care in Zimbabwe

Key Message

Clan Child Health Africa:

Builds onto the successes of Rights based strategic framework for CLAN to help ensure health equity for all children in Africa.

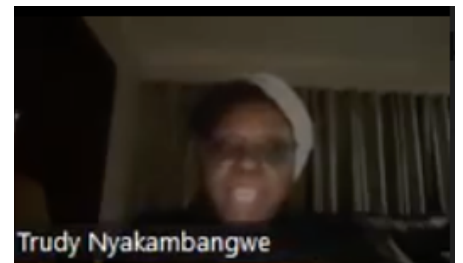
Active engagements in Uganda, Burundi and Zimbabwe



Partnerships Approach

All projects are community led and community driven

- Biggest need of community is access to medications, works with oversight of regional hospitals



CLAN donated funding for donation of mobile phones to families in Uganda and supply of CAH medicines in Zimbabwe

- Allows for increases community awareness
- Sharing resources – provision of medications to CAH community would not be possible without support from CLAN and Pakistan
- Increased knowledge



Caring & Living As Neighbours

Connect further with Child and Youth Care Zimbabwe at

Twitter: @childyouthcareZ

Instagram: @childyouthcarezim

Facebook: Child Youth Care Zimbabwe

Website: www.cyc.org.zw

INDONESIA - PARTNERSHIPS PREVENTING INFANT/CHILD MORTALITY, IMPROVING ACCESS TO ESSENTIAL MEDICINES, AND EXPANDING NEWBORN SCREENING

Presenter: Professor Aman B Pulungan - MD, PhD, FAAP, FRCPI (Hon.) and Agustini Utari - MD, M.Si.Med, PhD

Key Message

Recommendations on Transforming Access to Diagnostics:

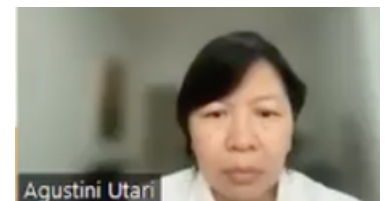
- Countries develop a national diagnostics strategy (evidence-based integrated & tiered network)
- Key point-of-care diagnostics available at all primary health-care centers



Partnerships & Collaborations for Children with NCDs in Indonesia

Patient Support Groups

- KAHAKI (Community for Families with CAH - Indonesia), Turner Syndrome Society of Indonesia, FOSTEO (forum Osteogenesis Imperfecta Indonesia), etc.



Grants & International Collaborations

- Collaboration with Changing Diabetes in Children
- Grant for type 1 diabetes education program "PEDIA Project" (CLAN-APPES & WHO NCD LAB)



Digital monitoring app for child health may help reduce incidence of malnutrition

- Allows for increases community awareness - PrimaKu encourages home monitoring, which promotes prevention
- Access to Telemedicine - PrimaKu allows doctors to reach patients in less accessible regions



Connect further with International Pediatric Association at

Twitter: @ipaworldorg

Instagram: @ipaworld_org

Website: www.ipa-world.org

INSULIN FOR LIFE- PARTNERSHIPS SHAPING HUMANITARIAN RESPONSES

Presenters: Dr. Alicia Jenkins - IFL Global, Aust. President, and USA Board Member, Professor of Diabetes & Vascular Medicine at the University of Sydney, Endocrinologist

Oleg Novikov - IVF, Volunteer Born in Kiev, Ukraine Diabetes Software Designer

IFL Goals

- Ease and save lives of poor populations with diabetes in disadvantaged regions
- Collect in-date insulin, glucose test strips, assist diabetes camps,
- HbA1c testing, complication/community screening, improve advocacy & research



Emergencies

- Diabetes supplies often not included in 1st responder shipment
- IFL can provide diabetes supplies & information (ex: insulin swapping chart
- IFL needs a “global village” in order to do so (ex: donors, industry, delivery teams, etc.)

IFL Aid to Ukraine

- IFL Affiliates in 7 Countries Sending Aid from March 1 2022 to present
- 91 shipments, 310 parcels, 5 pallets
- 140,000 mls insulin, 470 insulin delivery systems, 313,000 monitoring tools
- Delivery of additional drugs - CHA, thyroid Direct Relief aid links

Connect further with Insulin for life at

Twitter: @insulin4life

Website: www.insulinforlife.org



**INJECTING HOPE
SAVING LIVES**

www.insulinforlife.org

DISCUSSION/RECOMMENDATIONS ARISING

Presenter: Presenters: Carmen Auste, Co-Founder & CEO of Cancer Warriors Foundation (Philippines), Founding Member & VP of Cancer Coalitions (Philippines), Co-Chair @Mates4Kids
Dr. Kate Armstrong - President of CLAN and Co-Chair for Mates4Kids

Next Steps

- WHO - Connect countries & identify regional champions within CoP
- WHY - snapshot surveys to identify need
- WHAT - call to action – report from UNHLPF2022, Regular @MATES4Kids Working Group Meetings

- HOW - establish communities of practice – participate in global meetings to share successes
- WHEN - calendar of events
- WHERE - online & face-to-face – conferences, events

Participant recommendations

- Put together experiences and social innovations in a program policy brief for WHO, Ministers of Health, and other key stakeholders
- Diplomatic involvement & deeper engagement through embassy teams
- Funding from diplomats interested in involvement
e.g. US, UK, Canada, New Zealand, Germany, Japan, Australia, France

like Pakistan, Africa, Indonesia etc. to engage on a deeper level where over time its Embassy teams and Diplomats better understand how they could support CLAN?, Here I am thinking about the Canadian, USA, New Zealand, UK, Germany, Japan, Australian and French diplomats who would have an interest in potentially funding such important initiatives.

it would be good to put together these experiences and social innovations including the tech innovation of Indonesia in a program.policy brief for WHO, Ministers of Health and other key stakeholders

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