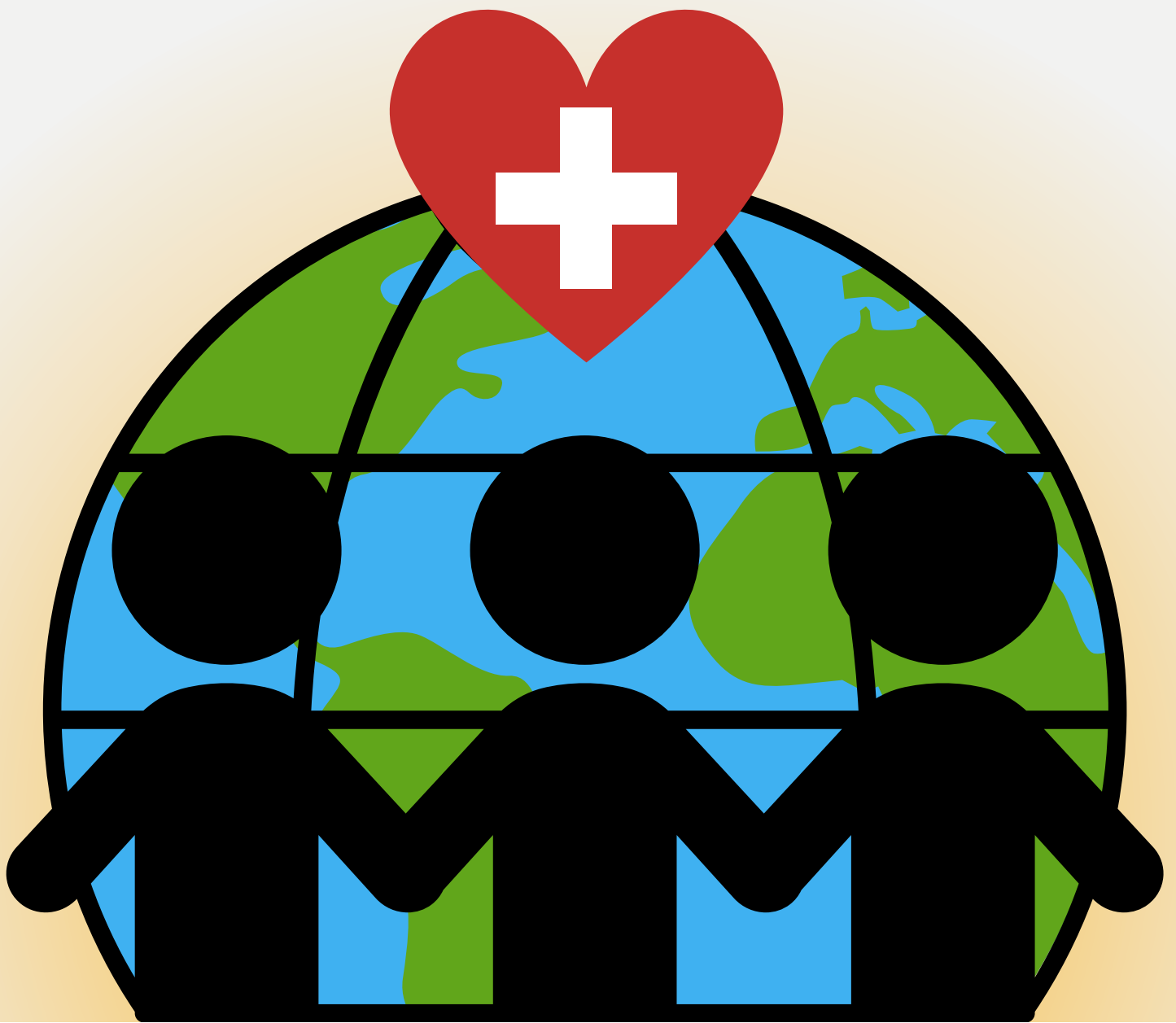


**@MATES4KIDS**

**MAXIMISING ACCESS TO ESSENTIAL SUPPLIES FOR CHILDREN**

# **2023 Activity Report**



## @MATES4Kids (Maximising Access to Essential Supplies for Children) Annual Activity Report 2023

@MATES4Kids is an international movement committed to reducing the preventable mortality associated with Congenital Adrenal Hyperplasia (CAH). CLAN (Caring & Living As Neighbours) is the founding Secretariat of @MATES4Kids and this Activity Report captures key initiatives and achievements of the movement from January 2022 to June 2023.

**Acknowledgement of Country.** In the spirit of reconciliation, @MATES4Kids acknowledges the Traditional Custodians of Country throughout Australia and the connections of Aboriginal and Torres Strait Islander peoples to land, sea and community. In particular, we acknowledge the Wallumedegal Peoples of the Eora Nation, on whose land CLAN (Caring & Living As Neighbours) is headquartered. We pay our respect to Elders past and present and extend that respect to all First Nations leaders around the world.

**Suggested citation.** @MATES4Kids (Maximising Access To Essential Supplies for Children) 2023 Activity Report. Australia: @MATES4Kids, September 2023. Available online at <https://knowledge-action-portal.com/en/cop-categories/mates4kids-%E2%80%93-maximising-access-essential-supplies-children-living-ncds>

---

CLAN is an Australian-based, not-for-profit, non-governmental organisation (NGO), approved by the Australian Government's Department of Foreign Affairs and Trade for Overseas Aid Gift Deductibility Status (OAGDS) and the Australian Taxation Office for Tax Deductibility Status. CLAN is fully compliant with the Australian Council For International Development Code of Conduct. CLAN was founded in 2004 and has been in formal association with the United Nations Department of Global Communications (previously known as the United Nations Department of Public Information for NGOs) since 2010, and in Special Consultative Status with ECOSOC since 2018.

CLAN is committed to full adherence with the ACFID Code of Conduct as it provides guidance and support that strengthens the ethical and transparent management of CLAN's activities to improve the health and wellbeing of children and young people living with NCDs and other chronic health conditions in resource poor communities, be they in Australia or abroad.



# Table of Contents

Executive Summary .....	1
Introducing @MATES4Kids .....	2
Strategic Framework .....	4
Underlying Principles .....	8
Founding Members of the Community of Practice .....	9
Community of Practice Update .....	10
Platform for Collaborating and Connecting .....	12
Introducing the Secretariat .....	14
Success Stories .....	15
Access to Medicines .....	15
Pakistan & Binden Pharma .....	15
Ukraine & Partnership with Direct Relief .....	16
Sri Lanka .....	17
Bolivia .....	17
Community Development .....	18
Zimbabwe .....	18
IMPE Summit .....	19
NBS .....	20
Indonesia at CSW67 .....	20
Other Achievements .....	21
Briefing Paper .....	21
High-level Political Forum Advocacy Statement .....	21
Call for Action .....	22

## Executive Summary

@MATES4Kids aims to reduce the preventable mortality associated with CAH by 30% by 2030. Despite major successes for the CAH community over the past two decades, if we are to accomplish this goal, we need to do things differently. It is time to work together like never before, think big, and change the landscape for the global CAH Community. Such action will require multisectoral, collaborative action on an enormous scale, with a rights-based commitment to improving access to essential medicines, strengthening community development, and scaling newborn screening (NBS). Childhood cancer and type 1 diabetes communities give us hope that such commitment and change is possible.

@MATES4Kids believes it is possible to achieve our goals through a rights-based commitment to three areas of focus: improving access to essential medicines, strengthening community development and scaling NBS. The efforts of the @MATES4Kids network are taking place across the globe in every WHO region, with regional champions and community members facilitating a continuous dialogue surrounding best practices, prominent challenges, valuable partnerships, and mutual goals. With the help of the WHO Knowledge Action Portal, which provides an online platform for the exchange of information, as well as regular Community of Practice meetings, members of the @MATES4Kids movement are taking advantage of various communication channels to work together.

This inaugural report (January 2022 to June 2023) details the foundational activities and structure of @MATES4Kids, as well as the activities conducted since the movement's inception. We are excited to share the many successes already experienced and the groundwork they lay for the future. In the lead up to 2030, the community is determined to continue capitalizing on a multistakeholder network of changemakers who will consistently collaborate to overcome the global inequities associated with CAH. It is our greatest hope that each year will bring us all one step closer to accomplishing the Sustainable Development Goals (notably SDGs 3.2.1, 3.2.2 and 3.4).

It is time to come together, as mates, and improve access to CAH supplies and care for #EVERYchild.

# Introducing @MATES4Kids

**@MATES4Kids is a coalition of like-minded organisations 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.**

## Vision

Every child living with CAH around the world might enjoy the highest quality of life possible.

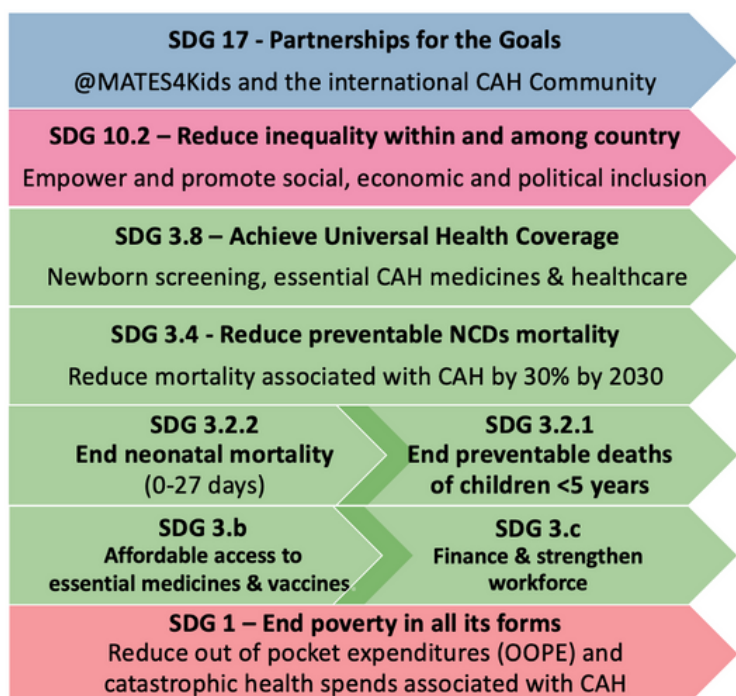
## Objectives

The @MATES4Kids movement proposes a collective, global and strategic focus on efforts to:

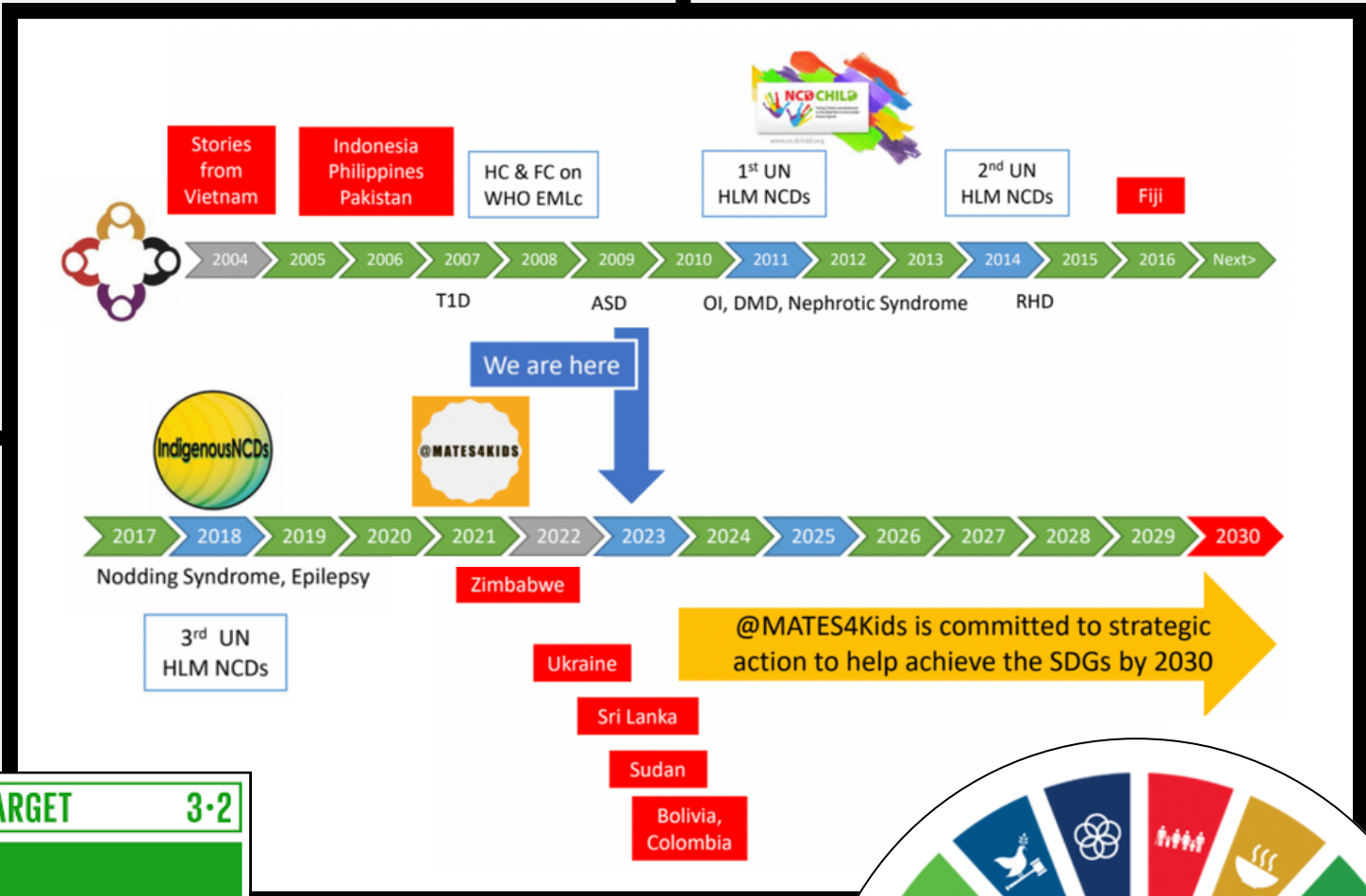
1. Improve access to essential medicines and equipment
2. Strengthen community development
3. Scale newborn screening (NBS)

For decades now, life for children living with CAH in high-income countries (HICS) has been made easier thanks to affordable access to the essential medicines hydrocortisone (HC) and fludrocortisone (FC). Indeed, the international CAH Community has progressively grown in size, strength and connectivity, with support from a broad range of multisectoral allies. Despite these achievements, equity has not yet been achieved for the international CAH Community. There still exist far too many countries with little or no affordable access to CAH medicines.

In the lead-up to 2030, as the world seeks to deliver on the Sustainable Development Goals (SDGs), it is time to work together like never before, think big, and change the landscape for the global CAH Community. Such action will require multisectoral, collaborative effort on an unprecedented scale, but will contribute to efforts to achieve a range of SDGs, including SDGs 1, 3, 10 and 17.



# @MATES4Kids Timeline



**TARGET 3-2**

**5 YRS**

END ALL PREVENTABLE DEATHS UNDER 5 YEARS OF AGE

**TARGET 3-4**

REDUCE MORTALITY FROM NON-COMMUNICABLE DISEASES AND PROMOTE MENTAL HEALTH



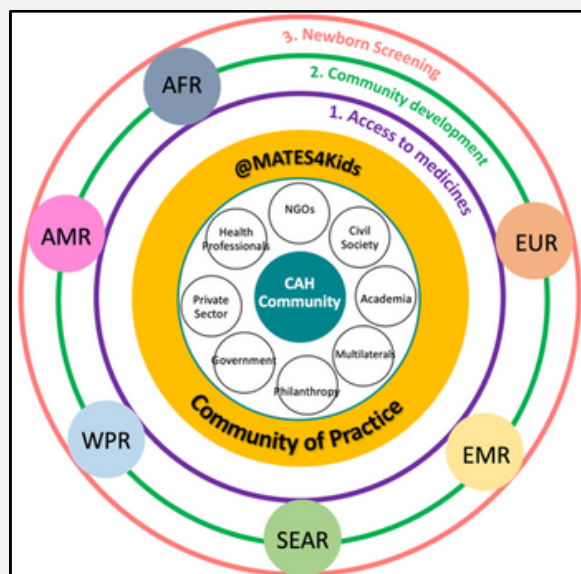
# Strategic Framework

Maintaining the CAH community at the central focus of collective action, @MATES4Kids has established a multistakeholder Community of Practice (CoP) to drive critical action through seamless collaboration and regular dialogue.

## @Mates4Kids recognizes the six WHO regions of the world:

1. The African Region (AFR)
2. Region of the Americas (AMR)
3. Eastern Mediterranean Region (EMR)
4. European Region (EUR)
5. South East Asian Region (SEAR) and
6. Western Pacific Region (WPR)

The @MATES4Kids CoP brings together a broad range of stakeholders, and facilitates collaboration between champions in each of these six regions so that achievements can be shared and critical action scaled locally



To achieve the goal of reducing mortality associated with CAH by 30% by 2030, the CoP makes a rights-based commitment to:



## 1. Improving access to essential medications and equipment

**Affordable access to CAH and childhood NCDs medications** must be achieved for every country. Hydrocortisone and fludrocortisone tablets are both on the WHO's Essential Medicines List for Children (EMLc), and must be included in every National Essential Medicines Lists (NEML) – most especially when CAH is included on national NBS panels. It is a fact that countries have introduced NBS Programs without first ensuring the medicines needed to treat the condition/s are affordably available. This is a tragedy for the families that are most affected.

Once hydrocortisone and fludrocortisone are included on NEMLs, they must be included in national insurance schemes. Universal Health Coverage (UHC) is essential for childhood NCD Communities. Systems must be in place to ensure families of children diagnosed with NCDs are not bankrupted by health expenditures.



## 2. Strengthening CAH and other childhood NCD Communities

Since 2004 CLAN (Caring & Living As Neighbours) has been collaborating with a broad range of stakeholders to drive change for CAH communities in lower-income countries. In line with CLAN's Strategic Framework for Action and five pillars, **quality of life** for children diagnosed with CAH and other NCDs must be improved through a holistic, sustainable community development approach that addresses the bio-psycho-socio and cultural needs of families. Even for children diagnosed with NCDs in resource-poor settings who have access to medication, multiple other barriers to a quality of life on par with their neighbours in wealthier countries exist and must be redressed.

Families of children living with CAH have consistently asked for help with five things:

1. Affordable access to essential medicines and equipment
2. Education, research and advocacy
3. Optimal medical management
4. Strong family support groups
5. Freedom from poverty and financial independence

These five pillars are a starting point for action. Ongoing consultation with CAH Communities is required to ensure the needs and perspectives of children and families living with NCDs are informing changes within and to health systems, and thereby informing efforts to improve health outcomes and reduce the preventable mortality and morbidity currently associated with CAH.

Codesign of all efforts with CAH Communities will be a necessary component of achieving the highest quality of life for all. Empowered NCD communities benefit children and families as much as they do health professionals and health systems.



## 3. Scaling Newborn Screening

NBS must be scaled globally, with an equity lens informing implementation. The inclusion of NBS in the development agenda and universal health coverage discourse is critical. Governments must invest in NBS technology along with accountability measures to ensure the best outcomes and promote equitable use of resources. In order to scale NBS, active dialogue surrounding available technology and its effectiveness is required. To facilitate this dialogue, data outcomes in resource-poor settings must inform an evidence-based approach, and remind policymakers of the benefits of NBS. This dialogue ultimately needs to culminate in an international agreement on the equitable implementation of NBS.

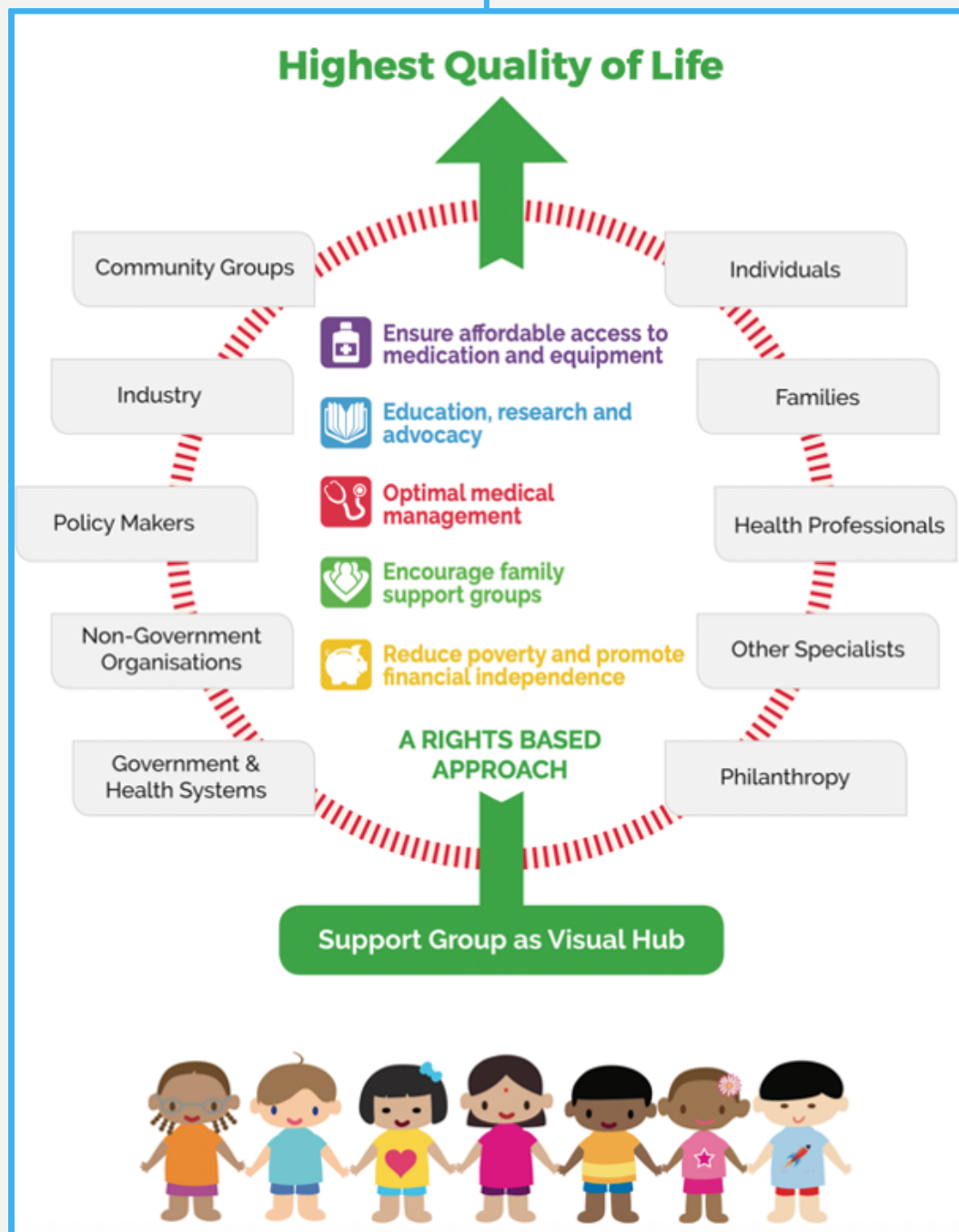
Screening for congenital hypothyroidism (CH) must always be the most urgent priority, as this is more common than CAH and contributes enormously to the burden of developmental delay globally. However, as has happened in all high-income countries, the expansion of NBS panels to include other NCDs such as CAH will soon follow screening for CH. As NBS Programs are progressively scaled, accountability measures must be in place to support continuous quality improvement initiatives that will drive the best outcomes and use of resources.



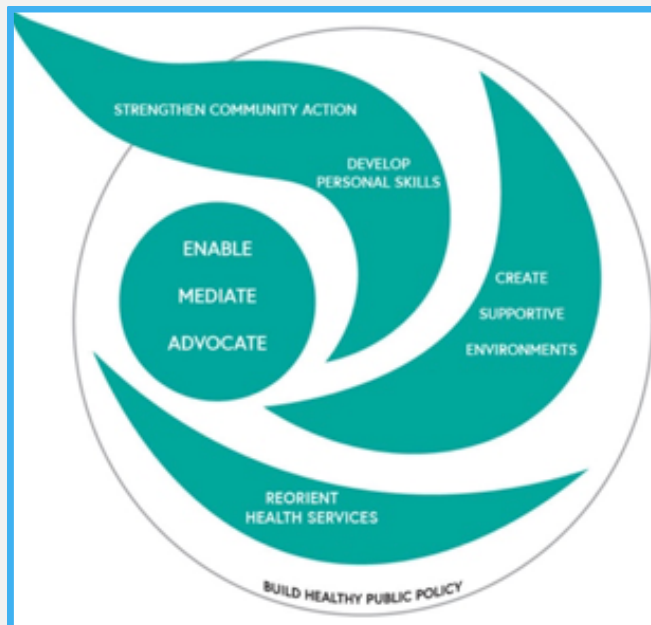
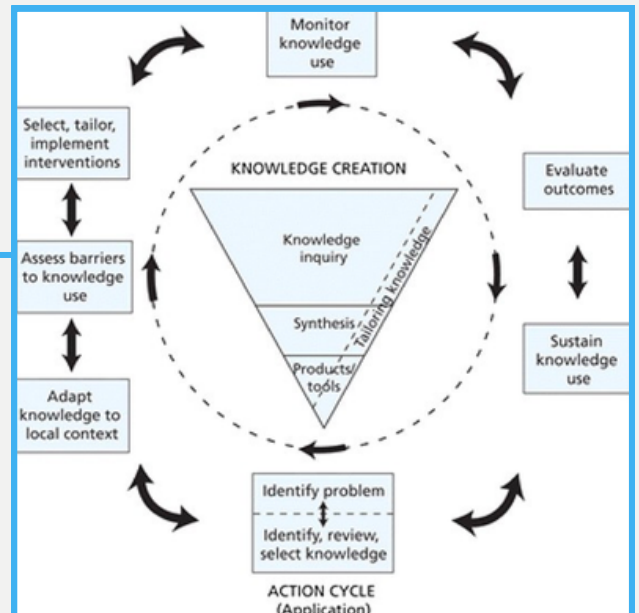
## Additional Frameworks

The work of @MATES4Kids is also informed by four other strategic frameworks:

1. **CLAN's Strategic Framework for Action**, which promotes a rights-based approach, focuses on a community of children living with a particular NCD as the visual hub of all collaborative action. This approach builds engagement between a broad range of multisectoral stakeholders and facilitates collective strategic action focused on five key pillars. @MATES4Kids seeks to specifically focus collaborative efforts on pillar one for the global CAH community: affordable access to essential CAH medicine and equipment.



**2. Knowledge to Action Framework,** which promotes an evidence-based, continuous quality improvement approach to improving health outcomes, with efforts adapted locally to ensure optimal impact of priority interventions. Knowledge, tools and resources are refined over time, thereby facilitating sustainable and scalable action to address specific problems.



**3. The Ottawa Charter,** which identifies five key priorities for action: create supportive environments, develop personal skills, reorient health systems, strengthen community action, and build health public policy. It also acknowledges the imperative to enable, mediate, and advocate. In doing so, the Ottawa Charter aims to promote health and well-being.

**4. The Pan American Health Organization (PAHO) Strategic Fund,** which offers a unique model whereby regional technical cooperation enables pooled procurement of essential medicines and equipment. There have been significant achievements by the Strategic Fund, and these will undoubtedly inform future initiatives to benefit childhood NCD Communities around the world. Two-way learning and consultation may also identify some potential opportunities to strengthen the Strategic Fund with regard to improving access for childhood NCD Communities.



# Underlying Principles

## Underlying principles guiding collaborative action for the global CAH Community and @MATES4Kids include:

- **Kids come first**—Children and young people living with CAH will always be the central and shared focus of @MATES4Kids.
- **A holistic view of health**—@MATES4Kids acknowledges the WHO definition of health (World Health Organisation Adopted by the International Health Conference in New York, USA on 22 July 1946, and came into Force on 7 April 1948), with a focus on body, mind and spirit, and an appreciation of the impact the socio-cultural determinants of health (SCDOH) (Marmot 2005) have on health outcomes.
- **Human rights-based approach**—Acknowledging rights and responsibilities as outlined in the United Nations' Convention on the Rights of the Child (United Nations 1990).
- **Equity**—Commitment to strive for excellence for all and respect, promote and protect the rights of children in high- and low-income countries to the highest quality of life possible.
- **Community development**—All children living with the same chronic health condition in a country are members of a community; these NCD Communities are considered interconnected and united at the local, regional, national and international level.
- **Community control**—People living with chronic conditions are experts and must be consulted at all stages when decisions are made around appropriate approaches and actions to drive change.
- **Person- and family-centred care**—Acknowledges the pivotal role children, young people and families play in all activities. Indeed, parents of children with chronic health conditions frequently commit to long-term action and advocacy to benefit not only their own children, but others with the same condition, and work tirelessly with caring health professionals and other stakeholders to facilitate real change.
- **Sustainable, ethical and transparent approaches to project management**—Commitment to the highest standards of accountability and reporting required of NGOs (by ACFID – the Australian Council for International Development) in Australia and to the United Nations (through GNEC and ECOSOC). @MATES4Kids is committed to sustainable approaches and responsible action in the face of climate change.
- **Multisectoral collaboration and partnerships**— Key to sustainability and success with a focus on education, research and advocacy.
- **Above all do no harm**—Overarching guiding principle and informs all actions.

# Founding Members of the CoP

CAH Stakeholder	Organisation name (confirmed)
CAH Communities	CARES (USA)
	CLIP (Pakistan)
	IKAHAK & KAHAKI (Indonesia)
	CAHSAPI (Philippines)
	Nigerian CAH Community
	Zimbabwe CAH Community
	European CAH Communities
	CLAN Africa
Health professionals	APPES (Asia Pacific Pediatric Endocrinology Society)
	IPA (International Pediatric Association)
	PSPME (Philippines Society of Pediatric Metabolism & Endocrinology)
	IDAI (Indonesian Pediatric Society – Ikatan Dokter Anak Indonesia)
	ICPE (International Consortium Pediatric Endocrinology)
	Society of Paediatrics and Adolescents Endocrinology for Nigeria (SPAEN)
	SPED (Society Pediatric Endocrinology & Diabetes)
	APPA (Asia Pacific Pediatric Association)
Other NGOs	IndigenousNCDs
	NCD Child
	Life For A Child
	Cancer Warriors, the Philippines
	GiveAsia, the Philippines
	CLAN (Caring & Living As Neighbours)
	Global Pediatric Endocrinology and Diabetes (GPED)
Academia	Lehigh University (USA)
Other	TBC
Pharmaceutical organisations	Manufacturer of hydrocortisone and fludrocortisone tablets in Pakistan is currently collaborating with CLAN and health professionals in Zimbabwe to facilitate access.

# CoP Update

The @MATES4Kids CoP is bringing together a broad range of stakeholders from across the globe to meet, connect, exchange knowledge, advocate, and raise awareness of issues facing the NCD community. The @MATES4Kids CoP uses the WHO's Knowledge Action Portal (KAP) as a platform to facilitate communication and collaboration.

## Structure

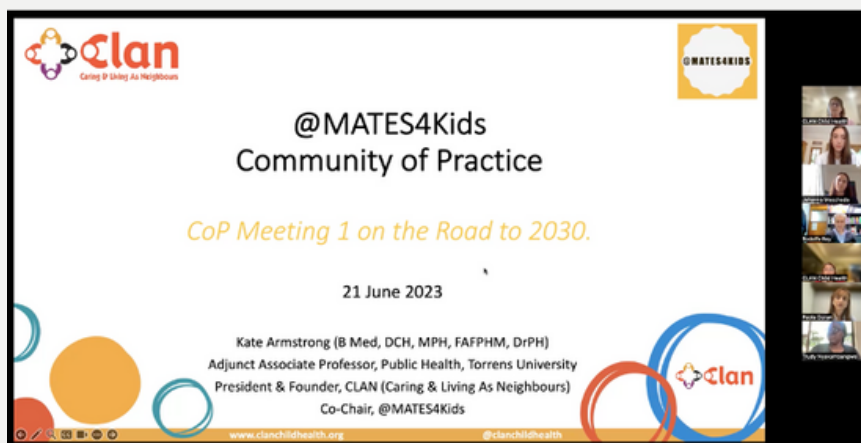
@MATES4Kids recognizes the six WHO regions of the world and collaborates with champions in each of these regions to facilitate and scale action locally. The CoP fosters collaboration through quarterly meetings where members receive the opportunity to share their successes, challenges, and other relevant insights with colleagues. Presenters are asked to specifically follow the 4P structure:

1. **Progress** - general updates on where things are at
2. **Pearls** - success stories that other CAH Communities and partners could learn from (with an emphasis on how it was achieved)
3. **Priorities** - Key challenges and problems the region will be focusing on in coming 3-6 months
4. **Partners** - who they worked with or plan to work

At each quarterly meeting, three regions report on their achievements and status, enabling each region to report twice each year. This rotation of meetings allows countries in similar time-zones to connect together in real time (AFR, AMR and EUR champions meet together, as do EMR, SEAR and WPR champions). Where possible, conferences and other events are leveraged to bring stakeholders together (as occurred in March 2023, with the International Meeting of Pediatric Endocrinology (IMPE) in Buenos Aires). Minutes from this meeting (including video recording) are available on the WHO KAP.

## First CoP Meeting

@MATES4Kids is excited to share that the first CoP meeting was a great success. An online meeting brought together 21 participants from across the globe to discuss their unique perspectives and relevant knowledge. This first meeting served as an opportunity to share information, introduce and welcome participants and stakeholders from AFR, AMR and EUR regions. An additional goal of the meeting was to introduce participants to the WHO KAP.



## **@MATES4Kids was proud to have the following speakers attend and address their respective topics:**

### **1. Kate Armstrong “CoP Meeting 1 on the Road to 2023”**

Kate welcomed attendees and reiterated the mission of @MATES4Kids, the group's three main objectives, alignment with the Knowledge to Action Framework, and an ultimate commitment to centring the CAH community. She provided several updates, shared upcoming events, and introduced the Secretariat team.

### **2. Sam Sieber from WHO Global Coordinating Mechanism on NCDs – Knowledge Action Portal Introduction**

Sam provided a helpful overview of the KAP, demonstrating how members of the CoP can register and access our page. He took everyone on a tour of the platform and explained all relevant functions of the KAP.

### **3. Tania Sanchez Bachega - “Newborn Screening in Brazil: Past, Present, and Future Perspectives”**

Tania discussed the state of NBS in Brazil, sharing research regarding the economic benefits and cost-effectiveness of avoiding late diagnosis through NBS. Despite the nation's public NBS practices since 2000, she talked about the inequality in the regional distribution of NBS and healthcare resources, particularly regarding rare disorders.

### **4. Johanna Meschede and Manuela Broesamle - CAH International**

Johanna and Manuela talked about the backstory and important work of CAH International. They shared about the current efforts to create workgroups with volunteers from a multitude of countries and to conduct patient surveys to better understand CAH patient and caregiver lifestyles. They aim to continue working to make research and other resources available online to the public.

### **5. Paola Duran - “GPED Survey Update for Latin America” and “Colombia Preliminary Profile”**

Paola shared updates for both Latin America broadly as well as her home country of Colombia. She discussed the recent distribution of a GPED survey on access to medicines to Mexico, Argentina, Bolivia and Colombia. She also discussed success in getting HC to Bolivia thanks to a large multistakeholder effort. She and her team are also making progress in improving conditions for children with CAH through actions such as gathering survey data for a national registry, strengthening CAH communities, and scaling universal access to NBS.

### **6. Prisca Mureriwa and Trudy Nyakambangwe - “CAH in Zimbabwe”**

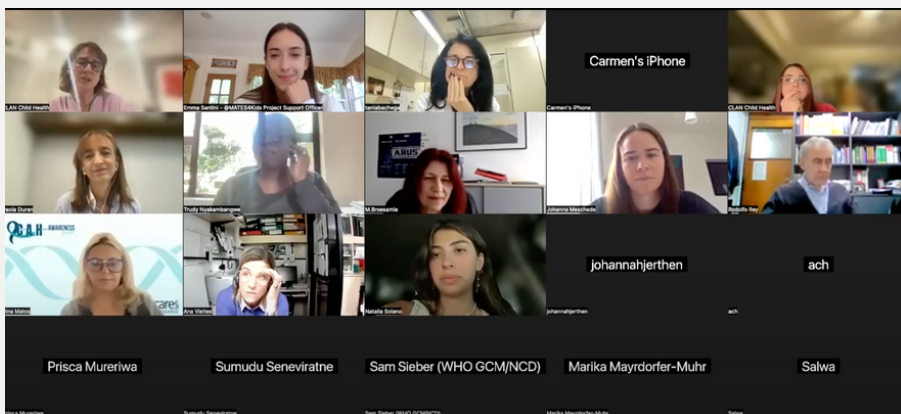
Prisca and Trudy shared that in their home country of Zimbabwe HC and FC are not readily available in public health facilities although they have received donations and currently work to make sure patients are receiving the drugs consistently. They discussed the strength of their CAH patient support groups and immense progress in running the DSD/CAH dedicated clinic which is retaining patients and seeing regular follow-ups.

### **7. Salwa AbdulBagi - Status of Sudan**

We were inspired to hear from Salwa who is navigating the challenges faced by CAH patients which have recently been amplified due to Sudan's civil war. Dialling in from Egypt, she stated that CAH is very difficult to diagnose, particularly outside of Khartoum, and that HC and FC are not readily available. Prior to the war, they had been preparing to have their first parent meeting and she is currently hoping to arrange shipments of HC and FC to Sudan.

### **8. Manuela Broesamle - CAH across Europe**

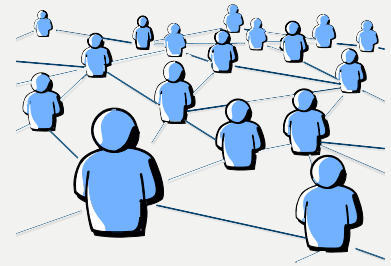
Manuela discussed that the treatment of CAH patients varies widely across Europe, a challenge combatted by the introduction of a European reference network for endocrinology. She shared information about current efforts to improve the education of physicians, increase access to medicines and the number of specialists with appropriate expertise throughout Europe, ensure important medical devices remain on the market, and introduce legal regulations to protect children who undergo sex operations.



*@MATES4Kids is grateful to everyone who participated and made this meeting such a success. This first CoP meeting facilitated connections, supported networking, shared more detailed information about the KAP, and allowed for improved access to a variety of key resources. Meeting minutes (and a video recording) are available on the KAP.*

# Platform for Collaborating and Connecting

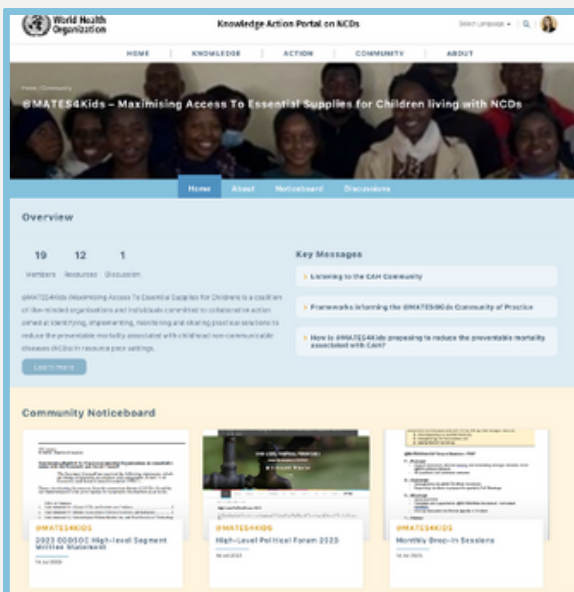
@MATES4Kids uses the **WHO KAP on NCDs** as the primary platform for connecting our CoP. The KAP is a “knowledge sharing and community platform dedicated to enhancing NCD prevention and control through multisectoral and multistakeholder collaboration.” It will facilitate accessible information and regular dialogue among our global network to drive practical action. @MATES4Kids believes the exchange of knowledge, resources, success stories, ideas, and more will profoundly benefit the international CAH Community and those who work to make it better.



On the KAP, various organizations, initiatives, and movements are represented by their own unique “community” page. Such pages can be open to any KAP user or restricted only to members of the community who must be approved by moderators in order to engage with the page. @MATES4Kid’s CoP is the latter, with the hope it remains an intimate network of individuals who are committed to active engagement and deeply connected to our mission.

@MATES4Kids would like to extend our sincere appreciation to Sam Sieber from the WHO Global Coordinating Mechanism on NCDs for his continued support and collaboration in establishing our CoP. It is through his assistance and attentiveness that our CoP has become such an effective place for collaboration. We thank Sam and his colleagues at WHO for their hard work in creating a space that will improve the lives of people living with NCDs on a global scale.

**We encourage everyone to take a tour of our current CoP on the KAP:**

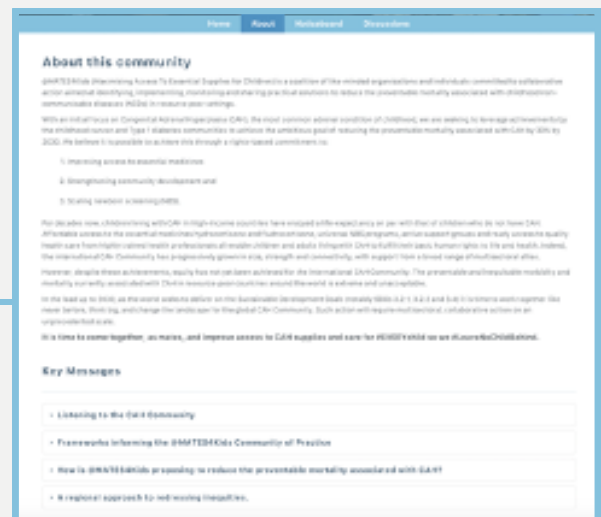


## Home

The home page essentially offers a summary of the rest of the CoP. Once a user gains access, the first thing they will see is the running count of members, resources, and discussions, as well as an introductory paragraph and a few of our key messages. The user will also be able to see a few of the most recent uploads to the community noticeboard in addition to upcoming community events on a calendar.

## About

When a user wants to know more about @MATES4Kids– our background, mission, vision, areas of focus, etc.– they can visit the About page to read a brief summary about the movement. This introduction to who we are is accompanied by four key messages, which discuss the values and frameworks most important to achieving change.





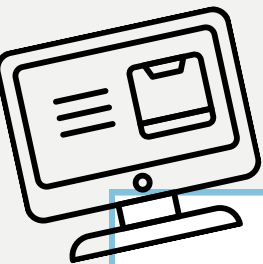
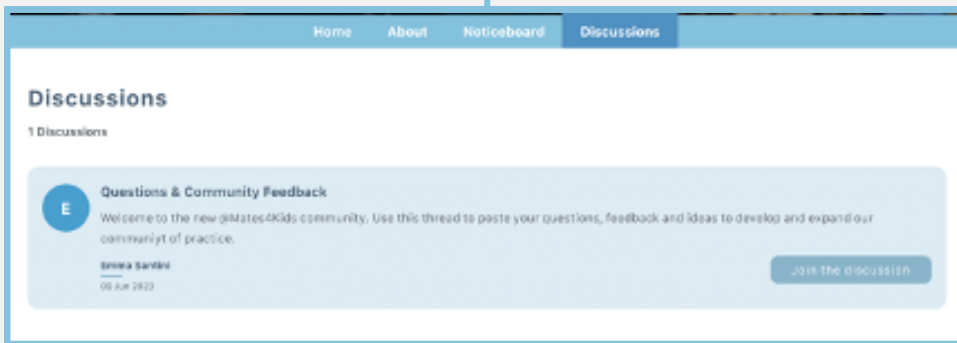
### Noticeboard

The Noticeboard is a place for updates and news that warrant the attention of our community members. When there are CoP announcements, they will be found on the Noticeboard, typically with important links to external pages.



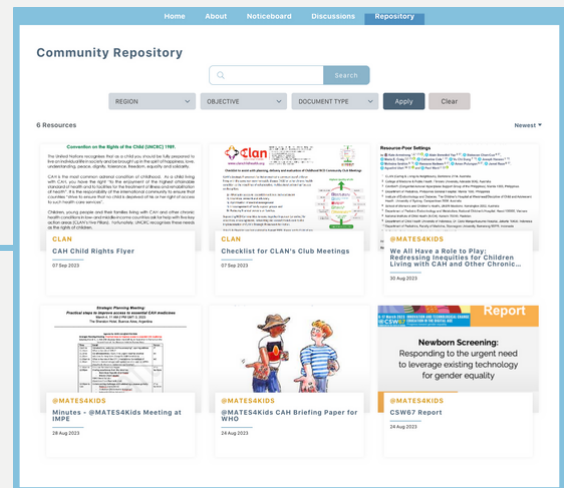
### Discussions

The Discussions page allows our communities to talk about important topics in a public fashion. Where there are subjects that require discourse, perhaps help is needed to overcome a hurdle or clarify an uncertainty, the discussion page will facilitate conversation among members allowing them to post their thoughts and leave comments.



### Knowledge Repository

The Knowledge Repository is the key centre for members to access resources and share critical information. It contains various types of documents ranging from published articles to meeting minutes. Community members have the option to filter the Knowledge Repository by WHO region, area of focus, and document type.



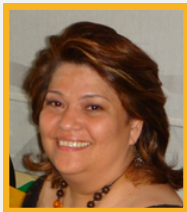


# Introducing the Secretariat



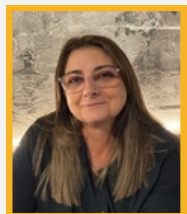
## **Kate Armstrong - Co-Chair**

Kate is the Co-Chair of @MATES4Kids and President of CLAN, co-founding the organization in 2004. Kate is a Public Health Physician and committed to equity for children and young people who are living with chronic health conditions in vulnerable circumstances. Her public health thesis focused on nephrotic syndrome in Vietnam. Kate is married to the co-founder of CLAN, Dave Hansen, and lives in Sydney, Australia.



## **Carmen Auste - Co-Chair**

Carmen is a seasoned international consultant and development practitioner with wide ranging expertise. Carmen is the Chief Executive Officer of Cancer Warriors Foundation and Vice President of the Cancer Coalition Philippines. As past president of Childhood Cancer International, Carmen is well placed to help the @MATES4Kids coalition learn from the successes of the childhood cancer community, Carmen is passionate about ensuring childhood cancer survivors enjoy affordable access to hydrocortisone and fludrocortisone medicines also.



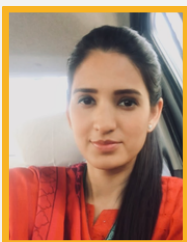
## **Cath Cole - Project Manager**

Cath Cole is the Project Manager of @MATES4Kids and the Vice President of CLAN. She has enjoyed a long career in government and has developed skills in several areas including policy development, project management, development and delivery of education and training, and preparation of foundational documents such as strategic and business plans. Cath was the Secretary from the time CLAN was incorporated as an independent Association through the Department of Fair Trading for four years and since 2011 has been active in the role of Vice President supporting and promoting the work of CLAN.



## **Emma Santini - Project Support Officer**

Emma Santini is the Project Support Officer for @MATES4Kids and the former United Nations Youth Representative for CLAN. She is a graduate of Lehigh University earning degrees in international relations and economics with a concentration on global sustainable development. Following the completion of her degree, she spent 9-months in Indonesia gaining fluency in Bahasa Indonesia and collaborating with CLAN's Indonesian partners to strengthen the nation's NCD community development. In addition to her role with @MATES4Kids, she is currently employed by the U.S. International Trade Administration. Emma is from New York, USA.



## **Rabia Baloch - Research Officer**

Rabia is a public health professional with 7+ years of experience in working with nonprofit and academia in Pakistan. She is currently doing a research fellowship at Aga Khan University focusing on maternal nutrition and birth outcomes in low- and middle-income countries. She has a strong desire and passion to contribute to public health globally through evidence-based research. Her research focus lies in the area of NCDs in children and adolescents. She has been supporting CLANs activities for last few years in voluntary capacity. She currently resides in Canada and aims to pursue a role in healthcare leadership.

## **Consultancy - Public Health Matters:**

Anthony is a public health physician who has worked in public policy, health promotion, digital health, and Aboriginal health. His health protection experiences include pandemic emergency response and environmental health. Anthony believes that 'health for all' is not just a pipe dream, but achievable in our generation.



## **Anthony Zheng, BMed MD MIPH FAFPH**

Anthony is a public health physician who has worked in public policy, health promotion, digital health, and Aboriginal health. His health protection experiences include pandemic emergency response and environmental health. Anthony believes that 'health for all' is not just a pipe dream, but achievable in our generation.

## Access to Medicines

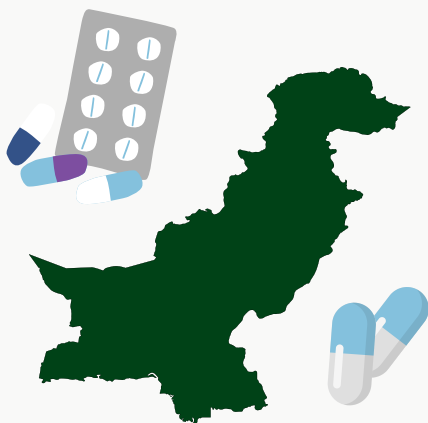
### Pakistan & Binden Pharma



One of the pressing challenges that Pakistan had been grappling with pertained to the availability and accessibility of essential medicines for Congenital Adrenal Hyperplasia (CAH). These vital medications were being imported from foreign countries, incurring substantial costs. In an earnest attempt to address this predicament, a solution was devised: local manufacturing. To embark on this path, it was imperative to ensure that these medications were included in the WHO's list of essential medicines.

Initially, local manufacturers exhibited a lack of interest due to the relatively modest profit margins stemming from the limited consumer base. However, in a laudable endeavour to safeguard human lives, Dr. Jamal Raza, the Director of NICH (National Institute of Child Health), undertook the initiative and succeeded in persuading one of Pakistan's local manufacturers. Dr. Latif Sheikh, serving as the Chief Pharmacist at a tertiary care private hospital, played a pivotal role in facilitating this transformative process. Tabros Pharma assumed the mantle of manufacturing these essential medicines, christening them as "Corticort 10 mg" (hydrocortisone) and "Flucort 0.1 mg" (fludrocortisone acetate). The cost of these medications was significantly lower than that of the previously imported counterparts. Hydrocortisone, once priced at 1 USD per tablet, now costs a mere 2 cents per tablet, while fludrocortisone, formerly priced at 1.4 USD, now stands at a mere 4 cents.

The year 2019 bore witness to the global impact of the COVID-19 pandemic, compounding the issue of medicine distribution in Pakistan. People found themselves expending substantial sums and effort on travel to procure these life-saving medications. In a collaborative effort supported by CLAN, a solution emerged: the medicines were dispatched directly to the doorsteps of individuals residing in rural areas across Pakistan. This proactive measure was implemented to ensure that no child was left without access to essential CAH medications, thereby averting life-threatening situations due to the lack of access.



Following the triumphant establishment of local CAH medicine production in Pakistan, the initiative took flight on the global stage in April 2022, with sustained backing from CLAN. These crucial medicines were exported to Zimbabwe, followed by a subsequent export to Sri Lanka in 2023. At the heart of this international endeavour, Mr. Muzamil Barry from Binden Pharma played a pivotal role in facilitating exports to other countries. Remarkably, the latest updates bear testament to the fact that not a single child afflicted with CAH has perished since the commencement of medicine exports to Zimbabwe.

# Ukraine & Partnership with Direct Relief



On March 7, 2022, the @MATES4Kids network urgently pivoted after receiving a request to assist with access to CAH medicines in Ukraine amidst their tragic and ongoing conflict. With thanks to Life for a Child, an NGO in our network championing efforts for children living with Type 1 diabetes, @MATES4Kids connected with Direct Relief for the first time, creating the foundation for a strong relationship and commitment to ongoing collaboration. A meeting with WHO later that month solidified the need for a multistakeholder approach to achieving access to medicine for children in Ukraine and helped identify priorities for critical action, including:

- Strengthen needs assessment & emergency response capacity of WHO relevant to childhood NCDs. Explore opportunities to support WHO to engage technical persons to assist with Needs Assessments/data & evidence-based approach to humanitarian donation response; more accurate estimates of the number of people who need support needed
- Identify conditions & medicines & equipment that should be integrated within emergency response lists for childhood NCDs
- Secure emergency CAH Medicines supplies for Ukraine CAH Community. International CAH Community will continue to facilitate short-term humanitarian donations for Ukraine CAH Community using identified routes to date
- Include CAH medications in list of drugs that should be integrated within emergency responses
- Review the humanitarian donation list to ensure all key childhood NCDs / medicines are included

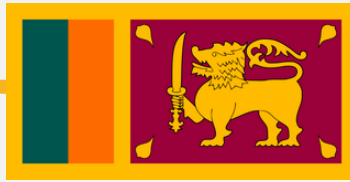


Following several additional meetings, including with the Ukraine team themselves, @MATES4Kids submitted an application to Direct Relief to commence processes required for emergency shipments of supplies. At the time, T1D supplies were sufficient, however, Ukraine was still in need of essential medicines for CAH patients as well as people living with other paediatric endocrine conditions. By May of 2022, all immediate medicine and equipment needs had been met, and emergency supplies of fludrocortisone, hydrocortisone, and L-Thyroxine had arrived.

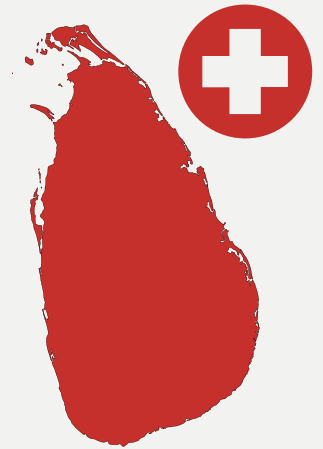


As of November 2022, all medicines required for the management of paediatric endocrine conditions in Ukraine were available to doctors and families. @MATES4Kids sincerely thanks Direct Relief and the many civil society organisations who assisted in achieving this remarkable outcome. This experience of securing supply of essential medicines for children in Ukraine serves as a promising example of how @MATES4Kids may approach similar humanitarian emergencies in the future.

## Sri Lanka



In 2022 CLAN received a request from paediatric endocrinologists in Sri Lanka for assistance securing access to hydrocortisone and fludrocortisone tablets for the 200+ children living with CAH in their country. The financial crisis in Sri Lanka was threatening access to affordable essential medicines, and families living in the most disadvantaged circumstances were particularly vulnerable. With thanks to the CAH Community of Germany and Binden Pharma in Pakistan (manufacturers of high-quality, affordable hydrocortisone and fludrocortisone tablets), CLAN was able to courier a one-year supply of enough medicine to treat at least 30% of all children with CAH in Sri Lanka for a 12-month period. The medicines arrived safely in Sri Lanka in March 2023, and doctors in Sri Lanka have been distributing the medicines to those children and families in greatest need. Sincere thanks to all involved in making this wonderful international collaboration possible.



## Bolivia



Members of the @MATES4Kids network experienced collaborative success in improving access to HC and FC in Bolivia. Bolivia currently mandates NBS, however, there is no access to HC or FC. Normally it is obtained from Argentina thanks to the commitment of paediatric endocrinologists like Dr. Noemi Oropeza, who bring will bring the medicine from across the border to families who need it. Over the past year, efforts from GPED, overseen by Dr. Jean Pierre Chanoine, helped to relieve Bolivia's challenges in ensuring access to HC and FC through working with the Canadian NGO Health Partners International (HPI). HPI works with pharmaceutical companies in Canada to send donations of essential medicines to low-income countries. They exclusively work with communities outside of Canada and their model ensures the medicines are always provided free of cost, although the organization typically requires the medicines to be brought in person to the country of interest by a carrier.

Arrangements were made to exchange the medicine at a meeting in Buenos Aires, however, due to political conditions in Bolivia the plan was not able to proceed as expected. Instead, HPI worked with Bolivia to overcome this challenge and made an exception to their usual procedure. They instead allowed GPED to ship the medicines to Bolivia, which were received by Dr. Bany Seaone from Santa Cruz and distributed by paediatric endocrinologists throughout the country. The boxes were well distributed to several different regions, with 21 sent to Santa Cruz, 8 to Cochabamba, 8 to La Paz, 2 to Oruro, and 1 to Chuquisaca.

This great success can be attributed to the dedication of paediatric endocrinologists across the Americas. GPED now works with two colleagues in Bolivia, at least one pharmaceutical company in South America, and hopefully with the families and the health authorities in Bolivia to actively support registration in the country. This will support an uninterrupted supply of HC and FC to ensure that once children are diagnosed they may also be treated.

# Community Development

## Zimbabwe



Zimbabwe has demonstrated the power of community development for CAH patients, with thanks to the country's dedicated health professionals, led by Dr Prisca Mureriwa, local NGOs (notably Child Youth Care, led by Trudy Nyakambangwe), Sally Mugabe Children's Hospital in Harare and Ministry of Health officials.

With the help of CLAN, Zimbabwe initiated the very first CAH patient support group meeting in June 2022. They have shared that there has been a great impact on the children and families involved. First, there is regular dialogue through a CAH WhatsApp group in a local language, facilitating a means for organization of and invitations to support group meetings. Through these meetings and the network they foster, patients improved their access to free medical consultations. There are now less hurdles to accessing medical guidance and education on their child's condition. This is strengthened through engaging various types of experts to volunteer their time and support the community. For instance, this past June, they connected the support group with a psychiatrist who came to speak to them about the coping with and overcoming the mental toll of CAH.



An example how the support group impacts children living with CAH is the story of siblings Takunda and Makanaka. Makanaka was fortunately diagnosed when she was born, and despite adversity she is growing well. While Takunda was never diagnosed with CAH, doctors in Zimbabwe suspected he may have been misdiagnosed. The family worked together with the support group to reach a better place and are now positioned well to handle condition and even support other families at the same time. During one of the CAH support group meetings, Takunda and Makanaka presented what they had gone through and how they are empowered by the support group. This is what community development is all about— sharing experiences, inspiring one another, and connecting with people who understand what it is like to live with CAH.

This holistic approach to community development is uplifting CAH patients and their families, and Trudy shares that their meetings “empower them not only economically, but encourages them to claim their rights in the healthcare ecosystem so that they can receive the services they deserve.”



# IMPE Summit

Agenda for IMPE CAH@MATES4Kids

Strategic Planning Meeting: Practical steps to improve access to essential CAH medicines

Thursday March 9, 10:00 AM (Virtual) and Friday March 10, 10:00 AM (Virtual) from the second floor of The Sheraton Hotel (Buenos Aires)

Time	Detail	Present
10:00 to 11:00am	Introduction, welcome and "kick-off" opening address What is the role of GPED?	JP*
11:00am to 11:30am	CAH@MATES4Kids / CLAN / The urgent need for practical solutions for long-term shortage of CAH Community	MA
11:30am to 12:00pm	What is the role of the CAH Stakeholder Consortium of Pediatric Endocrinology and Diabetes such as APPE?	MLC
12:00pm to 12:30pm	Global Pediatric Endocrinology and Diabetes Society Focus on the American Region Sharing experiences from the Americas - American Region (CLAN, MEND) - Mexico City (CAH@M)	JP to facilitate
12:30pm to 1:00pm	Break (Guests invited) Questions from floor welcomed	
1:00pm to 1:30pm	Understanding the regions and addressing common global issues - Global Health Issues - Diabetes (What is the MEND?) - Endocrine (What is the MEND?) - Nutrition (What is the MEND?) - Pediatrics (What is the MEND?)	JP to facilitate
1:30pm to 2:00pm	Regional discussion - Commitment / roles and responsibilities - Agree on a list / approach / ways of working together - Agree on a list of priorities - Agree on a list of indicators	ML to facilitate
2:00pm to 2:30pm	Regional discussion - Agree on a list of priorities / roles and responsibilities - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together	ML to facilitate
2:30pm to 3:00pm	Regional discussion - Agree on a list of priorities / roles and responsibilities - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together	ML to facilitate
3:00pm to 3:30pm	Regional discussion - Agree on a list of priorities / roles and responsibilities - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together - Agree on a list of indicators / ways of working together	ML to facilitate

\* Light refreshments will be provided

Community development not only benefits people living with NCDs but also their health professionals who work to diagnose and treat conditions like CAH. By bringing members of the @MATES4Kids network together for the first time to discuss mutual goals for the movement, paediatric endocrinologists came together as one community, fostering connections and cultivating solidarity in pursuit of a brighter future for children living with CAH across the globe.

In April of 2023, @MATES4Kids conducted an inaugural meeting co-chaired by CLAN and GPED (Global Paediatric Endocrinology and Diabetes) which convened at the IMPE (International Meeting of Pediatric Endocrinology) Conference, allowing interested stakeholders to share experiences, identify priorities and agree on future strategies. 16 participants joined in person and 9 participants joined via Zoom

Stakeholders aimed to discuss issues around access to medicines that are common to paediatric endocrinologists in different settings, learn how PAHO supports access to medicines in Latin America, understand the CAH@MATES4Kids movement, propose concrete measures by which GPED and ICPE can engage in the CAH@MATES4Kids movement, and seek endorsement on proposed next steps.

IMPE 2023 facilitated communication between global and regional paediatric endocrine societies and participants agreed to an implementation plan for strategic action in the six WHO regions utilising the Knowledge To Action Framework. The group developed tools to aid the identification of priorities, guide implementation, monitor progress and evaluate outcomes include: CLAN Snapshot Survey; CAH Health Needs Assessment; CAH Equity Scorecard; Child Health Equity Checklist Count (CHECC) Scorecard and @MATES4Kids Monitoring Indicators. @MATES4kids also determined that champions for each WHO Region and a CoP will facilitate a Continuous Quality Improvement approach to critical action with an agreed timeline. Finally, members discussed that drug/monetary donations from organizations such as Direct Relief, GPED, CARES Foundation, the international CAH Community and CLAN have already supported CAH Communities in Ukraine, Sri Lanka and Zimbabwe and will hopefully work with @MATES4Kids to do so in the future.



We extend our gratitude to presenters John-Pierre Chanoine, Maria Craig, Elbi Morla, Raul Calzada, Christopher Lim, Aman Pulungan, Jamal Raza, Prisca Kudzai Matyanga, and Salwa Musa, as well as Rodolfo Rey who helped make the meeting possible.



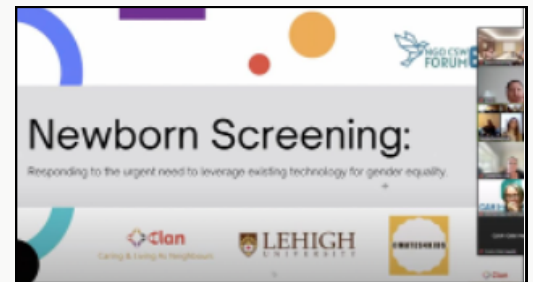
# Newborn Screening

## Indonesia at CSW67



CLAN engaged in events relating to the United Nations Commission on the Status of Women 67th (CSW67) Session to support the work of the @MATES4Kids (Maximising Access to Essential Supplies for Kids) movement. The CSW67 Priority theme was 'Innovation and technological change and education in the digital age, for achieving gender equality and the empowerment of all women and girls'. The Review theme was 'Challenges and opportunities in achieving gender equality and the empowerment of rural women and girls'. CLAN's parallel event at the conference highlighted the urgent need to scale NBS as part of a comprehensive and strategic approach to achieving the goals of @MATES4Kids.

CLAN was proud to host a hybrid Parallel Event for the Commission on the Status of Women 67th Session at the United Nations Church Centre on the 6th of March 2023, and partner with global changemakers to discuss the role of NBS in driving gender equity in the contemporary technological age. CLAN's Parallel NGO Event was entitled 'Newborn Screening: Responding to the Urgent Need to Leverage Existing Technology for Gender Equality'. The event brought together experts from around the world to highlight the importance of scaling NBS to achieve the SDGs and reduce gender inequalities affecting young girls with NCDs in resource-poor settings. Speakers from Australia, Austria, Indonesia, New Zealand, Pakistan, Zimbabwe and the United States of America participated, representing a broad range of NGOs and organisations working in the field of NBS and caring for children living with NCDs.



The event began with a welcome by United Nations Youth Representative, Nikki Pasterczyk, and an introduction to CLAN by Ms Sofia Rousseau. With thanks to CARES Foundation, we began the event with a success story of NBS, from the mother of a child with CAH who achieved diagnosis through NBS. CLAN's President and Co-Chair of @MATES4Kids, Dr. Kate Armstrong, then shared about the coalition's mission, vision, and relationship to NBS.

The next segment of the event involved keynote speakers to discuss the efforts to scale NBS currently taking place in Indonesia. The first speaker, the Honourable Mr Budi Gunadi Sadikin, Minister for Health for Indonesia shared the bold vision for Indonesia to expand NBS across the Archipelago region, justified by the burden of disease arising from a lack of screening for conditions like CAH and the demonstrated positive outcomes associated with improved NBS. Following this, Professor Dr Aman Pulungan from the International Paediatric Association shared how NBS will reduce mortality and achieve the SDGs, by contrasting the distribution of both CAH and NBS coverage across regions and reflecting on the results of an Indonesian cross-sectional multi-section study of NBS. Professor Aman explored the need for scaling NBS, including the outcomes of inaccessibility of NBS, and highlighting obstacles facing the scaling of NBS in specific regions. CLAN Intern Fatima Idaayen then discussed why NBS is so important for achieving gender equity, reflecting on the inequitable burdens of congenital disorders upon girls and female caregivers, and sharing the results of interviews with 40 Indonesian families and their concerns arising from late diagnosis of CAH. To wrap up this section, CLAN Intern and current member of the @MATES4Kids Secretariat Emma Santini analysed the cost-effectiveness of NBS, highlighting the need for economic analyses to promote policy-making discussions.

***The @MATES4Kids network in Indonesia demonstrated both the importance of high-level advocacy as well as the multifaceted ways to strengthen NBS.***

[\*link here\*](#)



# Other Achievements

## Briefing Paper



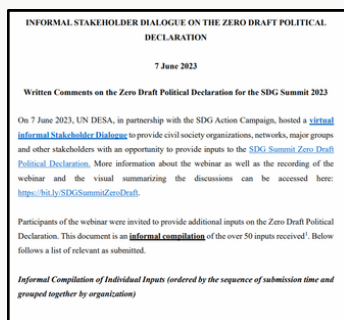
In February 2022, the @MATES4Kids movement prepared a Briefing Paper outlining our ambitious goals and proposed activities to help achieve the SDGs.

The briefing paper combines expertise, insights, data and examples from around the world to paint a detailed picture of the current circumstances and challenges facing the international CAH Community, and outlines a path forward for change. This paper presented a specific request to the World Health Organisation to work with @MATES4Kids to develop an innovative forum. From such collaboration, strategic action will identify the critical, practical, scalable actions needed to redress inequities and optimise affordable access to the essential medicines and equipment needed by #EVERYchild living with CAH around the world if they are to survive and thrive.

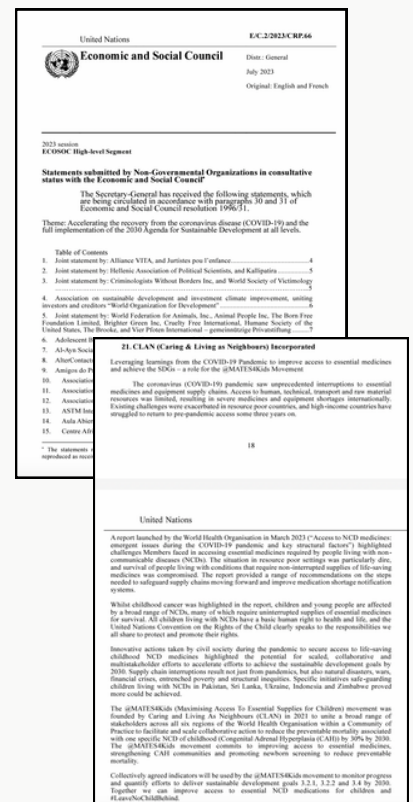
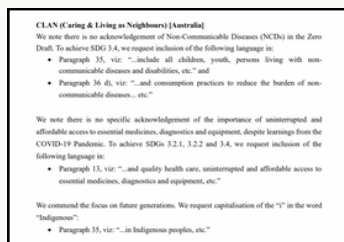
## High-Level Political Forum Advocacy Statement

@MATES4Kids is grateful for continuous opportunities at the United Nations to advocate at the highest levels, and share the voices of CAH Communities in lower-income countries on the international stage.

In July 2022, CLAN's written statement for the 2023 High-level Segment, detailing the objectives of the @MATES4Kids movement, was published and available to read on the [2023 ECOSOC High-level Segment](#) and [2023 High-Level Political Forum websites](#).



In June of 2023, CLAN supported the @MATES4Kids movement at the high-level by engaging in the informal Stakeholder Dialogue by providing inputs to the [SDG Summit Zero Draft Political Declaration](#). CLAN requested clear acknowledgement of NCDs and suggested changes in language in line with SDG 3.4. Additionally, in recognition of SDGs 3.2.1, 3.2.2, and 3.4, CLAN championed one of the @MATES4Kids priorities through requesting inclusion of language that makes specific reference to the importance uninterrupted and affordable access to essential medicines, diagnostics, and equipment. Finally, the input from CLAN requested capitalization of the "i" in the work "Indigenous" to further demonstrate respect for all members of the international CAH Community.





## Call for Action

Achieving the vision, mission and objectives of  
@MATES4Kids will take a village...

We encourage everyone to get involved – together  
we can make a difference!

To find out more, please visit @MATES4Kids on the  
WHO KAP and contact the champions in your  
region who are driving change.

#MATES4Kids

#LeaveNoChildBehind

#AccessToMedicines

#EVERYchild

#NewbornScreening

#WeAreCAH