@MATES4KIDS

MAXIMISING ACCESS TO ESSENTIAL SUPPLIES FOR CHILDREN

Activity Report

July 2023 - December 2024

@MATES4Kids (Maximising Access to Essential Supplies for Children) Annual Activity Report 2023-2024.

@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 July 2023 to December 2024.

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.

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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.

We are committed to protecting our planet through sustainable practices and responsible resource management. Recognising the link between planetary health and human well-being, we strive to integrate sustainability into all we do for a healthier future.

Caring & Living As Neighbours

www.clanchildhealth.org

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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:

1. Improving access to essential medicines
2. Strengthening community development
3. 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 (KAP), which provides an online platform for the exchange of information as well as regular Community of Practice (CoP) meetings, members of the @MATES4Kids movement are taking advantage of various communication channels to work together.

This annual report (July 2023 - December 2024) details the foundational activities and the structure of @MATE4Kids, as well as the activities and events we participated in during the last year. 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.

As the world moves toward 2030 and the delivery of the Sustainable Development Goals (SDGs), it is time to collaborate like never before, think boldly and transform the landscape for the global CAH community. Achieving this will require an unprecedented multisectoral and collaborative effort, but it will contribute significantly to advancing multiple SDGs, including SDGs 1, 3, 10 and 17.

SDG 17 - Partnership for the Goals
@MATES4Kids and the international CAH community

SDG 10 - Reduce Inequality within and among countries
SDG 10.2 - Promote universal social, economic and political inclusion

SDG 3 - Good health and well-being
SDG 3.8 - Achieve Universal Coverage
SDG 3.4 - Reduce preventable NCD mortality
SDG 3.2.2 - End neonatal mortality (0-27 days)
SDG 3.2.1 - End preventable deaths of children <5 years
SDG 3.b - Affordable access to essential medicines & vaccines
SDG 3.c - Finance & strengthen workforce

SDG 1 - End poverty in all its forms
Reduce out-of-pocket expenditures (OOPE) and catastrophic health spends associated with CAH

@MATES4Kids Timeline

HC & FC on WHO EMLc

1st UN HLM NCDs

2nd UN HLM NCDs

2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 Next

CAH

T1D

ASD

OI, DMD, Nephrotic Syndrome

RHD

@MATES4Kids established

We are here

2017 2018 2019 2020 2021 2022 2023 2024 2025 2026 2027 2028 2029 2030

Nodding Syndrome, Epilepsy

3rd UN HLM NCDs

Colombia
Sri Lanka
Kenya
Nigeria
Solomon Islands
Indonesia
Uganda
Zimbabwe

4th UN HLM NCDs

@MATES4Kids is committed to strategic action to help achieve the SDGS by 2030

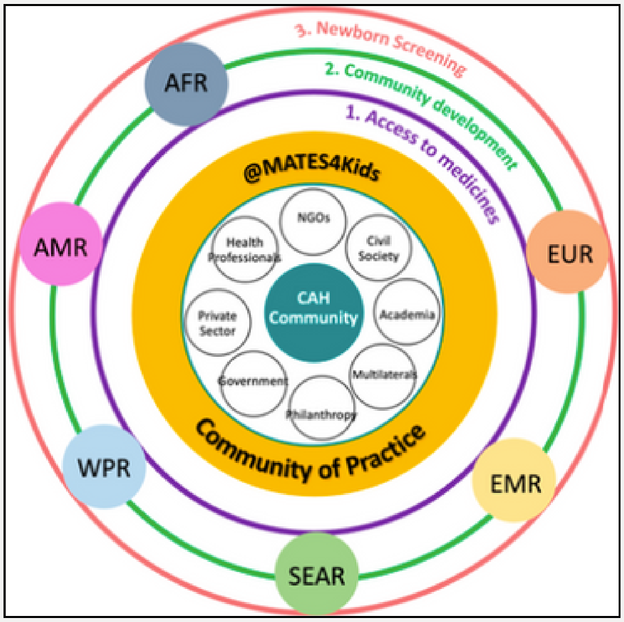
Strategic Framework

Maintaining the CAH community as 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:

- The African Region (AFR)
- Region of the Americas (AMR)
- Eastern Mediterranean Region (EMR)
- European Region (EUR)
- South-East Asian Region (SEAR)
- Western Pacific Region (WPR)

The @MATES4Kids CoP unites a diverse range of stakeholders, fostering collaboration among champions across six regions to share achievements and scale critical action locally.



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

Improving access to essential medications and equipment

Strengthening CAH and other childhood NCD Communities

Scaling Newborn Screening

Improving access to essential medications and equipment

Affordable access to medications for CAH and childhood NCDs must be prioritized in every country. Hydrocortisone and fludrocortisone tablets, both included in the WHO's Essential Medicines List for Children (EMLc), should be incorporated into every National Essential Medicines List (NEML). This is especially crucial in countries where CAH is included in national NBS panels. Unfortunately, it is not uncommon for nations to implement NBS programs without first ensuring that the necessary medicines are affordably accessible. This oversight creates a devastating burden for affected families, leaving them without the lifesaving treatments their children need.

Inclusion of hydrocortisone and fludrocortisone in NEMLs is only the first step. These medications must also be covered under national insurance schemes to ensure affordability and accessibility. Universal Health Coverage (UHC) is vital for supporting childhood NCD Communities. Robust systems must be established to prevent families of children diagnosed with NCDs from facing financial ruin due to healthcare costs. No family should have to choose between their child's health and their financialstability.

Strengthening CAH and other childhood NCD communities

Since 2004, CLAN has worked collaboratively with a diverse range of stakeholders to drive meaningful change for CAH communities in lower-income countries. Guided by CLAN's Strategic Framework for Action and five pillars, the organization is committed to improving the quality of life for children diagnosed with CAH and other NCDs. This is achieved through a holistic, sustainable community development approach that addresses the biological, psychological, social and cultural needs of affected families.

Even in resource-poor settings where children with NCDs have access to medication, numerous barriers prevent them from achieving a quality of life comparable to their peers in wealthier nations. These barriers must be addressed. Families of children living with CAH have consistently identified five critical areas where support is needed:

- Affordable access to essential medicines and equipment
- Education, research and advocacy
- Optimal medical management
- Strong family support groups
- Freedom from poverty and financial independence

These five pillars serve as a foundation for action. However, ongoing consultation with CAH communities is essential to ensure that the needs and perspectives of children and families living with NCDs are central to health system reforms. By prioritizing their voices, we can improve health outcomes and reduce the preventable mortality and morbidity associated with CAH.

Co-designing all initiatives with CAH communities is essential to achieving the highest possible quality of life for all. Empowered NCD communities benefit not only children and families but also strengthen health professionals and systems, fostering a more equitable and sustainable future.

Scaling Newborn Screening

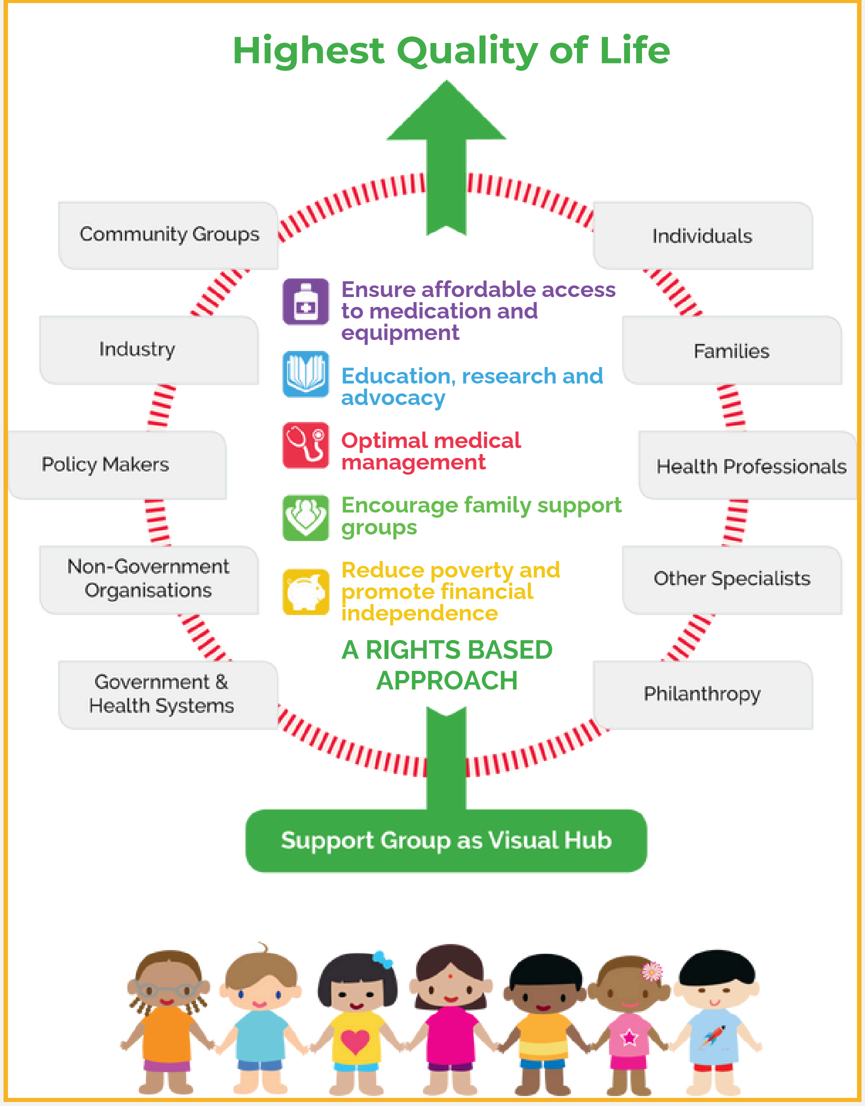
NBS must be scaled globally, with equity at the forefront of implementation efforts. The inclusion of NBS in global development agendas and universal health coverage discussions is critical. Governments must invest in NBS technology while establishing accountability measures to ensure optimal outcomes and promote the equitable use of resources. Scaling NBS requires active dialogue about available technologies and their effectiveness. To inform this dialogue, data from resource-poor settings must guide an evidence-based approach, highlighting the benefits of NBS and reinforcing its value to policymakers. Ultimately, this dialogue should lead to an international agreement on the equitable implementation of NBS.

Screening for congenital hypothyroidism (CH) must remain the highest priority, as CH is more prevalent than CAH and contributes significantly to the global burden of developmental delay. However, as seen in high-income countries, the expansion of NBS panels to include other NCDs, such as CAH, will naturally follow CH screening. As NBS programs are progressively scaled, accountability measures must be established to support continuous quality improvement initiatives. These measures will ensure the best possible outcomes and the efficient use of resources, paving the way for equitable and sustainable NBS systems worldwide.

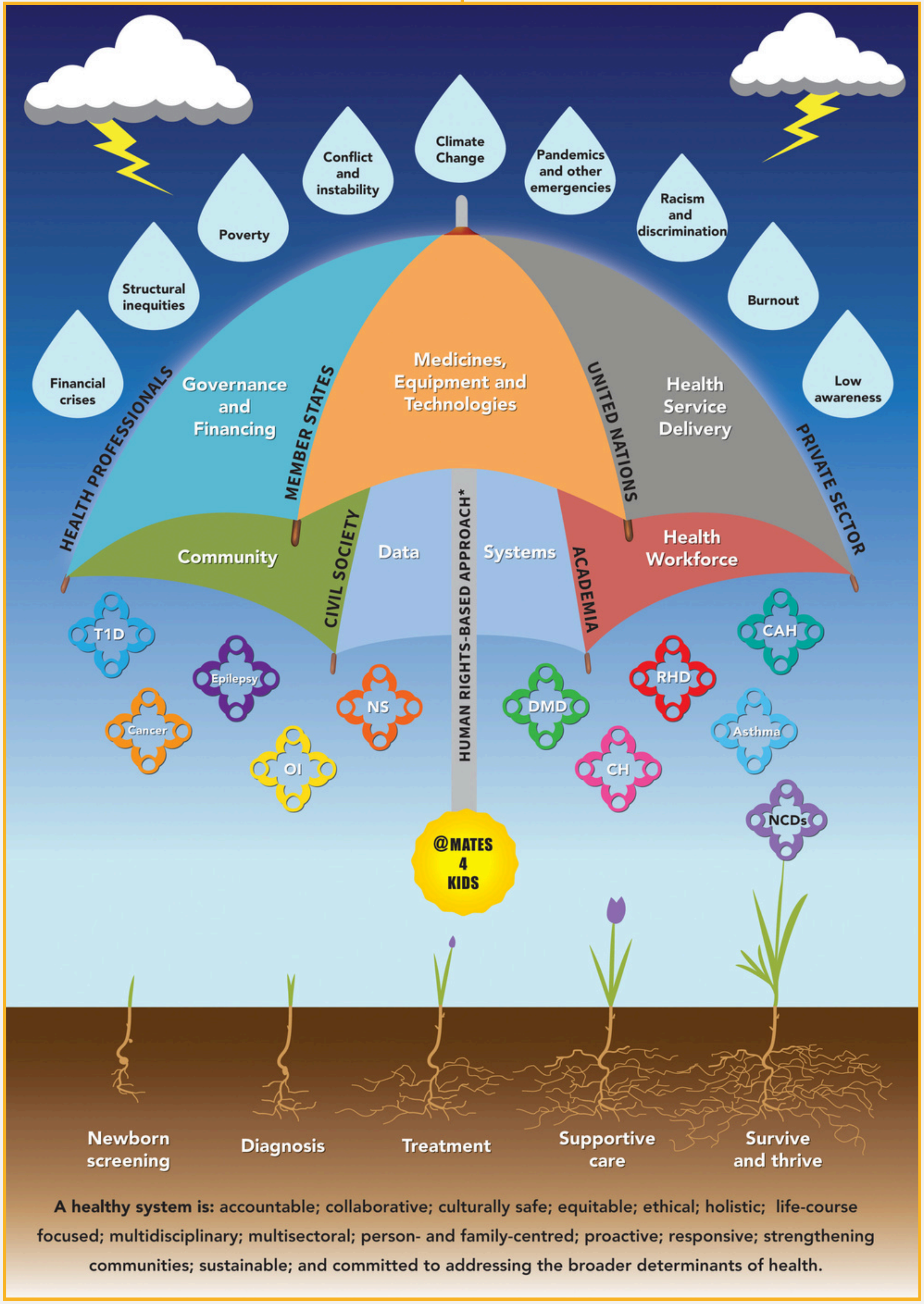
Additional Frameworks

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

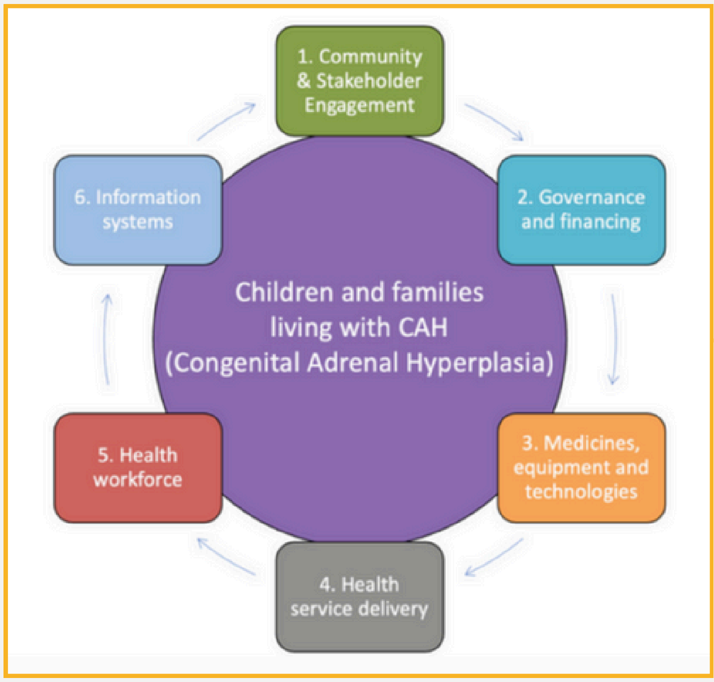
1. **CLAN's Strategic Framework for Action**, which promotes a rights-based approach, focuses on a community of children living with a particular NCD as the visual hub for all collaborative action. This approach builds engagement between a broad range of multisectoral stakeholders and facilitates collective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



2. **The @MATES4Kids Umbrella** is a healthcare strengthening approach to protecting and promoting the rights of children living with CAH and other childhood NCDs to survive and thrive.

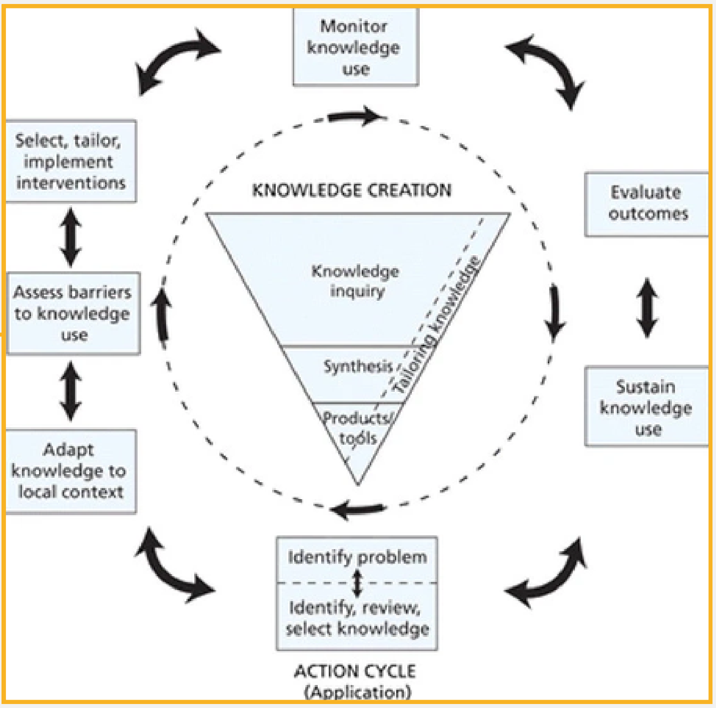


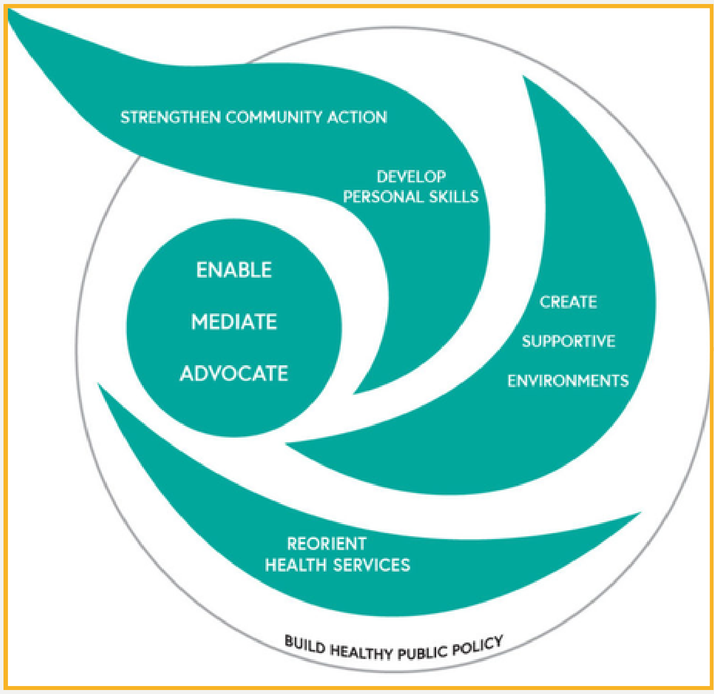
A healthy system is: accountable; collaborative; culturally safe; equitable; ethical; holistic; life-course focused; multidisciplinary; multisectoral; person- and family-centred; proactive; responsive; strengthening communities; sustainable; and committed to addressing the broader determinants of health.



3. The **WHO's Six Building Blocks for Strengthening Health Systems**, adapted with a person-, family- and community-centred approach, offers a powerful framework for collective action that is founded on meaningful engagement of people with lived experience to achieve healthy communities.

4. **The Knowledge to Action Framework** promotes an evidence-based, continuous quality improvement approach to enhancing health outcomes. It emphasizes locally adapted efforts to maximize the impact of priority interventions. By refining knowledge, tools and resources over time, the framework ensures sustainable, scalable solutions to address specific health challenges effectively.





5. **The Ottawa Charter** outlines five key action areas: creating supportive environments, developing personal skills, reorienting health systems, strengthening community action, and building healthy public policy. It emphasizes the strategies of enabling, mediating, and advocating to empower communities and address the broader determinants of health, promoting equity and well-being globally.

6. **The Pan American Health Organization (PAHO) Strategic Fund** facilitates pooled procurement of essential medicines and equipment through regional technical cooperation. Its significant achievements provide valuable insights for future initiatives benefiting childhood NCD Communities globally. Ongoing two-way learning and consultation can further enhance the Fund's impact by identifying opportunities to improve access and equity for these 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 the impact of 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 levels.
- **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-centered 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.

Community of Practice Update

The @MATES4Kids CoP (Community of Practice) brings 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 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 have the opportunity to share their successes, challenges and other relevant insights with colleagues. Presenters typically follow the 4P structure:

1. **Progress**: General updates on current activities and milestones achieved
2. **Pearls**: Success stories highlighting lessons and strategies that other CAH communities and partners can adopt
3. **Priorities**: Key challenges and focus areas for the next 3-6 months
4. **Partners**: Collaborations, including past and planned partnerships

At each quarterly meeting, three regions report on their achievements and updates, ensuring each region reports twice a year. This rotation allows countries in similar time zones to connect in real-time (e.g., AFR, AMR and WPR champions meet together, as do EMR, SEAR and WPR champions). Whenever possible, conferences and events are leveraged to convene stakeholders, such as during the 77th World Health Assembly (WHA77) in Geneva in May 2024. Meeting minutes and recordings are available on the WHO KAP.

June 2023
CoP #1
AFR, AMR EUR

September 2023
CoP #2
EMR, SEAR WPR

December 2023
CoP #3
AFR, AMR EUR

February 2024
CoP #4
CSD

March 2024
CoP #5
CSW

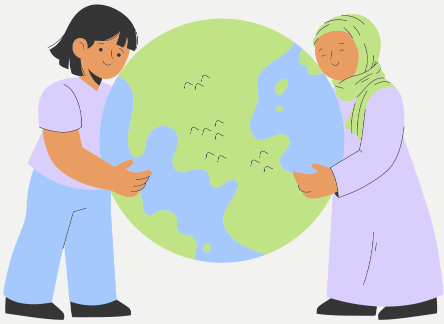
May 2024
CoP #6
WHA77

May 2024
CoP #7
SIDS4

August 2024
CoP #8
AFR, AMR EUR

December 2024
CoP #9
EMR, SEAR, WPR

Connecting on the Knowledge Action Portal



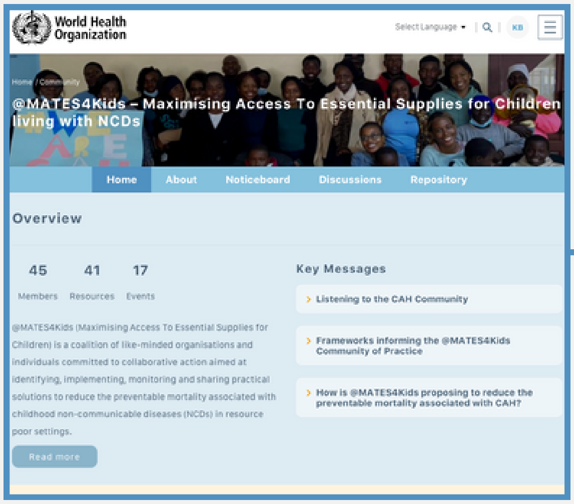
@MATES4Kids uses the WHO Knowledge Action Portal (KAP) on NCDs as the primary platform for connecting our Community of Practice (CoP). The KAP is a "knowledge-sharing and community platform dedicated to enhancing NCD prevention and control through multisectoral and multistakeholder collaboration." It facilitates accessible information and regular dialogue among our global network to drive practical action.

@MATES4Kids believes that the exchange of knowledge, resources, success stories, ideas, and more profoundly benefits the international CAH Community and those working to improve it.

On the KAP, various organisations, initiatives and movements are represented on the "community" page. These pages can either be open to all KAP users or restricted to members approved by moderators. @MATES4Kids' CoP is in the latter category, ensuring it remains an intimate network of individuals 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 live of people living with NCDs on a global scale.

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



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

Overview

45 Members
41 Resources
17 Events

@MATES4Kids (Maximising Access To Essential Supplies for Children) is a coalition of like-minded organisations and individuals committed to collaborative action aimed at identifying, implementing, monitoring and sharing practical solutions to reduce the preventable mortality associated with childhood non-communicable diseases (NCDs) in resource poor settings.

Key Messages

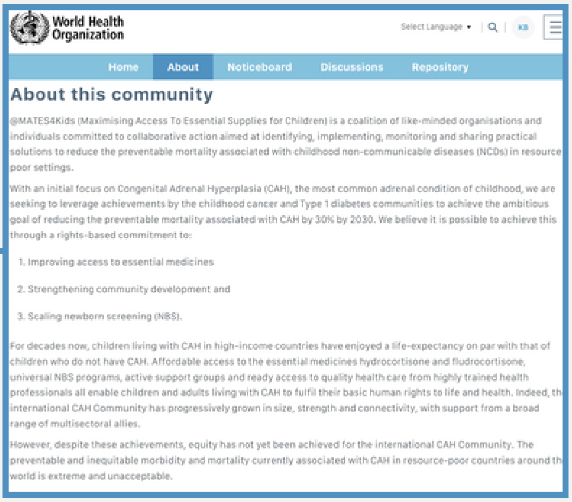
- Listening to the CAH Community
- Frameworks informing the @MATES4Kids Community of Practice
- How is @MATES4Kids proposing to reduce the preventable mortality associated with CAH?

Home

The home page provides an overview of the rest of the CoP. Upon gaining access, users will first see a running count of members, resources, and discussions, along with an introductory paragraph and key messages. They will also find recent uploads to the community noticeboard and a calendar highlighting upcoming community events.

About

When users want to learn more about @MATES4Kids—our background, mission, vision and areas of focus—they can visit the "About" page for a brief overview of the movement. This introduction is accompanied by four key messages that highlight the core values and frameworks essential to driving change.



About this community

@MATES4Kids (Maximising Access To Essential Supplies for Children) is a coalition of like-minded organisations and individuals committed to collaborative action aimed at identifying, implementing, monitoring and sharing practical solutions to reduce the preventable mortality associated with childhood non-communicable diseases (NCDs) in resource poor settings.

With an initial focus on Congenital Adrenal Hyperplasia (CAH), the most common adrenal condition of childhood, we are seeking to leverage achievements by the childhood cancer and Type 1 diabetes communities to achieve the ambitious goal of reducing the preventable mortality associated with CAH by 30% by 2030. We believe it is possible to achieve this through a rights-based commitment to:

1. Improving access to essential medicines
2. Strengthening community development and
3. Scaling newborn screening (NBS).

For decades now, children living with CAH in high-income countries have enjoyed a life-expectancy on par with that of children who do not have CAH. Affordable access to the essential medicines hydrocortisone and fludrocortisone, universal NBS programs, active support groups and ready access to quality health care from highly trained health professionals all enable children and adults living with CAH to fulfil their basic human rights to life and health. Indeed, th

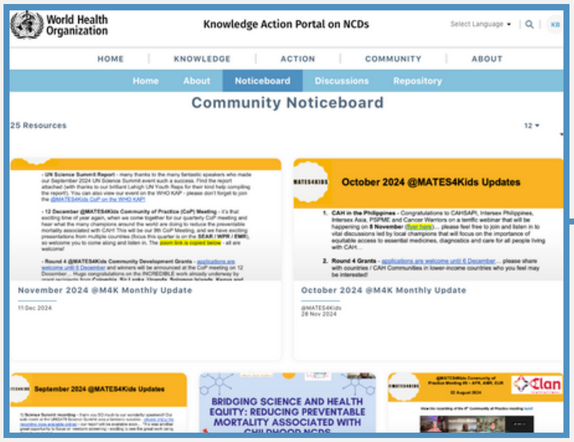
international CAH Community has progressively grown in size, strength and connectivity, with support from a broad range of multisectoral allies.

However, despite these achievements, equity has not yet been achieved for the international CAH Community. The preventable and inequitable morbidity and mortality currently associated with CAH in resource-poor countries around th

world is extreme and unacceptable.

Noticeboard

The "Noticeboard" serves as a hub for monthly updates and important news for our community members. CoP announcements will be posted here, often accompanied by key links to external pages for further information.



Community Noticeboard

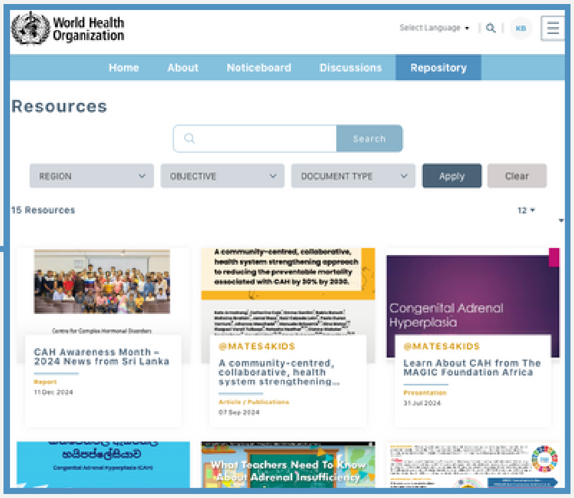
25 Resources

November 2024 @M4K Monthly Update
11 Dec 2024

October 2024 @M4K Monthly Update
@MATES4Kids
28 Nov 2024

Repository

The "Repository" is the central hub for members to access resources and share essential information. It includes a wide range of documents, from published articles to meeting minutes. Community members can filter the "Repository" by WHO region, area of focus, and document type for easier navigation.



Resources

15 Resources

CAH Awareness Month – 2024 News from Sri Lanka
Report
11 Dec 2024

@MATES4KIDS
A community-centred, collaborative, health system strengthening...
Article / Publications
07 Sep 2024

@MATES4KIDS
Learn About CAH from The MAGIC Foundation Africa
Presentation
31 Jul 2024

Register on the KAP and join our community!

We regularly update our CoP on the KAP- join our community to stay informed and engaged!

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 is 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 the 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.

Katie Blomkvist - Project Officer

Katie Blomkvist is the Project Officer for @MATES4Kids and one of the current United Nations Youth Representatives for CLAN. Katie is currently a graduate student at Lehigh University pursuing her Master's in Public Health. With experience in public health research, global advocacy, and refugee resettlement, Katie is committed to advancing health equity and social justice. Katie is from New Jersey, USA.

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.

Community Development Grants

In 2024, CLAN (Caring & Living As Neighbours) celebrated its 20th anniversary by launching a @MATES4Kids grant initiative to support innovative community-driven projects addressing the needs of CAH communities in resource-poor settings. This initiative aligns with @MATES4Kids' goal of reducing preventable mortality associated with CAH by 30% by 2030 through sustainable, collaborative solutions.

As part of this commitment, @MATES4Kids have announced nine recipients of AUD $1,000 Community Development Grants. These grants were awarded to projects focused on:

1. Improving access to life-saving CAH medicines,
2. Strengthening CAH communities, and/or
3. Scaling Newborn Screening (NBS) programs to enable early diagnosis

By 2030, @MATES4Kids aims to deliver 40 grants, fostering equity and innovation in global health. Eligible projects are required to prioritize low- and middle-income countries and engage local stakeholders, including health professionals and individuals living with CAH. This program underscores the shared mission of @MATES4Kids and CLAN to reduce preventable morbidity and mortality associated with CAH and to empower communities worldwide.

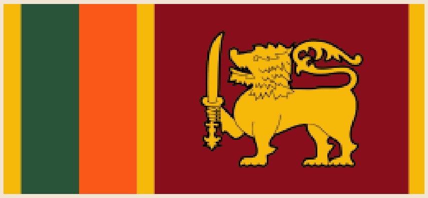
Round 1 February 2024	**Round 2** May 2024	**Round 3** September 2024	**Round 4** December 2024
• Colombia • Sri Lanka	• Kenya • Solomon Islands • Uganda	• Nigeria	• Indonesia • Zimbabwe • Kenya

Round 1

Colombia

Fundación SiEndo
Fundación Cardioinfantil

Dr. Paola Duran Ventura, Chief of Paediatric Endocrinology at Fundaciòn Cardioinfantil and the Director of Fundación SiEndo, organised Colombia's first CAH Club meeting in March 2024. Supported by a Community Development Grant, the team developed a culturally tailored Health Needs Assessment and educational resources to help children understand their bodies and CAH. While parents attended educational presentations, children played and learned in a supportive environment. The event also fostered a sense of community, as many children met others with the same condition for the first time.



Sri Lanka

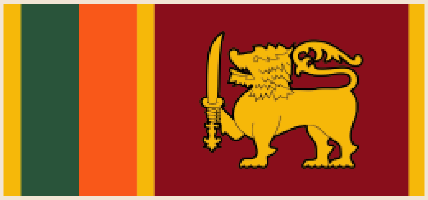
Centre for Complex Hormonal Disorders at the University of Colombo

The Centre for Complex Hormonal Disorders organized CAH Awareness Day in June 2024, bringing together 90 participants. The event launched a community support group to address challenges in education, advocacy and care for individuals with CAH. Families and affected individuals shared resources, received emotional support, and participated in educational sessions, resource translation, and legal assistance for birth certificate corrections.

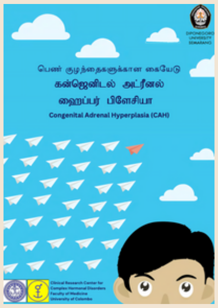
Sameera, a 23-year-old university student thriving with CAH in Sri Lanka, shares a message of support for the CAH community ahead of their inaugural CAH Club Meeting.

Sri Lanka

Lady Ridgeway Hospital for Children



This project, led by Dr. Thisura Nelaka de Silva at Lady Ridgeway Hospital for Children in Sri Lanka, aims to improve awareness and knowledge of Congenital Adrenal Hyperplasia (CAH) among patients and families by developing and distributing an educational booklet in Sinhala and Tamil. Given the lack of patient education materials, language barriers, and limited healthcare resources, the initiative seeks to enhance disease understanding, improve treatment adherence, and encourage patient support networks to reduce sociocultural stigma. The project's impact will be assessed through pre- and post-intervention knowledge assessments and monitoring of patient adherence over six months.



Round 2

Kenya

Kenyatta National Hospital

University of Nairobi Department of Paediatrics & Child Health

Dr. Phoebe Wamalwa, President of the Paediatric Endocrine Society of Kenya (PESK) and a paediatric endocrinologist at Kajiado County Referal Hospital, is leading efforts to strengthen Kenya's CAH community. The initiative focuses on educating healthcare workers, raising public awareness, conducting baseline research and establishing patient and caregiver support groups. Training programs will equip healthcare workers with the knowledge to diagnose and manage CAH early, while social media campaigns will reduce stigma and misinformation.

Solomon Islands

Taking Paediatrics Abroad
National Referral Hospital

Taking Paediatrics Abroad (TPA), in collaboration with the National Referral Hospital in Honiara and A/Professor Shubha Srinivasan from The Children's Hospital at Westmead, is supporting newborn screening for congenital hypothyroidism in the Solomon Islands. This initiative will enable early detection and treatment, preventing severe disability and improving long-term health outcomes for affected children. The project's success highlights the importance of community development, education for healthcare staff and family support to ensure effective screening, treatment and ongoing monitoring for newborns in the Solomon Islands.

Uganda

Kawempe National Referral Hospital
Mulago Specialised National Referral Hospital

Dr. Kobel Esther, a paediatrician at Mulago National Referral Hospital, and Andrew Twineamatsiko from CLAN Child Health Africa will organise Uganda's first CAH Community Development event. The team will develop training sessions and educational resources to strengthen early CAH diagnosis through newborn screening. While health workers attend capacity-building workshops, families will engage in discussions to better understand CAH. The event will also foster collaboration between hospital leaders and paediatric endocrinologists to improve specialised care and referral pathways for newborns.

Round 3

Nigeria

Society of Paediatric Adolescent Endocrinology in Nigeria (SPAEN)

Dr. Elizabeth Oyenusi, a leading paediatric endocrinologist and a key member of SPAEN, organized Nigeria's first CAH Community Development Program in 2024. The initiative focuses on educating healthcare providers, parents, and caregivers on identifying and managing Congenital Adrenal Hyperplasia (CAH). The program includes integrated training sessions for doctors, nurses, and traditional birth attendants, ensuring early diagnosis and improved treatment outcomes. Meanwhile, parents engage in support group discussions, while children participate in interactive learning activities. This landmark event strengthened Nigeria's CAH community, fostering awareness, advocacy, and improved access to care.

Round 4

Indonesia

KAHAKI Foundation

Dania Jaslim, a representative from KAHAKI Foundation, will organise a community-focused initiative aimed at supporting children with Congenital Adrenal Hyperplasia (CAH) in Central Jakarta, Indonesia. The KAHAKI Foundation is developing a comprehensive program that includes educational events and support groups designed to improve access to CAH medicines and scale newborn screening programs. The initiative will focus on increasing awareness and understanding among families of children with CAH, providing essential resources, and facilitating collaboration with Prodia Laboratories to offer discounted medical services.

Indonesia

Indonesian Pediatric Society
Diponegoro National Hospital

Dr. Agustini Utari, Tri Indaah Winarni and Irene Astrid Larasati aim to enhance healthcare professionals' understanding of Congenital Adrenal Hyperplasia (CAH) and the recently launched newborn screening program, particularly as a pilot project begins in key cities. The project will develop educational resources, such as booklets and videos, and offer webinars and training sessions focused on CAH screening and management. By increasing knowledge and improving early diagnosis and treatment, the initiative seeks to ensure better outcomes for individuals with CAH. People living with CAH will actively participate through storytelling, and the project will be linked to Diponegoro National Hospital.

Kenya

MAGIC Foundation Africa

Riziki Syombua, a representative of the MAGIC Foundation Africa in collaboration with the Paediatric Endocrine Society of Kenya (PESK) and Kenyatta National Hospital (KNH), spearheaded Kenya’s first CAH awareness initiative in 2024. The team conducted extensive community outreach through social media, hospital partnerships and educational sessions. A key focus was breaking taboos surrounding CAH, empowering affected families, and advocating for newborn screening programs. While parents attended expert-led discussions, children engaged in interactive activities designed to build confidence and a sense of belonging. The event fostered a strong support network, giving many children and families their first opportunity to connect with others facing the same challenges

THE MAGIC FOUNDATION

Zimbabwe

Endocrine Southern Africa Trust

Child and Youth Care (in partnership with CYC Zimbabwe)

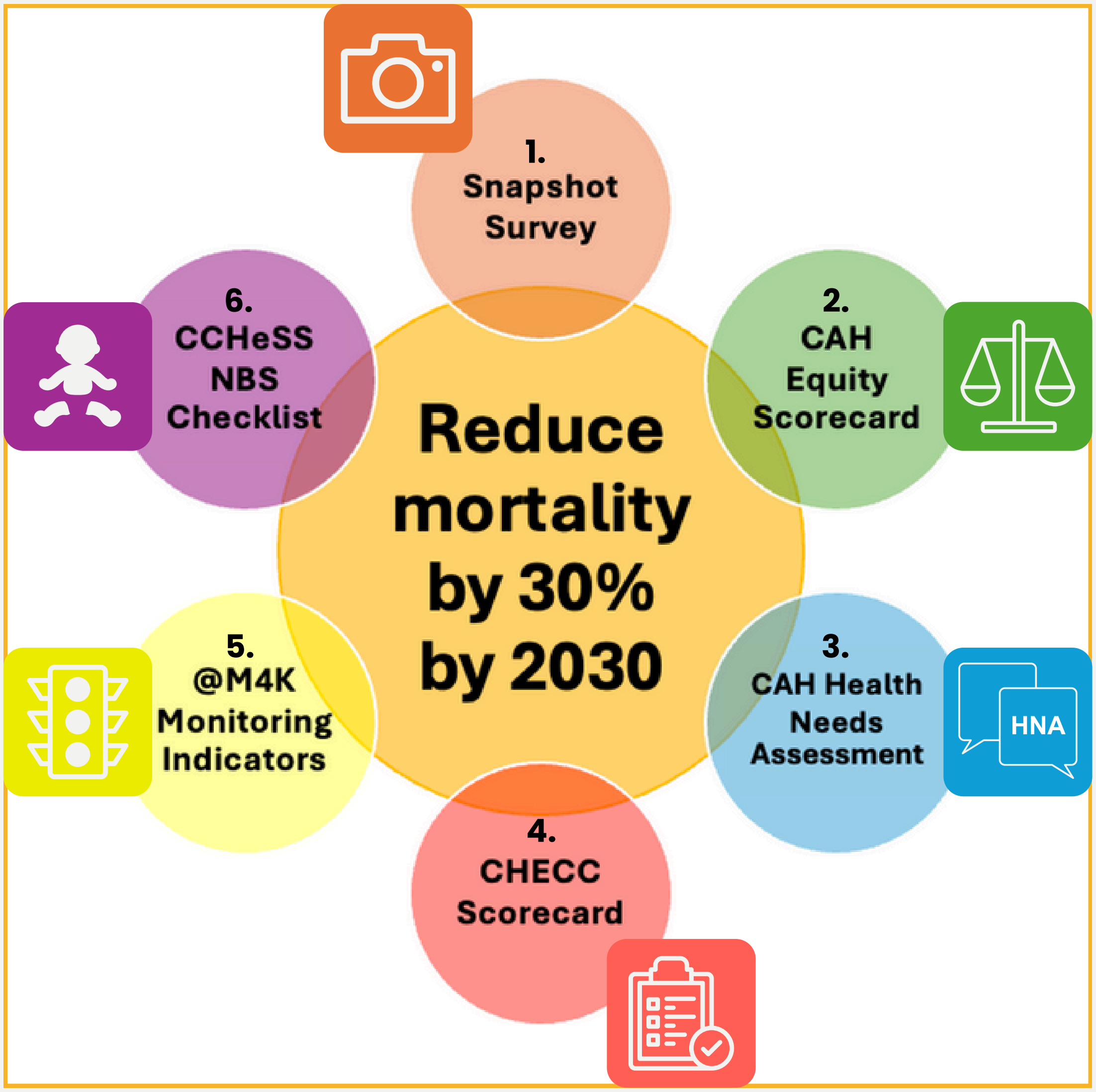
Zimbabwe’s first CAH workshop was held in August 2024, supported by a Community Development Grant. The initiative focused on educating families about CAH surgery, medical pathways and psychosocial support. A culturally tailored approach included in-depth interviews with patients and caregivers to address challenges and expectations. While parents participated in expert-led discussions, children engaged in activities designed to boost self-esteem and body confidence. The event also fostered a strong sense of community, allowing families to connect, share experiences, and build a lasting support network for continued advocacy and care.

CHILD AND YOUTH CARE ZIMBABWE
WE BUILD, GROW, NURTURE AND CARE

@MATES4Kids is committed to delivering 40 Community Development Grants by 2030. Stay connected with @MATES4Kids for updates on upcoming grant opportunities!

Indicators to Track Progress

To track our collective progress toward 2030, we have designed six tools to collect data and demonstrate our advancements:



1. Snapshot Survey

A paediatric endocrinologists' assessment of the key priorities for children living with four childhood NCDs in their country: type 1 diabetes (T1D), congenital adrenal hyperplasia (CAH), congenital hypothyroidism (CH) and osteogenesis imperfects (OI). This rapid assessment is administered as a 10-minute online survey to identify challenges, priorities and support ongoing monitoring.

2. CAH Equity Scorecard

A rapid, quantitative and comparative assessment of the structural and systemic challenges and inequities that may prevent children and families living with CAH from achieving the highest possible quality of life. This 20-question scorecard produces a score out of 30 to assess and identify priorities and support ongoing monitoring.

3. CAH Health Needs Assessment (HNA)

A detailed survey for CAH community members, ideally conducted at CAH support group meetings with the assistance of caring health professionals. The HNA facilitates a deeper understanding of the challenges and burdens faced by people living with CAH in a specific country.

4. Child Health Equity Checklist Count (CHECC) Scorecard

A rapid assessment of 10 evidence-based socio-economic and cultural indicators associated with adverse health outcomes for children living with NCDs. It enables quick identification of children at risk of not surviving or thriving with an NCD. An optimal score (0/10) reflects fewer indicators associated with adverse outcomes, while a score greater than 3 suggests a child is at significant risk.

5. @MATES4Kids Monitoring Indicators

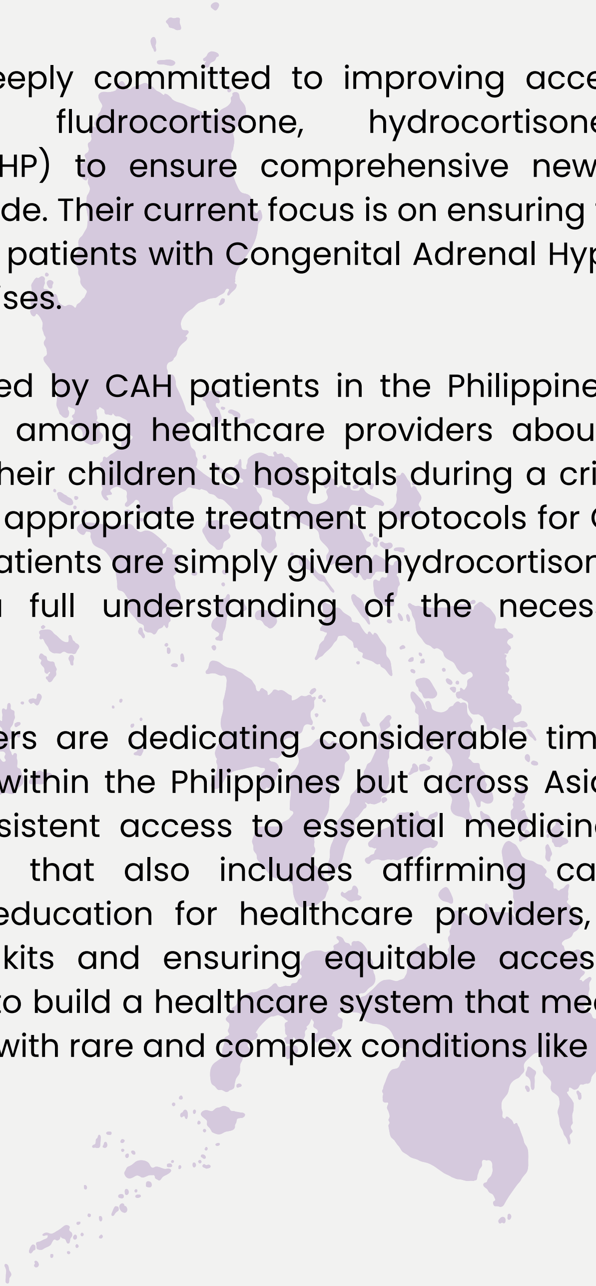
An annual, rapid "traffic light" assessment of how a country is progressing in addressing structural barriers to reducing mortality associated with CAH. This tool helps countries track and visually display progress on an annual basis.

6. CCHeSS (Community Centered Health System Strengthening) NBS Checklist

Based on the WHO's six building blocks for health system strengthening, this checklist rapidly assesses a country's approach to NBS. It provides a framework for collective reflection on national NBS programs and evaluates how well. they meet the needs for children with the conditions included in the screening panel.

Hearing from Local Champions

Improving access to essential medications and equipment: The Philippines

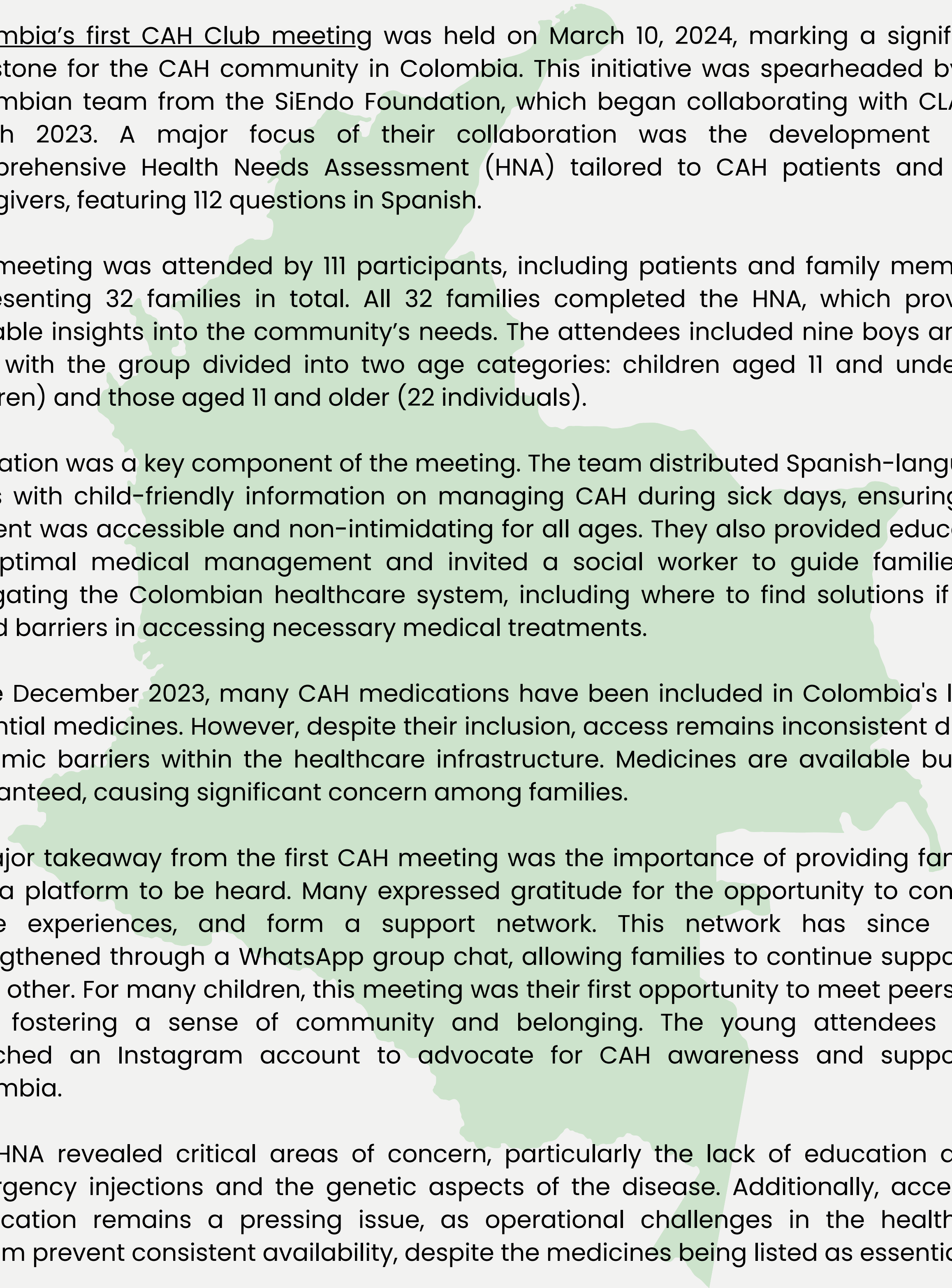


The Philippines team is deeply committed to improving access to essential medications such as fludrocortisone, hydrocortisone, and 17-hydroxyprogesterone (17-OHP) to ensure comprehensive newborn screening (NBS) is conducted nationwide. Their current focus is on ensuring that emergency kits are readily available for patients with Congenital Adrenal Hyperplasia (CAH), especially during adrenal crises.

A significant challenge faced by CAH patients in the Philippines is the lack of awareness and knowledge among healthcare providers about the condition. Often, when parents bring their children to hospitals during a crisis, the medical staff are unfamiliar with the appropriate treatment protocols for CAH. This results in suboptimal care, where patients are simply given hydrocortisone injections in a hospital setting without a full understanding of the necessary long-term management.

To address this, stakeholders are dedicating considerable time and effort to develop solutions not only within the Philippines but across Asia. Their broader objective is to ensure consistent access to essential medicines and provide comprehensive healthcare that also includes affirming care for intersex individuals. By improving education for healthcare providers, increasing the availability of emergency kits and ensuring equitable access to necessary treatments, the team aims to build a healthcare system that meets the needs of all patients, including those with rare and complex conditions like CAH.

Strengthening CAH and other childhood NCD communities: Colombia



Colombia's first CAH Club meeting was held on March 10, 2024, marking a significant milestone for the CAH community in Colombia. This initiative was spearheaded by the Colombian team from the SiEndo Foundation, which began collaborating with CLAN in March 2023. A major focus of their collaboration was the development of a comprehensive Health Needs Assessment (HNA) tailored to CAH patients and their caregivers, featuring 112 questions in Spanish.

The meeting was attended by 111 participants, including patients and family members, representing 32 families in total. All 32 families completed the HNA, which provided valuable insights into the community's needs. The attendees included nine boys and 23 girls, with the group divided into two age categories: children aged 11 and under (10 children) and those aged 11 and older (22 individuals).

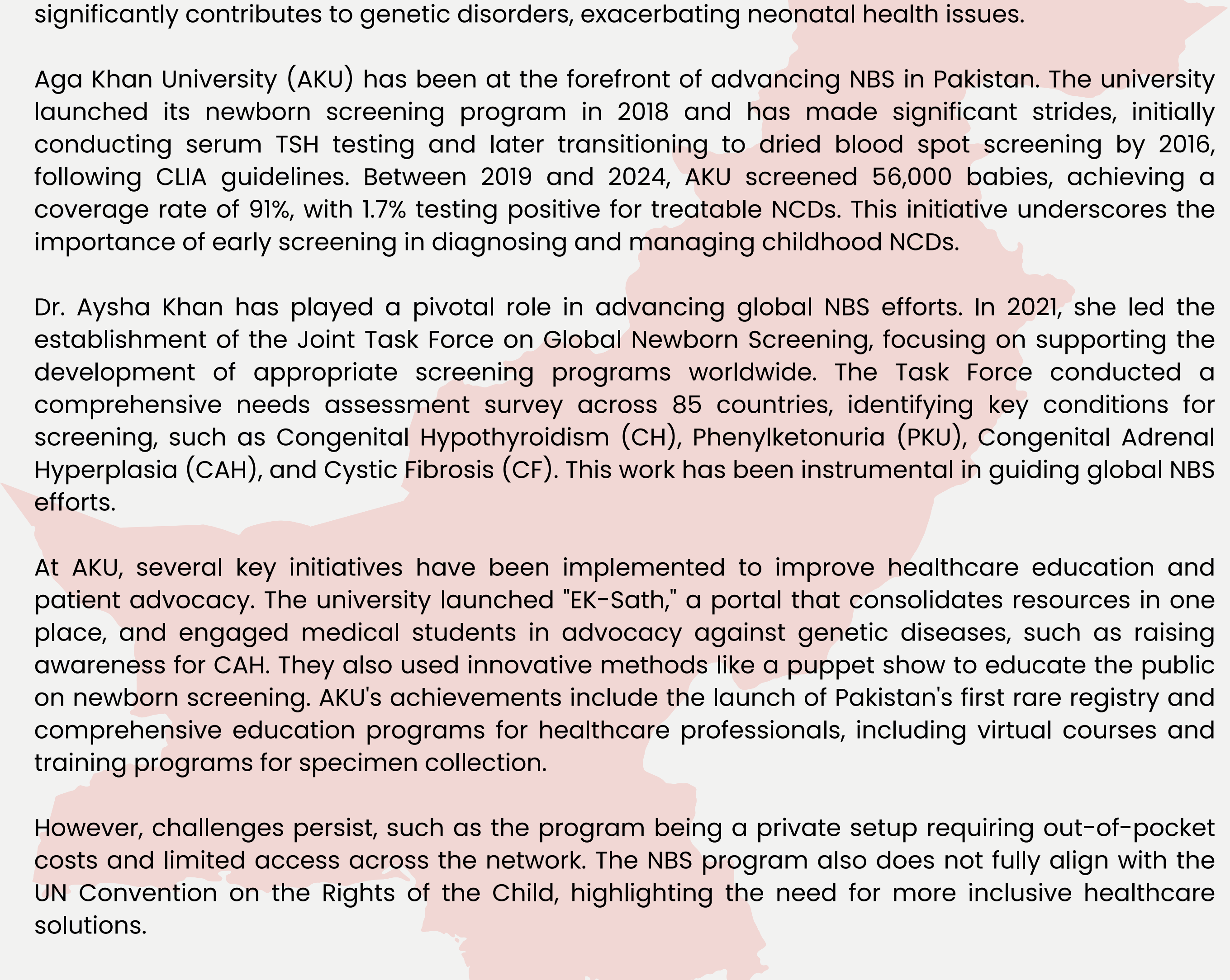
Education was a key component of the meeting. The team distributed Spanish-language flyers with child-friendly information on managing CAH during sick days, ensuring the content was accessible and non-intimidating for all ages. They also provided education on optimal medical management and invited a social worker to guide families on navigating the Colombian healthcare system, including where to find solutions if they faced barriers in accessing necessary medical treatments.

Since December 2023, many CAH medications have been included in Colombia's list of essential medicines. However, despite their inclusion, access remains inconsistent due to systemic barriers within the healthcare infrastructure. Medicines are available but not guaranteed, causing significant concern among families.

A major takeaway from the first CAH meeting was the importance of providing families with a platform to be heard. Many expressed gratitude for the opportunity to connect, share experiences, and form a support network. This network has since been strengthened through a WhatsApp group chat, allowing families to continue supporting each other. For many children, this meeting was their first opportunity to meet peers with CAH, fostering a sense of community and belonging. The young attendees even launched an Instagram account to advocate for CAH awareness and support in Colombia.

The HNA revealed critical areas of concern, particularly the lack of education about emergency injections and the genetic aspects of the disease. Additionally, access to medication remains a pressing issue, as operational challenges in the healthcare system prevent consistent availability, despite the medicines being listed as essential.

Scaling Newborn Screening: Pakistan



Pakistan faces an urgent need to implement Universal Newborn Screening (NBS) programs to address high neonatal mortality rates and improve the management of treatable childhood NCDs. Despite efforts by the government and international organizations like the WHO, neonatal mortality has remained high, largely due to limited NBS coverage, which is still below 1%. The predominance of a privatized healthcare system, with 70% managed by the private sector, complicates efforts to implement widespread health initiatives. Furthermore, the high prevalence of consanguineous marriages, where over half of marriages are between first cousins, significantly contributes to genetic disorders, exacerbating neonatal health issues.

Aga Khan University (AKU) has been at the forefront of advancing NBS in Pakistan. The university launched its newborn screening program in 2018 and has made significant strides, initially conducting serum TSH testing and later transitioning to dried blood spot screening by 2016, following CLIA guidelines. Between 2019 and 2024, AKU screened 56,000 babies, achieving a coverage rate of 91%, with 1.7% testing positive for treatable NCDs. This initiative underscores the importance of early screening in diagnosing and managing childhood NCDs.

Dr. Aysha Khan has played a pivotal role in advancing global NBS efforts. In 2021, she led the establishment of the Joint Task Force on Global Newborn Screening, focusing on supporting the development of appropriate screening programs worldwide. The Task Force conducted a comprehensive needs assessment survey across 85 countries, identifying key conditions for screening, such as Congenital Hypothyroidism (CH), Phenylketonuria (PKU), Congenital Adrenal Hyperplasia (CAH), and Cystic Fibrosis (CF). This work has been instrumental in guiding global NBS efforts.

At AKU, several key initiatives have been implemented to improve healthcare education and patient advocacy. The university launched "EK-Sath," a portal that consolidates resources in one place, and engaged medical students in advocacy against genetic diseases, such as raising awareness for CAH. They also used innovative methods like a puppet show to educate the public on newborn screening. AKU's achievements include the launch of Pakistan's first rare registry and comprehensive education programs for healthcare professionals, including virtual courses and training programs for specimen collection.

However, challenges persist, such as the program being a private setup requiring out-of-pocket costs and limited access across the network. The NBS program also does not fully align with the UN Convention on the Rights of the Child, highlighting the need for more inclusive healthcare solutions.

To overcome these challenges, prioritizing NBS within government health agendas, securing sustainable funding, and enhancing public education to increase awareness and acceptance of screening programs are essential. Strengthening local leadership, gaining federal government support, and fostering collaboration among various stakeholders—including NGOs, academic institutions, healthcare professionals and community organisations—are crucial steps. Additionally, developing local production capabilities for screening kits and essential medical supplies will further support the sustainability and effectiveness of NBS programs in Pakistan.

Event Participation

@MATES4Kids and CLAN actively participate in events hosted by the UN and WHO to amplify its mission, foster collaboration and influence global health and policy discussions. These events provide opportunities to:

- Advocate for the needs of childhood NCD communities
- Collaborate with policymakers, scientists, and other NGOs to establish partnerships and align efforts on shared goals
- Showcase innovative solutions, such as point-of-care testing and newborn screening, while learning from others to enhance impact
- Raise awareness of @MATES4Kids' initiatives and achievements
- Contribute to shaping policies and strategies that promote health equity and improved outcomes for childhood NCD communities

From July 2023 to December 2024, CLAN and @MATES4Kids participated in five events. Learn more about our events below.

United Nations 62nd Commission for Social Development (CSocD62)

6 February 2024

Newborn Screening: Promoting Equitable Healthcare Regardless of Economic Status

CLAN and @MATES4Kids hosted a virtual event at the 62nd Session of the United Nations Commission for Social Development to discuss the critical role of NBS in reducing preventable mortality of NCDs, particularly CAH. The event highlighted NBS progress in Indonesia, Mexico and Sri Lanka, focusing on challenges like access to screening, efficiency and equitable distribution of resources. Emphasizing the importance of scaling NBS programs, the discussions aligned with the SDGs, particularly 3, 10, and 17, and underscored the need for international collaboration to ensure NBS reaches every child by 2030.

COMMISSION for SOCIAL DEVELOPMENT

United Nations Headquarters, New York

United Nations | Department of Economic and Social Affairs

Official Event Report

Newborn Screening: Promoting Equitable Healthcare Regardless of Economic Status

62nd Session of the Commission for Social Development

February 5-14, 2024

Clan Caring & Living As Neighbours

@MATES4KIDS

LEHIGH UNIVERSITY

68th Non-Governmental Organization Commission on the Status of Women Forum (NGO CSW68)

13 March 2024

Accelerating Gender Equality and Empowerment for the International CAH Community

CLAN and @MATES4Kids were proud to host a virtual side event at NGO CSW68 featuring speakers from Indonesia, Sri Lanka, the Philippines, Colombia, Fiji and Zimbabwe to highlight the role of newborn screening, access to medicines and community support in promoting gender equality and empowering CAH communities. The event focused on addressing gender inequalities faced by those assigned female at birth with CAH in resource-poor settings, emphasizing the importance of early diagnosis, treatment, and reducing stigma. It underscored these efforts as vital for achieving the SDGs and advancing health and gender equity by 2030.

10 - 22 MARCH 2024
NGO CSW FORUM 68
The civil society gathering in NYC
parallel to the United Nations
Commission on the Status of Women

United Nations
Economic and Social
Council (ECOSOC)

Official Event Report

Accelerating gender equality and empowerment for the international CAH Community

68th Session of the Commission on the Status of Women

1-12 March 2024

Clan
Caring & Living As Neighbours
@MATES4KIDS
LEHIGH UNIVERSITY

77th World Health Assembly (WHA77)

26 May 2024

What will it take to scale #NewbornScreening so that #EVERYnewborn has an equal chance to life and health?

CLAN and @MATES4Kids were honored to co-host a hybrid side event at the 77th World Health Assembly in Geneva, Switzerland, in partnership with Yayasan Kesehatan Anak Global (YKAG), the International Society for Neonatal Screening (ISNS), the International Paediatric Association (IPA), the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) and the Indonesian Ministry of Health. The event emphasized the importance of collaborative efforts across sectors, promoting political will and sustained commitment and prioritising early screening to improve health outcomes. It also highlighted the need to include children in global priorities, encourage community engagement for greater impact and ensure that solutions are sustainable and systems-based.

Official Event Report

What Will It Take to Scale #NewbornScreening So That #EVERYnewborn Has an Equal Chance to Life and Health?

77^{th} World Health Assembly

26 May 2024

Clan
Caring & Living As Neighbours
@MATES4KIDS
YKAG
ISNS
IPA International Pediatric Association
Every Child · Every Age · Everywhere
IFCC International Federation of Clinical Chemistry and Laboratory Medicine
Kemenkes

4th International Conference of Small Island Developing States (SIDS4)

30 May, 2024

Investing in Tomorrow: Strengthening Newborn Screening for Resilient and Prosperous Futures in Small Island Developing States

CLAN and @MATES4Kids proudly hosted their first virtual side event at SIDS4, bringing together global experts to emphasize the critical role of initiatives in achieving SDGs and addressing newborn screening access inequalities affecting children and adults with CAH and other NCDs in resource-poor small island developing states. Speakers from Niue, the Philippines, the Solomon Islands, Indonesia, the United States, New Zealand and Australia participated, representing various NGOs, organizations, and CAH communities within the @MATES4Kids network.

United Nations | 2024 SIDS Conference
27-30 MAY, 2024 - ANTIGUA AND BARBUDA

Official Event Report

Investing in Tomorrow: Strengthening Newborn Screening for Resilient and Prosperous Futures in Small Island Developing States

4th International Conference for Small Island Developing States

27 – 30 May 2024

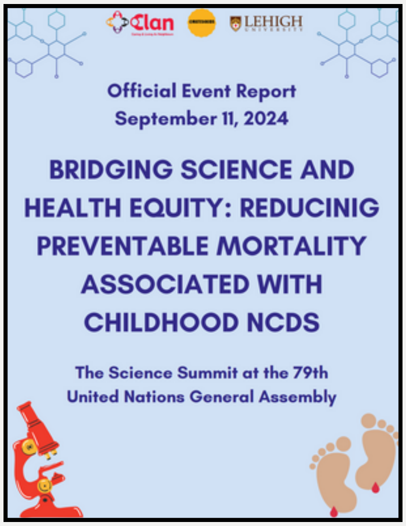
Clan Caring & Living As Neighbours | @MATES4KIDS | LEHIGH UNIVERSITY | ISNS

Science Summit at the 79th United Nations General Assembly (SSUNGA79)

11 September, 2024

Bridging Science and Health Equity: Reducing Preventable Mortality Associated with Childhood NCDs

CLAN and @MATES4Kids were proud to host a virtual side event at the Science Summit at the 79th United Nations General Assembly to discuss how we can improve healthcare for children with NCDs, focusing on expanding newborn screening, enhancing diagnostics, and building healthcare capacity. Key challenges include limited access to diagnostic tools, high treatment costs and insufficient healthcare infrastructure in low- and middle-income countries. Addressing these barriers requires stronger policies, increased awareness, and international collaboration to ensure early detection and better care for affected children.



Clan | LEHIGH UNIVERSITY

Official Event Report
September 11, 2024

BRIDGING SCIENCE AND HEALTH EQUITY: REDUCINIG PREVENTABLE MORTALITY ASSOCIATED WITH CHILDHOOD NCDS

The Science Summit at the 79th United Nations General Assembly

Other Achievements

On 12 February 2024, CLAN UN Youth Representative Nikki Pasterczyk shared her lived experience as the sibling of a young person whose life was transformed by NBS in the United States of America. Nikki shared her insights and statement at the CSocD62 General Discussion at the United Nations Headquarters, specifically on how NBS promotes health equity regardless of economic status. Watch Nikki’s statement here.

It was encouraging to note the several side events at WHA77 highlighting the importance. of newborn screening. Notably, on 28 May 2024, a resolution was passed by Member States formally acknowledging newborn screening, which:
(OP)1. INVITES Member States, in accordance with national context and priorities:
(6.) to consider implementing a universal newborn screening programme including comprehensive birth defect screening, including specific needs and considerations for diagnosis, management and long-term care of children with birth defects.

World Health Organization

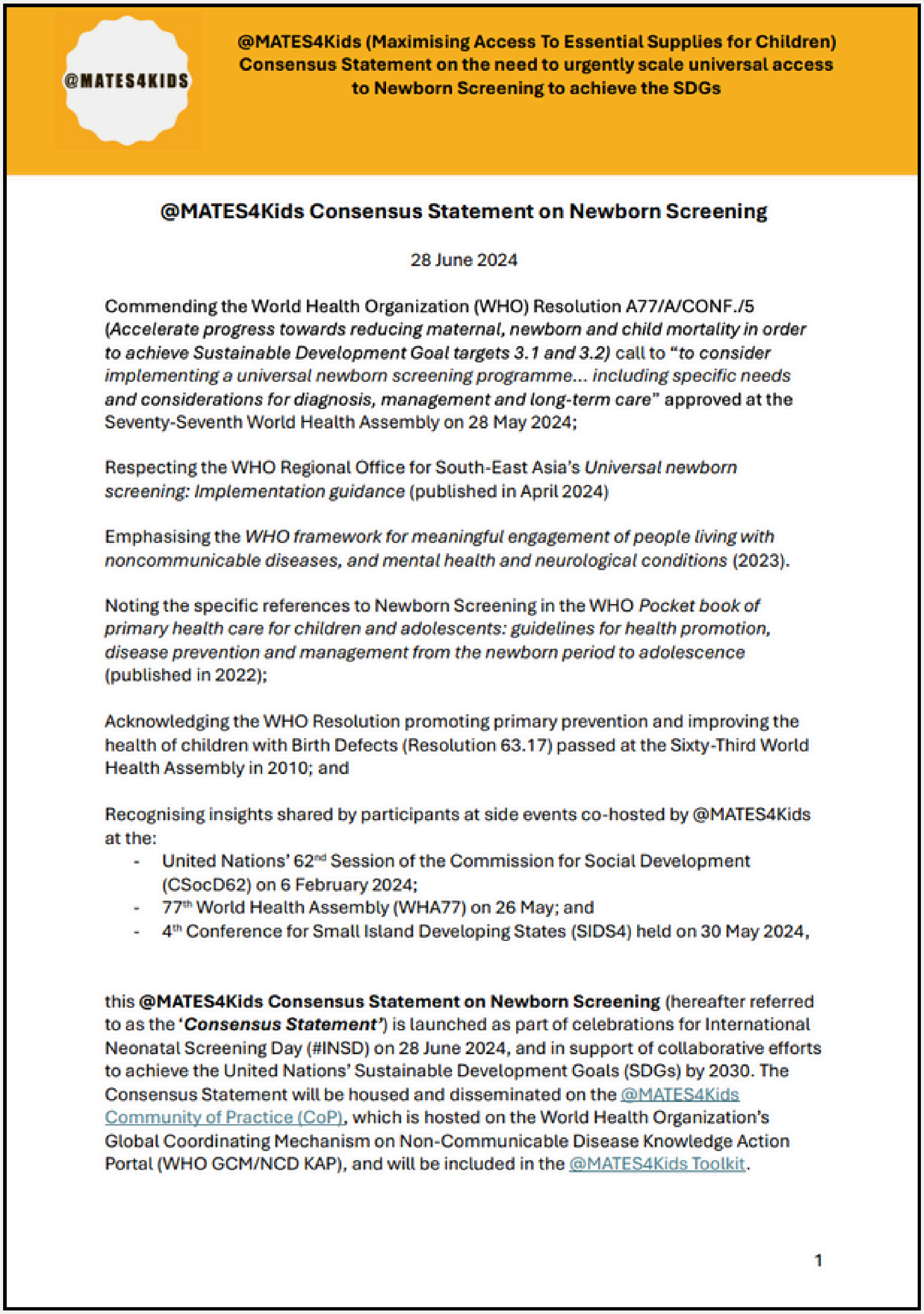
SEVENTY-SEVENTH WORLD HEALTH ASSEMBLY
Agenda item 11.7

A77/A/CONF./5
28 May 2024

Accelerate progress towards reducing maternal, newborn and child mortality in order to achieve Sustainable Development Goal targets 3.1 and 3.2

Draft resolution proposed by Botswana, Canada, Denmark, Djibouti, Egypt, Ethiopia, Finland, Gambia, Kenya, Kuwait, Lebanon, Monaco, Netherlands (Kingdom of the), Nigeria, Norway, Panama, Paraguay, Sierra Leone, Somalia, South Africa, Sweden, United Kingdom of Great Britain and Northern Ireland, United Republic of Tanzania and United States of America

The @MATES4Kids Consensus Statement urges scaling up universal NBS to reduce child mortality and achieve the UN SDGs by 2030. It emphasizes equitable access, health system integration, and community engagement, offering strategies and recommendations to strengthen NBS globally, especially in low-resource settings The Consensus Statement was launched on International Neoonatal Screening Day, 28 June 2024.



@MATES4Kids (Maximising Access To Essential Supplies for Children) Consensus Statement on the need to urgently scale universal access to Newborn Screening to achieve the SDGs

@MATES4Kids Consensus Statement on Newborn Screening

28 June 2024

Commending the World Health Organization (WHO) Resolution A77/A/CONF./5 (*Accelerate progress towards reducing maternal, newborn and child mortality in order to achieve Sustainable Development Goal targets 3.1 and 3.2)* call to "*to consider implementing a universal newborn screening programme… including specific needs and considerations for diagnosis, management and long-term care*" approved at the Seventy-Seventh World Health Assembly on 28 May 2024;

Respecting the WHO Regional Office for South-East Asia's *Universal newborn screening: Implementation guidance* (published in April 2024)

Emphasising the *WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions* (2023).

Noting the specific references to Newborn Screening in the WHO *Pocket book of primary health care for children and adolescents: guidelines for health promotion, disease prevention and management from the newborn period to adolescence* (published in 2022);

Acknowledging the WHO Resolution promoting primary prevention and improving the health of children with Birth Defects (Resolution 63.17) passed at the Sixty-Third World Health Assembly in 2010; and

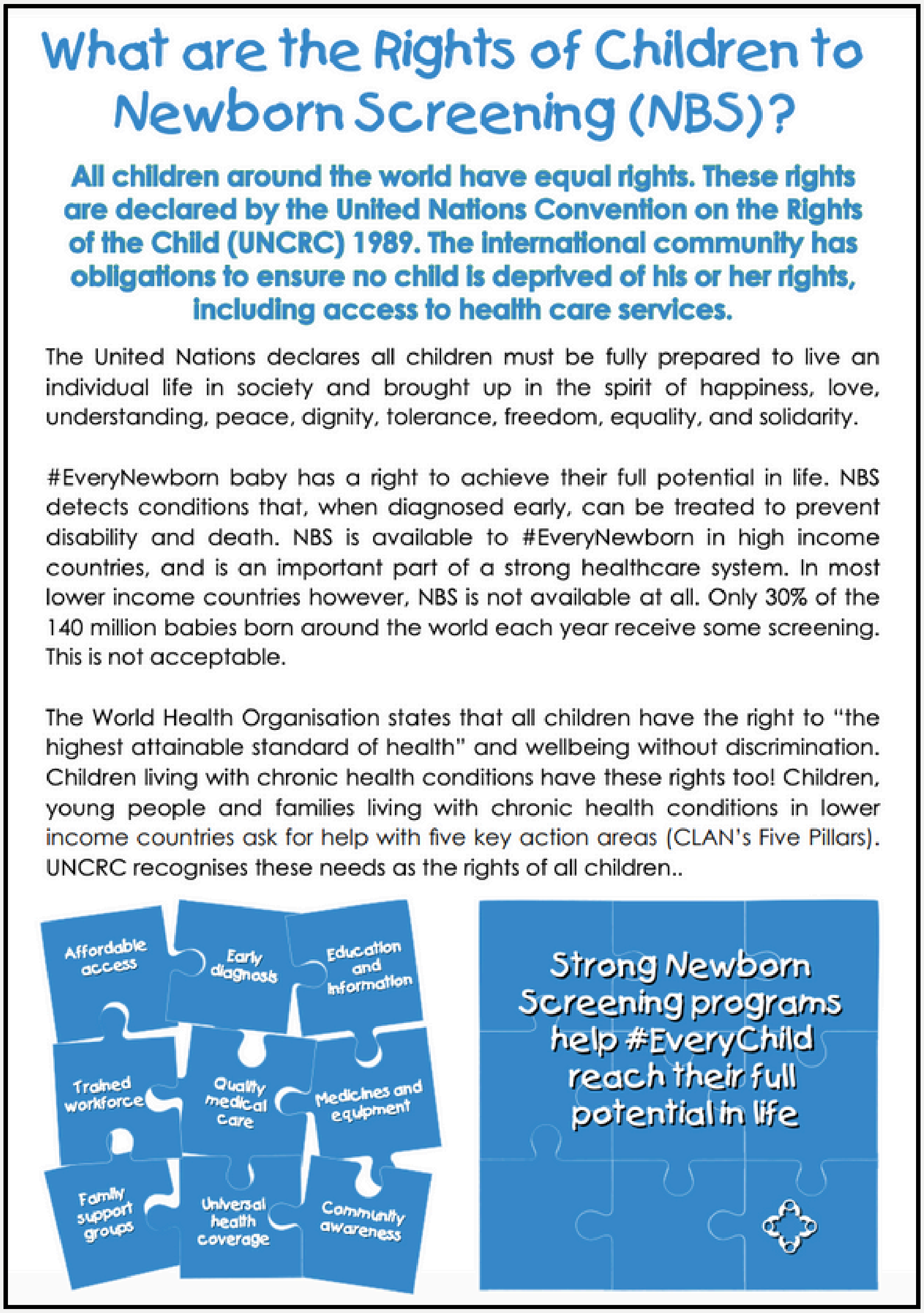
Recognising insights shared by participants at side events co-hosted by @MATES4Kids at the:

- United Nations' 62nd Session of the Commission for Social Development (CSocD62) on 6 February 2024;
- 77th World Health Assembly (WHA77) on 26 May; and
- 4th Conference for Small Island Developing States (SIDS4) held on 30 May 2024,

this **@MATES4Kids Consensus Statement on Newborn Screening** (hereafter referred to as the '***Consensus Statement***') is launched as part of celebrations for International Neonatal Screening Day (#INSD) on 28 June 2024, and in support of collaborative efforts to achieve the United Nations' Sustainable Development Goals (SDGs) by 2030. The Consensus Statement will be housed and disseminated on the @MATES4Kids Community of Practice (CoP), which is hosted on the World Health Organization's Global Coordinating Mechanism on Non-Communicable Disease Knowledge Action Portal (WHO GCM/NCD KAP), and will be included in the @MATES4Kids Toolkit.

1

@MATES4Kids launched a Newborn Screening Child-Friendly Flyer on International Neonatal Screening Day on 28 June 2024!



What are the Rights of Children to Newborn Screening (NBS)?

All children around the world have equal rights. These rights are declared by the United Nations Convention on the Rights of the Child (UNCRC) 1989. The international community has obligations to ensure no child is deprived of his or her rights, including access to health care services.

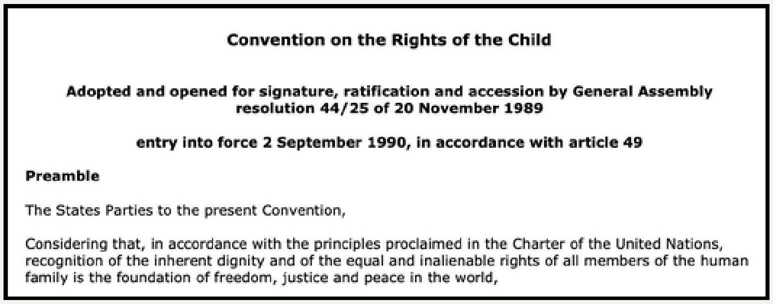
The United Nations declares all children must be fully prepared to live an individual life in society and brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality, and solidarity.

#EveryNewborn baby has a right to achieve their full potential in life. NBS detects conditions that, when diagnosed early, can be treated to prevent disability and death. NBS is available to #EveryNewborn in high income countries, and is an important part of a strong healthcare system. In most lower income countries however, NBS is not available at all. Only 30% of the 140 million babies born around the world each year receive some screening. This is not acceptable.

The World Health Organisation states that all children have the right to "the highest attainable standard of health" and wellbeing without discrimination. Children living with chronic health conditions have these rights too! Children, young people and families living with chronic health conditions in lower income countries ask for help with five key action areas (CLAN's Five Pillars). UNCRC recognises these needs as the rights of all children..

Strong Newborn Screening programs help #EveryChild reach their full potential in life

This flyer is a comprehensive advocacy tool focused on Newborn Screening (NBS) and the rights of children, particularly in the context of global health equity. It emphasizes the importance of ensuring that all newborns, regardless of their geographic or economic circumstances, have access to essential health services, including early detection and treatment of congenital conditions.



Convention on the Rights of the Child

Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989

entry into force 2 September 1990, in accordance with article 49

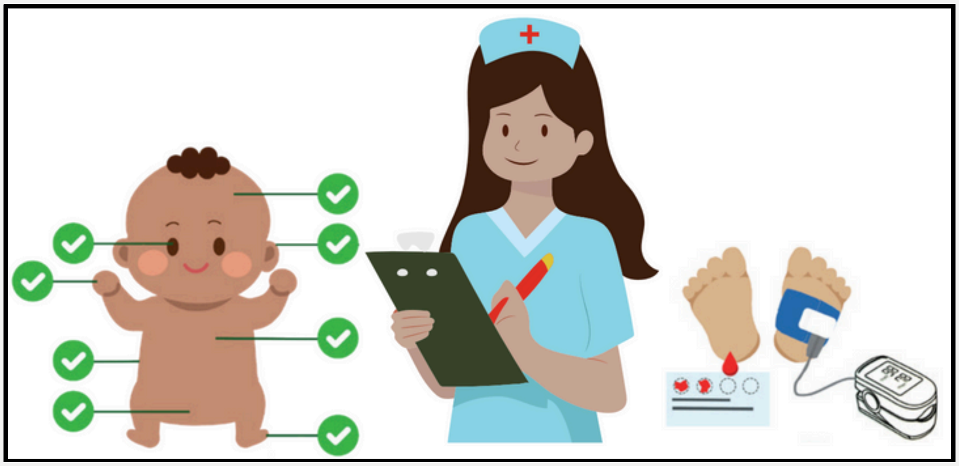
Preamble

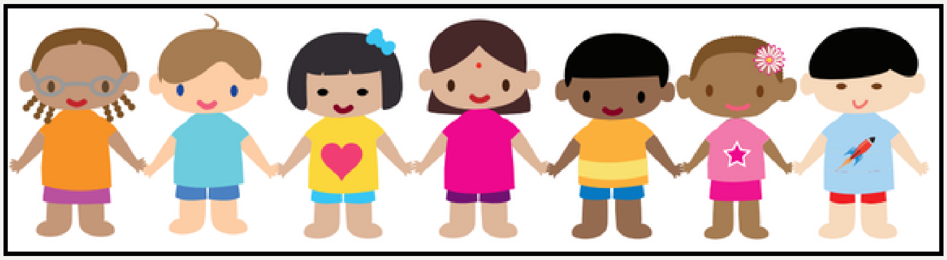
The States Parties to the present Convention,

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

The flyer highlights the United Nations Convention on the Rights of the Child (UNCRC), adopted in 1989, which declares that all children have equal rights, including access to healthcare. It stresses that these rights are universal and must be upheld for every child, irrespective of their background or disability.

The flyer argues that the inequity in access to NBS is unacceptable and calls for universal access to NBS as an essential component of a strong healthcare system.



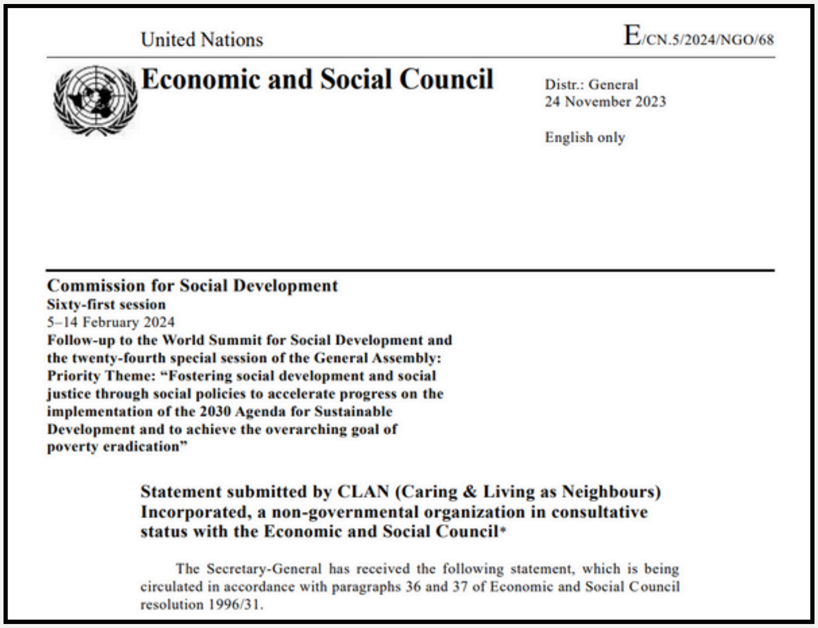


The flyer emphasizes the importance of global collaboration and awareness to address the disparities in access to Newborn Screening (NBS) and ensure that no child is left behind in receiving life-saving screening and treatment.

@MATES4Kids launched a briefing paper titled “A community-centred, collaborative, health system strengthening approach to reducing the preventable mortality associated with CAH by 30% by 2030” at the Science Summit on 11 September 2024. The briefing paper analyses the current situation and uses an adapted version of the WHO’s Six Building Blocks for Strengthening Health Systems to present an evidence-based approach to practical action to help reduce the preventable mortality associated with CAH in lower-income countries and globally.

A community-centred, collaborative, health system strengthening approach to reducing the preventable mortality associated with CAH by 30% by 2030.

Kate Armstrong[1], Catherine Cole[1], Emma Santini[1], Rabia Baloch[1], Mohsina Ibrahim[2], Jamal Raza[3], Raúl Calzada León[4], Paola Duran Ventura[5], Johanna Meschede[6,7], Manuela Brösamle[6,7], Dina Matos[7,8], Ilisapeci Vereti Tuibeqa[9], Natasha Heather[10,11], Dianne Webster[10,11], Paul Hofman[11], Agustini Utari[12, 13], Aman Pulungan[12,14], Salwa Musa[15,16], Rodolfo A. Rey[17], Maria Craig[18], Vu Chi Dung[19], Jean-Pierre Chanoine[20], Carmen Auste[21]



United Nations E/CN.5/2024/NGO/68

Economic and Social Council

Distr.: General
24 November 2023

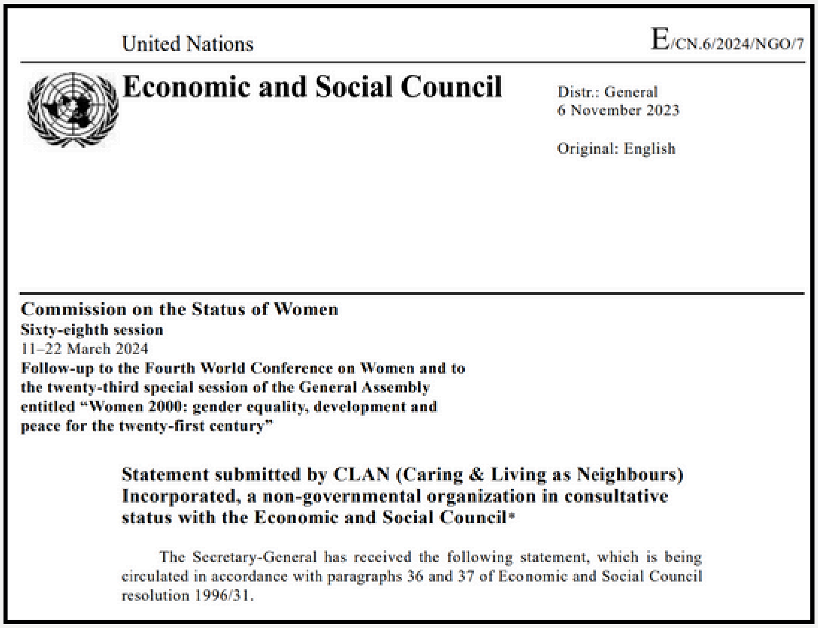
English only

Commission for Social Development
Sixty-first session
5–14 February 2024
Follow-up to the World Summit for Social Development and the twenty-fourth special session of the General Assembly: Priority Theme: "Fostering social development and social justice through social policies to accelerate progress on the implementation of the 2030 Agenda for Sustainable Development and to achieve the overarching goal of poverty eradication"

Statement submitted by CLAN (Caring & Living as Neighbours) Incorporated, a non-governmental organization in consultative status with the Economic and Social Council*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

CLAN submitted a written statement to CSocD62, advocating for scaling universal NBS to address NCDs in low-resource settings, aiming to reduce preventable mortality and improve access to healthcare. Through @MATES4Kids, CLAN promotes social justice and the 2030 Agenda for Sustainable Development, focusing on equitable access to treatment and expanding NBS globally.



United Nations E/CN.6/2024/NGO/7

Economic and Social Council

Distr.: General
6 November 2023

Original: English

Commission on the Status of Women
Sixty-eighth session
11–22 March 2024
Follow-up to the Fourth World Conference on Women and to the twenty-third special session of the General Assembly entitled "Women 2000: gender equality, development and peace for the twenty-first century"

Statement submitted by CLAN (Caring & Living as Neighbours) Incorporated, a non-governmental organization in consultative status with the Economic and Social Council*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

CLAN submitted a written statement to CSW68, advocating for universal NBS to address NCDs in low-resource settings. NBS can reduce childhood mortality, particularly for girls, by ensuring early diagnosis and treatment. CLAN called for global scaling of NBS and improved access to healthcare to combat gender and health inequities, supporting the achievement of the SDGs.

Call for Action

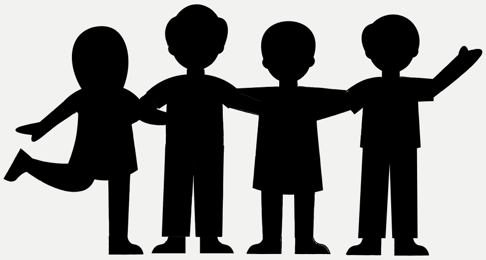
Achieving the vision, mission and objectives of @MATES4Kids requires a collective effort. We encourage everyone to get involved—together, we can make a difference!

To learn more, visit @MATES4Kids on the WHO KAP platform and connect with the champions in your region who are leading the change.

Stay Connected With Us!

Twitter/X: @MATES4Kids
Instagram: @MATES4Kids
Email: info@clanchildhealth.org
LinkedIn: @MATES4Kids
Facebook: CLAN Child Health
Youtube: CLAN Child Health

#MATES4Kids
#LeaveNoChildBehind
#AccessToMedicines
#EVERYchild
#NewbornScreening
#WeAreCAH



Clan
Caring & Living As Neighbours

@MATES4KIDS